







Co-tutorship process with high-risk children: an evaluation of the *Rede Mãe Paranaense*

Processo de cotutela de crianças de alto risco: avaliação da Rede Mãe Paranaense

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ABSTRACT

Objective: to understand how the co-tutorship between primary health care and the referral outpatient clinic from the Mother Network from Paraná (*Rede Mãe Paranaense*) in the follow up of high-risk children. **Methods:** qualitative study carried out by understanding the process of co-tutorship between primary health care and the referral outpatient clinic of the Stork Network (*Rede Cegonha*) in the follow up of high-risk children. The study included 28 coordinators of primary health care and two representatives of the high-risk clinic. Data collection was carried out through interviews that were transcribed and underwent thematic category analysis according with Bardin's principles. **Results:** data analysis led to the creation of the category Communication between primary health care and outpatient clinics: outcomes of the (dis)continuity of care to high-risk children. It became clear that the process of co-tutorship has weaknesses that prevent the provision of integral care. **Conclusion:** fragmented communication and lack of alignment between the services, in addition to not acting like co-tutors as they provide care to children and their families lead to shortcomings in the attention provided. **Contributions to practice:** the study allowed for the identification of weaknesses that can be crucial for future interventions in the high risk child-care network.

Descriptors: Continuity of Patient Care; Referral and Consultation; Health Information Exchange; Primary Health Care; Child Health.

RESUMO

Objetivo: compreender como se processa a cotutela entre atenção primária à saúde e ambulatório de referência da Rede Mãe Paranaense, no seguimento de crianças de alto risco. **Métodos:** estudo qualitativo, desenvolvido por meio da compreensão do processo de cotutela entre atenção primária à saúde e ambulatório referência da Rede Cegonha, no seguimento de crianças de alto risco. Participaram do estudo, 28 coordenadores da atenção primária e dois representantes dos ambulatórios de alto risco. A coleta de dados ocorreu por meio de entrevistas, que foram transcritas e submetidas à análise categorial temática conforme os pressupostos de Bardin. **Resultados:** da análise dos dados emergiu a categoria Comunicação entre atenção primária à saúde e ambulatórios: desdobramentos na (des)continuidade do cuidado prestado às crianças de alto risco. Evidenciou-se que o processo de cotutela apresenta fragilidades que comprometem a integralidade da assistência prestada. **Conclusão:** a comunicação fragmentada e a falta de alinhamento e de posicionamento de cotutela entre os serviços no contexto da atenção às crianças e seus familiares geram fragilidades no atendimento. **Contribuições para a prática:** o estudo permitiu identificar fragilidades que podem ser cruciais para intervenções futuras no âmbito da rede de atenção infantil de alto risco.

Descritores: Continuidade da Assistência ao Paciente; Encaminhamento e Consulta; Troca de Informação em Saúde; Atenção Primária à Saúde; Saúde da Criança.

Introduction

The history of public policies in the mother-child field is marked by several initiatives, always seeking to improve the quality of care and reduce the morbidity and mortality in this population group. This was the perspective that led to the creation of the Health Care Network for Women and Children, known as Rede Cegonha (the Stork Network). The goal of this initiative was guaranteeing the reproductive rights of women in a safe and qualified way, following the child from birth till their second year of life. This network seeks to provide integral follow-up to the dyad, aiming to reduce mother and child mortality⁽¹⁾.

One of the strategies from the Stork Network to reduce mortality is stratifying risk, that can be classified as usual (no risk), intermediary (socioeconomic risk), or high (perinatal asphyxia, hyperbilirubinemia with exchange transfusion, delayed neuropsychomotor development, premature birth, low weight at birth, genetic diseases, positive neonate triage, vertical transmission diseases, and severe malnutrition). According with the principles of the Stork Network, this stratification takes place, ideally, in the maternity ward, to provide the high-risk child with a faster and more efficient access to specialized services. Speed is of the essence to identify development and child growth issues as early as possible, thus avoiding negative outcomes⁽²⁾.

Specialized outpatient care follow up, when necessary, should be done together with the Primary Health Care (PHC), to guarantee the continuity of care. Thus, teams should work to ensure they can provide integral care and continuously handle the case as recommended, using a Plan of Care and sharing it with the PHC. This process of sharing the care is called co-tutorship⁽³⁾.

Furthermore, the development of the assistance provided between these health care levels should be input in the child's logs, since this is a legal document and a mean to share information between the services. Nonetheless, the logs are seldom used during

care, making dialog between sectors and effective co-tutorship of patients difficult⁽⁴⁻⁵⁾.

Furthermore, the lack of articulation between the levels of health care impairs the co-tutorship of child follow up, since, due to the lack of information, conducts cannot be adapted⁽⁶⁾. It has been shown, increasingly, that all health services, regardless of level of specialization, should articulate to the advantage of the patient, guaranteeing that the child receives adequate co-tutorship. This is the only way to reach the goals of the Stork Network^(1,7).

Therefore, we believe that the alignment between primary care spheres and high-risk centers should be a priority to guarantee that these children receive quality effective assistance, in addition to being useful for the management of indicators and to analyse the impact of the actions of the network. Evaluating the operationalization of the services allows for the receiving of information to guide managers regarding the functionality and results of these practices for the population, since the health system is a complex network, as it has interfaces with other sectors⁽⁸⁾.

Considering the above, this study is justified as it is necessary to continuously and systematically evaluate these services, identifying shortcomings or gaps in the co-tutorship process in the Stork Network, aiming to improve the quality of the attention it provides. The following guiding question was used to direct this study: How does the co-tutorship between primary care and the Mother Network from Paraná (*Rede Mãe Paranaense*) take place in the follow up of high-risk children? The objective of this study was to understand how the co-tutorship between primary health care and the referral outpatient clinic from the Mother Network from Paraná (*Rede Mãe Paranaense*) in the follow up of high-risk children.

Methods

This is a qualitative study carried out to understand the co-tutorship process of high-risk chil-

dren between the primary health care and the high-risk outpatient clinics. The study was directed by the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ). The population was formed by those responsible by the high-risk ambulatories and by the coordinators of primary care of each city.

The high-risk clinics of the Stork Network include a multiprofessional team formed by nurses, pediatricians, physical therapists, and social workers. It stands out that all workers from the Stork Network, regardless of their level of health care, receive in-person and online training regarding the functioning of the network.

The inclusion criteria were: professionals who are in the same role for at least one year and have been working with the health of high-risk children. Professionals who are on leave or vacation were excluded.

The field of study included the two outpatient clinics of the Stork Network from the 15th Health Region of the State of Paraná, Brazil, and the thirty cities that are part from of their area of coverage. Each city has one primary care coordinator and each clinic has one leader. The 30 city representatives and the two clinic representatives were invited, since all of them were in accordance with the inclusion criteria. Nonetheless, there were two refusals, justified by the lack of time due to work overload during the COVID-19 pandemic. Therefore, both high-risk outpatient clinic representatives and 28 primary health care coordinators participated of the investigation.

Data collection took place from March to April 2021 by a single interviewer, experienced in field research and interviews. The name of each eligible participant was used to make a previous contact and present the study, providing ethical instructions and making a formal invitation. After it was accepted, the meeting was scheduled according with the availability of the participant. The interviews took place individually, via *Google Meet*. All interviews were recorded and transcribed in full. Before the interviews started, the Free and Informed Consent Form was read, and

the participant was recorded consenting to participate and to be recorded.

The following guiding question was used to conduct the interviews: How does the co-tutorship between primary care and the Stork Network take place in the follow up of high-risk children? Each interview lasted for a mean of 20 minutes. Information about educational level, profession, gender, age, and time working in the profession were also collected. The data from the interview was transcribed in full with the aid of the software Microsoft Word 2019®, and sent to all participants via e-mail, so the reading, revision, and approval of the interview could be carried out.

Data was imported into the software NVivo Release, version 1.6.1® and analyzed using the categorial content analysis technique proposed by Bardin. This technique has three stages: pre-analysis, material exploration, and treatment of results, the latter being associated with interpretation. The first stage is the recognition of all materials, followed by data systematization and codification. In the second, raw data is aggregated in homogeneous units to facilitate describing and characterizing the content, which is then organized in units of meaning⁽⁹⁾. The third and last stage is characterized by the use of data in literature about the topic, which is then associated with the results found⁽⁹⁾. A word cloud was developed in the same software using data from the interviews. It considered words that had at least five letters in Portuguese and was based on how frequent their appearance was.

One category emerged from the content analysis of the interviews. Coordinators from the primary care were identified by the acronym PAPS, formed by the first letter of the Portuguese sentence “primary health care professionals”. The outpatient clinic representatives were identified using the acronym “PAAR”, for the Portuguese words for “professionals from the high-risk outpatient clinic”. In both cases, numbers indicating the order of the interviews were added to the acronym to guarantee that their identities would remain confidential.

The study respected all directives from Resolution 466/12 from the National Council of Health, being submitted to the Ethics Committee for Research with Human Beings at the Universidade Estadual de Maringá under Certificate for Submission to Ethical Appreciation 24906719.9.0000.0104 and opinion 4,594,485/2021.

Results

30 health professionals participated in the study, 28 from primary care and 2 from the high-risk outpatient clinics from the region of the study, 28 participants were nurses, 1 was a social worker, and 1 was a nutritionist. Their mean age was 38 and most were female (96.6%). The mean time working in this position was seven years.

To bring the reader closer to the content generated in the interviews, the Word Cloud method was used. It identifies the words that were transcribed the most, and shows them in a larger size than the others: child (191), risk (111), consultation (64), outpatient (63), lack (62), municipality (53), return (52). Figure 1 shows the word cloud.



Figure 1 – Word cloud of the discourse of the health workers from the primary care and the high-risk clinic. Maringá, PR, Brazil, 2021

The content analysis led to the thematic category of Communication between primary health care and outpatient clinics: outcomes of the (dis)continuity of care to high-risk children.

Communication between primary health care and outpatient clinics: outcomes of the (dis)continuity of care to high-risk children

Communication between the high-risk clinics and the primary care has important shortcomings that impact on the process of co-tutorship of high-risk children. The absence of children from the high-risk service is notified to the primary care via e-mail. However, there is no open communication channel regarding the moments when the patient goes to the services: *The service sends us an e-mail so we carry out active searches when there are absences, but it doesn't keep us informed about how the treatment of this child is going, we stay blind, uninformed, we don't know* (PAPS 1). *They sent us e-mails telling us that these children were absent... These e-mails stopped coming. And we have this issue that we are not getting a nice feedback about these consultations, we don't know what's going on* (PAPS 10). *I get no feedback, not information exchange. They don't tell us who was scheduled as high-risk. We kind of know, through the prenatal follow up, when the child is high-risk and when that's not the case. But after that, we can't tell* (PAPS 14).

This lack of dialog between services is frustrating for those who are working in primary care, as they do not know how to aid in the therapeutic process of their patients. The lack of more effective information exchange can lead to missing information and confusion during assistance, affecting the child and the family: *Sometimes we learn about it when the mother tells us. The we are: "oh, that's right", kind of, "Wow! The mother is the one who told me." It's very frustrating* (PAPS 4). *I feel there's no feedback... So we get kind of lost, without knowing what is going on. In the and we have to ask everyone what is going on to try and find it. So we get lost, I think that's the most bothering issue* (PAPS 28). *I have a report of maternity discharge in the child's log, and I get some data from there. And then when she goes to these high-risk consultations, I learn about it by reports the mother gives me, but I mean, the role of the outpatient clinic, I got no feedback on that* (PAPS 15).

It stands out that referral and counter-referral are the basis of the Stork Network and are essential for its proper working. To do so, the dialog between all members of the network must be clear and dynamic.

The clinics have particular ways to communicate with the primary health care. The most commonly used are e-mails, phone calls, and WhatsApp: *Everything goes through me, so I can authorize it, but since, in general, there is no waiting line, everyone can go (into consultations). Sometimes, he primary health unit itself gets in touch to reschedule (absentees), or even to ask about the follow up of the child... Our routine communication with the primary care is just warning them about who didn't come each day (PAAR 1). We work a lot with phone contact, you just have to call and we can discuss the follow up (PAAR 2).*

Communication governs the Stork Network as a whole. Therefore, when it is not effective, there are many repercussions on the services at hand, prejudicing the co-tutorship of the assistance provided: *What happens in our city is that the clinic wants to know why the child didn't go to a certain consultation... But we don't get feedback, they don't tell us what they do over there, so we don't know if our conduct here is in conflict with theirs or not (PAPS 4). We have a pediatrician and he comes every Wednesday, and then we schedule the consultations. He has his pediatric conducts, I don't think we have co-tutorship of the patients because we don't know what they're doing in high-risk. Here, we do what we see we must do (PAPS 8).*

Fragmented communication and the fact the services do not act as co-tutors as they provide care to children and their families lead to information conflicts. The conducts between the services can be in conflict when there is no effective dialog. This can lead the family to choose a single service where to take their children, to the detriment of one of the principles of the Stork Network: *Normally, when they start going to a place and then come to the unit, they don't come that much, they don't come back. When they go to the high-risk, they don't want to come here to the unit because their follow up is there. Then they say that it's too confusing because we say something, and the clinic says another (PAPS 9). Our high-risk children don't come back to the clinic, it's the city... they don't get out with return papers anymore. We have been answering to this need of the children here in our town (PAPS 11). The mother herself refuses, "I am in town, why should I have to go elsewhere if here's where I trust", so the follow up ends up happening in the city (PAPS 14).*

The follow up in high-risk clinic and primary care is prescribed by the network. Nonetheless, as the

reports above indicate, there are still shortcomings in this follow up process. In this setting, one must understand what the services need to help the network to function properly. There are suggestions to improve feedbacks about co-tutorship follow ups of patients via e-mail or even via phone: *For the tutorship to work, they could talk via e-mail, something like that you know, telling the town "hey, this is a high-risk child who receives attention in the clinic on this and that day and time", you know, we don't get that feedback and it would be really interesting. After that we could communicate using the health care plan, but we don't communicate like that (PAPS 19). Mothers find it very difficult to follow up in both places, many work, and there's no transportation after all. So that's really difficult. If there was dialog between services, we could take turns, each place attending on a date, then, the chance for the family to go to both services would increase (PAPS 22).*

The Stork Network prescribes that the multidisciplinary care provided to the health of the child should continue. However, the lack of individualized plans for the health care of patients leads to shortcomings. Without a strategy of care that can guide practices in partnership, actual co-tutorship is impossible. Many interviewees reported the feeling of working blindly: *We don't know how to work in a multiprofessional or multidisciplinary way. We need to discuss cases together. We talk about case management, but we don't do that yet, we only discuss cases after death. We need to learn to work together, I just don't know how we would integrate the services, but improving communication would help a lot (PAPS 28). Each team provides its childcare, knows its children. They follow up every case... but we never receive a care plan, we don't know what the high-risk clinic is doing, we are blind, trying to guess... so we end up going ahead (PAPS 2). We don't get a counter-referral from the clinic. There's nothing telling us when the child should go back, or what they need us to do... (PAPS 11).*

Outpatient clinics, in turn, seem too strained by work overload, which justifies, up to a certain point, the absence of a proposal of care due to the excessive number of consultations. Nonetheless, care projects are expected to be implemented soon: *Actually, when the child comes to the clinic, there's already a scheduled consultation. So, actually, unfortunately, I can't follow up that closely, I can only do it at the time of consultation, really, because we attend so many patients*

every shift, the schedule is full... but I'm a bit relieved by knowing they follow up in the primary care (PAAR 2). I know we have been failing, but we aim to implement a care plan as soon as possible. We guide the families, but the information unfortunately doesn't always get to the primary care (PAAR 1).

Discussion

The integration between primary health care and high-risk outpatient clinics has been impaired by a lack of dialog which may impact on the quality and continuity of the follow up provided to high-risk children.

It is important to highlight that miscommunication may have negative effects on the health state of the child, leading their families to become overloaded, as they are tasked with the role of messengers of the explanation between services. Furthermore, the family of the child is not formed by trained health professionals capable of properly transmitting the information about the high-risk child⁽⁷⁾.

This study showed that the services dialog between themselves via e-mail, but only to reschedule children who were absent to their consultations. In other cases, information regarding the patient being followed up in the high-risk clinic did not reach the primary health care. A study carried out in Massachusetts, in the United States, discussed the use of a handoff strategy, that is, the transfer of an individual between services through a telephone interaction, aided by technology, or in-person, showing good results⁽¹⁰⁾.

The use of informal communication methods, such as personal phones and social networks (WhatsApp), between specialized and primary care, is important for the follow up of the patient⁽¹¹⁾. However, the lack of information exchange between services, be it formal or informal, implies in gaps in the assistance and therapy of the patients who come back into primary care.

As a result, the continuity of care should combine three elements: the coordination of interventions,

information flow, and interpersonal relations⁽¹²⁾. Therefore, when health services attend patients simultaneously, they must have good communication, since the poor functioning of one of these systems may have a negative impact on the effectiveness and quality of the global care provided to high-risk children and their families⁽¹³⁾.

Even with advances in primary care and in the other components of health care network, a study carried out with nurses from the mother-child care network of Paraná showed that, even when the child receives follow up in childcare, there is no knowledge about the referral service for high-risk children, which is a gap in information that makes their work more difficult⁽¹⁴⁾.

Furthermore, the barrier in the dialog of professionals, both between peers and with patient parents, in addition to the lack of articulation and counter-referral between specialized and primary care, can significantly prejudice the continuity of care⁽¹⁵⁾. Therefore, the services must be improved via effective and dynamic dialog, so there is access to care and to the support provided to ensure effective bonds between the childcare network services⁽¹³⁾.

An intercommunication strategy is the one that takes place in written form or via phone, bringing secondary and primary health care closer, to guarantee integral care⁽¹⁶⁾. An integrated informatized system would be crucial for the exchange of information between the services. However, this reality is not common in the Brazilian setting⁽¹⁷⁾.

Nevertheless, even considering the absence of counter-referrals, restricting communication with secondary care, the primary health care should seek integrating childcare with other elements of care. Therefore, a good functioning of the process of care and dialog are essential for services to give support to children and their families⁽¹⁶⁾.

Intercommunication is essential for the success of the Stork Network, and communication issues prejudice the co-tutorship in the assistance. As a result, the dialog and the good transmission of messages be-

tween health workers and high-risk children families are an essential attribute to create trust and promote bonds between the parties. Guaranteeing an effective communication process also allows us to investigate the quality of the follow up in both health services (primary care and high-risk outpatient clinic). However, some workers in the health services are not aware of their importance in the actions to do so, and it is essential to train health workers for a good communication, thus increasing the possibilities of integrated care between health care services⁽¹⁸⁾.

When there is conflicting information due to miscommunication between services, families often choose to follow up their children in a single service. Considering this context, families end up choosing the service that is closer to their community, in this case, the primary health care⁽¹⁹⁾.

When the high-risk children is not followed-up properly, the Stork Network does not work as prescribed, making it necessary to adopt strategies to improve the responses given by primary and specialized care when they share the follow up. This can be done using the means available in these settings, as the participants in the study suggested, via e-mails and phone calls. Therefore, the continuity of care should be a responsible practice, that provides guidance to the health workers involved in care and to their relatives. Therefore, the nurse, together with the multiprofessional team, should verify whether the attention continues to be provided efficiently in the primary health care⁽¹⁵⁾.

It also stands out that, even when the health teams are engaged in the follow up of high-risk children, it is necessary to guarantee access to technological resources, such as computers and phones with internet access, in addition to constant training sessions about the functioning of the child health care network. Otherwise, it would not be possible to monitor the continuity of child care in both levels of attention⁽²⁰⁾.

One of the weaknesses found in the co-tutorship between the services was the lack of individualized plan for each high-risk child, since, in the absence

of a strategy of care, there is no co-accountability. The lack of directives for care and follow up cause health workers to provide fragmented assistance. Therefore, to reach positive results for the health of the children followed up, be it in the long or short term, the care must be planned jointly, and there should be well-placed means for the family to be informed and encouraged to participate in the process⁽¹⁹⁾. Only through this integration and using effective communication the assistance provided to the health of the child can have continuity, fitting the directives of the Stork Network.

Among the justifications for the absence of a care project, the representatives of the high-risk clinics reported work overload due to the high number of consultations. Despite recognizing how challenging it is to overcome these issues, managers should be prepared to face these obstacles and overcome them, to guarantee an effective response to the needs of the population, in the search for humanized treatment to the demands of society. Thus, the lack of articulation between the different levels of care is not only a gap in the referral and counter-referral system, but also prevents the optimization of assistance, which, in turn, overloads a service that is insufficient to attend all delayed health care demands. This setting is a warning about the challenges in front of health managers, who need to create communicational strategies between the different health care networks, thus sharing the responsibility and decisions about the patient⁽¹³⁾ and diluting the overload of the system by optimizing its resources.

It should also be mentioned that, in February 2022, the Stork Network was replaced by the Mother-Child Care Network, which prescribes improving the health care provided to this public. The Mother-Child Care Network is very similar to the Stork Network in essence and goals, but has received a larger budget to optimize their actions in the reduction of mother-child mortality. Nevertheless, reflecting on the functioning of the network as it is established is highly important, and this can be done through continuous evaluations and by surveying its strengths and weaknesses, to

subsidize an intelligent use of resources that can help reaching the objectives of reducing mortality. The findings of this study indicate the importance of aligning strategies that favor the dialog between services, enabling an effective co-tutorship process, increasing the quality of the care provided to the dyad high-risk child/mother.

Study limitations

The limitation of this study is the fact that the method does not allow generalizing its results to other realities. However, data were collected until exhaustion, allowing for its conclusions to be used in other similar settings or contexts of assistance.

Contributions to practice

This study enabled a reflection about the importance of co-tutorship between primary health care and referral outpatient clinics in the follow up of high-risk children, allowing us to show weaknesses that can be crucial points for future interventions in the network of high-risk children health care.

Conclusion

The communication between high-risk outpatient clinics and primary care has relevant shortcomings that impact on the process of co-tutorship in the care of children and their relatives, thus compromising the quality of care in the Rede Mãe Paranaense. These findings mean that local representatives of the network - managers and workers - are responsible for finding solutions for the weaknesses found, overcoming their limitations, and attempting to reach the goals of reducing mortality in this setting.

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