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Articles

Silences, voices and losses: maternal experience in communicating bad news in a neonatal Intensive Care Unit

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Silencios, voces y pérdidas: experiencia materna en la comunicación de malas noticias en la Unidad de Cuidados Intensivos neonatal (resumen: p. 17)

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This article aims to analyze the mothers' experience related to communication in the Neonatal Intensive Care Unit (NICU), within the context of palliative care, with an emphasis on the communication of bad news. This is a qualitative study using a narrative approach and content analysis. The results show that unclear and non-empathic communication intensified maternal suffering, while active listening, empathy, and respectful silence contributed to emotional support during grief. It is concluded that humanized communication practices, centered on families' emotional needs, favor care and interaction in the NICU, contributing to the training of professionals better prepared to deal with the complexities of neonatal grief.

Keywords: Health communication. Neonatal palliative care. Humanization of care. Narrative inquiry.

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Introduction

Delivering bad news in the neonatal setting, especially when it involves the imminent end of a life that has just begun, is one of the most complex challenges in healthcare practice. For families, this moment is profoundly disruptive, as it pits expectations of life against the pain and unpredictability of loss. In the neonatal intensive care unit (NICU), the fragility of the newborn intensifies this suffering, making it visible and constant. The continuous sound of medical equipment and the technical dynamics of care are in contrast with the families' subjective experience, marked by uncertainty about the prognosis and the anticipation of grief[1,2].

This background, however, often involves healthcare professionals who perceive themselves as ill-prepared to handle the communication of bad news. Studies indicate that both trainees and those already practicing report insecurity and insufficient preparation to conduct these conversations in an ethical and sensitive manner, highlighting persistent gaps in academic training and continuing education. Such weaknesses are not limited to individual competencies but reflect training models historically centered on cure, technical objectivity, and disease control[3].

Parents and family members, in turn, report a lack of emotional support and difficulties in their relationship with the team in the face of imminent mortality. Unclear or overly technical communication undermines trust-building and tends to reinforce distant approaches, which remain common in healthcare services. The literature indicates that the communication of bad news, although recognized as a fundamental pillar of palliative care, continues to be learned informally and in an unsystematic manner, which limits its incorporation as a reflective and shared practice[4].

Against this backdrop, communicating bad news goes beyond the transmission of clinical information and involves presence, listening, and acknowledging the other person's suffering. It is a relational practice in which words, gestures, and silences play a central role in building humanized care. The way this communication is conducted can mitigate or intensify the suffering resulting from the loss, directly influencing families' grief experience and the quality of the bond established with healthcare professionals[5].

Thus, the central question of this study seeks to understand, from the mother's perspective, how the healthcare team communicates with a mother facing the imminent loss of her child. The objective is to analyze the mother's experience regarding communication by healthcare professionals in a neonatal ICU, within the context of palliative care, with an emphasis on the communication of bad news.

Given the above, narrative research was chosen as the methodological approach, as proposed by Clandinin and Connelly[6], as it allows for an in-depth exploration of the mother's subjective experience, considering the meanings attributed to communication in the context of neonatal bereavement.

Methodological itinerary

Approaches

This study follows a narrative research approach, a qualitative method that seeks to understand individual experiences through the stories told by participants.

The qualitative approach, in this context, allows for access to the meanings attributed to experiences, valuing not only the reported events but also the way they are constructed and shared[6]. Furthermore, qualitative analysis emphasizes the interpretation of the meanings present in the accounts, considering the subjectivity and social context in which they are produced[7,8].

Narrative research, as a specific methodology, guided the collection, analysis, and interpretation of the stories told by the mother about her experience of communication with the neonatal ICU team, standing out for its ability to offer a detailed understanding of human aspects[9].

In this context, the use of personal narratives allows for a sensitive access to the reality of neonatal bereavement, offering an empathetic perspective on these experiences, which can transform the training of healthcare professionals, as this method enables a deeper understanding of the individual experiences of bereaved family members[10]. The narrative presented proved relevant to understanding the phenomenon under study, contributing to the achievement of the research objective by offering significant insights into the maternal experience.

This approach recognizes the importance of subjectivity and the unique perspective of each individual, considering that the stories told by the mother reveal emotions and values—contexts we call lived experience—constructed by people over time[9,11].

Given the special and complex nature of the NICU environment, it was deemed essential to explore the nuances of communication to identify strategies that promote welcoming, empathy, and effectiveness in information sharing, enabling the formulation of effective care practices grounded in humanization[10].

Thus, the researcher acted as a facilitator of the listening process, adopting an empathetic and respectful stance, allowing the participant's voice to be expressed authentically, without generalizations.

Participant

The research was intentionally conducted with a mother, chosen for her relevant experience in neonatal palliative care and her willingness to recount her story in detail during a semi-structured interview. The study followed the ethical principles set forth in Resolution No. 466/12 of the National Health Council, through a Free and Informed Consent Form.

This approach provided a rich contribution to the training of healthcare professionals and ensured depth in the study. It should be noted that contact with the

participating mother occurred exclusively for the purposes of the research, without any prior professional care relationship.

For confidentiality purposes, the mother is identified in this study by the code name Violeta. The code name was chosen because, in some religious traditions, this flower is considered a symbol of deep love, faith, and spiritual connection. She shared her experience, which was marked by intense feelings in her interactions with the healthcare team and permeated by emotional challenges. Throughout her life, she lost three children, two of whom were in palliative care, and her first experience of loss occurred at age 21.

The choice was made with care to capture the depth necessary for addressing the topic[9,11], using an approach grounded in the spontaneity of the mother's narrative, rich with feelings and details that comprehensively captured the challenges, emotions, and meanings involved in communication within this highly sensitive context. Furthermore, the selection of a single participant aligns with the principle of intentionality, which aims not at representativeness but at the depth of the study, allowing the personal story to be explored in its entirety and bringing to light aspects that might remain invisible in a study with multiple participants[12].

Data collection

Data collection was conducted through an online interview via Google Meet, in a private, quiet, and welcoming setting. The authors previously defined the semi-structured interview script, with questions designed to support the achievement of the objectives: Could you share your experience with palliative care and the loss of your child? What were the strongest feelings you experienced throughout the process? Did you experience anticipatory grief? How did you feel supported by the healthcare team during the palliative care process and after the loss of your child? In your view, how could healthcare professionals have contributed to ensuring your child's dignity in the final moments of life? What message would you like to convey to healthcare professionals regarding how to improve care for mothers experiencing neonatal loss?

This methodological approach provided flexibility and ensured coverage of the previously outlined areas of interest, striking a balance between guidance and freedom so that the mother could express herself naturally. By allowing the participant to feel at ease exploring her experiences and feelings, the semi-structured format facilitated the emergence of authentic and profound accounts, essential for understanding the complexity of the experience of neonatal loss and interaction with healthcare professionals[13]. To facilitate the recording and analysis of the information, the interview was recorded and subsequently transcribed.

Data analysis

The analysis followed an approach grounded in the interpretive paradigm, which seeks to understand the meanings constructed by participants based on their experiences[9]. To explore the depth of the maternal narrative, the study employed

qualitative analysis techniques, combining narrative analysis[11] with the content analysis proposed by Bardin[13].

In the data analysis, an interpretive approach was developed focused on identifying themes, patterns, and relationships present in the collected narrative. This method allowed for an understanding of the complexity of the reported maternal story, preserving the richness of details and exploring the depth of the shared experience. The search was not only for recurring elements but for particularities that offered new perspectives on the specific meanings of the experience[9,11].

For greater methodological rigor, the content analysis proposed by Bardin[13] was used. This technique was chosen for its ability to systematize information and facilitate the identification of relevant themes, as well as to highlight significant relationships in the accounts. Content analysis offers a structured path to uncover the meanings implicit in participants' statements, allowing individual narratives to be transformed into coherent and aligned thematic categories[13].

Thus, the combination of these techniques allowed for an in-depth interpretation of the narratives and, at the same time, structured the findings in a coherent manner aligned with the research objectives.

Ethical considerations

The research was approved by the Research Ethics Committee of the Professor Alberto Antunes University Hospital (HUPAA), under opinion no. 5.755.126/2022, in accordance with the ethical principles established by Resolution no. 466/2012 of the National Health Council (CNS).

The participant was informed about the study's objectives and signed the Informed Consent Form (ICF), authorizing the recording of her account, with a guarantee of confidentiality and anonymity.

Results and discussion

The narrative of Violeta emerges—a fictitious name for a 29-year-old Brazilian mother who, while facing the pain of loss, is also pursuing a career in healthcare. About to complete her undergraduate degree, her journey is intertwined with the experience of grief. She refers to herself as the mother of "invisible children." Her experience, marked by interactions with the healthcare team, was permeated by intense emotional challenges. Along the way, she lost three children, one of whom had the opportunity to receive palliative care from diagnosis until death.

This account was constructed within a context of skilled listening, in which the interview process facilitated the expression of her experiences. The researcher adopted a sensitive listening approach, respecting the silences, pauses, and emotions expressed throughout the narrative. During the interview, Violeta reported feeling that her emotions were validated, even in the face of intense pain and the experience of her child's terminal illness.

Thus, the narrative reveals distinct experiences of grief, ranging from losses without the possibility of a farewell to those accompanied by late palliative care, highlighting how different modes of communication—or their absence—directly impacted the processing of suffering and the experience of finitude.

Content analysis allowed us to identify emerging and relevant themes, such as welcoming strategies, the forms and challenges of communication and listening—central elements in the interaction between healthcare professionals and families facing neonatal terminal illness. Below, we explore these categories, highlighting their implications for clinical practice and the strengthening of neonatal palliative care.

Empathy in practice: put yourself in my shoes

In Violeta's narrative, empathy, mediated by communication, transforms the experience of loss.

> I lost a pregnancy at 24 weeks, with no room for explanations or a farewell, which made me feel isolated and abandoned. In the case of my 1-year-old son, although there was palliative care in his final days, the experience of finitude was still distressing. In the 26-week pregnancy, however, I was able to create memories and say goodbye, making the mourning less lonely and more meaningful. (Violeta)

The possibility of saying goodbye was a decisive factor in the mourning process, as evidenced in the narrative presented. In losses without the opportunity to say goodbye, the absence of memories intensified the suffering. In contrast, in the pregnancy where it was possible to create memories and perform farewell rituals, the grief was described as marked by pain, but also by the possibility of reframing, in line with what Lucini and Rieth[14,15] discuss when addressing the transformation of suffering into concrete memories.

The level of welcoming also proved to be uneven across the experiences described throughout the narrative. A technical and distant attitude was associated with a lack of emotional support, while listening, silence, and presence characterized the care as humane, even in the face of imminent death[16-18].

The fear of loss and the sadness over the impossibility of changing the outcome accompanied the entire process, while the need to remain by her son's side demanded constant emotional strength, even in the face of the awareness of his terminal condition.

Violeta shared her experience with anticipated suffering while accompanying her second son's illness, highlighting the difficult realization that loss was imminent:

> Yes, during my second son's illness, when the possibility of loss became a reality. This knowledge brought with it a clear perception of the fragility of life, but also of the difficulty in being supported during the palliative care process. (Violeta)

In this context, anticipatory grief emerges as a valuable strategy by enabling family members to gradually prepare for the loss, contributing to a less abrupt coping with grief and the construction of healthy emotional memories[16,17].

Souza et al.[16] highlight that this emotional preparation facilitates families' adaptation, while Bisotto et al.[17,18] emphasize that active involvement in patient care helps family members better understand the situation, creating emotional memories that endure after the loss. Furthermore, it offers caregivers an opportunity for emotional growth, helping them find meaning in this process[3].

> It allows me to create memories, for it is through them that I will continue to live and know who I am. (Violeta)

The symbolic construction of memories during mourning was one of the forms of maternal resistance against the idea that loss could not leave a tangible mark. She sought to give dignity to moments that could easily be dominated by suffering and apathy. The literature on mourning and neonatal loss reinforces this perspective, highlighting the importance of affective memories, even in the face of death[15].

Communication took on distinct forms across the reported losses. In some situations, information was conveyed in a fragmented or insufficient manner, hindering understanding of the situation and the grieving process. In another experience, even though the diagnosis was serious and time was short, clear communication enabled the mother to understand the process of finitude and participate in decisions, fostering the creation of memories[19].

Violeta's experience highlights the importance of protocols that prioritize welcoming practices in neonatal palliative care. She emphasizes the value of silence during moments of intense emotional distress, stating that "what is most needed is a silent presence," reflecting the relevance of nonverbal communication. Recognizing and respecting these moments is essential, reinforcing the need for professionals to understand therapeutic silence as part of care[20]. For the mother, such situations prevented her from experiencing meaningful goodbyes.

In this case, the diagnosis of a serious or terminal condition was not followed by early palliative care, which would have influenced the creation of emotional memories. Welcoming for the family before the irreversible worsening of the condition, and affectionate touch are effective strategies for creating a bond of trust between healthcare professionals, patients, and family members, facilitating the coping with grief and the making of difficult decisions[19].

Attentive listening and empathy, when they acknowledge the pain and the imminence of the terminal phase, transform each interaction into genuine care, allowing the mother to feel seen and welcomed. These moments of empathy, in addition to being significant for the individual experience, are essential for helping families cope with loss and for creating a grieving experience more deeply connected to the children's emotional memories[19,21].

Empathy, often considered an innate quality, can, in fact, be cultivated and refined through practice. According to Krznaric[21], this skill constitutes an active process of

connection and engagement with different perspectives and experiences. In pediatric palliative care, this ability is essential, allowing professionals to form humanized bonds and offer emotional support to families. Empathy, more than a virtue, is a competency that must be trained and incorporated into practice, promoting meaningful interactions and compassionate care[22].

Communication as a pillar of care: what aren't you telling me?

This category highlights the importance of communication (verbal and nonverbal) between family members and the team of care professionals as an essential pillar of the care provided to patients and their families.

More than the transmission of technical information, communication in this context requires sensitivity, clarity, and empathy, as it involves, in addition to diagnoses and prognoses, the building of bonds.

> I wish the professionals had the courage to look me in the eye to explain what was happening and what the possibilities were, even though a physical cure was no longer among them. (Violeta)

This comment highlights the communication breakdown in palliative care, which intensified the mother's suffering and helplessness. The absence of effective dialogue hindered her grieving process and her understanding of the situation, reinforcing the importance of empathetic and transparent communication in end-of-life contexts[13].

It is urgent that professionals recognize grief not merely as a biological process, but as a profoundly human phenomenon, which demands not only technical competence, but also humanity, empathy, and a genuine commitment to the emotional well-being of patients and their families[23].

From the mother's perspective, insufficient communication was even more devastating in the second loss. Upon being informed of her son's terminal condition, there was no time left to prepare or create moments of farewell. Violeta was enveloped in an "emotional fog," with reality only partially revealed, lacking the tools to cope with the gravity of the situation[3].

Although the healthcare team intended to protect the family, it ended up alienating them, intensifying their pain. Communication failures in the neonatal ICU generate insecurity and helplessness, as parents do not always understand the clinical picture or therapeutic options, increasing anxiety and suffering and hindering emotional preparation for outcomes, as highlighted by Araújo et al.[23].

Violeta's narrative highlights that technical clarity must be accompanied by sensitivity, as words can either comfort or exacerbate pain[24,25]. The importance of active listening and humanized communication in neonatal bereavement. To this end, the emotional training of teams must be continuously improved. Interdisciplinary training and specific protocols in neonatal ICUs ensure a family-centered approach, integrating technical care and emotional support[20,26-28].

From the mother's perspective, clear and transparent communication is crucial for her to face the painful reality of loss. For Violeta, this communication is not merely a choice but the foundation of emotional preparation for what lies ahead, as emphasized by Riessman[19,20].

The importance of improving care for mothers experiencing neonatal loss is underscored:

> I know that many times I will be vulnerable, having to say goodbye to someone I love and for whom I planned a whole life ahead, but I understand that it is not up to you to decide whether my child lives or dies. Look me in the eyes and show me that the care provided goes far beyond the physical dimension, because I won't have time for doubts, and I need to know that the best care is being offered. (Violeta)

What Violeta conveys to us is a lesson that, even in the darkest moments, compassion, transparency, and respect for human dignity can make pain more bearable, allowing meaningful memories to be preserved in her memory[29,30].

The need to feel the team's effective contribution to ensuring her son's dignity in his final moments is expressed by the mother:

> Just as it was my wish that the palliative approach had been offered even before the active process of dying began, ensuring the dignity of life at all times. (Violeta)

The narrative highlights communication in neonatal end-of-life care, showing that Violeta perceived the team avoiding talk of death, as if it were a failure in care[31].

> I felt as though the medical team avoided talking about mortality, as if it were the result of a failure in the care they provided. So much so that, in my opinion, they spoke with me/recommended palliative care too late, three days before the death, even though the process of finitude had already been observed earlier, even by laypeople. (Violeta)

Medical guidelines require that the professional clearly inform about the disease, therapeutic options, and, when appropriate, palliative care, allowing for informed decisions by patients and family members. However, some doctors, fearful of dampening the family's hope, may withhold information[32].

The lack of dialogue with the team intensified the mother's pain. She needed not only to understand the terminal diagnosis but also a sensitive perspective on the process. Communication, more than just conveying information, should express empathy, build trust, and consider nonverbal aspects, as highlighted in reports from patients and families in palliative care[15].

Communication regarding terminal illness must be conducted in a sensitive and open manner, allowing families to prepare emotionally and experience the moment

with dignity Touch and symbolic gestures are fundamental strategies in building emotional memories and in the experience of saying goodbye[33].

Nonverbal communication, such as glances, gestures, and even silence, plays a fundamental role in this process. Often, families' emotional signals manifest in body language and silent gestures, especially when words fail to capture the depth of their pain[25].

> When my son dies, you don't need to say anything to me, for there are no words capable of soothing my pain; just be present in silence—silence is precious... (Violeta)

The account highlights that communication difficulties are not limited to individual skill deficits but reflect professional training and institutional logic historically guided by technical objectivity and efficiency. In this context, sensitive listening, attention to nonverbal cues, and silent presence tend to be undermined, especially in palliative care settings marked by emotional and work overload[34].

In the context of neonatal palliative care, families seek more than technical information about their children's health status. They yearn for the assurance that care is humane, welcoming, and grounded in principles of dignity[35]. For families, the assurance that patients are being cared for with respect and compassion is crucial, especially at a time of imminent loss.

Clear and compassionate communication between the healthcare team and families directly impacts maternal emotional well-being and the grieving process[36]. Zampoli[34] highlights that open communication fosters understanding of the clinical situation and participation in decision-making, supporting a less traumatic farewell process that is consistent with the unique needs of each family.

Listening to voices: hear my pleas

In this category, the importance of the team's sensitive and empathetic presence stands out—a presence that perceives emotional needs even when words are not enough[24]. Experiencing the profound pain of loss, Violeta reflects on the role of the healthcare professional

> I know there are protocols that may restrict holding the baby, physical contact, photos, and privacy, but I also know that you can make possible everything you want and that is within your reach. It is not easy, but it is possible. You can be a bridge to preserve infinite memories. (Violeta)

This statement highlights that, even with formal restrictions, the professional can facilitate meaningful moments of connection between mother and child. The literature reinforces that neonatal palliative care must balance clinical requirements and the emotional needs of families[24,33,35].

Violeta's emotional preparation for finitude was inevitable, but the team's conduct intensified her sense of helplessness. Professionals need to detach themselves from cultural and emotional values, recognizing the biomedical and cultural context, so that empathetic communication goes beyond the technical and meets the emotional and social needs of families[15].

Violeta asks that professionals speak courageously about mortality, allowing her to experience her final moments with dignity and understanding, even without the possibility of a cure. The statement "I would like you to look into our eyes..." reveals the need for human recognition in the care process. Even while overwhelmed by pain and conflicting emotions, the desire to be seen and accepted beyond her son's clinical condition. The request to "look into our eyes" translates into a search for empathy, respect, and validation of the maternal experience, highlighting the importance of the relational bond between the team and family members.

Studies indicate that nonverbal communication, such as eye contact, is an essential resource for conveying presence, trust, and welcoming attitudes to families in situations of vulnerability[1,2]. In this sense, it is evident that, in the context of care, not only are technical procedures fundamental, but also the quality of communication and the presence of professionals, which can alleviate suffering and strengthen mutual trust. This understanding aligns with the principles of humanization in healthcare, which emphasize a holistic approach and the valuing of the subjectivities involved in the process of illness and care[3,4].

During their professional practice, a team experiences moments of both joy and profound sadness. The death of a patient often triggers an intense sense of helplessness, which can lead to emotional destabilization. This vulnerability, in turn, can result in a distant and evasive attitude on the part of the professional, compromising the quality of communication and, consequently, the relationship with patients and family members[37].

Given this challenging scenario, studies indicate that structured training is fundamental for the continuing education of healthcare professionals, including the development of emotional competencies. This process contributes to strengthening professional confidence, enhances interactions with families, and supports care practices based on respect, active listening, and recognition of suffering[19].

The relationship of trust between families and healthcare professionals, therefore, is decisive in ensuring that, even in the face of pain, care remains humanized and respectful. The mother's perception of communication with healthcare providers is relevant, as it reflects her emotional suffering and her adaptation to her child's terminal condition[36,38].

Violeta concludes her narrative by emphasizing that healthcare professionals are true bridges that help families preserve endless memories, even in the face of pain.

Interpretive synthesis

In the reported experience, the introduction of palliative care occurred at an advanced stage of the clinical course, limiting the time available for preparing for the farewell and intensifying the mother's suffering. Nevertheless, the account allows us to understand how different modes of communication can either enhance or undermine care for families, with direct impacts on the experience of grief. The uniqueness of the account, in this sense, constitutes analytical power rather than a methodological limitation, as it sheds light on sensitive dimensions of care in contexts of finitude.

Final considerations

Based on the narrated experience, this research contributes to the field of palliative care and health communication by highlighting the importance of sensitive approaches centered on the emotional needs of families in the neonatal ICU. Giving voice to the grieving mother demonstrated that care goes beyond the technical dimension, requiring empathy, transparency, and the creation of meaningful memories, even in end-of-life contexts.

Although the study focuses on a singular experience, its findings can inspire practices and reflections in similar situations, broadening understanding of neonatal grief and encouraging improvements in communication between healthcare professionals and families. Strengthening dialogue and relationships built on listening, presence, and the validation of suffering proved central to the quality of care and dignity in the context of neonatal end-of-life care.

Data Availability

Research data is only available upon request.

Authors' contribution

All authors contributed to the conception and design of the study, participated in the analysis and interpretation of the data, collaborated on the drafting and critical revision of the manuscript and approved the final version of the text.

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Conflict of interest

The authors have no conflict of interest to declare.

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Este artigo analisa a experiência materna relacionada à comunicação na Unidade de Terapia Intensiva neonatal, no contexto dos cuidados paliativos, com ênfase na comunicação de más notícias. Trata-se de pesquisa qualitativa, com abordagem narrativa e análise de conteúdo. Os resultados evidenciam que a comunicação pouco clara e não empática intensificou o sofrimento materno, enquanto a escuta ativa, a empatia e o silêncio respeitoso contribuíram para o apoio emocional durante o luto. Conclui-se que práticas comunicativas humanizadas, centradas nas necessidades emocionais das famílias, favorecem o cuidado e a interação na UTI neonatal, contribuindo para a formação de profissionais mais sensíveis à complexidade do luto neonatal.

Palavras-chave: Comunicação em saúde. Cuidados paliativos neonatais. Humanização do cuidado. Pesquisa narrativa.

Este artículo analiza la experiencia materna relacionada con la comunicación en la Unidad de Cuidados Intensivos (UCI) neonatal, en el contexto de los cuidados paliativos, con énfasis en la comunicación de malas noticias. Se trata de una investigación cualitativa, con abordaje narrativo y análisis de contenido. Los resultados muestran que la comunicación poco clara y sin empatía intensificó el sufrimiento materno, mientras que la escucha activa, la empatía y el silencio respetuoso contribuyeron al apoyo emocional durante el luto. Se concluye que las prácticas comunicativas humanizadas, centradas en las necesidades emocionales de las familias, favorecen el cuidado y la interacción en la UCI neonatal, contribuyendo a la formación de profesionales más sensibles a la complejidad del luto neonatal.

Palabras clave: Comunicación en salud. Cuidados paliativos neonatales. Humanización del cuidado. Investigación narrativa.