Family-centered care in neonatal intensive units: The perceptions of nursing technicians

O cuidado centrado na família em unidade de terapia intensiva neonatal: Conceções dos técnicos de enfermagem

Cuidados centrados en la familia en una unidad de cuidados intensivos neonatales: Concepciones de los técnicos de enfermería

Abstract

Background: Using the child- and family-centered care (CFCC) model provides neonatal units with considerable benefits, such as decreasing parents' suffering through their participation and autonomy, increasing breastfeeding rates, and decreasing sequelae of prematurity in infants.

Objective: To understand nursing technicians’ perceptions of CFCC delivery in a neonatal intensive care unit (NICU).

Methodology: A qualitative research study was conducted at a NICU of a teaching hospital located in the interior of São Paulo, Brazil, using open and semi-structured interviews with six nursing technicians. Data were analyzed using thematic analysis, based on the principles of CFCC.

Results: The study identified the six themes Integrating families into the care process; Promoting the family unit’s closeness; Welcoming the family unit; Sharing information with the families; Recognizing the NICU as a stressful environment for families; and Limitations of delivering CFCC at the NICU.

Conclusion: The results show that nursing professionals have a limited understanding of CFCC and that it is crucial to include this topic in the education of future professionals and continuous training activities.

Keywords: family nursing; communication; neonatal nursing; family; intensive care units, neonatal

Resumo

Enquadramento: O cuidado centrado na criança e na família (CCCF) em unidades neonatais possui diversos benefícios como diminuir o sofrimento dos pais pela sua participação e autonomia, aumento do aleitamento materno, diminuição de sequelas da prematuridade.

Objetivo: Compreender as conceções de técnicos de enfermagem sobre o CCCF praticado em unidade de terapia intensiva neonatal (UTIN).

Metodologia: Investigação qualitativa desenvolvida em UTIN de um hospital-escola localizado no interior de São Paulo, Brasil, com entrevistas abertas e semiestruturadas junto a seis técnicos de enfermagem. Os dados foram analisados por análise temática, à luz dos pressupostos do CFCC.

Resultados: Foram encontrados seis temas - Incluir a família no cuidado, Promover a aproximação da unidade familiar, Acolher a unidade familiar, Partilha de informações com a família, Reconhecer a UTIN como ambiente estressor à família e Limitações para oferecer o CFCC na UTIN.

Conclusão: O estudo evidenciou limitações na compreensão do CFCC pelos profissionais de enfermagem e a necessidade de incluir o assunto na formação dos futuros profissionais e em atividades de educação continuada.

Palavras-chave: enfermagem familiar; comunicação; enfermagem neonatal; família; unidade de terapia intensiva neonatal

Resumen

Marco contextual: El cuidado centrado en el niño y la familia (CCCF) en las unidades neonatales tiene varios beneficios, como reducir el sufrimiento de los padres mediante su participación y autonomía, aumentar la lactancia materna, reducir las secuelas de la prematuridad.

Objetivo: Comprender las concepciones de los técnicos de enfermería sobre el CCCF practicado en una unidad de cuidados intensivos neonatales (UTIN).

Metodología: Investigación cualitativa desarrollada en una UTIN de un hospital universitario situado en el interior de São Paulo, Brasil, con entrevistas abiertas y semiestructuradas a seis técnicos de enfermería. Los datos se analizaron mediante análisis temático, atendiendo a los supuestos del CFCC.

Resultados: Se encontraron seis temas - Incluir a la familia en los cuidados, Promover la cercanía de la unidad familiar, Acoger a la unidad familiar, Compartir información con la familia, Reconocer que la UTIN es un entorno estresante para la familia y Limitaciones para ofrecer el CCCF en la UTIN.

Conclusión: El estudio puso de manifiesto las limitaciones en la comprensión del CCCF por parte de los profesionales de enfermería y la necesidad de incluir el tema en la formación de los futuros profesionales y en las actividades de formación continuada.

Palabras clave: enfermería de la familia; comunicación; enfermería neonatal; familia; unidades de cuidado intensivo neonatal

How to cite this article: Costa, J. S., Motaes, E. S., Carmona, E. V., & Mendes-Castillo, A. M. (2022). Family-centered care in neonatal intensive units: The perceptions of nursing technicians. Revista de Enfermagem Referência, 6(1), e21144. https://doi.org/10.12707/RV21144

Revista de Enfermagem Referência 2022, Série VI, nº1: e21144
DOI: 10.12707/RV21144

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Introduction

The hospitalized neonate has weaknesses and vulnerabilities that require specialized care. Implementing this type of care demands going beyond technical knowledge, involving family members and the health professionals’ cooperation between themselves (Hasanpour et al., 2017). The child- and family-centered care (CFCC) model consists of an approach in which the child and family are the focus of care. It is based, among other factors, on information sharing and collaborative care (Davidson et al., 2017). Nursing professionals should welcome family members during the newborn’s (NB) hospitalization and identify and meet their needs with a multi-professional team. However, when discussing this interaction, the literature emphasizes the role of nurses. Thus, the present study focuses on nursing technicians who, in Brazil, are the mid-level nursing professionals more numerous in neonatal units in the country. These health professionals must understand the relevance of families’ full-time inclusion and participation. Families’ participation and collaboration are vital for the NB’s recovery and benefit both. Although families’ importance in care is already recognized, nursing professionals still need to fully understand what it means to include family members in neonatal care. Thus, it is essential to understand nursing technicians’ perceptions of CFCC to gather information to develop strategies and interventions promoting this care delivery model in neonatal intensive care units (NICUs). This study aims to understand nursing technicians’ perceptions of CFCC delivery in NICUs.

Background

Some studies have related families’ lack of familiarity with hospital settings to feelings of fear and insecurity, which reflects the urgency of consolidating horizontal interactions between families and health teams. These interactions enable disease prevention, health promotion and recovery and promote the infants’ comfort, well-being, and quality of life (Enke et al., 2017; Weber et al., 2021). According to Waddington et al. (2021), the close relationship between NBs and parents is vital for infants’ development in the first years of life. Thus, families’ presence during NBs’ hospitalization is essential. The CFCC model is defined as the professional support provided to the child and family through a process of involvement and participation based on negotiation and empowerment. This approach emphasizes health professionals’ and family members’ sharing of responsibility for infants’ health care (Davidson et al., 2017). According to the Institute for Patient- and Family-Centered Care, four pillars support all levels of care throughout the life cycle: dignity and respect (health professionals must listen to and respect the perspectives and decisions of patients and families); information sharing (to communicate and share information thoroughly and objectively with patients and families so that it is relevant and clarifying); participation (patients and families must be supported and encouraged to participate in the care process and decision-making in the manner they choose); and collaboration, involving patients and families, in which health care professionals together with patients and families contribute to developing, implementing, and evaluating policies and programs, health care facility and professional education planning, and health care delivery (Davidson, 2017).

Several studies have highlighted the relevance of CFCC in NICUs. Units implementing this model decrease parental distress through participation and autonomy in care delivery, promote breastfeeding, and decrease sequelae of prematurity, among other benefits for infants and families (Coats et al., 2018; Davidson et al., 2017; Mirlashari et al., 2019; Waddington et al., 2021; Zhang, at al. 2018). Separating neonates and families can negatively impact clinical stability, well-being, and neurological development. These effects, combined with parents’ anxiety, fear, depression, and post-traumatic stress, can dramatically impact the family-baby relationship, resulting in unfavorable outcomes (Hasanpour et al., 2017; Richards et al., 2017; Waddington et al., 2021).

Research Question

How do nursing technicians delivering care in a NICU perceive CFCC?

Methodology

A qualitative descriptive study was conducted at a highly complex NICU of a public teaching hospital located in the interior of São Paulo, Brazil. The NICU where this study was conducted is responsible for delivering care to about 3,000 NBs annually and is the reference health care unit for 42 municipalities. The NICU has 30 beds, and parents can stay in the unit 24 hours a day. This study’s sample consisted of nursing technicians. The inclusion criteria were to work for at least one year in direct patient care in a NICU and to belong to the unit’s permanent professional staff. Professionals on vacation or medical/maternity leave were excluded. The study’s first author collected the data from February to April 2018, using qualitative semi-structured interviews. The interviews included the open-ended questions “How do you define CFCC in a NICU?” and “Which care activities do you perform aimed at the family of the hospitalized neonate?”.

The interviews were conducted in a single meeting, in a private room within the NICU. Participants’ confidentiality and anonymity were guaranteed in any disclosure of the research results. The interviews were recorded and transcribed in full immediately after they were conducted. The interview transcripts were coded with the initials NP (Nursing Professional), followed by the number of the order of their participation (from 1 to 6) to ensure the nursing professionals’ anonymity. Data collection was ceased according to the principle...
of saturation (Fontanella et al., 2008), which suspends the inclusion of data when the data collected respond to the study's objective and start to repeat themselves or be redundant.

The frame of reference used for data analysis was the CFCC model (Davidson et al., 2017), and thematic analysis was the method adopted. In the thematic analysis, first, the interviews were broken down into units of meaning, which were then grouped according to their similarity regarding the theme addressed. Next, the grouped data were examined to ensure that each theme's references were included and compared. The themes were grouped, and data were analyzed considering the adopted frame of reference, resulting in six themes (Pope & Mays, 2009). This research was approved by the Research Ethics Committee under opinion number 2,362,084, in accordance with the ethical standards required by Resolution number 466/12 of the Brazilian National Health Council (Brazil, 2012).

Results

Six nursing technicians, with 2 to 24 years of professional experience in NICUs, with a mean of 11 years and 9 months, and a mean age of 40, participated in this study. Among the interviewees, two worked in the morning, one in the afternoon, and three at night.

Considering the nursing technicians’ perceptions of care delivery to neonates from a child- and family-centered perspective, the analysis organized the collected data into the following six themes: “Integrating families into the care process;” “Promoting the family unit’s closeness;” “Welcoming the family unit;” “Sharing information with the families;” “Recognizing the NICU as a stressful environment for families;” and “Limitations of delivering CFCC at the NICU.” The themes are presented below and exemplified with the participants’ transcripts.

Integrating families into the care process

For nursing technicians, integrating families into the care process in the NICU means encouraging participation in care delivery, promoting breastfeeding, and encouraging the presence of the mother and other family members:

“I encourage . . . the family to provide care, particularly breastfeeding, the care activities, to participate, okay?” (NP4).

“Okay . . . yes, we encourage touching, the family members themselves caring for the baby, pumping breast milk, breastfeeding, we encourage the visit from other family members, siblings, we are always inviting them to come.” (NP1).

The health professionals believe that families can be included in care delivery regardless of the complexity of the NB’s medical condition. Therefore, involving the mother/father in care delivery is a way of promoting their bonding, guiding them on how to begin contacting with their children, even when they are still inside the incubator and with other devices:

Parents’ guidance begins in the incubator . . . So they start with touching, and as the mother and the father are coming, they can do skin-to-skin. Put [the baby] in skin-to-skin contact with the father or the mother, and then they can change the baby [‘s diaper], even inside the incubator. They can change [the baby] and give the milk through the tube. They use the syringe. We fill the syringe with the milk, and they hold it. (NP6)

According to the nursing technicians, the parents’ participation in care delivery brings benefits to the family:

“And their participation, helping, changing diapers, cleaning [the baby's] mouth . . . Giving the milk, it gives [parents] confidence and comfort so they can go home and come back tomorrow to help again.” (NP7).

Promoting the family unit’s closeness

Regarding this theme, professionals highlight the strategies adopted to promote the closeness between parents and NBs:

Yes, I think we need to integrate the mother into the NICU experience, bring her close to [her] NB, who is different from what she idealized, get her involved in care delivery, always encouraging breastfeeding, milk pumping and as soon as possible putting the baby in her lap, always stimulating her to touch [her baby], to have contact with [her baby], both the mother and the father. (NP1)

Welcoming the family unit

The professionals mention the significance of a professional practice that welcomes the family members and shapes itself to their needs, valuing the role and knowledge of the family:

Look, not everybody can do this . . . establish a relationship with the person, not everybody. As I told you, sometimes some people treat everyone like, “This is how I am, and that is it.” I think that in nursing, you can't be like that. In nursing, when you come to work, you must forget your ego. (NP6)

We are here as professionals. I cannot come up to the family and tell the mother, “No, I know, I know everything, leave it. It is not like that.” It is not. The mother knows the child deeply. It is not because I have a degree, because I am from the nursing [team], that I am everything. That when the family comes, I have to show them that I am the professional. I, the one who knows, the one who understands, right? (NP6)

The nursing technicians also value the moment parents are experiencing and attempt to understand their feelings, reactions, and attitudes in an individualized way while trying to establish a good relationship with them: “But you can say it ten thousand times, ten thousand times . . . they will ask [ask the same thing] because it is shocking [experience]. And many have never thought about being in a place like this, it is the first time.” (NP5).

For these professionals, welcoming also means offering the resources and support families need:

I think there should be a place for them to stay . . .
Sharing information with the families
The interviewed nursing technicians believe that sharing information with the families is an essential measure to involve them in the NBs’ care, considering the patients’ characteristics and the unit’s routine: “Ah, I think that the professional, nurse or technical team, must identify parents’ concerns, depending on the gestational age with which the child was born.” (NP6)

But, well, a part of our communication is in writing. I offer some guidance after the admission that parents have in writing, okay? But this guidance is more related to the environment and some issues regarding visits: it does not relate to the NB. (NP6)

Recognizing the NICU as a stressful environment for families
The professionals identify the NICU as a stressful environment for families because of the environment itself, equipment and alarms, and the experience families have there:

Then, he (the father) looked at us and said: “My God, what is this? I had no idea that 620g would be this, this size.” I said: “Do you want to touch [your baby] with your hand? Just wash your hand or rub some alcohol on it, and you can touch [your baby] with your hand.” “No, I do not know how to handle this” (the father replied). [The baby] is too small, I mean, he thought about the size. He did not think about other problems much worse than the size, okay? (NP5)

Apart from the environment, nursing technicians also describe the moment of discharge from the hospital as stressful for families, which interferes with understanding the information given:

I think [the stress] is higher when they go home because they will be alone at home. You can tell that, sometimes, they are not even listening to what (the professional) is saying. So, we tell them what is essential at that moment because there is no point in telling them everything that will happen during hospitalization or that can probably happen during hospitalization if they are not assimilating [that information]. (NP6)

Limitations of delivering CFCC at the NICU
Nursing professionals believe that promoting CFCC is not a simple task. They report several difficulties in including family members in moments, for example, of medical complications with the NB or during invasive procedures:

Look, what I do to try to include the family ... sometimes it is impossible for the family to provide care, we usually let them change a diaper, okay? Give some milk, something, but depending on the severity of the baby [s condition], you cannot let the mother touch [the baby], okay? Baby with minimal handling protocol, heart disease, severe, what do I do to try to include the mother... when the mother comes, I tell her what happened to the baby. I think this is something that calms them down a lot. (NP2)

Since the unit does not have an environment favorable to parents’ presence, due to its physical layout and the absence of living rooms or dormitories for family members to stay during the night, parents are usually present only at the beginning, which hinders the contact with professionals:

“I cannot talk about it because it is difficult . . . At night it is more difficult to come, okay . . . Some mothers stay at night. At night it is difficult for us to have contact with them” (NP4).

The professionals also report men/fathers’ resistance to participating in care delivery, explaining it:

I always ask if the father wants to roll the baby from prone to supine position, change [the diaper], but the fathers are still somewhat resistant. They have two objections: “no, I prefer you let the mother do it.” Ah, but the mother is fragile, she had a baby, “No, let her do it” (father’s reply). And also: “no, I do not know how to change a diaper.” Here, there are many humble people from the rural areas, a bit [ignorant], okay. These men think, “no, I do not change diapers, I am a man,” and there is a lot of that too. (NP2)

Discussion
This study shows the actions carried out by nursing technicians concerning the families’ integration into the NICU and how these actions permeate their perceptions of CFCC (Davidson et al., 2017; Hill et al., 2018; Richards et al., 2017; Zhang et al., 2018).

The theme “Integrating families into the care process” regards the encouragement of the family’s participation in care delivery to the neonate and the stimulation of the family-baby bond, actions that prove the recognition of the family as a care unit. The following actions were considered essential in neonatal care: to place the NB on the mother’s lap as soon as possible; to encourage touch; to facilitate the contact between parents and the baby; to stimulate breastfeeding; and to pump breast milk to maintain lactation, as recommended by Waddington et al. (2021).

Despite recognizing some relevant aspects of this approach, the nursing professionals also point out limitations to the parents’ involvement in care delivery based on the time they spend at the unit. One example is skin-to-skin care, which should not be linked to the frequency with
which parents go to the unit, and must be promoted even in sporadic visits. Among the benefits of this practice are the development and strengthening of bonding, the parent’s feeling of inclusion and security, the maintenance of neonates’ body temperature and colonization with microorganisms from parents’ flora rather than hospital flora, and the promotion of breastfeeding (Pados & Hess, 2020; Kuo et al., 2021).

The theme “Promoting the family unit’s closeness” included the actions performed by professionals to encourage family members’ participation in caregiving. According to the Institute for Patient- and Family-Centered Care, family member participation is one of the pillars supporting all levels of care. Patients and families must be supported and encouraged to participate in care and care-related decisions in whatever manner they choose (Davidson et al., 2017). In this sense, the data found aligns with the principles of the CFCC model. The participants also highlight the importance of assessing the NB’s medical condition to offer parents clear guidance, mainly when this means that there will be less interaction between them. Family participation in neonatal care brings benefits such as reducing professional workload, increasing care-related satisfaction, reducing adverse events, offering comfort to and welcoming the family vulnerable due to the hospitalization experience, and reducing the length of hospitalization (Boyamian et al., 2021). However, integrating the family into the care process requires more than encouraging or delegating already standardized tasks. This integration must be part of care planning. It must be understood as an intentional and systematized care intervention in which needs and potential are assessed. The results found in this study also point to the need for greater care planning to include the family systematically, beyond routine activities such as diaper changing, breastfeeding, and skin-to-skin care, and moving towards shared decision-making.

The results also demonstrate the perception that the father is less present than the mother, thus, with fewer opportunities to be included. Nevertheless, it is possible to observe that, when identifying this situation, the nursing technicians act intentionally to include the fathers. This position from the nursing team is desirable, as the literature reports that professionals working in neonatal units are mainly focused on meeting the needs of the NB to the detriment of those presented by the mother and even more of those presented by the father (Noergaard et al. 2018).

The NICU where this study was conducted allows parents free access 24 hours per day, having a pre-established visiting schedule only for siblings and grandparents. The nursing team also works in the kangaroo unit, encouraging parents to provide full-time care until their babies are discharged from the hospital. Care actions fostering greater family-baby closeness are prioritized to be performed when the parents are present, such as bath time. Thus, the family units are encouraged to be present, participate in care delivery, and monitor their NBs’ evolution, which corroborates what some authors recommend (Davidson et al., 2017; Waddington et al., 2021). It is worth noting that nursing technicians did not mention any objectives of the CFCC model beyond the performance of tasks promoting the family members’ acquisition of skills for the physical care of the NB.

Considering the theme “Welcoming the family unit,” the data observed align with the adoption of the welcoming strategy, which is essential for identifying parents’ needs, understanding the moment they are experiencing, and promoting the reflection on the importance of the family’s integration into the NICU. Adopting welcoming attitudes by establishing relationships based on respect and trust promotes strong therapeutic alliances between patients, health professionals, and families (Coats et al., 2018; Sampaio et al., 2017). One of the core principles of the CFCC model is the importance of dignity and respect for establishing a partnership benefiting all the stakeholders involved. Treating with dignity and respect means listening to and respecting the views and decisions of patients and families, whose values, beliefs, and cultural backgrounds must be considered when planning care (Davidson et al., 2017). However, this study did not identify any reference to family members’ opportunity to make choices or be included in decision-making. This lack of evidence demonstrates that the nursing team’s understanding of the CFCC model is still superficial. The nursing team must be trained to recognize situations threatening the family’s autonomy and intervene on its behalf.

Nevertheless, some professionals recognize the family’s role in the NICU, considering that health professionals are not the holders of all knowledge. The mother is recognized as the one who knows her NB best and, together with the family, has much to contribute to the health team’s care delivery and evolution. Thus, knowing the mother and the family is extremely important to identify the best way to act with them.

It was possible to observe that professionals attempt to establish a good relationship with families. Daily and frequent contact is the basis of this good relationship, which develops bonding, trust, and a sense of security. Nursing technicians’ interaction with family members allows them to recognize the family’s needs, fears, anxieties, and distress, as well as understand that each family is unique and requires specific interventions (Enke et al., 2017; Hasanpour et al., 2017; Waddington et al., 2021). However, while professionals recognize that this is not always possible, they do not identify the need for knowledge acquisition and skill development in this area. The nursing technicians signaled as one of the unit’s needed investments a facility for family members to rest, allowing the NB to be accompanied 24 hours a day. This aspect must be planned and included in the budget to promote the presence of family members in the unit.

In the themes “Sharing information with the families” and “Recognizing the NICU as a stressful environment for families,” the health professionals emphasize the importance of recognizing the family’s concerns/needs to promote actions. They recognize that the intensive care environment is characterized by events and situations that impact families, which makes it necessary to use resources to improve communication and decrease stressors, as the
literature recommends (Coats et al., 2018; Enke et al., 2017). The lack of clear and objective information is one of the factors responsible for causing parents’ anxiety and limiting their participation in care delivery (Waddington et al., 2021).

Nursing technicians recognize the importance of providing information in a gradual, timely manner, according to the moment being experienced, as recommended by the literature (Davidson et al., 2017; Hill et al., 2018). However, there is a need for resources, skills, and strategies to improve communication in the unit, considering that parents/family members are frail, anxious, and distressed, which makes it difficult for them to understand the information provided. Information sharing with parents and family members is not only a facilitating factor for inclusion in neonatal care but is also used to decrease stressful events in the NICU (Waddington et al., 2021). According to the interviewed professionals, the neonate’s hospital admission and discharge are moments when the families require a lot of guidance. Some strategies to facilitate information assimilation include providing guidance to two people responsible for the NB instead of just one and offering this guidance in writing in a didactic and visual manner, using a folder or manual. This way, it is possible to take home and check in case of doubt. The NICU is an environment where the technology employed is unknown to lay people, fueling parents’ fears. Thus, professionals must make parents more familiar with the purpose of the machines, alarms, and devices used (Hill et al., 2018).

Considering the “Limitations of delivering CFCC at the NICU,” nursing technicians pointed out daily medical complications and worsening of the neonate’s medical condition as limitations to parents’ involvement, as well as the lack of facilities promoting the family’s full-time stay in the unit. Professionals believe it is necessary to include families in some of the NB’s care activities, which also aligns with the families’ wish to be included in their babies’ care delivery and procedures. Being present and monitoring their children’s treatments brings security, and families’ more active participation allows them the understanding that everything possible is being done.

The neonatal nursing team’s practice still limits parents’ participation by requesting that they leave during procedures in which they could be present, such as infusion therapy and several other procedures which their presence does not hinder. This situation is also observed in studies that broaden the discussion on family participation by integrating them into care planning and delivery, including during cardiopulmonary resuscitation and tracheal intubation (Silva et al., 2020). For CFCC to occur, all stakeholders must collaborate. Patients and families need to be integrated into an institutional structure, and health care professionals must contribute along with patients and families to building, implementing, and evaluating strategies for care delivery, health care facility design, and professional improvement. (Coats et al., 2018; Davidson et al., 2017; Hill et al., 2020). For CFCC to be fully implemented, the unit must have facilities to accommodate family members and promote their presence. Therefore, it is crucial to expand social support, services, and institutions that can help the family during this period of hospitalization.

**Conclusion**

This study demonstrates that, although open to this model of care, nursing technicians have a limited understanding of CFCC. Moreover, these professionals must improve their interaction with family members, acknowledging them as co-responsible for care delivery to the hospitalized neonate. Regarding its implications for practice, this study identified the need for theoretical-practical and awareness-raising training in CFCC by implementing professional training courses and in-service training. In the NICU environment, professionals must understand the family unit as a focus of attention for care delivery. Thus, to implement CFCC and accomplish the model’s purposes, it is necessary to study, plan, train, and reorganize the work process. This study has a limitation. The results presented focus exclusively on the reality of the Brazilian culture regarding both the routines and training of mid-level professionals. Future studies should develop and evaluate interventions to raise nursing technicians’ awareness of the CFCC model.

**Author contributions**

Project administration: Mendes-Castillo, A. M. Conceptualization: Mendes-Castillo, A. M., Costa J. S. Investigation: Costa, J. S. Formal analysis: Costa J. S. Supervision: Mendes-Castillo, A. M. Validation: Moraes, E. S., Carmona, E. V., Mendes-Castillo, A. M. Visualization: Moraes E. S., Carmona E. V., Mendes-Castillo, A. M. Writing - Review & Editing: Moraes, E. S., Carmona, E. V., Mendes-Castillo, A. M.

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