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NON-ADHERENCE TO OUTPATIENT FOLLOW-UP BY WOMEN WHO EXPERIENCED SEXUAL VIOLENCE¹

Tatiane Herreira Trigueiro², Marcelo Henrique da Silva³, Deíse Moura de Oliveira⁴, Maria Cristina Pinto de Jesus⁵, Miriam Aparecida Barbosa Merighi⁶

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² Ph.D. in Health Sciences. Professor, Department of Nursing, *Universidade Federal do Paraná*. Curitiba, Paraná, Brazil. E-mail: tatiherreira@ufpr.br

³ Ph.D. in Health Sciences. Nurse, Municipal Department of Juiz de Fora. Juiz de Fora, Minas Gerais, Brazil. E-mail: marcelohenfermar@gmail.com

⁴ Ph.D. in Health Sciences. Professor, Department of Medicine and Nursing. *Universidade Federal de Viçosa*. Viçosa, Minas Gerais, Brazil. E-mail: deisemoura@hotmail.com

⁵ Ph.D. in Nursing. Professor, Department of Fundamental Nursing, *Universidade Federal University de Juiz de Fora*. Juiz de Fora, Minas Gerais, Brazil. E-mail: mariacristina.jesus@uff.edu.br

⁶ Ph.D. in Nursing. Professor, Department of Maternal-Infant and Psychiatric Nursing. School of Nursing, USP. São Paulo, São Paulo, Brazil. E-mail: merighi@usp.br

ABSTRACT

Objective: to understand the reasons for non-adherence to outpatient follow-up by women who experienced sexual violence.

Method: qualitative study based on the Social Phenomenology of Alfred Schütz, carried out with 11 women who received medical care in a specialized service. For data collection, interviews with open-ended questions were carried out from October 2014 to April 2015. The resulting content was organized in categories and understood based on the framework adopted.

Results: a lack of coordination among services to receive women was evidenced, as well as their suffering in having to report the assault several times, and embarrassment in the presence of healthcare professionals. Even without completing outpatient follow-up, women expect to overcome the violence suffered, giving new meanings to their lives, by returning to their studies and work.

Conclusion: the perspective of these women shows important issues to be considered by healthcare professionals. These include the coordination among services of the healthcare network and improvement of care, with valuation of the intersubjective relationship between women and professionals, as a way to increase adherence to outpatient follow-up.

DESCRIPTORS: Sex offenses. Rape. Nursing. Ambulatory care. Health care.

NÃO ADESÃO AO SEGUIMENTO AMBULATORIAL POR MULHERES QUE EXPERIENCIARAM A VIOLÊNCIA SEXUAL

RESUMO:

Objetivo: compreender os motivos da não adesão ao seguimento ambulatorial por mulheres que experienciaram a violência sexual.

Método: pesquisa qualitativa fundamentada na Fenomenologia Social de Alfred Schütz, realizada com 11 mulheres atendidas em um serviço especializado. Para obtenção dos dados, utilizou-se a entrevista com questões abertas, realizada entre outubro de 2014 e abril de 2015. O conteúdo foi organizado em categorias e compreendido a partir do referencial adotado.

Resultados: evidenciou-se a falta de articulação da rede de atendimento para o acolhimento da mulher, o seu sofrimento em ter que relatar diversas vezes nos serviços a agressão e o constrangimento diante dos profissionais de saúde. Mesmo não tendo concluído o seguimento ambulatorial, a mulher espera superar a violência sofrida, ressignificando sua vida por meio da volta aos estudos e ao trabalho.

Conclusão: a perspectiva destas mulheres mostra pontos relevantes a serem considerados por profissionais de saúde. Estes incluem a articulação entre os serviços que compõem a rede de atendimento e a melhoria do acolhimento, com valorização da relação intersubjetiva – entre a mulher e os profissionais – como um caminho para aumentar a adesão ao seguimento ambulatorial.

DESCRIPTORIOS: Violência sexual. Estupro. Enfermagem. Assistência ambulatorial. Atenção à saúde.

LA NO ADHESIÓN AL SEGUIMIENTO AMBULATORIO POR MUJERES QUE SUFRIERON VIOLENCIA SEXUAL

RESUMEN

Objetivo: comprender los motivos de la no adhesión al seguimiento ambulatorio por parte de mujeres que sufrieron violencia sexual.

Método: investigación cualitativa fundamentada en la Fenomenología Social de Alfred Schütz y realizada con 11 mujeres atendidas en un servicio especializado. Para la obtención de los datos se utilizó la entrevista con preguntas abiertas que se llevó a cabo entre octubre del 2014 y abril del 2015. El contenido se organizó en categorías y fue comprendido a partir del referencial adoptado.

Resultados: fue evidente la falta de articulación de la red de atendimento para el acogimiento de la mujer y su sufrimiento al tener que relatar el problema varias veces en los servicios para agresión, y también, el constreñimiento ante los profesionales de la salud. Aún sin haber concluido el seguimiento ambulatorio, la mujer espera superar la violencia sufrida encaminando su vida por medio del regreso a los estudios y al trabajo.

Conclusión: la perspectiva de estas mujeres muestra aspectos relevantes a ser considerados por los profesionales de la salud. Los mismos incluyen la articulación entre los servicios que componen la red de atendimento y la mejoría del acogimiento, con valorización de la relación intersubjetiva, entre la mujer y los profesionales, como un camino para aumentar la adhesión al seguimiento ambulatorio.

DESCRIPTORES: Violencia sexual. Estupro. Enfermería. Asistencia ambulatoria. Atención para la salud.

INTRODUCTION

Sexual violence brings important consequences to women's health. With regard to their physical health, it increases the risk of contamination from sexually transmitted diseases (STDs), and may lead to unwanted pregnancies, in addition to physical injuries, such as hematomas and genito-anal laceration. Concerning mental health, it may cause depression, anxiety, panic disorder, isolation, and several psychosomatic disorders, including suicide.¹

The Brazilian Ministry of Health suggests that specialized services that provide care to these women carry out outpatient follow-up, with the first medical care within 72 hours after the event (D0). From then on, returns should be scheduled for 30 days (D30), 45 days (D45), 90 days (D90), and 180 days (D180) after the assault.²

This follow-up has been one of the greatest challenges faced by healthcare professionals, because it requires continuity of care, which depends not only on their performance, but also on women's adherence. Therefore, adherence to follow-up is a dynamic, multi-determined process, under the responsibility of the patient and the healthcare team. The abandonment of outpatient follow-up may compromise the health of the person who suffered sexual violence, as well as reflect the ineffectiveness of care provided by the services to these users.³

Suspension of treatment and low demand for the healthcare service by people who suffered sexual violence have alarming proportions, which is highlighted in international^{4,5} and national^{6,7} studies. In the Netherlands, a study carried out with 108 women who experienced rape showed that 82.4% used the emergency service; however, 50% of them did not finish the antiretroviral treatment.⁴ In Mexico, a study carried out in three cities showed that of the 545

women in situation of violence, less than 50% sought the healthcare service after the event. The highest demand was by those who were sexually abused (25%), of these, only 19.45% finished treatment.⁵

In Brazil, a study carried out in Campinas, a city in the state of São Paulo, showed that the non-adherence rate to outpatient follow-up was 24.5%.⁶ In Curitiba, a city in the state of Paraná, a retrospective study analyzed 1,272 medical records of cases of sexual violence from 2009 to 2013, and evidenced that, of the total who received medical care, only 30.9% attended the first medical return, and an inexpressive percentage (6%) of women attended the fourth and last medical appointment.⁷

Based on these findings, the following questions guided the present study: what leads women who suffered sexual violence to non-adherence to outpatient follow-up? What are the expectations of women who do not adhere to outpatient follow-up for their lives, after suffering sexual violence? The aim of the present study was to understand the reasons for non-adherence to outpatient follow-up by women who experienced sexual violence.

The development of the present study brings significant contributions for dealing with the theme adherence, which is currently one of the most discussed in the healthcare area. Based on women victims of sexual violence, the findings of the present study contribute significantly for enabling the emergence of aspects inscribed in the subjectivity of the women who experienced this type of violence, and who did not adhere to outpatient follow-up. When bringing up this dimension, which emerges from the experience and report of the women themselves, the present study may help healthcare professionals in developing strategies to enable the continuity of care for women in outpatient follow-up, minimizing

the possibility of abandonment of the treatment.

METHOD

Qualitative research based on the Social Phenomenology of Alfred Schütz, using the following assumptions: intersubjectivity, pool of knowledge, biographical situation, motivation “why” and “for”, and typification. The core of this philosophical framework refers to the social action of the person in the world of life. This is a social and intersubjective world that constitutes the setting and object of human actions. Action is a human behavior projected by individuals in a conscious and intentional way, which includes projects, expectations (reasons for) and actions performed (reasons why).⁸

People act according to their biographical situation, which is constituted by history, based on their previous subjective experiences. This experience aggregates a pool of knowledge that is available and accessible, according to this situation. The pool of knowledge consists of information passed by parents, educators, and experiences lived. The typification of the lived experience is obtained from the organization of a subjective system of analysis that aims to achieve an intersubjective structure of meaning.⁸

The setting of this study was an emergency care service to people who suffered sexual violence, located in a teaching hospital in Curitiba, a city in the state of Paraná (Brazil). This service is part of the Brazilian program called *Programa Mulher de Verdade*, which offers comprehensive care to women's health. The multidisciplinary team that works in this service is made up of a nurse, a gynecologist, a social worker, and a psychologist. In addition to these professionals, the service also receives undergraduate students and resident physicians. The service flow is initially carried out by referral from other services when the time between violence and care is less than 72 hours, and when it does not involve chronic aggression.

In the first care (D0), the nurse receives the patient and requests the presence of the expert physician of the forensic medicine institute and the resident physician of the gynecology area for clinical care. In this stage, laboratory examinations are carried out and medications are administered to prevent the occurrence of STD and gestation caused by violence. If case of clinical indication, such as contact with mucosae, if the sexual abuse is not chronic, and the elapsed time between violence and the first care is less than 72 hours, the administration of post-exposure prophylaxis of risk for the human

immunodeficiency virus (PEP) is carried out for 28 days, according to the service's protocol.

After the evaluation of the first care, women who had indication for PEP are guided and directed to medical returns after the reference service, around 30, 90, and 180 days after violence. In the next medical appointments, examinations recommended by the protocol are requested, and guidance and follow-up of adherence to PEP are provided. In addition, the women are directed to psychological care and social service.⁹

Eleven women who met the following inclusion criteria participated in the study: being aged 18 years or older, having experienced sexual violence and sought care; however, not having finished outpatient follow-up, as recommended by the service protocol. Non-adherence was considered for women who initiated treatment but did not attend one of the three medical returns (D30, D90, and D180 days).

For selection of the participants, 42 medical records of women who received care in 2013 and 2014 were used, after six months from the date of the first care and who did not complete outpatient follow-up. Based on the medical records, 14 women were contacted by phone, and three did not agree to participate in the study, reporting difficulty in recalling the aggression suffered.

The interviews were scheduled according to date, time, and place chosen by the women who met the inclusion criteria of the study. These were carried out from October 2014 to April 2015, by means of the following guiding questions: Considering that you experienced a situation of violence, tell us what it was like to initiate treatment but not attend the medical returns? After everything that happened, how are you dealing with the situation? What are your expectations?

The number of participants was not pre-determined. Eleven interviews were carried out, and all of them were enough to respond to the questions and objective of the study. It is worth mentioning that the women were individually approached, with prior signing of an informed consent form. They were informed about their right to participate or not in the study, in addition to their right to give up participating at any time.

Before the interview, the women were asked permission for the use of a recorder to record the full interviews and for their subsequent analysis. The interviews had an average duration of 40 minutes. Confidentiality and anonymity were ensured by replacing their names with the letter W (woman), followed by Arabic numerals according to the order

of the interviews (W1 to W11). It is worth mentioning that the data were stored in a place of access to the research team.

For analysis of the interviews, the stages suggested by the scholars of the Social Phenomenology of Alfred Schütz¹⁰ were used: full transcription of the interviews; thorough reading of each interview to understand the overall meaning of the participants' experience; identification of the units of meaning (reasons why and reasons for of human action); grouping of the units of meaning according to convergences present in the interviews; elaboration of specific categories of what was experienced, which enabled the understanding of the phenomenon studied; comprehensive analysis of the results according to the Social Phenomenology of Alfred Schütz; and frameworks associated with the theme.

The research project was approved by a human research ethics committee under protocol no. 772.012 of August 26, 2014, with Certificate of Presentation for Ethical Consideration CAAE no. 31703914.2.0000.5392.

RESULTS

The mean age of the participants was 20 years, most were single, with incomplete high school. Most cases of sexual aggression occurred on the street, at night, by strangers.

The content of the interviews of the women who experienced sexual violence was organized into categories that express the "reasons why" of the human action investigated: "Lack of sympathy in care services"; "Embarrassment and suffering before healthcare professionals", and "Poor co-responsibility between women and healthcare professionals". The category "Search for overcoming sexual violence" reveals the "reasons for" non-adhering to outpatient follow-up.

Lack of sympathy in care services

A woman emphasized the path taken in healthcare services, situations regarding care provided by professionals, and especially, the lack of knowledge of these with regard to network services that provide care to women in situation of sexual violence: [...] *we arrived at the forensic medical institute and stayed about 30 minutes, and we were told that the care service was not there. Because I was a minor, they sent me to another hospital. After one hour and half waiting, a resident doctor came and started asking about what had happened. After everything, she told me that the medical care was not there (W4).*

According to women who suffered sexual violence, the delay and poor medical care caused stress and discouragement to continue the follow-up: *there was no scheduling for anything. I think that everybody was scheduled for eight o'clock and was called in order of arrival. So this matter of being there, facing a line, the time that you wait to get a paper to take a blood test, to come back later and wait again to take the result of the examination: the problem was the delay (W8).*

Another issue highlighted by the participants was the attitude of the healthcare professionals, revealing lack of empathy and disregard in the care received: *You arrive at the reception, and they do not know where you will receive care. They just say "hey! Go over there and they will inform you", and they do not know. You keep going until you find the right place. They do not assist you properly, because, besides not giving you information, they are not kind, they are extremely rude. It is like "hey, go find yourself the place to receive care". This upsets us, because you are there with your emotional shaken (W10).*

Embarrassment and suffering before healthcare professionals

Undertaking laboratory examinations was mentioned by the participants as a form of embarrassment and suffering: *in the paper, the reason for the request was written in huge letters. For me, everybody knew why I was going to take the examinations. This made me feel bad. [...] I thought everybody was looking at me (W1).*

The undertaking of gynecological examination in the healthcare services after sexual violence, especially by professionals of the male gender, was also a suffering factor: *I did not want to come back anymore because of the gynecological examination, I felt violated again, because it was a man. The embarrassment I felt because of this gynecological examination made me not come back (W2).*

According to the interviews, the involvement of students during the medical appointments was also cause for great embarrassment: *they had to remove the students. I know they need to learn [...]. It is much worse to be with two, three, four more people together. It should be only the psychologist, the doctor, in a private room. I think that this way, the number of patients returning would increase. Being with the professional and the residents do not work, I do not think it is a good idea. It is embarrassing and shameful (W7).*

Outpatient follow-up brings the occurrence to mind, which generates a range of feelings such as anguish, sadness, suffering, thus contributing to

non-adherence to this follow-up: *when I was told that I had to come back to the hospital, I felt bad, I did not want to come back anymore, for the same reason. I remembered what happened to me all over again, and I did not want to remember that [...]. I started to remember what happened to me, it made me sad, I felt like crying* (W3).

Poor co-responsibility between women and healthcare professionals

The interviews also show poor co-responsibility between healthcare professionals and the women who suffered sexual violence, which may have hindered the completion of outpatient follow-up: *when I returned to the other appointment, she caught the paper and just said that everything was fine. I thought that I did not need to come back and they did not call me, they did not contact me. I did not know if I had more medical appointments. She told me that there was no need to go to the hospital. So, I did not come back anymore* (W5).

Despite not completing outpatient follow-up, the participants of this study show the desire to resume life, trying to overcome the aggression suffered. The category: "Search for overcoming sexual violence" translates the "reasons for" their actions.

Search for overcoming sexual violence

The women of this study expected to overcome the consequences of the sexual violence suffered. To achieve this, they count on the support of family members and friends: *my daughter and my husband are reasons that make me want to move forward rather than only think about it. [...] my family, our home, things like these make me move forward* (W9).

The women who suffered sexual violence, after facing difficulties to resume their lives, try to give them new meanings. Study and work are pointed as guiding elements of this new meaning to be achieved: *I want to study again, go to college, get a job* (W6); *I want to graduate, make money, and be able to help people. I do not want to be alone here at home* (W11).

Even having abandoned outpatient follow-up, after reorganization and physical and mental recovery of the trauma suffered, some women seek healthcare services, showing concern with their health: *because I did not finish my examinations in the hospital, I sought the healthcare service later. I always try to make more examinations, to take care of my health* (W7).

DISCUSSION

The women's interviews showed the professionals' lack of knowledge regarding the functioning of the network services to people in situation of sexual violence, which led them to search for care. In addition, it was evidenced that these women had to wait for care for a long time, and which most times did not meet their expectations.

A study carried out with healthcare professionals who work in a primary health care service in a city in the Northwest of the state of Rio Grande do Sul, (Brazil), which is known as reference in primary health care, showed that comprehensive and coordinated care provided to women victims of violence is still a distant reality in many healthcare services. The lack of protocol and care flow in primary healthcare units of the city abovementioned confirm the need for efforts to integrate actions and services in the care for women victims of violence.¹¹

In Salvador, capital city of the state of Bahia, (Brazil), a study with healthcare professionals of services that provide care to people in situation of sexual violence showed that most professionals did not know about the services in the confrontation of this problem, as well as the importance of the coordination of the network services. It highlighted that inter-sector coordination requires qualified human resources that know about the existence of other services, their competences, and the role of the network in the confrontation of violence. It also emphasized the need for establishing good working dynamics that allows them spaces of communication with others services.¹²

It is of utmost importance to search for strategies of dissemination concerning the routine of each service provided by the institutions that integrate the network of care to people in situation of sexual violence, with the aim of improving the women's approach to these services.

The women's search for care includes medical appointments and examinations in primary healthcare units, emergency care units, forensic medical institutes, specialized reference centers, psychosocial care centers, and specialized police stations to assist women. This itinerary should not be considered negative, since it is an important support to people in situation of violence; however, it might inhibit and discourage the continuity of care. The women will have to seek several institutions, face long lines, and be exposed to different professionals who are often not qualified to work in this singular situation and carry out a consistent record with ac-

curacy, in order to prevent women from reporting the occurrence several times.¹³

A study conducted in Tanzania, in Africa, also showed deficiencies of services that provide care to women in situation of sexual violence, pointing barriers of accessibility, such as the long time expended to receive care and the lack of knowledge of health-care professionals of the forensic medical institute.¹⁴

Based on the complexity of the situation of violence to what women were exposed, it is of utmost importance that services have quality of care as a goal, as highlighted by the authors of a study carried out in Barcelona, Spain. According to them, the women should not have to wait to receive care and should be treated in a private place. The waiting time for the arrival of the medical examiner should not exceed 45 minutes and the total time of care should not last more than three hours.¹⁵

The way the professional assisted the women in situation of sexual violence and the care provided made them feel neglected and facing lack of empathy. The feeling that the service does not give credibility to their stories, added to the lack of privacy and adequacy of care, takes women away from the healthcare service. Professionals must show sympathy and understanding, willingness to listen with respect and interest, and they must be prepared to give these women support since the first care.¹⁶

The identification of sexual aggression printed in the requests of laboratory examinations was considered embarrassing by the women, since they reported being exposed before the working staff whenever they carried out these examinations. Therefore, it is worth mentioning the importance of observing ethical questions that include the women's right to privacy and confidentiality in not wanting to be exposed to strangers in a situation of sexual violence. In the United Kingdom, the care provided to people in situation of sexual violence has safety and privacy as prerogatives, which are considered important elements in the care for people who were sexually abused. Because these women experienced a distressing situation and felt embarrassed to talk about the subject, professional attitudes based on empathy, sensitivity, and ethics become necessary.¹⁷

With regard to the feeling of discomfort when undertaking gynecological examination, especially when carried out by male professionals and in the presence of students, a Brazilian study also showed that some women who were raped wanted to be treated by female gynecologists and refused to be treated by male professionals. Many of them left the

service, without undertaking laboratory examinations or receiving medications.¹⁸ An Australian study showed that women felt a higher level of comfort when they had already had experience with students, and when gynecological and obstetric examinations were carried out by female medical students.¹⁹

According to the interviews of the participants, the repetition of the assault's story might compromise even more their psychological condition. Care strategies must be thought by services that provide care to these women, with the aim of sparing them from remembering repeatedly an event that cause them psychological and emotional discomfort. In this perspective, a hospital in Barcelona, Spain, defined in its protocol of care that the medical examiner and gynecologist must treat the women together, in order to coordinate their actions, sparing them from repeating the story of aggression and duplicity of examinations, especially gynecological examinations.¹⁵

The women's negative experiences with care in the service specialized in sexual violence constituted a pool of knowledge that, when remembered by them, might have contributed to the non-adherence to outpatient follow-up. The Social Phenomenology of Alfred Schütz leads to the reflection on how objects and situations of the world of life are interpreted. All the world's interpretation is based on a pool of knowledge prior to the individuals' existence. They are known through members of the closest social group and the experiences lived are included in this pool of knowledge.⁸

The care provided to women in situation of sexual violence highlights the need of co-responsibility between them and the professionals who provide them care, with the creation of spaces so they are able to give meaning to the experience lived and overcome the aggression suffered. Therefore, it is worth mentioning the importance of the Brazilian National Humanization Policy (PNH, as per its acronym in Portuguese), established in 2003, which encourages questions such as communication between workers and users, with the aim of developing collective processes of confrontation of relationships of power, work, and affection.²⁰ Putting the PNH into practice involves a process of co-responsibility of care between healthcare workers and women victims of sexual violence, strengthening the intersubjective relationship, producer of bonds of trust, with possible developments in the adherence of these women to outpatient follow-up.

The interaction between the women who suffered sexual aggression and professionals who

work in the services shows weakness in face-to-face relationships, a fact that, in the present study, was considered a barrier so they could finish outpatient follow-up. Recalling the assumptions of the Social Phenomenology of Alfred Schütz, the understanding of the other, in the social world, occurs from social relationships established among human beings, with the face-to-face type as the strongest. This promotes a relationship of continuity, in which the participants are aware of each other, that is, they turn to each other.⁸

When reflecting about the experience of having suffered sexual violence, the women express their expectations, considering that the impact left by the aggressive event makes them give new meanings to their lives and encourages them to move forward.

In order to overcome the impacts of the violence, the women count on the support of family members and friends. This was essential so they could resume their studies and work. In the city of Salvador, Bahia (Brazil), a study conducted with women who suffered domestic violence from a community supported by a non-governmental organization (NGO), showed that help from religion, family, friends, and NGOs provided them support, favoring the recovery of their self-esteem and encouragement to resume their lives. Emotional, spiritual, and material support were considered elements that encouraged them to confront the situation of violence suffered.²¹

In Chicago, United States, a study conducted with Afro-American adult women who suffered sexual aggression showed that those who mentioned seeking social support services reported less symptoms of depression and post-traumatic stress, when compared with those who had less support. This support might contribute to diminish shame and create a feeling of safety.²²

Even having interrupted outpatient follow-up, the women showed concern in taking care of themselves. A study carried out in a Brazilian Family Health Strategy Unit in the city of São Paulo showed that, for some women in situation of violence, the possibility of attending healthcare services might be the only communication channel present in their reality, being, for them, a possibility of confrontation of consequences of the violence to their health.²³

It is worth mentioning that the present study enabled the production of evidence that corresponds to a group of women who live in the same time and geographical space, with similar cultural characteristics that cannot be not general-

ized, which constitutes a limitation of the present study. However, the perspective of these women shows important issues to be discussed by healthcare professionals, which include the coordination among services of the healthcare network and improvement of embracement, with valuation of the intersubjective relationship between women and professionals as a way to increase adherence to outpatient follow-up.

CONCLUSION

The approach of the Social Phenomenology of Alfred Schütz enabled to understand that the reasons for non-adherence to outpatient follow-up by women who experienced a situation of sexual violence refer to the scope of the service network that includes an unfriendly embracement of these women in healthcare services. In addition, the emotional weakness caused by sexual violence makes these women associate outpatient follow-up with the aggressive event, which discourages them to seek the service. Even without completing outpatient follow-up, the women expect to overcome the violence suffered, giving new meanings to their lives, by returning to their studies and work.

The results strengthen the importance in improving the protocols of care to women victims of sexual violence, which must include the directionality of care flows and the way these women are treated by professionals who provide them care, inside and outside the healthcare area.

Nursing, inscribed among several fields of knowledge necessary for discussion and confrontation of violence against women, must be established as a social practice that is willing to exercise an important political and ethical action, with the purpose of being responsible for the care of women in situation of sexual violence, so they are embraced and able to carry out outpatient follow-up.

The findings of the present study reiterate the need for professional qualification, so that humanized care with co-responsibility is the main aspect in care/follow-up of the group studied. This must begin in the professional training process of actors involved in the care for this public, including this theme in the educational curriculum, and continue as a permanent education policy supported by the municipal management, in order to break criticisms that emerge with respect to care for women in situation of sexual violence.

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Correspondence: Tatiane Herreira Trigueiro
Universidade Federal do Paraná
Av. Prefeito Lothário Meissner, 632 - Jardim Botânico,
80210-170 - Curitiba - PR
E-mail: tatiherreira@ufpr.br

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