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RESEARCH

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PALLIATIVE CARE OF NURSING IN THE PANDEMIC SCENARIO ACCORDING TO THE PACIFIC END-OF-LIFE THEORY

Cuidados paliativos da enfermagem no cenário pandêmico conforme a teoria de final de vida pacífico Cuidados paliativos de enfermería en el escenario de pandemia según la teoría del terminal de vida del pacífico

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ABSTRACT

Objective: to describe the care perspective of the nursing team in an Intensive Care Unit for patients diagnosed with COVID-19 and out of therapeutic possibilities, in the light of the Peaceful End of Life Theory. **Methods:** qualitative study supported by the Theory of Peaceful End of Life, in an adult Intensive Care Unit in Northern Brazil. The collection in the second half of 2020 obtained nine professionals, with a semi-structured script and subsequent analysis of three stages. **Results:** interrelationship between "Not feeling pain" and "Experience of Comfort", a polysemy of perspectives regarding "Experience of dignity and respect" and "Being at peace", whereas "Proximity to significant others" was totally affected. **Final considerations:** humanization precepts were in line with the theory, but the lack of standardization regarding pain assessment was a problem. Excluding significant others made peaceful end-of-life impossible for COVID-19 patients.

DESCRIPTORS: COVID-19; Coronavirus; Palliative care; Intensive care units; Critical Nursing.

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RESUMO

Objetivo: descrever a perspectiva assistencial da equipe de enfermagem em uma Unidade de Terapia Intensiva para os pacientes diagnosticados com COVID-19 e fora de possibilidades terapêuticas, a luz da Teoria de Final de Vida Pacífico. **Métodos:** estudo qualitativo com suporte da Teoria de Final de Vida Pacífico, em uma Unidade de Terapia Intensiva adulto do Norte do Brasil. A coleta no segundo semestre de 2020 obteve nove profissionais, contando com roteiro semiestruturado e posterior análise de três etapas. **Resultados:** inter-relação entre "Não sentir dor" e "Experiência de Conforto", uma polissemia de perspectivas quanto a "Experiência de dignidade e respeito" e "Estar em paz", já a "Proximidade com outros significativos" foi totalmente abalada. **Considerações finais:** preceitos da humanização alinharam-se a teoria, porém foi um problema a falta de padronização quanto a avaliação de dor. A exclusão dos outros significativos impossibilitou o final de vida pacífico para os pacientes com COVID-19.

DESCRITORES: COVID-19; Coronavirus; Cuidados paliativos; Unidades de terapia intensiva; Enfermagem.

RESUMEN

Objetivo: describir la perspectiva del cuidado del equipo de enfermería en una Unidad de Cuidados Intensivos a pacientes diagnosticados con COVID-19 y fuera de posibilidades terapéuticas, a la luz de la Teoría del Final de Vida Tranquilo. **Métodos:** estudio cualitativo sustentado en la Teoría del Final de la Vida en Paz, en una Unidad de Cuidados Intensivos de adultos en el Norte de Brasil. La colección del segundo semestre de 2020 obtuvo nueve profesionales, con un guión semiestructurado y posterior análisis de tres etapas. **Resultados:** interrelación entre "No sentir dolor" y "Experiencia de Confort", polisemia de perspectivas sobre "Experiencia de dignidad y respeto" y "Estar en paz", mientras la "proximidad a otras personas significativas" se vio totalmente afectada. **Consideraciones finales:** los preceptos de humanización estaban en línea con la teoría, pero la falta de estandarización en cuanto a la evaluación del dolor fue un problema. La exclusión de otras personas importantes hizo imposible el final de la vida pacífica para los pacientes con COVID-19.

DESCRIPTORES: COVID-19; Coronavirus; Cuidados paliativos; Unidades de cuidados intensivos; Enfermería.

INTRODUCTION

Intensive Care Units (ICU) serve patients in critical condition, relying on technological resources, despite the prevalence of techniques and equipment added to specialized professionals, it is necessary to understand the concept of finitude and the fear of patients that denotes uncertainty. It is known the increase of the palliative public in the ICU, living an uncomfortable experience and recognizing such a deprivation the nursing care will evaluate the function and cognitive dysfunction, identify demands, enhance comfort through goals and offer "resources for transcendence" and currently integrates with family care. ²⁻³

As of 2020, the spread of the Sars-CoV-2 virus, which causes Coronavirus Disease 2019 (COVID-19), has become a diagnostic, treatment, and care dilemma, creating constant pressure on professionals.⁴ Attention is paid to the potential for contamination, which is on average 22 days in feces and 18 days in exudative respiratory samples.

In relation to the principles in palliative care for COVID-19 it is necessary: therapeutic relationship; to evaluate acute conditions, underlying, fragilities, values and objectives of the patient; to explain and discuss options with the caregiver; treatment plan; and seek consent in decisions. The state should urgently recognize and guarantee palliative care for people with COVID-19 making personal protective equipment (PPE) available; making consultations during this period; and discussions about treatment objectives, besides alleviating pain to interfere in the aggravations that generate dependency and discomfort. 3,8-9

Nursing acts using the Nursing Process and its systematization based on theories or concepts. Therefore, it is urgent to address the Theory of the Peaceful End of Life of 1998, which deals with the development of a standard of care in a gastroenterological surgical oncology unit in Norway.¹⁰

Considering the intricate scenario of deaths one wonders: What are the perspectives of the nursing staff regarding nursing care in an Intensive Care Unit for patients diagnosed with COVID-19? The objective was to describe the perspective of nursing care in an Intensive Care Unit for patients diagnosed with COVID-19 and beyond therapeutic possibilities, in the light of the Pacific End of Life Theory.

METHOD

This is a qualitative descriptive study respecting the Consolidated Criteria for Reporting Qualitative Research (COREQ).¹¹⁻¹²

Relational statements of the Pacific End of Life Theory are: 1) pharmacological and non-pharmacological interventions for pain; 2) facilitating rest, relaxation, and comfort; 3) including the significant other in decision making; 4) emotional support and knowing what the needs are to give guidance, providing physical presence; 5) attending to the family's questions and suffering; 6) not feeling pain, giving comfort, allowing dignity, mediating peace and respect are the core of the process. Its outcome indicators are 1) Not feeling pain; 2) Experiencing comfort; 3) Experiencing dignity and respect; 4) Being at peace; 5) Proximity with significant others; and all statements are necessary for the completeness of this.¹⁰

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The site was a hospital in Northern Brazil that is a reference in infectology and treatment of Human Immunodeficiency Virus. The adult ICU scenario has ten beds, due to the institution's profile characterized by infectious and contagious problems most of the time all beds are in contact precaution. During the pandemic, the hospital had this structure for the exclusive care of those diagnosed with COVID-19.

The sample was intentional 13 of nine professionals, 5 women and 4 men, being 5 nurses and 4 technicians, the average age was 32 years, all of them professed Christian religions. Those included were from the morning and afternoon nursing teams, with more than 6 months of experience, who agreed, confirmed having assisted patients with COVID-19 and in terminality, the patients were sedated or comatose, intubated or tracheostomized, on mechanical ventilation, using vasoactive drugs and under hemodynamic monitoring. The exclusion criterion was refusal to participate.

An individualized semi-structured interview was used: "Feel No Pain" – What is your perspective about monitoring the patient in finitude; What is your perspective about pain relief; "Comfort Experience" – Which physical comfort measures are applied? And for prevention of physical discomfort?; "Experience of Dignity and Respect" – How is the inclusion of significant others in decisions accomplished?; How do you understand the patient's dignity, needs, and desires?; "Being at Peace" – How do you usually provide emotional support?; "Proximity to Significant Others" – How is the participation of significant others in the termination process facilitated at this time of pandemic COVID-19?

The interviews occurred in the second semester of 2020 and lasted an average of 20 minutes in the nursing management room, conducted by the first author (resident nurse) being audio-recorded and converted to MP3 and transcribed to Microsoft

Word files. The formation of a corpus to be coded counted on a matrix file resulting from the junction of the individual ones, and saturation was theoretical.¹¹ Data were analyzed with validation by experts in ICU and critically ill patients, and not by software according to three stages: 1) pre-analysis with floating reading; 2) exploration with categorization; and 3) interpretation.¹⁴

Resolution No. 466 of December 12, 2012 was complied with and everyone signed the Informed Consent Form after approval (CAAE 36935720.7.0000.0017). TE1, TE2 among others were employed for the Nursing Technicians and E1, E2 afterwards for Nurses.

RESULTS

Looking at the connection between axes, due to the lack of proximity to significant others the Pacific End of Life was not assured (Figure 1).

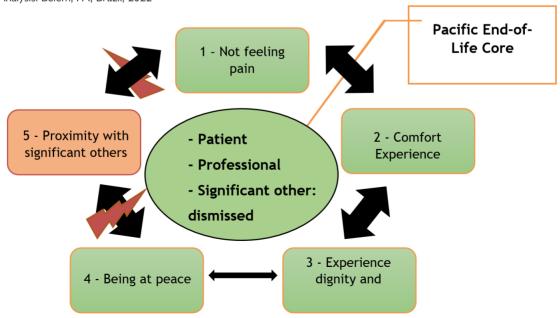
"Not feeling pain": investigating and acting on the non-apparent

The deponents link not having pain to comfort and highlight its signs.

When the patient is conscious and oriented, one of the most relevant aspects is pain. The patient that is intubated is more complicated for you to monitor, but there are ways to perceive it through facial aspects, generally feeling some spasms evidenced through these signs. We have pharmacological and non-pharmacological mechanisms. (Summary E1 and E2)

They are comatose, intubated, with analgesia and continuous sedation [...] the sedated present alterations in the

Figure 1 - Analysis. Belém, PA, Brazil, 2022



vital signs and through this we suggest that he presents some discomfort, then we look for a solution, probably the analgesia is not adequate and then we make associations between some analgesics. (Synthesis E3 and E5)

They frown, their eyes are narrower, they present tachycardia, altered breathing pattern, these signs suggest that he may be feeling pain, which is confirmed with analgesia. (E4)

The barriers to ensuring compliance with the axis are the state of unconsciousness and the lack of standardized scales.

Concern more with those who are unconscious, because the one who is conscious and oriented expresses his pain better. Applying adequate scales to intubated and sedated patients makes the work process better. (E1)

Knowing that pain is the fifth vital sign in palliative care, it must be well monitored and treated. Here no scale is used, we usually identify it with our experience, the application of a standardized scale would help us classify the level of pain and the choice of drug. Otherwise, only when he makes pain facies. (synthesis TE2, TE3, E2 and E5)

Nursing technicians evaluate pain in a basic way by means of facies, quickly citing drug analgesia.

For the assessment there are scales, but here we don't have them, we verify by the face. [...] when they are sedated you can see through the pain facies, the vital signs change, we have to find out and measure the pain through there. (synthesis TE2, TE3 and TE4)

Analgesia! Pain relief is very medicated. (synthesis TE1 and TE2)

When it is at the end and we notice the discomfort, we are oriented to increase the dose of fentanyl when he is sedated, or even morphine is prescribed. (TE4)

"Comfort experience": links between environment, hygiene and repositioning

It provides tranquility and peaceful satisfaction, for the fulfillment of the axis.

During the bath, we perform hydration, control light, room temperature, we can solve the problem in practical ways, for example, if the patient is cold, we can warm him up.

Receiving comfort is the patient's right, through our nursing prescription we provide comfort massage, analgesia, change of decubitus, temperature control, emotional support [...] the patient is already suffering and we cannot amplify this pain, but rather facilitate it. (I 2)

Keep the patient clean, pay attention to the question of rashes and skin lesions, maintain a dialog, especially for those who are conscious and oriented [...] To provide comfort is so simple, it is enough to have a human look. (E3 and E4)

Some on palliation are in a very accentuated organic deterioration, so we have to be careful about changing the decubitus, positioning in bed, comfort massages (E5)

The environment is an influential factor in this experience, light, sound and low temperature are cited.

It is cold all the time, it will depend on the amount of fat tissue, when the patient is very thin, we put a thicker blanket [...] In the ICU heating the water for the bath is essential for thermal control, try to minimize noise, pay attention to the cold, body temperature, another factor that I consider important is clarity, darkness. It can't be uncovered, these are small things, but they are comfort. (synthesis E3, TE1, TE3 and TE2)

For the nursing technicians, changing the decubitus is a remarkable means of relieving this discomfort.

Promote change of decubitus, even when we stay a long time in bed, we already get sore. (TE2)

Patient in left lateral decubitus for 2 hours and I see that 30 minutes have passed, I already worry, because I know that this position must already be bothering, I imagine myself standing in a bed in the same position and I know it would be a nuisance... (TE3)

The lack of inputs hinders the provision of comfort.

The hospital does not provide pneumatic mattress, hydrocolloid protection plate, to protect from injuries... (TE1)

"Experience of dignity and respect": valuing the human and the impacts of the COVID-19 pandemic

An attribute of the concept is value, involving being recognized and respected as an equal and not being exposed to anything that violates integrity.

Dignity and respect are primordial, we need to see this being as a client, not as a patient, he is there passively receiving care, but we cannot forget that he has his rights, wills and we need to respect dignity even in the post mortem, to put ourselves in the other's place [...] dignity is to guarantee rights, to provide humanized care beyond the physical, to also heal the social, mental and spiritual, to see this being in his entirety and make him included in this process. Many are intubated and in induced coma, however, explaining what will be done even when he is sedated, I already consider as an act of guaranteeing dignity (synthesis E1, E2 and E4)

The nursing technicians linked awareness to the expression of feelings and autonomy over the body.

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Dignity is much easier when the patient is oriented, because we notice that they are anxious, sad, and then we give emotional support. To have someone to change them is humiliating, it lowers their self-esteem. (TE1)

[...] intubated and sedated, we know that they are listening, so sometimes during the bath I am careful not to say anything that may upset them. This patient has a family, a job, a life. Dignity is to feel useful, I imagine that they feel hurt when they lose their autonomy and need other people to do things for them that they used to do alone (synthesis TE2 and TE4)

In this axis of the theory, the effects of the pandemic of CO-VID-19 are evidenced.

[...] I understand the moment we are going through, but put yourself in the place of this patient, at the end of his life and having his last moments away from those who love him, having only the presence of strangers, imagine how much this hurts his dignity. The conscious that enter palliation, ask a lot to spend the end of their lives with their families and the problem is that the pandemic took away this possibility. (synthesis TE1 and E3)

"Being at peace": development of interpersonal relationship

Being at peace means not having anxiety, restlessness, worries, and fear. We use strategies of proximity to the aware and the oriented.

I question terms such as religiosity, empathy, talk about questions of God, explain finitude as a passage. (E1)

Imagine this patient going through all that he is going through, totally defenseless, with wounded morals and still not being able to be close to those he loves, that's when we try to create bonds, provide peace through conversation, relaxation. Even sedated and intubated, I keep up my behavior of talking, I may not get verbal answers, but I know he is listening (synthesis E2 and E4)

Include him in his own care passing that tranquility, even knowing that he is leaving, making him feel a sense of duty fulfilled [...] we try to know his religious beliefs, give information when he is conscious and help in the acceptance. In this friendship that is formed when they are oriented, I gain their trust, I ask them what kind of music they like to listen to, I bring up several subjects and they become calmer. (synthesis E3, E5 and TE1)

The pandemic reflected directly on the interpersonal nursing process.

The pandemic has made our work very difficult, they must feel lonely and we give them company, feel sad and we give them affection. The emotional support helps them to be at peace. (TE2)

"Proximity to significant others": the distancing of the familiar

Proximity to those who care about the sick person has become impossible.

Before this virus, I tried to pass on security by giving concrete information to the family, the nurses use psychology in this shock when they receive the news, and we are very attentive when the family member is elderly. [...] I get sad and even emotional, even before this chaos, because it is in them that the pain will last, and it must be very hard. Due to the restriction they ended the visits and weakened a lot this bond between family and patient [...] there is no approximation of the family with the team and much less with the patient, there should be some way to approach nursing, we have a lot to contribute with information. It could be implemented the creation of a multi-professional team to act externally with the family at this time of pandemic. (synthesis E1, E2, E3, E4, E5 and TE1)

The challenge: how to give this support during what we are experiencing? I don't think that the family member is involved in the recovery, now even less, because of the pandemic. There is nothing that tries to bring the sick person closer to the family member, this needs to be implemented. Unfortunately, I didn't witness the family member receiving the news of palliation during the pandemic. It must be very sad to receive such news and not be able to give the last hug. (summary TE2, TE3 and TE4)

DISCUSSION

There were limitations for the peaceful end related to CO-VID-19 by overload, lack of material and it was noted that the biomedical character stood out as in other realities. Feference was made to the basic right to receive pain control, for relief of suffering with strong analgesics, and that they may need continuous sedation for relief of shortness of breath, anxiety and restlessness, the latter indicated in refractory symptoms such as delirium and dyspnea. Fe-18

Unveiling pain, it is explained that the assistance has attitudes of caring, sensitivity and compassion exemplified by the altruistic posture in imagining themselves as ICU patients. ¹⁰ It is emphasized that the axes completed each other dynamically and the "not feeling pain" interacted directly with the axis "experience of comfort". Thus, intermittent dosing and infusions of opioids and benzodiazepines are used, which depending on the severity of symptoms provide comfort especially in severe dyspnea.⁷

In addition, other ways to provide comfort are bed baths, skin hydration, lighting control, sound noises, and temperature. This maintenance foresees, on the part of the interprofessional team: avoidance of prolonged immobilization and unnecessary procedures, adjustment of the vital signs verification schedule and drug administration so that there are no interruptions in night rest, assessment of the need for probes and catheters, consideration of the possibility of early weaning, correction of dehydration, and discontinuation of potentially delirium-causing drugs.¹⁹

In the third axis, a certain limitation was noted in the understanding of the word dignity following the theory, however, important attributes such as humanization, respect, rights, autonomy, and self-esteem were mentioned. To guarantee dignity goes through complex decisions such as choosing who will be conducted to treatment with greater chances of cure – the "social exceptionality" of the team – to discern and make precepts that years ago were adopted more flexible. 10,20

However, even if the hospital visit as maintenance of dignity is necessary, the decrees of social distancing were considered, but as an alternative the use of technology could be implemented to facilitate contact.²¹ The loss of functions was pointed out, patients live experiences that are considered humiliating, distressing and painful.¹⁰

On the fourth axis, it was disserted about spirituality, friendship, trust, affection, emotional support and well-being being influential in the pacification of terminality. Palliative care is directed to these contingencies and inclusion of the significant others, something that was shaken.²² It is corroborated that the fifth axis was the most affected, many ICU did not allow visits and it is understood that the process of support to the family member was harmed, breaking the link of the theory. Interventions facilitating the participation of the significant other were frustrated, but because the first author was in the sector, it is known that the use of telephone or video call was maintained, for passing the medical bulletin between the team and the family member, or in the worst moments when it was necessary to have a conference to close the palliation proposal. There were no reports of psychological support or face-to-face contact between the family and the nursing staff.

The World Health Organization considers palliative care as the relief of biopsychosocial symptoms.²³ The limitations of the study are related to the difficulty in capturing the sample due to the time available to the interviewees.

CONCLUDING REMARKS

It was noticed that humanization was taken as a priority, in the perspective of the nursing team it was understood the lack of standardization for the implementation of the Peaceful End of Life, which is shown as a clinical model, evidenced by the lack of pain assessment scales as the greatest example of the lack of this standardization in the ICU. It is known that pain control is a priority issue that is hindered by managerial difficulties, associated to this the pandemic of COVID-19 was a challenge for front-line workers and that for sure were overloaded, thus, understanding how they think, act and manage is of extreme importance for

the development of the category and for the valorization of the nursing process and systematization.

The significant others have been shaken, and it is thought, with what was exposed by COVID-19, if terminality will continue to be non-peaceful due to this removal in other pandemic situations with a high risk of contamination and deaths. Based on this, what interprofessional strategies will be taken, making use of technology certainly, ensuring this contact? It can be noticed that nurses verbalized discomfort when dealing with the threshold of life in the pandemic, seeing themselves on the other side of care situations, not considering the end of life of those they assisted in the ICU as peaceful, because of deleterious statuses such as loneliness, anguish and "wounded morals".

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