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EXPERIENCES OF A NURSING TEAM WITH THE DEATH OF A HOSPITALIZED INDIGENOUS CHILD

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ABSTRACT: Descriptive, exploratory study, using a qualitative approach. The aim of this study was to learn the experiences of the nursing team in face of the death of a hospitalized indigenous child and the feelings that emerged from this experience. Participants were 11 professionals. Data were collected in the pediatric unit of a municipal public hospital in the interior of Mato Grosso state, Brasil. After analysis, the interviews were grouped into the following themes: feelings expressed by the caregiver; strategies for coping with death; support to the family in face of death; the experience of an indigenous *versus* a non-indigenous death; experiences with prejudice and negligence; the impact of death on the life and health of the professional; impact on the life of the professional; and psychological support to the professional. The nursing team suffers in face of the death of an indigenous child, which influences their lives and attitudes both in and outside the hospital environment.

DESCRIPTORS: Death. Health of indigenous peoples. Nursing team. Child.

VIVÊNCIAS DE UMA EQUIPE DE ENFERMAGEM COM A MORTE DE CRIANÇA INDÍGENA HOSPITALIZADA

RESUMO: Estudo descritivo, exploratório, com abordagem qualitativa. Buscou-se conhecer as experiências da equipe de enfermagem, com a morte de uma criança indígena hospitalizada e os sentimentos que emergiram dessa vivência. Participaram da pesquisa 11 profissionais. A coleta de dados foi realizada na Unidade Pediátrica de um hospital público municipal do interior do Estado de Mato Grosso. Após análise, as entrevistas foram agrupadas nos seguintes eixos temáticos: sentimentos manifestados pelo cuidador; estratégias de enfrentamento da morte; acolhimento à família perante a morte; o vivenciar da morte indígena *versus* não indígena; vivências com a negligência e o preconceito; impacto da morte na vida e saúde do profissional; impacto na vida do profissional; e apoio psicológico ao profissional. A equipe de enfermagem sofre frente à morte da criança indígena, o que acaba influenciando sua vida e suas atitudes, tanto no ambiente hospitalar como fora dele.

DESCRITORES: Morte. Saúde de populações indígenas. Equipe de enfermagem. Criança.

VIVENCIAS DE UN EQUIPO DE ENFERMERÍA CON LA MUERTE DEL NIÑO INDÍGENA HOSPITALIZADO

RESUMEN: Un enfoque cualitativo descriptivo, exploratorio. Tuvo como objetivo investigar la experiencia del personal de enfermería con la muerte de niños indígenas hospitalizados y los sentimientos que surgieron de esta experiencia. Participaron en la encuesta 11 profesionales. La recolección de datos se llevó a cabo en la Unidad Pediátrica de un hospital público municipal en el estado de Mato Grosso. Tras el análisis, las entrevistas fueron agrupados en los siguientes temas: los sentimientos expresados por el cuidador; estrategias de afrontamiento; el apoyo a la muerte de la familia antes de la muerte; la experiencia de la muerte indígenas *versus* no indígenas; experiencias de abandono y perjuicio; el impacto de la muerte, de la vida y de la salud profesional; impacto en la vida de los profesionales; y el apoyo psicológico profesional. El personal de enfermería sufre antes de la muerte del niño indígena que influye en sus vidas y actitudes tanto dentro como fuera del entorno hospitalario.

DESCRIPTORES: Muerte. Salud de los pueblos indígenas. Grupo de enfermería. Niño.

INTRODUCTION

"Parents should never have to bury their children. Culturally, there is the conviction that no pain is greater than the loss of a child, because it interrupts the expected cycle of life".[1:54] Life is always regarded as separate from death, this being conceived and experienced as a failure.[2]

Death is a loss that triggers a group of emotional, physiologic and behavioral responses.[3] This paradox between the inevitability of the organic death and the need for immortality can explain why the denial of death is inherent to people. This denial, although natural, can or cannot be reinforced by the cultural system.[4]

In every culture, death has always been reverenced with ceremonials and appropriate rites, and the dead were always respected. In the Western culture, as of the 20th century, death began to be concealed, distanced, hostilized, as an enemy to be defeated at any cost. Therefore, one does not speak or think of death, or at least, does so as little as possible. However, thinking about it can help accept it and face it as an experience as important and valuable as any other in life.[1,5-6]

In this life conception oriented to material accomplishments, early death is experienced with great resistance, because it is understood as an interruption in the life cycle and its subsequent discoveries.[2,7] Our culture conceives childhood as a period of expectations and, the child, as an innocent and fragile being, which leads the professional to feel an immense emptiness and impotence when facing his/her death.[8]

In hospitals, health professionals need to be prepared to receive and to take care of children, adolescents and their families, to understand the reactions and behaviors they present before death, and to assist them in their needs, during the terminal process.[9]

Our society has been neglecting the preparation of professionals in charge of delivering care to the individuals' physical and emotional needs, when their body functions begin to fail. Therefore, the educational approach is indispensable on the themes of death, losses and mourning in the work routine of health professionals, mainly those who deliver hospital care.[10]

At the present time, it has become quite common to health professionals, within hospitals, as well as at reference centers of these hospitals, the provision of services to indigenous people, mainly in the municipal districts where indigenous lands are located. This leads us to a reflection regarding the performance of health professionals, especially that of nurses, who deliver care to such people, during the period they remain in the hospital.

It is inevitable to health professionals who work with the most different human societies to understand cultural relativism, which implies in the importance of knowledge on habits, faith systems, health practices, cure/prevention and priorities of health. This perspective helps guarantee the understanding, participation and engagement of the community in health actions.[11]

The significant cultural diversity of indigenous Brazilians produces multiple forms of everyday life and multiple ways of understanding death, life, health and disease.[12] Thus, convergence to this point of reflection becomes imperative for the nursing staff and other health professionals since local reality is permeated by the ethnic-cultural meeting of diversities. According to data provided by the hospital under survey during the period between 2006 and 2010, by the death certificates (DCs), there were 253 deaths of children (from 1 to 9 years old), who were hospitalized, of whom 155 were indigenous *Xavante* children and 98 were non-indigenous.

Given the above and since this is a common situation in several Brazilian hospitals, it becomes relevant to know the experiences of nurses facing the death of hospitalized indigenous children, to understand the different ways of dealing with death, within the context of cultural diversity and thus contribute to provide better care to Indigenous families, in the process of terminal cases, outside their village.

METHODOLOGY

An exploratory and descriptive study, using a qualitative approach, was developed with nursing team professionals – nursing technicians and nurses – working in the pediatric unit of a public hospital in a municipality in the state of Mato Grosso (MT). A total of 11 professionals participated, all female, being a prerequisite to participate in the study to have already experienced the death of a hospitalized indigenous child.

In order to achieve the proposed objectives, a semi-structured routine of interviews consisting of open questions was used. The following

questions were made: a) How did you feel when experiencing the death of an indigenous child? b) What were the feelings that arose at that time? c) Did the death of an indigenous child affect your life or health conditions? d) What do you do or use to help you cope with this situation? e) What do you think of the hospital having a psychological support service that would help nursing professionals deal with this type of situation? f) Was there any change in your professional or personal life as of the experience of the death of an indigenous child? g) Is experiencing the death of an indigenous child similar to experiencing the death of a non-indigenous child? h) Do you feel prepared to support or help the family of an indigenous child at the time of death/mourning?

The interviews were conducted in the nursing room, since there was peace and quiet there, essential to conduct the interview; the responses were recorded (voice recording) and subsequently transcribed in full. Afterwards, content analysis was applied, as this is the most commonly used expression to represent the processing of qualitative research data,[13] i.e., with respect to research techniques that allow making replicable and valid inferences on data from a given context.

The study was developed once the research proposal was approved by the Research Ethics Committee of the University Hospital Júlio Müller, at the Federal University of Mato Grosso, under protocol n. 021/CEP-HUJM/2011.

In order to assure confidentiality of the respondents' identities, flower names were used to identify them in the presentation of excerpts from testimonials.

Thematic analysis was also used in the study because it involves a series of relationships and can be presented graphically by means of a sentence, in which the theme is the unit of meaning that is released naturally from an analyzed text.[13]

First, the interviews were subjected to multiple readings, with the formulation and reformulation of hypotheses and objectives, taking as a parameter the reading of the material and the initial questions. On a second moment, there was exploration of the material to reach the core of text understanding, i.e., finding the categories that are meaningful expressions or words, according to which the content of a speech would be organized. These categories emerged by the criteria of repetition and relevance.

From data analysis, it was possible to formulate the following categories: feelings expressed by the caregiver; strategies for coping with death; support to the family in face of death; experiencing an indigenous *versus* a non-indigenous death; experiences with prejudice and negligence; the impact of death on the life and health of the nursing professional; impact on the life of the professional; and psychological support to the professional.

RESULTS AND DISCUSSION

Among the feelings expressed by the caregiver, the powerlessness towards the death of a hospitalized indigenous child was mentioned by 73% of the nursing professionals, corroborating other authors.[9,14]

It is a feeling that there is nothing you can do. It is like this, as if we were useless [...] (Begonia).

Sometimes you, as a nursing technician, cannot do much, you cannot [...] *sometimes you see that the child needs a given procedure that is not within your scope, you know?* (Rose).

A study in a pediatric intensive care unit, with nursing professionals, points out that the feeling of impotence becomes more evident when faced with cases in which there were numerous and useless attempts to fight death.[15]

For some researchers, the feeling of powerlessness arises as a consequence of their own education directed to redeem life.[16-17] Health professionals often feel grief after the death of their patients, because of a sense of loss and emptiness.[16] The feeling of sadness was reported by 55% of the professionals participating in the study. Similar results were also observed in another study on the involvement of nurses in the dying process.[16]

[...] *indigenous people cry very loud, so that is very sad, you know? That mother crying, it is very sad indeed, it is quite moving* [...] (Rose).

Mercy and pity are the terms that often intertwine and confound, and when looking into the origin of these words, it is confirmed that both have similar meanings and translate a benevolent feeling towards the suffering of others. These feelings were quoted by 27% of the nursing professionals.

[...] *that feeling of pity for the child* [...] (Sunflower).

[...] *It hurts, hurts a lot, you know, I keep thinking a lot, even more when mothers are there* [...] (Orchid).

Other feelings mentioned were guilt, anger and frustration. Some authors point out that the feelings generated in the nurse may be enhanced when the death occurs in children whose bond with the staff is more consolidated, and time together with parents and the staff are triggering factors of these feelings, i.e., when there is attachment, bond.[9,16]

[...] *there are those kids you've learned to love* [...], *because sometimes we spend a lot of time together, we take care of that child, and then, like it or not, you create a bond with the child* [...] (Daisy).

If you already have an affective bond with the child, if the child has already been with you for a long time, yes. Now, otherwise, it does not make so much difference (Amaryllis).

Death frightens nurses and makes them reflect on their own finitude and that of their relatives, which makes the involvement more painful for the professional who got attached to a child who died.[15]

During the interviews, feelings of coldness and indifference also emerged when they remembered the experiences with the death of hospitalized indigenous children.

[...] *it is what all professionals do, that is why they say that, over time, everyone toughens up and in the end, death is already part of everyday life, you do not feel what you felt in the beginning. It becomes something mechanical; you get used to death* [...] (Amaryllis)

In their daily work, nursing professionals experience the suffering of the person receiving their care, and share with the family moments of pain and suffering. In pediatrics it is not different, since the involvement is even more intense, due to the sweetness and tenderness of children. Over the years, this routine of perpetual passages through painful experiences makes these professionals create defense mechanisms, i.e., true filters in an attempt to remain indifferent to the fact that in the past it hurt a lot, psychologically.

The first contacts with the occurrence of death are much more difficult and painful, but at each new experience professionals learn to deal with the situation.[14] Nevertheless, professionals are not adequately prepared to cope with death, which leads them to use coldness and indifference as a defense mechanism.[4]

Among the strategies to cope with death, faith comes up. It became evident in the speech of the professionals participating in the study that spirituality and religiosity were key points in facing death.

[...] *I did not have depression because I pray a lot, so I managed it* [...] (Orchid).

I am a strong person and I do believe in God [...] (Daisy).

I always put the child in God's hand and never worry. So, I sometimes keep thinking of them, but I always pray for them [...] (Sunflower).

These data are consistent with those found by other authors who emphasize spirituality and/or religiosity as positive coping factors for the event of pediatric death.[18-19]

Another strategy quoted by the professionals as a mechanism for coping with the death of a hospitalized indigenous child was chatting with friends and coworkers.

[...] *I talk a lot with my physiotherapist* [...]; *she helps me a lot* (Begonia).

[...] *I talk to other colleagues, we must really talk to get it out of our system* (Violet).

Of the 11 professionals interviewed, only one mentioned feeling prepared to support the family at the time of the death of a hospitalized indigenous child.

I feel [prepared], *because I give the most of myself and I try to talk, even before the child dies. You know, we talk a lot, I play a lot* [...] *with the mothers I try to talk, I think I am ready, yes* (Begonia).

The difficulty of the professionals to provide comfort to the family of the hospitalized indigenous child during the time of death was evident in this study, although the Ministry of Health[20] emphasizes that communication is the main difficulty in the care of the indigenous population, and this also makes it often difficult to diagnose and, consequently, provide treatment.

No, I do not feel prepared, because it is very complicated, because sometimes they have their ritual and I do not know it (Camellia).

No, I do not feel prepared. When the child dies, I even think I should talk, but what I do is run [...] (Tulip).

I do not feel well prepared, because their culture is different from mine [...] (Daisy).

The time of death of a child is difficult to be understood by the family, and nursing professionals need to develop a differentiated view within this subjectivity of mourning, since it is

experienced differently in each Brazilian region, in each culture, creed or religion. Understanding and accepting what seems to be so different is a step further in the path of comprehensive care, and even more, it is the deepest perception of the other. Providing comfort to an indigenous family who lost a child does not require participating in mourning rituals, not even speaking their language, or that the professional be part of their culture; on the contrary, it requires respect for their way of feeling, crying and expressing themselves.

Divergences were observed in the experiences reported by the nursing professionals regarding indigenous and non-indigenous death.

There is a small difference [...], *their relationship is stronger, this is what I experience, I do not know if it's just at the moment of death, but it seems that they are very close* [...] (Camellia).

[...] *we do not want to differentiate, but we end up doing so; we do not want, but it ends up being different; we see that their feeling is deeper than that of white men* [...] (Lavender).

The white child, not that it is a discrimination, but I feel more, because [pause] *the Indians have one child today, one child tomorrow, another child after, you know?* [...] (Daisy).

Actually it is quite different, because few Indians are concerned and involved with the treatment of the child (Violet).

Some nursing professionals expressed they perceived greater affection of indigenous peoples towards their children at the time of death, contrary to non-indigenous people. Perhaps this behavior is justified in the unique way the indigenous people experience grief, which in most cases, occurred with loud and prolonged crying in the pediatric unit. This way of expressing their grief for the loss is different in the perspective of nurses, because even if crying is common among indigenous and non-indigenous people, the way they cry and expose their suffering, more intensely, is what draws the attention of professionals.

On the other hand, two professionals expressed having perceived less affection of indigenous people for their children, due to the non-involvement with the hospital treatment, or because they had other children, which shows an obstacle to comprehensive and humanized care in the effectiveness of the principle of equity of the Brazilian Unified Health System.

Few professionals are capable of understanding that which is different. The manifestations of the indigenous family during treatment and facing death cause different feelings and more intense emotional responses in the nursing staff. The reports reveal ignorance on the part of the nursing professional on how the indigenous family experiences the hospital treatment.

Most companions of indigenous children during hospitalization, at the place of the present study, are female. The *Xavante* women were found to be very affectionate and careful with their children, but mostly in a hospital setting, they are shy and do not speak much, which may have been interpreted as a lack of interest in the treatment.

Some speeches show nursing experience with negligence and prejudice in their daily work:

[...] *it kills me, both as a doctor and as a nurse, I do not think it is a matter of taking a lot of opportunity; I just think that it ends up, I don't know, being an Indian, you know? I feel there is a difference* [...] (Rose).

[...] *we talked so much to the doctor, and the doctor did nothing. We said: doctor there is a suspicion, let's request the test, the sputum test, let's investigate. Nothing was done, and the child died* [...]. *We try, but he says: "I'm the doctor here"* [...] (Begonia).

Another study also confirmed an experience with negligence and prejudice undergone by nurses, who complained of the lack of complicity on the part of physicians, expected by them, especially in difficult moments of patient care.[21] In addition, other authors showed feelings of anguish, doubt and anger, experienced by the nurses as they believed having failed in providing care, not exhausted all of the alternatives to recover the patient's life, or even out of neglect on the part of other members of the health staff.[22]

Another point mentioned by the professionals was family negligence:

[...] *they arrived from the village already feeling sick, because in the village, they did not accept bringing the patients to the hospital* (Lavender).

[...] *negligence by the family itself. How could they let the children get to the point in which they arrived? Then they arrive here in the hospital and think that drugs, only drugs and care will solve, and it is quite not so* [...] (Daisy).

[...] *so we end up seeing the indigenous children, dying more due to lack of care of their family* (Amaryllis).

Contradicting these reports, the National Health Foundation points out that children are the priority in care of the *Xavante* District, considering that in all of the claims of the *Xavante* people their children are their greatest concern.[20]

For indigenous people, birth, life and death, for instance, are thought of and experienced in different ways, i.e. their way of seeing and feeling the world is very unique and therefore, failure to observe the subjectivity of other people whom they are destined to care for, as a health professional, is the same as not to observe oneself.

Regarding the impact generated by the daily familiarity with the death of a hospitalized indigenous child, perspectives were different.

[...] *this affects me a lot. Sometimes I'm at home, I keep remembering that, you know, it annoys me; it's awful, then I feel that it is harmful in the case of emotional health* [...], *it's something that you take with you for the rest of your life. I remember each one of the cases that happened.* [...] (Rose).

It is known that the activity in a hospital environment covers a number of factors causing unhealthiness and painfulness, producing hazards to the worker's health. The consensus is also that in the hospital organization there is hardly concern to protect, promote and maintain the health of their employees, which undoubtedly is a paradoxical situation, because, although the mission of the hospital is to save lives and recover the health of sick individuals, it favors the disease of people who work there.[22]

The speeches of the professionals show that, even claiming that death did not affect their lives and health, they ended up reporting feelings and symptoms related to health problems, psychological and physical in nature. These data were also found in another study in which complaints of nursing professionals were expressed by them as if they were not health problems.[23]

[...] *I get sad, but I do not carry this sadness home, kind of, I can balance it here. I feel bad, I feel sad, kind of shaken, I cry sometimes, but I do not cry in front of them. Sometimes I go somewhere else, I get sad, I sometimes cry the whole day, sometimes even when I leave here* [...] (Orchid).

Regarding the impact on their professional life, they mentioned personal changes, i.e., values and principles, which are actually positive, because a more human professional will always have a different look toward the needs of others.

[...] *value to life, I think we start valuing it more, and also how limited we are, we are very limited, and sometimes we think we are not* (Violet).

Mechanisms of projection and empathy involved in the nurses' act of care were also observed in this study, as well as in other studies.[15]

[...] *when we start in nursing, there is a feeling that* [pause], *I mean, we do not have much feeling, we work there basically for the money we want to get at the end of the month, then as time goes by, and you start dealing with children, you become a mother, you have a family of your own, then, it all gets different. So, it ends up being different, yes, the way we get to like them. You put yourself, at least I put myself, in their place* (Tulip).

I changed a lot, changed my way of being, changed my way of talking to people, to my kids at home, with my husband, I changed a great deal, you know, you change without realizing, you improve [...] (Lavender.).

Only one participant mentioned that living with the death of hospitalized indigenous children did not cause changes in her life.

The act of quit thinking about death does not retard or avoid it.[6] It is necessary to be prepared every day to face this task. Nevertheless, the vast majority of professionals is unprepared to deal with emotional aspects, including being in contact with their own emotions.[24-25]

All professionals interviewed in this study responded that it is extremely important to receive psychological support, discuss and work their emotions.

We must have a certain balance, have to have psychological preparation, otherwise you go nuts, right? (Daisy).

Despite being subject to experiencing daily episodes of death, nurses usually are not properly prepared to deal with such situations, since, during their academic trajectory, only the promotion and preservation of life are emphasized, rather than the preparation for death and the dying process.[16]

Changes need to occur simultaneously at schools and hospital institutions, that is, schools should prepare students to deal with life and death in hospitals, whereas hospital institutions could, with the help of continuing education, help professionals reflect on mourning.[9]

Therefore, due to the fact that most nurses have no theoretical basis, nor experience during college on thanatology, it is crucial to allow

students to expose their conflicts on the issue of death and know those who are dying, opening up a space, in the classroom, so that they can talk freely about the subject.[4,16]

Changes in curricular matrix are slow and bureaucratic, but essential, and quoted by various authors who stress the importance of the hospital organizational structure to provide resources that allow moments in which caregivers find support and safety, recycle their knowledge regarding the disease and activities in this area, minimizing negative feelings, reducing uncertainties as for the effectiveness of the treatment and leading to the pursuit of more humanized care.[10,12-13,15-17]

FINAL CONSIDERATIONS

The subject addressed in this study is inexhaustible, since the event of death is common in the routine of health professionals, and, because the phenomenon is boundless and has different faces, it is understood that the nursing staff experiences the process of death in agreement with the situation presented, but keeping preservation as a principle, as the greatest asset of life.

Once nursing professionals are faced with death, at work, they need to acquire knowledge and develop skills and abilities to face the death of the other. It is essential to develop skills to act in the process of terminal illness and bereavement in the patient's family, always remembering each of its social and cultural aspects. Helping patient and family, at a time of great suffering, is one of the greatest challenges that the everyday practice demands from nursing professionals, making it much more complex when it comes to the care of indigenous people, since the professional has no knowledge of the language, rituals or beliefs of these individuals.

In the experience of nursing professionals with the death of hospitalized indigenous children, feelings such as helplessness, sadness, guilt and anger emerged. To address and alleviate these feelings, the professional seeks the psychological support needed in religiosity and talking with friends.

It was evident that the death of hospitalized indigenous children affects the life and health of nursing professionals who work in the care of the hospitalized child, although, quite often, they ignore this fact. This leads to questions regarding the omission of mental health care for health professionals, especially the nursing staff, who constantly faces grief in their routine work.

Among the meanings assigned by nursing professionals to the death of indigenous children, cultural differences at the time of mourning are highlighted. It was then revealed the impact of cultural diversity within the hospital context and the obstacle of experiencing this as a caregiver, thus requiring a greater commitment of the healthcare team towards a perspective oriented to the differences and the search for a universal understanding of the other, irrespective of race, color or creed.

Another point highlighted is the lack of knowledge of the professionals regarding the indigenous language and culture, which makes it very difficult to provide comprehensive care, both in treatment, and at the time of death and subsequent comfort to the family. The magnitude of the health work with indigenous people is very different from the routine work with non-indigenous patients and requires a singular sensitivity at the time of care, also highlighting respect, dedication, involvement and patience.

Therefore, the inclusion of specific disciplines regarding the indigenous culture is suggested in technical and higher education courses, as well as the enhancement of university extension projects leading professor, student and nursing professionals to go beyond the hospital practices in the exercise of cultural relativism. The development of training, within the hospital scope, is also encouraged among the health team, so that care services to different populations may occur in a more comprehensive and humanized manner, valuing the principle of human dignity.

Hence, this study opens up new perspectives, several other experiences, understandings and interpretations for the experiences of nurses in the death and dying process of indigenous children. This study is expected to lead to the questioning of the current curricular matrix, and to the education of health professionals from the public and private network, as there are still professionals with difficulty in coping with death and mourning, in spite of these situations being part of the everyday life of all health care professionals, especially in the nursing area.

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