Moral distress of workers from a pediatric ICU

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Abstract

Pediatric intensive care units are complex hospital settings, which constitute a workplace with potential to generate moral distress for the employees. This research analyzes the moral distress faced by health professionals who are active in a pediatric intensive care units in the South of Brazil. It is a qualitative study in which dialectical hermeneutics was chosen as a method and epistemic matrix. The data shows perceptions of moral distress originated from the lack of material resources as well as the limits of humanization. The analysis of the category "moral distress: from the lack of resources to the limits of humanization" revealed a strong association between moral distress and ethical conflicts. Confrontation strategies foresee the fight for ethically committed public policies, recognition of the ethical dimension as a tool for a humanized working process and the application of this dimension in a healthcare network, as proposed by Mario Rovere.

Keywords: Stress, physiological-Morale. Stress, psychological-Morale. Bioethics. Intensive care units, pediatric.

Resumo

Sofrimento moral de trabalhadores de uma UTI pediátrica

Unidades de terapia intensiva pediátricas são unidades hospitalares complexas, constituindo cenário laboral potencialmente gerador de sofrimento moral ao trabalhador. Esta pesquisa analisou o sofrimento moral a que estão expostos profissionais de saúde que atuam em unidade de terapia intensiva pediátrica de hospital conveniado do Sistema Único de Saúde de um município do Sul do Brasil. Trata-se de estudo qualitativo em que se elegeu a hermenêutica-dialética como método e matriz epistêmica. Os dados apontaram percepções de sofrimento moral oriundo de carência infraestrutural e de fronteiras da humanização. A partir da categoria "sofrimento moral: da carência de recursos aos limites da humanização", a análise revelou forte associação entre sofrimento moral e conflitos éticos. Como propostas de enfrentamento, sugere-se a luta por políticas públicas eticamente comprometidas, reconhecimento da dimensão ética como ferramenta para processo de trabalho humanizado e aplicação dessa dimensão em rede de saúde segundo Mario Rovere.

Palavras-chave: Estresse fisiológico-Moral. Estresse psicológico-Moral. Bioética. Unidades de terapia intensiva pediátrica.

Resumen

Sufrimiento moral de los trabajadores de una UCI pediátrica

Las unidades de cuidados intensivos pediátricos son unidades hospitalarias complejas que constituyen un ambiente laboral que puede generar sufrimiento moral a quienes allí trabajan. En la presente investigación se analizó el sufrimiento moral al que están expuestos los profesionales de un equipo multidisciplinario de una unidades de cuidados intensivos pediátricos de un hospital del Sistema Único de Salud de un municipio del Sur de Brasil. Se trata de un estudio cualitativo en el que se escogió a la hermenéutica-dialéctica como método y como matriz epistemológica. Los datos señalaron percepciones de sufrimiento moral con origen en la carencia de infraestructura y de fronteras de humanización. A partir de la categoría "sufrimiento moral: de la carencia de recursos a los límites de la humanización", el análisis ha revelado fuerte asociación entre el sufrimiento moral y los conflictos éticos. Como propuestas de afrontamiento, se sugiere la lucha por políticas públicas con compromiso ético, el reconocimiento de la dimensión ética como herramienta para un proceso de trabajo humanizado y la aplicación de esta dimensión en una red de salud, de acuerdo a Mario Rovere.

Palabras clave: Estrés fisiológico-Moral. Estrés psicológico-Moral. Bioética. Unidades de cuidado intensivo pediátrico.

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Research

The work process, in the complex health-disease context, can often subject professionals to choices that they would not like to make. In this work environment, when one becomes incapable of acting according to one's choices or morality, one may suffer moral distress. Moral distress or moral stress can be defined as that generated from situations experienced by the professional in circumstances that expose the work ethics which can affect their mind, body and relationships. That is, circumstances in which the professionals know what should be done technically and according to their morals and ethics but, because of real or apparent limitations in the work environment, they are not able to act in accordance and comply with the norms required [1,2].

In a literature review, Silva [3] related the main causes of occupational stress to the professional category in Intensive Care Units (ICUs), encompassing physicians, psychologists and nurses. The main causes pertinent to physicians were identified as being work overload, multiple-jobs, intense professional responsibility, area of action, physician-patient relationship, social pressure and low remuneration in relation to the workday.

With regard to psychologists, constant contact with pain, death, distress; problems of fitting in the team; emotional involvement with patients and their families; crisis situations and lack of training in that field of the hospital were the major causes observed. Finally, regarding the nurses, diversity of activities, frequent interruptions, crisis situations, direct contact with patients' pain, low salaries and schedule mismanagement were the most influential factors. Considering that moral distress of professionals in children's ICUs requires contextualized ethical analysis, the study presented in this article sought to identify how moral distress manifests in professionals from a multidisciplinary team working in a Pediatric ICU of a university hospital in southern Brazil.

Methodology

This is a single case study [4] carried out through qualitative, exploratory and comprehensive research in a pediatric university hospital in a municipality in the south of Brazil, with data analysis of the hermeneutic-dialectic type. In the design of the study, it was considered that, in qualitative health research, experiences of the multi-professional team, in a specific context, are an example of a case study [5]. The phases that characterized this type of technique were observed: 1) definition of the conceptual- theoretical structure; 2) case planning; 3) implementation of a pilot test; 4) data collection; 5) data analysis; and 6) a study report and data interpretation [4,5].

Acknowledged and approved by the Research Ethics Committee of UNIVALI, in the state of Santa Catarina, Brazil, the research was carried out in accordance with the provisions of Resolution CNS 466/2012 (Resolução CNS 466/2012) [6]. The sample consisted of 18 participants, all of them professionals with higher education and members of the multidisciplinary team from the Pediatric ICU (PICU) that met inclusion criteria at the time of the research. The following criteria were used to select participants: 1) be working at the PICU of the hospital being studied; 2) be employed during the period of the research; 3) have completed higher education and occupy a position corresponding to their training; 4) agree to participate in the research; and 5) authorize the publication of the survey results.

During the first stage the objective was to select possible people to be invited to participate in the study. For this, professionals were listed by name, occupation and work schedules, totaling 18 participants. We then proceeded to the stage of making the invitations, made personally and individually between the 11th and the 18th August 2015. All those invited to participate met the inclusion criteria. The next stage consisted of individual semi-structured interviews for data collection from the 19th August to the 18th September 2015. Nineteen interviews were conducted, the first of which was considered a pilot test. After the necessary adjustments, highlighted by the pilot interview, the remaining interviews were carried out, which were identified by letters and numbers, from Q1 to Q18. The pilot interview was conducted with one of the team members and was not considered in the analysis, since it required structural adjustments.

The topic studied was chosen by the first author, inspired by discussions and roundtables held at intensive care conferences. The researcher is part of the study team and has been working in pediatric intensive care for more than 10 years, considering the topic, therefore, pertinent to the reality of her work. The interviews were conducted by the researcher herself.

The meetings with the participants took place individually, in a reserved room at the workplace, at an alternative time to that of the interviewee's working hours. The empirical material was recorded in notes and audio, and later transcribed with ethical rigor. The method adopted in the research was

personal testimony, in which the researcher defines topics, leads the discussion, and closes the interview at the opportune moment, even when dealing with *situations experienced* by the interviewee [7]. Because the researcher works in the PICU of the study, a relationship was established among co-workers.

In order to carry out the study, an agreement was signed by the institution. The researcher was free to develop the survey without any institutional interference, having undertaken a commitment to share the results with the institution, aiming at improving the environment and working relationships.

To base research on the production of thoughts about situations experienced means to center them on the 'representations of subjects'. This is, on the one hand, to study moral distress through individual narratives and unique experiences and, on the other hand, to identify the existence of moral distress in this team and how it is perceived by the participants, in addition to trying to define their main related or aggravating factors.

Hermeneutic-dialectics was chosen as the methodology and epistemic matrix, since this type of analysis allows the understanding of human relations and its interface in the health-disease process [8]. Considered in terms of the interface between social sciences with philosophy [9], dialectic hermeneutics allows the development of the interpretive process of the research object through the understanding and explanation of a given context [10]. Hermeneutics seeks to understand the context based on language and tradition, while dialectics seeks to understand reality through the explanation and interpretation of that language (used by the subject in a causal relationship). That is, conflicts and contradictions of a given reality can be interpreted and explained within these specific contexts. In this sense, the researcher, based on her personal experiences and theoretical knowledge, seeks to group meaningful expressions and words, from which specific categories and subcategories will emerge, resulting from the integration between understanding, explanation and interpretation of the investigated subject [9,10].

Through this approach, moral distress was analyzed in relation to the work process and its limitations, considering also the participants' knowledge, expressed verbally, for the definition of moral distress. In this phase, a few steps were followed [11]: 1) Systematic data sorting, with transcription of all the interviews, organized with notes made during the course of the interviews; 2) Classification, based on theoretical grounds, of data obtained . From that point onwards, after careful reading of the interviews, words/expressions/feelings more often related to moral distress were grouped and rearranged in order to identify relevant structures; 3) Final analysis, establishing relationships between collected data, theoretical references and analytical frameworks, and selecting categories and subcategories of the case study analysis.

In the final stage of the work, from the systematization of the accounts considered relevant (and more frequent) two different narrative units were created. The first unit, called "What is moral distress?", consisted of the definitions reported by the research participants through the words most often used to describe moral distress, as well as related feelings. In the analysis of the expressions on moral distress contemplated in this unit two subcategories emerged, grouped in a central category: "Moral distress: from the lack of structural resources to the limits of humanization". A further incursion into topics of techno-science and humanization in health was necessary, in addition to the theoretical framework already studied. Data was analyzed from the point of view of bioethics.

Profile

The study sample consisted of the 18 members of the multidisciplinary team from the Pediatric ICU of a university hospital in the South of Brazil, composed of seven physicians, five nurses, two physiotherapists, a psychologist, a social worker, a speech therapist and a nutritionist.

Regarding the distribution by gender, six interviewees were male and twelve female. Considering gender and profession, all male participants were doctors. The average age was 36.1 years, ranging from 24 to 51 years. The medical team had the highest average age, 42.4 years, the youngest were the nursing team, with an average of 27.8 years, while the other professionals presented an average of 35.6 years.

Of the 18 interviewees, only three worked exclusively in the Pediatric ICU. Of the 15 participants who did not work exclusively in PICU, among whom were all the doctors, two nurses and a physiotherapist, five worked in other sectors of the hospital under the same contract and ten reported having two or more jobs.

Regarding the time employed in the PICU after graduation, half of the respondents declared they had between ten and twenty years of experience,

six had less than ten years and three more than twenty years. The weekly workload dedicated to the Pediatric ICU was divided into intervals of up to twenty hours per week and more than twenty hours per week. Data show that ten professionals work more than twenty hours and eight of them less than twenty hours per week in the ICU.

When questioned about what is moral distress, 10 interviewees said they knew the topic, defining it in their own words, while eight did not know how to define it. However, with the follow-up of the interview, each participant was questioned regarding experiencing a situation that had generated moral distress, according to their own definitions and/or perceptions of the topic during the interview or the presentation of problem situations.

Based on the understanding of what was being defined as "moral distress," 16 interviewees acknowledged that they had experienced, at least once, a situation that generated such a sensation, while two responded negatively. Between the medical team and the nursing team, all professionals reported having experienced some situation of moral distress. This leads us to infer that professions that care for the patient longer (such as medicine and nursing) and work for prolonged periods in PICU are more susceptible to moral distress.

What is moral distress?

As discussed above, when questioned about moral distress, 10 professionals recognized the term and defined it in their own words, while eight did not know the expression and did not know how to define it. Among the definitions of moral distress presented, we can highlight:

"Perhaps (...) *the feeling of discomfort* (...) *not feeling able to do something or* (...) *that feeling of leaving work and not being able to do what you should have done, either because of* (...) *an institutional technical matter or your own technical matter, I think this is what makes me more* (...) *upset "*(Q7)*;*

"I think it's the emotional damage caused (...) *by your own perspective in relation to the patient"* (Q13)*;*

"Some sort of negative feeling (...) *I think that is what weighs heavily regarding working in the ICU"* (Q11)*;*

"Some situations in which we feel powerless (...) *to make some decisions, which leaves you so in the middle of a situation when it is difficult for you to choose what you are going to do"* (Q1)*.*

Moral distress can be defined as that *which strikes the mind, body, or relationships* resulting from a situation in which a person judges what is morally right, is aware of his or her responsibility, but feels his or her participation as ineffective in modifying that situation [12]. It can also be defined as a psychological imbalance caused by painful feelings arising from an inconsistency between the person's actions (influenced by individual, institutional or social barriers) and their convictions [13].

It can be noted, in the statements presented, elements indicating that the reality of moral distress is not a product of thought, but an effect of human activity, conditions and social relationships established in the work process. For example, when the interviewee talks about "*perspective in relation to the patient*" (Q13), it seems to infer that, when the professional fails to transform reality (to recover the patient's health / life), the professional gets frustrated, which ends up generating moral distress.

The same idea applies to other accounts. When another interviewee talks about negative feelings generated when leaving work with the feeling that "*not being able to do what you should have done* " (Q7) or when the worker feels "*powerless* (...) *to make some decisions*" (Q1), one can perceive a great similarity with feelings generated by the concrete performance of the professionals, the *locus* of the production of meanings, reinforcing the understanding that moral distress is the product of human activity.

When questioned about feelings related to situations understood as moral distress, the most frequent responses were: anguish, powerlessness, frustration, guilt, insecurity, incapacity, worry, embarrassment, tension, sadness, intolerance, indignation, anger, discouragement, apprehension, discontent, regret, lack of autonomy, anxiety, fear and pain in the face of death. In the narratives, two categories were found among the factors that triggered moral distress: 1) moral distress due to lack of resources (mainly in terms of technological resources) and 2) moral distress due to the humanization limits of the Pediatric ICU. Both subcategories will be analyzed below, based on the central category.

Moral distress: from the lack of structural resources to the limits of humanization

The interviewees were asked if they encountered any barriers (in the sense of obstacles / limitations) to perform their functions in PICU as they would like or if they always performed their functions as they would like. Of the 18 interviewees, 11 reported not always being able to perform their duties as they would like; one said that he/she never performs his/her duties as he/she would like and that he/she always encounters barriers; and six said they found no barriers. The twelve participants who reported limitations in the work process belonged to the medical and nursing team. Among the obstacles most frequently encountered to work at the PICU were structural issues, such as the shortage of equipment and technology, as in the following quote:

"For me moral distress is, it is when I (...) *would have some resource, there would be some resource* (...) *which would be more viable for that patient and, for lack of structure, the patient does not receive it. I feel a bit morally offended, because I participate in this scheme. I agree to work on this flawed scheme, right. And when we need it, I feel a lot of distress* (...) *maybe because I didn't fight more to have a structure for better service. I resigned myself to work in a place that is our daily life* (...) *meeting barriers, of which a lack of structure is the main one"*(Q17).

In this sense, the barriers found to perform good work in the PICU, as reported by this interviewee, refer to insufficient technological apparatus. Knowing that there are technologies that offer better treatment for patients, not having access to them causes distress. According to Piers et al. [14], when workers perceive care provided in the ICU as inadequate experiences, they are driven to acute moral distress, which increases the risk of exhaustion, which can compromise the quality of care provided and increase staff turnover. The ethical conflict can be generated when professionals make choices, because, when choosing, they transit between desire and need, renouncing other possibilities. This renunciation of other courses of action can generate uncertainty about the deliberate choice, which leads to mismatch in relational dynamics [15].

Coexistence with ethical conflict is part of human life, as desire, needs and possibilities are products of the experience of making choices. However, the practical consideration regarding the importance of naming daily factors that destabilize the healthy work process (in this case, the lack of structural conditions) is an ethical imperative that is put to the worker [15]. In the presented situation, it is understood that the renunciation would be regarding the fact that "*I didn't fight more to have a this* (...) *structure*" (Q17), and this renunciation (or choice) has a negative impact on his work and consequently on his daily life. The data shows the production of moral distress within ethical conflicts.

It is understood, then, that the autonomy of professionals is greatly compromised by their submission to the conditions of work imposed that, sometimes, limit their freedom of choice. This adverse situation leads to conflicts between freedom and duty, remembering that it is a singular context, in which a lack of resources can mean life or death. Berlinguer [16] attributes the disparity of access to the benefits of medical advancements according to the region of the world in which one lives, or the social class to which one belongs. According to the author, in the comparison between the industrialized world and poor countries, the latter present an average life expectancy 20 years lower and infant mortality from ten to fifteen times greater. Thus, in such contexts, the "right to health" seems to be only a theoretical statement for vast sectors of the population around the world.

Inequality in the distribution of structural resources is a global issue. At the UNESCO *World Conference on Science and the Use of Scientific Knowledge* [17], resource allocation was on the agenda, considering scientific research as a driving force in health and social protection, and that its best use could significantly improve the health of humanity. This observation makes it imperative to reduce disparities between developing and developed countries through equal access to science and technology, not only as a social and ethical requirement for human development, but also for the development of the scientific potential of communities worldwide.

In the testimony of another participant, one can perceive the distress caused by the State's lack of resolve in health matters: "*the desire you have is to shout, to demand of the State that they solve this problem. And you keep being distressed with the situation* "(Q1).

This type of response refers to the social context in which all interviewees are situated. As historical subjects of a broader collective - the country - they are influenced by historical facts, which produce and reproduce sociocultural perspectives segmented by gender, age, education, color, etc. As

a result, the study participants should be seen as members of a multi-professional team with higher education that work in a PICU of a country that has not yet been able to ensure, in practice and for all, legally obtained social rights. A nation in which, in the collective sphere, the guarantee of means is not universally allocated by the State.

In the absence of structural conditions that enable a quality work process, autonomy is reduced when professionals do not have the freedom to decide as to how they would like to carry out their activities. This can be seen in the interviewees' statements: "*... that feeling of leaving work and not being able to do what you should have done, either because of* (...) *an institutional technical matter or your own technical matter"*(Q7)*;* "Not having the autonomy that you should have" (Q11). When questioned about changes they would do to the work environment of the PICU, some suggestions came up from the research participants: "*the structure, right? We are always fighting for it*" (Q7).

Pediatric intensive care in Brazil has experienced great growth in recent years, following a worldwide trend. However, this growth occurred without proper strategic planning, and the result is regional and national inequalities, which are reflected in the lack of fairness in the distribution of beds. There are great contrasts, especially between the public and private sectors, varying from highly sophisticated units to others without the minimum necessary structure, which always penalizes the less favored portion of the population [18]. A study of the distribution of beds in Pediatric and Neonatal ICUs in the city of São Paulo perceived a disproportionate distribution, most of them located in the central region while the majority of the pediatric population resides in the peripheral areas of the city. Another important fact of this study was that, in general, there were excess private beds and a deficit of public beds [19].

In addition to the aspects already described, in eight interviews the participants made a direct correlation of moral distress to the humanization issues in the PICU, while, indirectly, 14 participants cited aspects related to humanization in the unit. These references included: limitations of the parents' access to the ICU (Q1, Q3, Q5, Q7, Q12, Q14); reduction of professional empathy (Q3, Q10); relationship difficulties within the team (Q2, Q4, Q5, Q16); conflicts with patients' relatives (Q9, Q11, Q15), difficulty in dealing with death (Q6, Q7, Q12, Q14, Q16); and physical exhaustion (Q14, Q16).

It is worth making a small digression here regarding the concept that guides the National Humanization Policy (Política Nacional de Humanização - PNH), formulated and launched in 2003 by the Ministry of Health in response to the significant number of complaints from users of public hospitals. [20] The term "humanization" was initially used to improve the quality of care for users of the Brazilian Unified Health System (Sistema Único de Saúde - SUS), as a tool capable of increasing the materialization of universality, equality of care and integral assistance, which are SUS' doctrinal principles [21].

Recently, this term has also been related to health workers, due to the demands of better working conditions, improved professional training and more effective ways of dealing with the impacts caused by the daily confrontation of illness and suffering. Meeting these demands could help these professionals cope with challenges posed by health care [22]. In a study done with ICU nursing staff, the idea of "humanizing" was summarized in the sentence *love your neighbor as yourself*. According to this same work, *humanizing is a measure that aims, above all, to render effective the assistance to the critically ill individual, considering him or her as a biopsychospiritual being* [23]. That is, humanization seems to be related to being welcoming, but also resoluteness and effectiveness.

Failures in the humanization process can lead health professionals to moral distress: "*Visiting hours. I think it's too little, I also understand the routines of the hospital, but still I think people focus too much on this routine issue* (...) *they do not put themselves in the other's place* "(Q3). From this, it can be understood that, although they have an established institutional role, "routines" end up depersonalizing care givers, because at the moment they are imposed they prevent one from considering what would be the best ethical conduct in each case. Like the speech presented, what would be the ideal time for parents to stay with their children hospitalized in the PICU?

According to Heck [24], in places where depersonalized processes prevail, there are no conditions to apply an array of responsible conducts. This statement seems to be reflected in another narrative, in which one can perceive that the interviewee interprets routines as imposed "rules", to which one must comply: "Not leaving the parents 24 hours in the ICU (...) *is a rule that has to be accepted* (...) *I do not think it's right to do that "*(Q14).

In the previous narrative, one can re-invoke the question of autonomy: how will professionals exercise their autonomy when "rules" that conflict with their morality are imposed? And how and with what internal resources would they consider if they were free to choose the course of action? The testimony again demonstrates the fragility of professionals in the face of the rules imposed, which do not allow their ethical exercise of choosing between two possible actions. This issue brings up the real dilemma experienced daily by professionals.

Medical ethics presuppose the duty of health professionals to act in the best interest of patients. However, professional action must also comply with the rules and regulations established by institutions so that they can provide services *en masse*, responding to the needs of many people. These two "obligations" may oppose each other drastically in some cases [25].

It is believed that this conflict is also another factor that leads professionals to depersonalization, as can be seen in the following quote: "*The person* (…) *creates a shell or another persona to work in here* (…) *things are very cold* (...) *I'm very cold in here* (...) *I cannot be moved by certain things* "(Q10). The section shows how the interviewee himself refers to the depersonalization fostered by the work environment.

Even if it stems from a defense mechanism in the face of situations that one cannot solve, the process comes to such a point that professionals lose empathy for others. Empathy can be defined as *a spontaneous feeling of identification with those who suffer, a process in which emotion is involved*, and can be the "bridge" between evidence-based medicine and patient-centered medicine [26]. The data revealed this erosion of empathy as a probable source of moral distress, since, later in his testimony, the same interviewee says: "*I think we should have a little more contact, as in other places, other units, other than in the ICU, people are much more receptive, they are much more human with each other. Here we end up being colder* "(Q10).

It can be noticed that the interviewee sees the PICU as a place of reduced empathy and humanization when compared to other sectors of the same hospital. Research carried out on humanization in the ICU [23] pointed out that in the real context of the unit there may be a dichotomy between theory and practice. This is because words such as "love", "caring", "dialogue", "privacy" and "attention" to patients and their families have been used to conceptualize humanized care. In practice, however, they mention attitudes, conducts and behaviors that characterize the ICU as a mechanical and hostile environment for patients, families and staff. Other testimonials have revealed that professionals do not feel like they are part of the work team: "*When I enter here, it's as if I freeze. I do not know if it's because I do not* (…) *I do not have an interactive relationship* (with the team) "(Q5). The feeling of not-belonging and the lack of interaction with the team can be sources of moral distress [3,27]. In order to adapt these relationships, the National Humanization Policy proposes an increase in collaboration and sharing among different role-players in the health field, in addition to the compilation of knowledge in order to create a new relational ethic [22].

In this sense, the study takes the opportunity to consider what can be done to minimize the moral distress caused by interpersonal relationships. From the data presented, it is inferred that it is possible to reduce the distress of these professionals through the deconstruction of the inter-professional relationship model and the construction of a new model, which is more cohesive and focused on teamwork. For this, it is necessary to develop, as a team, new relationship parameters, based on collective values that stimulate cooperation and create a bond.

In a paper titled "Health networks", Mario Rovere [28] proposes the formation of professional networks by strengthening the bonds between subjects as a way to overcome such dilemmas in the professional scope. The bonds between professionals must be strengthened in order to create a relationship of interdependence, generating a sense of belonging and strengthening identification with the work group. Five levels for the construction of networks are described: 1) recognition, 2) knowledge, 3) collaboration, 4) cooperation and 5) association. For each level, actions and values are linked [28].

The first level, that is, recognition would express acceptance of others: *the first point to begin to construct is to recognize that the other exists or, more precisely, that the other has the right to exist* [29]. In the day-to-day life, this means to recognize that others can say something important to improve the quality of services, it means taking them as subjects and taking into account what they say [28]. The second level is knowledge, when others are recognized as peers, when they express interest and opinions, and become important. On the third level, based on

interest and knowledge, episodes of collaboration, which consist of mutual and spontaneous help, begin to happen. Here the bonds of reciprocity begin to be structured [28].

The fourth level is found when there are some systematic forms of cooperation. This is a more complex process, because it presupposes that a mutual problem exists, and therefore there is shared problematization, in addition to a more systematic and stable way of working together, that is, the supportive sharing of activities. In the fifth level, in which there is an effective association, this activity becomes a kind of subliminal contract or tacit agreement, based on sharing resources, and in which trust is a fundamental value [28].

It is understood that, in order for humanization in the PICU to occur in a complete and appropriate way, it is fundamental to pay attention to the care of professionals working in the units. The work environment has a direct influence on the well-being of patients, family members and multi-professional teams. Strategies that allow contact and interaction, and improve the dynamics of the pediatric unit can be a basic premise for humanized care. From this principle, it can be inferred that it is possible to humanize the PICU starting with the humanization of professionals. Likewise, it is assumed that the humanization of care can hardly be possible without professionals being true to themselves.

The encounter with patients/relatives is not neutral, since professionals carries with them their own values and attitudes, that is, their way of being. Therefore, taking care of caregivers is essential [23]. In an article published in *Revista Bioética* in 2006, Gauer et al. [30] report difficulties of health care professionals regarding their self-care and propose strategies to improve such care, such as critical-reflective psycho-pedagogical workshops, psychotherapies, group therapies and work exercises.

Other factors mentioned by the interviewees that could be related to moral distress were the difficulties in dealing with death, and the fact of having to make difficult decisions under pressure and physical fatigue: "*It hurts a lot* (...) *it is difficult to deal with this, this part hurts too much. It harms you, not knowing sometimes if the patient is going to live or die* "(Q16). Asked about the sharing of these negative emotions, especially regarding death, most interviewees reported that they talk with their own family or with colleagues who are in the ICU at the time, as perceived in the following testimony: "*We end up always sharing with our work colleagues, even because everyone ends up suffering too. And, whether we want it or not, when we come home we end up sharing it with the family* "(Q15).

The fact that professionals share their distress with their families is related to definitions of moral distress previously presented. On the other hand, the sharing of this distress with their colleagues who are also in pain, might demonstrate that there may already be a certain "network of solidarity" among the work team. Physical exhaustion is an added factor to the scenario described above:

"We deal a lot with fatigue (...) *I think the problem with the ICU is fatigue* (...) *I'm on duty tonight and I worked all day* (...) *Then you wake up at seven in the morning and at three the following morning you still have not slept, have not eaten* (...) *And you will work all day tomorrow* (...) *You have to make decisions when you are exhausted. You have to have a quick lunch and run, you cannot rest "*(Q14).

Here important questions arise: 1) how can professionals exercise their autonomy and deliberate according to selected values in a state of physical exhaustion?; 2) what freedom of choice can someone have when subjected to a workload so physically and emotionally strenuous? The difficulty in dealing with moral issues can also be related to work overload or lack of infrastructure to perform their duties, as overwork does not always allow professionals to choose the most appropriate solution for the case [31]. Then, a cascade effect is observed: a lack of resources leads professionals to moral distress, routine lead to the mechanization of work which, added to multiple jobs, leads to depersonalization, which will also lead to distress. Likewise, death in the PICU leads professionals to distress, since, generally, they have no training to deal with the finitude of life. In addition, the association of death with the lack of resources and of humanization can greatly increase this distress.

Work plays a central role in our society. It is one of the main forms of identification, alongside gender and age. It is also a means of personal and family support, and should be a source of satisfaction. However, the work process, in the complex health-disease context, is an area with high potential for generating distress. According to data from the International Labor Organization, 160 million people worldwide will suffer from work-related ills, with health workers among the most affected [32]. In this *locus*, professionals are often subject to deliberations that go against the ethical

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exercise and the realization of selected values, and moral distress may ensue.

Final considerations

In the perspective of this study, moral distress was presented as that generated by the inability to act, at work, with the necessary freedom to make autonomous choices, and may be associated with ethical conflicts. The limitations/conditions imposed can have the most diverse causes and be from various spheres, causing in professionals emotional harm that can be perceived in their personal life, relationships, productivity at work, and even in their health. The data revealed that moral distress, produced in the context studied, is linked to the limitation of access to technological resources and to difficulties in developing and integrating a humanized health work process.

The lack of structural resources was pointed out as generating ethical conflicts and moral distress. The knowledge that there are expensive technological resources to effectively work in the PICU, and the realization that such resources are not available were presented as elements that reduce professionals' autonomy to decide the best course of action. This reality strengthens the power of vulnerability to which subjects, professionals and patients are subjected, since the lack of resources exposes them to greater susceptibility to harm.

In the interpersonal dimension, data pointed to failures in the process of humanization in the ICU as a source of moral distress: "*we are falling behind in this humanization issue*" (Q14). Routines and overwork were also cited as limiting humanization. According to testimonies, physical stress, in the same way as routines, can limit freedom and, consequently, autonomy. The main factor related to this exhaustion was the fact that many professionals have multiple jobs. The study signaled some measures to weigh up the excess rationalization pointed out in the data.

The moral distress arising from the ethical conflicts generated in the work process of this PICU can be minimized by applying the following means of action: 1) collective will to require public policies that are ethically committed, aiming at decent infrastructure work conditions; 2) recognition of the ethical dimension as a vital tool for a humanized work process, based on the strengthening of social relationships and the realization of values of solidarity, within the realm of freedom [34]. For this purpose, it is suggested bioethical areas for debate are created as an integral part of the quality of ethical relationships [35]; and 3) application of the ethical dimension in the construction of a health network, anchored in the perspective of Rovere [28] (recognition, knowledge, cooperation, collaboration and association).

By relying on peers, through more in-depth professional relationships, professionals can enhance their interaction with other team members, strengthen the sharing of experiences and responsibilities, and thus reduce the potential burden of moral distress.

This research was not intended to exhaust the issue of moral distress in health professionals working in Pediatric ICU, but to contribute to the vast field of care of caregivers, in which there is much more to investigate and discuss.

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Research

Appendix

Interview script
Pediatric ICU Workers

1) Questionnaire number: _____

2) Age: ( ) 20-30 years
( ) 30-40 years
( ) 40-50 years
( )> 50 years

3) Gender: ( ) M ( ) F

4) Professional qualification:
( ) doctor
( ) nurse
( ) physiotherapist
( ) nutritionist
( ) social worker
( ) psychologist
( ) Speech therapist

5) Graduation:

Location:_____

Time: ( ) <10 years
( ) 10-20 years
( )> 20 years

Specialization in pediatric intensive care: ( ) yes ( ) no

Location and year: _____

Block I - Process of working in the Pediatric ICU

1) Do you work exclusively in Pediatric ICU?
( ) Yes ( ) No

2) What is your weekly workload in the Pediatric ICU?
( ) Up to 20 hours
( ) More than 20 hours

3) How long have you been working in a Pediatric ICU?

( ) < 10 years
( ) 10-20 years
( )> 20 years

4) Do you have links to any intensive medicine / pediatric intensive care society?
( ) Yes ( ) No

Block II - Perceptions of Pediatric ICU professionals regarding moral distress and ethical conflicts/dilemmas

1) What is moral distress for you? (If interviewees cannot express a concept, ask them to represent moral distress in two words: Can you tell me two words that come to mind when you think about defining moral distress?)

2) In your work in the Pediatric ICU, can you always perform your duties as you would like or do you sometimes encounter some kind of barrier?

3) What kinds of feelings are generated in you when you cannot act as you would like to in your work at the Pediatric ICU?

4) Thinking about your working relationships (with colleagues, superior(s), patients, and patients' family members), do you remember any personal and/or clinical situations that have caused you moral distress?

5) (in case the previous answer was positive) Did you share this moral distress with a colleague, friend or relative?

6) In daily decisions, can you share your opinion with colleagues or do you usually have to take decisions alone?

7) What values do you consider fundamental to perform a good work process in the Pediatric ICU?

8) If you could change anything in your work environment, what change would you make?

9) Today, the issue of humanization in health work has been much debated. In your view, is it necessary to bring this topic into the work process? Why?

10) Why did you choose, among all health areas, pediatric intensive care?

11) Does the practice of intensive pediatric medicine effect your personal life?

Block III - Problematizations

1) Upon arriving at work, you learned that a nursing technician had been reprimanded because she had changed the medication at the start of her shift. Fortunately, the exchange did not result in any major effect on the patient. She confided in you that she recognized her mistake, that she had no reason to argue, but that she was distressed by the way she had been reprimanded and by the fact that she had worked with an understaffed team, since a colleague was absent. How do you position yourself in the face of this fact? What does her speech generate cause you to feel? How does this interfere with your work?

2) A 1 year old child has been hospitalized in the Pediatric ICU in serious condition since last week. During the week, family members began to make constant requests of you, who answered all the questions. While you consider that you have met the requests in a welcoming way and that they have understood the child's clinical situation, you find out that the family members were asking other colleagues the same questions and challenging the answers. The day you heard this, they again approached you and asked you everything again. How do you feel about this case? What is your attitude? What feelings does this generate in you? How does this situation interfere with your work?