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REFLECTIVE ANALYSIS ARTICLE

CARE FOR THE FAMILY BEFORE NEONATAL LOSS: A REFLECTION UNDER THE OPTICS OF THE COMPLEXITY THEORY

O CUIDADO À FAMÍLIA DIANTE DA PERDA NEONATAL: UMA REFLEXÃO SOB A ÓTICA DA TEORIA DA COMPLEXIDADE

EL CUIDADO A LA FAMILIA ANTE LA PÉRDIDA NEONATAL: UNA REFLEXIÓN BAJO LA ÓPTICA DE LA TEORÍA DE LA COMPLEJIDAD

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ABSTRACT

Objective: to reflect on care for the family in the face of neonatal loss. ***Method:*** a qualitative, descriptive, theoretical and philosophical study, using Edgar Morin's Theory of Complexity as a basis for this reflection. ***Results:*** the questions examined in this essay may support the reflection of health professionals, seeking a look at a family universe as a whole, without fragmenting the reality experienced by these families, breaking with the simplifying vision and allowing a closer understanding of reality. ***Conclusion:*** this reflection contributed to the better understanding of this difficult moment in family life and, thus, to favor the development of actions with which health professionals can assist in the care of these families. ***Descriptors*:** Family; Perinatal Death; Grief; Nursing; Nonlinear Dynamics.

RESUMO

Objetivo*:** refletir sobre o cuidado à família diante da perda neonatal. ***Método: estudo qualitativo, descritivo, teórico e filosófico, que utilizou a Teoria da Complexidade, de Edgar Morin, como embasamento para esta reflexão. ***Resultados:*** as questões examinadas neste ensaio podem subsidiar a reflexão dos profissionais de saúde, buscando um olhar para um universo familiar como um todo, sem fragmentar a realidade vivenciada por estas famílias, rompendo com a visão simplificadora e permitindo uma compreensão mais próxima do real. ***Conclusão:*** esta reflexão contribuiu para a melhor compreensão deste momento tão difícil na vida familiar e, assim, favorecer o desenvolvimento de ações com as quais profissionais de saúde possam auxiliar no cuidado a estas famílias. ***Descritores*:** Família; Morte Perinatal; Pesar; Enfermagem; Dinâmica não linear.

RESUMEN

Objetivo: reflexionar sobre el cuidado a la familia ante la pérdida neonatal. ***Método:*** estudio cualitativo, descriptivo, teórico y filosófico, que utilizó la Teoría de la Complejidad, de Edgar Morin, como basamento para esta reflexión. ***Resultados:*** las cuestiones examinadas en este ensayo pueden subsidiar la reflexión de los profesionales de salud, buscando una mirada al universo familiar como un todo, sin fragmentar la realidad vivida por estas familias, rompiendo con la visión simplificadora y permitiendo una comprensión más cercana a lo real. ***Conclusión:*** esta reflexión contribuyó a la mejor comprensión de este momento tan difícil en la vida familiar y así, favorecer el desarrollo de acciones con las que profesionales de salud puedan auxiliar en el cuidado a estas familias. ***Descriptores*:** Familia; Muerte Perinatal; Pesar; Enfermería; Dinámicas no Lineales.

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INTRODUCTION

When considering the mortality rate among children under five years of age around the world, 40% relate to neonatal deaths. Of these, 75% occur during the first week after birth and 25% to 45% occur within the first 24 hours of the newborn's life.[1]

According to the World Health Organization, [1] the neonatal period begins at the time of birth and ends at twenty-eight full days after childbirth. Neonatal death can be subdivided into early neonatal death, such as during the first seven days of life (0-6 days), and late neonatal death, which occurs after the seventh and before the twenty-eighth day of life(7-27 days).

The vast majority of neonatal deaths occur in neonatal intensive care units (NICUs), although literature[2] shows that parents have the option of taking the newborn child, at the end of life, to a hospice or homecare, under palliative care.

In this way, care is configured in a delicate and extremely sensitive context, which demands the specific skills of health professionals. For the family, due to stress and anxiety, the absorption of the news can be slow, and it may be necessary to repeat the information a few times[3], since some families need time to assimilate that the newborn baby is dying The education gap and practice for difficult conversations with parents are stressors for NICU professionals.[4]

Given this scenario, this work aims to propose a theoretical and philosophical reflection on the care of the family in the face of neonatal loss, from the perspective of the theory of complexity, by Edgar Morin.

OBJECTIVE

● Reflecting on care for the family in the face of neonatal loss.

METHOD

A qualitative, descriptive study consisting of a theoretical and philosophical analysis about care for the family in the face of neonatal loss. For that, Edgar Morin's Theory of Complexity was used as a basis for reflection. The previous realization of a literature review was opted for, allowing a broader approach on the subject. Afterwards, the results were presented and contextualized in three analytical axes: Family care in the context of neonatal loss; The family experience of neonatal mourning and Edgar Morin's "Complexity" and neonatal loss.

RESULTS AND DISCUSSION

♦ Care for the family in the context of neonatal loss

From the moment parents understand the complexity of the diagnosis and, consequently, experience the end of life of their newborn child, a delicate process begins. In the face of neonatal loss, it is necessary to establish relationships of trust with the health team in which information is shared in a timely manner and clear, objective and compassionate communication enables the family to find space to tell and elaborate its history. To do so, the team needs to unite skills to provide effective care at the end of life and in the grieving process of this family.[5]

The impact of the end of life of the newborn child is so intense that it can have repercussions on the family in a wide way, affecting the conjugality of the parents, with the increase of the number of separations, as well as the next pregnancies and also the relation between siblings.[2,6-7] Thus, the family needs effective communication strategies, in addition to therapeutic listening, to avoid feeling guilty and the feeling that the memories of the baby's end-of-life period are not enough for his or her history is immortalized for that family.[2]

One of the roles of nurses in NICU, who cares for the family of the newborn in the end-of-life situation, is to do it in a systematic and sensitive way, knowing that all their verbal and nonverbal movements will make a positive or negative difference in the future of that family.[4,8]

Parents are able to recall inappropriate attitudes, behaviors and comments from NICU staff members months and even years after the death of the newborn.[3] In addition, expectations from parents that are not met by the staff are remembered for the rest of their lives and can be attributed as a failure, putting them at risk for complicated mourning.[2]

In this way, the need for the team's education regarding effective and empathic communication in the care of the newborn at the final stage of life is reinforced. Still in this respect, a study that evaluated the care offered to end-of-life newborns and their families revealed that, despite the

reduction of therapeutic approaches, improvements in pain management and family support, a large number of newborns still receive aggressive end-of-life treatment in intensive care units.[9]

In addition, although the importance of psychosocial support with a holistic approach for families and follow-up in the grief process[9] is known, the provision of this care still lacks gaps. Staff should be trained in the basic principles of pediatric palliative care and must be prepared, with skills, to provide consistent, high-quality care at the end of the newborn's life.[9]

A systematic review, which sought a basis in the literature that showed the efficacy of mourning interventions in NICUs, showed that these interventions take various forms and are based on personal and / or team experience in current practice.[10] However, for the team, death is not an easy subject, discussed, explained openly and clearly.

Barriers in the context of the NICU, so that care occurs in a compassionate and effective way at the end of life, generate moral suffering, causing resentment, guilt, frustration and a sense of impotence. These barriers are associated with a lack of training or education, family culture, care of the NICU professional and culture, and consistency of care.[5,11]

Palliative care programs available to newborns and their families, regardless of diagnosis and time, are requested by care institutions for this population. It is proposed that this care occurs in four ways: physical and emotional support at the time of death; clear, consistent and compassionate communication; viability of shared decision-making and family support during the mourning process.[7]

Research shows the importance of developing and implementing programs that suggest protocols such as Hope and Healing [13], Gundersen Letheran Bereavement Services, March of Dimes and Wisconsin Stillbirth Service Program, as well as Guidelines such as The Royal College of Paediatrics and Child Health (RCPCH), [14] which include interventions that help the family from birth to death, [15] as well as guidance to health professionals on the best and most respectful way of handling the newborn.[16]

Acting in the daily life of the NICU requires emotional maturation and practical ability. This skill needs to be continuously exercised in hospital practice, beginning at the undergraduate level, with continuity in the postgraduate and in the learning processes present in training on the care at the end of life. Despite the recommendations of the British Association of Palliative Medicine (BAPM), multidisciplinary discussions rarely occur after the death of a newborn.

Education for coping with grief for health professionals is beneficial in minimizing some effects on the family's grieving process.[17] Being together with the family without a formal education, which does not happen or does not happen at the undergraduate level, is a factor for the nurse and who will need a bedside training in the NICU.

♦ **The family experience of neonatal mourning**

Knowing that mortality at the beginning of life is an event that has a strong impact on the lives of families and health professionals, it is important to bring to the scene of care, both in the theoretical and practical spheres, the factors and the involved in the grieving process.

Mourning is the consequence of the experience of loss and happens whenever life is affected by the end of a relationship, a project or a dream. It means intense emotional suffering caused by loss, it is a dynamic, individualized and multidimensional process by which the individual who has suffered the loss of something significant crosses.

Mourning leads to new perceptions and requires time for acceptance. A new form of relationship with the lost person begins to be processed, as well as a new construction of one's own identity in the absence of the person. The experience of mourning is subjective. Each individual has different reactions to dealing with loss and remembering situations, stories, and moments.[18]

In the daily care and care practices, different social actors, professionals, parents, mothers and families are in constant relation. A meaningful encounter enables exchanges between caregivers and caregivers. However, the way services are organized and the reality of health contexts can create barriers for the approximation between the professionals, the person being cared for and the family, not allowing this encounter to occur in an effective and sensitive way.[19]

It is a challenge for professionals to approach the families who are in mourning and to support them in facing this phase. Health professionals often find themselves unable to play this role.[20]

In view of these considerations, it is essential to listen to the voices of the neonatal nurses, who assist the families that lost their children early, to understand the process of caring at the end of life. To know how the relationships with bereaved families happen, what meanings the nurse gives, what interactions occur during this process, and their preferences, can strengthen basic concepts used in different theories and in the work of prevention of complicated mourning with the family.

♦ Edgar Morin's "Complexity" and Neonatal Loss

The word complexity comes from plexus, which means intertwined, woven together. Morin uses the metaphor of a contemporary tapestry, made up of yarns of different fabrics and colors, as a comparison to the complex way of thinking that needs to look at the different components, distinguishing the individual characteristics, without losing the notion of the whole, that is, the whole is at the same time greater and lesser than the sum of its parts. Thus, to know complex thinking, it is not enough to know the properties of all types of yarns used for their fabric, just as, when considering the set, the qualities of each yarn separately can acquire different configurations. if they inhibit or acquire a greater expression, depending on the context in which they are found.[21]

Morin focuses on the need for a knowledge that contemplates an enlarged view on the different dimensions present in a phenomenon, which also implies to recognize, more appropriately, the relations between the part and the whole and the whole and the parts.[22] It is fundamental to seek the relations and interrelation between each phenomenon and its context. Reciprocal relations of all / parts, such as a change at the local level, can have implications for the whole and how a change of the whole can have repercussions on the parts.[22]

Morin proposes complex thinking as a possibility of approach that considers what is "woven together". This implies considering the distinct parts that are articulated in the composition of the phenomenon, inserted in its context, including the contradictions in a dialogical perspective.[23]

For Morin, the dialogic principle is one of the fundamental principles integral to the complex thought that maintains the duality in the core of the unit. It is through dialogue that it is possible to contextualize the object, promoting the establishment of articulations, without eliminating the differences. Thus, in complexity, we find antagonisms and complementarities considered in different contexts.[21,23]

The limits of the health professional's training, based on the biomedical model, can have implications for the appropriation of this referential.[24] This fact is quite paradoxical, because it is precisely such appropriation, even with some limits, that can open possibilities for a new thinking and doing .

Complex thinking integrates modes of thinking in opposition to reductionist mechanisms. It is a mental activity that seeks to integrate the modes of linear and systemic thinking, simplifying and totalizing of the modern era, in an effort of thought, to promote union, operating with diversities of thoughts: the simple and the complex.[25] This complex way of thinking , when developed, produces a way of thinking based on a paradigm of knowledge construction, distinct from modern thought, requiring a departure from the Cartesian, common way of thinking and being, without ceasing to be a product of the Cartesian model in which constitutes himself as a person.[24]

It is imperative to visualize the context, the global, the multidimensional and the complex, because it is necessary to place the information and the data in its context so that, in this way, they acquire meaning. Just as every single point in a hologram contains the totality of the information it represents, each human being contains, in a holographic way, the whole of which he is a part and at the same time.[25-6]

This way of thinking makes it desirable for the question of the complexity of the health problems of human beings to be better worked by resorting to the reconnection of knowledge to the development of actions.[27] For Morin, in reconnecting knowledge, also for the reconnection of human beings.[28]

In understanding the human being as a complex being, the care directed to him is also a complex, interdisciplinary action,

directed towards transdisciplinarity. Interdisciplinarity, as an initial step towards transdisciplinarity, and transdisciplinarity itself as elements of Complexity.[29] Being care for the family that suffers the loss of the child that can be approached through interdisciplinarity and transdisciplinarity as a complex care.

Disorder and changes in its life cycle are facts present in the context of families and, consequently, this dialogic, order and disorder, is also contained in the work process in health, thus, care for the family that loses a child.

In thinking about neonatal loss, in the light of complexity, it is necessary to consider elements such as family structuring and dismemberment as important, since linearity and the circularity or recursiveness of the facts are subject to change, with the whole and the parts having equal weight, making it important to consider them together.[27]

In the case of neonatal loss, there is the construction and deconstruction of the family, with changes in this family that are continuous and dependent on the phases of life in which this family finds itself. Thus, complexity is a type of thinking that considers all influences received, internal and external, and still faces uncertainty and contradiction, while still living with the solidarity of existing phenomena. Emphasizes the problem and not the question that has a linear solution. Like man, a complex being, thought also presents itself.[30]

Suffering can show an affective unity present in everyone in the family, but at the same time, it can present itself peculiar to each subject. This suffering takes on multiple faces and is present at the different moments during the process of loss.

CONCLUSION

In caring for the family that has experienced a neonatal loss, the understanding that the real is complex requires the search for the vision of the whole, breaking with the simplifying vision of the reality experienced. Thus, this theoretical and philosophical reflection approximates the family care practice that suffers a neonatal loss with the assumptions of Edgar Morin's complexity.

For the articulation between complexity and neonatal loss, it is necessary to understand care as something that goes beyond, offered in an integral way, immersed in scientific knowledge and accepting the influences suffered by the family, through their relations with others and with themselves . It is a care without prejudices and judgments, with the purpose of understanding the individual / family as being single, complete and complex.

By using complexity, the purpose of this work is to better understand the condition of the family and, as a consequence, to prevent the structuring of fragmented care in the situation of the loss of a newborn. Thus, considering the complexity of the situation of loss of a child and the need to improve communication and care in this situation, the meaning of the loss is sought in order to improve the approach of families who experience this loss.

The phenomenon of neonatal loss involves multiple dimensions, at a peculiar moment in the life of the family, demanding specific demands, inserted in a family and social context, in addition to daily living with different professionals. Faced with this aspect, elements that lead to reflection on the construction of caring practices appropriate to the complexity of the human condition may be pointed out.

There is a need to be cautious about caring for the family that has suffered a neonatal loss, so that caregiving standards are not created, always taking into account the particularities of caring for the loss, without losing sight of the peculiarities of the human condition that are present beyond any situation.

REFERENCES

1. World Health Organization. Newborns: reducing mortality [Internet]. Geneva: WHO; 2012 [cited 2015 June 01]. Available from: http://www.who.int/mediacentre/factsheets/fs333/en/

2. Woodroffe I. Supporting bereaved families through neonatal death and beyond. Semin Fetal Neonatal Med. 2013 Apr;18(2):99-104. Doi: 10.1016/j.siny.2012.10.010

3. Cortezzo DE, Sanders MR, Brownell EA, Moss K. End-of-life care in the neonatal intensive care unit: experiences of staff and parents. Am J Perinat. 2015 July; 32(08):713-24. Doi: 10.1055/s-0034-1395475

4. Simwaka ANK, Kok B, Chilemba W. Women's perceptions of Nurse-Midwives' caring behaviours during perinatal loss in Lilongwe, Malawi: An exploratory study. Malawi Med J. 2014 Mar; 26(1): 8-11. PMID:24959318

5. Fenstermacher K, Hupcey JE. Perinatal bereavement: a principle-based concept analysis. J Adv Nurs. 2013 Nov; 69(11):2389-400. Doi: 10.1111/jan.12119

6. Cacciatore J. References in Psychological effects of stillbirth. Semin Fetal Neonatal Med. 2013 Apr; 18(2): 76-82. Doi: http://dx.doi.org/10.1016/j.siny.2012.09.001

7. Wool C. State of the science on perinatal palliative care. J Obstet Gynecol Neonatal Nurs. 2013 May/June; 42(3):372-82. Doi: 10.1111/1552-6909.12034

8. Scarton J, Poli G, Kolankiewicz ACB, Piovesan CL, Scarton J, Poli AG. Nursing: death and dying in a pediatric and neonatal intensive care unit. J Nurs UFPE [Internet]. 2013 Oct [cited 2016 July 12]; 7(10): 5929-37. Available from: http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/3324/pdf_3618

9. Wool C. Clinician perspectives of barriers in perinatal palliative care. MCN Am J Matern Child Nurs. 2015 Jan/Feb; 40(1): 44-50. Doi: 10.1097/NMC.0000000000000093

10. Donovan LA, Wakefield CE, Russell V, Cohn RJ. Hospital-based bereavement services following the death of a child: a mixed study review. Palliat Med. 2015 Mar; 29(3):193-210. Doi: 10.1177/0269216314556851

11. Silva LCSP, Valença CN, Germano RM. Phenomenologic study about experiences when living the death in the neonatal critical care unit. Rev Bras Enferm. 2010 Sept/Oct;63(50): 770-774. Doi: http://dx.doi.org/10.1590/S0034-71672010000500012

12. Souza LF, Misko MD, Silva L, Poles K, Santos MR, Bousso RS. Dignified death for children: perceptions of nurses from an oncology unit. Rev Esc Enferm USP. 2013 Feb; 47(1): 30-7. Doi: http://dx.doi.org/10.1590/S0080-62342013000100004

13. English NK, Hessler KL. Prenatal birth planning for families of the imperiled newborn. J Obstet Gynecol Neonatal Nurs. 2013 May/June;42(3):390-9. Doi: 10.1111/1552-6909.12031

14. Brooten D, Youngblut JM, Seagrave L, Caicedo C, Hawthorne D, Hidalgo I, Roche R. Parent's perceptions of health care providers actions around child ICU death: what helped, what did not. Am J Hosp Palliat Care. 2013 Feb; 30(1): 40-9. Doi: 10.1177/1049909112444301

15. Wool C, Côté-Arsenault D, Perry Black B, Denney-Koelsch E, Kim S, Kavanaugh K. Provision of services in perinatal palliative care: a multicenter survey in the United States. J Palliat Med. 2016 Mar;19(3):279-85. Doi: 10.1089/jpm.2015.0266

16. Mancini A, Kelly P, Bluebond-Langner M. Training neonatal staff for the future in neonatal palliative care. Semin Fetal Neonatal Med. 2013 Apr; 18(2):111-5. Doi: 10.1016/j.siny.2012.10.009

17. Jonas-Simpson C, Pilkington FB, MacDonald C, McMahon E. Nurses' experiences of grieving when there is a perinatal death. SAGE Open. 2013; 3(2):1-11. Doi: https://doi.org/10.1177/2158244013486116

18. Bousso RS. The complexity and simplicity of the experience of grieving. Acta Paul Enferm [Internet]. 2011 [cited 2017 Jan 15]; 24(3):7-8. Available from: http://www.producao.usp.br/bitstream/handle/BDPI/3955/The%20complexity%20and%20simplicity%20of%20the%20experience%20of%20grieving.pdf?sequence=3&isAllowed=y

19. Peng N, Chen CH, Huang LC, Liu HL, Lee MC, Sheng CC. The educational needs of neonatal nurses regarding neonatal palliative care. Nurse Educ Today. 2013 Dec; 33(12):1506-10. Doi: 10.1016/j.nedt.2013.04.020

20. Bousso RS. Um tempo para chorar: a família dando sentido à morte prematura do filho [Livre- docência] [Internet]. São Paulo: Universidade de São Paulo; 2006 [cited 2017 Jan 18]. Available from: http://www.teses.usp.br/teses/disponiveis/livredocencia/7/tde-27092006-104500/pt-br.php.

21. Morin E. Introdução ao pensamento complexo. 4th ed. Porto Alegre: Sulina; 2011.

22. Morin E. A cabeça bem feita. 5th ed. Rio de Janeiro: Bertrand Brasil; 2004.

23. Morin E. Ciência com consciência. 8th ed. Rio de Janeiro: Bertrand Brasil; 2005.

24. Menossi, MJ. O cuidado do adolescente com câncer: a perspectiva do pensamento complexo. [tese] [Internet]. Ribeirão Preto: Universidade de São Paulo; 2009 [cited 2017 Jan 17]. Available from: http://www.teses.usp.br/teses/disponiveis/22/22133/tde-09032010-165150/pt-br.php

25. Morin E. Os sete saberes necessários à educação do futuro. 2nd ed. São Paulo: Cortez; 2011.

26. Menossi MJ, Zorzo JCC, Lima RAG. The dialogic life-death in care delivery to adolescents with câncer. Rev Latino-Am Enfermagem. 2012 Jan/Feb; 20(1):126-34. Doi: http://dx.doi.org/10.1590/S0104-11692012000100017

27. Santos SSC. Education in nursing and the complexity. Contexto educação. 2005; 20 (74/75):103-17. Doi: http://dx.doi.org/10.21527/2179-1309.2005.73-74.103-117

28. Morin E. O método 6: ética. 3rd ed. Porto Alegre: Sulina; 2007.

29. Santos SSC. Teaching of gerontogeriatric nursing and complexity. Rev Esc Enferm USP. 2006 June;40 (2):228-35. Doi: http://dx.doi.org/10.1590/S0080-62342006000200011

30. Morin E. O método II: a vida da vida. 4th ed. Porto Alegre: Sulina; 2011.

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