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Itinerário terapêutico: a busca por cuidados de mães cujos filhos faleceram com menos de um ano

Therapeutic rout: the search for care of mothers whose children have died less than a year

La ruta terapéutica: la búsqueda de las madres lactantes cuyos hijos murieron en menos de un año

Daniel Moreira Paes Landim¹, Sued Sheila Sarmiento², Cláudio Claudino da Silva Filho³, Nayara Mendes Cruz⁴, Laisla Alves Moura⁵ e Lucia Marisy Souza Ribeiro Oliveira⁶

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ABSTRACT

Objective: recognizing the care trajectories of mothers whose children have died less than a year. **Methods:** this was a qualitative study conducted with pregnant women who reported fetal or neonatal death during the year 2012 in the countryside of Bahia municipality. To collect data, we used the in-depth interview and analysis content analysis technique proposed by Bardin. **Results:** one can see the clutter on the network of health care of women with predominance of dehumanization traits and difficulty by professionals in continuing care in other levels of care. **Conclusions:** the study of the care trajectories revealed itself as a tool of therapeutic rout invaluable to assess the functioning of health care networks, making visible successes and difficulties presented in the context of care to pregnant women.

Descriptors: patient acceptance of health care; pregnant women; health care.

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RESUMO

Objetivo: conhecer as trajetórias assistenciais de mães cujos filhos faleceram com menos de um ano. **Métodos:** tratou-se de um estudo com abordagem qualitativa, realizado com gestantes que referiram óbito fetal ou neonatal durante o ano de 2012 num município do interior da Bahia. Para a coleta de dados utilizou-se da entrevista em profundidade e para análise a técnica de análise de conteúdo. **Resultados:** pode-se perceber a desorganização na rede de atenção à saúde da mulher com predominância de traços de desumanização e dificuldade por parte dos profissionais em dar continuidade ao cuidado em outros níveis de atenção. **Conclusão:** o estudo das trajetórias assistenciais revelou-se como uma ferramenta do itinerário terapêutico inestimável para avaliar o funcionamento de redes de atenção à saúde, tornando visíveis acertos e dificuldades apresentados no âmbito da assistência prestada à gestante.

Descritores: comportamento de procura de cuidados de saúde; gestantes; assistência à saúde.

RESUMEN

Objetivo: conocer las trayectorias de atención de las madres cuyos hijos murieron en menos de un año. **Métodos:** este fue un estudio cualitativo realizado con las mujeres embarazadas que informaron de la muerte fetal o neonatal durante el año 2012 en el interior del municipio de Bahía. Para recopilar los datos, se utilizó la técnica de análisis de contenido de la entrevista en profundidad. **Resultados:** uno puede ver el desorden en la red de atención de salud de las mujeres con predominio de rasgos de la deshumanización y la dificultad de profesionales de atención continua en otros niveles de atención. **Conclusiones:** el estudio de las trayectorias de atención se reveló como una herramienta de itinerario terapéutico de gran valor para evaluar el funcionamiento de las redes de atención de salud, haciendo visibles los éxitos y las dificultades que se presentan en el contexto de la atención a las mujeres embarazadas.

Descriptores: aceptación de la atención de salud; mujeres embarazadas; prestación de atención de salud.

INTRODUCTION

Brazil has been reducing the infant mortality rate since the late 1980s, due to the increase of the educational level of the population, reduction of fertility rates, environmental interventions, nutritional improvement and progress in the quality and access to health services, reflecting the greater and better capacity to care for and meet the newborn.¹

In this context, proper care for newborns has been set as one of the challenges for the reduction of infant mortality rates in Brazil, given its contribution to the healthy development and growth, as well as the control and prevention of disease and injury.¹

However, studies about the therapeutic itineraries demonstrate the importance of the experiences of the subjects in the disease processes and the multitude of existing paths and choices in this process. The understanding of how individuals and social groups build their therapeutic itineraries is essential to guide new practices in health.²

When considering the diversity of assigned settings, this study considered the following concept of therapeutic itinerary: movements activated by individuals or groups

in the preservation or restoration of health. Referring to a succession of events and decisions that, aiming the treatment of the disease, builds a certain trajectory.³ This constitutive element or founding notion involves socio-cultural and individual health practices, undertaken in the paths taken by individuals in search for treatment to solve their problems.⁴ Therefore the following question was asked: "Which are the care trajectories of mothers whose children died less than a year?"

Recognizing the importance of studies that seek to present the user-drawn path and his family in the health/disease process, and thereby identifying the difficulties, obstacles, hardships and potential access to health services in the attention network for maternal and child health studied, the aim of this study was to recognize the care trajectories of mothers whose children died in less than a year.

METHODS

It is a qualitative study conducted with pregnant women who reported stillbirth or neonatal during 2012. This method lets you gather information about the history, relationships and perceptions of individuals regarding a phenomenon.⁵

To be included in the survey the woman needed her son's death to have occurred in one of the age groups of neonatal mortality: early neonatal death (in less than 07 days); Late neonatal mortality (between 7 and 28 days); and post-neonatal mortality (between 28 days and 01 incomplete year); or be configured with stillbirth. Six women collaborated with the study, the selection of participants was held at the Maternal Mortality Committee of the municipality locus of this study. Those departments are studied cases of maternal and infant mortality occurred in the municipality.

For data collection it was used the in-depth interview by audio recording, which seeks to collect answers from the subjective experience of a source, selected for holding needed information.⁶ Interviews were conducted during previously scheduled meetings through the Community Health Agents (ACS), as soon as the subjects agreed to participate in the survey and agreed to sign the free and informed consent.

The study was approved by the Research Ethics Committee and in Ethics and Studies (CEDEP) of the Federal University of Vale do Sao Francisco (UNIVASF) under the Protocol 0016/121212, respecting the ethical aspects recommended by Resolution 466/12 of the National Council Health, among which: the principles of autonomy, beneficence, non-maleficence, justice and equity. The interviewees were not exposed to physical and/or psychological risks, and had full liberty to refuse to participate or withdraw at any stage of the research, withdrawing their consent without any penalty.⁷ In addition, the confidentiality of information was guaranteed, being identified with the codename Mater, which means female figure socially responsible to play the role of mother, mothers'. Each mother was identified with letters of the alphabet ordered from A to L.

The data obtained in the survey was analyzed by content analysis technique⁸ and comprised three stages: pre-analysis, material exploration and treatment through interpretations. From this process, we sought to categorize the data, and thus made possible the emergence of “Weaving reflections on the therapeutic itinerary as evaluative practice of health comprehensiveness” and two subcategories: adversities in access to health and adversity services access as well the quality of care in the network of attention to maternal and child health.

RESULTS

Network of maternal and child health care

At first, it was necessary to detail how is the operation of the attention network to the woman in labor in the various segments of complexity, on the site chosen for this research.

Thus, it is known that the Juazeiro municipality is considered one of the development poles of the North macro-region of Bahia, along with the municipality of Petrolina, State of Pernambuco, neighbouring city, forming the Integrated Administrative Development Region Pole Petrolina/PE and Juazeiro/BA (RIDE), created on September 19th, 2001 by Complementary Law number 113, with the objective of coordinating and managing actions of the Federation, the States and municipalities in promoting projects aimed at economic strengthening and provision of infrastructure necessary for the development on a regional scale.⁹

Given this scenario, along with the assistance trajectories shown, health services in both counties will be appointed in a rather peculiar arrangement of network. Public health services used in the city of Juazeiro were: Family Health Units; Family Health unit, reference in prenatal high risk; Mobile Emergency Service; Juazeiro’s Municipal maternity; and Juazeiro’s Childs Hospital. Petrolina’s public services used were the Dom Malan Hospital, obstetric referral service of high risk in the region. Also, it was constantly perceived reference to performing ultrasound examinations in private services, the difficulty of access encountered by women in obtaining examination from the public system. In minor proportion, routine laboratory tests and medical consultations in private services were performed.

Preparing thoughts about therapeutic itinerary as evaluative practice of completeness in health

The therapeutic itinerary consists of a complex phenomenon involving many variables and circumstances. These by careful search paths were built indispensably from concepts that have settled on various treatments to meet a multitude of demands for health, access to varied Health Care Systems.

In this research it was assumed that the therapeutic itinerary as an evaluative practice, user-centered, valuing the

optical contributions of those who seek and experience care, the organization of health services and the resoluteness of their demands.³

However, it is significant to clarify that the intention of this research is to systematizing and weaving reflections on findings along the care trajectories that, despite raising repercussions with evaluative inferences, do not pretend to judge absolute failures form, nor assign blamed professionals, institutions and management of health services.

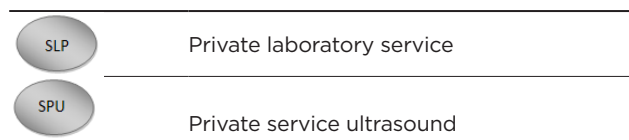
Graphical representations will be used to provide better visualization of the care trajectories of mothers in seeking care for themselves and minor children of a year over the care network for maternal and child health. These representations not intended to portray all the search times for care services, but the paths progressively outlined in the care trajectory.

The opportunity of explaining the trajectories will be presented important and contextual information of each case, with particular emphasis on the existence of deficiencies in access and/or quality of care throughout the different health services, and for the routes that should be undertaken, but it did not happen for several reasons.

The following pattern is exposed legend for interpretation of welfare trajectories shown.

Table 01: default caption of the graphical representations of the assistential trajectories on line focus on maternal and child health.

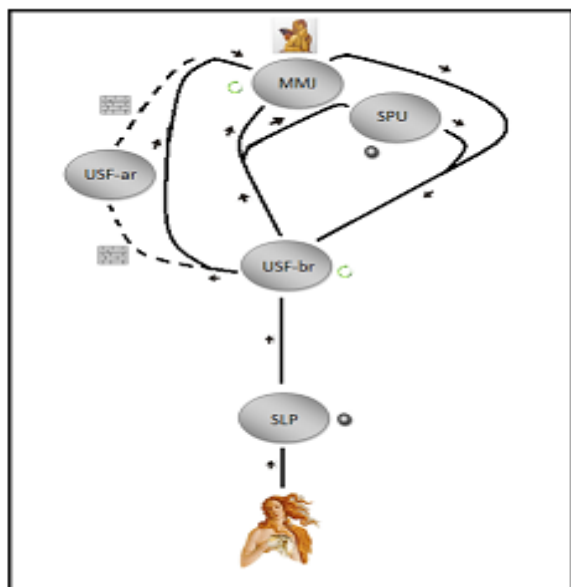
	Path travelled
	Path that should be followed
	Evidence of difficulty in accessing the service
	Signs of deficiency in service
	Continuum of care in service
	Occasional care in service
	Private practice of obstetrics and gynecology
	Children’s Hospital of Juazeiro
	Hospital Dom Malan (Outpatient)
	Hospital Dom Malan (Maternity)
	Private Hospital of Petrolina
	Municipal Maternity of Juazeiro
	Mobile Emergency Care Service
	Family Health Unit, prenatal low risk
	Family Health Unit, prenatal high risk



Adversities in access to health services

We present the trajectory of care Keeping A, talking about the lack of access to prenatal care, as a point to be reflected towards the proper functioning of the network of maternal and child care in the municipality locus of this study.

Figure 01: graphic representation of the trajectory of the Mater A.



Soon after the discovery of pregnancy, Mater A, immediately sought prenatal care in the FHU of her neighborhood, where she received basic care, continuous, and conducted laboratory tests. The ultrasounds were performed in MMJ, and tight supply that service in the core network, were also held in private service. The opportunity of performing ultrasound with six months of pregnancy in MMJ, Mater A, was warned by the doctor that her pregnancy was considered risky, and therefore forwarded to FHU, gateway and regulatory for specialized services, so that she could have access to healthcare flow of high-risk prenatal care. However, she did not have access to high-risk care because the medical reference service was on vacation and was not replaced by another professional. The service was “discovered”, specialized care no longer provided and comprehensive care was compromised.

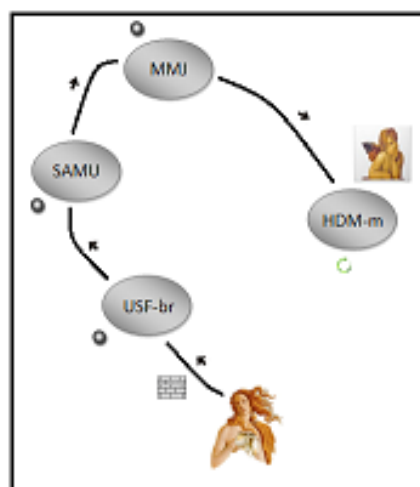
“The doctor told me that my pregnancy was at risk and that it was for me to search the station staff. Then by the time I got there the doctor was on vacation. So

my husband took me to a Maternity Health Unit. I was already completing six months”. (Mater A)

Mater A only got a scheduled consultation for prenatal high risk service when she was eight months pregnant, but was never attended, because before the scheduled date she gave birth in MMJ through vaginal delivery without difficulty, but the child was born dead.

Another aspect found on the difficulty of access of pregnant women to services was the professional conduct element in the provision of care, as presented in a clear and alarming way in care trajectory for Mater B, illustrated by the following graph:

Figure 02: graphical representation of the care trajectory of Mater B.



Two months pregnant, Mater B showed some signs and symptoms of pregnancy then sought the FHU of her neighborhood to find out if she was pregnant and then perform prenatal care.

However, during seven months she was pregnant was had only two pre-natal visits. This pattern of behavior was determined by the professional who led her prenatal, by difculting the acess to consultations by demanding the presentation of results and tests ordered for pregnant women in the previous query.

In this context, on the first prenatal visit that the patient underwent, at two months of pregnancy, the professional requested routine tests and a ultrasound. Mater B only could perform the subsequent consultation when she had the results of these tests at four months of pregnancy.

The second consultation also proceeded with the same modus operandi, other tests and a second ultrasound had been ordered and the patient was directed to return for subsequent consultation when she got the results. What did not came to happen because Mater B gave birth before that was possible.

When bleeding was detected, Mater B was moved to the MMJ through the SAMU and subsequently was transferred to the HDM.

“No. I went to have it in the afternoon and spent the whole night. And I went to the hospital the morning. [...] I went straight to the hospital for the girl to be born already. [...] it was then when I felt the bleeding, I said, look, I’m going to lose the baby, it seems. [...] Called the SAMU, took me to the Maternity. From there he said: You will have your pre-mature daughter, moved to Dom Malan and there I had the child”. (Mater B)

It can be seen a reversion in the trajectory of care modality that should have been provided at FHU, which was remarkably specific and technical, not exercising continued care to the prenatal needs.

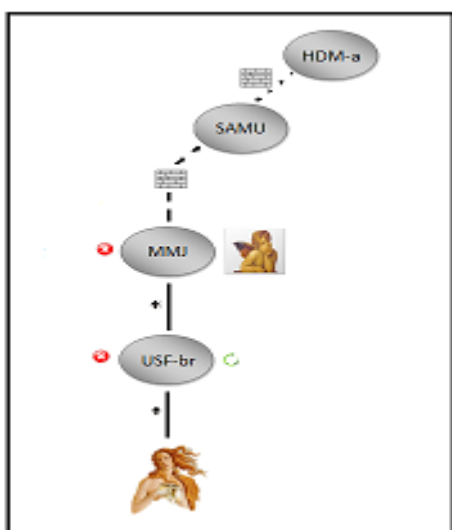
It was identified that Mater B received more care in the hospital service than in primary care which is contrary to what the public health policy advocates.

Adversity access and also in the quality of care in the care network for maternal and child health

The trajectories presented below exemplify situations of disability both in access to services and the quality of care, interfering therefore negatively on the health of mother and child, with culmination in neonatal death.

The following sets up graphical representation of the care trajectory of Mater C.

Figure 03: Graphical representation of the care trajectory of Mater C.



Mater C discovered she was pregnant from the confirmation after conducting ultrasound examination. Since then sought prenatal care at the FHU of her neighborhood, which occurred continuously.

During pregnancy she had an urinary infection that was ineffectively treated in the FHU and later had the outcome of preterm labor (TPP).

“The examinations indicated Infection. He (the doctor) did not prescribe any tablet or pill; just an ointment and also I lost fluid”. (Mater C)

The analysis of the prescription practices adopted is not made in this study regarding the treatment of urinary tract infection, but that care undertaken in curing the disease was not effective.

Now nearly six months pregnant, Mater C began to feel cramps and loss of amniotic fluid, however, did not realise that it was a labor and took too much time to seek help at the Maternity. The institution took too long to provide initial care, which further aggravated the situation.

Once care was received at MMJ she should have been forwarded to the HDM, through SAMU, because her son would be born pre-mature and MMJ did not had ICU (Intensive Care Unit). However, despite the SAMU ambulance having arrived to carry Mater C to HDM for Maternity, this path did not materialize because the ambulance was redirected to meet an accident that had just occurred.

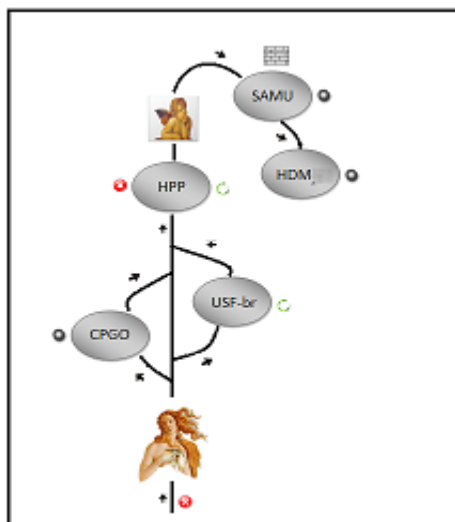
“Before the boy was born, they told me to wait for the SAMU. When the SAMU got there said they would not take me for what had just happened; an accident and they had to go help a person”. (Mater C)

Mater C, also reveals that the care she received at the Maternity was scarce and by lack of guidance the child nearly fell into the toilet during childbirth. Her son died with few hours of life.

Only after being admitted to the MMJ, Mater C found that her blood Rh factor was negative, different from her husband’s which was positive. And she remained hospitalized for about four days in the maternity waiting for immunoglobulin to arrive at the institution for therapy in cases related to hemolytic disease due to Rh incompatibility.

Mater D’s assistance trajectory, shown in Figure 04, also gives opportunity to rich reflections on quality of care.

Figure 04: graphical representation of assistential trajectory of Mater D.



Mater D had a healthy pregnancy and was quite frequent to maternal care. when feeling pain and contractions increasing progressively she sought the HPP, where she gave birth.

She reports that her birth happened very quickly, and that the professionals did not take into account subjective and emotional issues of the birth phenomenon, and it was essentially technicalities.

According to Mater D the newborn was attended by pediatrician who performed physical examination in the children, including auscultation and testified that the child was healthy and did not have any problems; although the newborn has drawn considerable amount of meconium during birth procedure.

“When the other day was the pediatrician came. [...] She put the device in the boy’s lungs, took off his clothes, everything, everything, everything, took off his clothes, did the exercise in the legs and said, mother your baby’s great, it is already been released (Cry...)”. (Mater D)

Mater D, even went home with the child, but still returned with the child to the HPP twice; getting the child admitted that second occasion. In this second phase, some circumstances lead to the inference that there was an attendance underestimation of the child’s health condition and/or an attempt to easing the problem that the newborn had in front of the mother.

“I took him when he got there she said, No mother with a fever he’s, but he did not have anything. Put the device in the boy’s chest and said he had nothing. When the pediatrician returned, she said, his chest is too sizzling, he swallowed much meconium”. (Mater D)

“When the other day was took blood and urine test, there have spoken: no mother, he is not anything, it’s just with a little infection”. (Mater D)

This obscurity of what really was happening to minimize the severity of the child’s health status generated in Mater D wrath and anger after abruptly knowing what was really happening.

And it was only medical malpractice, there cannot have died, he was healthy, healthy. Because it is not that I forced him to be healthy, the exams showed it. (Mater D)

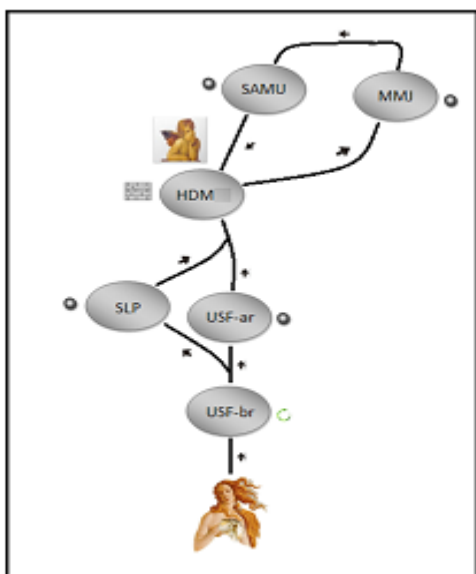
The child needs urgently to be transferred to the neonatal HDM ICU; however, there was some difficulty to access the SAMU service and some mistake regarding the use of appropriate equipment for carrying out transmission, which prolonged the time for the child to be admitted to the most appropriate service for its health needs.

“Then I saw that he was as bad as I Said So: let’s get it anyway? As I see that they are not taking any action I will take it by my own will, we will take it. If he’s already really dying will get him, we’ll see what happens. And when i was to taking him,they said: no, not now that SAMU already arrived. The SAMU who came did not come with a oxygen tank, then came the ambulance with oxygen. and only then released to Dom Malan.” (Mater D)

In HDM the child was attended and admitted to the ICU, but died of septicemia.

In the course of Mater E, Figure 05 followed a harmonious and smooth flow of care, with no evidence of problems or malpractice on access and quality of care, until the moment of birth. She Initiated prenatal care through primary care in the FHU of her neighborhood and with three months of pregnancy took an ultrasound in SLP, by which was found that the child had hydrocephalus and from this discovery received prenatal care at high risk, in a very accessible way.

Figure 05: graphical representation of the care path of Mater E.



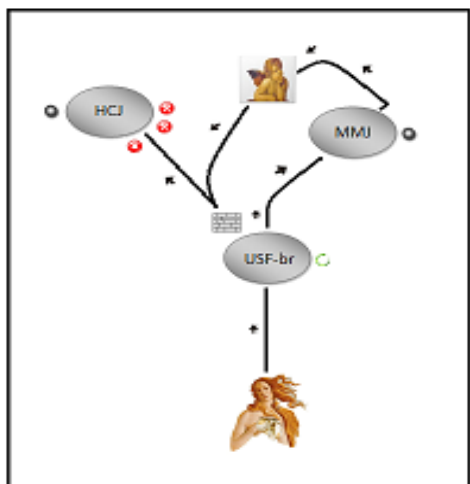
Evidence of Access deficiency occurred specifically in the HDM. As soon as labor pains started she headed for the HDM in Petrolina in search of assistance. However, she was not attended in the hospital because of allegations that the service was full of patients.

It was not taken into account the risk that her pregnancy had and also that the MMJ could not provide them with proper care quality and security. Since the reference for attention to high-risk birth in the region is the HDM.

As a result of the adopted strategy in MMJ it was realized that it would not be possible to carry out the delivery at the institution and had to transfer her to the HDM. But the child did not survive and died a few hours after birth.

The assistance trajectory of Mater F, displayed in Figure 06, also raises reflections about access and more pronouncedly, about the quality of care that happens in child care.

Figure 06: graphical representation of the care trajectory of Mater F.



During this trajectory there was no exhibit of health problems with the mother or indications of difficulty in access and assistance during prenatal care, in the neighborhood's FHU and either in MMJ during childbirth.

I went every month to go through the medical procedures. I Made the consultation and I would go, scheduled for her. [...] Asked how the baby was, looked at the baby, looked at the baby's heart, if everything was okay. [...] Everithing Happened correctly, nothing happened to me. (Mater F)

The day after the birth, mother and child were discharged from hospital and returned home. The child was born healthy and remained healthy at home for 28 days, after what started presenting illness.

Because she was changing color, was getting yellowish, she was soft, with hurting eyes, she had fever and ear pain. (Mater F)

With the recognition of the child disease, the family sought care for the child at the neighborhood's FHU, but the service had no medical professionals, therefore care to childhood diseases were not happening in that service.

Guided by FHU staff they sought treatment on their own in HCJ. The child's care in the hospital was considered of low quality and inefficient by the mother. As reported, there were serious shortcomings in care, with a severe case as outcome.

I found it very bad, they do not treat the people the right way. [...] For me it was not solving anything; it was worse. Bought two remedies for her, the girl got worse. Becoming yellowish and getting soft. (Mater F)

For three consecutive days they took the child to the HCJ in a context of progressive worsening of the health status of the child, who has not hospitalized.

According to medical reports, the girl did not present any health risk, and the conduct held for two consecutive days was: use of prescription drugs and return to the institution if there was no improvement. As a Result, the third consecutive time she sought care at the institution the child died at the hospital door.

He declined to hospitalize my daughter. Last time, it was also the same thing, did not took her in. [...] The doctors did not want to consult, they refused to hospitalize her. She came and died in hospital door. [...] they said that she was not feling anything and sent her back. [...] they said she had nothing and that she had to go home, and if

she got worse to return to the hospital. It was three days taking her to the hospital! Every day. (Mater F)

It appears with certain security, from what was reported by the mother, that the way the case was watched and conducted generated harm to the child.

She drew attention to another noteworthy point in the trajectory. When she got off the bus in HCJ door, the mother found that the child was dead, but was stunned and paralyzed, and had no attitude other than entering the institution for help in a troubled time with feelings of angst, anger and disbelief with the care provided in the hospital.

It was in the hospital door. She arrived there dead in my arms. [...] In the hospital door when I took off the face cloth she was dead. [...] She died in my arms at the door and I brought her home. I did not enter! Only I waited for her father to arrive and went home. [...] how will i think of entering with a dead girl? They did not do anything for her when she was alive, what would they do with her dead? I was desperate for having lost my daughter and to this day I think of her. Because giving birth is not easy and to lose, too, is not easy. Very angry. (Mater F)

DISCUSSION

It was observed in this study, adversity in the treatment network for maternal and child health studied, both related to quality of care, as the difficulty in access of pregnant women to various services such as high risk prenatal care, medical specialists, examinations, care of emergencies, among others, which inevitably resulted in losses in comprehensive care.

The comprehensive care is based on promotional activities; articulation of prevention, promotion and recovery; and ensuring attendance at all three levels of complexity, establishing itself as one of the pillars of the health system.¹⁰ Thus, health services and systems need to become more in tune with the real needs of people being necessary to organize obstetric and neonatal networks for care services, providing care to high-risk pregnant women and emergency situations, including referral mechanisms and counter-reference, thus enabling the fulfillment of one of the principles of the SUS, which is the integrality.¹¹

It is important to consider that difficulties in accessing services, not infrequently involve decreased quality of care provided to the individual throughout his trajectory in search for care. From this perspective, there is evidence that the maternal and perinatal mortality levels are influenced by the living conditions and quality of the provided prenatal and obstetric care.¹²

Thus, it is necessary to ensure the quality of antenatal care widening accessibility and this care, which includes guidance received, number of consultations, early prenatal care, increasing the supply of health services, access to

examinations and procedures, and the existence of formal mechanisms for referral and counter-referral between levels of care.¹³

The Mobile Emergency Care Service has been identified throughout the study with an important provision for continuity of care between services and the promotion of health in entirety. Related to the subject, a previous study aimed to characterize the care provided by the Mobile Emergency service in the city of Cuiaba and found that 13,6% of pregnancy-related care is, childbirth and postpartum, being the third most frequent among clinical causes.¹⁴

This study also signaled some situations of institutional violence and violation of women's and children's rights. In this context, an earlier study relates this phenomenon to the precariousness of the system, which in addition to subject their workers to unfavorable working conditions, such as lack of resources and low pay, also greatly restricts access to the services offered, making pregnant women, women in labor or in situations of abortion and postpartum women, undergo long traversies to find perinatal care or seat in the public system, submitting to serious risks for both their lives and those of their children.¹⁵

In face of what was discussed, we can see the immediate need to improve the structure and quality of the care network of health care for the mother and child as well as the qualification of attention of health professionals in pregnancy and childbirth in all services and levels of complexity, aiming at life quality from the comprehensive care and universal access to contain increasing morbidity and mortality rates of users for lack of access to these services and poor quality of care.

CONCLUSION

The study of welfare trajectories turned out to be a tool of the therapeutic itinerary invaluable for assessing the effectiveness of health care networks, making visible rights and wrongs of quality provided by the health services and pointing out aspects that are not being effective, providing opportunities like this that improvements can be made in a more targeted and systematic manner.

Despite the restrictions of the search locale, it is believed that this study reflects a phenomenon common to other municipalities in Brazil. Therefore, it is expected that this work will contribute to further discussions on the subject in question and its many ramifications and that will allow a contribution to those who struggle daily in the relentless pursuit of improving the quality of health care and of Care Networks to Maternal and Child Health.

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