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ORIGINAL ARTICLE

INVISIBILITY OF SOCIAL OPERATORS IN THE PUERPERAL WOMEN SUPPORT NETWORK IN THE CONTEXT OF HIV

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ABSTRACT

Objective: To understand the implications of operators in the social network of postpartum women in the context of HIV. **Method**: Qualitative approach, based on the theoretical and methodological framework of Lia Sanicola. The participants were six women, selected in a reference service, in a municipality in southern Brazil. Semi-structured interview technique for the construction of the social map. **Results**: In the primary network, the partner was the natural helper and the main support to carry out his treatment and this determines a protective effect for health care. In the secondary network, health professionals offer support in an isolated and fragmented way. And, when there is a rupture in social relations due to prejudice, discrimination and the enhancing of social isolation by the pandemic, the vulnerability of the puerperal women occurs. **Conclusion:** The invisibility of social operators in the secondary network of these postpartum women implies the crystallization of a standardized service model, indicating the need for changes, for an isolated practice of professionals and health teams with network interventions to resolve the demands of its users.

Keywords: Social Network Analysis. Postpartum Period. HIV. Health Care. Nursing. Women's Health.

INTRODUCTION

In the puerperal period, women experience the return of pre-pregnancy biological changes, as well as emotional changes, being a moment in which family members will present the need for adjustments in the dynamics of their social relationships, with a new family organization occurring. When this moment is associated with the diagnosis of infection by the Human Immunodeficiency Virus (HIV) of one of the members of this family, other feelings and expectations arise, as well as anguish about the management to prevent vertical transmission of HIV[1] and the need for continuity of care for women in the postpartum period[2].

Scholars highlight the importance of postpartum women having a social network permeated by family support as a strategy for coping with difficulties in this period when there are demands related to HIV infection[3]. In a study conducted in Colombia with 100 women with HIV infection, the participants presented an overall index of social support of 83% and perceived maximum social support, especially from the family[4].

In the framework of Lia Sanicola[5], the social network works as a system of relationships that connects people who have social bonds, and it is in these bonds that social support permeates. Thus, the primary social network consists of family, friendship, neighborhood and work ties, where reciprocity and trust circulate. People can develop the function of emotional and financial support, giving visibility to problems and the satisfaction of social and health needs, especially those that escape the capacity of care by health services. Three factors lead to the constitution of primary networks: the history of the subjects, the encounters and events that happen throughout

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life and the vital cycles in which the family constitutes the central node of this network. It is in this network that one learns to live in relationship, and each subject is given an identity and a sense of belonging[5].

Another concept is a secondary social network, related to health services in which professionals are considered as people who develop various functions in the context of a person's network, mainly related to informational and instrumental support. This may favor the continuity of HIV treatment after delivery[2], in which humanized practices based on support and reception imply favorable care outcomes[6].

Thus, knowing the primary and secondary network allows us to identify the natural and social operators of the network, as well as the type of support received, the predominant means of exchange between the network and the puerperal women and their implications for the health care of them.

In Lia Sanicola's framework [5], the natural operators can be family members, being the closest people who help. In addition, health professionals will be able to act as a social network operator. This operator facilitates processes and drives the demand of the health user from the individual to the collective scope and from dependence to autonomy, as two dialectical movements. For the author, this operator has the purpose of understanding the difficulties and problems present, motivating the division of responsibilities through a movement carried out in the network itself [5].

In the study on the subject, the member of the network who assumes the role of operator is identified as the one who acts in solving problems, contributing with solving interventions, and promoting alternatives for support[5]. Thus, the research question was: What are the implications of operators in the social network of puerperal women who are inserted in a social context related to the HIV epidemic? Thus, the objective was to understand the implications of operators in the social network of postpartum women in the social context of HIV.

METHOD

Study design

The study has a qualitative and analytical approach, based on the theoretical framework of Lia Sanicola[5]. The writing of the research followed the guidelines of the Consolidated criteria for reporting qualitative research (COREQ)[7].

Study participants and location

The study participants were six puerperal women who underwent monitoring in a reference health service for the care of people living with HIV and who had their delivery from September/2019 to November/2020). The service was in a university hospital located in the central region of the State of Rio Grande do Sul, Brazil. Inclusion criteria were the puerperal woman being in a period equal to or greater than 30 days after delivery, being HIV-positive or being different seropositive (couples of which only one partner is seropositive). Exclusion criteria: Difficulty in verbal expression; being in a closed prison regime; having as reference a regular source of health care the private service. We declare that there was no need to apply the exclusion criteria.

Data collection procedures

For the recruitment of the participants, a list was prepared with the full name of probable participants, consisting of 63 puerperal women and telephone contact: the telephone of 32 of them was outside the coverage area or disconnected; 13 of the puerperal women did not have a telephone number in the hospital record; 2 resided in other municipalities; and 10 did not accept to participate in the research. With those who agreed to participate in the research, a place and time were scheduled according to the availability of the puerperal woman. In total, 6 puerperal women were interviewed.

To safeguard privacy in data collection, two interviews were conducted in a room reserved at the institution and four were at the residence of the puerperal women, all at the participant's option. Data collection took place from September 2020 to January 2021. The number of interviews was not predetermined. The interviews ended when the internal logic of the

object of study was found, as well as the response to the objectives of the study[8].

For the interviews, a digital voice recorder was used, with a mean time of fifty minutes. A semi-structured instrument was used for the demographic, economic, social and clinical characterization of puerperal women. Then, after establishing an interaction and a relationship of trust, the construction of the map of the primary and secondary networks and the validation of the map and information by the participant herself began [5]. In order to identify the social operator and understand the relationships that the puerperal women had with their social network, questions were formulated focusing on the puerperal period and on the relationships of proximity, type of proximity and establishment of their social network (people and/or institutions), highlighting whether these facilitated the performance of their treatment and/or health care. In addition, open-ended questions were asked about the type of help they received. At the end (in validating the information), the map was shown to the participants, allowing them to freely express their perception about the active elements in their social network and the different types of support they could obtain for their health care.

Data analysis

For the analysis and interpretation of the data, anchored in the reference of Lia Sanicola[5], the members that made up the social network of these puerperal women and their links with people and institutions present in their lives were identified, and the social network of each of the puerperal women was described. After transcribing the interviews, an exhaustive and repetitive reading of each of the statements for analysis was performed [9]. That said, the registration and context units that constituted the pre-established thematic axes for the response to the analytical object were identified in order to understand the implications of operators in the social network of postpartum women in the social context of HIV.

ETHICAL ASPECTS

The study was approved by the Research Ethics Committee under opinion 3,920,839. The ethical aspects of the research were also met according to Resolution 466/12 of the National Health Council. The selected participants were initially invited and, after acceptance, gave consent by signing the Informed Consent Form (ICF). To maintain anonymity, participants were identified with P (participant) and numbered from 1 to 6 (P1 to P6).

RESULTS

The puerperal women interviewed were between 22 and 28 years old. Skin color was the self-reported information in which four declared themselves white and two as black. As for the marital relationship, all reported living with their partner. As for education, two declare having completed high school; while each of the others had incomplete education: incomplete university education, incomplete high school, complete elementary school and incomplete elementary school. The family income reported by the participants was around a minimum wage. All women underwent prenatal monitoring. Among the participants, two were different seropositive and four seropositive who underwent HIV VT prophylaxis. As for the type of delivery, three were cesarean sections and three vaginal deliveries. All report that they were monitored in the puerperium.

In the analysis of the empirical material of the interviews, it was possible to highlight the burden of care assumed by the puerperal women and to identify and characterize the members who were natural helpers distinguishing the social operators. Thus, two theoretical categories corresponding and convergent with the analytical framework will be presented: primary network of puerperal women and natural helpers, and secondary network and the invisibility of social operators.

Primary network of puerperal women and natural helpers

It was verified in the primary network of P1 that her husband is the person who collaborates so that the puerperal woman performs her health care and the only member of the primary network to know the diagnosis of P1. Therefore, her husband became the main support for her treatment.

> We have been married for three years, [...] we do this follow-up together, his viral load was much higher than mine, so we followed up, each time the viral

> load decreased, it was a celebration. [...] my relationship is very strong, we are in this together. (P1)

It was evidenced an articulation of the P2 primary network in an attempt to assist it with its health needs. As a result, some members of the primary network cared for and accompanied P2 during her hospitalization (boyfriend, mother and uncle), while others assisted in the care of the eldest son (father-in-law, mother-in-law, sister), since this was the interviewee's greatest concern. The primary network does not have a specific person who stands out for an autonomy movement, as the support was in the sense of sharing the division of the care of the children, considering this stage of life. P2 states that she had adequate support from the primary network, especially during her hospitalization, but also in daily activities and in the care of the oldest child during her puerperium.

> It is because he (boyfriend) was always there, he would go with me (neonatal ICU), he would go in there and stay with me, also at home, he also helped me ". (P2) "My uncle also when I was in the hospital he helped me a lot, he works there (HUSM) it was easier for him to stay with me. (P2)

In the P3 primary network, there was support from the partner with whom daily activities were shared and who was present during the puerperal pregnancy period.

> The strongest (bond) because he (partner) gave me support in every pregnancy when I didn't have these people around it was him, only him...(P3) [...] it was very good, very good (pregnancy), they helped me, gave me support and everything. [...] they helped me (primary network) to understand what I went through when pregnant (child's name). [...] Then my mother didn't live here, then my brothers were away, right. Then I didn't have as much support (first pregnancy). In this (pregnancy) they helped me understand what I went through. (P3)

P4 presents her partner who is a collector of recyclable materials, this helps in family income. In order to develop the activity, they are divided in the care of the children, while one goes in search of recyclable materials, the other takes care of the children. This is also how the organization maintains health care, when they need to go to a health service, the other stays with the children.

> Just always my mother-in-law and my husband. Now she (mother-in-law) is spending more time at the [reference hospital], because she has recently had her cancer operated on. (P4)

P5 highlights having a strong bond with her partner, she says that the discovery of the partner's diagnosis was during prenatal follow-up, being a surprise for both, but she always supported the partner in carrying out HIV treatment. She also reports that only she knows the diagnosis of her partner, and they chose not to expose the diagnosis of HIV to family and friends.

> If he did the treatment right, we could have a good life and everything would be fine. [...] When he found out, he wanted to break up with me. [...] Then I said it wasn't going to be because of a disease that I was going to leave him [...] no one knows [the diagnosis of HIV] [...] so because of this fact that I didn't want anyone to treat him differently, I chose not to tell anyone. Just between ourselves [...] My mother came to go to the hospital and I didn't let her, I was afraid that someone would talk (about HIV). (P5)

It was found that the support offered by the P6 primary network is mainly provided by the mother-in-law and the partner, who welcomed and supported her both for her health care and for the care of the newborn.

> They keep [daughter's name] for me to do my exams, my appointments, my things, right. She [mother-in-law] in this case takes care of [daughter's name], but she [mother-in-law] does not know much about health. [...]Then I found out that I was pregnant, my boyfriend always supported me, because he is my boyfriend; recently. At first I thought he was going to abandon me because of HIV. He was going to find his way in life, but no, he was a great companion. So he accompanies me to appointments, we eat together: we rent a little house. He's a great companion, you know, and he still is to this day, our bond is very strong. (P6)

Secondary network and the invisibility of social operators

P1 considers how the operators of the secondary network, the pharmacist of the reference service and the nurse of the specialized service, who contribute to the puerperal woman in the face of her health needs.

> The (pharmacist) gave me wonderful support, the clarification she gives you, so the security she gives as a professional and as a person, so she is an example of an empathic professional. [...] Where

> will I get money to buy [medicines] in the pandemic? There was no money so they got it, [name of the pharmacist] called Porto Alegre, got clearance for me to withdraw here. So it's a network of people trained to work with this [people living with HIV]. I received terrible care at some health units here in [name of city] during my pregnancy, as they refused to treat me when they saw that I was HIV positive. (P1)

In the secondary network of P2, the participant highlighted the support coming from the physician who works in two institutions accessed by her; however, her exchanges with other professionals were not observed. It was found that the secondary network had greater performance during the hospitalization period. It is noticed that the secondary network does not make a movement for the autonomy of the patient; there is a dependence of the puerperal woman and, at times, phenomena of discontinuity and wear.

> From here (BHU) they referred me (high-risk prenatal care), but before I did follow-up here, just like the physician asked, she wanted me to follow up here (BHU) too. She (physician) is a teacher at the (reference service), so when she didn't attend me there, she attended me here. (P2)

The members of P3's secondary network offer support in a fragmented way, establishing its dependence on its network. The puerperal woman attended two different health services during pregnancy, but performed her puerperal follow-up only in one service. It is noted that, in the secondary network, the Community Health Agent (CHA) stood out as a mediator and articulator between P3 and BHU, especially during the pandemic.

> Because I went to the clinic [mention the name of the Basic Unit] and there I said that I had an infection, the physician said that I didn't need to take medicine because it could affect the baby and since I didn't take it, the infection increased and other infections appeared. [...] He (CHA) came here to see how I was doing, if I needed a consultation at (BHU). I didn't need to go there; the community health agent made the appointment and called me. It was very important for me. Imagine at this point of the pandemic going out with my son. (P3)

It appears that P4 has become dependent on the secondary network to maintain its health care, which occurs in a fragmented way. In addition, P4 does not recognize in the secondary network a network operator who can assist her in the organization of health care.

> In both, the reference service and the Basic Health Unit. It's better there, I believe there are more resources there. In the reference service they were more attentive, you know?, there I knew everyone well, and here (BHU) I don't know anyone. [...] There at the (reference service), they advised me how to take the medicine correctly. (P4)

In the case of P5, it appears that the secondary network is unable to carry out exchanges in the relationships, resulting in a dependence of P5 in relation to the secondary network. Therefore, P5 does not develop a role as a network operator. This was also reported by P6, who presents the secondary network, all elements helped in some way, however, these elements did not carry out exchanges, they only provided support in isolation.

> My prenatal was very peaceful. At every appointment I was able to hear the baby, I managed to do everything correctly, and the physician and nurse were very nice. She (nurse - FHS) always explained everything so I think my prenatal care wasn't bad, it was really good. I liked it all. [...] Then it was right at the time of the corona virus. At that time I discovered that I was HIV positive (HIV diagnosis). So I felt alone, so they didn't let my partner see me; I went in alone, I was alone in the hospital and it hurt me a lot, you know? I left the hospital with the onset of depression, until now I take fluoxetine to calm down, because of everything that happened to me. (P5)

> They were very concerned [...] the emotional issue, the psychologist knew how to understand. At no point did they judge me; They gave me support in terms of looking for [name of the BHU], always having exams up to date and taking care [prophylaxis for vertical transmission of HIV] so that [daughter's name] wouldn't have anything. [...] that's how they talked at the time, not anymore. The consultations with the infectious disease specialist [...] referred us to a nutritionist and she gave us shakes to drink, because I lost a lot of weight. We were well received, it was very peaceful (P6)

In view of the results and interpretation in the light of Lia Sanicola's reference, it was possible to observe the two movements in which the operator could facilitate and support a change in the social network of the puerperal woman: the movement that goes from the individual to the shared dimension and the other that goes from the dimension of dependence to that of autonomy

(Figure 1).

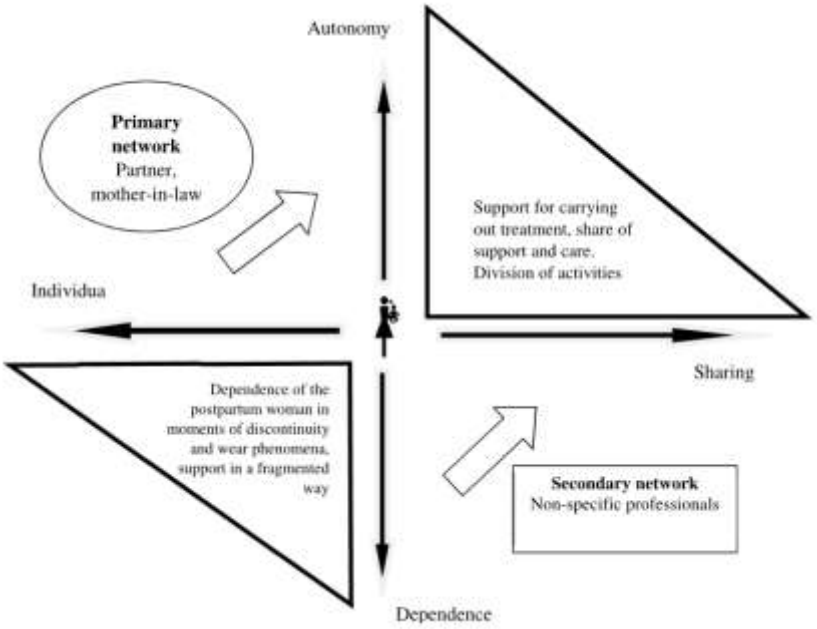

Figure 1. Adapted in accordance with the Sanicola reference [5].

DISCUSSION

In this study, it was possible to perceive, from the analysis of the social network of puerperal women inserted in a context related to the HIV epidemic, that there are people at the level of support and there are others at the level of more significant bonds in their social networks. It was possible to understand that when the puerperal woman has the support of her partner, the mother, other members of the primary network, this determines a protective effect for health care and when there is a rupture due to prejudice, discrimination and the enhancing of the isolation caused by the pandemic, the vulnerability of the puerperal woman occurs.

In the Sanicola framework, there is an indication that network operators are identified in the social network, which should promote interactions between members of the primary and secondary network. Likewise, the reference indicates a relationship of autonomy of the primary network with the secondary network; the latter, in turn, must provide assistance, but without replacing the former, always exploring its potential for social protagonism[5]. The bond indicators established by the puerperal women supported by the Sanicola framework were not identified in the present study.

Based on the analysis of the social network of puerperal women in the social context of the HIV epidemic, stigma, prejudice and discrimination emerged in the participants' statements, indicating the puerperal women's understanding of the need to silence their serology as a form of protection. This showed the implications of diagnostic confidentiality, such as the restriction of their social network, which indicates the need for educational interventions as a way to strengthen family support[10-11]. In some cases, it was observed that members of the primary network were unaware of the members of the secondary network. This can affect health care due to the lack of social support for puerperal women to maintain this health care.

In the primary social network, the partner provided emotional, affective, material support, helped in daily tasks and in the care of the newborn. In some cases, he helped the puerperal woman to maintain interactions with the primary and secondary network, moving from a position of individuality and dependence towards autonomy and sharing[5].

In a systematic review developed in Africa on the barriers and facilitating factors for the use of antiretroviral drugs in the prevention of vertical transmission (VT) of HIV, partner and family support was identified as a factor that can prevent

or facilitate the use of antiretrovirals. Likewise, a study developed in Russia with 200 seropositive mothers showed that those who had full support from their male partners were more likely to adhere to VT prophylaxis than those who did not have this support[12]. However, stigma and fear of disclosure of the diagnosis to partners is one of the barriers to VT prevention[13-14].

In an attempt to meet the needs and demands of their health in the secondary network, especially when the family environment is insufficient, puerperal women seek support in society in general. In this study, this support was represented by specialized care services, basic health unit and religious institutions.

However, the puerperal women exposed in their speeches experiences of prejudice and discrimination in an explicit or veiled way at the time they needed to access primary health care services. Therefore, people living with HIV do not access Primary Health Care services, because they sometimes feel uncomfortable in the unit environment[15].

There is still the fear of the community discovering the diagnosis or being discriminated against by professionals, which is evidence of the need to reorganize the health care model of people living with HIV in primary health care[16]. This stigma, inserted within the scope of health services, is a relevant reflection especially among women with HIV[17], as a study found problems in health systems that included weak interactions between staff and women, in addition to the lack of professionals and accessibility of services[18].

The attitudes of health professionals who assist puerperal women in the social context of the HIV epidemic directly reflect on the well-being and feelings of women. Thus, there is a need for welcoming these puerperal women by health professionals, since they can abandon treatment and progress to an unfavorable outcome, especially in the puerperium period, considering the barriers in adherence to puerperal consultation[19]. Women living in the social context of the HIV epidemic have the same reproductive rights as those who do not have the virus. Therefore, professionals should not make any value judgment in the face of pregnancy[20].

It is understood that it is important to reflect and discuss how to manage work in health services, thinking about minimizing weaknesses in the care of people living with HIV. The difficulties encountered by the puerperal women in this study may be due to the fact that, many times, the assistance provided is based on the knowledge that the professionals acquire in their work experience through informal learning. This ends up generating fear of becoming infected and often not feeling prepared to provide assistance[21].

In the secondary network, in some cases, it was possible to verify that the puerperal women access health services in search of guidance and clarification on treatment and health care. In these services, the pharmacists, nurses and physicians stood out, and the type of support provided was informative. As a result, it is essential for professionals to be involved in assisting puerperal women in favor of their autonomy, as well as to help in the search for other people and/or institutions that can support them in different perspectives for the continuity of care and retention in the service.

In an African study, it is noteworthy that retention in HIV care was more challenging during the postpartum period than during pregnancy. This associated maternal health with complications in delivery and cesarean section. Sociocultural and economic factors such as unemployment, underemployment, and debt coupled with HIV stigma created a significant barrier to retention[22-23].

In the care of people living with HIV, shared management of care is imperative, as a way to ensure the quality and continuity of care. The shared management between primary health care and specialized care service aims to: expand access, link to health services, improve care and prognosis of these people. Although primary care services are the gateway to the health system, even for HIV-infected women who are in the puerperal pregnancy period, access to and coordination of care are still insufficient[24-25].

Discussions about social networks allow us to elaborate a new paradigm, and it is important to understand the organization of society, establishing social ties and establishing roles and functions for these correspondents. This theoretical framework allows the indication of strategies and resources necessary for the recognition of the position occupied by people and/or institutions in the core of relationships,

whether in the primary or secondary social network. It also makes it possible to indicate new conducts and attributions regarding the properties of the social network from the perspective of care alternatives[5].

FINAL CONSIDERATIONS

It was possible to understand the implications of operators in the primary and secondary social network of postpartum women who are inserted in a social context related to the HIV epidemic.

In the primary network, the partner became the main support for the treatment of the puerperal woman, and this action was a protective effect for health care. However, it indicates that the network is restricted and that it deserves attention from health professionals in order to develop actions to strengthen and expand this network, as it will positively imply women's autonomy.

With regard to the secondary network, health professionals offered support in an isolated and fragmented way, favoring clinical intervention instruments. This action refers to the invisibility of the performance and purpose of social operators in the network of puerperal women in the context of HIV, which implies the crystallization of a standardized service model.

Therefore, changes in the isolated practice of professionals are necessary, considering that the health team of the service elaborates the planning of interdisciplinary actions and interventions to develop communication between those involved in the network for the process of resolving the demands in the service. Thus, the intervention of social operators in the network could reflect positively on the movement from dependence on the autonomy of puerperal women in health care.

INVISIBILITY OF SOCIAL OPERATORS IN THE PUERPERAL WOMEN SUPPORT NETWORK IN THE CONTEXT OF HIV

ABSTRACT

Objective: To understand the implications of operators in the social network of postpartum women in the context of HIV. **Method**: Qualitative approach, based on the theoretical and methodological framework of Lia Sanicola. The participants were six women, selected in a reference service, in a municipality in southern Brazil. Semi-structured interview technique for the construction of the social map. **Results**: In the primary network, the partner was the natural helper and the main support to carry out his treatment and this determines a protective effect for health care. In the secondary network, health professionals offer support in an isolated and fragmented way. And, when there is a rupture in social relations due to prejudice, discrimination and the enhancing of social isolation by the pandemic, the vulnerability of the puerperal women occurs. **Conclusion:** The invisibility of social operators in the secondary network of these postpartum women implies the crystallization of a standardized service model, indicating the need for changes, for an isolated practice of professionals and health teams with network interventions to resolve the demands of its users.

Keywords: Social Network Analysis. Postpartum Period. HIV. Health Care. Nursing. Women's Health.

INVISIBILIDAD DE LOS OPERADORES SOCIALES EN LA RED DE APOYO A PUÉRPERAS EN EL CONTEXTO DEL VIH

RESUMEN

Objetivo: comprender las implicaciones de los operadores en la red social de puérperas en el contexto del VIH. **Método**: enfoque cualitativo, fundamentado en el referencial teórico y metodológico de Lia Sanicola. Las participantes fueron seis mujeres, seleccionadas en servicio de referencia, en un municipio en el sur de Brasil. Para la construcción del mapa social fue utilizada entrevista semiestructurada. **Resultados**: en la red primaria, el compañero fue el ayudante natural y el principal apoyo para realizar su tratamiento y eso determina un efecto protector para los cuidados de salud. En la red secundaria, los profesionales de la salud ofrecen apoyo de forma aislada y fragmentada. Y, cuando tiene ruptura en las relaciones sociales por cuenta del prejuicio, de la discriminación y de la potencialización del aislamiento social por la pandemia, ocurre la vulnerabilización de la puérpera. **Conclusión**: la invisibilidad de operadores sociales en la red secundaria de esas puérperas implica la cristalización de un modelo de servicio estandarizado, indicando la necesidad de cambios, de una práctica aislada de los profesionales y equipos de salud con intervenciones en red para la resolutividad de las demandas de sus usuarias.

Palabras clave: Análisis de Red Social. Período Posparto. VIH. Atención a la Salud. Enfermería. Salud de la Mujer.

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