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Healthcare itineraries of women with histories of hypertensive syndromes during pregnancy

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This paper aimed to analyze the healthcare itineraries of women with histories of hypertensive syndromes during pregnancy. The method used was to study oral reports, and the results from 35 interviews were grouped into four thematic categories: comprehension of health and illness; perceptions of risk; institutional interactions; affective and family interactions involved in seeking care. Multiple situations of vulnerability affect the care itinerary, including difficulties in accessing specialized services and relationships with healthcare professionals. Knowledge and healthcare practices shared within the community are important resources in constructing care, which can also be affected positively or negatively by the dynamics of interactions within the affective-family network and by the social support received.

Keywords: Healthcare service access. Comprehensive healthcare. Pregnancy. Hypertension.

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Introduction



Hypertensive disorders of pregnancy constitute one of the major causes of maternal mortality and severe morbidity in Brazil^{1,2.} Pregnancy can be complicated by pre-existing hypertension and/or forms of gestational hypertension, including preeclampsia and eclampsia.

In Brazil, official data show an important prevalence of hypertension in women at reproductive age, representing 9.7% women between 18-24, 15.4% between 25-34 and 21% between 35-44 years old³. Chronic hypertension and history of hypertensive disorders in previous pregnancy represent reproductive risk and require total attention to reproductive health before, during and after pregnancy.

The Ministry of Health, through guidelines and actions, has invested in the quality of high-risk pregnancy management and implementation of a specialized services network⁴. The efficiency of this specialized assistance obviously depends on the implementation of proposals, issue of frequent discussions among managers and health professionals. However, in many situations, as in the case of hypertensive disorders, little attention is paid to the reproductive health of women in non-pregnancy periods, although the reproductive risk may already exist or persist after pregnancy. How do these women take care of themselves and are taken care of before the advent of a pregnancy? What about after a high-risk pregnancy, what is their health condition like? Do complications persist and threaten women health potentiating problems in future pregnancies?

The present study analyses healthcare itineraries of women with history of hypertensive disorders of pregnancy. Correlating healthcare itineraries and pregnant women with hypertensive disorders is relevant to the collective health field, given that the understanding of the course of actions and interactions with different healthcare systems, contexts and meanings of health and illness given by women allows professionals and public policy makers to improve attention to healthcare according to the principles of right to health, reproductive rights, comprehensive assistance and health promotion.

In this study, the term "healthcare itinerary" is used based on the theoretical fundamentals of the therapeutic itinerary category⁵. Different from "therapy", the notion of "care" allows a wider comprehension of physical, psychological, social and cultural dimensions involved in the health and illness experience, as well as in the discussion of prevention, promotion and health recovery practices⁶. When considering care provision along time, life condition, experiences and individual interactions with other people, groups and institutions are evaluated. When reproductive health is focused, dimensions other than gynecological and/or obstetric illnesses are involved, where the articulating nucleus is the commitment to promotion and practice of sexual and reproductive rights.

Subjects and methods



The present study was performed with a population of women who had labor in 2011, in a university maternity hospital in Rio de Janeiro city, which is reference in high-risk pregnancy. The method used was the study of oral reports⁷, focused on itineraries of healthcare provision. The inclusion criteria comprised history of hypertensive disorders in last pregnancy, regardless of age or labor type, and postpartum hospital discharge 6 to 18 months before interview. The purpose of this time gap was to analyze care provision after hospital discharge and to minimize the memory bias.

Data collection was performed by in-depth interviews, using a thematic list, to stimulate women to talk about their healthcare history. From a list of one hundred and eighty-nine eligible women, in chronological order according to childbirth date, sixty-three could not be contacted by phone and eight refused to participate in the study. Thirty-five women were interviewed between May and September of 2012. The material was audio-recorded and subsequently transcribed. Data collection was interrupted when content of narrative report was recurrent, reaching progressive saturation.

Following multiple readings, a comprehensive and comparative analysis was performed⁷, identifying relevant content, which was grouped in four thematic categories: understanding of health and illness, risk perceptions, institutional interactions and family-affective interactions involved in the search for care provision.

This study was approved by the Research Ethics Board of the Fernandes Figueira Institute/Fiocruz (CAAE 00842912.8.00005269). Fictitious names were used to guarantee anonymity.

Results

Over half of women were aged 20-35 years; thirteen women were over 35 and three were teenagers. Most women lived in Rio de Janeiro, declared their skin color as black, had life partners, and eight years of complete studies the maximum. Half of women performed no paid activity and thirty-two had family income lower or equal to three minimum wages, including seven women who lived under a minimum wage.

Sexual initiation occurred during adolescence for twenty-eight women; in one third of cases, before 15 years of age. Many women had history of three or more pregnancies (21) and had two or more living children (27). The great majority of pregnancies were unpredicted, either for being unexpected, for happening under contraceptive use or because women believed they were infertile or in the menopausal period.

Frequently, unexpected pregnancy stimulated doubt about its continuity. In some reports, women did not accept themselves pregnant, which caused late initiation of the prenatal care and/or



attempt of or actual abortion. History of abortion was a frequent event (13) and some women revealed to have performed this procedure under unsafe conditions.

Health and illness experiences

Many women were bearers of chronic diseases or health-risk conditions, such as chronic hypertension, diabetes, rheumatism, lupus, breast cancer, overweight, obesity, tobacco and alcohol abuse. The awareness of these conditions was acquired with time, when discomfort or symptoms appeared, motivating the search for healthcare. Before these events, these women's lives were little ruled by prevention or health promotion practices, except irregular gynecological appointments, or preventive care.

Only I did not care after myself very much. I did not have high blood pressure. I didn't feel anything... I mean, because I did not know, right? Also I did not care myself, did not go to the doctor, cardiologist. I always went to the gynecologist, but I did not care after myself (Berenice, 41 years old).

Health itself is not a central and primary object of investment, in a context where other needs are more persistent, like those related to household chores, children care and work outside the house, health service difficulties, and economical limitations, among others – frequently shared difficulties that restrict the possibility of help from family-affective networks. The absence of symptoms is often enough for women to believe they are healthy, so they fell well and carry on with life.

I actually went to the public health center, but I had to get up very early and wait in line to get a number and, I could not go, with G. a newborn and F. with about 2, my husband had to go to work. My sisters work. My mother works. There was no way I could get up very early in the morning and wait in line at the public health center with a caesarian surgery and two small children. Then, I quit it (Madelucia, 27 years old).

I kept saying, 'I have to do the preventive care', but about blood pressure... sometimes going to a doctor takes a lot of time and work. It is a difficult situation. I would like to have time for many things, but unfortunately I don't. I only go when I can't take it anymore (Aline, 34 years old).

The awareness of other health and care practices learned from family and community, as well as access and problem-solving difficulties in health services motivate alternative care practices. For disease treatment, consumption of vegetable juice formulas and different kinds of tea, such as parsley



root, cilantro, birdseed, sugarcane leaves, shell ginger, chayote, etc. are used. Chayote tea, specifically, was frequently mentioned as it is considered effective for blood pressure control, and can be used alternate or concomitantly with anti-hypertensive medication. Spiritual resources are also used as healthcare and disease control: consultations with fortunetellers "to take away negative energy or renew energy" (Bruna, 27 years old) and faith in home remedies.

I would drink tea. I did everything I was taught. A bunch of tea...cilantro tea, birdseed tea, sugarcane leaf tea, chayote juice. For me, the blood pressure went back to normal. I don't know if it was that faith I had in those medicines, but for me it worked. I would stop taking the medication to take tea (Carmen, 32 years old).

Awareness and unawareness of reproductive risk

The awareness of risks associated with reproductive processes occurred in different contexts. For many women, the news of the reproductive risk was given by health professionals, during pregnancy or after a miscarriage. Others presumed risky situations in case of pregnancy, even before a medical diagnosis, for being bearers of conditions like chronic hypertension or diabetes. One interviewed woman mentioned that she was hospitalized due to hypertension and, while observing other pregnant women in similar situations, she realized that she was also at risk. In none of these situations, the awareness of their own or the baby's health risk was a reason of fear or concern.

They said that the H. [reference-hospital] is only for high-risk pregnancies. In the room where I was, the girl said that her pregnancy was high-risk. I said: 'Then mine is too', but no doctor told that my pregnancy was high-risk... I was worried, right? I had preeclampsia (Grace, 17 years old).

The doctor on the day... I wasn't well, she talked to me. It was awful, because I thought about everything ... that I could die. I thought that my daughter... It was very bad... I was very worried about my daughter (...) I was very worried during labor. Even because of the risk of eclampsia and everything else. I was very scared. (Celia, 24 years old).

Before and after pregnancy periods, even for those with chronic conditions, the idea of "reproductive risk" tends to diminish; plunging to a type of unconsciousness status, and healthcare is not ruled by the perspective of reproductive health risk control by women or by the professionals who assist them. Specifically in the puerperal period, many women do not see themselves in a risk situation and are not instructed about the importance of clinical follow-up, focusing care on the newborn baby; caring for her health itself is voluntarily left in the background.



Reproductive planning practices are also a good example of little attention to reproductive risks out of pregnancy. Professionals who provide this assistance are very often not very attentive to the conditions and clinical records of women, for example, prescribing inappropriate methods, such as hormonal contraceptives for women with hypertension and diabetes. Even with history of high-risk pregnancy, either due to difficult access to health service, solution of problem (including the desired sterilization or vasectomy), or to the habit of self-medication, women frequently buy pills or injections directly from drugstores, which are taken without professional follow-up and, at times inappropriately, potentiating the already existing health risks.

He [the gynecologist] prescribed contraceptive pills to regulate my period, for blood pressure and metformin for diabetes. Then I got pregnant and miscarried it. The doctor said that it was because the metformin was very strong. It was 850. And captopril. Pregnant women cannot take these medications (Cassia, 37 years old).

I went to the public health center. It was my first appointment there and they said that I had high blood pressure. I was referred to the H. [reference- hospital] I smoked a lot then, and I still do. And up to this day I have high blood pressure. I take medication... I take pills... I used to take pills. I did not go to the doctor. I would take pills on my own account (Monica, 39 years old).

Care and management of high-risk pregnancy in health services

The concept that pregnancy requires medical follow-up and health care provision is general. Regularly, the basic health unit was the first searched service, and once the risk was diagnosed, women were referred to specialized service. Some women, aware of their health conditions, went directly to reference units.

I asked the health agent to book an exam for me there in the family clinic. I did the pregnancy test and it was positive, and my blood pressure was high. They said that I could not be doing the prenatal care there. Then I got the referral to come here [reference-hospital] (Maria, 38 years old).

Delay in the diagnosis of pregnancy, difficulty in accepting it, lack of family support or problems in the workplace were the mentioned reasons for late prenatal care beginning.



He [partner] said that he would stand by me, but he left me several times. He just disappeared, understand? (...) It was a pregnancy without support. I had no motivation for the prenatal care, or for anything (Aline, 34 years old).

The path between prenatal care in the basic care unit and the reference-hospital was not always straight. Some women had been referred by basic care professionals to units that did not attend maternal high-risk pregnancies and, in some reports, women went through a real journey in search of appropriate assistance. Others went to private doctors, before getting to the reference-hospital, after having received the diagnosis of high-risk pregnancy in the basic care unit.

First I tried to do it in Rocinha, where I live, but they had no treatment for diabetes and hypertension there. One [health professional] sent me to the Minhocão [municipal health center]. Minhocão also does not have it. Then, they sent me to Hospital Y. Then they sent me downtown, but I did not go. I went to a private doctor and asked him to refer me to H. [reference- hospital]. Then, he gave me the referral. Then I did the whole treatment there (Cassia, 37 years old).

In many ways, difficult access to efficient and resolving services influenced the itineraries. Despite financial difficulties, many women had access to private services for care provision. The distance between the hospital and the residence and lack of public transportation were also situations that impaired access to specialized care.

Whenever I need an exam, or a doctor, I always pay for an appointment. There are some cheaper clinics. This public hospital thing is very difficult. You never get it (Simone, 42 years old).

It took too long. It was tiring, because I had to take 4 buses. By the time I got there I was tired, but I liked it (Juçara, 33 years old).

Sometimes, the risk diagnosis and the referral to a reference-hospital were not performed by health professionals who followed the prenatal care in the basic care unit. A pregnant woman, who presented blood pressure increase during the prenatal care, making use of anti-hypertension medication prescribed by the health center doctor and history of emergency service use, was sent to the reference unit only at the moment of delivery. In another case, a woman reported that she did the entire prenatal care in the public health center, despite presenting high blood pressure and swelling. Her baby was born dead and she attributed this outcome to poor monitoring of hypertension treatment at the basic care unit.



The second baby I lost I had high blood pressure, but I did not feel anything. I did the treatment in the basic care unit. Prenatal care at the basic care unit really does not work. I was always very swollen, right? The sign of high blood pressure is swollen face, hand. (...) They would see my high blood pressure, would give me medication, but there I never had a follow-up. Maybe if they had seen that my blood pressure was altered, the baby would not have died (Alice, 35 years old).

In some cases, the path in search of care was marked by conflicting episodes with health professionals, from whom women felt judged, mistreated or discriminated by their health condition and reproductive desire. Women with history of hypertension and diabetes face discourses imposing limit to reproduction, which inhibit the chance of dialog over proper risk management of these conditions.

Because you are hypertensive and diabetic... It is complicated if you get pregnant. He [Doctor] said, 'the best you can do is to take medication for the rest of your life and don't get pregnant'. You mean that diabetic woman... I said that 'diabetic and hypertensive women have no right to be a mother! Only the good ones can be mothers. Why are you doctors here? To take care of the good ones?' I said exactly like this! He [doctor] was ignorant with me and I was with him too, because I treated him just as he was treating me. I told him: 'I am going to do the treatment, and I am going to do everything I can when I decide to get pregnant, to have my child. Whatever it may be.' Then he said, 'ok then, but here we have no treatment for you. '(...) 'Then you don't worry because I will not come here. I'll go to any other hospital, except here' (Cassia, 37 years old).

The quality of relationships established with health professionals and the development of bonds with the unit also influenced the healthcare itineraries. In the reference-hospital, service by different professionals during prenatal care was criticized by women who complained about lack of bond and confidence relationships, which caused simultaneous search for other care services.

I liked going to the emergency more than to the prenatal care. I would get too upset. Because each day is a different doctor who sees you and you have to tell everything again. When you have to repeat something many times to doctors, you end up leaving details behind. You think that he is not paying attention to the details. I preferred to go to the emergency, because it was a service that did not wear me out as much and there I think they did a more complete examination than here (Rosangela, 41 years old).

In turn, the possibility of access to medical technologies, mainly diagnostic ones, was very valued and contributed to a positive evaluation and compliance to the prenatal care in the reference-hospital.



Prenatal care there [reference-hospital] was the best. They ask a lot of exams when it's a high-risk pregnancy, right? I found it the best. I have nothing to complain. Even when I had my son there, I found the hospital, the doctors good (Beatriz, 27 years old).

In care provision itineraries, biomedical prescriptions are also considered, including changes of habits, particularly those involving food, alcohol and tobacco consumption. In general, there is a positive attitude towards these prescriptions; however, difficulties, resistance and conflicts frequently appear, being the responsibility often attributed to women individually.

'Oh doctor! Don't let me lose the baby'. Then the doctor said: 'Yes mom! But you should have... eaten less junk food, less salt. Now you are going to take the risk, because you caused this'. In the prenatal care, she [doctor] explained that I should not eat too much salt, but the fact is that I couldn't stand eating bland food. Then I'd put salt in the food. Then when I found out that I had high blood pressure, I had to run this risk (Gisele, 18 years old).

They prescribed me a balanced diet. I could not do this, not do that... And I would drink a lot, as a matter of fact, I still do. I drank during the whole pregnancy (Ivanilda, 29 years old).

High-risk pregnancy care and management in the family-affective circuit

The healthcare provision paths were significantly influenced by interaction strategies established by family-affective relationships. The quality of relationships with partners was rarely indifferent: in some cases, they were presented as a positive element for healthcare, stimulating prenatal care compliance, supporting in case of hospitalization, going to doctor appointments; in other reports, they were stress, vulnerability and violence causing agents, potentiating the risk condition.

The nurse said, 'you are going to have to be hospitalized'. Then I said, 'I don't want to. I'll go home'. Then I went home crying. I did not want to stay. I called my husband and he said: 'No. You are going to stay (...)' When he arrived home, I packed my things and he took me to the hospital with my mother. Then I stayed (Maria, 38 years old).

It's so different from when we were dating. Things change after marriage. That is sad. Very often I would tell my son: 'You see your father. Do not do the same things he does. He treats me...' [pause due to crying], with harsh words. Sometimes we're ok, we're happy, suddenly, I do not know what happens and he looks at me like that and begins to curse. He says that I am a bitch, that I am a whore, that I am good for nothing. (...) And my pregnancy was a great



suffering because of that too. (...) One day he attacked me really bad. (...) I did not come to any appointments after I left here [reference-hospital]. I had scheduled appointments, but I did not come. I went home and all the distress returned. I had no one to accompany me. I was full of stitches. It had nobody to stay with the baby (Augusta, 45 years old).

Other relationships in the family-affective support network also impact in the care provision process. Mothers and sisters were frequently relevant figures, but other relatives and neighbors were also mentioned. It is important to emphasize that, except the partner, the support network was predominantly feminine. This network was present in multiple moments: escorting in appointments, checking blood pressure, placing bandages, injection application, help in household chores and children care, exchange of medical and popular health knowledge, informal prescription of pharmaceutical medication and popular pharmacopeia products. At times, support networks also included healthcare providers, such as nursing technicians, which provided technical-affective quality to these relations.

My sister took a nursing course; she knows how to check blood pressure. She even checked it a few times after I had F., but it was good. I believe that after the pregnancy it returned back to normal (Madelucia, 27 years old).

If close relatives can be care facilitators, the presence of small children was pointed by some women as an obstacle. Women with small children reacted with "desperation", and at times, tended to refuse admission or anticipate discharge, in absentia of a health professional, for claiming to be the main or only caregivers of the children.

The doctor said: 'You are going to have to be hospitalized today to induce labor, because your blood pressure is too high.' I said: 'that's ok!'. Then I panicked, because I have two other children at home. I worry about the other two, you know? (Andreza, 31 years old).

They wanted to keep me there [reference-hospital] until the day my blood pressure dropped. It was not going to drop while I was there, because I have 4 other children at home waiting for me. How could I stay there? My grandmother is too old already to take care of them. (Ivanilda, 29 years old).

Discussion

Multiple health vulnerability situations - individual, social and programmatic⁸ – are present in these reports. They overlap and potentiate each other and, along with hypertension, increase the chances of negative outcomes for women and babies^{1,9}. Most women present sociodemographic



characteristics, such as low income, low schooling and black skin color, which are predictors of social inequalities and worse health status¹⁰.

Some abortion situations appeared in the reproductive paths, including unsafe situations. Abortion occupies the fourth maternal mortality position in Brazil, and post-abortion complications result in a great number of hospitalizations in the unified health system (SUS)¹⁰. If hospitalization due to unsafe abortion complications is associated with unfavorable socioeconomic conditions¹¹, women in the studied group profile, in the absence of comprehensive and effective healthcare provision, are potential candidates to composing the profile of maternal death statistics.

Specific differences were not observed when comparing healthcare itineraries of women with history of chronic hypertension during pregnancy or in previous pregnancies with itineraries of women whose first hypertensive episode occurred in the last pregnancy. The familiarity with conditions or chronic complications, systemic hypertension and/or other morbidities, not always resulted in regular search for professional services, although these actions are rhetorically respected. The awareness of being risk-condition bearers for reproductive life did not significantly affect the care itinerary, except during pregnancy. When pregnant, all women looked for health services and the central focus was the development and health of the baby, acting from this period on as caregivers. Out of pregnancy, the idea of risk in a future pregnancy was forgotten and, care – both in the woman and in the health professional perspective - was not ruled by this risk. A study with another population of pregnant women with hypertensive disorders also noticed that clinical monitoring of hypertension and attention to reproductive planning in the postpartum period were neglected.

For a better understanding of the care provision (during pregnancy)/non care provision (non-pregnancy) equation, it is relevant to consider how gender strategies operate in self-care practices. Self-care may sound for women and those in their inner circle as something selfish, conflicting with the availability for children and family care¹². In addition, there may divergences and conflicts between the medical discourse on epidemiological risks (calculated statistically) and the unprofessional understanding of the risks involving health: in the world of life, the normality-abnormality idea is more contextual, dangers and risks are evaluated using criteria associated with expectations, intentions and individual values¹³.

During pregnancy and in face of the news/awareness of reproductive risk represented by the hypertensive disorders, care provision in the formal health system is valued and searched for; "high blood pressure" appears in the collective imaginary as a condition that requires biomedical knowledge and resources^{14,15}. Assistance in a specialized maternity, with technological resources and sophisticated procedures is a privilege; the common sense on this topic is that the hospital is a place where "good service" is found¹⁴.



Although the Brazilian issue on access to prenatal care in basic care units is on the way to being solved¹⁰, this study reiterates the persistent problems of prenatal care quality^{16,17} and revealed difficulties in obtaining specialized services characterized by inadequacy of reproductive risk management, difficult relationship with health professionals, besides absence of an organized assistance network to guarantee care provision, for example, through reference and counter-reference systems. Studies on healthcare provision to hypertensive pregnant women correlate the inadequacy of prenatal care mainly to professional fault, at the technical or human relations plan^{9,16}. Prejudiced and authoritarian practices, with class and gender biases, towards the clinical conditions and reproductive intentions of women in this study were also reported in a study on institutional violence in public maternity hospitals¹⁸. The disrespect with sexual and reproductive rights and the imposition of standards and moral values presented by professionals are aspects of institutional violence against women¹⁹. All these aspects compromise integration, continuity and co-ordination of care²⁰ as well as the perspective of a comprehensive approach towards the health needs of subjects²¹.

When women need to work and take care of children and face difficulties accessing health services or economical limitation to meet their needs, the search for health services occurs primarily at a remedial extent, for treatment of signs and symptoms; promotion and prevention routines recommended by the public health discourse find little space in everyday life (except those regarding children). Canesqui¹⁴ observed that it is common for working-class subjects to ignore the hypertension diagnosis in the absence of physical symptoms, even distrusting the diagnosis, and correlating the disease itself to life circumstances (conflicts and family and work problems), as observed in this study.

The healthcare itineraries of women were not limited to professional systems. Caring for their own health was also handled using other knowledge (non-biomedical) shared in the community and aided by resources accessed in the community environment (teas, juices, infusions, prayers) ²². These "in loco practices", are supported by the belief and empirical evidence of the effectiveness of these resources. Herein, the logics that govern care provision itineraries did not compartmentalize in cure-prevention-promotion, but pointed to a wider understanding of the health-illness process and a more holistic sense of balance and well-being. Acioli²³ also observed different meanings for health and illness care between popular practices and the formal health system. For this author, in the comprehensiveness perspective, provision care networks comprise "a dynamic and productive articulation between everyday settings and practices developed in these settings, either related to social groups and movements, health professionals or local health providers".

The experience of the health and illness process and the itineraries in search of care provision were also significantly affected by the interactions established in family-affective networks^{14,15,24}. In many cases of this study, partners, relatives, friends and/or neighbors; mainly other women, appeared as supporting ties, such as a "cure resource" ¹⁴. The positive emotional, material, behavioral and



interactional effects of social support in illness-health processes have been discussed in the literature²⁵. However, domestic violence, other stress situations in the family or in the community and absence of people to share domestic obligations with can negatively affect care provision, as observed in this study. Women with small children fear getting sick; they deny or postpone their health needs²⁶.

Final considerations

The study of healthcare itineraries of women with history of hypertensive disorders of pregnancy revealed how vulnerability situations influence health-illness approaches, with threatening effects that are accumulated with time, accelerating what Judith Butler²⁷ entitled "a differential distribution of precariousness", which is associated with an uneven distribution of health, education, income, work, justice – including gender - and other social assets. Access and quality of assistance, interaction strategies with health professionals, outreach of the family-affective support network and self-sufficient care conditions are influenced by these inequalities.

The paths followed by women in search of healthcare revealed how distant we are from achieving the comprehensiveness perspective. Fragmentation and reduction²¹ are persisting characteristics in the health approach: cure; prevention and promotion; basic and specialized care; care during pregnancy and in non-pregnancy periods; medical issues and sociocultural contexts; individual responsibility and collective care management; and professional health systems and other care systems appeared as distinct aspects.

Further studies are necessary to better understand the contexts of health and illness processes and care provision relations in time and space, allowing the development of care provision lines, using more comprehensive and humanized approaches, to support subjects on the care provision process, guaranteeing the right to health.

Collaborators

Rozânia Bicego Xavier, Claudia Bonan, Kátia Silveira da Silva and Andreza Rodrigues Nakano worked together in all stages of the manuscript production.

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