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# The experience of the critical patient's relative in contact isolation

## *A experiência vivenciada pelo familiar do paciente crítico em isolamento de contato*

## *La experiencia vivenciada por el familiar del paciente crítico en aislamiento de contacto*

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**ABSTRACT**

**Objective:** To describe the experience of a family member of a critical patient in contact isolation. **Methods:** This is a qualitative study, carried out in 2019, in a transplant unit of a public hospital in Fortaleza, Ceará, Brazil, whose participants were 17 relatives of patients who were hospitalized in the High Complexity Postoperative Unit in contact isolation. Data collection took place through semi-structured interviews, with thematic analysis being carried out, from which three categories emerged: The family member's experience at the time of the visit; Faith as support for coping while waiting for your family member to recover; and The feelings experienced by the need for isolation. **Results:** The findings revealed the need for precaution for isolation, which greatly scares family members and the importance of using devices, preventive and protective measures, a context in which faith and hope end up giving way to discouragement and sadness. The fear of the unknown and of contracting the illness of your relative brings an ambiguous feeling. **Conclusion:** It was perceived in the statements that religion, spirituality, and belief have a fundamental role in the daily lives of family members and the recovery of patients in hospitalization, bringing more security and strength in the whole process.

**Descriptors:** Nursing; Patient Isolation; Critical Care Outcomes.

***RESUMO***

***Objetivo:*** *Descrever a experiência vivenciada pelo familiar de paciente crítico em isolamento de contato.* ***Métodos****: Estudo com metodologia qualitativa, realizado em 2019, em uma unidade de transplante de uma instituição hospitalar pública, em Fortaleza, Ceará, Brasil, cujos participantes foram 17 familiares de pacientes que se encontravam internados na Unidade Pós-operatória de Alta Complexidade em isolamento de contato. A coleta de dados ocorreu por meio de entrevista semiestruturada, sendo realizada a análise temática, a partir da qual emergiram três categorias: A experiência do familiar no momento da visita; A fé como suporte para o enfrentamento na espera da recuperação do seu familiar; Os sentimentos vivenciados pela necessidade de isolamento.* ***Resultados:*** *Os achados revelaram a necessidade da precaução por isolamento, que assusta muito os familiares, e a importância do uso de aparelhos, de medidas de prevenção e de proteção, contexto em que a fé e a esperança acabam dando*



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*vez para o desânimo e tristeza. O medo do desconhecido e de contrair a doença de seu familiar traz um sentimento ambíguo.* ***Conclusão****: Percebeu-se nas falas que a religião, espiritualidade, crença, tem papel fundamental no dia a dia dos familiares e na recuperação dos pacientes em hospitalização, trazendo mais segurança e força em todo processo. A reação dos entrevistados diante da necessidade da utilização de equipamento de proteção individual, tanto pelos profissionais como por eles mesmos no período da visita, mostrou que foi interpretada como "nojo" para tocar em seus familiares.*

***Descritores****: Enfermagem; Isolamento de Pacientes; Resultados de Cuidados Críticos.*

***RESUMEN***

***Objetivo:*** *Describir la experiencia vivenciada por el familiar de paciente critico en aislamiento de contacto.* ***Métodos****: Estudio con metodología cualitativa realizado en 2019 en una unidad de trasplante de una institución hospitalaria pública de Fortaleza, Ceará, Brasil, cuyos participantes fueron 17 familiares de pacientes ingresados en la unidad postoperatoria de alta complejidad de aislamiento de contacto. La recogida de datos se dio a través de entrevista semiestructurada y se realizó el análisis temático de lo cual emergieron tres categorías: La experiencia del familiar durante la visita; El apoyo de la fe para el afrontamiento de la espera de la recuperación de su familiar; Los sentimientos vividos debido el aislamiento.* ***Resultados:*** *Los hallazgos revelaron la necesidad de precaución por el aislamiento que asusta mucho los familiares y la importancia del uso de aparatos, de medidas de prevención e de protección, contexto en el cual se cambia la fe y la esperanza por el desánimo y la tristeza. El miedo del desconocido y de tener la enfermedad de su familiar lleva a un sentimiento ambiguo.* ***Conclusión****: Se percibió en las hablas que la religión, la espiritualidad y la creencia tienen el papel fundamental en el cotidiano de los familiares y para la recuperación de los pacientes ingresados que tienen más seguridad y fuerza en todo el proceso. La reacción de los entrevistados ante la necesidad de la utilización de aparato de protección individual por los profesionales y por ellos mismos durante la visita ha sido interpretada como "aversión" de tocar sus familiares.*

***Descriptores****: Enfermería; Aislamiento de Pacientes; Resultados de Cuidados Críticos.*

## INTRODUCTION

The disease that leads to hospitalization has aspects of a physical and psychological order that weaken patients and family members, occurring, at the same time, a breakdown of the family design and deconstruction of known concepts[1,2]. Instigated by the anguish of death that usually appears in these moments, the critical patient, as well as the family, is faced with difficulties in coping with the situation of illness[3].

The placement of hospitalized patients in isolation is done to protect the immunocompromised patient from others (reverse isolation) or to protect others from the patient's infectious process (isolation)[4]. Both situations require limiting contact to prevent the spread of pathogens, as healthcare-related infections (IRAS) have an impact on lethality, hospitalization, costs, and the emergence of antimicrobial resistance, which gives IRAS special relevance to health public[5].

In this direction, in addition to drugs, precautionary contact measures used to prevent the spread of microorganisms of epidemiological importance are part of the treatment[6]. Among the main precautionary measures of contact in patients detected with resistant multidrug microorganisms, are hand hygiene, the constant use of the apron and gloves, and the isolation of the patient[7].

The family situation consists of permanent stress, internal suffering, increased anxiety, fear of the unknown, and apprehension about the decisions to be made and situations to be faced. Between 25% and 50% of family members of critically ill patients experience psychological symptoms, including acute stress, post-traumatic stress, generalized anxiety, and depression[8].

The hospitalization process can also lead to an ambiguous feeling of compassion and gratitude with fragility and fear, since, for the effective treatment of critically ill patients, numerous invasive procedures are necessary, as well as the use of a technological arsenal that scares and hurts the family member, which can generate apprehension, despair, and impotence[9].

When a patient in intensive care is in contact isolation, it generates a crisis, in which the individual is faced with the uncontrollable and fragile human condition. Information on the need for contact isolation is offered to family members when the bacteriological result is positive or when it is transferred from another institution[10]. In this context, techniques and equipment are used as a means of preventing the spread of microorganisms in the hospital environment, which is called contact precaution[11].

In addition to these relevant aspects, contact isolation symbolizes an attack on the structure of the family personality, in addition to designating an accidental crisis in human life. The family member observes and analyzes the way the health team assists their loved one in blocking the spread of these infections in the hospital environment and countless thoughts permeate their mind in the immeasurable world of unknown contact[12].

The understanding of the experience and feelings presented by family members of the critical patient in contact isolation will certainly fill an important gap for health promotion in this context, improving family care, reducing fear and anxiety, in addition to sensitizing family members on the issue of blocking the spread of these contact infections[13].

In this perspective, the National Health Promotion Policy (*Política Nacional de Promoção da Saúde - PNPS*), revised in 2014, has as one of the transversal themes the production of health and care, which conceives to aggregate the theme in networks that provide humanized care practices that promote dialogue erecting practices based on comprehensive care and health[14]. Thus, care related to isolation must contain aspects of family inclusion from the perspective of the expanded clinic and the co-responsibility of care for the prevention of injuries, health promotion, and rehabilitation[15].

Thus, it is questioned, how the family member experiences the moment and the feelings when visiting the family member who is in contact isolation. Therefore, the objective of this study was to describe the experience and feelings experienced by the family member of the critical patient in contact isolation.

## METHODS

It is an exploratory and qualitative study characterized by the investigation of beliefs, perceptions, and opinions that result from the human interpretation of their experiences and feelings[16]. The research took place at the Transplant Unit of the General Hospital of Fortaleza, in Fortaleza, Ceará, Brazil, considered the largest public hospital in the state network, being a reference for the tertiary level in kidney transplants, corneas, neurosurgery, orthopedics, vascular surgery, neurology, ophthalmology, rheumatology, nephrology, and high-risk obstetric[17].

For the visit of family members in this unit, a period of 60 minutes is allocated, in the afternoon shift, and this moment is accompanied by nurses and other professionals who make up the unit's health team.

Family members were invited at the time of the visit, through a formal invitation by the researchers, who explained the purpose of the study to each one. The sample was selected as their relatives entered into contact isolation, being excluded family members with fourth-degree kinship, due to the emotional distance, and family members of children, due to the specificity of this population. Thus, the sample comprised 17 relatives of inpatients who were in contact with isolation.

Data collection took place from August to September 2019, through semi-structured interviews recorded individually after the moment of the visit, to preserve the individuality and uniqueness of the participant. The choice for the development of this technique in this study was due to the possibility of collecting subjective data, proper to qualitative research, related to the values, attitudes, and opinions of the interviewees, data that could not be obtained through a questionnaire[18].

The interview script was divided into two stages: in the first, personal data were obtained, such as age, sex, origin, education, marital status, family income and kinship, and the second consisted of a guiding question to describe the experience of the critical patient's relative in contact isolation: how do you describe your experience and feelings when visiting your relative who is in contact isolation?

The interviews took place individually, in a friendly atmosphere between interviewer and interviewee, in a private room at the health service, lasting 20 minutes each, being recorded in mp3 to ensure reliable material for analysis. The sample closure occurred when the research objective was reached, taking into account the thematic saturation criterion[19]. Subsequently, all the interviews were transcribed in a text editing program.

For the systematization and analysis of the data, content analysis was used, specifically, the thematic analysis, which consists of a set of communication analysis techniques aiming to obtain, by systematic and objective procedures for describing the content of messages, indicators that allow the inference of knowledge related to situations[20]. The testimonies were exhaustively analyzed in an attempt to raise indicators that led to the inference about the researched theme. As a result of the number of interviewees 'statements, the analysis proceeded through a series of statistical procedures to correlate the linguistic context and the categories of the groups relevant to the interviewees' statements. Subsequently, the content analysis of the interviews was processed using the IRAMUTEQ software[21], retaining the descending hierarchical classification.

A semantic range was generated from the retention of words by the similitude analysis, in which the connection between the words contained in the corpus and between them is identified, highlighting the words: “isolation”, “faith”, “coping”, “family” and “visit”, all interconnected, the word “isolation” located at the central point, which has the largest number of connections. In this way, it was possible to infer about the categorical analyzes from the affinity relations between the classes, emerging three categories: faith as support for coping while waiting for your family member to recover; the experience at the time of the visit; the feelings experienced by the need for isolation.

The research is part of an umbrella project in search of subsidies for the construction of educational technologies. It was submitted to the Research Ethics Committee of the *Hospital Geral de Fortaleza* and approval was obtained with Opinion No. 2,435,893. Participants signed the Free and Informed Consent Form, identified by the letter “E”, meaning interviewee, followed by a number.

## RESULTS AND DISCUSSION

In this space, the results of the study will be presented and discussed. Initially, the personal data of the interviewees, and then the thematic categories that emerged from the study.

### Personal data of interviewees

The study had a sample consisting of seventeen participants, ten males, and seven females. Regarding age, individuals were between 23 and 56 years old. Regarding the origin, seven were from Fortaleza; ten were from other municipalities in Ceará and other states. As for the level of education, seven had primary education; eight had secondary education, and two, higher education.

Regarding marital status, twelve were single and five were married (stable union). Regarding family income, the only one reported income of three salaries, with a similarity between income with one and two salaries. Regarding the degree of kinship, five children, three brothers, three cousins, two uncles, a niece, a mother, a father, and a wife were identified.

### Faith as a support for coping while waiting for the recovery of your family member

This category refers to the feeling facing the news of isolation and faith as a support to face the family’s recovery. The concern for their relative, as well as the uncertainty of response to treatment, is expressed with anguish and attachment to religion to relieve suffering and bad thoughts:

> *“[...]I was always Catholic; I believe in God, I always pray. When she got this infection, I prayed a lot more, and those bad thoughts came out of my head.” (E4)*
>
> *“I get worried [...] My brother has someone else’s kidney and another bacteria that doesn’t die, it gives me distress [...]But the suffering of the machine was too much for him. The way is to pray for him to get well soon.” (E8)*
>
> *“[...]I never miss Mass, I always say my prayers at home and my friends always tell me that I am in their prayers. I have a lot of faith that he will be fine.” (E2)*

Faith and religion as a support for coping while waiting for the recovery of their family members emerge with emphasis when the man does not find a logical explanation for the problem he is experiencing. In this way, new formulations and new meanings give sense to the world within the context of faith[17].

The health-disease process seen by the religious person goes beyond the sphere investigated by the doctor. The disease appears as a disruption of balance, which not only affects the physical but includes other areas that harmonize the individual (such as well-being, work, food, comfort). Religious practices bring to their followers the explanation and solution of problems[22].

One aspect that religion and medicine share is suffering. Medicine aims to alleviate suffering, a process in which it is not olone. The role of families and other social contacts takes on importance in providing meaning to suffering and its moral experience. These reasons are the same that lead suffering individuals and theirs to seek religion, which will contribute to making suffering more bearable[23].

Thus, religion is considered family support, in which hopes are rebuilt and, thus, the family member can think about the improvement of their loved ones:

> *“I haven’t felt any happiness for a couple of days ... It seems my strength is gone, I lost faith. My mom waited so long for this transplant and now she got this resistant bacteria...” (E17)*

> *"I didn't lose faith. [...] We have to trust that we have a greater being, which is Jesus Christ, Our Lady, the saints, the angels; trust that our lives are in God's hands, that his will be done." (E2)*

Religion and faith are frequently used resources, especially when it comes to the hospital environment. It is common to hear phrases like "if God wants, I will improve, I am feeling better"; "Thank God, you need to have faith in God to improve". Such phrases point to the relationship of religion or faith with optimism, hope for improvement, in the search for strength in a superior being who can help. This faith helps to face invasive procedures, to eat even when there is no appetite as if the belief was that God is already going to do his part, so it is up to the patient to cooperate and do his part[24]. The relatives have in religion comfort and response to what they are going through, since faith exercises an important emotional balance and, with spirituality, it is characterized as a powerful resource for strengthening family bonds[25].

**The experience at the time of the visit**

This category deals with the experience of family members at the time of the visit. Full of uncertainties, family members, when making their visits, are faced with cautious protective measures and, for lack of teaching about the importance of wearing ornaments, they classify the professionals' behavior as strange, rude or disgusted by the patients:

> *"I was shocked when they gave me the apron, gloves and mask. I was worried. [...]I immediately thought it was something very serious, but I didn't have the courage to ask." (E8)*
>
> *"Guys, what a horrible visit! The nurse telling me to do a lot of things: wash your hands, put on your apron, mask and gloves ... It's my mom, you know? I was so angry, I will never be disgusted with her and God will not let me get this infection." (E16)*
>
> *"[...]Then I was told that I couldn't take anything, only if it was a glove ... I found everything very strange and rude." (E6)*

For the investigated visitors, there was a feeling of fear and awe when they were approached by professionals to use protective equipment and when they saw their relatives full of medication equipment and monitoring, which led to the analysis of whether they understood the need for all that, as companions should receive clarification about what contact precautions are, to stimulate their engagement, increase the chances of success and reduce the chances of unwanted events resulting from the assistance.

Adequate and up-to-date knowledge on aspects related to hand hygiene and the use of protection in contact precautions helps health professionals because of its applicability in the care scenario[26].

The fear of the unknown accompanies them during visits. Bacteria, as they are classified by them, can be transmitted to them during visits. On the other hand, other interviewees say they are not afraid of catching diseases, as they are their relatives:

> *"I was impressed with how much serum and medicine my nephew was taking... I was worried about not taking this disease from him to my children, God forgive me..." (E13)*
>
> *"[...]I thought this isolation story was very strange ... Everyone was 'disgusted' by my cousin... I gave it a kiss to show that I wasn't disgusted." (E12)*
>
> *"When I heard about the bacteria, I was afraid to get it. But then I was there, at the time of the visit, I didn't say anything... I spent the day thinking and afraid to get this disease from him." (E14)*
>
> *"God forgive me, but I was very afraid of getting this infection ... I felt so bad. My dad and I here with his 'disgust'." (E15)*

As perceived, the word "disgust" was presented on several occasions. Probably, it expresses the distancing of the professional, that is, the lack of humanization of care and adequate reception to the family by health professionals[27]. Contact isolation involves not only the hospitalized user but also the whole family, who experiences hospitalization daily and who often falls ill psychologically due to the distance imposed[28].

For health promotion, in the moment of isolation of a loved one, nurses and other health professionals need to add in their care the inclusion of the family by welcoming, listening to their needs and resolving interventions[29].

The family is a powerful ally of the health team, so knowing your characteristics, needs and expectations favor quality care, contemplating humanization, bonding, and communication, important aspects for health promotion, with family-centered care, already present in the Ministry of Health's National Policy for Critical Patient Care[30].

Some companions of the present study reported in a terrifying manner the way they are approached for the use of personal protective equipment (PPE) because they cannot understand why they should protect themselves when they come into contact with a family member they love so much and are not disgusted with. Regardless of the type of infection, a set of measures must be adopted to care for hospitalized patients when there is a risk of contact with blood, bodily fluids in general, secretions and excretions, solution of continuity of the skin and mucous membranes[31].

It is necessary to guide visitors about the clinical condition of the patient who is in isolation. Explain the use of protective equipment and hygiene routines, showing more clearly the need for all that, involving them in the process. Enable the understanding of the health condition and living with the disease so that there is adherence to the care and routines necessary for the quality of care and prevention of hospital infections[32].

Health professionals should make family members aware that the measures adopted are fundamental so that there is no transmission of bacteria/viruses, removing the impression that their family member is being treated with disgust. Transmission by skin-to-skin contact and contact with environmental surfaces is related to failures in the use of personal protective equipment, failure to wash hands, breaking aseptic techniques, among other factors[33].

Another study shows that the involvement of companions in the care process at all levels of health care can contribute to the satisfactory performance of professionals concerning patient safety, being co-responsible care partners, mainly in activities related to maintaining a safe environment, such as hand hygiene and the use of personal protective equipment[34].

**Feelings experienced by the need for isolation**

This category deals with the feelings of family members, the importance of using devices, preventive and protective measures, a context in which faith and hope end up giving way to discouragement and sadness:

> *"[...]I was discouraged myself, several times ... The situation was very sad, Seeing my cousin breathing through devices ... I cried a lot." (E9)*
>
> *"Every night I thought: will he be discharged tomorrow? Will it be later? That wait [...] gave us that sadness, right? I lost hope..." (E7)*

When the patient is hospitalized, factors such as distance, not being able to contribute to his improvement directly, the situation of uncertainty, the possibility of death and, in some cases, the lack of response to treatment, cause a feeling of anguish and sadness for the family[35].

In this category, it was observed that family members, often, when faced with contact isolation, are concerned only with the health of their family members, and not with the collective present there, is difficult to interpret these needs for them. When guided by professionals on the necessary behaviors, they do not think they are a gain, as they already have a multi-resistant germ, showing discomfort when having to wear a protective barrier, such as an apron and gloves[36].

On the other hand, when family members are informed about the reason for the isolation and use of ornaments to protect patients, they think differently, they find the work of professionals to be careful and organized:

> *"They have so much care ... Very impressive. Everything to protect people from this infection. There are apron, glove and mask for everyone who visits ... Very organized." (E14)*
>
> *" [...]The third time I went to visit, it was already different. Another nurse explained to me very gently about the bacteria, I thought it was very important and I saw that they were not disgusted, but carefully." (E12)*

A study carried out on the prevention of cross-infection between companions and patients in a hospital environment[37] observed that the lack of transmitted information leaves both the companion and the patient vulnerable to acquiring and transmitting hospital infections. Information was offered to the companions of the present study, with good receptivity and adherence, such as hand washing, no accumulation of unnecessary objects and absence of signs and symptoms of infections while patients remain in the hospital for contact isolation, as the treatment is long and cautious to guarantee the improvement and, finally, the leave.

As the days go by, hope diminishes. For the control of hospital infections, a nursing action is to control the flow of people in the Intensive Care Unit (ICU), because visitors, family members, and other professionals of the institution can be potential sources of transmission. An important action adopted in the ICUs is the appropriate and specific clothing[37].

To carry out an effective treatment, procedures are necessary, such as punctures, invasive procedures, catheterizations, aspirations and a whole technological apparatus, which can cause an impact on the family member,

scaring them, due to the lack of knowledge. If all this is not combined with the explanations of the health team, it can generate apprehension, despair, and impotence in the family[38].

When, without waiting, the patient is diagnosed with an infection that requires isolation from contact, the news can frighten the family members a lot. The fear of the unknown, of this very strong bacterium, which makes your family member need more care, even causes revolt:

> *"I spent a lot of time to understand this situation ... I was disgusted when I heard that my father had a strong infection. Is it worth knowing who was to blame? It won't change anything ... I'm very sad, but in front of him, I give the greatest strength, you know?" (E1)*

> *"[...]When the doctor said that my father had a very strong bacterium, my ground disappeared ... My heart beat very fast ... I couldn't believe a news like that..." (E5)*

In need of precautionary contact, with positive culture results, professionals should guide the companions at the time of the visit. Otherwise, this attitude can lead to the idea that patients should be isolated from other people. The companions, when not being instructed, come to think about the existence of something serious[38].

The impact of the study in question is reinforced for the PNPS[14], which aims to promote dialogue, raises practices based on comprehensive care and health. In the case of this study, professionals must, in a humanized way, raise family awareness about the importance of isolating their patients and the need to use personal protective equipment when visiting the isolation unit for their patient's recovery and protection of the familiar.

Thus, humanization permeates the relationship with ethics and the reception of family members and patients, as well as respect for their rights. Difficulties appear with the precepts of the National Humanization Policy to ensure and execute the assistance practices based on humanization[39], when the professional emphasizes more the technical part, so as not to spread the contamination of the pathogen, than welcoming the family member.

It is noteworthy that the current study has limitations, which mainly include the fact that it involved only family members at the time of the visit, which made it difficult to generalize the results. Finally, the findings indicate that the patient and his family must be welcomed not only in their biological needs but in the use of communication, being relevant as a practice closely related to the humanization of care.

As the National Humanization Policy aims to train professionals whose practice must be guided by actions with technical, scientific and human efficiency, ethically, respecting the individuality of the patient and with a holistic view, improvement courses are suggested for the entire team of these professionals, to minimize the problems detected here.

## FINAL CONSIDERATIONS

The study sought to identify the perception of the experience lived by the family member of the critical patient in contact isolation. It was realized that the presence of the family member is indispensable, and that, many times, he is so weakened by the whole situation that he ends up looking for faith and religion to remain strong in the whole process of illness and hospitalization of his family member.

Another important aspect was the respondents' reaction to the need to use personal protective equipment, both by professionals and themselves during the visit. Family members understood isolation as a kind of "disgust" by professionals concerning their loved ones.

Ambiguous feelings were observed between fear of catching the disease at the time of the visit, thanks for so much care, and revolt for the need for isolation.

## CONFLICTS OF INTEREST

The authors declare that there were no conflicts of interest.

## CONTRIBUTIONS

**Lorena Guimarães Oliveira**, **Gabriela Nunes Monteiro** and **Vanessa Leitão Azevedo** contributed to the preparation and design of the study; the acquisition, analysis and interpretation of data; writing and / or revising the manuscript. **Rita Mônica Borges Studart** contributed to the preparation and design of the study; writing and / or revising the manuscript. **Aglauvanir Soares Barbosa** and **Celi Melo Girão** contributed to the writing and / or revision of the manuscript.

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