The mothers' experiences in the pediatrics hemodialysis unit

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Abstract

Introduction: The need for hemodialysis exerts a deep impact on the lives of children and adolescents with end-stage kidney chronic failure and their mothers, who predominantly assume the care related to treatment. The hemodialysis requires that the mother accompanies the child during sessions at least three times a week and, since it is not a healing practice, they also experience the waiting for a kidney transplant, attributing different meanings to this experience. **Objective:** To understand what it means for the mothers to accompany the child in a Pediatric Hemodialysis Unit and to construct a theoretical model representing this experience. **Methods:** The Symbolic Interactionism was adopted as a theoretical model and the Grounded Theory as a methodological framework. Data were collected through interviews with 11 mothers. **Results:** The comparative analysis of the data enabled the identification of two phenomena that compose the experience: "Seeing the child´s life being sucked by the hemodialysis machine" expresses the experiences of the mothers that generates new demands to comprehend the new health conditions of their children and "Giving new meaning to the dependence of the hemodialysis machine" that represents the strategies employed to endure the experience. The relationship of these phenomena allowed the identification of the main category: "Having the mother's life imprisoned by the hemodialysis machine", from which we propose a new theoretical model. **Conclusion:** The results of the study allow us to provide a theoretical ground for planning an assistance that meets the real needs of the mothers, identifying aspects that require intervention.

Keywords: hemodialysis units; hospital; mothers; renal dialysis; renal insufficiency.

Introduction

Chronic Kidney Disease (CKD) incidence and etiology vary with age. Congenital malformations and obstructive uropathy are the most frequent causes in children before age 5; while hereditary and acquired kidney diseases prevail in the age group of 5 to 15 years.[1,2] CKD treatment requires therapeutic measures, such as conservative treatment, with the use of medicines and strict diets to slow kidney function worsening, reduce symptoms and prevent CKD-related complications.[3]

When the glomerular filtration rate is below 15 ml/min/1.73 m^2, the patient requires renal replacement therapies, such as peritoneal dialysis, hemodialysis or kidney transplantation.[4] This stage can also be referred to as "end-stage kidney disease".[5] Kidney transplant is considered the optimal treatment for children and adolescents with advanced chronic renal failure, because dialysis carries risks - which increase with treatment duration.[6] The National Transplant System (SNT) coordinates and regulates the Brazilian Public Healthcare System's transplant program. Since its creation in 1997, the number of kidney transplants increased from 920 in 1988 to 4,630 in 2010. The SNT establishes that for a period of 90 days after the onset of dialysis, dialysis units must present the qualified patient or legal

representative, the option of enrolling in the kidney transplantation program. Annually, Brazil holds around 300 pediatric renal transplants, which represents, on average, 6.5% of transplanted patients in the country.[7]

It is often necessary to undergo hemodialysis while waiting for a transplant. According to the Dialysis Census of 2011 from the Brazilian Society of Nephrology (SBN),[8] there are about 92,314 dialysis patients in Brazil in 643 Dialysis Centers. The census shows 2,010 patients aged 1-12 years and 577 patients aged 13-18 years. Dialysis treatments available in Dialysis Centers are: peritoneal dialysis, conventional or intermittent hemodialysis and continuous replacement renal therapies.[9]

Hemodialysis is not curative and it is generally carried out for a period of approximately four hours per day, with the need to be performed three times a week in specialized centers.[10] Hemodialysis is a process of filtering and cleaning the blood from undesirable substances such as creatinine and urea, which need to be cleared from the human bloodstream due to deficiency in the filtering mechanism in CKD patients. In hemodialysis, solutes are transferred between the blood and the dialysis solution through an artificial semipermeable membrane (dialysis filter or capillary) through three mechanisms: diffusion, which is the solute flow according to the concentration gradient, where mass is transferred from a place of higher concentration to one of lower concentration, it depends on the molecular weight and characteristics of the membrane; ultrafiltration which is the removal of fluids through a hydrostatic pressure gradient; and convection, which is the loss of solute during ultrafiltration, when solute is dragged in the same direction as the flow of liquid through the membrane.[11,12]

Children and adolescents undergoing peritoneal dialysis or hemodialysis are considered individuals with special health care needs and depend heavily on technology, creating greater demands for care in terms of patience, monitoring and intensity. Women take on the role of primary caregiver for technologically dependent children, devoting themselves entirely to care. This condition leads to social isolation, suffering and stress, negatively affecting their well-being.[13]

The caregiving mothers of CKD children may have a tendency to deny negative perceptions and feelings related to the care of their sick children due to social image and the consequent idealized self-image of the maternal function - which brings about strong feelings of guilt.[14] According to Tong *et al.*,[15] parents of CKD children have reported profoundly negative experiences vis-à-vis the care of their children. Parents find themselves burdened with the need to give medication, ensure proper nutrition and undertake ongoing clinic visits, experiencing emotional chaos and stressful relationships.

In reviewing qualitative studies on the family's experience of having a child with CKD, the authors concluded that the treatment causes major disruption in family dynamics, often causing conflict and divorce. In addition, the family is constantly tired and loses its personal freedom because of the attention that the child requires.[16]

The results of a German study involving parents of CKD children show that both father and mother have greater psychological distress, lower quality of life and feel more depressed when the child is on dialysis, when compared to other treatments - and this can be interpreted as a reaction to a challenging care routine.[17]

Families of children or adolescents with CKD undergoing treatment with peritoneal dialysis or hemodialysis must face the shock of disease irreversibility, the imminent danger to life and the drastic impact it has on daily life.[18] However, children, adolescents and adults in hemodialysis and their families realize the achievement of renal transplantation as the only chance of returning to live a normal life.[19,20] Waiting for the transplant is a critical phase determined by family uncertainties regarding the procedure and prognosis. At this stage, the family lives a state of alert, acting to ensure that the

child is able to receive the organ whenever called upon.[20] Kidney transplantation is seen by the mother sometimes as promising in terms of quality of life for the children or as a therapeutic possibility which brings about extreme anguish at the immediate and distant future.[21] In a study involving parents of children in pre-transplant, the authors found that 21% reported clinically significant distress. Therefore, healthcare professionals should assist in building coping strategies to decrease the psychological distress of parents of patients in pre-transplant.[22]

The emotional health of pediatric patients with chronic renal failure and their caregivers is crucial in the course, prognosis and therapeutic success. Compliance to treatment may be positively influenced by appropriate multidisciplinary support to the family, which must be prepared not only from a technical and clinical perspective, but should also be educated about human prospects regarding suffering.[23,24]

Despite the national and international literature documentation regarding the experience of families with a CKD child, few studies address the feelings and needs of families of children and adolescents undergoing hemodialysis, mainly focusing on the maternal experience in this context. Thus, this study shows the relevance of considering the subjectivity of mothers of children and adolescents on hemodialysis, seeking to reveal how they experience the situation and follow their children on hemodialysis, thus being able to provide theoretical support for planning care that meets their real needs, identifying aspects that require intervention.

Theoretical and methodological framework

We used the Symbolic Interactionism as a theoretical framework, it enables understanding the meanings assigned by the mothers to their experience in accompanying their children with end-stage CKD to a Pediatric Hemodialysis Center and how these meanings are the result of interactions of the elements involved in the process. Symbolic Interactionism is considered an interpretive science that aims to represent and understand the process of creation and the meaning humans assign to the reality they live in.[25] The selected qualitative approach to this study was the Grounded Theory. This approach refers to the theory discovery from data systematically obtained and analyzed by constantly comparing them, a coming and going to data, from collection to analysis and analysis to data collection.[26] Data was collected in a Pediatric Hemodialysis Center of a public hospital in the city of São Paulo. This center is constantly receiving children and adolescents aged 0 to 18 years and referring them to kidney transplantation, creating rotational groups, made up regardless of gender and age.

Because of the qualitative nature of the study and because the data collection should be directed to the development of theoretical constructs, we shall use the "theoretical sample method". The theoretical sample is the process of collecting data for the purpose of generating theory, in which the researcher simultaneously collects, processes and analyzes the data and decides what data to collect next and where to find it, in order to develop the theory.[26,27] Data was collected all the way to the theoretical saturation, when there was repetition and lack of new information and growing understanding of the concepts identified. So, we recruited 11 mothers who accompanied their children to hemodialysis. We collected the data by interviewing the mothers. Only after approval by the Institutional Ethics Committee the mothers were invited to participate in the study. All were informed about the study objectives and signed the Consent Form.

The interviews began with a starter question: "How is it for you to accompany your child on hemodialysis?". As the categories were formed, we added new questions that could clarify the ideas they brought up. All interviews were recorded and later transcribed verbatim. They lasted between 50 to 100 minutes. After the first two interviews, the authors started an open

code processing, studying each interview line by line. We chose to work with *in vivo* codes, which help us preserve the meanings of the participants concerning their own opinions and behaviors in the coding.[28] Codes were grouped one by one through the comparison process, by their similarities and conceptual differences, thus forming categories. Categorization is defined by a process of grouping concepts that prove to be relevant and part of the same phenomenon.[27-29]

As we coded and categorized, we asked questions that could follow the data, thus seeking other elements until filling up the categories and reaching theoretical saturation. The constant comparison method was adopted during the process to help identify and develop the categories. Moving on with the analysis, we reached the next step called theoretical coding, in which the focus is on specifying categories to a phenomenon, from the aspects that stand out from it. To build a Data-Based Theory, it is essential that the researcher has theoretical sensitivity to understand the subtleties behind the meaning of data. There is a constant process of questioning the data: does the data show changes over time? Does data comparison generate and expand ideas? These questions keep the researcher focused on seeking patterns among incidents that reveal concepts that go beyond fact descriptions.[30]

In the final stage of data analysis, we sought to understand the central phenomenon, one that constitutes the link between categories and features a higher level of abstraction. The core category is the central phenomenon, in which all other categories are integrated around. It is one that appears wide and abstract enough to include and express all others.[27]

Having followed all the steps, it was possible to propose a Framework that explains the experience of mothers when accompanying their children to a Pediatric Hemodialysis Center. To validate the Framework, we use the strategy of showing it to two mothers who had already been interviewed; both could relate to the experience, considering that the Framework really portrayed what they had experienced.

Results

From the analysis of the phenomena and how they interact with each other vis-à-vis the mother's experience, it was possible to identify the core category: having life imprisoned by a machine - that integrates the phenomena: seeing her son's life being sucked into the machine, giving a new meaning to hemodialysis.

The mother's experience is first described with expressions like "it's scary", "he will die in the machine", "the machine will suck all my child's blood". However, the process also involves the strategies used by mothers to stop believing that her child's life will be sucked by the hemodialysis machine, looking for ways to adapt to the situation.

The phenomenon having life imprisoned by a machine consists of the following categories: suffering the impact with the existence of hemodialysis and feeling powerless. The beginning of the process is marked by mothers suffering the impact of hemodialysis, characterized by fright, fear of the unknown and denial of needing hemodialysis. The mothers enter a new universe, without having chosen to inhabit it. They are frightened by the information that the child requires hemodialysis. Initially, they deny the current reality. Mothers fear the likelihood that their child may die in the machine, because they know nothing of the procedure and consider it aggressive given their child's frailty, building beliefs that bind blood circulation in the machine to their children's lives being sucked into the machine. The hemodialysis machine, a scary and unknown object, represents a threat to life and demand that they are constantly monitoring the child when subjected to the procedure. During the experiment, mothers are perceived feeling powerless. Mothers are faced with intense changes in their daily lives that cause a feeling of being trapped with her son within the care of the hemodialysis machine, feeling hindered in their ability to act; not engaged in leisure activities and having less time for household chores and taking care of herself. Furthermore, having life

imprisoned by a machine makes them move away from the other children to be with the one who is sick. Thus, experiencing constant concern with the other children because they realize that the time devoted to them is now shorter.

Mothers, having life imprisoned by a machine experience difficulty to continue working, because they take on the responsibility to accompany their children to the hemodialysis sessions. Thus, determined to take care of their children who depend on a machine, they need to give up work to ensure that the new routine involving the treatment of the child is met.

Upon complying with the new routine of taking their children to the hemodialysis sessions, these mothers are having their lives imprisoned by a machine. It makes them feel distressed to stay in the hemodialysis sessions, for those are tedious and uncomfortable, causing fatigue and impatience; they feel as mere spectators of the sessions, having their hands tied. Sadness is triggered by the sense of impending death of their children in a threatening universe that brings intense changes to maternal routine and demands continuous adaptations.

The mothers reported that their children incurred significant losses due to dietary restriction and limited participation in leisure and school activities. Given this context, they feel concerned and powerless to change this condition.

The second phenomenon, giving new meaning to hemodialysis comprises the following categories: incorporating everyday care, needing to have the courage to face reality, strengthening with the interactions and waiting for a new kidney. New meanings help mothers cope with the experience of accompanying the child to hemodialysis, having life imprisoned by a machine. In the face of suffering, the feeling of entrapment and fear of impending death of a child, they start on a series of reflections and actions geared towards giving a new meaning to their current lives.

Mothers add this special care to their day--to-day lives. As they recognize the need for hemodialysis, they realize that the procedure protects their children from death and then the hemodialysis machine takes on a new meaning - the threat of death gives place to preservation of life. Having life imprisoned by a machine, they understand that they need to have the courage to face reality, seeking to have the strength and determination to continue taking their children to hemodialysis and not give up coping with a difficult and painful reality that presents itself to them. The mothers realize that it takes courage to persist and not get taken down by the existence of an uncertain future.

The mothers become stronger with the interactions experienced during the study. They developed trust relationships with the staff through an open channel of communication through which subjective maternal issues are approached, feeling emboldened, even after having their child's life imprisoned by a machine.

The dialysis machine is no longer an unknown object, as the team explains its operation. Mothers seek to understand how the machine operates, by asking questions to the team and feeling safer and less fearful about the possibility of imminent death of a child connected to the machine. Thus, mothers get support from the team.

Mothers develop meaningful relationships and solidarity ties within the Pediatric Hemodialysis Center they go and it redefines the experience with the help of other mothers. Mothers redefine the experience when seeing that there are mothers in situations of greater difficulty - those who can be helpful in helping them to develop courage. The interaction between mothers and the ability to share experiences produces a sense of identity, feeling understood and encouraged through the experience.

The mothers notice that their children improve with hemodialysis. Therefore, to see that the child is doing well with hemodialysis is a strategy for dealing with this situation of seeing her son's life sucked into the machine. The moms notice that the children are more willing to play, perform school activities and develop more quickly. The interaction with the child promotes a redefinition of the

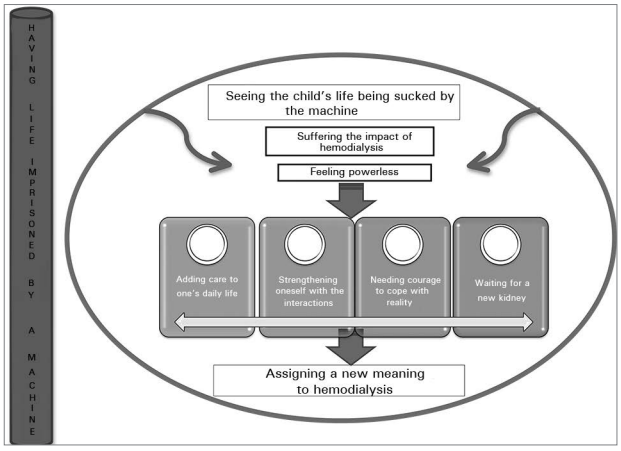
treatment to which he or she is submitted to, as it progressively tears down the maternal belief permeated by the imminence of death in the machine when she feels more comfortable, seeing her child doing well.

Family presence is essential for the mother during this process of having life trapped by a machine. Family members assist in reorganizing daily life, helping them to meet practical demands imposed by the hemodialysis treatment, helping take care of the other children or take them to the Center, and providing emotional support - the mother feels better with family support.

The mothers endure the experience and, through actions/interactions, they procedurally change the meanings given to hemodialysis; new feelings and beliefs are triggered, as well as behaviors necessary for the rearrangements required for coping with such a painful and dreaded event, which is to have a child undergoing hemodialysis.

The mothers wait for a new kidney and wish the transplant can preserve their children's lives without having to depend on a machine. That is what drives mothers to withstand an uncertain future. They are sure that they will continue investing in hemodialysis sessions to keep the child alive, even if they have to follow with the treatment of having life imprisoned by a machine. Throughout the process, the transplantation is conceived as liberating for herself and her child, and as the only possibility of resumption of the life they had before. Concurrently, there is the fear associated with the surgical risks - the possibility of her child dying of renal graft failure. The aforementioned Framework is based on having life imprisoned by a machine, integrating all components related to the situation experienced by the mother who accompanies her child to the hemodialysis sessions. The process of having life trapped by a machine is shown on Figure 1, below.

Figure 1. The Framework: "having life imprisoned by a machine".



Understanding the maternal experience

The need for hemodialysis not only causes a challenging routine for mothers, but intense distress for having to live with the existence of the machine. Faced with an unfamiliar machine, mothers construct beliefs regarding this object that holds a child connected to the extracorporeal blood circulation and suffer from the impact of hemodialysis. Maternal beliefs must be understood and further investigated so that healthcare professionals can identify and assist in the deconstruction of imaginary scenarios that hamper mothers in the process of facing this new reality. In this study, the perception that the machine "sucked the blood" leads to maternal beliefs in the imminent death of her child, feeling frightened and constantly threatened by the machine. The dialysis machine is a physical object, but when mothers see it as a threat to the lives of their children, it becomes a symbol.

From the interactionist perspective, when mothers engage with the machine connected to the child, they make it a symbol of threat and death. This representation drives the mothers' actions - following the child up close during the hemodialysis procedure, even though feeling harrowing when near the machine.

One of the categories highlighted in this study is the mother feeling powerless, pointing to the existence of a marked change in their daily lives caused by the need to accompany the child to the hemodialysis center three to five times a week.

With the need for hemodialysis, an unknown reality, brings about instant change to their lives. Having a child under hemodialysis makes family members reorganize their lives in order to cope with a clinical picture that is uncertain as to its development and the need to constantly be in a hospital setting, causing a social, emotional and physical burden.[31]

Having to give up work, represents the loss of a social place due to the difficulty to maintain a work routine. The mother's internal interaction process, as own identity and self-judgment, becomes shaken. However, the mother abdicates from work to accompany the child. Realizing the limited daily routine and feeling distressed in the hemodialysis center. They impress a new way of being in the world and also of auto-interaction. There is intense isolation and social restrictions in the lives of caregivers of children with end-stage CKD.[12] Life becomes focused on the child's care and time is perceived as limited.

Routine carries the singular mark of the individual, and is shaped by her needs, values, beliefs and afections.[32] Thus, the possibility of daily life gaining new forms requires that mothers give new meanings to the experience and the changes it will entail, supporting this new reality. In an interpretive process, the mothers incorporate this new way of caring for the child, adjusting their lives to the hemodialysis routine, giving new meaning to hemodialysis. The mothers add the child's care to their everyday routine, being able to organize themselves emotionally, taking on as a maternal duty the burden of accompanying the child to hemodialysis and pledging to administer the medication. They feel overwhelmed, but interpret the importance of hemodialysis as maintainer of the child's life.

From the perspective of symbolic interactionism, social interactions are dialectical processes because individuals construct social groups of which they are part, but at the same time, these groups interfere in the individual's behavior. When we interact, we become a social object for one another, we use symbols, make decisions, change directions and define reality.[30]

Mothers become stronger with the interactions. With the experience of accompanying the child to the hemodialysis sessions, the mother's interaction with the health team, with the other mothers at the Center, with the family core and the child himself, enabling the construction of new meanings to hemodialysis.

In interacting with their children, mothers noticed a clinical improvement they can perceive and that goes beyond the results of tests translated by the staff. Thus, the mother gets comfort from this improvement, earned over the course of hemodialysis. The results of this study show that family members are essential in the process of mothers reorganizing their routines, usually the burden falls on the mother, and having relatives willing to take responsibilities minimizes the fatigue and stress associated with this maternal burden. Mothers also reported the family as a source of emotional support. Strengthening family ties is essential for the mother to feel able to deal with this situation.[33] To encourage family members to share feelings with each other enables efficient communication, leading to a healthy tacking of the problem.[34] In addition, a better understanding of the machine results in decreased fear of hemodialysis. Families need to feel safe in communicating with healthcare professionals, receive clear information and acquire knowledge about the disease and treatment, which may help significantly decrease the levels of anxiety and stress.[35,36]

Facing a high-tech environment awakens feelings of insecurity, there is a need to familiarize patients and families to the new and unfamiliar culture of hemodialysis treatment.[37] The family requires a meeting space for dialogue, where they can share the knowledge among everyone involved in the child's care, demonstrating everyone's commitment and interest.[38] The hemodialysis center healthcare professional can stick to just the technical act of turning the machine "on" and "off", keeping away for the care itself, which involves presence, maintaining dignity, interactive action and dialogue.[39] It is important to open space for mothers to communicate their needs, which is something that should be valued in the care process, because during the entire process, the mothers feel their lives are being trapped by a machine.

This study also showed us that mothers share their experiences with other mothers in the Hemodialysis Center, and this exchanges of experiences can be seen as a social support network and source of empowering.[10] In several interviews carried out in a study involving parents of CKD children, the authors reported that parents found relief and minimized the severity of the problem

when compared with more desperate situations experienced by other families.[12]

In our investigation, renal transplantation is represented by the waiting for a new kidney category. While that means freedom from the hemodialysis machine and a daily routine, trapping also produces uncertainties regarding the success of kidney transplantation and the surgical risks. Literature shows that this waiting causes anxiety because the parents of children waiting for renal transplantation express uncertainty about the kidney graft, but wish more social freedom and interaction within the family after the transplant.[12]

The interviewed mothers use terms like "start...", "...now", suggesting temporality associated with the experience; i.e. early treatment frightens and brings the belief that the child would die connected to the machine, but "time" and the actions/interactions enable a redefinition of this reality.

Upon indicating temporality, it strengthens the argument that mothers experience changes during the process and redirect their actions. The hemodialysis machine becomes familiar and less frightening. The objects represent social products and therefore are shaped and transformed from the social interaction process.[30]

Changes in feelings and behaviors at different stages of the mothers' experience are due to a progressive construction of new meanings resulting from interactions during the ordeal of accompanying the child to the Pediatric Hemodialysis Center, represented by the phenomenon giving new meaning to hemodialysis.

Within the perspective of Symbolic Interactionism, human beings are both agent and subject, determined and determinant of social life. With the Framework used in this study, we managed to understand not only how mothers interpreted the facts around them and acted based on their convictions, but also how they were transformed by an interpretive process resulting from actions/interactions.

Final remarks

As to the implications of this study vis-à-vis the context of health in hospital care, we believe this paper may contribute to the professional work of multidisciplinary teams who tend to mothers of children and adolescents submitted to hemodialysis, as it brings more knowledge on the maternal experience understanding in the Pediatric Hemodialysis Center.

Understanding the mother's experience and recognizing the strategies used by them must be considered at the time when planning the care, fostering social interactions and increasingly producing room for listening and dialogue, reducing the social stress imposed by having life imprisoned by a machine.

Literature shows that the lack for rooms for dialogue and sensitive listening have not contributed to coping with the situation of the vulnerability of families who live through the chronic condition of their children.[34] This way, healthcare professionals must deal with the maternal subjective dimensions and the unpredictability of relationships without prevailing only the interactions based on clinical complaints or situations associated with the therapeutic procedure.

Thus, it is necessary to build on interventions that enable the mother to talk about her fears, difficulties, desires and the hemodialysis procedures her child is being submitted to, and be able to assign less suffering meanings, better elaborated during the experience, seeing the child's life being sucked by the machine.

Healthcare professionals must understand the needs of the families, their beliefs, values and habits to facilitate the building of proper, dignified and individualized care.[38] The child's care implies to consider the child's binding with the mother, in which the wellbeing of one has a direct impact on the other's and proper child care goes through educating and involving the mother in the care process.[33]

Thus, the Framework with this central category of having life trapped in a machine, represents the process that explains the meaning mothers assign to their experience of accompanying their children to hemodialysis sessions in a Pediatric Hemodialysis Center. It is a process, as per established by the Grounded Theory, it should not be given as finished; and it can be expanded or modified from the time other data is added to understanding this reality.

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