

# Reference and counter-reference health care system of infant discharged from neonatal unit: perceptions of primary care health professionals<sup>a</sup>

*Referência e contrarreferência do bebê egresso da unidade neonatal no sistema de saúde: percepção de profissionais de saúde da Atenção Primária*

*Referencia y contra referencia del bebe egreso de la unidad neonatal en el sistema de salud: percepción de los profesionales de salud de la Atención Primaria*

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## ABSTRACT

**Objective:** To identify how the references and counter-references occur in the care of preterm, low and/or very low birth weight newborn after discharge from the Neonatal Unit in the Health Care System. **Methods:** Qualitative, exploratory-descriptive research. A total of 31 professionals from the Primary Health Care Units, Joinville/SC, were interviewed from September to October, 2014. Categorical thematic content analysis was used. **Results:** Three categories emerged. Communication between the reference hospital and Primary Health Care Unit; Follow-up records of preterm and/or low weight infants; Hospital visit as strategy to guarantee the references and counter-references. The health professionals considered the process of reference/counter-reference to be precarious, without adequate records of procedures performed and referrals made, and that the Children's Health Record Book was insufficiently used. **Conclusion:** It is necessary to strengthen inter-institutional communication to guarantee adequate reference/counter-reference among the health services, and to make professionals aware of the importance of the records.

**Keywords:** Child Care; Primary Health Care; Infant, Premature; Health Services.

## RESUMO

**Objetivo:** Descrever a percepção dos profissionais de saúde da Atenção Básica acerca da referência e contrarreferência no cuidado do bebê pré-termo, de baixo e/ou de muito baixo peso ao nascer egresso da Unidade Neonatal no sistema de saúde. **Métodos:** Pesquisa exploratório-descritiva qualitativa. Foram entrevistados 31 profissionais nas Unidades Básicas de Saúde de Joinville/SC, de setembro a outubro/2014. Utilizou-se a Análise de Conteúdo categorial temática. **Resultados:** Emergiram três categorias: Comunicação entre o hospital e a Unidade Básica de Saúde de referência; Registro do acompanhamento do bebê pré-termo e/ou de baixo peso; A visita hospitalar como uma estratégia para garantir a referência e contrarreferência. Para os profissionais de saúde o processo de referência/contrarreferência é precário, sem registro adequado de condutas e encaminhamentos e a Caderneta de Saúde da Criança é subutilizada. **Conclusão:** É necessário fortalecer a comunicação interinstitucional, para garantir a referência/contrarreferência adequada entre os serviços de saúde, bem como sensibilizar os profissionais acerca da importância dos registros.

**Palavras-chave:** Cuidado da Criança; Atenção Primária à Saúde; Prematuro; Serviços de Saúde.

## RESUMEN

**Objetivo:** Describir la percepción de los profesionales de salud de la Atención Primaria acerca de la referencia y contra referencia en el cuidado del bebé prematuro, de bajo y/o muy bajo peso al nacer, egreso de la Unidad Neonatal. **Métodos:** Investigación cualitativa, exploratoria, descriptiva. Participaron 31 profesionales de Unidades Básicas de Salud de Joinville/SC entre septiembre y octubre de 2014. Se utilizó el Análisis de Contenido Temático. **Resultados:** Emergieron tres categorías: Comunicación entre hospital y Unidad Básica de Salud de referencia; Control de la inscripción del bebé prematuro y/o de bajo peso al nacer; La visita hospitalaria como estrategia para asegurar la referencia y contra referencia. Para los profesionales, la referencia/contra referencia es insuficiente y la Libreta de Salud del Niño está subutilizada. **Conclusión:** Es necesario fortalecer la comunicación institucional para garantizar los servicios de salud de referencia/contra referencia y sensibilizar a los profesionales sobre la importancia de los registros.

**Palabras clave:** Cuidado del Niño; Atención Primaria de Salud; Prematuro; Servicios de Salud.

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## INTRODUCTION

The growing concern about premature birth is directly related to the high rates of neonatal morbidity and mortality, because according to the World Health Organization (WHO), prematurity is ranked the second cause of death of children under the age of five years, since 75% of these deaths could have been avoided by means of simple actions, such as the use of antenatal corticosteroid, antibiotics, surfactant administration, nitric oxide and high frequency ventilation.<sup>1</sup>

In 1999, with the proposal to humanize hospitalized Neonatal Care, surge no Brazil the policy of humanized care of low-weight newborn infants ("Norma de Atenção Humanizada ao N de Baixo Peso (NAHRNBP)" - Kangaroo Method (KM)<sup>2</sup> appeared in Brazil. Considered a Public Health Policy in the country, it proposed a new perinatal care model. Although it was composed of various integrated actions, the Method is recognized by early skin to skin contact offered by the "Kangaroo Position". It is performed in three stages, with the first being in the Neonatal Intensive Care Unit (NICU) and in the Conventional Neonatal Intermediate Care Unit (CNICU); the second in the Kangaroo Neonatal Intermediate Care Unit; and the third after discharge from hospital, at home.<sup>2</sup>

In the third stage of the KM, when discharge from hospital occurs, the children are followed-up in an outpatient clinic. The suggestion is that three consultations should be held in the first week, two in the second week, and one weekly consultation as from the third week, until the baby attains a weight of 2.500g.<sup>2</sup>

At present, the Brazilian Ministry of Health (BMH) proposal is that at least one weekly consultation should be held at the hospital of origin, and the further consultations at the Primary Care Unit (PCU) with Family Health Strategy (FHS) teams, including the Home Visit (HV).<sup>2</sup>

It is, however, known that articulation of the primary and tertiary health levels is still weak, and this follow-up of preterm and/or low birth weight babies is almost predominantly carried out at hospital level.<sup>3,4</sup> The process of reference and counter-reference in the health system is still timid, and communication among professionals of the tertiary service and PCU occurs in an inefficient manner.

In Brazil, the PCU has been developed with the purpose of favoring approximation between the health service and community by means of receptivity and relationships of confidence that favor the tie. This is strengthened by the FHS as the priority model, composed of a multi-professional team that acts by attending populations in defined territories, which enables planning. Among the professional activities are attendance of programmed actions and spontaneous demand; favoring health promotion and prevention of diseases, and providing care centered on the user. In 2006, the National Policy on Primary Care ("Política Nacional da Atenção Básica (PNAB)" was launched which, among other regulations, includes the need for agreements and establishment of references and counter-references.<sup>5</sup>

Starting from the presupposition that not all preterm babies discharged from a Neonatal Unit (NU) have a fixed reference in

the network and facilitated access to child-care/follow-up that meets their specific needs; and considering the literary frailty of the topic, the second guiding question arose: What is the perception of health professionals in Primary care concerning the references and counter-references in the care of preterm, low and/or very low birth weight babies after discharge from the Neonatal Unit in the Health Care System? In search of answers to this question, the objective of the study was established as follows: To identify how the references and counter-references occur in the care of preterm, low and/or very low birth weight babies after discharge from the Neonatal Unit in the Health Care System.

The authors believe that the study brings important subsidies to favor inter-institutional communication, guaranteeing an adequate flow of attendance.

## METHODS

This was an exploratory-descriptive research with a qualitative approach, conducted in the primary units of the Brazilian Health Care System ("Sistema Único de Saúde") (SUS) of the municipality of Joinville, SC, Brazil. The referential used in the research was based on the policies of humanized neonatal care - Kangaroo Method, and the national primary health care policy.

The municipality of Joinville is located in the North of the State of Santa Catarina (SC), Brazil. With respect to PCU, the municipality has 57 Primary Health Care Units (PCUs) distributed throughout nine health regions, and of these PCUs, 31 have complete FHS teams (54.38%).<sup>6</sup> This municipality has an important project that is being developed by the City Hall, denominated - Strategy for Monitoring Children at Risk - Precious Baby Program ("Estratégia de vigilância à criança em condições de risco - Programa Bebê Precioso"), implemented in 2009, with the goal of reducing infant mortality and fully meet the needs of children at risk, from 0 to 11 months and 29 days old, discharged from the NU.<sup>7</sup> By means of the Precious Baby Program it was possible to reduce the infant mortality coefficient of the city, which was 10.1 newborn deaths per every thousand births in 2008, to 7.4 in 2012, considering that the national mean is 15.7 deaths per thousand births.<sup>8</sup>

The participants of this study were professionals from the PCU health teams, and the inclusion criteria were as follows: doctors, nurses and nursing technicians who had been working in the PCU for a minimum of six months, in fixed employment or under contract, and who had attended preterm, low and/or very low birth weight babies, referenced by the Precious Baby Program. The exclusion criteria were: professionals on vacation, leave of absence or who were away from work in the last six months. The number of participants was defined by data saturation.<sup>9</sup>

The coordinator of the program identified 29 PCUs that had attended "Precious Babies" in the years 2013 and 2014, and of these 15 PCUs were visited to perform data collection, seeking to attend to the majority of the nine health regions.

Data was collected by means of semi-structured interviews from a guide script that was validated by three researchers of the area, in the period from September to October 2014. The questions asked in the interview covered questions relative to the PCU professional's knowledge about care of the preterm, low and/or very low birth weight babies at birth, on discharge from the NU, the specific care they demanded, and the reference and counter-reference process of this population in the health service. The invitation to participate in the study was made personally, and interviews were scheduled according to the date and place of preference of each health professional. When the professional was not available on the date scheduled for holding the interview, due to demand of the unit or other particularities, the interview was re-scheduled.

The interviews were held by the main researcher who acted in the municipality investigated and who had experience with the methodological strategy. Interviews were held in a calm, reserved room with a minimum of external influences, and were also recorded and transcribed by the main researcher. In three interviews the participants refused to be recorded; their rights were respected and the data were registered right away to assure their originality. The duration of interview varied from eight to 35 minutes.

The data were analyzed by using Content Analysis of the thematic categorical type proposed by Bardin.<sup>10</sup> As regards method, this proposal consisted of a set of techniques for the analysis of communications with the aim of obtaining indicators, by means of systematic and objective procedures of content description of the messages, which allowed the inference of knowledge relative to the conditions of production/reception of these messages.<sup>11</sup> This was followed by the stages of pre-analysis, exploration of the material and or codification and treatment - inference and interpretation - of the results.

In the pre-analysis stage, the interviews were transcribed, the body of analysis was read Superficially, and hypotheses were formulated. In the stage of exploration or codification of the material, the data obtained were categorized from exhaustive reading and data saturation in the speeches. In the stage of inference and interpretation, the data were analyzed in the light of the theoretical referential, which in this study were the Public Health Policies.

The study complied with the regulations for research activities and interventions with human beings, in accordance with Resolution 466/12 of the National Health Service, with inclusion of the study participants after formal authorization by means of signature of the Term of Free and Informed Consent (TFIC). The participants were identified by the letters "E" for Nurses, "M" for Doctors and "T" for Nursing Technicians, to guarantee anonymity. The research project was submitted to "Plataforma Brasil" under Certificate of Presentation for Ethical Appreciation (CAAE) No. 34169514.0.0000.0115, and was approved by the Ethics Committee on Research with Human Beings of the State Secretary for Health of Santa Catarina (SES/SC) under the consubstantiated report number 767.502, of August 27, 2014.

## RESULTS AND DISCUSSION

The participants of the present study were 31 professionals from the PCU, among them 14 nurses, nine doctors (six doctors from the FHS and three pediatricians) and eight nursing technicians. The majority of the professionals were women, and the age range was distributed between 27 and 60 years. Of the participants, 64.5% formed part of the FHS; the time of work in the PCU varied from eight months to 27 years, and time since graduation from two to 36 years. Of the total number of interviewees, 29% had another employment tie, with this number being more significant in the category of doctor; 71% were specialized, with a higher percentage of the professionals with higher education; 45.2% had received some type of training in work with reference to child-care.

The results are presented in the following categories: Communication between the reference hospital and Primary Health Care Unit; Follow-up records of the preterm/or low birth weight babies; Hospital visit as a strategy to guarantee the reference and counter-reference system.

### Communication between reference Hospital and Primary Health Care Unit

During the course of the study, some weaknesses were identified in the notification process of the PCUs for starting follow-up of the baby discharged from the NU in PC. In the municipality studied, notification for including the baby in the Precious Baby Program occurred by sending a specific document of the program, and sending the Declaration of Live Birth (DLB) to the child's reference PCU.

Eventually, the authors observed delays in sending the mailbags containing these documents, which exposed the preterm babies, low and/or very low birth weight babies to risk on arriving at home. When questioning the PCU health professionals about how they perceived the process of reference and counter-reference between the hospital and PCU, they reported a discrete or almost no communication between the different levels of care.

*Out communication is very deficient. At times the counter-reference is very rough, but it is better to have a rough counter-reference and for us to know and feel more tranquil, because this came with a signature and stamp, rather than the patient simply being lost in limbo without knowing where to go (M8).*

*There is not much counter-reference; the patient is left rather loosely in the network. The patient comes and goes, "pops up here, pops up there" and the mother doesn't know what to do (E8).*

We observed the communication between the services still frequently occurs in an informal manner, "behind the scenes", when the professionals who work in the two levels of basic care pass on information to which they have access. The present

study pointed out that this communication is even weaker when it concerns a baby discharged from a private hospital, perhaps due to the fact of the baby's follow-up - in the majority of cases - also occurs in a private consulting room, with the pediatrician of the child's health insurance plan, so that the relationship of these families with the PCU is restricted only to having vaccinations and the Guthrie test (often called the 'Heel Prick Test') applied, for example.

*Communication is good, because the work colleague also works in the (public) maternity unit, and makes this "mid-way connection" (T3).*

*preterm babies that come from the (public) maternity unit, arrive very well, notified as Precious Babies, with a summary of the discharge, everything comes very well noted, and there is always a written remark "follow-up in your PCU". I think they prioritize this well[...]. I perceived no difficulties with communication. Whereas it is the preterm babies that I receive from private services that are complicate [...]. The scope of the Precious Baby Program was to cover all the babies of Joinville, but those that were born in private clinics ended up not being referenced, this reference and counter-reference from the private clinic to the health unit does not usually occur (M2).*

The services present deficient communication, and this solitary attendance between the professionals make it difficult to potentiate and provide continuity of care. This weak communication between the health professionals transfers the responsibility for the difficult mission of making counter-reference to the patient - in this case, to the baby's care givers. This being so, it depends on your abilities to provide continuity of follow-up and many end up wandering around in a health system that still has a weak flow.

In Brazil, the present movement of health care systematization has been focused on service offered in a shared network, with emphasis on health promotion, as opposed to the segmented, episodic, curative care still in force. This change in model is, however, a daily challenge to the health care managers and professionals.<sup>11</sup>

The hierarchical organization of the health services are premises of the organizational dynamics of SUS, enabling planning and facilitating access by the population.<sup>12</sup> The Health Care Networks are organizational arrangements that determine the flows in SUS, and have the PCU as the port of entry to the system.<sup>5</sup>

For efficient integral care, the reference and counter-reference is known to be necessary among all the levels of health care.<sup>12-14</sup> The counter-reference places shared responsibility among the health services, particularly for cases of patients at risk.<sup>15</sup> The family must not be held solely responsible for the task of seeking an itinerary for resolving the health requirements of children.

The weakness of an articulated network of health care services for children that would guarantee the effectiveness of reference and counter-reference has also been observed in other studies that have pointed out the lack of knowledge of the PCU with reference to babies' discharge from hospital.<sup>13,16</sup>

Follow-up of babies discharged from NU demands differentiated care, which is facilitated by a closer relationship between the reference hospital and PCU; this favors the exchange of information and continuous follow-up, and meets the special needs of these children.<sup>17,18</sup> The Precious Baby Program is an initiative that favors the conditions that are at present being proposed by the Ministry of Health (MH): communication and counter-reference between the hospital and PCU, guaranteeing the continuity of care.<sup>2,17-19</sup>

### **Follow-up records of preterm and/or low birth weight babies**

Formal communication relative to the process of reference and counter-reference of follow-up of the preterm and/or low birth weight baby in the reality studied, when it does occur, is done through the record of the discharge summary in which the tertiary sector provides the PCU with the information about the baby during hospitalization; and records in the Child's Health Book (CHB). Both documents are delivered to the family members, and thus the children are vulnerable to the extent of their care givers' capacity to pass on the information correctly.

*Frequently the mother does not know how to tell was the specialists told her, at times she doesn't understand, There are mothers who are well instructed, know how to report what the specialist said, but there are mother's who don't know how to say this. [...] I think this part of the communication is bad, it should be better. Particularly because, in Primary Care, we are the ones who carry out the monthly follow-up of these babies (M3).*

*They send the well explained report, but sometimes the mother does not bring these documents, and we end up not knowing about some intercurrent, or some care we have to take as regards the baby. It depends on the mother keeping the document and delivering it to us. It would perhaps be interesting to send the discharge summary by mailbag, and not by the mother - from professional to professional (M5).*

*I think it is a very unreliable communication. It exists, it is a process, we are going in the direction of this, but at a very slow pace. We also have no counter-reference from the premature outpatient clinic. We only know what the mother tells us. She tells us what she feels like telling, or what she remembers. Poor thing! (E13).*

The professionals of the PCU complain of the lack of follow-up records, making it difficult for them to perform follow-up in the primary sector. The low level of use of the CHB was pointed



out, frequently justified by the significant demand and work overload with which health professionals are generally faced. Incomplete filling out of the CHB, irrespective of the reasons for this, on the one hand makes it impossible to provide the child with full care, and on the other, it may induce families to believe that it is not important to use the Child's Health Care Book. The quality of these records has also shown to be deficient. Some professionals consider them insufficient, or not very specific, technocratic, and without presenting a proposal for the continuity of care.

*On discharge, the CHB comes with a discharge summary, but it is something very hospital-like. It is very punctuated. "Intubation, received amikacin", you know, something very hospital-like. It doesn't give much of a hint about what we could be helping them with; what we could do here in Primary Care at home level to help with follow-up. In the discharge summary, in truth they make a summary of the hospitalization. It is not a proposal about what to do from now on (E6).*

*What I receive in terms of reference and counter-reference in my child-care work is written in the child's health book, which at times comes filled out, and at times not filled out. Sometimes I ask the mothers about certain things, and they don't know how to inform. I ask mothers to bring the information in writing, sometimes some professionals write something, but this is not general, and normally this information is verbal. And so, with bits of information, you try to create a history. It is very complicated. Technically, we have nothing in writing (M8).*

The professionals pointed out good communication with the public maternity unit for scheduling with the specialties, however, they usually do not receive any counter-references of these consultations. The municipality recommends that referral to specialties must be done with the proper reference/counter-reference forms, filled out by the FHS doctor, and the counter-reference must be guaranteed by the PCU of origin of the patient, duly filled out by the specialist.

*The counter-reference is extremely poor, it is null. Perhaps, if this feedback were to occur, it would avoid many re-consultations or unnecessary consultations with specialists. If there were a counter-reference, it would be very good; the mother would bring the baby for consultation, and show me what went on at the consultation there. This would help be a great deal in my consultation "Oh, so this was done, so the child is like this [...]". I say there is selfishness and laziness on the part of professionals, of the type "I will do my part, and the others just get on with it the best way they can". (E6).*

Similar studies have also identified that the records of children's attendance were performed in a very succinct manner,

with vague and insufficient notes.<sup>20-22</sup> An integrative review of the literature pointed out that since the creation of the CHB, difficulties have been observed regarding their correct filling out by professionals; and that although they now present a discrete improvement in recording data such as weight and height, the data are not transferred to the graphs.<sup>21</sup> The failure to record the activities leads to waste and lack of information. The adequate use of the CHB constitutes a right of the child population, because it is an important health document of children, and is considered the one who always accompanies the child With your health history. The parents must be oriented how to use the information contained in the CHB.<sup>14,21</sup>

### **Hospital visit as a strategy to guarantee the reference and counter-reference system**

For cases of unsatisfactory evolution of babies during their hospitalization in the NU (children at risk who require special care, who present delay or difficulty in development), a hospital visit made by the PCU team is recommended. The aim of this action is to receive the family, present the baby's clinical condition to the PCU team, and after discharge, guarantee a consultation at the reference PCU in up to five days after discharge from hospital.

The hospital visit proposed by the Precious Baby Program is an initiative that has been shown to be successful in facilitating communication among the levels of health in the municipality studied, favoring strengthening of the reference and counter-reference process. This proposal is in line with the MH recommendation for involving the PCU teams in the care of the preterm and/or low birth weight babies, with emphasis on babies that are participating in the third stage of BMH, guaranteeing shared responsibility for care between the hospital and PCU.

The professionals interviewed pointed out the importance of this activity as a possibility of strengthening the ties between the families and professionals; moreover, it was an important time for more detailed transmission of the babies' condition and their needs for care after discharge.

However, due to some weaknesses in the matter of sending the notification documents to the PCUs, some units did not make the hospital visit because they were not informed in time of the need for this, and received notification only after the baby had been discharged. Therefore, it is necessary to review the process of notification to guarantee that this activity that has shown to be so valuable does indeed occur. Although in some situations telephone contacts requesting the visit have been reported, considering the present connectivity of the virtual world, the authors suggest that these notifications should be made by e-mail, and no longer by fax or mailbag.

*When I made this visit, it was very interesting, I was very well received, and they provided me with all the information about the child. I went back well prepared to guide care of the child and provide this mother with support at home (E12).*

*I think it was important to go to the maternity unit, because working in family health, you assume the population and it is important to appreciate the tie.[...] So visiting the hospital in a situation such as this of the Precious Baby, I think is very important, for the mother who may have done her prenatal checks with you, she also did the prenatal check at the maternity unit, and her tie is strengthened. Not only getting to know the child's situation itself, but it is the creation of a tie. And this mother certainly ends up bringing the child for a consultation every month (M8).*

*I think this visit is very important, very important indeed! Because until we receive the discharge summary, there are many hospital terms that are not experienced by us in Primary Care, so I think this verbal communication and presence at the maternity unit favors communication and helps us with providing care at home. It is always going to be better than a record only on paper (E12).*

The guidance of the multiprofessional team during hospitalization is fundamental for safe care provided at home, and therefore, communication between the tertiary care service and the PCU in this process will amplify the family's confidence for developing care of the baby.<sup>15,18,23-25</sup>

The authors suggest that nurses should be responsible for the initial contact with the PCU, passing on important information about the children's period of hospitalization, scheduling the hospital visit and guaranteeing the first consultation at the PCU, and this may be an important strategy in overcoming the gap existent between the hospital and the PCU.<sup>26</sup> Proposals that seek de-hospitalization and propose care at home require agreements and guarantee of access to all levels of health, with well-established flows of reference and counter-reference.<sup>27-29</sup>

## FINAL CONSIDERATIONS

The model of health care in the country is formed by a hierarchical network that still presents weak communication among the various levels of care. The health professionals interviewed pointed out that the process of reference and counter-reference occurs in a timid manner, without adequate records about procedures and referrals made during attendance of the children, in addition to insufficient use of the Child's Health Book (CHB). The task of passing on information and guaranteeing counter-reference was given to care givers, making the attendance of these babies vulnerable.

As regards attendance of babies discharged from the NU, the authors point out the importance of performing an articulated network service that recommends anticipated communication between the maternity unit and the PCU. The hospital visit was shown to be an adequate strategy for closer relations between health professionals and families, guaranteeing integral care and favoring the tie with the community.

The limitations of this study are on the focus of the subjects that occurred, pointing out exclusively the perceptions of health

professionals in primary care about the process of reference and counter-reference regarding these babies. Therefore, the authors recommend that similar studies should be conducted, which investigate the perceptions of family members and professionals about the phenomenon at the tertiary level.

Considering the results of this study, it is necessary to strengthen the model of inter-institutional communication, guaranteeing an adequate flow of reference/counter-reference that includes all the health services of both a public and private nature. Moreover, the authors expect that health professionals will be made aware of the importance of records when attending children.

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