

## Referral and counter-referral of children in chronic condition: perception of mothers and secondary care professionals

*Referência e contrarreferência de crianças em condição crônica: percepção de mães e profissionais da atenção secundária*

*Referencia y contrarreferencia de niños en condición crónica: percepción de madres y profesionales de la atención secundaria*

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### ABSTRACT

**Objective:** to identify the effectiveness of the referral and counter-referral system for children with chronic conditions as perceived by mothers and care personnel of specialized care services. **Method:** this qualitative study conducted semi-structured interviews of mothers and specialists at specialized care centers of a state capital in Brazil's Northeast, between December 2018 and March 2019. **Results:** as referral has been instituted in the Family Health Strategy as indispensable criterion for scheduling appointments, referral is effectively in place. However, the specialized care services are not counter-referring, as this is not required in the health system. The specialists fail to complete the counter-referral form, making it ineffective and hindering continuity of care. **Conclusion:** health personnel need to recognize that counter-referral is a tool fundamental to longitudinal care that meets the health needs of children with chronic conditions.

**Descriptors:** Child; Mothers; Referral and Consultation; Chronic Disease.

### RESUMO

**Objetivo:** identificar a efetivação do sistema de referência e contrarreferência de crianças em condição crônica na percepção de mães e profissionais dos serviços especializados. **Método:** estudo qualitativo, mediante entrevista semiestruturada, com mães e especialistas em centros de atenção especializada de uma capital do Nordeste, entre dezembro de 2018 e março de 2019. **Resultados:** por ser iniciada na Estratégia Saúde da Família e critério indispensável para a marcação da consulta, a referência é efetiva. Porém, a contrarreferência, não é realizada pela atenção especializada, pois não é exigida na rede de atenção à saúde. Os especialistas não preenchem o formulário de contrarreferência, tornando-a inefetiva, com comprometimento da continuidade do cuidado. **Conclusão:** a contrarreferência precisa ser reconhecida pelos profissionais de saúde como ferramenta fundamental para um cuidado longitudinal, que atenda às necessidades de saúde da criança em condição crônica.

**Descritores:** Criança; Mães; Encaminhamento e Consulta; Doença Crônica.

### RESUMEN

**Objetivo:** identificar la efectividad del sistema de referencia y contrarreferencia de niños con condiciones crónicas percibidas por las madres y el personal de atención de los servicios de atención especializada. **Método:** este estudio cualitativo realizó entrevistas semiestructuradas a madres y especialistas en centros de atención especializada de una capital del estado en el noreste de Brasil, entre diciembre de 2018 y marzo de 2019. **Resultados:** como referencia se ha instituido en la Estrategia de Salud de la Familia como criterio indispensable para la programación citas, la referencia está efectivamente en su lugar. Sin embargo, los servicios de atención especializada no son contrarreferencia, ya que esto no es requerido en el sistema de salud. Los especialistas no completan el formulario de contrarremisión, lo que lo vuelve ineficaz y dificulta la continuidad de la atención. **Conclusión:** el personal de salud debe reconocer que la contrarreferencia es una herramienta fundamental para la atención longitudinal que atiende las necesidades de salud de los niños con enfermedades crónicas.

**Descriptores:** Niño; Madres; Derivación y Consulta; Enfermedad Crónica.

## INTRODUCTION

The referral and counter-referral system is an organizational method of health teams work practices. It is a mechanism for making referrals of users to the different services of the Health Care Network in order to facilitate their access when seeking these services. In the operation of this system, the referral and counter-referral form is filled out by a graduated professional who is responsible for users' service at the institution<sup>1</sup>.

The completion of this form favors the flow of information when the user travels through different services and levels of health care, and works as a strategy to achieve the comprehensive care proposed by the National Health System

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(Brazilian SUS)<sup>2</sup>. The relevance of the functioning of this system is recognized for the care and follow-up of children with chronic conditions who need continuous care.

The following health problems are considered a chronic condition: present for more than three months; with three or more clinical episodes per year, in which the adequate recovery cannot be expected, leading to the onset of more symptoms and possible loss of functional capacity and promoting changes in various areas of the life of affected individuals that demand differentiated care<sup>3</sup>.

The child with a chronic condition needs greater care support, sometimes permanent, based on a mutual relationship of trust between professionals, family members and sick people, with the aim to make such care effective, efficient and of quality<sup>3,4</sup>, and ensure its longitudinality and continuity<sup>5</sup>.

When the continuity of care is provided by the referral and counter-referral system, a continuous and effective order and flow of information is established, thereby improving the quality of care. In this context, professional commitment to the transmission of care information through the counter-referral documentation is essential<sup>6</sup>.

In a study, the lack of communication between health professionals was pointed out as one of the weaknesses in the care of children with chronic conditions, since it disrupts the continuity and organization of care offered in the network. The lack of connectivity between services, managers and health professionals was identified, which caused that information on the care offered to children in chronic conditions was not transmitted from one service to the other and professionals of a service did not receive information about the care provided<sup>7</sup>.

In another study, it was found that countless health teams do not take responsibility for implementing the referral and counter-referral system. Therefore, the transmission of information is not viable and it is difficult to establish a relationship of mutual trust, continuity and comprehensive care<sup>8</sup>.

The lack of communication between specialized services and primary care hinders the idealization of the Health Care Network, which in essence, should be integrated by the referral and counter-referral system<sup>9</sup>. Thus, health care for children with chronic conditions in the Health Care Network becomes deficient, and the care based on comprehensiveness and equity does not happen in practice<sup>7</sup>.

The fragmentation of this care is recognized from the moment when users are referred to specialized services, and most are not counter-referred with the specific documentation of the service for Primary Health Care (PHC). Most of the existing gaps are a result of the professional performance at the specialized level, in the communication between the professionals that disrupts the continuity of care and the service to users<sup>7</sup>.

Faced with this problem, the following question was asked: "How do professionals from outpatient specialty services and mothers perceive the effectiveness of the referral and counter-referral system for children with chronic conditions?". Knowledge about this reality may provide important subsidies and help to guide the family on the continuity of care through referral/counter-referral, which is one of the pillars of comprehensive care for children with chronic conditions.

In addition, communication between professionals, family members and patients is indispensable for the strengthening and effectiveness of the system, although there are gaps in this regard, and weaknesses in the flow of the referral and counter-referral system, such as not completing the form, which makes children's follow-up and return to PHC difficult. To this end, the objective is to identify the performance of the referral and counter-referral system of children in chronic conditions in the perception of mothers and professionals from specialized services.

## METHOD

This is a descriptive qualitative study conducted in three Centers of Comprehensive Care to Specialized Health (Brazilian CAIS / Polyclinics) located in a large city in the state of Paraíba. These centers belong to SUS and offer primary care services, diagnostic tests and specialized care.

Five mothers of children with chronic conditions and five specialists who provide follow-up care for these patients were selected proportionally in the three centers. The choice of mothers was random and met the following inclusion criteria: mothers of children under 12 years of age with a chronic condition; able to understand and express the interview questions. Criteria for health professionals were: being a permanent employee of the health service for more than six months and having experience with care for children/families in chronic condition. Mothers of children with chronic conditions diagnosed less than six months earlier were excluded, as well as health professionals on sick leave or away for training or vacation.

Interviews were performed between December 2018 and March 2019, audio recorded upon signature authorization, lasted 30 minutes, and guiding questions were used. For mothers: "*How was scheduled the first consultation with the*

*specialist?”; “What difficulties were encountered when scheduling this consultation at CAIS?”; “What guidelines were received for the continuity of child care with the Family Health Strategy (FHS)?”. And for professionals: “How do children in chronic conditions arrive for care at CAIS?”; “After the consultation with these children, what is your procedure for the continuity of care?”; “How is the communication and integration between professionals of this service and other professionals/services of the Health Care Network that also provide follow-up care for these children?”.*

The privacy and anonymity of participants was guaranteed and the collection was ended by the sufficiency criterion, when the study objective was reached<sup>10</sup>. Mothers were identified by the letter M and professionals by P, followed by the sequence number of interviews.

The empirical material was fully transcribed and thematic analysis<sup>11</sup> was performed according to the following steps: organization of the material and first classification; successive readings, development of the horizontal map, apprehension of relevant structures; transversal reading, regrouping of data in categories to reach the objective of the study. The constructed themes were: Referral of children in chronic condition; and Counter-referral of children in chronic condition. The “Consolidated criteria for reporting qualitative research” (COREQ) checklist was used for the scientific support of each stage of this study.

The study was approved by the Research Ethics Committee, Protocol 0151/17, in compliance with the legislation in force in the country. Participants signed the Informed Consent form.

## RESULTS

Five out of the ten participants were mothers, aged between 24 and 37 years, with study time between nine and 11 years; three were housewives; one, a civil servant and one, self-employed and the number of children varied between one and three. Children with chronic conditions were between five and nine years old, two with congenital heart disease, two with Diabetes Mellitus and one with epilepsy.

Among the five doctors, three were male and two were female, aged between 32 and 59 years. The training time ranged from five to 25 years, and the majority had two specializations. The length of experience at CAIS ranged from one to ten years.

### Referral of children in chronic condition

The care demanded by children with a chronic condition goes beyond what FHS professionals can offer and requires referral to specialized services and guidance to family members. For scheduling the first consultation at the outpatient service, the user is referred by the FHS, carrying the institution’s own reference form duly completed, as only by presenting it in the consultation appointment sector does one have access to the Health Care Network specialist.

*I always took him to be seen there [FHS] where I live, but as his problem is more serious, the doctor there [FHS] was unable to treat, so she made the referral on a form, gave it to me and told me to bring him here [CAIS]. (M2)*

*I took her to the health center [FHS] in the neighborhood and the doctor made a referral to bring her here [CAIS]. I came with this referral and right here I scheduled it. (M1)*

In the opinion of specialists, the referral is implemented in all care provided to children with chronic conditions, since referral by the FHS is essential for scheduling an appointment at the CAIS. In situations where the family lives in an area not covered by some FHS, direct contact with CAIS professionals ensures follow-up.

*Either they are referred by the FHS of origin or they are seen here at the FHS of CAIS itself and here they schedule an appointment with the specialist. Patients who do not have FHS in their area can seek care here and, if they need a specialist, the professionals here at CAIS already make this connection with us. But they never schedule an appointment directly with the specialist without having been seen at the FHS. (P1)*

*All those served here [CAIS] arrive referred by the FHS. It is a protocol, only schedule an appointment with the CAIS professional if you have the referral form filled out. (P3)*

It was identified that the formal referral filled out in an institutional form is made to schedule the first consultation with the specialist, or when the child in a chronic condition is referred by one specialist to another, in the same service or between different specialties, and the following consultations are scheduled by doctors themselves after treatment.

*We have a routine: after child care, in the same room, we already schedule her return appointment. As these are patients who need frequent follow-up, we avoid leaving it in the hands of the responsible caregiver in order to avoid the risk of not scheduling and the child does not continue the follow-up. (P1)*

*We are the ones who schedule the appointment, the user only comes to make the first consultation; the others, we already schedule as soon as we finish the service. They just need to come in the arranged day to be seen. (P4)*

### Counter-referral of children with chronic condition

After the consultation, specialists do not make counter-referrals of children in chronic condition and their mothers to the FHS with the counter-referral form filled out, because they do not even guide the patients to return to their referral unit. This leads to the child/mother's understanding that, from that moment on, they no longer need to return to the FHS, interrupting the network care. The lack of counter-referral to the FHS contributes to the fragile link between families and Family Health Teams (FHT).

*No, they didn't give me anything and they didn't even guide me back to the FHS. We are in follow-up treatment only here [CAIS] now. (M1)*

*Usually, I do not fill out, since patients do not even use this form. After they are served here [CAIS], they no longer return to their units. [FHS]*

*Then, it becomes unnecessary work to fill out a form that will never be used. It's a waste of time. I only complete it if it is a case of real need. (P5)*

*Usually, I don't fill it out. I was never required [referring to managers and/or other Health Care Network professionals] to complete this form, after we serve the child here [CAIS]. (P2)*

This reality reflects mothers' lack of knowledge about the counter-referral to the continuity of care at the Health Care Network, as well as the lack of appreciation of the segment by the FHS. The precarious functioning of the network and the fragile guarantee of comprehensive care are evident.

*I don't know this paper [counter-referral]. Nobody [FHS professionals] has ever sets foot on my sidewalk at home to know anything. That's why I don't go back to the FHS. (M4)*

*They do not serve us well even inside the FHS, let alone go to the person's home, they won't. I just go to the FHS to get a prescription. I think the doctor does not fill out this form [counter-referral] because he knows that I will not go back there [FHS]. (M5)*

In the mothers' perception, care is better in the specialized service because it is more resolute. Thus, they do not feel the need to receive the counter-referral to the FHS.

*We are in follow-up treatment only here [CAIS] because the service is good. Her problem is solved and I don't need the form [counter-referral] to go back there [FHS]. (M1)*

*After the doctor from here [CAIS] started seeing him, I only go back to the FHS for the dentist. The doctor here [CAIS] is very good, after I got care for him here, I don't even need the things from there [FHS] anymore. (M2)*

When it comes to making referrals for children with a chronic condition for the opinion of other specialists, the counter-referral form is duly completed with the relevant information, and handed over to mothers for the child's follow-up.

*The child goes from one specialist to another through a referral, the same way she gets here at the CAIS. A specialist colleague only sends the child to the other specialist after completing the referral form. This is routine for people in the service: to fill out the information in the counter-referral fields. (P4)*

*When the child goes back to the specialist who made the referral, he must have the completed counter-referral form in hand. This is one of the few cases in which counter-referral is used by us specialists. This is a requirement made by all CAIS specialist doctors. It is a way for us to know precisely everything that has been done with the child. (P3)*

### DISCUSSION

The results presented show significant gaps in the Health Care Network referral and counter-referral system. The referral process is performed by the FHS only in the first care of the child with a chronic condition with the specialist, while the counter-referral process is performed only between specialists, but not with the FHS.

When the professional refers the user with the duly completed referral form including all necessary information for the continuity of care, he respects the constitution of an organized referral network<sup>1</sup>. In a study, was highlighted that mothers of children with chronic conditions positively evaluated compliance with the referral flow, which strengthens the idea that according to their mandatory nature, referrals are properly made<sup>12</sup>.

For the guarantee of follow-up of children with chronic conditions who do not have a referral FHS, the effectiveness and benefit of making an appointment directly at the specialized service without going through the regulation system was evident, which demonstrates the weaknesses in the care flow<sup>13</sup>.

However, the lack of counter-referral to the FHS prevents the recommended care for these children. The causes of this gap are the lack of a counter-referral request from the FHS doctor, as this would emphasize the need for its performance, and the resistance of secondary care professionals to take responsibility for completing these forms and forwarding them to other services<sup>9</sup>.

In the reports of specialists, it became evident that the counter-referral process is not part of their daily activities, and the reason is that managers do not require it and children do not return to the FHS. Thus, children do not return to the unit of origin and when they do, there are no records of data and the information depends on the guardian's understanding, which may lead to the loss of part of it<sup>12</sup>.

Satisfaction with the service offered at the specialized center promotes a relationship of trust, facilitates contact, offers professional care for children and family members, and motivates users' desire not to return to the FHS, since the specialist service provided is considered to be of quality<sup>2</sup>.

The lack of coordination and communication between services and workers' lack of knowledge about the functioning of Health Care Network are evident, as each professional seeks to meet users' needs in isolation. Hence the need for multidisciplinary work, the training and preparation of health professionals on care coordination in the Health Care Network in order to agree on care flows that can solve users' needs<sup>14</sup>.

On the other hand, the counter-referral process is performed among specialists, although it is unsustainable for reaching the Health Care Network objectives and shows gaps in its execution. In a study, was found the occurrence of the counter-referral between specialists, because they are demanded to do it and professionals feel obliged to properly fill out the institution's specific form. The exchange of information and network only happen when it comes to the care flow between professionals from specialized services, which favors the loss of quality in the care offered<sup>14</sup>.

The referral and counter-referral system should be an organizational method to achieve the aim of comprehensive care of the Health care Network. This system would benefit children with chronic conditions and their families through the early identification of clinical changes, a systematic and uninterrupted segment, thereby minimizing health damages and contributing to a better quality of life of those involved.

However, in professional practice, the system is ineffective, present weaknesses in the effectiveness and quality of care offered by health services, and actions are not performed in integration<sup>15</sup>. The referral and counter-referral system occurs in an uncoordinated manner due to the incorrect use of communication instruments intended for referring users within the network<sup>16</sup>. As a consequence, there is a lack of coordination between the FHS and specialized health care services, which contributes to the discontinuity of care<sup>16</sup>, brings difficulties to the health care of children with chronic conditions and their families, and exposes the weaknesses in the process of care management<sup>7</sup>.

The Health Care Network has not yet been put into practice in the daily actions of professionals in the health field, especially with regard to ensuring continuity of care for children with chronic conditions. In general, children are referred by the FHS to a specialized service and, at that point, the cycle of continuity of care is broken<sup>13</sup>. The search for integration in health care within the Health Care Network is a challenge, because the process is complex, covers the primary, secondary and tertiary care levels, and involves professionals from different specialties who need to work together and in coordination<sup>17</sup>.

Therefore, for the effective referral and counter-referral process and appropriate functioning of the Health Care Network in order to ensure continuity of comprehensive care for users, the awareness of those responsible for the child, the training of health professionals in services and the articulation between managers and professionals who provide direct care to this population are necessary. This will strengthen the link between users and different services and professionals thereby ensuring comprehensive care<sup>18</sup>.

The limitations of this study include the group of professionals, as only doctors were interviewed, because the other categories were resistant to participate. Further studies on this topic involving other categories of specialists who assist children with chronic conditions are needed.

## CONCLUSION

In the Health Care Network of the municipality studied, the referral by the FHS in the first contact is made, whereas the counter-referral, in most cases, is not. In this perspective, the lack of counter-referral between specialized services and primary care increasingly distances children with chronic conditions from the FHS.

Thus, the need for a closer look and the institution of policies in the municipalities for the organization of flows and counterflows between Health Care Network services and professionals. The development of a work to raise the awareness of mothers and specialized professionals is necessary when making counter-referrals in the care of children with chronic conditions in specialized services.

The contribution of this study is to awaken a reflection on the importance of communication between the different professionals/services in the Health Care Network about children with chronic conditions and their families, thereby making the referral and counter-referral system effective for the longitudinality of care.

We emphasize the importance of continuing studies related to the theme in order to identify gaps in the Health Care Network in other municipalities and implement national strategies that improve the care offered to this population.

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