
Chronic Health Conditions in Childhood and Adolescence and the Formation of Care and Support Networks

Camila Aloisio Alves

Additional information is available at the end of the chapter

<http://dx.doi.org/10.5772/59060>

1. Introduction

Addressing care and support networks issues in the chronic health conditions context for children and adolescents requires understanding chronicity within the contemporary scenario and its nuances, both as a trace of epidemiological transition and through experiences that emerge from dealing with illnesses.

Chronicity features the healthcare offered to patients as complex, since it requires specialized professional expertise, as well as the mastery of specific technologies and assistance techniques. Relationships established among professionals, patients and their families are quite intense and interactive, due to the need for continuous monitoring. At the same time, chronic patients need a sort of care which is not provided by specific actions from certain specialties only. It requires coordination among fields of knowledge and actions from different professionals and institutions.

According to the experience of patients and families, chronicity is complex because of all the repercussions it has on their lives. Experiencing pain, suffering, and distress facing diagnosis, treatment and rehabilitation are among the set of conditions that shape chronic disease frames in children and adolescents. Management of everyday life undergoes changes, and the search for appropriate treatment leads patients and their families to the establishment of an itinerary towards getting health services.

Care and support networks raise as key elements to healthcare practices applied to chronic children and adolescents, helping them withstanding the impact from such experiences and, at the same time, to be able to walk the paths to meet the necessary healthcare practices for their illness conditions. Chronic conditions demand a necessary care which needs to be

structured in order to encourage exchanges among different individuals, institutions and social sectors. From the care and support network's perspective, the other one can be seen and understood *"as a living being in a state of interrelation and interdependence with all phenomena, which means enhancing pediatric practice"* [1, p.174].

Thus, the current chapter will address chronic health conditions in childhood and adolescence from a social anthropological perspective, therefore giving visibility to experiences emerging from clinical practices involving illnesses in order to be able to set the role played by care and support networks within this context.

2. Chronic health conditions

Brazil's demographic and epidemiological profile has undergone deep changes over the last century. In the early twentieth century, Brazil was a country characterized by high mortality rates caused by infectious and parasitic diseases. Due to the contribution of health and sanitation technologies, such as vaccination, hygiene, childcare and investments in health education, the country has seen its population grow and increase its life expectancy over the decades.

Chronic degenerative diseases have become more significant, prevalent and incident as an epidemiological feature of this change, even if concurrently with infectious and parasitic diseases in their epidemic or endemic form.

Chronic health conditions were gradually taking up space in service dynamics, professionals' trainings, health policies, pharmaceutical industry production, research and scientific studies. Such Brazilian profile, in line with other developed or developing countries, indiscriminately affects regions and social classes [2].

In the course of an individual's life, the emergence of a chronic health condition usually involves permanent changes in his/her usual routines, intrapersonal and interpersonal relationships, eating and physical habits, and the interaction with health services. Such changes can be explained by the need to introduce control, preventive and protective measures against the disease. People with chronic diseases need more supportive, planned and integrated healthcare. They are patients who need support from their communities and also need comprehensive policies for preventing or effectively managing chronic conditions. The optimal treatment for chronic conditions requires a new healthcare system model [2].

The new model indicated by the World Health Organization requires professionals able to establish an integrated and interdisciplinary care system as well as to create links among subjects, services and care levels.

With the emergence of chronic conditions, the Brazilian healthcare system faces illness profiles that require continuous attention, with measures aimed at both treating and managing the condition, as well as preventing it at different levels. The system bottleneck regards the worsening of the chronic conditions. Its impact is felt when clinical status worsens, thus

increasing the demand for admission to ICU beds. The exacerbation of chronic conditions impacts on care provision costs and on the financial investment in medicines, supplies and technological resources to be used in treatments.

Chronic conditions impose a limit to health professionals due to the search for a resolutive care aiming at healing. Furthermore, chronic patients need more frequent and intense contact with professionals. It requires such professionals to develop dialogical and communicative skills that make patients feel welcome.

In this sense, chronicity brought into question the way services work and how health professionals interact in order to provide care. As chronicity happens, disciplinary separating among professional categories has become critical and requires an integration exercise based on dialogue and interdisciplinary attitudes.

3. Chronic health conditions in childhood and adolescence

Regarding child and adolescent health context, demographic and epidemiological transitions meet what was observed in the general population. It is characterized by the increase in overweight, childhood obesity, reduced malnutrition and reduced mortality rates among children at the age group from two months to five years.

The list of chronic conditions that affect children and adolescents is extensive. According to Castro and Piccinini [3, p. 624] they can be listed as follows: Organic chronic diseases (e.g.: cystic fibrosis, congenital heart diseases, chronic renal failure, biliary atresia, cirrhosis, cancer, hemophilia, AIDS); Physical impairments (e.g.: deformity or absence of a body limb, cleft lip and palate, visual and hearing impairment); Learning disabilities and neurological disorders (e.g.: epilepsy, cerebral palsy, attention deficit); Mental illness (e.g.: autism); and also Psychosomatic diseases (e.g.: asthma, obesity).

Technological and scientific contributions, in addition to control and prevention measures, have had a strong impact in this scenario. They allowed increasing survival rates of children who were born with or developed some of these pathologies.

The basis of these conditions articulates biological, psychological and/or cognitive aspects. Therefore, they seriously impact the lives of patients and their families enabling the development of limited functions or activities and affecting their social relationships when taking under account their dependence on medicines, medical technologies and special diets [4].

Chronicity experiences might begin early in pregnancy. Giving birth to a baby at risk may trigger a chronic condition already expected, felt and experienced throughout all pregnancy stages. A number of feelings such as fear, uncertainty, doubt, anger and guilt can be felt at each pregnancy month, thus requiring preparation procedures so the family can be ready for the labor.

A baby who shows some problem early in pregnancy, during labor or shortly after it is considered a baby at risk and such risk may trigger a chronic condition. Prenatal medical

practices together with tests, investigations, monitoring procedures and counseling are extremely important to ensure good assistance [5].

Current technologies and proper prenatal assistance throughout pregnancy include being aware of the pregnancy evolution as well as of risks and possible outcomes, all based on diagnoses. Risks and/or chronic conditions in children are experienced from early pregnancy stages. It means that the arrival of these children can be prepared, although it is nonetheless distressing.

Experiencing chronic diseases in its core means facing the uncertainty of future life conditions that affect not just the medical approach, but and above all, the destiny of patients who, in many cases, see themselves as suppressed of the possibility of making long-term projects.

Giving birth to a baby diagnosed with some risk and/or chronic condition requires the presence of trained professionals and technologies capable of supporting life within the delivery room. The use of striking technologies within the chronic conditions context involves family and children during pregnancy, labor and throughout the child's life [5].

After such baby is born, he/she begins a bond building process different from that which happens with "normal" babies, those with no chronic conditions. It happens due to the need of taking the child away from the mother – the first stays in the ICU whereas the mother stays in the hospital room. "This is a difficult time, as well as it is to be discharged without being able to take the baby home" [6, p 24].

According to Braga and Morsch [7], getting into an ICU full of devices, sounds, tough situations, tubes, wires and requirements can be an experience surrounded by feelings such as fear and bewilderment, even for parents who were informed and prepared to face the birth of a child at risk.

Gradually, the family needs to know the world around the baby and how to communicate with the child, as well as to understand what is happening and how to recognize the baby's reactions.

According to Braga and Morsch [8], parents usually need a waiting period before they can begin to approach the child. Such period holds both the fear of losing the baby and the search for ways to establish parental relationship. Through this relationship built in the ICU environment, they begin to establish familiarity with and get aware of the care environment.

According to the authors, mothers have difficulties in expressing and developing their primary maternal concerns¹ because such concerns are mediated by another type of concern which is related to monitoring the child's health clinical evolution [7].

Thus, accessing, learning and mastering the knowledge and techniques which are common in the biomedical scenario are gradually learned and experienced by parents. These competencies

¹ The primary maternal concern develops itself from the beginning of the pregnancy, becoming more intense in the final pregnancy period and after birth. It can last for months after the delivery. It is a mother's psychological state in which her sensitivity to the child becomes exacerbated [9].

and skills are incorporated and implemented in the course of the child's life, whether in hospital, either at home.

Children born with chronic conditions, and diagnosed in the very first moments of life, are assisted by Neonatology. If they survive, they are transferred to pediatric wards. The adaptation to everyday life, in face of a chronic condition, is implemented from the moment the child is transferred to the NICU. Professionals follow the child's health evolution and his/her possible needs of other services such as Intermediate Care Unit, Pediatric Surgery and Pediatrics.

Neonatal and pediatric patients living with a chronic condition since early age explore the world and develop their perceptions, emotions, learning and relationships through and despite their condition, knowing no other way to walk through life. In addition, just as the children, family members improve through experiencing hospital relationships and procedures, and by learning new ways of being mothers, fathers, brothers, grandfathers, grandmothers to chronic babies.

However, the onset of a chronic condition may occur during the development of the child and it can also lead to changes in both patients and families routines. From the very beginning of the investigation up to the confirmation of the clinical condition, children begin to adapt themselves to new circumstances and deal with suffering, possible limitations and with the fear of dying [10]. Cystic fibrosis is an example of this kind of situation, since it only shows its first symptoms later in the child's life.

The emergence of a chronic disease in adolescence causes a sudden interruption of "normal" life. The onset of chronicity in a teenager's life interferes in bonds built among peers and in important moments experienced with friends and family. Adolescence is strongly related to different discoveries (body, sexuality and forms of sociability), as well as to the construction of identity and dreams to be fulfilled in the adulthood. It is a time of discovery, growth, development and expansion of autonomy. When the chronic condition onsets, it causes gaps in this process and may trigger the cycle of feelings reported by Faulhaber[12]: anger at the news, depression in face of the symptoms and changes in routine, apathy in face of a life limited by the illness and hospital environments, and resignation towards an unchangeable condition.

Whether they are diagnosed at birth or later in life, chronic health conditions in children and adolescents are permeated by high institutional processes, the transferring of responsibilities among professionals, and the greater occupation of hospital areas by family members since part of the family life is moved to the hospitalization context.

Accordingly, hospitalization or even re-hospitalization are experiences marked by a double break: for the mothers, regarding the family routine; and for patients, regarding the familial and social scene, with changes in habits involving: attending school, being with a group of friends, going to parks and practicing sports [11].

These changes cause strange feelings towards the hospitalization experience which will be felt differently by patients and their families. References from children and adolescents life context are replaced by light colored walls, invasive procedures, medicines, machinery, new terms and words, and by pain and suffering, thus modifying patients' life routine [13].

In cases of children with chronic conditions, their relationship with the illness changes and new skills are learned by them. Many of them grow up dealing with life limiting situations and learning to incorporate the hospital space into their everyday life.

Taking into account that children with a chronic condition may become a chronic adult¹⁴, it is essential considering that his/her growth will be linked to such care relationships. Therefore, it is necessary to overcome the developmental view that sees children as beings under formation and incomplete and who, therefore, need to follow cultural and educational standards in order to regulate and normalize their future as adults [15].

Castro's [15] theory of action emphasizes the importance of legitimating children and adolescents as individuals able to exercise their rights by their ability to act in and understand the world. This statement is not different from the aforementioned, since it takes chronic health conditions in children and adolescents under account because through each diagnosis there is a story of life to be lived, told and respected.

4. Chronic health conditions under anthropological and sociological perspectives

The care given to a chronic condition patient requires concerns about his/her life path. Different surveys and studies were developed aiming to understand such path. It allowed building a consistent knowledge framework about chronic health conditions in order to better address them.

Socio-anthropological studies provide key elements for understanding chronic conditions, since they focus on the illness experience and its consequences in the individuals' lives. Studying the socio-cultural dimension of chronic conditions is a task aimed at understanding a subject's life element that explains and represents the sociocultural and family context [16].

Socio-anthropological studies on chronic conditions emerged in the 70s. Since then, studies have sought, despite the range of diseases that compose such conditions, to make distinctions among them and to understand the experience of living with the disease [11].

Chronic conditions force patients to live a life with uncertain course of events. Such uncertainty affects both the patients who are managing their lives, and health professionals who use some resources in order to provide care [11].

Canesqui [16] conducted an extensive and thorough documentary study, given her 25 years (1980-2005) of anthropological research in international journals of reference in the area. The synthesis produced by the author revealed that chronic conditions point out aspects related to private and everyday life, routine breaks, managing the disease and life itself. She also emphasizes that the care provided to the patient is not limited to the hospital environment.

The experience of a chronic disease can be understood as socially constructed, being inserted in time and in the social and historical space. When faced by a chronic disease, everyday life's structure is transformed, changed, thus requiring subjects to mobilize resources from different

orders so they can deal and cope with the disease, making their life trajectories being traced according to the possibilities and limitations imposed by the disease. It is an adjustment process with moments of accommodation, struggle and redefinition [16].

As the chronic disease evolves, it changes the patients' perceptions about themselves, the same way that it encourages the production of strategies for coping with it. Inevitably, the chronic disease causes the subject to be in touch with the possibilities of exercising some autonomy in life [16].

Living with the disease requires the subject to build strategies to deal with the different spheres of life, seeking re-adaptations that are able to establish a rhythm for the course of their lives [11].

In this sense, having or developing a chronic condition involves, according to the patients perspective, rebuilding their personal identity that is constantly shaped by the disease and its limitations. This reconstruction can be related to living with aesthetic changes, depending on technology, learning new body movements and adopting preventive measures [16].

In the set of studies on the subject, there is one developed by Goffman [17] which addresses stigma as an experience that may be related to having a chronic condition able to affect and deteriorate patient's identity. Regarding the identity of a chronic condition patient, Canesqui [16] points out the existence of two possible explanations. The first one emphasizes the strength of the community, with its rules represented as expectations and stereotypes expressed in personal experience conditioning. The second one has the opposite sense; it demonstrates that the individual's experience with the disease stimulates collective actions. According to the second line of thought, there are researches focused on the legitimacy of chronic conditions, such as backaches, arthritis and arthrosis, that are not valued or are not subject to constant suspicion, due to lack of etiologic evidence. Such studies focus on the subjects' pilgrimage through health services and their struggle against the way they are labeled.

Other than that, chronic conditions, when diagnosed inside the womb and/or at birth, mark the history of the child and his/her family, whether for the fact that they are not going to meet the expectations and dreams of a "normal" life, or for the need of re-adaptation in face of possible limitations and/or routine changes imposed by the condition itself.

The experience of a chronic condition is not limited to the patient. It also involves the family and health professionals. A Mexican study [18] investigated the perspectives of patients and health professionals (medical and non-medical) in face of chronic diseases. Results showed different aspects, demonstrating that the point of view on a particular experience (social role, life path, etc.) is related to the individuals' role within the social relationship context.

The patients highlighted the disease symptoms, the emotional manifestations in face of the challenges of living with pain, limitations permeated by health professional orientations (diet, medications, activities, procedures), and they also pinpointed aspects related to religiousness and spirituality as elements of support, strength and belief. Relatives were sometimes mentioned as supporting elements, or as conflict sources due to the difficulties of dealing with the patients' limitations regarding special care [18].

Non-medical professionals highlighted patients' emotional breakdown resulting from difficulties to deal with their conditions and physical problems arising from clinical worsening. They also underlined the economic and labor effects arising from the partial or total suspension of their labor activities. In addition, they mentioned the uncontrolled clinical state of health in face of the failure in following the doctor's requirements or the difficulty in having access to the necessary resources [18].

Finally, doctors prioritized the emotional manifestations, symptoms and organic signs, the effects from prescriptions that sometimes are followed, sometimes are not, the explanations of genetic background, featuring a more prescriptive relationship with the patients [18].

In this context, it is possible to understand that, during more than 30 years of socio-anthropological studies, the objects varied and results revealed different experiences from living with chronic diseases, placing subjects with chronic conditions in the center of both the analysis and the synthesis. Chronic conditions represent not only an epidemiological and demographic movement of a population's social dynamics and health, but they also refer to ways of experiencing life, existing in the world and establishing relationships.

5. Care and support networks

Due to the complexity imposed by chronic health conditions to children and adolescents, the development of a comprehensive caregiving system that articulates different specialties and integrates health services network is seen as necessary. The experience of chronicity in children and adolescents, besides affecting their life trajectories, involves the intense participation of family members accompanying them. The chronic condition requires continuous and long-term care which is, in general, provided and managed by family members. Family involvement comes with significant changes in family members' routines. Moving to a new house or switching and sometimes losing the job is likely due to the need of providing continuous care to the children.

Temporality in chronic conditions leads to exacerbation and stabilization periods. It requires families to take different measures in order to provide care. In stabilization times, the family's rhythm is driven to be reconfigured in order to deal with a new routine, which is marked by constant monitoring signs, symptoms, medication and nutrition management. On the other hand, in exacerbation times, the demand for health services is more intense.

Therefore, in addition to the technical aspects that characterize healthcare qualification, such as intensive, nutritional, respiratory and environmental cares, the support provided to family members is seen as a necessary element to the composition of a comprehensive care.

The comprehensive care for chronic health conditions in children and adolescents involves not only the use of hard technologies, such as equipment, medicines, medical examinations and procedures, but also soft technologies², such as welcoming families and a dialogic relationship that enables family members to be co-involved in and take co-responsibility for providing care to the children. All these elements ensure that caregiving for chronic health conditions in

children and adolescents is complex and multifaceted, since it must be thought under a horizontal and humanized perspective.

Families should be considered as primary caregiving units, systems of belonging that value the bond and ties of solidarity, trust and donation, to which resources must converge, relying on the organization of practices from networks and links [20, 21].

The way children and families face chronic disease is associated with family organization and interaction factors. The support from the family and social ties, the family support networks as well as patients' protection networks serve as a social fabric that which allows improving the management of experienced situations. The construction of support networks among family members and friends can happen during the process of looking for care and support. Building such links helps ensuring patients' well-being [11, 22].

In the context of chronic conditions, the experience lived by family and friends who are united by bonds and ties, in facing adverse situations and reconfiguring their life routines, is studied by authors who address therapeutic itineraries and care trajectories [20, 21, 23, 24].

The formation and structuring of networks from links and bonds established among family members and friends are not fixed. They can change according to the momentary needs, showing reticular and individual movements that happen within and between networks [20].

The formation of networks in the context of chronic health conditions in children and adolescents is a feature that should be considered as an integral part of caregiving. For many families, the sense of belonging to a network of friends, families, neighbors and professionals represents a great difference in their life trajectories. Through such networks, one can access services, share experiences and build knowledge about the experienced problem.

Care and support networks can be woven and built in different spaces where patients and their families seek for care and treatment. There are contact points for networks conformation among friends and family community, as well as among and within health services.

In hospitalization contexts, as children and adolescents with chronic conditions show higher average length of permanence in hospitals and accompanying people have their presence guaranteed by law throughout the hospitalization process, family members get to know and learn about the logic of hospital functioning and about procedures and clinical parameters. The intensity of such experience puts accompanying people of different patients in contact, so they are bonded by the common experience of being chronic children caregivers.

A common identity is built among family members, and through it, they are able to share the burden of hospitalization. It creates opportunities for exchanging experiences, sharing knowledge, trust and solidarity thus contributing for the family to feel safe. Many times, the

2 According to contemporary authors, such as Merhy et al. [19, p. 121], the work in health services is considered as alive, because its object is not fully structured and its actions are configured as intervention processes in action, working through relationships, subjectivities confluence, in addition to the structured technological knowledge. The used technologies can be considered as "soft, soft-hard and hard". The first one relates to the production of bonding, welcoming, autonomy and management; the second one refers to the structured knowledge in different specialties, and the last one relates to the technologies applied to the field.

absence of a mother-who needs to go home to change clothes and take care of other children-is feasible because another mother, who accompanies her child in the next bed, makes herself available to take care of the child during maternal absence.

Therefore, the use of resources such as family groups is essential to the trajectory of chronic children and adolescents caregivers. In groups composed of family members, individuals who experience adverse situations are able to share common experiences since they are gathered by their children conditions. It allows creating bonds and ties, even if temporarily, which are strong in their ability to add value to therapeutic itineraries and caregiving trajectories [20, 21, 23, 24].

Strategies to support relatives and patients are also found in hospital environment and they work as networks of affection, care, support and assertion to the individual's identity beyond the pathology. Recreational activities, open visits for siblings and grandparents, hospital classes and reading programs are among such strategies.

Recreational activities should compose the scene of support networks for patients, because playful activities used as a therapeutic resource deals with social, cultural and psychological aspects. Through playful activities, experiences related to the hospital environment, such as discomfort caused by procedures, pain and fear find another communication channel. Furthermore, affection bonds and relationships are exchanged through the contact with professionals who propose such activities.

Playing is an activity that favors the creation of alliances and interactions among patients, their families and professionals, allowing the construction of a new social network and helping to decrease the sense of isolation and loneliness caused by hospitalization [25]. Regarding the child/accompanying person relationship, playing can also rebuild fragmented ties derived from the family chaos caused by the disease [26].

Including "playing" in hospitalization contexts both respects the uniqueness of each child and serves as a means of expressing their pain and their joy. Playing helps democratically transforming the hospital space by valorizing the individual's experiences and autonomy exercises [13].

In addition to recognizing children and adolescents as individuals, hospital classes serve as elements working on cognitive and skills development. Besides contributing to the education of hospitalized children and adolescents, hospital classes represent a care technology by contributing to their quality of life. This is an element of social inclusion, which recognizes patients as individuals with rights that must be preserved [27]. Such classes recognize the dignity of patients, which should be respected as well as their chronic condition. Reading programs working through the playful aspect of reading to babies, children, adolescents and their families follow the same direction. Such resources give rise to other ways of understanding the patients beyond their clinical condition, encouraging playfulness and joy.

The introduction of siblings' visits to the hospital context is another important aspect. This is a strategy that helps the sibling at home to get closer to the new family member. For mothers, it is a means of integrating the family, reducing concerns, enabling rapprochements and conversations that can modulate the experience for everyone involved in the process.

According to Morsch and Braga [28], the siblings' visit is a time of family integration. Given children's spontaneity, questions, new meanings, gestures and behaviors emerge from the siblings gathering, allowing possible barriers between the hospitalized baby and his/her relatives to be broken.

According to the American Academy of Pediatrics and the Ministry of Health in Brazil through the Children's Program, the siblings visit practice is stimulated due to its results focused on healthcare humanization, favoring bonds of affection and links among family members and the hospitalized child. However, the entry of siblings should always be accompanied by a conversation with the professionals in charge in order to clear out doubts regarding how to proceed in such moments [28].

Authors [28] reported the benefits identified in meetings that happen during the hospitalization of children and adolescents: they provide a reduction in children complaints in face of an unknown situation and, in small children, improvements can be observed in possible associated symptoms, such as: sleep, eating, and defecation disorders. Closeness among siblings helps building a sense of belonging.

Similarly, the presence of grandparents in the hospitalization context has been studied as a feature that allows the development of an extended mothering³, favoring the support for parents who usually get emotionally worn by the child's hospitalization. Since grandparents did not undergo the psychological transformation of pregnancy, childbirth and puerperium, they become key figures to offer more support [8].

The possibility of a grandmother to be present during her grandchild's hospitalization favors sharing experiences with someone the mother trusts. As for the baby, according to Braga and Morsch [8] (p. 82), *"we can make him/her [the child or baby] feel welcome to the world, to the extent that he/she will have more interlocutors to expand his/her communication skills."*

The great potential of networks formed within chronic conditions care environment is to recognize individuals and their needs, and through such recognition, produce subjectivities born from more dialogue interactions among professionals, caregivers and patients. It contributes, therefore, to rescue the autonomy of individuals involved with caregiving and of those who need it [29].

By the strategies described in the preceding paragraphs, it is possible to see the inclusion of children and adolescents as individuals with rights, as well as the recognition and establishment of affection bonds and support among individuals (professionals and family) who work with caregiving to chronic children and adolescents. Ties and bonds built through such strategies help coping with the pain and anguish derived from chronicity and contributes to sharing strategies and solutions related to them.

Therefore, professionals can also be individuals who contribute to the construction of a care network, by developing comprehensive care strategies, articulating sectors and services as well as by sharing information with family members.

³ The term extended mothering refers to the inclusion of individuals or a group of family members in contexts in which a caretaker is absent. They can support, participate and follow the pregnancy and the early baby care [7].

The role of professionals in this context is crucial and it can go beyond the institutions' walls, facilitating the articulation among services during the search for specialized references. Building a horizontal relationship with family members and a detailed knowledge of each case can assist patient and family mobilization through the health network. Favoring the conformation of such ties and the users path through the network by accessing other health care networks is a movement called by Fontes [30, p.124] as "social relay". Through "social relay", it is possible to build "networks of networks", which helps empowering the family in face of the child's chronicity.

In the study by Alves, Oliveira and Mourão [31], empowerment was analyzed according the patients, families and professionals involved in caregiving to chronic mental health conditions. As for patients and their families, empowerment comes from the experience acquired through knowledge, information and qualification on the disease. Such a concept makes sense when individuals are able to relate, talk and have more freedom to live, speak, participate and exchange experiences. As for professionals, empowerment is built by favoring patients' better understanding of their disease and of the world they live in, as well as by contributing to the exercise of their autonomy.

However, in Brazil, when people speak about networks outside hospital walls, the scenario seems to be fragile, still under construction and with little dialogue process among institutions, whether because of the almost lack of services and support actions, or because professionals do not know where and who to look for. Support networks conformation is still very limited to some professionals' initiatives in seeking for access and articulating demands to the existing services in the territories. Such scenario weakens the establishment of bonds and caregiving which could strengthen the integration among services and care levels.

In the Brazilian context of child health care, there is the "Child-Health Network". Such network was launched in the 90s and was formed by voluntary associations that recognized each other and organized themselves aiming to provide support and social monitoring to chronic children and adolescents and to their families. Moreira [32], when analyzing the associative construction based on the willingness and solidarity found in such arrangements, highlights the donation system born from it, since it is possible to recognize the role of reciprocity in relationships. Reciprocity operates in the donation process on the part of those seeking to help and of those who receive such help. The association mediates relationships and monitors benefited families by introducing sociability mechanisms among individuals. Thus, it operates on a horizontal field of relationships towards a common project, opening itself for cultivating personal relationships [32].

In order to provide a comprehensive care for children and adolescents with chronic health conditions, it is necessary to integrate services and care levels. Professionals' synergy efforts can be increased through such integration.

Network conformations, inside or outside of the services, can be understood as a means to produce association and interaction among individuals. Social capital and symbolic exchanges circulate through social networks in which professionals help each other and assist users, allowing donation to be enabled by the giving, receiving and reciprocating circuit [33].

From the public health policies perspective, in recent years in Brazil, the investment in care network conformations has been growing in view of the impact of chronic health conditions prevalence and incidence. Mendes [34] indicates the prospect of care networks articulated by Primary Health Care as a proposition for rethinking the chronic conditions care model. The main aspect in such proposition is to overcome the health system fragmentation to the extent that, through PHC, it would work in coordination with other care levels, exceeding the hierarchical pyramid vertical logic of complexity levels.

Health care networks are "polyarchic organizations of health care services linked by a single mission, common goals and by a cooperative and interdependent action. They allow a specific population to be provided with a comprehensive and continuous support, which is coordinated by Primary Health Care " [34, p. 2300]. Based on such understanding and conformation, networks would establish ways of providing a more resolute assistance to patients. It is important to emphasize that the model seeks to articulate services and provide continuous care so that the user is the center of a line of conduct. It is also important that the actions can be articulated in different levels. In addition, health professionals should not be the ones exclusively in charge of the care, since such charge should be shared among all subjects.

WHO [2] highlights that chronic conditions imply a paradigm shift not only in performing, but also in organizing and managing health activities and services in order to allow an alignment of sector policies, by emphasizing prevention based on scientific evidences and developing an articulated and integrated system focused on the patient, his/her family and community.

The requirements placed by WHO [2] and Mendes [34] concern the demands imposed by chronic conditions to health services due to the gap existing in the historically constructed health care model. However, one of the central aspects related to chronicity is at the heart of this issue: the prolongation of an incurable condition that changes the individual's life routine and that occupies the center of all social relationships [11].

The profile of a demand arising from chronic conditions concerns a kind of care that is not extinguished by the time the patient is discharged. Providing a continuous care is essential, but the unpreparedness of the other network edges results in the non-inclusion of patients in other care levels, because there are no pacts or flows to guide both professionals and users.

According to Sousa, Erdmann and Mochel [35] the comprehensive care provided to chronic children and adolescents finds little or no assistance structure to fit the demands beyond hospital walls. Similarly, there is no effective reference and counterreference system for different the care levels.

Caring for chronic conditions requires not only academic and human training and investments focused on the hospitalization process, but also the management of levels, processes and flows that compose the health system.

Support networks are not just resources to be accessed but, above all, they are means of enhancing care, indicators that measure how much the formation of bonds and support is necessary to caregivers' trajectory: professionals and family. Undoubtedly, networks represent

elements that point to health actions verticality failures and to the inevitable articulation and integration path among services and subjects.

According to Moreira and Goldani [14, p. 322], the current demands and new knowledge are shaping "new pediatrics" in which hospital-centered models are not efficient because they require greater articulation among services and care levels.

It is understood that, regarding support networks for chronic patients, there are stronger and weaker links. Some of them have greater chances of being developed and others are in an institutional radius of limited action sphere, such as family context issues. However, the more difficult the access is to networks, the greater the chance for professionals to feel frustrated in their work, since their action towards the child is limited, once they can only perform within their medical specialty.

Caring for chronic children and adolescents requires us to be able to look, understand and act in a comprehensive manner, which can only be achieved if there is a field of possibilities for exchanging, sharing as well as for establishing horizontality in services and among social actors.

As for a schematic approach, the discussion and reflection highlighted above and those that surround the Brazilian health policies scenario are shown in the Table 1. below:

Health System				
Levels of care	Primary care	Secondary care	Tertiary care	Quaternary care
Services	Family health Homecare Core support to family health	Specialized health centers, polyclinics	Hospitals and reference centers	
Care and support activities	Makes the connection with the family, longitudinal follow-up of cases, articulates local services for support, assists in the integration of chronic children and adolescents back into society through intersectoral action, supports parents in caregiving	Diagnosis exam support, between appointments, consultations with specialists	Family groups/ Sibling visits. Hospital classes/ Recreational activities/ reading programs	
Areas and support services	Diagnostic support services/ Pharmaceutical care/ Emergency care			

Table 1. Organizing the health system, levels of attention and services to help chronic children and adolescents, according to the Brazilian experience:

The health system can be organized into attention levels (primary, secondary, tertiary and quaternary) that present services able to develop the actions of their competence. The study focused in promotion, prevention and assistance in the primary health attention. Brazil stands out for its family health strategies, the family health support and homecare; all of them comprised by services that set straight contact with families in order to give follow up on the cases. They articulate the local support services and help integrating chronic children and adolescents back into society through inter-sectorial actions as well as they give support to parents on caregiving.

The secondary level regards to services and procedures that aim at giving support to primary care, especially for chronic patients' caregiving, diagnosis exams support, inter-consultations and specialized consultations. Thus, it minimizes visits at the hospital to less complex activities and helps preventing complications and new hospital admissions.

Hospitals and reference services that can develop support activities and care to chronic children and adolescents and to their families, providing them with group ludic activities, visits from grandparents and siblings, besides activities focused on the pedagogical development such as classes and reading programs are found in the tertiary and quaternary levels.

Patients and their families must be in the center of the concerns not just from the health area but from all the areas involved with taking care of these individuals (education, social assistance, support associations, among others). According to the demands from the scenario of illnesses in chronic children and adolescents, effective answers result from the inter-section of different society sectors.

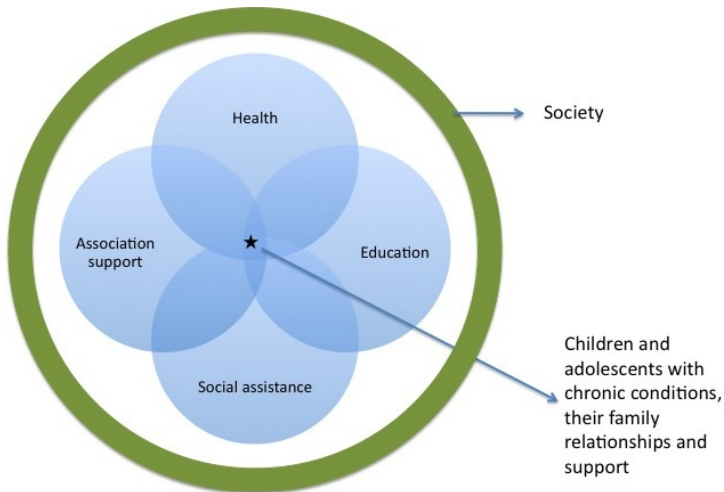


Figure 1. Picture of the articulation among society sectors focused on the care to children and adolescents with chronic conditions:

6. Final consideration

The contemporary health scenario has shown that chronic health conditions in children and adolescents do not refer to pathologies that are segregated to few groups of patients. These are health problems that cause serious effects on the lives of patients and their families, and that reorganize health services and professional practice, in general, affecting all society. Thus, they are conditions requiring the execution of a comprehensive care built by health, education and social assistance intersectorial fields.

Sociological and anthropological studies have shown that experiencing a chronic disease affects the lives of both the individuals and their family members, marking family routine management as well as patient's identity construction.

Chronic health conditions in children and adolescents should be understood beyond a demographic and epidemiological transition feature. They do not represent the end of a life, but an opening to other ways of being together in care encounters. Chronicity is a condition that can potentially create and reinvent ways of life and health. New meetings happen and, therefore, new bonds and forms of sociability and association can be built.

By understanding that chronic health conditions in children and adolescents represent different diseases which require multiple investments, promoting care and support networks helps generating greater integration among individuals, institutions and care levels.

Therefore, in this scenario, networks formation is multifactorial and multifaceted. It involves relationships among professionals, patients and their family members in whatever care context. Likewise, it requires institutional articulations which are both internal to the services that serve children and adolescents, and external, when involving other health system sectors. This set of links and bonds helps healthcare system to find solutions born from joint efforts.

The production of horizontality among individuals and institutions can generate a much more intense and rich field for knowledge and expertise exchange, allowing patients to be understood in a much more comprehensive and integrated manner. It also enables creating a kind of action that is, in fact, communicative.

In order to do so, it is necessary to revisit models used for professional training, services and health system organization so that the network perspective is a guiding principle in the exercise of horizontal actions and interactions among individuals.

Author details

Camila Aloisio Alves

Address all correspondence to: camila.aloisioalves@gmail.com

Fernandes Figueira Institute (IFF/Fiocruz) and Petrópolis Medical School, Brazil

References

- [1] Santa Roza, E. Um desafio às regras do jogo: o brincar como proposta de redefinição da criança hospitalizada. In: Santa Roza, E.; Reis, E. S. (orgs) *Da análise na infância ao infantil na análise*. Rio de Janeiro: Contra Capa Livraria, 1997, pp. 161-187.

- [2] World Health Organization. Cuidados inovadores para condições crônicas: componentes estruturais de ação: relatório mundial. Brasília. 2003
- [3] Castro, E. K., Piccinini, C. A. Implications of Physical Chronic Disease in Childhood to Family Relationships: Some Theoretical Questions. *Psicologia: Reflexão e Crítica*, 2002, 15 (3) pp. 625-635.
- [4] Silva, M. G. N. Chronic childhood: concept, prevalence and emotional repercussions. *Revista de Pediatria do Ceará*, 2001, 2 (2) pp. 29-32.
- [5] Moreira, MEL.; Bomfim, OL.; Llerena Jr, J. Esperando um bebê de risco. In: Moreira, MEL.; Braga, NM.; Morsch, DS. Quando a vida começa diferente: o bebê e sua família na UTI neonatal. Rio de Janeiro: Editora Fiocruz, 2003, p. 15-22.
- [6] Moreira, M.E.L.; Bomfim, O.L. Um nascimento diferente. In: Moreira, MEL.; Braga, NM.; Morsch, DS. Quando a vida começa diferente: o bebê e sua família na UTI neonatal. Rio de Janeiro: Editora Fiocruz, 2003, pp. 23-28.
- [7] Braga, N.M.; Morsch, D.S. Os primeiros dias da UTI. In: Moreira, MEL.; Braga, NM.; Morsch, DS. Quando a vida começa diferente: o bebê e sua família na UTI neonatal. Rio de Janeiro: Editora Fiocruz, 2003, pp. 51-68.
- [8] Braga N.M.; Morsch, D.S. Maternagem ampliada. In: Moreira, MEL.; Braga, NM.; Morsch, DS. Quando a vida começa diferente: o bebê e sua família na UTI neonatal. Rio de Janeiro: Editora Fiocruz, 2003, p. 81-98.
- [9] Piccinini, C. A. A preocupação materna primária em mães de bebês nascidos pré-termo. Dissertação de mestrado. Porto Alegre. Universidade Federal do Rio Grande do Sul. Instituto de Psicologia. Curso de Pós-Graduação em Psicologia. 2009
- [10] Pierre, A.; Kaufmann, A.; Waissman, R. Vivre une maladie grave: analyse d'une situations de crise. *Revue Française de Sociologie*, 1991, 32 (4) pp. 652-655.
- [11] Adam, P. ; Herlizch, C. Sociologia da doença e da medicina. 1a. São Paulo: Edição EDUCS. 2001.
- [12] Faulhaber, M. C. B. Enfermaria e o Adolescente. Disponível em: http://www.soperj.org.br/novo/publicacao_detalhes.asp?s=Publica%E7%F5es%20dos%20Comit%EAs&id=216. (acessado em julho, 2014).
- [13] Mitre R.M.A. O Brincar no Processo de Humanização da Produção de Cuidados Pediátricos. In: Humanização dos cuidados em saúde: conceitos, dilemas e práticas. Deslandes, S.F. (org). Rio de Janeiro: Ed. Fiocruz. 2006, pp. 283-300.
- [14] Moreira M.E.L. & Goldani M.Z. Child is the father of man: new challenges for child health. *Ciência e Saúde Coletiva*, 2010, 15 (2) pp. 321-327.
- [15] Castro LR. Da invisibilidade à ação: crianças e jovens na construção da cultura. In: Crianças e Jovens na construção da cultura. p.19-46. Rio de Janeiro: Nau Editora – FAPERJ, 2001.

- [16] Canesqui AM. Estudos Socioantropológicos Sobre os Adoecidos Crônicos. In: Olhares Socioantropológicos sobre os adoecidos crônicos. Canesqui AM (org) São Paulo: HUCITEC/FAPESP. 2007, pp.9-49.
- [17] Goffman. I. Estigma – Notas sobre a Manipulação da Identidade Deteriorada. Rio de Janeiro: Editora Guanabara, 4a. Edição. 2004
- [18] Mercado-Martinez; Hernandez-Hibarra. Chronic illness from the perspective of patients and health professionals: a qualitative study in México. Cad. Saúde Pública, 2007, 23 (9) pp. 2178-2186.
- [19] Merhy EE. Em busca do tempo perdido: a micropolítica do trabalho vivo. In: Merhy EE., Onocko R R. (orgs). Agir em saúde: um desafio para o público. São Paulo: Hucitec, 2007, pp. 71-112.
- [20] Santos de Araújo, I. F., Bellato, R., Hiller, M. Itinerário terapêutico e redes para o cuidado na condição crônica: algumas experiências. In: Pinheiro, R., Martins, P.H. N. Avaliação em Saúde na perspectiva do usuário: abordagem multicêntrica. Rio de Janeiro, Recife e São Paulo: CEPESC/IMS-UERJ; Editora Universitária UFPE; ABRASCO, 2009, pp. 203-216.
- [21] Lopes, A. F. C., Walty, C. M. R. F., Duarte, E. D., Ditz, E. S., Lopes, T. C. Práticas de integralidade e as redes sociais: possibilidades avaliativas para a construção da cidadania de famílias de crianças em condições crônicas. In: Pinheiro, R., Matrins, P.H. N. Avaliação em Saúde na perspectiva do usuário: abordagem multicêntrica. Rio de Janeiro, Recife e São Paulo: CEPESC/IMS-UERJ; Editora Universitária UFPE; ABRASCO, 2009, pp. 217-228.
- [22] Viana, V., Barbosa M.C.; Guimarães, J. Chronic disease in children familiar factors and quality of life. Psicologia, Saúde e Doenças, 2007, 8 (1) pp. 117-127.
- [23] Bellato, R., Santos de Araújo, L.F., Faria, A.P.S., Correa da Costa, A. L., Maruyama, S. A. T. Itinerário terapêutico de famílias e redes para o cuidado na condição crônica: alguns pressupostos. In: Pinheiro, R., Martins, P.H. N. Avaliação em Saúde na perspectiva do usuário: abordagem multicêntrica. CEPESC/IMS-UERJ; Editora Universitária UFPE; ABRASCO, 2009, pp. 187-194.
- [24] Costa, A. L. R. C., Figueiredo, D. L. B., Medeiros, L. H. L., Mattos, M., Maruyama, S. A. T. O percurso na construção de itinerários terapêuticos de famílias e redes para o cuidado. In: Pinheiro, R., Matrins, P.H. N. Avaliação em Saúde na perspectiva do usuário: abordagem multicêntrica. Rio de Janeiro, Recife e São Paulo CEPESC/IMS-UERJ; Editora Universitária UFPE; ABRASCO, 2009, pp. 195-202.
- [25] Mitre, R. Brincando para viver: Um estudo sobre a relação entre a criança gravemente adoecida e hospitalizada e o brincar,. Dissertação de mestrado, Rio de Janeiro: Instituto Fernandes Figueira, Fundação Oswaldo Cruz. 2000.

- [26] Mitre, R.; Gomes, R. The play promotion in the context of childhood hospitalization as a health procedure. *Ciência e Saúde Coletiva*, 2004, 9 (1) pp. 147-154.
- [27] Holanda, ER.; Collet, N. The difficulties of educating children with chronic illness in the hospital context. *Rev Esc Enferm*, 2011, 45 (2) 381-389.
- [28] Morsch, D.S.; Braga, N.M. Os irmãos do bebê. In: Moreira, MEL.; Braga, NM.; Morsch, DS. Quando a vida começa diferente: o bebê e sua família na UTI neonatal. Rio de Janeiro: Editora Fiocruz, 2003, pp. 97-106.
- [29] Duarte, MCS; Moreira, MCN. Autonomy and care in pediatric intensive care: the paradoxes of practice. *Interface*, 2011, 15 (38); pp.687-700.
- [30] Fontes, B.A.S.M. Sobre trajetórias de sociabilidade: a ideia de rede de saúde comunitária. In: Martins, PH; Fontes, B. Redes sociais e saúde: novas possibilidades teóricas. Recife: Editora Universitária da UFPE. 2004, pp.121-139.
- [31] Alves, T.C., Oliveira, W.F., Vasconcelos, EM. The viewpoint of users, families and professionals about empowerment in mental health. *Physis Revista de Saúde Coletiva*, 2013, 23 (1) 51-71.
- [32] Moreira, M.C.N. Dádiva, reciprocidade e associação em rede na área da saúde: uma perspectiva sócio-antropológica. In: Martins, PH; Campos, RBC (org) Polifonia do dom. Recife: Editora Universitária da UFPE, 2006, pp.285-310.
- [33] Moreira, M.C.N. Dádiva e rede na saúde: circuitos de troca e construção de estratégias de cuidado. In: Pineiro, R.; Mattos, RA. (Org.) Razões públicas para a integralidade em saúde: o cuidado como valor. Rio de Janeiro: CEPESC – IMS – ABRASCO, 2007, pp.301-316
- [34] Mendes, EV. Health care networks. *Ciência e Saúde Coletiva*, 2010; 15 (5) 2297-2305.
- [35] Sousa F.G.M, Erdmann A.L., Mochel E.G. Limiting conditions for integral care for a child in Brazilian primary health care. *Texto Contexto Enferm*, 2011; 20 (no. Esp) 263-71.

