
CHILDREN AND FAMILY LIVING WITH CHRONIC CONDITIONS: MESOSYSTEM IN CONNECTION WITH PROGRAM VULNERABILITY¹

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ABSTRACT: This study was aimed at understanding the perceptions of families of children who live with chronic conditions concerning the components of their vulnerability situation and relating them with Socio-Ecological Theory. This is a qualitative, descriptive and exploratory study, involving nine families of children living with chronic conditions, who were admitted to a teaching hospital in the city of Porto Alegre, located in the state of Rio Grande do Sul, Brazil, using creativity and sensitivity dynamics and content analysis. Three categories emerged and the second of them, the vulnerability of programs and their insertion into the mesosystem of healthcare institutions, is explored herein. The institutional or programmatic component of vulnerability connects the individual and the social components, involving the monitoring of prevention and care programs. It can be noted that there is a link between the ecological environment systems and the components of vulnerability situations which, when identified, allows for the implementation of healthcare actions directed at children and their families.

DESCRIPTORS: Vulnerability. Family. Pediatric nursing.

CRIANÇA E FAMÍLIA CONVIVENDO COM A DOENÇA CRÔNICA: MESOSSISTEMA EM LIGAÇÃO COM A VULNERABILIDADE PROGRAMÁTICA

RESUMO: Este estudo objetivou conhecer as percepções de familiares de crianças que convivem com doenças crônicas sobre os componentes das situações de vulnerabilidade relacionando-os com a Teoria Sócio-Ecológica. Trata-se de uma pesquisa qualitativa, exploratório-descritiva, realizada com nove familiares de crianças que convivem com doenças crônicas e hospitalizadas em um hospital-escola do município de Porto Alegre, Rio Grande do Sul, utilizando-se dinâmicas de criatividade e sensibilidade e o referencial de análise de conteúdo. Emergiram três categorias, sendo aqui explorada a segunda, vulnerabilidade Programática e sua inserção no mesossistema das Instituições de Saúde. O componente institucional ou programático da vulnerabilidade conecta os componentes individual e social, envolvendo o monitoramento de programas de prevenção e cuidado. Observou-se uma ligação entre os sistemas do ambiente ecológico e os componentes das situações de vulnerabilidade, que ao ser identificada, possibilita o incremento das ações de saúde voltadas a criança e sua família.

DESCRIPTORES: Vulnerabilidade. Família. Enfermagem pediátrica.

NIÑO Y FAMILIARES QUE VIVEN CON UNA ENFERMEDAD CRÓNICA: MESO SISTEMA EN RELACIÓN CON LA VULNERABILIDAD PROGRAMÁTICA

RESUMEN: Este estudio investigó las percepciones de las familias con niños que viven con enfermedades crónicas en los componentes de las situaciones de vulnerabilidad en relación con la Teoría Socio-ecológico. Este es un estudio cualitativo, exploratorio, realizado con nueve miembros de la familia de los niños que viven con enfermedades crónicas y hospitalizados en un hospital universitario en la ciudad de Porto Alegre, Rio Grande do Sul, con la dinámica de la creatividad y la sensibilidad y de referencia (Análisis de contenido). Surgieron tres categorías, se explora aquí la segunda categoría, Programa de la vulnerabilidad y su inserción en el mesosistema del centro de salud; La familia, como un espejo de las vulnerabilidades: la estructura de la macro se explora aquí. El componente institucional o componentes programáticos de vulnerabilidad conecta individual y social, que implica la supervisión de los programas de prevención y atención. Existe un vínculo entre los sistemas de medio ambiente ecológico y los componentes de las situaciones de vulnerabilidad, que, una vez identificados, permite el aumento de los programas de salud dirigidos a los niños y sus familias.

DESCRIPTORES: Vulnerabilidad. Familia. Enfermería pediátrica.

INTRODUCTION

This study intends to present the results of a research entitled - Situations of vulnerability and ecological environment: intersections in the day-to-day lives of families of children with chronic conditions,¹ undertaken with family members of children who have chronic conditions and were admitted to Pediatric Hospitalization Units from the *Hospital das Clínicas* in Porto Alegre, in the state of Rio Grande do Sul.

With the purpose of understanding the perceptions of these family members concerning the components of vulnerability situations and their relation to the systems described in Urie Bronfenbrenner's Socio-Ecological Theory,² three categories of analysis emerged - Family microsystem: construction of the individual component of vulnerability, The vulnerability of Programs and their insertion into the mesosystem of healthcare institutions and The family as a reflection of vulnerabilities: the macrosystem structure. The results of the second category are presented in this article.

The Socio-Ecological Theory sees the environment as a series of structures, fitted one inside the other. In the innermost level (microsystem) is the immediate environment, which the developing person is in, such as a house or a classroom. At the next level (mesosystem), there is not only the simple environment, but also the relationship between them. At the third level (exosystem), it is assumed that development is affected by environments in which the person is not even present and, at the last level (macrosystem), the idea of the whole large cultural human organization is raised, including the notion about the effects of temporality. The mesosystem relates to the set of two or more microsystems which the developing person actively participates in (for example, the family-school relations), as well as their interrelations. The processes that operate in the different environments where the person often circulates are interdependent, since they affect each other.¹⁻²

One of the conceptual divisions that operationalize the concept of vulnerability, and which is used in the present study, is the organization in social, individual and programmatic vulnerability. The programmatic component is related to the social resources that individuals need to protect themselves effectively and democratically from damages to their health. For this, the existence of programmatic attitudes aimed in this direction is essential. The greater the degree and quality of the commitment, resource, management and

monitoring of national, regional or local programs of prevention and care related to health issues, the greater the chances of channeling the existent social resources to strengthen the individuals.³

The concept of vulnerability that interconnects individual, social and programmatic aspects recognizes the social determinants of the disease and stands as an invitation to renew healthcare practices, such as social and historical practices, involving various sectors of society.⁴⁻⁵

The understanding about the context families are inserted in is essential to establish an adequate planning of healthcare actions, directed at promoting their wellbeing. The context, in which the transformation actions concerning the conditions of vulnerability are allocated, is often represented by conflicts and dilemmas that are aggravated by the fact of having their children in hospital, mainly due to a disease with chronic aspects and reserved prognosis.

Based on the above, the importance of establishing a study about the perceptions of families can be highlighted, not only about the care delivered to the children, but also about the environment they are inserted in and their relationship with it. It is expected that this research will promote discussion on the theme, because this needs constant improvement and problem-solving actions based on scientific knowledge, together with humanity, sensitivity and transforming attitudes, as these are essential tools in the daily care of the inseparable unit children-family.

METHODS

This is a qualitative, exploratory and descriptive research, undertaken in the Pediatric Hospitalization Units 10th North and 10th South of *Hospital das Clínicas* in Porto Alegre, in the state of Rio Grande do Sul, providing care to children with chronic or acute health problems, among which the following can be mentioned: congenital syndromes, endocrine and metabolic disorders, sickle cell disease, cystic fibrosis, gastric and liver disorders and seasonal respiratory diseases.

Families of children living with chronic conditions participated in the study, and nine was the number intentionally selected. The number of participants was considered sufficient, based on the information saturation criterion.⁶

Data collection took place through interviews and the construction of a genogram and an ecomap of the families, creativity and sensitivity

workshops and participant observation. The material was analyzed through Content Analysis,⁷ involving several stages briefly described below: a) Pre-analysis: stage of organization and preparation of material through exhaustive reading, choice of documents to be submitted to analysis and creation of assumptions for further analysis. The information investigated in this stage results from the following material, collected through the research activities: information about the participants (i.e. age, gender and level of education), obtained through the completion of a standard identification form, family genogram and ecomap, developed by the researcher in conjunction with the participants; observation of activities recorded in a standardized instrument; artistic productions based on the families' expressions (posters manually designed by each of them), as well as their photographic records; transcriptions of audio recordings of participants' statements taken during the workshops; b) Scanning of the material: carried out through the division into categories by aggregating units of meanings of the same semantic criteria. Therefore, the themes that represented certain meanings, when grouped, formed the categories; and c) Interpretation of the obtained data: stage in which the description of the categories and subsequent interpretation of each took place, merging the discussions between the statements, the literature, and the thoughts of the researcher.

An Informed Consent Form was presented to the participants in order to inform them about the objectives of this study and that this did not present any risks, as well as about the voluntary nature of their participation, with the possibility of withdrawal at any time without prejudice to the people involved, and anonymity was guaranteed through the use of numerical codes in the dissemination of the research results. Data collection began after approval for the research project had been obtained from the Research Ethics Committee of the Hospital das Clínicas in Porto Alegre, which was registered under number 09-081.

RESULTS

The proposal of an intersection between the Vulnerability Conceptual Framework and Urie Bronfenbrenner's Socio-Ecological Theory intends to raise questions that figure in many people's minds, reflecting the realities of society and its contemporary organization, as in this example: Nowadays, is it still possible to reduce individual

behaviors to actions considered risky, without analyzing the context in which these actions take place? Is it possible to fit an individual within a group with greater or lesser inclination to some grievance? This means accepting that the levels of the ecological environment, called systems, encompass the components of vulnerability in an encounter determined by difficulties, overcoming and translated in human existence.

Therefore, in order to provide support to these ideas, and based on the analysis of the information resulting from the material obtained in the various stages of this research, the category vulnerability of Programs and their insertion into the mesosystem of Healthcare institutions was evident, which seeks to present a similarity between Urie Bronfenbrenner's Socio-Ecological Theory² and the Vulnerability Conceptual Framework,⁴ shown in the daily routine of families of children living with chronic conditions.

The concept of programmatic vulnerability is located inside the children's mesosystem in two main areas: the first is part of the scope of the committees responsible for developing healthcare policies, and the second is related to the actions and cooperation of family members or people in charge of caring for the children concerning the transformation of a vulnerability context. The changes to life organization are the most evident in the daily routine of children living with a chronic disease and their families. The mesosystem the children living with a chronic disease are inserted in extends beyond the microsystems composed of the family unit, such as the school or the community, to include the hospital world and the peculiarities arising in the therapeutic process.

Children living with chronic conditions, when entering the hospital world, do not only extend the constitution of their mesosystem. When starting a continuous treatment, associated with frequent hospitalizations, outpatient care appointments, close contact with several healthcare professionals, children and their families are faced with the weaknesses concerning the organization of the current healthcare system and its impacts, mainly when this involves people who have a lack of or no financial resources.

The microsystem formed by the hospitals reflects the difficulties of the programs and policies that govern it. It is immersed, and often submerged, in what can be called situations of programmatic vulnerability, that is, when healthcare services have an inappropriate resources manage-

ment that compromises the commitment to their organization and quality.⁴

The institutional or programmatic component of vulnerability connects the individual and social components. It involves the level and quality of the commitment, resources, management and monitoring of national, regional or local prevention and care programs, which are important to identify needs, channel existing social resources and optimize their use. The programmatic component makes us place the educational dimensions beyond the normative and object-centered nature, leading to the articulation between healthcare interventions and programmatic actions and, specially, to the reconsideration of healthcare as an encounter of individuals.⁸

Situations of programmatic vulnerability, or rather, their translation in everyday healthcare delivered to people, have a close relationship with many other aspects of society's organization, being these financial, geographic or cultural.⁴

In answering the questions presented to them about the facilities, difficulties, needs and support in living with chronic conditions, in their daily lives, the families could point out a direct proportionality between the limits and the possibilities in healthcare for children and families, which are perfectly expressed in the statements of the study participants.

The first aspect that emerges from the participants' statements relates to the programmatic vulnerabilities and their inclusion in the children's mesosystem. This happens in relation to the access to healthcare services as a vulnerability factor for the families because many of them are forced to travel from an interior town to a center located in the state capital for the treatment of a particular disease, often travelling long distances, using improper transport facilities and along poorly maintained roads, thus being exposed to several uncomfortable situations and risks.

The participants reported their frustration for not having healthcare institutions capable of providing them treatment in their home towns, or at least some support, direction and appropriate referral, conducted in an ethical and equitable manner for all patients. These situations are shown in the statements:

[...] first of all, the distance, due to the fact that I live very far, not only me, but many people whom I have spoken with. Until she [child] has come here, I thought it was something. I had never been to Porto Alegre. And when I came here, she was two months

old, now she is four. Look, in these trips I have made, in the middle of fourteen people inside a van to get here, I have met people who went through things that I had not even imagined going through (P. 3).

[...] in the healthcare institutions, I think the following: things change from place to place. For example, where I live, in the countryside, this is a serious problem. I think that if it is for one, it is for all. And this does not often happen there (P. 4).

The difficulty in accessing healthcare services is an important factor of vulnerability.⁹ Thus, vulnerable are all of them who have lost the right to live, to be provided with education and healthcare, or those who have the conditions to do these things threatened. That is, these people not only suffer from the lack of access to institutions and services, they are also affected in their dignity and right to life.¹⁰

The limited access to services makes the children victims of a situation that is beyond their control. This access can result from the responsibility of public healthcare policies and/or from the circumstances of families, which result from their personal characteristics, such as cognitive abilities, degree of accountability for the health and wellbeing of their children, or even from the lack of clarification concerning the paperwork required for the effective use of healthcare services.

However, healthcare services do not always present difficulties and challenges. In praising the care received in their hometown, the participant shows, in the following statement, how essential it is for the children and their families to receive effective information and actions directly in the town where they live. Even if in their hometown there is not the medical solution for the demands of the disease, the way in which the referral among services is conducted makes access easier, reduces the burden of stressful situations and permits attention to other important factors, such as the emotional aspect of the children and their caregivers.

Institutional assistance is what I represented here [drawing] as an open door. We had assistance. When we were there [hometown], for example, she [mother] called here [hospital] and said: 'look, the baby has problems' and they were already referred to the doctors there [hometown] and the doctors here [hospital] already gave the instructions. And over there, they had never heard about this, because over there this disease does not exist. As for finding a doctor, it was not difficult, we had more facilities to get to the current date, which was the transplant (P. 7).

Precariousness and scrapping are characteristics of some healthcare institutions the families

met on their journey in search of quality care for their children. In these places, the programmatic vulnerability situations are present in the way care is delivered, or in the physical structures and organization of the hospitals and healthcare units. The following statements demonstrate this situation:

[...] *SUS in my town is chaos. You cannot get one exam done through SUS. You cannot get a consultation through SUS. It is hard to get a guaranteed thing. Until we got to a place that investigated, that was concerned about it. Because it is like this in my hometown. The important thing for them is not to find out the reason. In my hometown, they do not believe in prevention. I believe this does not only happen in my hometown, but in many others too* (P. 3).

[...] *twenty years ago, we could choose what doctor we wanted to see, or go to the Public Healthcare Centre where he/she worked. I have treated my children only with the doctors from SUS. Look, you [participants] stop thinking that SUS is very bad. SUS is not bad. But it depends on its structure* (P. 1).

In addition to the states not having an appropriate distribution of institutions capable of providing care in relation to chronic conditions – in particular the rarest ones – families are forced to face situations, such as professionals' lack of skills and knowledge concerning their children's diseases, which causes anxiety, insecurity and increases the suffering and difficulties they go through.

There are many people who regularly face several difficulties, especially regarding planning and resources, in order to perform their duties with conscience and dignity and to minimize situations of programmatic vulnerability. The actions of the professionals are crucial, especially when healthcare services, and consequently their users, receive their effects. Each professional is a member of the children's mesosystem, since the institution they work for and their work become part of their families' and their own environment. Based on this, their characteristics can be considered as defining of this system.

In some places, the lack of financial resources, as well as the material and technical precariousness are likely to have greater significance. Even inserted into this context, the effective communication between healthcare professionals and patients can contribute to the quality of care and treatment, thereby generating improved health. In other words, more cultural and linguistically sensitive interaction between healthcare professionals and patients can cause an improvement

in terms of prevention, diagnosis, treatment and management of healthcare actions¹¹.

The families, even immersed in situations of pain, difficulty and suffering, often feeling abandoned and without means to solve the problems caused by chronic conditions, show to be very thankful and valued as a result of the care received at healthcare units. In this organized context, there are skilled healthcare professionals who are concerned with the children's wellbeing. These institutions represent a safe place in the lives of these families and many of them show their gratitude for the meal served to them, for the word of explanation addressed to them, in short, for all the care that is provided to them. The participants understand this as "something good that is done for them", as it is pointed out in the following statements:

[...] *you have support to face your difficulties. Being them doctors, nurses, maids, all of them, because nobody works alone, it is a team. I see that everything moves and circulates around benefits to the patients. I am generally thanking everyone [cry]. We see the dedication of the nurses in teaching the children. She [child] had to learn to carry out insulin injections, she [child] needed courage [cry], needed incentive to inject herself. Through their work [healthcare team], we get inside their lives and are part of each other's lives. This is real life, and it is living. And if it were not like this, it would not be worth it* (P. 1).

[...] *here [hospital] they do not only provide assistance to the children, they also provide it to their mothers, to their caregivers. We have a lot of support and professionalism. Thanks God, they are very important people to us. They always try to explain everything to us and nothing very hard to understand, always in a language we can understand. They always respect our pain a lot, our sorrow. In the joyful moments, they celebrate with us. Just by the fact that you know they will give you one meal in the morning, one at midday and one at night, which is what the body needs. Otherwise, people can pass out in the corridor and they need to be strong to face all these days. This is very important* (P. 5).

Health professionals who interact daily with hospitalized children and with the difficulties the families face, often lacking not only financial resources, but also hope and strength to face their children's disease, are aware that they need to adapt their conduct to the life context, to the features of each family member, with a view to effective treatment and a successful medical process. The demonstration of concern with the context

each family lives in and the manner in which they develop health care is a practical example of the performance of the healthcare team. This action goes beyond the lack of resources or the deficit in public health policies: it results from an individual performance and commitment.

Professional Nursing, for example, when approaching each family's reality, has the ability to promote an identification of needs and difficulties, thus establishing a strong bond and a trust relationship, which provide effective support. This situation is confirmed when families become the focus of care, when all members are valued and invited to participate in the care for the children, thus contributing to a supportive and beneficial environment for the children's growth and development, beyond the limits imposed by the situations of programmatic vulnerabilities.

Caring is a practice naturally performed by human beings. Being concerned about someone, loving, respectful, careful, are some adjectives that define care. For healthcare professionals, including nurses, caring is to be open to others, to use technical-scientific and expressive knowledge, to interact with others with respect, sensitivity and expressing themselves through touch or look.¹²

Considering the humanization of healthcare practices means to consider the value of the various stakeholders in the healthcare process: users, workers and managers; to promote the autonomy and the role of these people, to increase the degree of co-responsibility in healthcare management, to establish bonds of solidarity and collective participation in the management process, to identify the social needs of healthcare, the changes in the care and management models of working processes, aimed at the needs of citizens and the promotion of health¹³.

FINAL CONSIDERATIONS

Whilst proposing a reflection throughout this article about the situations of programmatic vulnerabilities inserted in the mesosystem of children living with chronic conditions, in the first place, the difficulties are noted that result from the implementation of public health policies, healthcare programs and actions directed at grievance prevention. However, some considerations can be made herein with regard to the origin and formation of these vulnerability situations.

The main one leads to the view that programmatic vulnerability is a consequence of the

combination of individual vulnerability situations. Programmatic vulnerabilities are a reflection of human actions, performed by people who have the duty of constructing, implementing and evaluating policies and programs with practical application in the daily reality and organization of healthcare services.

The approach built on the notion of programmatic vulnerability recognizes the insufficiency of isolated interventions in producing significant changes in the health of population groups and stimulates the development of actions that address a wide range of needs. Therefore, it strengthens a work process based on the complex integration of individual and collective actions, remedial and preventive, articulated in a care system in progressive levels of actions.¹⁴

The individual component of vulnerability is constructed and constructs the programmatic component in a bidirectional relationship that leads our thoughts to the level of individual responsibilities. The components of vulnerability situations, as well as the systems of the Socio-Ecological Theory, present a relationship of mutual belonging and construction.

The experiences of families showed the human dimensions that caused reconsideration of actions and of the meaning of existence as a whole. Therefore, it should be mentioned the importance of research in relation to the ecological environment theme should be mentioned and, above all, about the individual, programmatic and social components of vulnerabilities.

Studies about families of children living with chronic conditions, and which value their thoughts and expressions, are relevant to the quality of care. The investigations concerning issues that relate the Vulnerability Conceptual Framework and the Ecological Environment constitute the basis for deeper and better reflections about this subject, and also turn into actions that, when implemented, are of great value for professional practice, mainly for improving the living conditions of the children and their families, which is the primary reason for their development.

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