

## Psychological Recovery after Critical Illness and Stay in Hospital ICU

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**Abstract:** The effects of critical illness and hospitalization in intensive care units (ICU) have been associated with the presence of negative psychological consequences. This study explores the experiences of sick people who were admitted to an ICU, seeking to know its repercussions on the self. In-depth qualitative interviews and participant observations were carried out with two people since their ICU admission until at least six months after discharge from the unit. Data was analyzed following an adaptation of the clinical qualitative method within a longitudinal frame and interpreted with Winnicott's psychoanalytic perspective. This research managed to describe participants' lived experiences and the ways they affected their psychic organization. To the interviewed, these experiences configured threshold situations which promoted a process of psychic disintegration. Psychological recovery, then, depends on the articulation of lived experiences, and is supported by facilitating intersubjective relationships that promote the expression of personal potentialities.

**Keywords:** ICU, Intensive Care, Mental Health, Psychological Recovery, Patients.

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### Recuperação Psicológica após Adoecimento Grave e Internação em UTI

**Resumo:** Os efeitos do adoecimento crítico e da hospitalização em Unidade de Terapia Intensiva (UTI) têm sido associados a consequências psicológicas negativas. Este estudo investiga as experiências de pessoas adoecidas que foram internadas em UTI, buscando compreender suas repercussões no self. Foram realizadas entrevistas qualitativas em profundidade e observações participantes com duas pessoas, desde a admissão na UTI até, no mínimo, seis meses após a alta. Os dados foram analisados seguindo uma adaptação do método clínico qualitativo, em um enquadre longitudinal, e interpretados a partir da perspectiva psicoanalítica winnicottiana. A pesquisa descreveu as experiências vividas pelos participantes e a forma como elas afetaram sua organização psíquica. Para os entrevistados, essas experiências se configuraram como situações limite, que estimularam um processo de desintegração psíquica. A recuperação psicológica, por sua vez, depende da articulação das experiências vividas, e é sustentada por relações intersubjetivas facilitadoras que promovem a expressão de potencialidades pessoais.

**Palavras-chave:** UTI, Cuidado Intensivo, Saúde Mental, Recuperação Psicológica, Pacientes.

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### Recuperación Psicológica después de una Enfermedad Grave y Admisión en la UCI

**Resumen:** Los efectos de una enfermedad grave y de la hospitalización en Unidades de Cuidados Intensivos (UCI) se asocian a consecuencias psicológicas negativas. Este estudio abordó las experiencias de personas enfermas hospitalizadas en UCI, con el fin de comprender sus repercusiones en el self. Se realizaron entrevistas cualitativas a profundidad y observaciones participantes con dos

personas, desde la admisión en la UCI hasta, por lo menos, seis meses después de haber dado el alta el paciente. Los datos se analizaron de acuerdo con una adaptación del método clínico cualitativo, en un marco longitudinal, y para su interpretación se aplicó la perspectiva psicoanalítica winnicottiana. La investigación describió las experiencias de los participantes y la forma como estas han afectado sus organizaciones psíquicas. Según los entrevistados, las experiencias se configuraron como situaciones límite, las cuales han promovido un proceso de desintegración psíquica. La recuperación psicológica dependió de la articulación de las experiencias vividas y estuvo sostenida por relaciones intersubjetivas facilitadoras, las cuales promovieron la expresión de potencialidades personales.

**Palabras clave:** UCI, Cuidado Intensivo, Salud Mental, Recuperación Psicológica, Pacientes.

Long-term follow-up has shown that people discharged from ICU often show physical difficulties, such as weakness, pain, and lack of appetite and psychosocial difficulties, such as anxiety, insecurity, sadness, impairment of social and family relationships, and restrictions to performing daily and occupational activities for at least a year (Ewens, Hendricks, & Sundin, 2018; Turnbull et al., 2016). For Deacon (2012) and Rattray, Johnston, and Wildsmith (2005), the consequences of critical illness and admission to ICU may promote poor recovery, with impaired physical and mental functions and decreased quality of life due to loss of these functions and several physical and psychological adverse symptoms. Sukantarat, Greer, Brett, and Williamson (2007) and Wolters et al. (2016) state that many critical illness survivors, irrespective of the presence of physical impairment, will show delayed recovery of their previous health status and will remain at an increased risk of death for some years.

The experience of needing intensive care, unlike other forms of hospital admissions, can produce suffering due to its association with painful procedures, a sense of helplessness and hopelessness, loss of control, and the imminent threat of death (Wu, Cho, Chow, Tsang, & Tse, 2018). Wade et al. (2018), Wolters et al. (2016), and Sukantarat et al. (2007) show a high incidence of psychological symptoms, even when patients remain in an ICU for one or two days, highlighting the potential impact of ICU hospitalization on patients' psychological conditions and quality of life. Psychological symptoms includes significant level of anxiety, depression, and post-traumatic stress, even after they leave the ICU. Moreover, they may experience hallucinations and nightmares, in addition to the sensation of a strange or unreal body, intense tiredness or episodes of delirium accompanied by indistinct memories (Agard, Egerod, Tonnesen, & Lomborg, 2012; Deacon, 2012; Engström, Andersson, & Söderberg, 2008;

Johnson, Winsome, & Wendy, 2006; McGiffin, Galatzer-Levy, & Bonanno, 2016; Samuelson, 2011). After leaving the ICU, people can show vivid and unpleasant recollections of their ICU admission and strange memories of perceptive experiences, associated with a feeling of being in another place, living a different situation or fighting for survival (Karlsson, Bergbom, & Forsberg, 2012; Löf, Berggren, & Ahlström, 2006; Rattray et al., 2005; Zetterlund, Plos, Bergbom, & Ringdal, 2012). The authors further highlight that, as a result of their vivid and intense nature, these memories are highly disturbing and may be evoked a long time after discharge from the ICU. According to Lykkegaard and Delmar (2013), people that underwent intensive care tend to experience high levels of dependency and significant reduction in their self-care competencies, increasing the feeling of vulnerability and restrictions after the discharge. Furthermore, the difficulties in remembering events occurred in ICU stress the feeling of confusion, reaching even body perceptions, (McGiffin et al., 2016; Samuelson, 2011). These symptoms can be understood as the effects of a psychic disorganization process related to the critical illness and admission to ICU.

Within the Brazilian context, the scientific literature points to similar results regarding the consequences of ICU admission on patients' mental health, finding PTSD and anxiety and depression symptoms, which also affected patients' quality of life, associated to physical and psychological conditions (Calsavara, Costa, Nobre, & Teixeira, 2020; Costa, Marcon, & Rossi, 2012; Righy et al., 2019; Rosa et al. 2019; Rovatti, Teodoro, & Castro, 2012; Teixeira et al., 2021). Costa et al. (2012) and Rovatti et al. (2012) found that patients' psychological symptoms also included affective or illusory memories, feelings of hopelessness, and fear and loss of control, which they experienced vividly, thus evoking anxiety and behavioral changes.

Despite the growing recognition of the necessity of clinical follow-up interventions after ICU discharge, knowledge about symptom evolution and the factors which may contribute to its prevention and recovery is still limited. Note that most such study findings arise from cross-sectional measurements via systematic evaluation instruments (Jackson & Jutte, 2016; Rattray et al., 2005). In general, such studies seek to measure psychological symptoms at different time points, starting from ICU discharge to identify and quantify possible psychological symptoms and highlighting the relevance of increasing the knowledge on how people experience critical illnesses and ICU admission, their subsequent psychological condition, and the course of their mental recovery from a longitudinal perspective.

## **Theoretical and empirical background**

### **Emotional maturity and the notion of a facilitating environment**

Winnicott (1990), an English pediatrician and psychoanalyst, offers a conception of human development that emphasizes the role of a facilitating environment and its effect in the establishment of relationships. For the author, the social environment plays an active role in the process of the constitution of the self, which extends throughout the life of an individual. Therefore, the constitution of the self is possible from the inter-human encounters which occur in this environment. These encounters are fundamental for psychic transformation when characterized by the devoted availability one shows to the needs of another person. Such an encounter between the person and the social environment occurs based on the potential compatibility between the needs of a person and how the other perceives and behaves before them (Mizrahi, 2010). Thus, caregivers must adapt to people's particular needs, offering little resistance to their creative vital force since they perceive it as a part of it. Under this condition, Winnicott (1945/2000) claims that life, if sheltered by a facilitating environment, can flow continuously, promoting the constitution of the self via spontaneous articulation of what is experienced. The constitution of the self therefore results from establishing an integration of lived experiences. Mental unity and an integrated self is not permanently and completely achieved, but belongs to a dynamic

process, which, in association with the environment, can succeed or fail (Winnicott, 1945/2000).

Furthermore, the author highlights that situations in which the environment is stressful or poorly adapted to the necessities of the person impose the task of dealing with excessive environmental demands, which leads the person to react to this environment with little spontaneity. When reality becomes too demanding and with little connection with previously lived experiences, the achieved unit of the self thus far is at risk of psychic disintegration, manifested by the potential loss of the psychic organization previously achieved and of the notion of self as experiences disintegrate (Winnicott, 1990). This disintegration can occur in situations of extreme emotional overload (lived as catastrophic experiences) and when the person fails to receive proper care via interhuman encounters, causing a deep feeling of existential emptiness and experiences of unthinkable agonies (Winnicott, 1960/1988, 1969/1994).

Winnicott (1960/1988, 1945/2000) recognizes the fundamental relation between the environment and tending to basic human needs as a body conception and the subjective perspectives of what is bodily experienced. The author understands that people become distinguished beings from an imaginative elaboration of their feelings, somatic parts, and functions which are experienced since the beginning of their lives in a continuous process. They mentally develop their body schema directly from reality. From this contact with the world, they personally appropriate their anatomical sense, feelings, movements, and general functioning of the body, which promotes accommodation of the psyche in the body and gives meaning to physical experiences (Winnicott, 1990, 1945/2000). Therefore, the human psyche is anchored on the imaginative elaboration of the bodily experience, related both to organic possibilities and to personal previous experiences. From the starting point of Winnicott's theory, critical illnesses and treatment procedures adopted in ICUs impose changes to the body schema the ill have reached throughout their lives, which can lead to psychic disintegration and demand a process of reintegration of this new schema.

This comprehensive approach of the self-constitution as an integrated self, dependent on a facilitating environment, highlights the processual nature of human constitution, which can be affected by lived experiences. In this sense, Winnicott's theory (1945/2000, 1969/1994, 1990)

widens the possibilities for understanding the experiences lived by people in ICUs and other possible environments after discharge, evaluating them as environments which can both potentially favor or disfavor the integration processes of the self.

This study aims to discuss the experience of critical illness and admission to an ICU. It explores experiences of psychological helplessness and mental breakdown and the ill's mental health and self-perception outcomes. It also intends to reflect on the need to reconstruct the unconscious body schema and the importance of supportive relationships in this process.

### **Design and methods**

This is a multiple-case study with qualitative strategies of data collection and analysis. This study was simultaneously conducted with a known number of cases to study a phenomenon or general condition (Stake, 2000).

### **Study context: a tertiary hospital and its intensive care unit**

This study was conducted at a public university hospital in a medium-sized municipality in the state of São Paulo, Brazil. The intensive care unit of this hospital has a general and mixed division with nine beds, allocated in a same collective room, which offers intensive care to adults with various pathologies and in critical clinical conditions. We should mention that one of the authors worked as a psychologist and researcher at this university hospital, which enabled encounters with people's lived experiences when they were critically ill and needed intensive care for the first time, as well as with their caregivers' experiences. Therefore, this study was designed from an empirical context inspired by the demands which emerged from it.

### **Ethical considerations**

This study was approved by the Ethics Committee in Research of the Hospital in which it was conducted. Only those participants who agreed and signed an informed consent forms were included. They have been substituted for fictitious ones to ensure patient confidentiality.

### **Data collection**

Data collection was designed to apprehend the experience of severe illness and admission to the ICU from a processual and longitudinal perspective.

At least three in-depth interviews were carried out with each participant at different chronological moments to assess participants' experiences related to the ICU admission, its emotional repercussions, their daily lives, and their social re-insertion after discharge. The first interview took place within a month after discharge from the ICU, aiming to find how patients experienced their critical illness, the admission to the ICU, and their first actions toward resuming their routines after intensive care. Thus, participants were asked to describe their experiences using the initial guiding question: *Can you tell me about the time you spent in the ICU?* Participants were interviewed in the hospital ward (due to their specific health needs) in a room which preserved accessibility, privacy, and confidentiality and lasted from 1h30 to 2 hours.

Moreover, two further interviews were carried out with each participant three and six months after discharge from the ICU. These interviews were conducted to increase our understanding of the course of experiences subsequent to their critical illness and admission to the ICU, using the initial guiding question: *Tell me a little about how your life has been since leaving the ICU.* These interviews took place in consulting rooms at the ambulatory facilities of the hospital, which preserved privacy and confidentiality in situations in which participants would attend medical consultations. Some interviews took place in participants' homes due to their preferences or to the fact that they would only return to the hospital in an inconvenient moment for data collection. When the interview was carried at participants' home, the researcher managed to carry them in a private and comfortable place, protected from disturbances. These interviews lasted from 1h30 to 2h30. In situations in which participants needed to cancel or reschedule interviews due to clinical impairments related to the disease, phone contact was kept to maintain their bond with the researcher. All interviews were recorded and transcribed in full within a maximum period of two days after they took place, the moment in which data analysis started.

The collection of participants' observations, understood as the systematic natural observation of groups of people in their daily lives, were carried out by visits with volunteers, wherever they were (ICU, ambulatory care unit, hospital ward or at their home). During the selection phase, the researcher managed to regularly visit the ICU, seeking to reach familiarity with the ICU routine and follow patients' clinical

evolution. Sick people were invited to join this study during their ICU admission, when they showed clinical conditions which assured their comprehension and the free will to choose whether they wanted to participate. After ICU discharge, participants were observed in the hospital ward, in an ambulatory context or in participants' homes. These observations, carried out with to maintain a proximity between the researcher, participants, and the situations experienced by them, were immediately recorded and organized in a field journal.

## Data analysis

The clinical qualitative method was adapted for data analysis (Turato, 2008): 1) First level: introductory reading of the registered material in a maximum period of two days after its collection to impregnate researchers with the material and facilitate the perception of the covered themes, contradictory dimensions of the descriptions, and silenced themes; 2) Second level: reading of all collected material from each participant, carrying a deep analysis of what was uniquely lived by each of them which considered their particularities. Researchers sought to find how participants' experiences were organized throughout time, their repercussion on one's self (regarding psychic disintegration expressions), and the way they engaged in a self-integration movement. 3) Third level: identification of the common elements in participants' analyzed second-level personal and singular experiences; composition of two comprehensive axes on the manifestations of psychic disintegration caused by the critical illness and intensive care needs; and further developing of the discussion on the collected data regarding the adopted theoretical framework. Data analysis, in all its levels, was reviewed by an independent specialist researcher to assess its coherence and appropriateness.

## Participants

Critically ill people admitted to intensive care for the first time were invited to participate in this study according to the following inclusion criteria: 1) showing an unexpected and unprecedented critical illness; 2) ages between 25 and 50 years; 3) a minimum stay in the ICU of three days; 4) need of at least one procedure with advanced life support technology; and 5) residing within a radius of 100 kilometers from the city in which the study was developed. Exclusion criteria included a) no clinical-neurological

conditions to participate in the interviews upon discharge from the ICU and b) incomplete participation in data collection.

Of 122 critically ill people, aged between 25 and 50 years, who were admitted to the ICU between July 2011 and August 2012, 107 were excluded due to the following conditions: ICU stays shorter than 72 hours and/or readmission, death, or residing more than 100 kilometers away. Therefore, 15 critically ill people were eligible to participate in our study. Of these, nine had no clinical-neurological conditions to participate in the interviews upon discharge from the ICU and were thus excluded. Among the six critically ill people who met our inclusion criteria and participated in the beginning of data collection, two completed the interviews over a six-month period.

## Analysis and discussion

We organized our data analysis into two topics: 1) each participant's characteristics and clinical history, and 2) their lived experiences regarding their ICU stay and discharge throughout time, from a longitudinal perspective, disposed in two comprehensive axes, named: *Experiences of becoming ill – angles of understanding* and *Long-term challenges for psychic rehabilitation*.

## Description of participants

Participants showed a previously healthy status, no chronic illnesses, and irregular use of hospital services. We summarize their clinical background below:

Vitória (36 years old, divorced, mother of four children) received a diagnosis of adenocarcinoma of the rectum, suffered infectious complications post-chemotherapy, and showed a suspected intestinal sub-occlusion; remaining in the ICU for 19 days. She was on mechanical ventilation, vasoactive drugs and underwent hemodialysis and a tracheostomy. After discharge from the ICU, she remained on the ward for five days, during which the medical team planned a procedure to remove the tumor. Then, 70 days later, physicians operated her, removing her rectum was amputated and implanting a colostomy. In the following period, Vitória felt intense pain, showing an abdominal infection which required further surgical intervention, besides dealing with the expectation of continuing chemotherapy treatment. After her discharge from the ICU, Vitória went home to her

children eight months later and planned to resume work, facing the challenge of dealing with the colostomy.

Isabela (37 years old, married, mother of two children) was run over on a public highway, resulting in mild traumatic brain injury, fractures, abrasions, and the need for orthopedic surgery on her right leg. She showed signs of serious infections, with acute respiratory failure and the need for repeated surgical approaches on the operative wound. She received mechanical ventilation and vasoactive drugs and underwent hemodialysis and a tracheostomy. She remained in the ICU for 15 days, experiencing periods of intense mental confusion, having difficulties communicating, and seeming scared by her surroundings. Isabela was on orthopedic rehabilitation for 25 days in the ward, but showed severe difficulties performing the exercises (in addition to fear) and new episodes of hemodynamic instability due to altered renal function and infections. At the time of discharge from the hospital, Isabela seemed insecure about her recovery and the possibility of going home. She maintained a moderate level of confusion about herself and what had happened to her and an intense fear of being on a public highway. Then, six months after leaving the ICU, Isabela was on a rehabilitation treatment (which significantly improved her condition) but still showed episodes of forgetfulness.

## Comprehensive axes

### *Axe 1: experiences of becoming ill – angles of understanding*

From participants' perspective, becoming critically ill is a "threshold experience," an unknown reality characterized by confusion, disorientation about facts, and intense anguish and fear about their own life and the future, as Isabela's description illustrates.

*I remember up to a certain point of the day I went there [ICU](...) that my son was there. After that, I don't remember anything else. I don't know if it was fever or what it was. Shoulder pain, wasn't it? I don't remember that I was in the ICU. I don't remember. And being there was very confusing because, when I was there in an induced coma, I dreamed many things. I dreamed that I was at my house, that my house had been totally bombed, the way I didn't want it. I wanted to get up but couldn't (First interview with Isabela, in the hospital ward).*

The experiences connected to becoming critically ill within the ICU context challenge people with the imminence of death and the loss of control and predictability of events. It also subject them to situations of manipulation and invasion of their own body, in which they have no control. According to Lykkegaard and Delmar (2013), people admitted to ICUs experience a high degree of dependence and an expressive reduction in their self-care abilities, which intensifies their sensation of vulnerability and limitation.

Furthermore, Isabela's difficulty of remembering ICU events intensified her feelings of confusion (which even reached bodily perceptions), leaving her without knowing exactly if what impeded her memories was the fever or the shoulder pain. These 'threshold experiences' contribute to the appearance of psychopathological symptoms such as intense anxiety, cognitive difficulties, memory problems, and delirium episodes – which has been a highly prevalent manifestation in ICUs (Girard et al., 2010; Karlsson et al., 2012; McGiffin et al., 2016; Needham & Korupolu, 2010; Samuelson, 2011). Isabela referred to episodes of delirium during most of her stay in the ICU. This reiterates the threshold nature of critical illness experiences since delirious perceptions are frequently combined with feelings of fear (Zetterlund et al., 2012), accentuating mental confusion. Critical illness entails living with physical and psychological precariousness and may put in question patients' sense of existing in the real world. In this sense, we should consider how the loss of health leaves the person vulnerable, which may relate to a potential risk of psychic organization disintegration. Critical illness, in particular, may represent a sufficient overload to promote the transitory loss of the person's capacities and psychic organization.

Critically ill people describe experiences of confusion and disorganization, as defined by Winnicott (2000), such as gathering memories which are unclearly connected, experiencing difficulties establishing a temporal sequence of events, describing what happened to them, and communicating with healthcare providers and caregivers, which might constitute manifestations of a disintegration process. Moreover, people also refer to thoughts and perceptions which are disconnected from the reality and organized in a delirious account of their hospitalization, which may signal the intensity of the disintegration process. Thus, critical illnesses and admission to intensive care may involve the loss of the integrated self, which patients can

no longer articulate in their personal histories, becoming psychopathological manifestations.

*I remember like it was all real. They gave me a shower (pause). Yeah, maybe they really were giving me a shower. I don't know. But I remember that they gave me a shower, they laid me on the bed, the same as in the ICU – which has a tall bed, which has a tall thing. And I stayed there. . . . I was in a cubicle, where there was one of these things here (oxygen tubes on the wall), which I thought water passed through. And I thought about breaking it to drink water. Up to then, it was all right, but... on the hospital wall, I was in a tight little space that could only fit a bed; creatures and monsters appeared... They said that if I didn't do it the correct way, the system would never let me go. It was madness! After that, I felt sick. I was suffocating, no, they took away the air. Talking to my mum, it coincided with the time when I got worse there in the ICU, and it was midday, and I almost died. I remember that. But then a nurse came and said: "My God, let me give you suction!" And she did and it relieved me. I spent a night totally tormented in this hospital. And that nurse forgot to put me in or take me down in the elevator so I could leave. That was when she decided to take me to her house (First interview with Isabela, in the hospital ward).*

We should highlight that, although these delirious experiences failed to correspond to what actually happened, they retain some relation with what Isabela experienced in the hospital. Real elements of her surroundings, such as the faucet of the oxygen system on the wall and the ICU bed, and other real experiences, such as the shower, her husband and mother's visits, the moment at which she "suffocates" and the change of hospitals, appear mixed in her delirious experiences. We also find references to physiological aspects, such as thirst, and feelings, such as of being sick or dying. Therefore, the loss of the integrated self and the fragmentation of experiences may promote the appearance of psychopathological symptoms but not necessarily involve a definitive rupture with reality. Winnicott (1960/1988) indicates that an intrusive experience with the potential to interrupt the continuous sequence of experiences that constitute the self may result from contact with a varying environment. Thus, this characteristic of the environment may lead

to hyperactivity in mental functioning as an attempt to compensate for shortcomings and protect people against unbearable anguish. We can consider that, in critical illness, ongoing occurrences may lead to failures of the environment with intrusive potential. Studies have described the high degree of dependence and lack of control as examples of these occurrences, which can constitute a greater threat to patients than the possibility of death (Lykkegaard & Delmar, 2013).

Note that these delirious experiences have a certain order, even if incomprehensible *a priori*. From the perspective of Winnicott's theory, the person remains in constant interaction with the world, and one's behavior is the best possible considering the game established between their internal resources and present conditions (Mencarelli, Bastidas, & Vaisberg, 2008). Transferring these considerations to life-threatening situations, experiences of delirium may constitute the best possible organization of conduct of a person on that occasion. Moreover, these experiences have a sense of expressing people's anguish at facing loneliness, strangeness, and the incapacity to move or communicate. We can recognize them, then, as an action of the critically ill person which may carry a relevant message regarding their necessities. The content of delirious experiences may offer clues to healthcare staff on how to respond to the question: what does the person experiencing this condition need? Perhaps the psychological difficulties during an ICU stay express aspects related to the psychic organization of the critically ill and possible ways to deal with and give meaning to these events. This highlights the importance of refraining from ignoring or disregarding these psychopathological symptoms but, instead, analyzing them, considering their possible meanings and putting them into the perspective of an ongoing suffering which supportive interactions between healthcare providers and the ill might attenuate.

It is interesting to note that, despite these psychopathological manifestations (which are connected to a process of psychic disintegration), critically ill people are not in a passive condition either during hospitalization or after discharge. They retain aspects and capacities which enable them to act toward psychic rehabilitation. We can observe a constant effort to bodily and imaginatively organize perceptions in an attempt to give meaning to their experiences. Therefore, in a threshold situation such as that imposed by critical illness, the possibility of regaining/remaking the

organization of psychic experiences seems to come from and relate to what happens with the body. From the perspective in Winnicott (2000), the constitution of the sense of self depends on the imaginative elaboration of bodily parts and functions and connected feelings to construct a mental schema of the body. This schema reflects a personal appropriation of bodily functions and gives meaning to physical experiences. It is then that an indwelling of the sense of self inside the body may be conceived, as the self and the body overlap and identify with each other (Winnicott, 2000). Critical illnesses and patients' consequent admission to ICUs might jeopardize the meaning of lived experiences and the lodging of the notion of self in one's own body since it imposes modifications on how the body works, is manipulated, and is perceived. Thus, the person who becomes critically ill might experience moments in which the self is lost and recognizing the body as one's own becomes a challenge. On the other hand, in a context which might compromise their symbolic capacity, the available language to reconstruct the meaning of experiences seems to the body language (or a language which flows through the body). Thus, for a certain time, critically ill people might be unable of understanding and dealing with reality from a verbal description as this involves a preserved and active symbolic function which can represent experiences in a verbal record. These people may need to begin a process of comprehension and articulation of their experiences based on what the body feels and performs. As such, body manipulation procedures in health care seem to be relevant in the process of integrating experience.

*Remember that I told you about when they took me out of the bed, with all the patience in the world, and turned everything off (equipment) – they put in a chair, a television, a cushion and then they turned everything on again. At that moment, I felt important, as if I made a difference. They just cared. So, I wasn't afraid the next day when I asked to get out of bed again nor the day after because they helped me with so much affection, turned on all those things, made me comfortable, and held me. I think the first time it wasn't even for a minute because I couldn't steady my legs. Maybe, if someone had said something like "Hey, you cannot do it!"; "Hey, it won't work!" I wouldn't have tried to stand up again the next day. So, it's very delicate,*

*because it's not someone else who's there, it's you. You are so upset and disbelieving that whatever someone does, at times is small but can do you a lot of harm and the other person, sometimes, doesn't even notice (Fourth interview with Vitória, in the hospital ward).*

The experience of getting up and standing contains important characteristics responsible for facilitating psychic rehabilitation since it was presented and performed in a way which enabled Vitória to accompany and recognize the beginning and the end of the activity, besides recognizing her body and affective perceptions. Furthermore, we found the mutuality between Vitória and healthcare providers, as they performed the action with intimacy and as a group, whereby the people involved were physically and affectively harmonious, which promoted adequately coordinated actions in accordance with Vitória's conditions. Lykkegaard and Delmar (2013) state that when care is personalized to meet patients' needs without them excessively asking for help, we find a possibility of patients perceiving the experience as positive and the condition of dependence as bearable.

However, few experiences in ICUs have these characteristics. Usually, several actions take place at the same time, with several healthcare providers interacting and performing procedures on the ill. For example, Vitória describes a situation in which the noise of staff using a sink close to her bed suddenly interrupted her sleep. Thus, experiences are frequently interrupted due to overlapping events, such as dressing a wound, preparing for a procedure, and simultaneous injections. In these situations, bodily integrity, in association with its attributed meanings, is threatened, characterizing care as a violation (Lykkegaard & Delmar, 2015).

For an experience to be fully lived and have the potential to promote psychic rehabilitation, events should take place one at a time, with healthcare providers' empathy and dignity. The organization of care activities should consider this element, especially for staff involved in bodily care procedures, such as nurses and physical therapists. Valuing the articulation of bodily and psychological experiences should not only be based on promoting contact and providing information to the ill about what is happening to them but also on organizing the events in terms of complete mutual

experiences. Winnicott (2000) states that the repetition of complete experiences favors perceptions of permanence, consistency, texture, and rhythm and can accrue into and articulate increasing awareness based on familiarity.

Furthermore, it is via the relations the body has with the world around it that people can transform themselves (Stein, 1933/2003). This highlights the need to consider the effects of treatment on people not only from physical/bodily marks or consequences but also as elements which may interfere in the psychophysical unit of a person. Therefore, the dimension of corporeality, referred to as moments of strangeness regarding one's own body, (e.g., the critically ill seeking autonomy of movements or the performance of small bodily gestures) is fundamental to constitute and rehabilitate the self. Thus, body manipulation, invasive procedures, and quality of interactions are factors which affect how the ill maintain or lose mental health in an ICU context, including their participation in the transformation of the self, the imaginative body schema, and the meanings attributed to events. Hope and empowerment can emerge from the perception of performing acts which are more integrated and functional. It is as if the broken experiences were once again articulated by the bodily relations established with the world, enabling people to recover their own recognition as human beings. Vitória's testimony evinces that she is a constant observer both of the environment and of herself. She interrelates with the world, which informs her about her fragile condition and encourages the possibility of renewing her capacities. Therefore, this indicates the importance of an attentive eye of healthcare providers toward the ill's movements and bodily acts and their needs for support and care. This openness in caring for people and their psychophysical integrity may contribute to regaining the preserved or conquered capacities, promoting psychic rehabilitation.

Another aspect we should highlight relates to Vitoria telling she "wasn't afraid the next day when I asked to get out of bed again, nor the day after, because they helped me with so much affection, turned on all those things, made me comfortable, and held me," emphasizing the importance of the other in providing support in physical and psychological actions. Winnicott (1945/2000, 1969/1994) states that if these actions are performed by someone who is unprepared or weakened, including from a psychological

point of view, another caregiver must support, sustain, and contain them. This attribute refers to the availability and capacity to receive, tolerate, and facilitate possible but imperfect actions so they can be gradually modified and refined. The high degree of vulnerability of the critically ill, both from the physical and psychological perspective, makes this type of support especially important for people's capacity to reestablish themselves. This support should be flexible as it has the peculiarity of having to adapt to constantly changing needs (Pimentel & Coelho, 2009). Therefore, the course of development by the ill during critical illnesses and their admission to ICUs can be constructed in connection to the reality being experienced.

Thus, what seemed to be at risk for Vitória and Isabela during their moments of extreme vulnerability was the integrated self and their possibilities for action. What seemed to help them sustain reasonably integrated experiences were the relationships established with people who could recognize them. Here, the expression "relationships with people who could recognize them" relates to the contact with people who acknowledged their needs and could do something about them either by meeting these needs or by being a partner who provides support when meeting needs is impossible. When these relationships failed to enable Vitória or Isabela to feel seen or recognized, the imminence of finitude and of the impossibility of staying alive became dominant. As Ambrosio and Vaisberg (2009) indicate, in vulnerable situations, opportunities of caring for oneself depend on the active and ethical participation of the human environment, which supports and promotes the constitution of self.

#### *Axe 2: long term challenges for psychic rehabilitation*

Long-term follow-up of the critically ill's experiences shows that the appearance of new challenges and needs and the constant uncertainty about the event that occurred characterize the course of serious illnesses and their rehabilitation process. By her perceptions on becoming ill and her evolution, Vitória feels the threatening nature and an intense helplessness toward treatments, offering elements for reflection on the extended process of recovering from a critical illness:

*Before, I thought it was enough to really believe in something and it would happen. But it's not like that! Sometimes, even when we really believe and*

*we really want something, that thing still doesn't happen. I came here (ward) to take some medicine and I almost died. I thought that the medicine would cure me, and it almost killed me. And I didn't even realize that. I went there (cancer ward). I was sleeping and if I didn't wake up, I would have never known. That's scary! I keep imagining: what if I take anesthesia and I don't come back? What if I have chemotherapy and don't come back?* (Second interview with Vitória, in the medication room of the outpatient clinic).

The uncertainty related to treatment results and illness evolution leads to the feeling that an encounter with finitude is inevitable. Discharge from the hospital, subsequent treatment at different setups, the appearance of new health problems, complications from previous procedures, and the need to overcome treatment stages uncover and confirm personal limits. Critical illnesses thus evince a scenario of extensive, long lasting, and, at times, subtle physical and psychological limitations, as exemplified by Isabela: "I can't remember my clothes, can you believe it? I don't remember what clothes I have, I don't know if I have a skirt... I open my wardrobe and can't get anything, can't get dressed" (Second interview with Isabela, in the ICU). These limitations interfere in daily life and in any activity, demanding constant adaptation and transformation. Since limitations can show such diverse and particular characteristics, we can only identify them by taking an interest in knowing how the ill have been living and how they rate their lives. Agard et al. (2012) and Oeyen, Vandijck, Benoit, Annemans, and Decruyenaere (2010) indicate that signs of psychological difficulties tend to appear later on, after the resolution or accommodation of physical problems. These authors state that people who show significant cognitive impairment after discharge from ICUs will need to relearn simple day-to-day activities, such as getting dressed. They further mention that despite suffering a great impact on their capacities, they may be unable to recognize, accept or comprehend the gravity of their situation. Karlsson et al. (2012) and Ewens et al. (2018) highlight the importance of healthcare providers' partnership and participation and the performance of care in accordance with the ill to promote security, belief in improvement, and the sense that they are able to face their fragilities. According to these authors, the number of difficulties and their long duration emphasize the importance of creating follow up/rehabilitation

programs for people who suffer from critical illnesses and are admitted to ICUs.

According to Deacon (2012), these programs have the objective of promoting the continuity of treatment in other healthcare services after discharge from hospital. In these new contexts, such programs can inform healthcare providers on diagnoses, initial treatment plan, and tailored health actions. Our follow-up of both participants show their difficulty to find treatment continuity after discharge. Vitória and Isabela's accounts indicate that in the vast majority of situations in their pursuit of other healthcare services, the only information on diagnoses, hospitalization period, and the procedures that they had undergone came from their own verbal accounts. In their perceptions, if a document was available, such as medical prescriptions, it usually lacked sufficient instructions. Isabela described the only exception, which concerned her physiotherapeutic treatment, performed at a basic health unit in her municipality. She described that the evaluation performed at the hospital to define the exercises and weights to be used to rehabilitate her leg were prescribed in a document prepared for the healthcare providers at that basic health unit. All other healthcare aids, such as collecting information on and access to an alternative therapeutic measure to a colostomy bag (which Vitória sought), and the recommendation of an antidepressant for Isabela, stemmed from their own active search, disconnected from the services which initially provided treatment or were selected for continuing treatment.

The discontinuity of treatment during their trajectory across different health services seemed to relate to a communication failure among healthcare services, whereby the procedures initiated in one were abandoned in the next. The transfer of information seems to be under responsibility of the ill and their caregivers, who must describe diagnoses and wait for a definition of procedures. Such situation can be a solitary challenge and may constitute a stressor of sufficient magnitude to compromise patients' psychic rehabilitation. The absence of assistance during migration from one service to the next and the lack of mutuality in the new relationships may increase the risk of relevant aspects of the illness being improperly reported, such as complications, technical procedure specifications, and conducts associated with those diagnoses, increasing patients' feelings of helplessness.

Furthermore, an integrated treatment can arise by the constant contact with the ill and an open curiosity about circumstances beyond the medical-hospital context, thereby identifying areas of difficulty. With such information, referrals can occur in accordance with present necessities, and strategies on the best way to follow up successes or failures of the recommended treatments can be planned. Therefore, recovery occurs based on attention to patients' movements and constant availability to offer and seek out the necessary technical resources in partnership with the ill. We should also emphasize that this type of action can assist in identifying limitations and capacities both at the physical and psychological level, contributing to a care strategy that assists the ill to achieve a living condition with as few restrictions as possible.

*I think that my personality is much stronger. I said to him (husband): "I don't want you to stay with me as if it were an obligation. Because if you feel it's an obligation and there's no love anymore..." Is it difficult? Yes, it is. Are we in a difficult situation? Yes, we are. But I don't want to live with someone who is unhappy. I want to be happy. I think that he got scared. Then, he said: "You aren't well. You aren't well." I said: "I am fine. I'm fine in the head. Some things happened but I'm ok, I know what I'm saying." I think that he got scared, you know? Because I want to live my life with him or without him. Life is very precious, you understand? (Third interview with Isabela, in the ICU).*

Both Isabela and Vitória talk about having plans for different areas of their lives, seeking alternatives to help them enjoy life from a new perspective since the perception that *life is very precious* has become very evident for both of them. Thus, analysis of participants' accounts enables us to understand the experience of becoming critically ill as a potentially favorable moment to accomplish personal transformations. Likewise, Agard et al. (2012) found that, regardless of the number of clinical complications, critically ill participants expressed a strong motivation and showed personal resources to seek the best physical and psychological recuperation possible. They reported perceiving new qualities in life, with renewed feelings of connection with their

caregivers and their families and feelings of gratitude for being alive. Therefore, critically ill people seem to have the resources to enable them to think about and pursue changes based on demands their situations bring. It is interesting to note that accomplishing these changes seems to involve the need to defend their own state of health and their capacity to choose based on free will. Therefore, this shows the importance of assisting the ill to examine their experiences, identify values which are coherent with what they have experienced, and to reformulate their life projects.

## Conclusions

Critical illnesses and hospitalization in the ICU, as participants experienced it over at least six months after discharge from intensive care, contained experiences which confronted them with threshold situations. Such situations promoted a process of psychic disintegration, manifested by confusion, disorientation about the facts, delirious and intense anguish, and fear about their own life and future, as well as transformational experiences stimulating a connection with life. These experiences represented an important overload, involving the risk of either closing down into a paralyzing isolation with a precarious mental health state or opening up to integrate the experience of becoming ill in an updated sense of self which would be liable to transformations.

The authors conclude that the recovery process from a critical illness involves not only reestablishing bodily functions and controlling physical symptoms but also recuperating the self and identifying who one can become as a result of these experiences. This recuperation seems to take place via the movements of the ill and those of the relationships which can be established with the environment while they remain in ICU and upon their discharge. Our analysis of participants' reports showed their difficulties resuming their life, which go beyond the physical impairments due to critical illnesses, highlighting the necessity of continuous support in facilitating environments.

To be constituted as a person, as an integrated self, involves combining, articulating, and manifesting what one is, thinks, hears, sees, and feels (with the help of the environment) and being able to recognize affective states and bodily changes as part of the self (Winnicott, 2000). Thus, considering the context of health under investigation in this study, it is evident that the reformulation of life projects

and the constitution of the person depend a lot on the relationships established with healthcare providers, including a human and ethical dimension. Constructing another meaning for the history of a person and articulating past experiences, potentialities, deficiencies, and the awareness of the present and future expectations, seems to be infiltrated by how healthcare is performed. Such construction seems to particularly relate to the way some aspects of care are processed, such as how relationships are established, body management procedures are performed, and how the body is re-presented to the ill.

The relationships participants in this study maintained with healthcare providers seemed to enable them to hold on to life and achieve enough body function to remain alive. This is a silent movement, which seems to accompany their critical illnesses and represent associated possibilities of transformation. We should highlight that people, even if in a state of critical illness, have this capacity, which, when recognized by healthcare providers, can promote the delivery of care with greater potential to aid. Therefore, healthcare providers should keep an attentive and curious eye toward the critically ill to obtain elements to help to establish a connection which favors physical and psychic recuperation.

In this study, participants performed reformulations of their life projects, which opened up a new and more authentic way to live. This indicates a potential flexibility of the perspectives contained in life projects, contemplating new ways of living and recovering, even if they are unable to regain their previous health status. Thus, the relationships established between healthcare providers and the ill seem to have the potential to interfere in the latter's evolution course of progression.

We should mention some difficulties and limitations in the accomplishment of this study. One such was the challenge of following up people in critical conditions and learning about their experiences in depth, as they showed a high degree of vulnerability and fragile social conditions. Therefore, our search for eligible participants frequently faced deaths or the impossibility of interviewing and visiting them either due to medical conditions which challenged the "traditional" application of research instruments (for example, interviewing a tracheotomized person, or a tumultuous environment) or due to sudden alterations in treatment or clinical status. These difficulties imposed a restriction on the number of participants

in this study and demanded the researcher's availability to adjust to complete data collection. This flexibility was fundamental for the acquaintance and learning of participants' experiences and is in line with the proposals of this study. These difficulties highlight the relevance of discussing data with the chosen reviewer to sustain a continuous recursive reflection on the researcher's perspective within a qualitative research context. We hope that this study can promote an increased understanding of the necessities of people who suffer from critical illnesses and contribute to the planning and establishment of innovative initiatives in ICU healthcare, such as the ones mentioned herein, including its contribution to the current scenario emerged from the COVID-19 pandemic.

In this sense, we should mention that we conducted this research in a period which preceded the COVID-19 pandemic, starting from the point of view of patients' with critical illness admitted to ICU; experiences which showed their repercussions to the self and their psychic organization. The pandemic brought components which can significantly amplify these resonances, such as unfamiliarity and lethality of the disease, its physical repercussions (such as severe respiratory failure), and significant delirium episodes which require rapid and aggressive therapeutic maneuvers and barriers to interpersonal contact due to the security requirement of healthcare providers' equipment, making these patients almost invisible and unrecognizable and enlarging their feelings of loneliness and disorientation, as we found. Thus, this study offers resources to assess patients' and caregivers' experiences and how the current scenario can affect and amplify them. This framework, shows a remarkable need and relevance for new studies which seek to continue and enlarge the comprehension of how people subjectively experience severe illnesses and ICU admission – as well as possibilities of sustaining integral human relationships within this specific context – during and after the COVID-19 pandemic. Furthermore, we highlight the need of investigations on professionals' perspective since, with the pandemic, they were exposed in a different way to the unknown, to contamination possibilities, high rates of therapeutic failures, and work overload, which can resonate on their health status and on the possibility of sustaining a human presence in the work environment without excessively sheltering themselves on technical attitudes.

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