

## Governance and support from the secondary social network in health care for children and adolescents with chronic diseases

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**Abstract** *The objective of this qualitative study was to analyze the structural characteristics of the governance system and support offered by the secondary social network in health care for children and adolescents with chronic diseases. The study was carried out at Family Health Strategy (FHS) units, a specialized outpatient clinic, and a public pediatric hospital in João Pessoa, Paraíba, Brazil, from February to October 2013, using semi-structured interviews and focus groups. The participants included six managers, 14 health professionals, and 12 family caregivers of children or adolescents with chronic diseases. The data were analyzed according to the principles of thematic content analysis. The governance system found in health care for children and adolescents with chronic diseases was collaborative. Additionally, the limitations of managerial public governance were clear, weakening the secondary social network with repercussions regarding the support offered to the family and cooperation between services. This reality can have a negative impact on the quality and effectiveness of the care provided to children and adolescents with chronic conditions, as it does not meet the real needs of this population.*

**Key words** *Chronic disease, Clinical governance, Comprehensive health care, Pediatric nursing*

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## Introduction

In the health care network (HCN), the term “governance” is defined as an organizational arrangement composed of different institutions responsible for formulating strategic decisions. These institutions organize and coordinate interactions between their actors, the ground rules, and principles in order to generate a cooperative surplus, increase interdependence, and obtain effective economic results to promote the health care of the population<sup>1,2</sup>.

In health care, three governance systems are particularly noteworthy: clinical, public, and collaborative governance. Clinical governance is defined as a structure through which health service organizations take responsibility for continuously improving the quality of their services and maintaining high care standards by creating an environment where excellence in clinical care prevails<sup>3,4</sup>.

According to the organizational arrangements of the HCN, the public governance system can be institutional, managerial, or financial. Institutional governance is represented by the managing bodies of the Unified Health System (SUS), Brazil’s public health system. Managerial governance is carried out through the structuring of groups in charge of thematic HCNs, which make diagnoses, establish priorities, and design HCNs. These are implemented through regional action plans, whose financial governance delineates the budget and allocation of financial resources for health care providers involved in the plan<sup>5</sup>.

Collaborative governance, in turn, can be defined as the set of instruments that facilitate the coordination and execution of activities shared by the actors involved in networks. These activities – developed in partnership – are carried out with the aim of guaranteeing access to health actions and services with a medium to high level of technology, necessary for the comprehensive care of the users, through referral centers or according to local agreements, and considering the risk stratification and clinical guidelines defined by the federal, regional, or local management<sup>6</sup>.

Another network of sharing involved in collaborative governance is the social network. This is understood as a set of interpersonal relationships that determine a person’s characteristics, such as habits, customs, beliefs, and values, and helps minimize the demands of caring for and coping with chronic illness. This network can provide emotional, material, and informational support to people with care needs of the social network<sup>7</sup>. One

study<sup>8</sup> indicated that the lack of this assistance by the social network ultimately accentuates the difficulties in coping with and caring for health, particularly in the case of children and adolescents with chronic diseases, resulting from the need for lifestyle changes and alterations in the family routine.

While family, friend, and neighbor relationships characterize the individual’s primary social network, contact with health institutions represents the relationship established with the secondary social network<sup>7</sup>.

In Brazil, the HCN of people with chronic diseases is one configuration of a secondary social network of SUS services, whose objectives include evaluating comprehensive health care for people with chronic diseases, promoting and expanding strategies for health promotion and protection, and preventing complications, as well as diagnosis, treatment, rehabilitation, harm reduction, and health maintenance<sup>9</sup>.

The components of the HCN of people with chronic diseases include basic care services; specialized outpatient clinics; hospitals; support, logistics, and regulatory systems; and the health governance system<sup>9</sup>. However, the provision of these services is not always compatible with the real demands. Furthermore, there are weaknesses in the agreements between the HCN actors in terms of ensuring operational viability and the financial resources necessary to provide all the support that this population needs<sup>10,11</sup>.

Considering that chronic health conditions demand continuous care and frequent interventions by health professionals, in addition to prompting lifestyle changes, particularly for children and adolescents, these weaknesses have a negative impact on the quality of life.

This is a worrying reality, as the significant increase in chronic diseases in childhood and adolescence is a serious public health problem. A study carried out in the United States revealed that 23.6% of the population aged 3 to 17 years had one or more chronic condition(s)<sup>12</sup>. In Brazil, a national study showed that the prevalence of chronic diseases is high and associated directly with increased age; they were observed in 9.1% of children aged 0 to 4 years, in 9.7% of children aged 6 to 13 years, and in 11% of adolescents aged 14 to 19 years<sup>13</sup>. In light of this reality, national<sup>14,15</sup> and international<sup>16</sup> studies have identified challenges that must be overcome in order to build a care model that responds to the unique characteristics of this population.

In this sense, it is important to carry out studies on the arrangements of health governance and

the support of social networks, as they can provide assistance to better confront the challenges inherent in the organization of services and the knowledge of the HCNs' ability to effectively respond to the health needs of children and adolescents with chronic diseases.

The objective of the present study was therefore to analyze the structural characteristics of the governance system and support offered by the secondary social network in health care for children and adolescents with chronic diseases.

## Methods

A qualitative descriptive study was conducted, whose construction and analysis discuss the findings from the perspective of health governance, as organizational, political, and social network arrangements.

Data were collected between February and October 2013, first at a tertiary referral hospital for the treatment of children and adolescents with chronic disease in João Pessoa, Paraíba, where the families were initially seen, and then at Family Health Strategy (FHS) units. The hospital is a public, non-profit institution that provides care and supports teaching, research and outreach, offering both hospital and outpatient services. The participants were 12 family caregivers, 14 health service professionals, and six managers in the municipal health network.

The inclusion criteria for the family caregivers were being over 18 years old and being primarily responsible for caring for a child or adolescent with a chronic disease. Caregivers of a child or adolescent who had been diagnosed with a chronic disease less than one year prior were excluded.

The family members included nine mothers, two aunts, and one father, ranging from 23 to 45 years of age; two were illiterate, seven had eight or less years of education, and four had more than eight years of education; three were employed, one was unemployed, and eight were homemakers. Half of the families lived in the municipality under study and the other half lived in other municipalities in the state. The chronic diseases of these children/adolescents included thalassemia; asthma; chronic renal failure; laryngotracheomalacia requiring tracheostomy; liver cirrhosis; chronic liver disease; HIV; Tay-Sachs disease; congestive heart failure; heart disease; rheumatic fever; mental retardation; cerebral palsy; esophageal atresia; systemic lupus erythematosus; tu-

berculosis; depression; and cystic fibrosis. The time elapsed since diagnosis ranged from one to ten years, and half of the patients had more than one chronic disease. The ages of the children/adolescents ranged from one year and five months to 17 years.

The inclusion criteria for the health professionals were having worked in the position and service in question for at least six months and being a nurse or doctor responsible for serving children/adolescents with chronic diseases, or, at the FHS, being a community health agent. In total, there were nine professionals from the FHS and five from the hospital, of whom two were from the outpatient clinic and three were from the pediatric clinic. Among those who worked at the FHS, there were three professionals from each position (doctor, nurse, and community health agent); the employment time of the community health agents ranged from 1.5 to 9.5 years, while the nurses had an average of six years, and the doctors had between one and five years. At the hospital, there was one medical resident, with an employment time of two years; a doctor, who had been working for 10 years; and three nurses, with between five and 13 years of employment time.

The managers were selected according to the following inclusion criteria: working in the field of child and adolescent health and having been in the position for at least six months. Five of the managers had degrees in nutrition and one had a degree in physical therapy; they had been working in their management position from one to 4.5 years.

Semi-structured interviews and focus groups were used with the caregivers, both guided by the trigger question: "What HCN services were sought out by the family and what did each one do to help them care for the child/adolescent with a chronic disease?" The caregivers living in the municipality under study indicated the FHS services for their coverage area, and the researcher visited these services in order to interview the health professionals. The other professionals in the HCN and the managers were selected randomly, according to the inclusion criteria of this study.

The guiding question of the semi-structured interview for the health professionals in HCN services was, "Tell me about caring for the child/adolescent with a chronic disease and their family in the service where you work"; for the managers, it was, "What is your perception of health care for children/adolescents with chronic diseases in the municipality?"

Data collection was concluded when the empirical material collected was considered sufficient to draw a comprehensive picture of the reality explored<sup>17</sup>.

All material produced was subjected to thematic content analysis, and the data were triangulated; the different views of the participants were integrated in order to develop the analysis structures around issues central to the study object and construct the empirical categories in three stages: pre-analysis, with an exhaustive reading for an initial organization of the empirical material; coding and construction of the themes and categories; and, in the last stage, the final analysis with an interpretation of the results<sup>17</sup>. Based on the analysis, two categories were constructed: governance in health care for children/adolescents with chronic diseases, which addresses the respondents' perception of the type of governance system for care in the HCN; and institutional support for care, referring to the type or lack of support offered to families seeking services at the three levels of health care.

The study followed ethical research principles and was approved. All participants signed a free and informed consent form. To ensure anonymity, the participants were identified by letters, with C for caregivers, P for professionals, and M for managers, followed by an ordinal number. In the case of caregivers who participated in one of the two focus groups, totaling nine members, the letter G and the number corresponding to the group were included after the letter C (CG1 or CG2).

## Results

### Governance in health care for children/adolescents with chronic diseases

Health care for children/adolescents with chronic diseases included aspects of collaborative governance, which involves interventions by different actors, including professionals working in the HCN and local managers, who carry out their actions based on regional and national health policies.

Although there is recognition of the importance of welcoming and advising the family, as well as cooperation among actors from different care levels, in the managers' perception, the care pathway needs to be expanded beyond actions focused on monitoring child care, given the specific problems of children/adolescents with chronic diseases and their families.

*The care pathway of children's health still needs to move just a bit beyond growth and development and really expand to the issue of comprehensive care. [...] The thematic area is still very focused on the programs that the ministry recommends, although a child with chronic illness has not stopped being part of that universe (M3).*

*At the beginning of the year, WGs [work groups] [...] have an annual planning session for the care pathway and meet monthly to develop and discuss these actions in the municipality, usually with a backer [manager] from each district and people from the Health Department in the thematic area. [...] one of the first things I asked myself was, why isn't there a WG for children's health? There isn't one for children's health because it's already part of the Health in School Program [Programa Saúde na Escola - PSE]. [...] Children's health care has been limited to school activities and childcare consultations [...] in terms of chronic diseases, I don't see that kind of up-close monitoring or greater assistance for the mother; instead, it's as if they'd rather refer them to a more competent service and be rid of all responsibility (M5).*

One of the challenges in the planning and continuity of care is the condition of social vulnerability, which affects the professionals' ability to problem-solve.

*In the case of [a child with sickle cell anemia], there are two unemployed adults in the family and two children, one who is two years old, who has sickle cell anemia, and another who is eight months old. They have no income... I've communicated with them, brought the nurse and case manager there; we even managed to register them for food assistance. [...] but even so, it's losing a lot of consults medical for child is, because there's no way for them to find transportation. [...] there are problems that haven't been solved (P4).*

Another challenge to ensuring the continuity of care and effectiveness of the governance system is related to difficulties in interactions and a poor flow of information among primary care, specialized, and hospital professionals, which interferes with their cooperation and the pursuit of a collaborative solution to problems:

*[...] there is still a huge drop-off when the child moves from primary care to specialized care, because sometimes they leave and don't come back with the right information. We don't know what was done with that child's care; the procedures, the advice, sometimes it doesn't come in the correct form; the system becomes weak because the instrument hasn't been filled out correctly [...] It's difficult for you to remove those people or make*

them aware that their work involves a much larger context (M4).

The governance system involves a shared management between the different actors in the HCN. However, according to the participants, this cooperation is not always present, and when it is, it is weak, disjointed, and based on an exchange of favors.

*When they're discharged, I work out a system for them to return, either to me or to the outpatient clinic. Here, we don't have a post-discharge outpatient clinic, which is a failure in our pediatric service. [...] When it's a patient of a specialist, [...] when they're discharged, I bring them to the specialist. [...] and when it's someone who doesn't have anyone to care for them, I ask them to come back, I give them an appointment, and receive them here. If I have to do an intake exam then I do it, but it's also wrong to do it that way because it doesn't go in their chart. It's just one more good deed that might not actually be worth it. [...] when the network functions, it's a network that functions through favors. I call a colleague who works in neurology somewhere and they will receive my patient, because I can't get them received here. Or, we use NGOs [non-governmental organizations]. They are our plan B, which we carry out according to our influences (P6).*

*[...] I took all the documentation and went with her to the Family Health Program [Programa Saúde da Família - PSF]. I talked to the head nurse, who said she could schedule an appointment in about 15 days because it was very difficult to make an appointment with a hematologist; it would take a long time through the SUS. We got in touch with my cousin who works at [public hospital] and knows Doctor [hematologist]. She called his clinic, told him about the situation, and he told us to come in the next day (CG2).*

In the managers' perception, the lack of evaluation indicators also undermines the monitoring and management of cases:

*[...] there are no indicators for the health of children with chronic diseases. [...] I think the municipality is still very poor in this area (M5).*

In addition to conditions of social vulnerability, cooperation between the different care levels, and the organization of indicators that support governance in health care for children and adolescents with chronic diseases, the organization of the transportation system is also essential, in order to facilitate the flow of these children/adolescents through the HCN services, particularly those with a precarious socioeconomic status or who live in another municipality. However,

this is not a simple procedure, as this service is not always available to the population, and it is sometimes necessary for the transportation to be appropriate for the chronic illness.

*There's a 16-year-old boy with chronic neuropathy who isn't making progress in his development because he's bedridden and needs transportation to be available every day. [...] for physical therapy alone, he would have to go three days a week, and he needs to be at [philanthropic institution] every day, and in the municipality there is no service available that supports the family in this aspect (P10).*

In addition to this transportation difficulty, an ignorance of the flowchart for referring chronic disease cases also interferes in the health governance system.

*I don't know the entire care network, or the flowchart that must be followed. [...] We have been referring them almost randomly [...] (P12).*

#### **Institutional support of the secondary social network for care**

The support offered by the secondary social network, characterized primarily by the public services of the HCN, was centered on material support and the availability of professionals to provide care at the EFS unit or in the home.

*[...] because she [the child's grandmother] has a friend, and through that friend, she was able to get his [child with tracheostomy] supplies; otherwise, he would already be dead, waiting for the supplies. Fortunately, the hospital provides all the supplies he needs (CG1).*

*Sometimes they're discharged and they don't have money to buy the medication; we go to the pharmacy [at the hospital] and we talk, we explain the family's situation, and we get the medication [...]. It isn't routine for the hospital to give medication to all the children who are discharged, and especially to those who have financial constraints (P5).*

*[...] they asked for all kinds of tests and found that he had chronic anemia. So then he began to be monitored by the doctor at [hospital], and he was very well cared for. After I began to follow-up with her, he didn't need hospitalization anymore. She would take care of him at home, I would give him the medications, and any time I needed, I could call and she was available (CG1).*

The availability and support offered by the professional from the specialized service was also helpful when there was a need to hospitalize the child/adolescent.

[...] *Truthfully, I haven't found any other doctor like him, because it isn't just any doctor who gives his phone number to a patient's mother, and we call him and it isn't a big deal; he doesn't cringe. Recently, I was at [hospital]; they didn't have a bed open, I was waiting for a bed to open up, and I called him. He immediately got a bed for her and told her to come in on Monday* (C3).

Although the support of the HCN is recognized, there are still gaps in this support system for family members, and the professionals or the users themselves use the informal network or the bonds of friendship to be able to schedule tests, find a bed at a hospital, or make appointments with specialists, as well as obtain help solving any problems that might come up when caring for children/adolescents with chronic diseases.

*Sometimes, we get children who [...] need a CT scan and it's taking a while to have it done. We get in touch with colleagues who work in other services and expedite these tests, marking them as urgent. [...] So we make an effort in the sense of seeing what the child needs* (P1).

*Doctors sometimes circumvent hospital regulations to try to expedite the process. They say the child has been hospitalized and needs to have an ultrasound, so that the appointment will be sooner. [...] They are discharged, then they come back the next day to have the test [...] Sometimes, it's a child who has a chronic illness and they don't need to be hospitalized unnecessarily* (P5).

Other obstacles identified in the support of the secondary social network are the difficulties in accessing some health services, the time elapsed before the disease is diagnosed, and the lack of specialized services distributed equally throughout the state, resulting in the family needing to move to another city/state for their child's treatment, affecting their routine.

[...] *when they saw me at five o'clock in the afternoon, they told me to go to [private pediatric hospital], which is private and expensive, knowing that I couldn't afford it. [...] I went with all the tests, [...] really, it was all private and expensive for me, and I couldn't afford it. So I was desperate, it was six o'clock at night, because I live in the interior of the state and I didn't have a car to go home that late. [...] It was six o'clock at night and the security guard came in and spoke to the doctor, who is a kidney doctor [...]. I know he had very good intentions towards me. So I went and he made the referral quickly, signed it, and admitted my daughter to the ICU* (CG1).

*Not all of them discover [the diagnosis], and that was my case. They sent me home to prepare for*

*the burial. [...] So I got on the radio and found a bed at [hospital] in São Paulo. We discovered that it was cirrhosis and a liver transplant was needed* (CG2).

[...] *I had to leave my house, my husband, everything, to come here and live at the hospital [laughs]. There's a hospital in my city; if the structure is present, why not be hospitalized there? [...] Everything is concentrated here [in the capital]. So I believe that we need more investment because everything is concentrated in one place* (CG2).

## Discussion

The practice of health governance is a complex process that involves the inclusion of governmental and non-governmental actors at the primary, secondary, and tertiary care levels<sup>1,18</sup>. This study highlighted aspects related to the type of governance exercised by professionals from the primary and tertiary levels of the HCN, in the planning and development of actions for the care of children and adolescents with chronic diseases.

Although Ordinance 483/2014<sup>9</sup> defines the responsibilities of each component in the governmental sphere of the HCN for people with chronic diseases, emphasizing the need for integration and connectivity between the different care points, one study<sup>11</sup> identified limitations in terms of cooperation between professionals and their preparation for caring for children and adolescents with chronic diseases, corroborating the findings of this study.

From the participants' perspective, the governance system was collaborative, defined based on shared relationships among professionals, managers, and users caring for children and adolescents with chronic diseases. This is the most common type of governance system in the HCNs of the SUS<sup>1,6,19</sup>, although equally essential in this network are the definitions of care practices and protocols, established by clinical governance and the institutional, managerial, and financial arrangements organizing the managing bodies of public governance<sup>4,5</sup>. Health care networks are organized and operationalized through the establishment of care pathways, in order to define the actions and services that will be offered by each component and express care flows according to the health needs of people with chronic diseases<sup>5</sup>.

Although the establishment of care pathways is a great achievement of the current national health policy, there is a lack of specific procedures for the referral and treatment of chronic diseases

in the field of child/adolescent health. The focus is still on acute situations, rather than chronic conditions<sup>20</sup>. This study thus demonstrates the need to expand care pathways to address the health of children and adolescents with chronic diseases, now limited to the work groups of the Health in School Program.

The social vulnerability of much of the population using public health services—demonstrated by the lack of resources, transportation, a defined flowchart, and materials needed for treatment—hinders the care practices of professionals and continuity of care in the home.

This underscores the value of governance and the support provided by social networks for confronting the challenges inherent in the organization of actions and services with low, medium, and high levels of complexity, in order to respond to health needs and ensure humanized care for the population<sup>21</sup>.

The lack of cooperation between professionals from different care levels—demonstrated by the gap in the referral and counter-referral system—is another challenge of collaborative governance, which should create mechanisms facilitating communication between the actors in the HCN, in order for them to share decisions and responsibilities<sup>22</sup>.

Given the weaknesses in the shared management of care for children/adolescents with chronic diseases, the informal pursuit of specialized services—through contact with friends—becomes an option for both users and professionals.

One study<sup>18</sup> corroborated this finding by stating that the governance system is also involved in the informal activities of people or non-governmental organizations, which take on certain behaviors in order to meet their needs or respond to their demands. However, another study<sup>23</sup> emphasized that a care network should not be composed solely of these relationships; it is essential to have institutional support through a confluence of political and socioeconomic elements, as well as to share risks and processes from the perspective of the HCN, in order to ensure the continuity of care.

Another important aspect in regional planning for effective interventions in the HCN consists of improving the mechanisms for monitoring and evaluating the actions carried out in the network<sup>5</sup>, as the managers emphasized.

As one of the components of network governance, primary health care is considered the coordinator of care, responsible for meeting the users' needs and optimizing the services provided

and access to other services, as well as promoting health and strengthening the social networks of the population being served<sup>9,22</sup>.

In the perspective of health governance, the support offered by the secondary social network is essential to the care of children/adolescents with chronic diseases. In the present study, this institutional support was primarily material and emotional, enabling access to medications and the hospital network and establishing a trusting relationship between the family and the health professional.

Studies<sup>24,25</sup> have shown that, when planning care for people with chronic diseases, it is increasingly necessary for the professional to consider issues such as social support and networks, comprehensive care, health education, and recommendations for self-care, which is an element that will allow them to adapt to their new condition and, consequently, improve their quality of life.

In addition to the need for the family to adapt to changes in their routine, a chronic health condition also involves professionals acting as protagonists of governance and having a conception of networking, in order to strengthen inter-sectoral relationships and the connections between different actors, directing resources for the benefit of the population being served<sup>26,27</sup>. This way, the governance practice of the HCN for children/adolescents with chronic diseases will also be strengthened.

In short, the main barriers to governance identified in this study, at the level of health care for children and adolescents with chronic diseases, refer primarily to the absence of work groups and evaluation indicators, hindering the effectiveness of the care pathway and the planning of actions. Furthermore, the lack of continuity in care—in relation to the referral and counter-referral flow and cooperation between services—is associated with the social vulnerability experienced by families, which are also aspects that should be valued by health governance as factors essential to a quality health system.

It should be noted that the difficulties found in this study resemble other life cycles<sup>25,28</sup>, implying the need to make the agents working in the HCN aware of the necessity to rethink the modes of caring for people with chronic diseases.

One limitation of this study is the limited number of participants, which means that the results cannot be generalized. However, the study has expanded the understanding of the factors involved in the governance system and the support provided by the secondary network, with regard to

care actions for children/adolescents with chronic diseases and their families.

### **Conclusion**

The results showed that the governance system in health care for children and adolescents with chronic diseases was collaborative. However, given the care needs of this population, the secondary social network showed weaknesses in regard to support for family members and cooperation between the services. This is due to the limited managerial public governance system, emphasizing the need to implement policies and expand care pathways.

Despite all the advances in the expansion of the primary care network and organization of the other components of the HCN, in the daily routine of the services, strengthening the support and access offered to the families of children/adolescents with chronic diseases is one of the challenges to ensuring the continuity of care and problem-solving.

It can be concluded that the weaknesses in the governance system and in the support provided by the secondary social network can have a negative impact on the quality and effectiveness of the care given to children and adolescents with chronic conditions.

### **Collaborations**

VM Nóbrega and MHN Souza participated in the study conception and design, analysis and interpretation of the data, and in drafting the final text; MM Santos and MEA Silva participated in the analysis and interpretation of the data and in drafting the final text; and N Collet participated in the critical review and in drafting and approving the final version.



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