



## Experience of a nurse in transpersonal caring for families of neonates discharged from the intensive care unit\*

*Vivência de enfermeira no cuidado transpessoal às famílias de neonatos egressos da unidade de terapia intensiva*

*Vivencia de enfermera en el cuidado transpersonal a familias de neonatos egresados de la unidad de cuidados intensivos*

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### ABSTRACT

**Objective:** To describe the lived experience of home nursing in transpersonal care for families of neonates discharged from the intensive care unit. **Methods:** A qualitative research of the descriptive case study type. We used the *Theory of Transpersonal Caring*, operationalized by the caring process of Lacerda. Seven families were followed and became study participants. Data were collected by means of documents and archived records. **Results:** The care practices of family caregivers, their demands and needs; and, the importance of nursing in the process of hospitalization, discharge and home care were detected. **Conclusion:** This pathway enabled understanding that the actions of caring must be allied to humane care, and of the necessity for investment in research capable of combining home care with transpersonal caring in nursing and other health care professions.

**Keywords:** Home nursing; Nursing theory; Nursing care; Family; Infant, newborn

### RESUMO

**Objetivo:** Descrever a vivência de enfermeira domiciliar no cuidado transpessoal às famílias de neonatos egressos de unidade de terapia intensiva. **Métodos:** Pesquisa qualitativa tipo estudo de caso descritivo. Utilizou-se a Teoria do Cuidado Transpessoal operacionalizada pelo Processo de Cuidar de Lacerda. Sete famílias foram acompanhadas e tornaram-se participantes do estudo. Os dados foram coletados por meio de documentos e registros em arquivo. **Resultados:** As práticas de cuidados do cuidador familiar, suas demandas e necessidades; a importância da enfermagem no processo de hospitalização, alta e cuidados domiciliares foram constatadas. **Conclusão:** Esse caminhar possibilitou compreender que as ações do cuidar precisam estar aliadas ao cuidado humano, e à necessidade de investimentos em pesquisas capazes de aliar o cuidado domiciliar ao cuidado transpessoal na enfermagem e demais profissões da área de saúde.

**Descritores:** Assistência domiciliar; Teoria de enfermagem; Cuidados de enfermagem; Família; Recém-nascido

### RESUMEN

**Objetivo:** Describir la vivencia de enfermera domiciliaria en el cuidado transpersonal a familias de neonatos egresados de la unidad de cuidados intensivos. **Métodos:** Investigación cualitativa de tipo estudio de caso descriptivo. Se utilizó la Teoría del Cuidado Transpersonal operacionalizada por el Proceso de Cuidar de Lacerda. Fueron acompañadas siete familias tornándose participantes del estudio. Los datos fueron recolectados por medio de documentos y registros en archivo. **Resultados:** Las prácticas de cuidados del cuidador familiar, sus demandas y necesidades; la importancia de la enfermería en el proceso de hospitalización, alta y cuidados domiciliarios fueron constatados. **Conclusión:** Ese caminar permitió comprender que las acciones del cuidar necesitan estar aliadas al cuidado humano, y a la necesidad de inversiones en investigaciones capaces de aliar el cuidado domiciliario al cuidado transpersonal en la enfermería y demás profesiones del área de la salud.

**Descriptores:** Atención domiciliaria de salud; Teoría de enfermería; Atención de enfermería; Familia; Recién nacido

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## INTRODUCTION

Throughout its history, nursing has been constructed in the light of a humanistic basis of health care, which seeks meaning in human existence. It is through the care for people and life, on a human approach, that the true professional identity happens, therefore the essence of nursing is built based on interpersonal relationships<sup>(1)</sup>.

In this context, it is noted that the role of care is threatened by the rise of medical technology; the preservation and advancement of care are important issues for nursing now and for the future<sup>(2)</sup>. It is believed that the care can be effectively demonstrated and practiced only in a transpersonal manner, in which the care awareness goes beyond the biological or material dimensions, being able to transcend time, space and physical body<sup>(3)</sup>.

Therefore, a transpersonal caring relationship connotes a special kind of caring relationship, a union with a person who raises the consideration of the other as a whole and for their being-in-world, in which nurse and client become one, this is the moment that care is achieved and the two beings are tuned into body and soul in the relationship<sup>(2,3)</sup>.

According to the Theory of Human Caring<sup>(2,3)</sup> proposed by Jean Watson, in which the presence of the other needs to exist, and this is perceived as being unique, sacred and active throughout the process, it is necessary to reflect on the care provided to newborn (NB) and his family, so that by caring for the baby, the family is also cared, especially the mother of this baby, who is usually a constant presence in everyday of the Neonatal Intensive Care Unit (NICU).

To look at the mother, to empathize, to listen to their doubts, anxieties and difficulties, to show presence, guide, accompany, to facilitate in their decision-making, looking at the body as a single structure in which mind and spirit integrate, to promote recovery capacity, to be able to overcome moments of pain, suffering, separation, anguish and fear, this is transpersonal care.

The neonatal care followed the world trend and advanced over the last decades, with the introduction of more effective therapeutic resources, latest technology and human expertise. However, this scientific-technical advance provides care that transcends the physical body to a secondary level. At times, not focusing on important aspects such as family presence, individualized care, and even, appreciation of the sociocultural dimensions of clients<sup>(4)</sup>.

Therefore, it is important and necessary that the entire team of professionals act as a triad: mother-infant-family, being prepared to ease family suffering caused by the hospitalization of the child through a human child-centered care and to their family.

Taking into account the principle that neonatal care is not limited to guaranteeing the survival of

extremely premature infant until discharge, it is clear that the monitoring and adequate support for babies and children discharged from neonatal units are still huge challenges in our area<sup>(5)</sup>. Thus, it is necessary to invest our attention to the moments after hospital discharge, following up those children in ambulatory clinics, health units and at home.

Based on 8 years of experience in the NICU and through observations and inquiries made to the parents at the time of discharge, by the first author of this study, it was possible to perceive that many feel unprepared for this moment. Additionally, as an aggravating factor, many mothers do not rely on help from partners, family or friends when they return home.

Being aware of this reality and recognizing the importance of caring in a transpersonal way for the nursing practice, the question arose: how do home nursing experience a transpersonal care to families of infants discharged from NICU? To answer this question, the following objective was established: to describe the experience of transpersonal home nursing care to families of infants discharged from NICU.

## METHODS

This is a qualitative research of a descriptive case study, conducted in the NICU of a private philanthropic hospital, reference for high-risk pregnancy and for participants' home.

As strategy for the selection of participants, visits to the NICU were done in order to meet and get close to families who experienced the hospitalization of an infant and who fulfilled the following inclusion criteria: to be a parent or family member of a discharged neonate from the NICU, to be aged over 18 years old, who have experienced a baby hospitalization in the NICU for the first time; to be a resident in the city of Curitiba; to agree to participate in the study by signing the Consent Form; to be a parent or a relative of a newborn in need for specific care at home, with consequent increased demand for family care after hospital discharge. Supported by this delimitation, seven families were selected and monitored; they composed the total number of participants of the study, among which the main medical diagnosis for hospitalization of the NB was prematurity and perinatal asphyxia, with a mean hospitalization of 59 days (ranging between 35 and 96 days).

In this study, it is noteworthy that the family is understood by the definition expressed by Faro<sup>(6)</sup> citing Penna

*Dynamic unit consisted by people who perceive themselves and live as a family, in a time space, united by ties of consanguinity, affection, interest and/or donation, structured and organized, with rights and responsibilities, living in a certain environment, influenced*

*socially, economically and culturally. Also people who have built a life history and who have their own identity, sense of ownership, creating and transmitting beliefs, values and knowledge.*

During the months of October 2008 to April 2009, 21 visits to the NICU and 39 home meetings were done, totalizing approximately 90 ninety hours of transpersonal care occurred at home, 26 people were involved, study participants, family members, among them: mothers, fathers, brothers, sisters, grandparents, cousins, besides discharged neonates and neighbors.

The research project was approved by the Ethics Committee of the Evangelical College of Parana, Protocol No 5641/08.

To respect the anonymity of participants, in conformity with Resolution No 196/96, families were coded with the following names: Stars, Flowers, Planets, Colors, Luminous Stars, Fish and Precious Stones.

Documents and records on file were used for the collection of evidences. The documents were composed of records of birth of the newborn, NICU admission form, evolution of clinical condition and nursing, vaccination certificate, discharge summary, prescription drugs for the hospital discharge and, field and methodological journals, which appeared after home meetings with the families participating in the study. The records on file were made by the referrals made by medical staff and the register of admission book of newborns in the study local unit.

A case study method recommends that it is established a general analytical strategy and specific analytical strategies which help setting priorities for what to analyze and why <sup>(7)</sup>.

Thus, it was established as the general analytic strategy "relying on theoretical propositions," which are represented here by the process of taking care of Lacerda <sup>(8)</sup>, composed of four phases: initial contact, becoming close, transpersonal relationship and separation; and the elements from clinical caritas process <sup>(9)</sup>, expressed in ten elements, briefly presented here as: **Element 1** – Practice love and kindness, **Element 2** – to be authentically present, honoring the deep belief system; **Element 3** – cultivation of spiritual practices; **Element 4** – to develop and maintain an authentic caring relationship, help trusting; **Element 5** – to be present and supportive to the expression of feelings; **Element 6** – to creatively use one's self and the paths for knowledge; **Element 7** – to teach and learn experiences that address the whole person, remaining within the other referential; **Element 8** – to create a recovery environment; **Element 9** – to assist with basic needs; **Element 10** – to be opened and attentive to the spiritual mysteries and dimensions of life and death.

The usage of the care process of Lacerda <sup>(8)</sup> aims at operationalizing the application of the Theory of Human

Caring <sup>(2,3,9)</sup>, since the theory does not have a nursing process which can guide the application of his theory.

As a specific analytical strategy, the standard combination was selected. By this means, it is understood that the comparison of an empirically-based pattern with a provided pattern, which consists in adjusting the evidence collected to a set pattern <sup>(7)</sup>. In the case of this study, the standard refers to the Care Process proposed by Lacerda <sup>(8)</sup>, which, with the Theory of Human Caring <sup>(2,3,9)</sup>, supported the data collection and analysis and composed the theoretical framework of this text.

## RESULTS

As a manner of presenting the results, it was decided to use only the stage of synthesis from the crossed cases, because this stage contemplates the totality of cases included in the study, moment after the individual description of the seven involved cases. These were analyzed with each other and appropriate to theoretical framework that guided the research. For these purposes, the phases that constituted the Lacerda <sup>(8)</sup> caring process as a presentation strategy was used.

### Initial contact

The first phase of care <sup>(8)</sup> had the common feature to all participants in its beginning, during the infant's hospitalization in the NICU. The fact facilitated the entrance into the home and the continuity of the remaining phases, due to the fact that the families already knew the researcher.

The initial contact led to an approximation with some values, anxieties and other feelings expressed by families, which enabled a broader understanding of family relationships and assisted in the continuity of home care.

It is important to highlight that the phase separations were only didactic, since it is difficult to delimitate the exactly time in which one phase ended and the other began, still being able to return to phases at later times in cases of non-progression of caring relationship.

By changing the environment of care from the NICU to their homes, there was the need to continue the initial contact, to understand the specificity of the environment in which the family dominates the environment while the professional needs to understand their role, respect limits, values, cultures, beliefs and still assume the unexpected, using competence and expertise through various kinds of knowledge, skills and, above all, sensitivity to be able to meet the demands of care for these clientele.

It was possible to verify that biological questions were focused during care, in this phase, by six of

seven families followed, because when entering into a completely unknown environment, with cultures, beliefs and peculiar values, I felt insecure, afraid of the unknown and not knowing if I would achieve the purpose that I had. Thus, the first meetings at home had an own characteristic, a focus on the biological aspects. This was a way found to try to advance in the care relationship in the initial phase. Biological aspects brought greater safety, by reason of being “object” of the first author’s professional experience and previous studies content. To clarify the above, a quote extracted from the report coming from the home meetings were recorded in the researcher journal.

*[...] The grandmother, Mrs. Betta, helped the development of the meeting, with inferences, questions, suggestions in caring for the baby since the mother Corvina little commented, just answered what was asked and evolved slightly when it came to biological aspects of the baby, the way used in this first meeting in an attempt to achieve a better involvement with the family. Elements 1 and 2 were used in the search for an approximation, bonding and a meeting between us, so that other aspects could be shared. (Fish family)*

Thus, in only one family the characteristics were different, the family relationships were highlighted since the first home meeting, an aspect that justifies the expressive use of elements 1 and 2 of clinical caritas process, referring to the practice of love and kindness, the authentic presence and honor to the belief system of the being cared <sup>(3)</sup>.

As more meetings would happen, the relationship evolved and other topics arose. Gradually, the biological dimension was exceeded by the transpersonal aspect, members would disinhibit and become more spontaneous. They realized that the presence of the nurse would not only help them to understand the demands of infant care, but their care needs, sharing feelings, situations of everyday life and thus it was possible to start another phase of the care process, becoming close.

### Becoming Close

As the second stage would continue the need for integration and interlacing of the beings involved in the care process was highlighted, due to the fact of having difficulties of progression in the relationship with two families (Luminous Stars and Fish), such as: introspection, short speeches without development of the subject and long periods of silence, that is the reason why the Becoming Close phase had to be extended in order to the relationship evolve and, we could go for the transpersonal meeting.

*[...] She was short in her answers, she said it was okay [...] keeping a retracted posture and downcast eyes. [...] Corvina [...] did not prolong the conversation, changed the subject, talking to her son [...]. (Fish family)*

During the development of this phase, several elements from clinical caritas process were used with the purpose of involving beings in the relationship of caring to go towards union. Therefore, the elements 2 and 5 were more present with ten and nine uses, respectively, being applied to all families participating in the study.

This is due to the fact that in the becoming close phase, the relationship has evolved and other subjects emerged from contact between humans. The professional is placed in a listener position and the being cared, exposes facts more naturally than during the initial contact established by the proximity to the nurse. However, it is not enough to listen to the feelings expression, whether positive or negative, it is necessary to respect their beliefs, their culture and their subjective world life, without analysis or judgment and, therefore, the second element has its place.

*Other important facts emerged in relation at this time [...] faith in church and in alternative therapies [...]. Big Bear puts strength and confidence in church and in God, her faith is clear and presented at all times. She believes and considers graces divine works. [...] The mother questioned the usage of herbs in the umbilical stump of his son, because she always uses it, but she often take it off the day of the meetings [...]. (Family Stars)*

One aspect of particular importance at this stage emerged in five families. The maternal speech and observations performed to the families allowed us to realize that mothers caring for discharged babies from NICU experience a daily practice of self-careless. To illustrate the above, we refer to a quote, extracted from report emerged from the home meetings registered in the researcher journal.

*[...] (Sun) Complained that she wasn't feeling well, had dizziness, headaches, weakness and talked about her health, her self-care and postnatal consultations. It was noticed that she had forgotten herself. [...] In addition, she has neither eaten properly nor conducted to medical monitoring [...]. (Luminous Stars Family)*

### Transpersonal Meeting

To achieve the transpersonal care and the recovery of beings involved, the element 2 of clinical caritas process was used in all cases in which this stage was contemplated, ten usages, being considered the most expressive.

Other important elements which assisted the nurse to reach the transpersonal care was element 3, applied seven times within five families, the element 6 with six uses in five cases, and the elements 8 and 10, both with four uses in four and three families, respectively, noting that only five families reached completely this phase of the care process.

On the other hand, the element 9 had the lowest number of applications; it was used three times with

three families, which connotes the focus of this phase in subjective aspects, spiritual, artistic practices of care-recovery, energy exchanges, care consciousness, recovery environment, beyond attention of the spiritual mysteries, existence dimensions and care of the soul.

The phase of transpersonal meeting provided the unveiling of feelings, sensations and emotions in people involved in the care process, so when they separate would be recovered, transformed and able to pursue their lives independently, but they would be restored and overcome their difficulties.

Thus it was possible to understand the importance of faith and spirituality for some families. Much more than the realization of any care, guidance, empathic listening or therapeutic touch, faith moved the family and determined the events, successes, victories and overcomes.

*Big Bear told the facts with downcast eyes, warm voice and tears in her eyes. She states that prays considerably and that has the help of God and the church so that her daughter "opened her eyes" when still time and Father forgive her and bring her back home. [...] Puts strength and confidence in the church and in God, her faith is clear and present at all the times. She believes and considers the graces, divine works. (Family Stars)*

However, the transpersonal meeting failed to be achieved with two participants. With a family, this phase was initiated, but not completely covered. The relationship was unilateral although there was involvement; the issues that emerged were uniquely from the family and had no union of selves. In another case, circumstances that occurred during development of the relationship with the family Luminous Stars, made it difficult and ultimately impossible to reach this stage. The parties have changed and strengthened, but there was no union.

It is worth noting that each family has a proper time to enter and advance in the relationship. They have peculiarities that can affect the transition of each phase, perhaps, the time required for this to happen was not enough for this family.

### Separation

In the last phase of the care process, the elements 8 and 10 were most used, which reflect this special moment in the care relationship, and it refers to the creation of a recovery environment and the attendance of the spiritual mysteries in life and death dimensions.

*[...] In the seventh and last meeting with this family, Orchid was happy with a relaxed and relieved aspect. She mentioned that she can reconcile her activities with the baby's routine. She was relaxed, with plans for the future, mature about past difficulties and those still to come. She spoke about the research, how she felt to participate in it, her expectations and the realization of the experienced process. [...] She stated she will miss the meetings and she feels alone even before the end and she knows the need to*

*overcome this moment, but she is strengthened to face the situation. (Family Flowers)*

With four families, the separation came from researchers because they understood that the objectives had been achieved and that both, the caregiver and the being cared, should liberate the bond established, therefore they were changed and strengthened to continue life. With two families (Colors and Planets), the end of the process came from the participants and, with (Precious Stones Family), the beginning of the separation came from the researchers, but it ended abruptly because of the baby's death.

## DISCUSSION

When referring to the first phase of care proposed by Lacerda <sup>(8)</sup>, it must be understood that the care in the home environment has developed its own characteristics, and at this phase the issues relating to the housing context are more expressive. The professional, by moving into this place, needs to be prepared for this practice, because home care cannot be seen as an extension of hospital care. It is unique.

The nurse needs to know the reality, family relationships, characteristics of each family and, therefore, the nurse must understand that the home is dominated by the client; it is their refuge, their territory, a private space. Entering this universe is to penetrate the family's life, revealing their secrets and interfering with their intimacy. It is an incursion in a place considered sacred to many.

The home context should be perceived by a broad perspective that goes beyond the physical space, which considers the environment as a set of things, events and humans beings correlated between them, which represents particular, interfering and simultaneous character <sup>(10)</sup>.

On initial contact, the nurse must be present, respect beliefs, habits and subjective way of life, so such actions can support continuity of care in other phases and, so, beings cared feels respected and valued, strengthening the possibility of a successful relationship. However, the professional may use strategies that seek involvement from humans and that answer the desires of subjects of care, in addition to serve as mechanisms to achieve the goals proposed by the researcher caregiver.

In addressing the becoming close, the second phase of care, linked to the transpersonal care, it may appear in front of the professional, the real opportunity to establish a relationship of help and trust, throughout which it might be possible to identify the multidimensional needs of the being cared, and to develop a care which manifests itself through the presence, attitude, music, touch and even silence, among others <sup>(11)</sup>. But, for transpersonal nursing care to be

possible and real, there should be an interlacing of the living spaces of those involved, in which occurs the possibility of the professional caregiver, who perceives the subjectivity of the other and vice versa. Such event will only be achieved if those involved in the process participate in a genuine and integral way <sup>(12)</sup>.

In this perspective, the nurse is able to perceive subjective aspects of another, which often are not noticeable even for those who face them. The careless practice of itself may be one of those aspects, which was present in five of the seven families studied. One can understand the care of oneself as a necessary prerequisite to care for others, since this does not imply the renunciation and mortification of the caregiver <sup>(13)</sup>.

The third phase of care called transpersonal meeting, represents the union, the meeting between human beings involved in the relationship, in a transcendent way, inter subjective, harmonic and mutual <sup>(8)</sup>. To reach the transpersonal care, it is important that nurses make use of scientific knowledge acquired and learned during their graduation and professional experience, but, in which associates to this knowledge “awareness, sensitivity, aesthetic knowledge, artistic and intuitive knowledge to identify emerging needs of the being cared” <sup>(14)</sup>.

For this, the element 6 of the clinical caritas process provides subsidies to achieve this condition, being one of the most prevalent elements during the development of this phase. Element 10 was, another element, very present, which means that does not exist in our minds and in modern science explanations for all the life-death and for all human conditions faced, however, we must be opened to the uncertainties that we cannot control and allow even a “miracle” in our lives <sup>(5)</sup>.

Concluding the process, there is the separation; it is established the moment that ends the relationship which can occur with the maturity of the parties or abruptly without having transformation, either by client indenting, or the need for further preparation of nurse or client, or by the need of another professional support <sup>(8)</sup>.

Regarding the last fact, it is noteworthy that for the effectiveness of home care, teamwork is essential in which the professional and family perform different functions and roles, but with a common purpose, the welfare of the client <sup>(15)</sup>. Thus, active nurse in the home care has among its responsibilities to identify

the demand of care for other professionals, because teamwork is essential to the professional security who is with the client at the moment and the own client who will have its need satisfied <sup>(16)</sup>.

Therefore, the transpersonal care, understood and reached with the development of this study, “allows a better understanding of themselves to better know the other, promotes the expansion of restructuring capacity” and is able to embrace and value the triad body-mind-spirit and change the focus of care, from the focus of healing to the recovery and love <sup>(17)</sup>.

## FINAL CONSIDERATIONS

Based on the process experienced, the practices of care from home caregivers were evidenced and their demands and needs for care, in addition to the importance of the nursing staff in the process of hospitalization, discharge and home care, as well as the weaknesses and strengths of the health system.

It might also be noted that coming close with the participants during hospitalization favored the home meetings, and it promoted the deepening of the relationship of care and the achievement of the transpersonal meeting. Thus, the process experienced in the application of elements in the clinical caritas process and in the caring process points towards the need for involvement and mutual attitude between the human beings in the relationship of care, for the purpose of transpersonal care happen and its recovery is achieved.

It was also noted the need for a deep reflection regarding the aspects related to graduation and nursing practice, being able to awaken the professional care that transcends the physical body and involves the other in the relationship of caring, in addition to equip future professionals to the particularities of home care.

This report enabled us to understand that the objective actions of care must be allied to human care, expressively, so that the nurse takes different approaches before the family caregiver. It was also possible to realize the inevitability of changes in institutions providing health services, with the purpose of offering conditions for the development of transpersonal care, in addition to investments in research allying, home care with transpersonal care, in nursing and other health professions.

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