

# Infantile Hospitalisation and Chronic Disease

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## 1. Introduction

This chapter attempts to characterise the process of chronic disease and infant hospitalisation, the relationship between healthcare professionals, children and their families, in addition to considering the implications which chronic disease has throughout the life of the child and their family. The chapter also considers the changes in the field of pediatrics, its gaps and shortcomings and its position in the biomedical field, defining technical and scientific principles.

The chapter intends to contribute to the construction of knowledge within pediatrics in the face of contemporary concerns and reflections about chronic disease which can serve as a reference point for the promotion of healthcare strategies, principally specialised hospital care, for those children in hospital care.

With the evolution of diagnostic methods and new treatment methods there has been a great deal of discussion and research into chronic disease and its implications for the lives of child suffers. Chronic disease effects millions of people throughout the world, however, it is fundamental that we reflect upon the peculiarities involved when this experience occurs during childhood. To be able to speak of chronic illness and of infant hospitalisation, it is necessary to locate this stage of the child's development, which we refer to as childhood, whilst also considering the role which children occupy in contemporary society from the vantage point of healthcare.

Until the 18<sup>th</sup> Century children were the responsibility of the family which ensured the transmission of physical life, family possessions and names, but had no specific concern with educational. The State and charity were utilised only in cases of abandonment (Aries, 2009).

However, from the Renaissance to the Enlightenment the concern with children's health intensified, beginning from a sense of conservation and protection of childhood originating with mercantilism, and later, to capitalists with the intention of strengthening and expanding armies and a necessity for abundant labour power. Educational performance, which began to take centre stage in shaping children, was dominated by vigilance and discipline and was concerned with morality and a sense of responsibility. Likewise, the Family was elected as the principle cell in which to focus hygiene, nutrition and control (Aries, 2009).

Medicine fitted the function of guiding, controlling and instructing families and society with regard to treatments, clothing, toys, education and nutritional timetables, and was founded on the new knowledge of comprehensive childcare. A rational and scientific model emerged from within pediatric care providing the rules and norms for medical and educational practice towards children. (Rago, 1987; Zanolli & Merhy 2001)

Childhood, as the object of study taken by medicine, focused its attention on the confluence of three privileged axes: high infant mortality rate, abandoned children and a repositioning of the doctor figure as central in the medicalisation of the family (Rago, 1987).

Raised to a privileged position of knowledge and understanding about the best ways to maintain a clean and healthy life, medicine now assumed the political role of recovering the trajectories of childhood, hitherto unproblematic, and began to fulfil the task of intervening in private households.

In addition to education, impoverished and abandoned children were disciplined through professional institutions such as orphanages. They provided both discipline and new knowledge which was transmitted through the punitive and repressive model, restructuring both habits and customs (Rago, 1987).

The study of hygiene brought to social life new practices and norms of personal hygiene, familial hygiene and for the home, focusing principally on maintaining and sustaining healthy children and the formation of strong citizens, who would be able to work in the future. The relationship between childhood and adulthood was established and the way in which an individual had been treated during childhood came to be the main determinant for their future possibilities of a healthy adult life. Thus, hygiene became a central concern for governments and states in producing subjects and families and was directed towards protecting physical and emotional intimacy (Costa, 1983).

Later, children's health became harnessed to maternal health, originating in the binomial of mother-child. A proposal to protect the mother-child's health was developed, planned and implemented through specific programs and standards of healthcare. However, with this move towards preventative and communitarian medicine, a new proposal was presented focusing on comprehensive healthcare, both rationalising and hierarchical, establishing networks of hospital and outpatient services. There was a refocusing on the concepts of multiple causality and risk in the understanding of children's health. The fight against infant mortality was centred on discourses and practices directed towards understanding the social determinants of the health-disease process and of the necessity to expand assistance until adolescence. A shift occurred from focusing on childcare to focusing on disease, in which healthcare became organised and systematised into standards of care (Zanolli & Merhy, 2001).

An important characteristic of early pediatric hospitals is the absence of the mother or any other relative during the child's stay in hospital with the exception of official visiting hours. Contact, between healthcare teams and family members, was limited to passing on information during discharge, during visits and during more delicate procedures such as surgery.

During these moments of contact with the family, Winnicott (1982) highlights that whilst there were positives aspects for the child and their families they also generated mixed

feelings amongst parents who assessed their children as being excessively sad. For professional healthcare workers it represented extra work re-stabilising and re-establishing the child after the conclusion of the visit.

With the subsequent inclusion of the family and/or the companion in the universe of hospitalisation, a change of focus was required from professional health workers, which had previously concentrated solely on the child and their pathology, in order to create a more comprehensive understanding of the condition of infant hospitalisation. Pediatric care once again came to have the family as its goal, which was considered as the primary unit of care, whilst not forgetting to take into account valued technological advances included within the healthcare perspective (Collet & Rocha, 2004).

Considering the course which infant care has taken since the 18<sup>th</sup> century it is possible to see that not only were concerns diversified, but that there were also changes in practices of care, control, education, training and protection.

Throughout the 20<sup>th</sup> Century, with the widening in scope of the role of medicine and increasing specialisation and technological development, infancy gained the same number of dedicated professionals as adults, composing a long list of healthcare professionals such as endocrinologists, neurologists, psychiatrists, infectologists and gastroenterologists amongst others.

Moreover, it is not possible to approach this subject matter without taking into consideration Human rights. If before the Enlightenment the child was just another familial entity, the 20<sup>th</sup> Century has repositioned the child at the centre of Human rights legislation with the stated objective of protecting them.

The United Nations (UN) adopted The Geneva Declaration of the Rights of the Child for the first time in 1924. However, with the changes to the political landscape during this period, the theme achieved a greater impact with the Universal Declaration of Human Rights (UN, 1948), through which it became universally recognised, for the first time, that the child should be subject to special care and attention, as stated in item 2, of article 25 (XXV) "motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection".

Later, with the Declaration of the Rights of the Child (UN, 1959), ten basic principles were established - the right of the child to special protection; to be given the opportunities and facilities necessary for healthy and harmonious development; access to the benefits of social security, including adequate nutrition, housing, recreation and medical services; to receive education and protection against all forms of negligence, cruelty and exploitation - becoming a landmark and guide for the performance of both public and private institutions and professionals.

In Brazil, the federal constitution of 1988 establishes in article 227, the Rights of the child and the Statute of the Child and Adolescent (SCA, 1990) which regulated the article and was drafted based upon the International Instruments of Human Rights of the UN, and in particular, the Declaration of the Rights of the Child. Considered a landmark in Brazilian constitutional protection of children and adolescents, the SCA stipulates in article 4 that "It is the duty of the family, the community, society in general and public authorities to ensure, with absolute priority, the effective implementation of the right to life, health, nutrition,

education, sport, leisure, professional training, culture, dignity, respect, freedom and family and community”.

Five years later, Brazil promulgated resolution 41 on October 13<sup>th</sup> 1995 which was directed specifically towards the Rights of hospitalised children and adolescents. The resolution is composed of 20 rights including protection, care, use of procedures to minimise pain and the recognition of pediatric patients as subjects with rights within institutional healthcare.

However, it is not possible to discern the same concern and legal protections in relation to children and adolescents in different countries. The situations of war, famine, poverty and malnutrition produce refugees, orphans, and the displaced children of territorial and political conflicts on a daily basis.

The path to the concrete realisation of such rights is long and faced with many obstacles, which includes the way in which children are viewed and understood by adults – subjects who need to be represented by another voice in order to be heard.

The developmental approach to the child, of being in a process of formation which is incomplete and therefore requiring of norms and standards so that the social and cultural debt of becoming adult can be paid off through education and through the adult figure as a spokesperson for the child is criticised by Castro (2001), which brings to light a new concept of childhood.

In his theory, Castro (2001) emphasises the importance of legitimising children as being capable of exercising their rights through their capacity for action within and understanding of the world. Both adults and children become perceived and understood as belonging to different age-group categories with different roles and performances in society.

Qvortrup (2007) demonstrates in his study that the attitudes of society in relation to children are ambiguous because whilst at the same time as establishing rules and rights to protect children, society departs from these very same rules and rights in relation to adults. Without belittling the importance of ensuring these rights and protection to children, since childhood and politics are inextricably linked, present criticism and construction focuses on the movements of children only as edification materials for future generations and training as political subjects (Qvortrup, 2007).

However, this critical task becomes a great challenge when the conditions of chronically ill hospitalised pediatric patients, who find themselves with reduced levels of autonomy, are dependent upon technology, relatives, social support networks and the performance of professional health workers, are assumed.

## **2. Chronic disease in childhood**

By chronic disease is understood those diseases that present prolonged periods of suffering, are incurable, and have profound effects on the everyday life of sufferers, affecting social relations, the family and health institutions (Canesqui, 2007). Chronic diseases during infancy may be considered as events which have a biological, psychological and/or cognitive basis, with a prolonged periods of suffering which may produce limitations in functions or activities, a loss of social relationships, pharmaceutical dependency, special dietary requirements, medical technology, specialised equipment, personal assistance,

comprehensive healthcare which not only includes medical attention but also other professional healthcare assistance such as psychologists, occupational therapists, nurses and physiotherapists amongst others, which need to be accommodated in different ways in the various spaces of sociability (Silva, 2001).

According to the World Health Organisation (WHO, 2003), a chronic condition constitutes a health problem which demands permanent health care and management over prolonged periods of time, even years or decades. Understanding chronic diseases involves addressing a vast array of diseases including both transferable diseases (HIV/AIDS) and non-transferable diseases (cardio-vascular, cancer and diabetes) and physical disabilities (amputations, blindness, and chronic joint diseases) which, although seemingly distinct from each other, all require permanent care.

Chronic diseases have assumed a new place in healthcare in light of the available technological support and scientific advances which have led to increased survival rates for this group of pathologies. There has been a demographic and epidemiological transition in pediatric care which can be characterised by the increase of chronic cases of overweight patients, infant obesity, reducing malnutrition and a reduction in infant mortality rates between the ages of two months and five years, actions aimed at increasing breast feeding, access to pre natal care, treating pneumonia, diarrhoea and the administration of vaccines (Moreira & Goldani, 2010).

This has had a profound impact on hospital care and point towards the construction of a new model of healthcare which should be expanded to included the prevention and treatment of infant diseases to guarantee the health of individuals so that they can grow and develop. The child is now dependent on technology – an increased population has grown quantitatively and now demands specialised treatments and services (Moreira & Goldani, 2010).

The wide variety of rare infant diseases which are genetic in origin and their subsequent survival is dependent upon both the type of healthcare offered and the available technology. The technologically dependent child, besides demanding new services, establishes a permanent relationship with the various stages of assistance. There are children who are born with chronic diseases, who are assisted by neonatology and in order to survive are transferred to pediatric wards. Institutional processes and transfers of responsibilities between professionals are developed as well appropriating hospital space for family members due to the changes involved in going from being part of life to being hospitalised.

Against this background of demographic and epidemiological changes, pediatric practices were being developed which included diagnostics and the administration of both human and financial resources in order to improve the assistance and healthcare given to patients (Moreira & Goldani, 2010).

However, the experience of chronic disease has at its core the uncertainty of future life and affects not only medical conduct, but above all, the course of the life of the patients who, in many cases, find themselves unable to plan long term for the future (Adam & Herzlich, 2001). Furthermore, chronic disease can alter our everyday routines and habits, which in the case of pediatric patients includes going to school, their circle of friends, visiting parks and practicing sports.

The diagnosis of chronic disease alters the everyday routine of the patient and their family, from initial investigation until confirmation of diagnosis, at which point patients begin to adapt to their new circumstances and learn to deal with the suffering, possible limitations and fear of dying (Pierre et. al., 1991).

Often, due to diagnostic examinations, this routine can even begin intrauterine with certain types of disability or disease being detected and corrective procedures initiated, for example in cases of spina bifida and heart disease. At other times, the baby can present signs or symptoms of chronic disease immediately from birth, thus initiating diagnostic procedures which can interfere with the construction of the mother-child bond and the establishment of the baby's routine.

Thus, the experience of living with chronic disease from birth implies a series of changes to the lives of the baby and family. Discipline is amongst the numerous challenges faced in everyday life, regardless of whether or not treatments require medication. This implies amongst other concerns, the frequency with which patients have to undergo examinations, consultations, medical procedures and hospitalisation (Vieira & Lima, 2002). Besides dealing with the behaviour and conduct of different healthcare professionals, chronic diseases can cause changes in routine which range from those effecting the family, such as those responsible becoming unemployed in order to care for the patient, having to move home in order to be closer to hospitals and health centres, structural changes to the house, to problems at school whether due to architectural barriers, adaptation or rejection of the pedagogical model or rejection by peers.

The constant concern with the care of the child from infancy becomes so great that it can interfere with the spontaneity of maternal care. Depending on the severity of the situation, accurate knowledge of the disease, the quality of interaction with healthcare staff and previous experience, the mother in question may think that she is incapable of providing the necessary care for her baby. The mother wrongly assumes that care is only a technical competence. Thus, it is fundamental that healthcare professionals are attentive to the need of encouraging and stimulating the participation of the mother, not only during the routine of medical treatments but also in nurturing the baby (Winnicott, 1988).

The chronic condition is presented as a delicate reality, becoming a private personal experience that the other does not access, dependent upon constant communication between the subjects. Because it is a private experience of the subject, it is not easily established making the job of deciphering chronic pain necessary amongst healthcare professionals (Baszanger, 1991).

The manner in which the child and the family face chronic disease is associated with the organisation and interaction of the family. The support of family and social ties, support networks for the family and protection of patients serve as a social fabric which permits a greater range for management of encounters and constructing ties which can ensure the well-being of patients (Adam & Herlizch, 2001; Viana et. al. 2007)

The physical pain, the psychic suffering and the deleterious effects of medical procedures are not always taken into consideration in healthcare practices. A narrow view of the experience of the chronic condition, which is defined as only discomfort and/or physical limitation, ignores or minimises the greater meaning and experience of the pediatric patient

(Charmaz, 1983). Considering that a child suffering from a chronic condition can become a chronic adult, it becomes essential that the individual stages of life and their respective experiences receive special attention in the context of hospitalisation and healthcare. For Moreira & Goldani, (2010: 324) *“health conditions in early life are strong determinants of adult health and this has not received sufficient attention”*.

For these authors the field needs more profound and systematic studies which are not limited to personal experiences, case studies, expert recommendations or small clinical trials which have made the child a *“therapeutic orphan”* (Moreira & Goldani, 2010: 325).

### **3. The hospitalisation process and the phases of infant and juvenile development**

It is important to highlight that every child has a chronic disease, regardless of any diagnosis, first and foremost, that of being a child. This fundamental and obvious condition is unfortunately often forgotten by healthcare professionals, implying that the general level of maturity and response expected of these small patients is not consistent with the evolutionary period in which they find themselves. Thus, it is fundamental to consider the aspects of infant development and the principle characteristics of each phase when reflecting upon the attention paid to the health of chronically diseased children.

During the first two years of a baby’s life the baby literally discovers the world through its relationship with the maternal figure and her corporal reactions and sensations. The child moves from a state in which everything resolves around them to the discovery of the outside world

The child’s behaviour is based upon the perceptions constructed through the sensory exploration of the world and physical activities. Disease and medical procedures which cause pain and discomfort can seriously compromise the baby’s relationship with their environment and themselves (Muriel et. al. 2011).

This is a period in which the child avoids the unknown, experiences distress and anguish at the mother’s absence, what Bowlby (1984) describes as attachment. Because of this, situations of chronic disease and fear can trigger extreme reactions including crying, frightened expressions, inertia and greater dependency in their behaviour. Fear can be aroused by the presence of unknown persons, unknown places or situations, and the response will vary depending on a child’s age, duration of separation and the degree of deprivation to which the child has been exposed (Bowlby, 1984). In spite of knowing the importance of early experiences in the baby’s life, we still see, in practice, some healthcare professionals that believe that because of the fact that their client doesn’t present a developed verbal language, chronic disease will somehow not have so many repercussions in their lives.

After this period, the child enters the Pre-operational phase (Piaget, 1976) where its first mental concepts are formed and the process of internalising reality commences. The imagination finds itself indulged in activity and mental reasoning but forms magical beliefs and inadequate concepts characterised by ego-centrism and animism. Accordingly, it is fundamental to take care with the information given to children because their thinking is egocentric and they are unable to articulate or relate to different points of view to their own.

Similarly, the notions of time and reversibility are still under construction. Because of this, children often find it difficult to understand why it is necessary for them to have to undergo certain treatment which they sometimes associate with discipline and punishment (Santa Roza, 1997).

Often, even simple activities like playing with other children or siblings can become compromised. This may occur because of limitations arising from the intense routine of treatment, the care taken when in contact with other people (avoidance of trauma or bacteria) or the parents fears in relation to any other eventuality that they think threatens the health (and consequentially the life) of their children.

At school age, between the ages of six to twelve, the child will gradually become increasingly mature for their physical, intellectual and social condition. It is a phase of investment in physical activities and of greater socialisation. However, sufferers of chronic conditions may find themselves unable to participate in conventional social interaction and banter, which gives rise to the possible loss of friendship ties and changes in familial relationships. Further, the comprehension of death which chronic disease brings with it becomes more accessible through language and abstract content (Muriel et. al., 2011).

Amongst adolescents, who experience a phase characterised by the involvement of formal identification, an appreciation of more abstract aspects through a greater intellectual and emotional contribution, the experience of chronic disease can place them in conflict with their desire to live a more autonomous life and the dependency imposed on them by their chronic condition (Muriel et. al., 2011).

In all of these phases, it is important to point out that school should be considered as a primary partner in this process, which implies the availability and time to receive children with special requirements, for example, those who have had tracheotomies, gastrostomies or colostomies, administered food absences due to prolonged periods of treatment, the possible structural and architectural barriers and the relationship with other children.

However, school may also represent a challenge for children with chronic diseases due to the fact that it may expose children to more vulnerable situations, to being stigmatised by their colleagues and even bullying. The corporal changes entailed as a result of chronic diseases may provoke changes in body-image, the generation of feelings of inferiority, depression and embarrassment from the perception that they are different from their peers (Castro & Moreno-Jiménez, 2007)

Because of this, it is important to point out that the monitoring of children with chronic diseases involves knowledge from various disciplines. The participation of different healthcare professionals aside from doctors, psychologists, social-workers, occupational therapists, physiotherapists, and speech-therapists is fundamental.

Another important aspect of treatment, frequent in the lives of chronically diseased children, is hospitalisation, whether due to the deterioration of the patient or as a strategy for administering specific medication and procedures. Regarding the hospitalisation of a child or adolescent, in general, what is observed is conformation of this delicate moment for the family requiring a reconfiguration of the everyday life and the assimilation of the disease which may also induce subjective changes. At the moment of hospitalisation, the experience for the pediatric patient is marked by the rupture from the everyday routines of school,

friends, family, peers and games. In general, "the activity and freedom characteristic of childhood are replaced by passivity, leaving few options for the child to make choices" (Mitre, 2006; 286).

This change produces an estrangement from the experience of being in hospital which will differ amongst patients and their relatives. The points of reference in a child's and adolescent's life are replaced by pale walls, invasive medical procedures, medication and machinery, new words and phrases and the sensation of pain and suffering changing the everyday routines of these patients (Mitre, 2006).

The hospitalisation of children may be considered as a potentially traumatic event when the full complexity of the human dimension is not fully considered (Santa Roza, 1997). Generally, models of care still favour the disease and view the child only as a sick body. We have to consider the diverse aspects involved in the process of hospital care when working with children, everything from the presentation of physical space to treatment routines, so as to avoid iatrogenesis (Santa Roza, 1997).

Bearing this in mind, we observe an increasing concern with the physical environment of hospitals and health centres, especially in pediatric wards. However, it is still common in hospitals and health centres to find the presence of unwelcoming and stressful stimuli. Unfamiliar and noisy equipment, a plethora of monitors with artificial lights, pipes and tubes and needles and tweezers comprise, in general, a threatening and unfamiliar setting.

With the evolution of technology, and this is not a criticism, merely an observation, some hospital wards nowadays resemble spaceships, both architecturally and in terms of the complexity of equipment. This is due to advancements in diagnostic and therapeutic procedures, modern criterias of optimising resources, and newly discovered diseases, micro-organisms and consequent treatments. However, this has led to an increased concern with creating healthcare spaces separate from society, isolating the infirm and setting the hospital in areas outside of cities apart from everyday life (Antunes, 1989).

In contrast, in economically disadvantaged areas, it is still common to find areas being used as pediatric wards which previously had been intended for use by another clientele, or still further, had been intended for completely different purposes. This may involve places with no windows or natural light, only cold light and few objects which remind you that this is a space for children.

The importance of windows to the outside world is discussed in the work of Antunes (1989), where he says, irrespective of what a patient sees, it can be a landscape, cars, people, they see what does not exist in the hospital, a life full of movement and they are reminded of the temporary suspension of their freedom and autonomy as a result of hospitalisation. In the case of infant hospitalisation it is not only the patient who is subject to the architecture of the hospital. The accompanying person, usually the mother, is also hospitalised together with the child and ends up feeling "trapped" in an environment which sometimes appears far removed from everyday life.

This can contribute to augmenting the feeling of anxiety caused by the concern for the sick child and as well as for other related situations, such as concern for another child who remained at home, the abandoned job, the lack of support from a partner or family. All of these questions will be reflected in the relationship established between the child and their

carer, a relationship which, principally during hospitalisation, needs to be capable of providing the necessary support for the child experiencing this period (Mitre, 2000).

Compounding hospitalisation still further, the child is subjected to situations in which they do not have any choice. Despite the necessity and effectiveness of hospitalisations the child is extremely susceptible to experiences which can cause stress and suffering.

The feeling of discomfort and pain is one of the characteristics which may accompany the hospitalised child. This is both connected to the clinical condition of the patient, which is presented through painful symptoms causing discomfort, as well as certain medical procedures. The procedure may be a simple puncture, present in almost a hundred per cent of hospitalised children because of the need for effective and immediate medication, or other equally invasive procedures such as the insertion of different tubes to drain various bodily fluids and gasses, the use of catheters or other probes (Mitre, 2000). Depending on the child's age or clinical condition the child is unable to verbalise these feelings.

The simplest everyday routines are changed due to the fact of hospitalised. The hours of the day change, sometimes sleep is interrupted by the routines of the ward, having to constantly take temperatures, blood pressure, listening for respiratory and circulatory problems and the taking of medication.

Feeding habits and hygiene routines change as well. Sometimes food is restricted (or even temporarily suspended) depending on the clinical condition of the child or the particular procedure (examinations, intravenous procedures and punctures and surgery amongst others). Hygiene habits may change depending on the time and the place, some patients are required to make use of probes or even have to resort to using nappies. In certain cases patients have to be bathed in bed which can lead to discomfort and embarrassment especially with older children. Moreover, in some places, generally public hospital wards, many children and their families and friends have to share the same space without any privacy (Mitre, 2000).

Besides all this, during hospitalisation the child is kept away from their friends, family, toys and school; ultimately, their life. This period is often experienced by the child as a gap in their life and as if everything appears to be in parenthesis. Everyday life appears so distant that some patients lose their notions of time and space. Once, a child asked if the hospital had an exit door and elevator to descend to the street. For him, there only appeared to be an entrance (Mitre, 2000).

Santa Roza (1997) describes how in this environment the child experiences situations which, even when they don't constitute a new experience (as in the case of repeated hospital admissions), may still sometimes be perceived as frightening. During hospitalisation, the child begins to live intensely with the sliding fortunes of their body, experiencing their suffering, the suffering of their family and of other children. Sometimes they are present to witness death; other times, they fear their own. Fear, anxiety and anguish accompany the hospitalisation process. In general, the child is unable to comprehend why they have to pass through these unknown experiences which produce fear. This situation may stimulate fantasies and thoughts about guilt or punishment as well as the fear of abandonment and death.

For child sufferers of chronic disease and/or serious clinical conditions the situation is made worse because, in general, hospitalisations occur frequently and for certain children the hospital is the everyday routine. Some patients are hospitalised several times a year whilst others may stay in hospital for months on end. There are still those patients who come and go with such frequency that they begin to spend more time in the hospital than at home.

It is common to know the seriousness of the condition even if it has not already been clearly stated. The concern with death exists and manifests itself in different ways. Some children joke about this whilst others pass comments about other children who have died.

Kudo & Pierri (1993) point out that amongst the various factors which directly influence the way in which a child will react to the process of hospitalisation are; the type of and degree of the affective bond established between mother-child before being hospitalised, the child's personality, the length of stay and the attitude of hospital staff towards them and the child's age.

Gonzaga & Arruda (1998) highlight, based upon various interviews with hospitalised children, that care can be offered by various people during the administration of services but that the action of one doesn't minimise the effects of the others but instead the benefits are congregated. The different actors can become sources of care and of feeling cared for. However, examples of a lack of care were also mentioned including attitudes of disinterest shown by healthcare professionals (doctors and nurses), not executing procedures to alleviate pain or the execution of procedures in a cold and mechanical manner without due respect and understanding towards the condition and sensitivity of pain. All of these actions contribute to the increased anguish and stress that the hospitalised patient experiences.

It is important to note that the introduction of play and recreational activities presented positive results about the experience of infant hospitalisation. Considering that playing is a fundamental childhood activity it should also be present during the period of hospitalisation. Its absence can lead to the impairment of motor, cognitive, perceptive and emotional functions. (Mitre, 2006).

Play places the hospitalised child in a similar position to other children instead of the difference imposed on them by chronic disease (Mitre, 2004). It is an activity which furthers and supports the creation of alliances and interactions amongst children, carers and healthcare professionals allowing for the construction of a new social network whilst also helping to diminish the sensations of isolation and solitude that hospitalisation causes (Mitre, 2000). Also, in the child-carer relationship, play can help reconstruct ties which have become fragmented due to the familial breakdown caused by the illness (Mitre & Gomes, 2004).

Play and recreational activity also makes possible the expression of feelings, ideas, fears, affections and habits. Because play is something which belongs to an individual, social and cultural repertoire, it is conducive to the child identifying with familiar elements and situations whilst in the hospital environment (Mitre, 2006).

To value and stimulate play as a possible means of self-expression is to recognise that if you work with children it is necessary to respect the uniqueness and specific needs of each child. Thus, play in hospital can be considered as a democratic place where individual experiences are valued and the possibility of choice and the exercise of autonomy exist (Mitre, 2006).

#### 4. Parental approach to chronic disease and the hospitalisation of the child

Chronic disease in children and adolescents, besides bringing new variables into the lives of the patients, imposes on the parents the need for developing new routines and acquiring new knowledge about the conduct and the care of children.

According to Alves (2009), mothers who live often with the hospitalisation process of children learn to provide care and are able to supervise the work of providing assistance, judging if they are “right or wrong” in accordance with what they have learnt.

By exercising their role of providing care to the child, mothers have a function which permeates meanings in the universe of nursing, whilst the nurse is, in these cases, in a place which does not have clearly demarcated boundaries in the delivery of healthcare. This confusing and ambiguous situation can create conflicts and disagreements with regards to knowledge and information. However, the disposition of mothers to provide care should not be taken as a rule in the same way that it is not specialised care (Alves, 2009).

The development of care by carers, in general, does not form part of the same option. The experience of chronic disease, gradually, inserts them into the hospital routine where they learn and act. The permanent presence of companions imprints another dynamic in the assistance process, because it provides the opportunity to learn some new technical abilities and to amplify other knowledge about the functioning of the hospital and of therapeutic techniques (Lima, Rocha e Scochi, 1999).

The presence of the family within the context of the hospitalisation of children and adolescents represented an advance in the relationship between the users and the hospital space, but as an isolated initiative it didn't recognise or take into account the need to understand the dynamics involved in the process of chronic disease in children and adolescents. The presence of the carer needs to be tracked by a therapeutic project which integrates patient care because the carer is attached to assistance and meaning is related to the patient's disease.

As a vehicle for providing access to the knowledge of patients and carers, dialogue and guidelines are indispensable resources. The construction of a therapeutic project, which integrates knowledge and establishes performance guidelines within each stage of patient care, can be a great resource for structuring and organising more harmonious and co-responsible relationships.

At this point the ability and capacity for communication, dialogue and a host of other demands and opportunities for the autonomous expressions of the family, comes into play. Sharing the provision of care with carers requires the exercise of co-participation. A space for dialogue is needed which enables the different actors to express their doubts and feelings. This space can not be attached to the duration of time in hospital, but rather instituted as a means for the management of daily services.

The investment in the relationships between healthcare professionals, patients, and their carers, founded and guided by such factors as the initial contact and dialogue between patients and doctors, may empower the role and autonomy of children and their carers.

The appreciation of knowledge of paediatric patients about the process of chronic disease and the relationships which they experience within the context of hospitalisation are as

important as the experiences of carers. The right of children to express themselves can provide valuable information for healthcare practices which may be reconsidered in favour of a more comprehensive and friendly service.

Beginning with this understanding, it is possible to construct relationships within healthcare which will not be guided by the subjection and control of the patient, but where you can affirm the capacity of the paediatric patient to express, create and reinvent standards which make possible for autonomously administering the margin of risk to life, amplifying capacities for coping with the disease together with the most important relationships.

The recognition, on the part of healthcare teams, of the conditions in which the body is encountered, the subjectivity of the patient, is the first step towards incorporating a new understanding of the patient, taking into consideration the factors involved in the patient's life.

Taken as a proposal to consider care as a value (Pinheiro, 2007), understanding it as an integral action which has meanings related to the understanding of healthcare such as the right to medical and other specialised treatments, allows the patient to actively participate in the decisions taken in regard to the conduct of their own case.

Healthcare begins when a dialogical relationship between the patient and healthcare professionals is initiated, which transcends the simple game of the active questions of healthcare professionals and the passive responses of patients towards the construction of a space of exchanges, where the medical knowledge of the doctor incorporates itself into the lived experiences of the individual. With this, it is possible to establish relationships which are guided by partnership between people which have the objective of finding the shortest route to the restoration of health.

Caprara e Franco (1999) emphasise the need to overcome both the informative model that relays information and the paternalistic model which protects the patient from their own disease, towards a model of communication which includes other important actors in the life of the patient. It is an overcoming which requires a change in attitude and understanding about the healthcare process and the place of the other within this relationship.

For Deslandes (2004a), the possibilities of communication are related to the social position which individuals occupy. In the relationship between doctors and patients there exists, historically, a differentiation between the place and value of their speech.

However, the construction of an active communication begins by recognising the place of the patient as that of a subject in the relationship. According to Deslandes (2004b), the necessary movement in order to change this logic of attention within healthcare not only incorporates a new understanding of patients and their lived experiences, but also a change which observes the organisational culture in which are concentrated the relationships of knowledge-power, gender and social status. These are these factors present in the organisational culture which are able to feed certain types of relationships between the actors in institutions.

Healthcare taken as a value, (Pinheiro, 2007) proposes that we recognise the ethos of the cared for and of the provider of care, which requires including in the relationship the

dimensions of individual life with its habits and customs and communitarian life, both being originating dimensions in the character and identity of the subjects. It is to be able to incorporate the ethos of the other in a process which extends itself making that therapeutic moment a unique moment of contact and dialogue.

## 5. Final considerations

It is important to highlight that working closer with chronically diseased children implies certain challenges can't be ignored by healthcare professionals. Firstly, every child, independent of their diagnosis, should be perceived as and treated as a child and not only as a clinical case or disease. It is not enough to have knowledge and mastery over techniques and procedures, it is also necessary to have knowledge of infant development and the perception that care is not limited to treating only symptoms. Part of the professional role should include helping children to deal with the barriers which originate with disease and expanding their limitations in favour of greater quality of life.

The various forms of healthcare need to be introduced to the child, not merely as the recipient of diagnostic and therapeutic techniques, but rather as a subject that possesses various ways to elaborate their experiences of living with chronic illness. The ways which children elaborate about the experience are different from adults, but this doesn't render them incapable of valuing the experience and extracting from it new meanings which healthcare staff can help to produce.

Hospitalisation contexts carry the potential to produce something new, transmuting into new pathways which allow for new perspectives as well as generating closure, diminishing the creative wagers of the subjects. The potential to change situations which cause fatigue, polarisations of care and dichotomies of knowledge is contained in the capacity to unite healthcare staff collectively towards an objective, the construction of which is shared between the patient, family and healthcare professionals (Alves, 2009).

In this sense, the meetings with each patient can promote changes in the perception of the subject because there are moments which are full of creative possibilities orientated towards solutions for coping with chronic infant disease, producing positive changes for the patients, families and healthcare professionals.

The participation of relatives in the hospitalised context and care of chronically diseased children also needs to be rethought so that the dichotomies and disputes of space and knowledge can be broken down. Learning about care inevitably occurs in families which accompany the daily care provided to the child making this experience a way to integrate different cultural knowledge and values.

Within the world of attention and assistance, acceptance and dialogue are wires, not only permeated by concepts and theoretical frameworks, but through the capacity to meet and produce subjectivity, revising values, perspectives and expectations.

To this end, necessary changes to the dynamics and processes of healthcare staff are needed, beginning with a management model which is shared and constructed in a collective fashion between healthcare professionals and the users of such services in order that it may become possible to break and minimise distance and to value the capacity for collective union.

Finally, to highlight the contribution of Ayres (2005), in relation to the concept which he calls Projects for human happiness. For the author, this concept refers to the idea of lived experiences, positively valued, which are not dependent on a state of complete well-being in the life of the subjects. In cases of disease, these projects can be constructed from the various values and guidelines which orientate healthcare. He makes the salient point that happiness materialises in the lives of individuals through the construction of everyday life projects, a concept which can't be defined universally or as an external entity. Projects for human happiness are associated with the capacity to overcome obstacles and move in the direction of values held by both the individual and collective.

The way to construct, in healthcare, Projects for human happiness involves the evaluation of values which orientate the processes of chronic disease and healthcare, as much as in regards to the integration of care by the different actors who participate, as well as the closer cultural, economic and social ties between healthcare professionals, patients and relatives. Above all, the view of the child should be complete, going beyond the supposed organic limitations and inability to express feelings and experiences.

There exist many different ways for the child to access the contents of pain and happiness. Nevertheless, a leading Projects for human happiness agent for carriers of chronic disease requires going beyond the implementation of technical methods and procedures or structural knowledge of disciplines, in order that new meanings and new ways of listening and new points of view can be expressed in spaces of care and attention.

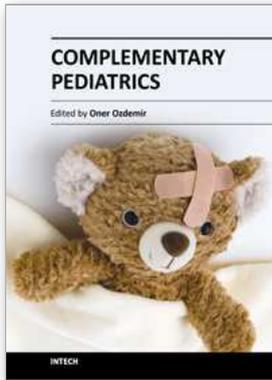
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