

## MODELING OF FAMILIAR CARE IN A CHRONICAL CONDITION BY ADRENOLEUKODYSTROFY<sup>1</sup>

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### ABSTRACT

This article aimed to understand how the family care is for children in a chronical condition by adrenoleukodystrophy. It is set up as a situation study, whose body of analysis consists of "care routines" recorded during thorough interviews conducted with the parents of the sick child, and collected in the matrix research. The scenes analyzed show the parents' continuous care, permanent and intensive for the child. During the development of this care, we highlight the peculiar communication established with the child; the constant care directed to the child's needs; the readiness of care; and the incorporation of diverse knowledge in the process. We understand that the family also develops in the professional context of the care since, most of the time, the family is alone. Finally, we ponder that the intensive efforts undertaken by parents allow them to modeling very personalized care, capable to envelop the complexities of the diseased child's needs.

**Keywords:** Family. Childcare. Nursing. Chronic Disease.

### INTRODUCTION

Chronic conditions are shown as a public health problem of great magnitude and since 2002, the World Health Organization (WHO) warned to its increase in alarming rate around the world. That year, the WHO estimated that, until 2020, they would respond by 78% of the global diseases in developing countries; and redefined as "chronic conditions" the non-communicable and communicable diseases, as well as the structural incapacities, in consideration of their persistence in time and need of permanent care management<sup>(1)</sup>.

The concern with the management of chronic conditions was repeated in 2012 by the Pan-American Health Organization (PAHO), and its approach emphasizes, with regard to health services, the ability of professional care,

longitude for consideration to the prolonged and complex treatment, requiring constant care, both in relation to the therapy itself, as to situations that may affect the progression of the state of health of the ill person. In providing substantial care to the ill person, such an approach emphasizes self-care, family and community care<sup>(2)</sup>.

The effects of illness by chronic condition fall especially on the family, because it is who experience the continuity and permanence of care required<sup>(3)</sup>. From this observation as increasingly frequent reality and the demands of care that entails, the interest in conducting this study arose, based on the experience of a family that experiences the chronic condition for adrenoleukodystrophy (ALD), having as privileged the family care.

The ALD is a rare injury, genetically determined by recessive gene linked to sex. It

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most commonly affects boys during infancy and, initially, may or may not present adrenal insufficiency; it carries a variety of neurologic manifestations, such as hyperkinetic behavior, neurological regression, and sensorineural deafness optic atrophy. The white demyelination substance is progressive and the neurological condition deteriorates, resulting in complete incapacity, vegetative state or death<sup>(4)</sup>.

In the case of chronic condition experiencing leading to death, as ALD, it is considered that health services should develop palliative care, that do not fall in the preventive actions nor should their healing foundation principles of quality of life and dignity of the human person, embodied in the first article of the Federal Constitution in force in Brazil<sup>(5)</sup>. It is highlighted that every child has infra-constitutional protection given by the Statute of the Children and Adolescent, ensuring the right to health and integral priority to receive protection and help in all circumstances<sup>(6)</sup>.

In relation to family care, we assume that it has a small-scale dimension we can refer to as “modeling the care”, alluding to the work of sculptor who performs his work in clay, single-mode. Also the care will be modeled by the family in accordance with “the way it experiences the illness of one of its members, the possibilities and conditions for the ill person’s own care”<sup>(7:20)</sup>.

On family experience covered in this study, the modeling approach of care aimed at highlighting the way a family experience the illness of its younger son by ALD proving personal care, preserving his dignity in the course of the illness and life, since the child is wholly dependent on that care.

The importance of the study is to address the care in the family perspective, pointing to the ways the family produces essential and specific care for the health of a sick member<sup>(8)</sup>. To know this production can bring some indications for the improvement of professional practices in health, with accent for the nursery who takes care as its singular object. It is pointed out thus, the need for such practices to integrate the family care

effectively, increasing it; and, without transfer to the families their responsibility in care<sup>(3)</sup>. Thus, we aim to understand how the family produces child care in chronic condition by ADL.

## METHODOLOGICAL COURSE

Qualitative study that allows understanding of the experiences, stories, relationships, perceptions, knowledge and ideas resulting from interpretations that people make of their living<sup>(9)</sup>. It was developed through the situation study that includes the context of everyday life and the peculiar experience of illness and care of people and their families, being possible to trace some wider inferences from this micro-reality and give importance to several relations established during their lives<sup>(10)</sup>.

The theme discussed here, family care, was in “scenes of care” (SC) obtained from the collection of movie images of the matrix search database to which this study is linked. From this collection we chose the images generated on in-depth interview held with the family of the study, which used the footage as one of the registration methods.

This is the Belchior’s family, 11 years old child at the time of this study, presenting the most serious and fatal ALD, with neurological deficits and sharp engine, for which the care, of professionals and families, were constant and increasingly intense as his illness progressed. Belchior’s parents are Baltazar, 49 years old whose works as a plumber; and Maria, 50 years old, public servant in housekeeping function in a secondary-level health unit in Cuiabá-MT. We emphasize that all names are fictitious to preserve the anonymity of the participants of this study.

The interview occurred in family residence meetings in Cuiaba-MT, from May 2010 to January 2011, a total of six, with approximate duration of one hour and 30 minutes each. These meetings, two were filmed (the third and fourth), generating two hours and 20 minutes of filming. The film record was done with digital camera fixed on a table in the living room of the house, scenario of the interview.

The use of video in the collection of data in research constitutes indirect observation method

and allows obtaining a lot of data that are not possible by other means<sup>(11)</sup>. The footage, originally considered only as a support to the observation, made us see the continuously care carried out by parents to the son, unveiling in act during the course of each date of interview; because, while they narrated the illness Belchior history, parents were trying to meet his care needs, being registered by the video the way the performed it.

Thus, although not previously planned for such a purpose, the filming brought into evidence several scenes of care to Belchior at the time of the interview of his parents, which allowed us to understand some dimensions of the experience of care and illness that extrapolated from the speaking dimension, showing it as “care act”.

The corpus of analysis was composed of a selection of scenes from Belchior’s care. It is known that there is no single way to collect, transcribe and encode a set of data that is true with reference to the original text. The important thing, then, is to be as explicit as possible about the resources that were used and the analytical procedures<sup>(12)</sup>. Therefore, in data treatment, our first step was to attend both meetings filmed, first without audio, so that was prioritized the understanding and detailing of the scenario, place occupied by people, placement of bodies, gestures, movements, attitudes, expressions and other elements that could highlight how family care was directed to the child. This phase allowed us to “image description” in text. We return, then, to watching footage once more and by detaining us in several scenes, validating if the textual description and image were in line and giving their details. At that stage was employed the footage with audio, clearing doubts with respect to the events. With this, we rewrote the description of images incorporating details previously unnoticed, or improving descriptions already carried out.

We produced two plans to record in the proceedings of each scene: a) a narrative plan, in which it was possible to follow closely the lines, and these said of how the illness has been establishing in the life of the child and the family, the parents’s pilgrimage in search

of professional care, the numerous difficulties faced, among others. In other words, the story of illness and care experienced by them; b) a plan of imagery, purely visual content, constituted by the description of appearances on stage, the development of gestures and movements and the scenario of the room.

We performed, then, the analysis of the textual description of the images identifying the units of meaning and registering our first observations and questions. We related, then, such units and corresponding observations using different color markings throughout the text. With this design, there was the grouping on an axis of meaning, configuring the empirical category of this study: “Modeling family care” which shows the family child care happening. The empirical fragments we employed in the composition of the results were named SC, for the description of pictures, not being therefore subject’s narratives.

The evaluative research that guides the methodology conduction of this study is approved under 671/CEP-HUJM/09, under the aegis of the Resolution 196/96 of the National Health Council. This approval includes the composition of the research database, the production of images, as well as the use of the database for new studies, being the interviewed subjects aware through the signing of an informed consent.

## RESULTS AND DISCUSSIONS

### Modeling family care

When we observe the scenes revealed in the movie images, we were able to highlight the many dependencies of Belchior and his intense care need, resulting from the organic deterioration by the disease. Thus, it was important to make a brief account of the evolution of his illness and the context in which care takes place.

Parents, Baltasar and Mary, began to realize that something was wrong with the health of the child when he was seven years old, period of their literacy. The illness manifested initially by cognitive difficulties perceived by parents when accompanied in the

realization of the school activities. The delay to the diagnosis of interlocutory appeal generated much anguish, while the symptoms intensified and his state of health were aggravating. In carrying out this study Belchior had limitations, movements speech, vision, swallowing and being totally dependent on the care of the family.

The family resides in peripheral and working-class neighborhood. The house is simple, small rooms, with few old-looking furniture, lined up against the wall. In the living room there are two and three sofas covered with a hood, a table, two chairs and a bookcase that accommodates the television. In one of the rooms, seen from the image of the room, we noticed that there were two beds together the walls, a wheelchair, mattresses and a small furniture that housed a television.

Besides to this scenario, the images show a large stature to be an 11 years old child, unable to move, sitting on a chair and needing support to sustain his torso and head, already without any control of motion and position, with his hands and arms stunted. His look seems vague, as well as his face, not expressing joy nor sorrow; everything that comes out of his mouth are noises and saliva that can no longer swallow. His food is carried out by a gastrostomy and his father mobilizes from time to time, from the chair to the wheelchair or the sofa, carrying him in her arms. These fragments of scenes refer to imagine others, to peculiar dynamics of the family, especially the constant presence of the father and mother organizing and delivering care that Belchior needs, continuously, for a living.

The routine of the child care provided to the parents build knowledge about his injury and treatment and, especially, keen perception of his physical and emotional needs. Living with chronic condition implies also learn from and about it<sup>(13)</sup>. Such learning allows parents to meet the needs of the child through peculiar and subtle communication that was being elaborated by other means, enhancing facial and bodily expressions vowel sounds, given the absence of speech in children. The

following excerpt shows how the father seek to understand the needs of the child:

At one point Belchior turns subtly the head toward the father who's sitting around on the sofa. Baltasar realizes the movement of the child as if it were a call and he answers, asking him what he meant by that. [...] Belchior makes movements with his mouth and his father extends his arm and puts his hand on the boy's forehead, bringing his head forward, makes a cuddle and up to fix him in a more comfortable position. (SC)

We realize that these rudimentary manifestations of communication are not always highlighted with intensity and/or intentionality by Belchior, and his understanding is largely dependent on the parents' perception of effort. Thus, even if the child is unable to pronounce most words, Baltasar talks with him and proves to be considerate, which stresses the affective dimension of this care. Such an attitude of the father allows us to corroborate with the meaning of the term care as being a loving, welcoming attitude of care and involvement with those to whom we are affectively bound and we love<sup>(14)</sup>.

The concern of parents in knowing how is Belchior and leave him as comfortable as possible is noted through the constant looking directed at him. The following are some fragments of these "perspectives of care", especially how they take turns in a continuous care to him, as if noting the possibility of needing something:

When his dad gets up to reposition the pillow behind his back's son, because he was without support, the mother back the look at Belchior. [...] At some point, after Baltasar get up to find some documents to show the researchers, Maria is watching his son for approximately 10 seconds. [...] While Baltasar speaks with the researchers, the mom bends over to look at Belchior and the bag of nutrition, and resolves up to straighten him out on the chair [...]. (SC)

We believe that the family is a system composed of bonds, whether they are emotional, social or economic, having a specific dynamic, amenable to modifications depending on the moments of the life of each one of its members, the example of when a disease occurs. In that

circumstance, the health problems of a member affects all others<sup>(15)</sup>.

During all the time of the meetings, even involved with the interview, parents were attentive to the care of the child, sometimes together and sometimes separate, while one was taking care of him, the other gave attention to the interviewer. Among those care we observed the cleaning of saliva that dripped; change the position of the child in the chair; repositioning of the head that often clung to the sides; change the position of the legs; neck massage during crisis of choking; washing the probe power supply; exchange of Belchior from the chair to the sofa and checking the lower limb edema.

This care, formerly absent in family life, now intrinsic part of his daily life, makes us agree with authors<sup>(16)</sup> when saying that the illness sets in other normality in people's lives, affecting them significantly in various dimensions of their daily lives. This understanding in distance from the concept of disease as a morbid, biological and physical entity, extending it to the notion of illness as part of the daily lives of the processes of life.

To get a sense of the frequency the care was held in Belchior, we stopped to count the number of times that care actions occurred in the period of time taken, which showed some form of care happening every six minutes.

Study of the same family<sup>(7)</sup> showed that this intense demand continuous uninterrupted care and complex was decisive for parents to conciliate their respective jobs so that they can stay long enough at home to Belchior's care in the on-call system. Although the inbred family of Maria and Baltazar is quite extended, parents take for themselves the responsibility for child care, given his very characteristics, both in the technical aspect of his realization, as well as characteristic of communication with Belchior. In some scenes we highlighted the minutiae that involve care that Maria performs to Belchior:

Maria gets up to take care of the child that is in use of a gastric tube to feed due to the inability to swallow. She withdraws the probe extension off the chest of the child tries to steady his head with pillows and clears the saliva ran from his mouth.

[...] On one occasion in which Belchior's saliva oozes out of the mouth, the mother gets up taking a fabric on the chair to dry it, and reposition his legs he had extended. (SC)

The assumed body position, of Maria and Baltasar, when sitting on the sofa, announces that they are prepared to raise at any time, denoting concern in answering his son quickly at the slightest sign of need. This position is alternated between the two, as well as assumed by both, reflecting their readiness for the care. In the scene below, with Baltasar, a little of this readiness for child care is shown:

[...] Maria and Baltasar are sitting on a three-seater sofa and Belchior in a chair next to them. She, sitting on the edge of the sofa, more distant from Belchior, had the back supported on the backrest of the sofa and the elbow propped on the arm of it, apparently comfortable seating. Baltasar occupied the other seat, next to Belchior. Without the back in the sofa, she had the body tilted forwards and her elbows supporting on her legs. (SC)

The presence of a loved one sick causes the family try to reorganize to offer the best living conditions and care for him. The disease surpasses the limits of the body of the ill child, affecting the entire family organization by the appearance of signs and symptoms of injury, causing the parents who care for a constant concern<sup>(15)</sup>.

Also in the environment we notice the care with cleaning, such as using only of white sheets and pillowcases in the chair that housed Belchior and several pillows used to support his body. This can be based on family knowledge linked to scientific knowledge, both mediating understandings about health and cleaning in the care of Belchior, as we can see in the following scene:

[...] On the third date, Belchior was accommodated beside the sofa, in a chair, apparently being covered with pillows beneath white sheets [...]. The researcher moves the camera, making Belchior appearing in the video, sitting to the left of the sofa, in the chair, which again was lined with sheet and white pillows. (SC)

The use of white fabrics to envelop Belchior might suggest to understand more easily dirt and thus change his clothes earlier; allowing also the

use of bleach in the wash for better cleaning. Whatever the reason the use of white fabrics, it is evident concern for the welfare of Belchior, as in the next scene, in which the parent substitutes the tissue that fell to the ground on the other clean:

At one point, Baltasar brings the head of Belchior forward looking best comfort for him and the piece of white cloth that helped support him, falls to the ground. Baltasar took it from the ground and leads into a room, enters another room with empty hands and comes back with a new fabric, also white. He put it back on the side of the head to support his child. (SC)

With the necessity of Belchior to be fed by a gastric tube, the family had to learn about the time of infusion of diet, its wash, as well as to monitoring of the equipment life to change it, among other small details of this technical care. It is possible to see the skill with which Baltasar executes in the following scene:

Baltasar appears disconnecting to the double via of gastrostomy probe gear and connecting a syringe to it, which seems to contain water to wash it. After, he disconnects the double nutrition probe. (SC)

It is in the family and for it that essential health care are produced, since the affective interactions necessary for the full development of the personality and mental health of its members, learning hygiene and food culture, adherence to prescribed treatments for services, such as medication, diet and preventive activities <sup>(8)</sup>. We emphasized, however, that the care for Belchior was performed solitarily by the family and although it is up to the nursing professionals to perform care similar to the evidenced to Belchior, as the particular nutritional tube, his parents sought to acquire skills of different natures, even health care, to produce all the required care for him, including “shifts” interspersed with each other because the care dependants were complex and uninterrupted.

When it comes to disabling aggravations, that the care dependence is even greater, the family sees the urgent need to incorporate professional knowledge and acquire technical skills <sup>(17)</sup>. A study <sup>(13)</sup> points out that the chronic condition requires great efforts from

the family for the care to the sick person, and also be professionalize, aiming at better preparation for caregiving. We realized that Belchior’s parents sought to incorporate and implement some professional knowledge in childcare, such as in the evaluation of swelling in the lower limbs of the child, as described below:

Baltasar is always very loving, after looking at the feeding bag of Belchior, he gives a few slap on the child's leg and squeeze it as a sign of affection. He seems to notice something different in the contact and solve he presses the anterior tibial region to verify if it is swollen. (SC)

Parents have cited the movie *Lorenzo’s oil* <sup>(18)</sup> as an important source of knowledge for Belchior’s care. The film was based on a true story, having as main character a child with ALD. We realized that parents have done, with very similar gestures, a practice of care that also is in the film by the character of the mother when the child-character chokes on his own saliva. Although the scientific basis of this practice may not be known for them, use it as they enjoy its benefits, as when Belchior also chokes with saliva:

It is realized that Belchior has great difficulty in swallowing, because he chokes on his own saliva and parents try to help him by changing the inclination of his body and massaging his neck. (SC)

It is understandable that the search for scientific knowledge for this family was in its practical effectiveness - in benefit of Belchior for his care; that is, the extent of the difficulties faced by the child, increasingly aggravated in his condition, and the need to add new elements to the care. Thus, parents understand the small details involving the specialized care, as well as the ability in its execution, seeking to embed it in a certain order practice of family life. We showed the existence of tacit knowledge, built in everyday experience and sustainer of the family care, which incorporates specific knowledge to the field of health, as the family realizes that is understandable and of possible execution, making it useful in the care of the child.

We can consider this tacit knowledge constructed by the family as being the “practical success” of care, i.e., referring to the value that

an action, such as health professional field techniques, assumes to people on the grounds of the symbolic implications, relational and materials of these actions in everyday life<sup>(19)</sup>. In this way, the knowledge produced about health and illness is from experience, that is, of its meanings, being the experienced in itself a means of knowledge. In this everyday experience, families develop a holistic understanding of the illness, because the disease is not a lived reality of objective understanding, but of interpretative perception, contextualized in space and time of events.

Therefore, the logic of knowledge in family, layman knowledge, is that not all its elements are associated with science, being imbued with affective considerations, with the function to interpret the experience, so that the information gained from the scientific knowledge is a secondary element to this knowledge<sup>(20)</sup>. The concern for offering the best living conditions for the ill child is certainly linked to parents' feelings about her, evidenced in frequent gestures of affection of the scenes.

The human being seeks to consciously take care of each other, where care is made with love and also shows concern and zeal about the being who loves, or engaged affectively<sup>(14)</sup>. Then, we believe that every illness experience is unique to the ill person and the family who experience it; and, in this, the family produces a handcraft care to the ill person, i.e. modeled as its potential to care, the singularities of the person that needs to be looked after and the senses ascribed to this experience. We understand the experience of illness as an event that is synthesized to live, being that the conception of "synthesizing" as the relation of things or people, being both originally different qualities, becoming, mutually, of different ways, by combining, engaging and confusing<sup>(16)</sup>.

## FINAL CONSIDERATIONS

The scenes of care analyzed in this study took place in a short period of time, not being taken as the totality of care to Belchior. However, such fragments of the time allowed to highlight the efforts of parents in producing, continuously, care to Belchior. Paradoxically, it gives us a sense of what we do and its complexity, including professional care, since caring for Belchior solitarily most of the time, due to little support received of health professional.

Eternalized in image and liable to search description, such scenes showed some among the thorough child care gestures, the scenario in which he is, Belchior in his total dependence of the parents and themselves in their readiness to take care.

We can affirm that the family develops a form of care and personalized care that requires great effort of preparation, especially in chronic condition of permanent and progressive character. Thus, by introducing it in daily lives of family, the experience of illness by ALD demanded intense production of continuous care, uninterrupted and more complex, affecting family significantly in various dimensions of its life.

Family care was molded in the conviviality around their parents' constant presence along the son, through efforts to understand his diverse needs, embracing in full mode, considering what he is and means to them. Therefore, it is intense affective dimension that mold such care.

This study highlighted the unique and vital importance of family care in an ill child's life, and should be valued as such. In this way, it is sought to highlight the urgency of health professionals being closer to the family, in order to contribute to the ill childcare and enhance, preserve and strengthen the potential of care of their own family.

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## MODELAGEM DO CUIDADO FAMILIAR NA CONDIÇÃO CRÔNICA POR ADRENOLEUCODISTROFIA

### RESUMO

Este artigo objetivou compreender o modo como a família produz o cuidado à criança em condição crônica por adrenoleucodistrofia. Configura-se como um estudo de situação, cujo *corpus* de análise foi composto por "cenas de cuidado" filmadas durante entrevista em profundidade realizada com os pais de criança adoecida, mantidas

em acervo de imagens da pesquisa matricial. As cenas analisadas evidenciaram os esforços dos pais em produzir cuidados contínuos, permanentes e intensos à criança. No desenvolvimento deste cuidado, destacamos o estabelecimento de comunicação peculiar com a criança; os olhares de cuidado constantemente direcionados às suas necessidades; a prontidão para cuidar; e a incorporação de saberes diversos no cuidado. Compreendemos que a família desenvolve, também, cuidados do âmbito profissional, visto que, na maior parte do tempo, cuida solitariamente. Ponderamos, por fim, os intensos esforços empreendidos pelos pais permite-lhes a modelagem de cuidado personalíssimo, capaz de abarcar a complexidade das necessidades da criança adoecida.

**Palavras-chave:** Família. Cuidado da Criança. Enfermagem. Doença Crônica.

## MODELADO DEL CUIDADO FAMILIAR EN LA ENFERMEDAD CRÓNICA POR ADRENOLEUCODISTROFIA

### RESUMEN

Este artículo tuvo como objetivo entender cómo la familia produce el cuidado al niño con enfermedades crónicas por adrenoleucodistrofia. Se configura como un estudio de situación, cuyo corpus de análisis fue compuesto por "escenas del cuidado" filmadas durante la entrevista en profundidad realizada a los padres de los niños enfermos, mantenidas en la colección de imágenes de la investigación matriz. Las escenas analizadas mostraron los esfuerzos de los padres para producir cuidados continuos, permanentes e intensos al niño. En el desarrollo de este cuidado, se resalta el establecimiento de comunicación peculiar con el niño; el esmero en la atención constantemente dirigida a sus necesidades; disposición para el cuidado; y la incorporación de diversos conocimientos en el cuidado. Comprendemos que la familia desarrolla, también, cuidados del contexto profesional, ya que, en la mayor parte del tiempo, esta cuida sola. Ponderamos, por último, que los intensos esfuerzos hechos por los padres les permite el modelado del cuidado personal, capaz de abarcar la complejidad de las necesidades del niño enfermo.

**Palabras clave:** Familia. Cuidado del Niño. Enfermería. Enfermedad Crónica.

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