Health assistance path of women between diagnosis and treatment initiation for cervix cancer

Trajetórias assistenciais de mulheres entre diagnóstico e início de tratamento do câncer de colo uterino

Priscila Guedes de Carvalho¹, Gisele O´Dwer², Nádia Cristina Pinheiro Rodrigues³

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ABSTRACT This study aims to analyze the health assistance pathway of women living in Rio de Janeiro city diagnosed with cervix cancer who were referred for treatment in a referral oncology unit. In the first stage of the study, we evaluated time elapsed between the cancer diagnosis and the treatment initiation of women enrolled in 2014, taking as reference the time limit of 60 days established by the Brazilian Federal Law 12,372/2012 for treatment initiation at the Unified Health System (SUS). In the second stage, we analyzed the narratives of five women regarding their paths towards health services since the diagnosis up to the first therapeutic intervention, taking into account the aspects of comprehensive health care. It was observed that 88% of the treatments started after the 60-day legal period and that 65.5% of the women received a diagnosis in an advanced stage of the disease. The treatment initiation mean was 115.4 days. Main problems seized in path analysis concern the availability of services and the integration of actions throughout the different levels of health care, as well as the lack of information on the disease and the purpose of PAP smears.

KEYWORDS Uterine cervical neoplasms. Early detection of cancer. Women's health services. Health services accessibility.

RESUMO O estudo se propôs a analisar as trajetórias na assistência das mulheres residentes no Município do Rio de Janeiro diagnosticadas com câncer de colo uterino que foram encaminhadas para tratamento em unidade de referência na atenção oncológica. Na primeira etapa do estudo, avaliou-se o prazo entre a confirmação do diagnóstico e o início do tratamento das mulheres matriculadas no ano de 2014, tomando como referência o prazo de até 60 dias fixado pela Lei Federal nº 12.372/2012 para início de tratamento do câncer no âmbito do Sistema Único de Saúde (SUS). Na segunda etapa, analisaram-se as narrativas de cinco mulheres sobre os caminhos percorridos na assistência desde a descoberta do diagnóstico até a primeira intervenção terapêutica, a partir de aspectos do cuidado integral em saúde. Observou-se que 88% dos tratamentos se iniciaram após o prazo de 60 dias e que 65,5% das mulheres foram diagnosticadas com doença avançada. A média para início de tratamento foi de 115,4 dias. Os principais problemas apreendidos na análise das trajetórias foram os relacionados à disponibilidade dos serviços e à integração das ações nos diversos níveis de atenção, bem como a falta de informação sobre a doença e o objetivo da realização do exame preventivo.

Introduction

Cervix cancer is one of the most serious threats to women’s lives. The estimates show that more than one million women suffer from the disease throughout the world, most of them being found in underdeveloped and developing countries. Over the past three decades, the disease rates have fallen in most developed countries, largely as a result of programs involving tracing and treatment of previous injuries. In contrast, rates concerning the majority of developing countries remained unchanged or even increased. The disease mainly affects women of lower socioeconomic levels facing difficulties of access to health services. It is the consequence of health inequality once it depicts a preventable and unfair morbidity.

Persistent infection by Human Papillomavirus (HPV) is the main cause of growth of cervical intraepithelial neoplasia (previous injuries) and cervix cancer. There are approximately 200 HPV genotypes, eighteen of which are closely related to cancer growth, especially the genotypes 16 and 18, which are responsible for 90% of the cases. Therefore, the disease is sensitive to Primary Health Care (AB) actions, whereas the technologies for control – diagnosis and treatment of previous injuries – are already laid down and allow for the cure for approximately 100% of the cases detected in early phases.

In Brazil, cervix cancer is the third most frequent tumor attacking women, after breast and colorectal cancers. According to the National Cancer Institute José Alencar Gomes da Silva (Inca), the estimates of new cases in Brazil reaches 16,370 cases each year of the biennium 2018-2019, meaning a rate of 15.43 cases to every 100,000 women. Apart from the non-melanoma skin tumors, cervix cancer is the most incident in the North Region. In the Midwest and Northeast regions, it places the second position, and the fourth position in Southeast and South regions.

The high rates of incidence and mortality in Brazil justify the implementation of national actions addressed to prevention and control. Thus, it is of capital importance that AB develops, improves and implements public policies emphasizing women comprehensive health care. The Family Health Strategy (ESF) plays a fundamental role in this context since the practice of articulation between prevention and health promotion generates a favorable tracing scenario. The work of community health agents becomes essential once it contributes to the identification of the target population and to the tracking of women who fail to carry out the preventive test.

The strategy defined by the Ministry of health (MS) for tracing cervix cancer and its previous injuries is the PAP smear, addressed to women over 25 years old with sexual activity and up to 64 years old, when it can be interrupted if at least two consecutive negative tests were recorded over the past five years. However, it is observed that in Brazil the age of most women who perform the test stays under 35 years old, despite the higher risk be detected in this age group. This tracing pattern is considered opportunistic, i.e., the test is carried out only when the woman seeks health service for other needs.

The consequence of this logic is the testing of women outside the target age group, which is equivalent to only 20% to 25% of all the tests. In addition, approximately half of the women is tested within an interval of a year or less, while MS recommends a three-year interval for cases of two annual tests without changes. This tracing profile reveals also a contingent of women whose control is beyond what recommended by national guidelines as a contingent who does not control at all.

The cervix cancer prognosis depends on the disease extent at diagnosis, being its mortality rate strongly associated to the
diagnosis in advanced stages. Although access to the preventive test has increased in Brazil, it was not sufficient to decrease mortality trend. Late diagnosis reveals, above all, a lack in quantity and quality of cancer services. This reality is credited to difficulties in access to health services and programs; the Unified Health System (SUS) sub-capacity to absorb the demand; and difficulties of municipal and state managers as for the definition of assistance flows to enable appropriate referral of women carrying altered test results.\textsuperscript{10,11}

Another aspect to be considered is the time elapsed between the diagnosis and the treatment initiation. The availability and quality of health services directly influence on the survival of patients, which is increased or decreased upon the access to health services, the existence of tracing programs, the effectiveness of interventions, and the availability of diagnose and treatment resources.\textsuperscript{12} In 2011, the Federal Court of Accounts (TCU) released a technical report based on data provided by the Outpatient Information System (SIA) and by the Hospital Cancer Records (RHC), indicating that cancer treatments delivered by SUS did not occur in adequate period of time.\textsuperscript{13} In order to establish deadlines that ensure timely treatment of patients diagnosed with cancer, Federal law 12,732/2012 granted a period of up to 60 days from the date of the diagnosis confirmation by pathological report, or in shorter period, for the patient with malignant neoplasm to start the treatment at SUS.\textsuperscript{14}

Given the above, this study aimed to verify whether treatments for cervix cancer in a SUS reference unit of oncology care in the Municipality of Rio de Janeiro took place appropriately. The study also intended to characterize the trajectories in the care of women who were under treatment, and to identify the possible reasons of early detection and interfering factors that determined the correct time for treatment initiation.

Methodology

This qualitative and quantitative study has been developed in two stages. The first one had as purpose to evaluate, by means of the review of medical records, whether the first therapeutic intervention was timely carried out from the date of diagnosis. The deadline set by Law 12,732/2012 is 60 days.

Based on management data released by the reference institution in oncology, the collection of all women enrolled in the Service of Gynecology in 2014 with pathology associated to the International Statistical Classification of Diseases and Related Health Problems International Code of Diseases (CID 10) C53, i.e., cervix malignant neoplasm, was carried out, as well as the identification of users’ municipalities of residence with such profile. As for calculating the time elapsed between diagnosis and treatment initiation, medical records were selected from women who reported to reside in the Municipality of Rio de Janeiro. Information were extracted from records regarding age, date of registration at the institution, date of diagnosis, date of report revision by the Pathology Anatomy of the reference unit, clinical stage of the disease, starting date of treatment and prescribed treatment – combination of surgery, radiotherapy and chemotherapy; solely radiotherapy; or palliative chemotherapy.

Absolute frequencies and means were calculated based on data description. Tables
and maps illustrated the analysis by means of software ArcGIS (10.4) and Excel (2013).

The second stage characterized and analyzed the path of women diagnosed with cervix cancer under care. Interviews were conducted by applying semi-structured questionnaire, which dealt with the regularity in the use of health services and type of service used; experience with preventive gynecological test and consultation; experience in the discovery of cancer; waiting time for diagnostic confirmation; quality of care in the various services; access to various services; participation and autonomy in treatment decision; and expectation of improvement in services.

The use of qualitative methodology has the purpose of analyzing meanings assigned by subject to facts, relations, information, experiences and practices related to the program or service under evaluation and with which they interact. This purpose is obviously understandable, i.e., reconstruction of the meanings assigned by subjects with the support of their experiences and representations, which are circumscribed by a set of interactions in a given social and cultural situation, and that build a single context not generalizable. In addition, such experiences are associated with a political project to ensure voice and empower the various sectors participating in the assessment. The construction of therapeutic itineraries as evaluative practice proposes in-depth interviews, since they constitute a set of actions that build the users options, their experiences, frustrations and success in the resolution of their requests.

In view of the complexity of this approach, transversal to the fields of anthropology, psychology, sociology and health, we decided to reduce the methodology to just the description of women trajectories by using the theory of therapeutic itineraries as support. Therefore, despite its limits, the description of trajectories while under care becomes timely since the information provided are useful and contribute to the debate about those paths, when users seek and are subjected to care within the service responsibilities.

According to the guidelines defined by MS, the cervix cancer line of care is composed of four guidelines: prevention and early detection; National Program of Cytology Quality; access to diagnostic confirmation; and appropriate and timely treatment. That line of care aims to ensure the woman the humanized and integral access to the actions and qualified services so to promote prevention, access to previous injuries tracing, early diagnosis, and appropriate and timely treatment. The analysis of care trajectories of women interviewed was held based on two of these care guidelines: prevention and early detection and appropriate and timely treatment.

The eligibility criteria for the interview included women over 18 years old, diagnosed with cervix malignant neoplasms after 1 January 2014, residing in the Municipality of Rio de Janeiro and in good clinical condition.

This study was submitted to the Research Ethics Committee of the institutions involved and approved under CAAE #40510215.0.0000.5240. Women who met the eligibility criteria were invited to participate in the interview, and those who accepted were informed about the goals and purposes of the study, as well as their risks and benefits.

Results e discussion

Analysis of time elapsed between diagnosis confirmation date treatment initiation

In 2014, 1587 users were enrolled in the Gynaecology service of the reference unit
in oncology care. Of this total, 839 women had their diagnosis classified as code CID 10 C53 – cervix malignant neoplasm. After identification of places of residence informed by the 839 women, it was found that the reference institution of this study served, in 2014, 838 users from 57 municipalities in the State of Rio de Janeiro. The capital alone forwarded 360 users, equivalent to 43% of the total of women forwarded to the unit with the CID C53.

The fact that the reference institution located in the capital assisted users from 57 municipalities among 92 in the State of Rio de Janeiro (or 62%) also suggests either an overload of SUS units or a deficit in the number of specialized units carrying out the treatment of this type of cancer in the interior of the State, among other causes. Since time is crucial for the treatment initiation, the forwarding of users by means of the adjustment system for the capital, region with the highest number of units designated for the treatment, is necessary so to ensure that this initiation occurs in the shortest time possible.

The 360 women who reported as place of residence the Municipality of Rio de Janeiro live in 91 different districts (figure 1-B). Thus, it was possible to determine the number of users forwarded by Programmatic Area (AP) (figure 1-A). The Programmatic Area 3.3, which encompasses the districts of Madureira and adjacencies, forwarded the largest number of women in 2014. However, the five districts concentrating the largest number of forwarded women are located on the west side of Rio de Janeiro, being them Campo Grande with 21 users; Bangu, Realengo, Santa Cruz with 17 users each; and Guaratiba with 14 users.
Figure 1. Distribution of the number of cases of women referred for cervix cancer treatment in reference unit in 2014 according to place of residence. (A) Number of cases as to programmatic area of residence; (B) Number of cases as to district of residence.
As for time calculation between the diagnosis confirmation and treatment initiation, we analyzed the electronic records of the reference institution and the physical records of those 360 users that informed to reside in the Municipality of Rio de Janeiro. From the analysis, 139 records were excluded for not containing the necessary information that allows for the calculation of time elapsed between the diagnosis confirmation and treatment initiation. Thus, 221 patient records were selected, which are equivalent to 61.4% of the records identified initially.

The 221 patients’ records were divided into two groups, organized as for the diagnosis results. The first included the 47 women diagnosed with Cervix Intraepithelial Neoplasia (NIC), as are called the cancer previous injuries; and the second included the 174 women diagnosed with invasive cervix cancer. As to the analysis of time elapsed between diagnosis confirmation and treatment initiation, medical records of women diagnosed with NIC were not taken into account since pre-invasive injuries show slower evolution, in addition to having simpler treatment pattern and demanding less complexity in assistance, contrary to what happens when a process attacker is already in course. So, medical records of 174 women diagnosed with invasive cancer remained for analysis, as shown in figure 2.
Among the 174 women diagnosed with invasive cancer, 114 (65.5%) showed locally advanced disease at the time of the initial assessment for the treatment definition. The data is troublesome, given the reduction of cure possibility in such cases. Late diagnosis results in more aggressive and less effective treatments, increases the physical and emotional commitment both of the woman and her support network, raises the disease mortality, and increases hospitalization and medicines costs. Such reality highlights the low capacity of the health system to promote the disease tracing and control, once the treatment of previous injuries prevents invasive cancer from progressing.

The average age of women carrying invasive cancer was 49.9 years old, being the youngest 23 and the eldest, 93 years old. The average age of women diagnosed with Cervix Intraepithelial Neoplasia was 38.9 years old, being the youngest 22 years old and the eldest, 76.

As for the calculation of time elapsed between the diagnosis date and treatment initiation, dates of diagnosis confirmation and first therapeutic intervention were taken into account. Table 1 contains the average days for treatment initiation for each type of intervention.

Table 1. Average time in number of days for the beginning of treatment counted from the date of the diagnosis confirmation of women residing in the Municipality of Rio de Janeiro, 2014

<table>
<thead>
<tr>
<th>Type of treatment</th>
<th>Number of users</th>
<th>Average time for treatment beginning (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgical</td>
<td>48</td>
<td>104.8</td>
</tr>
<tr>
<td>Conjugated (radiotherapy and chemotherapy)</td>
<td>86</td>
<td>116.8</td>
</tr>
<tr>
<td>Only Radiotherapy</td>
<td>17</td>
<td>142.6</td>
</tr>
<tr>
<td>Palliative chemotherapy</td>
<td>03</td>
<td>71.3</td>
</tr>
<tr>
<td>Total</td>
<td>174</td>
<td>115.4</td>
</tr>
</tbody>
</table>


The average time for treatment initiation was 115.4 days, approximately 56 days after the 60-day deadline period set by law. This finding reveals that health system did not cope with the demand of the majority of users carrying the disease with respect to the timely treatment initiation. Although law #12,732/2012 entered into force in May 2013, it was found that only 21 treatments (12%) of the total 174 cases were initiated within 60 days after the diagnosis confirmation date.

The late response was observed in all types of procedures for the treatment of cervix cancer. The shortest waiting time referred to palliative chemotherapy (71.3 days). The waiting time for surgical or conjoint treatments – major recommended therapeutic procedures – exceeded 100 days. Regarding the delay in the treatment of patients requiring radiotherapy, 2014 was characterized by numerous problems related to the service lack of availability in both the State and the Municipality of Rio de Janeiro.

Court ruling determined that, as from 10 July 2014, all patients under radiotherapy treatment in hospitals located in the Municipality of Rio de Janeiro should be registered in a single file in the Regulation System (Sisreg). The city manager remained as the sole responsible for taking
the necessary steps as to the scheduling of initial tests before the radiotherapy providers. The initiative of organizing a waiting list to reduce the gap before treatment initiation was not sufficient to cope with the needs of the majority of women forwarded to the reference unit.

**Trajectories through health care of women diagnosed with cervix cancer**

The interviews were conducted from September to December 2015 in the multidisciplinary consultation office of the reference unit’s chemotherapy clinic. During the period available for conducting the interviews, six women agreed to participate in the research and two of them refused. One of the women who agreed to participate, despite having declared to reside in the Municipality of Rio de Janeiro, reported that all her care path until the forwarding to the unit had been held out of the Municipality, for which she had moved less than three months before the interview, and was living with family members so to be closer to the treatment site. For that reason, the interview was not considered for analysis. Thus, the care paths of five women were analyzed and identified in this research as M1, M2, M3, M4 and M5. **Charts 1 and 2** describe the profiles of the women interviewed and the respective care paths.

**Chart 1. Profile of women interviewed in the oncology reference unit in 2014**

<table>
<thead>
<tr>
<th>Woman</th>
<th>Age</th>
<th>State of origin</th>
<th>Education</th>
<th>Marital status</th>
<th>Children</th>
<th>District</th>
<th>Current occupation</th>
<th>Last test</th>
</tr>
</thead>
<tbody>
<tr>
<td>M1</td>
<td>35</td>
<td>RJ</td>
<td>High school</td>
<td>Single</td>
<td>1</td>
<td>Realengo</td>
<td>Businesswoman</td>
<td>2011</td>
</tr>
<tr>
<td>M2</td>
<td>31</td>
<td>RJ</td>
<td>High school</td>
<td>Married</td>
<td>2</td>
<td>Senador Camará</td>
<td>Administrative</td>
<td>2012</td>
</tr>
<tr>
<td>M3</td>
<td>58</td>
<td>RJ</td>
<td>High school</td>
<td>Divorced</td>
<td>4</td>
<td>Pilares</td>
<td>Housewife</td>
<td>Do not remember. A long time ago. 11 years without sex intercourse</td>
</tr>
<tr>
<td>M4</td>
<td>60</td>
<td>RN</td>
<td>Medium school. Incomplete</td>
<td>Divorced</td>
<td>4</td>
<td>Ramos</td>
<td>Pensioner and beneficiary of Bolsa Família</td>
<td>2005</td>
</tr>
<tr>
<td>M5</td>
<td>42</td>
<td>CE</td>
<td>Illiterate</td>
<td>Single</td>
<td>2</td>
<td>Vila Kennedy</td>
<td>Housewife</td>
<td>2013</td>
</tr>
</tbody>
</table>

**Chart 2. Care path of women assisted in the oncology reference unit in 2014**

<table>
<thead>
<tr>
<th>Woman</th>
<th>Private health coverage</th>
<th>Following-up by ESF</th>
<th>Prior gynecological symptoms</th>
<th>Stage of diagnosed tumor</th>
<th>Time in days between diagnosis confirmation and enrolment in the reference unity</th>
<th>Time in days between diagnosis confirmation and treatment initiation</th>
</tr>
</thead>
<tbody>
<tr>
<td>M1</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>IIB</td>
<td>130</td>
<td>259</td>
</tr>
<tr>
<td>M2</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>IB2</td>
<td>7</td>
<td>34</td>
</tr>
<tr>
<td>M3</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>IIB</td>
<td>2</td>
<td>44</td>
</tr>
<tr>
<td>M4</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>IIB</td>
<td>20</td>
<td>167</td>
</tr>
<tr>
<td>M5</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>IIB</td>
<td>12</td>
<td>136</td>
</tr>
</tbody>
</table>
Understanding of women interviewed about prevention and early detection

The difficulty in accessing the preventive test provided by SUS was the first aspect regarding the organization of AB health services and has direct impact on early prevention and detection. M1 and M2 reports depict an example of access barrier to preventive test under SUS:

[...] they asked to do the preventive test, I had to go to the lecture and I couldn’t, there was no way to go. So I spoke: or I go to work, or I go to the lecture. (M1).

[...] the service is increasingly precarious. I live in an area considered dangerous, for no reason they close the care unit. And then, as it is very difficult, you leave it alone. (M2).

Other barriers reported by women as for the access to preventive test were the work and the responsibility for raising children and supporting the family. Long daily work journeys and the everyday overload might discourage the taking of tests regularly\textsuperscript{2,20-22}. According to Mattos, when we look for the organization of the services in terms of completeness, we “seek to expand the perceptions of the groups’ needs, and wonder about the best ways to respond to such needs”\textsuperscript{23(62)}. Therefore, the organization of health services must include women who cannot attend within the Basic Health Units (UBS) working hours. Brito-Silva et al.\textsuperscript{10} reinforce that the difficulty of access to the AB is connected to a dynamics of service characterized by low flexibility in scheduling appointments and by bureaucratization. These restrictions hinder and discourage the search for the service by women.

The experience of taking the preventive test under the private health sector reported by M2 also demonstrated the low quality of services: “... every time I bled, so I got traumatized, got a panic of that experience. It always hurt me ...”. In addition to the physical pain during the procedure, the user also reports to having gone through embarrassment situations, what discourages the gynecological care on a regular basis.

M2 report corroborates the findings of several studies on the reasons that interfered negatively on the regularity of the preventive test. Experiences of abuse or indignities suffered during the test associated with the lack of information about the objective of the preventive test and restricted access to health services are factors that contribute to the emergence of feelings like shame, pain, fear and embarrassment. Subjective aspects are crucial in the adherence to the prevention and care routine since bad and painful experiences move away and discourage the continuity of a care routine\textsuperscript{2,20-22}. In this sense, all professionals involved in the disease tracing, either under SUS or private assistance, must be qualified to recognize and deal with such issues.

A feature common to all interviewed women was the search for a gynecologist appointment after symptoms indicating gynecological alterations. This is a common behavior and expresses the understanding of health care based on the disease. Some of the leading gynecological symptoms, such as pain, discharge, itching are addressed as an indication for the preventive test, reinforcing the connection of preventive behavior to a complaint, especially related to infectious diseases\textsuperscript{22}. On the other hand, more severe symptoms referred by the interviewed women, such as vaginal bleeding and odor discharge, can be related to advanced stages of the disease, evidencing a late diagnosis, thus less healing possibilities\textsuperscript{9,11}.

AB, in particular ESF, should provide special care to women bearing a history of HPV infection as well as other risk factors, like smoking, multiparity, immunosuppression and early initiation of sexual life,
as advocated by the Brazilian guidelines of disease tracing. Campaigns are important due to the convenience of opening hours and nimbleness of service, but they are not sufficient, since they are addressed to respond solely to the needs of women who look for the services\textsuperscript{21,22}.

Respecting preventive practices, even despite two women out of five having been referred for treatment by the ESF (M1 and M5), these reported not to have received health care professional guidelines on prevention. The women lack of information about the purpose of the test and the care routine periodicity was also another issue:

*Because I had the idea that preventive test just detected inflammation and nowadays I know it’s not like that [...] main objective is to verify the existence of cancer cells.* (Interviewed M2).

*I took long to search for precisely because I had not any discharge, [...] I have not had sexual intercourse for eleven years.* (Interviewed M3).

These reports confirm the findings of studies revealing the women lack of knowledge concerning the preventive test objective, which is mistakenly associated with the prevention of Sexually Transmitted Diseases (STD) and other gynecological diseases\textsuperscript{2,20-22,24}. The ignorance about the test can compromise the decision of searching for the health service once PAP smear is not associated with a preventive practice. Andrade et al.\textsuperscript{22} also note that this reality is observed in health practices when professionals prioritize their guidelines during the preventive completion, paying less importance to the information about its purpose. Such behavior connects the preventive action to the fulfillment of goals, making the activity a merely mandatory one.

Another issue involved in the adherence of preventive practice is that concerning moral values contained in the meanings and practices related to the disease. It becomes more difficult to visualize cervix cancer as a potential risk for those women who have a regular partner, no sexual activity and are aged. Thus, information on the disease and its preventive objective are recommended for this particular group of women\textsuperscript{2}.

Given this scenario, it is necessary to broadcast the information to the target age group of women about HPV infection, the disease tracing by means of the preventive test and its recommended periodicity. Media campaigns are important, but they do not minimize the health care responsibility of the professional to perform a humanized procedure, with educational and understanding approach during consultations, watching out for the cancer health-disease process, the woman feelings regarding the test and her socio-economic and cultural condition\textsuperscript{21}.

**Understanding of women interviewed about appropriate and timely treatment**

The narrative of women paths through health care showed that AB acted diligently in the referrals of M2 and M3 users. In these two cases, UBS acted directly on the referrals. In this study, M2 and M3 care paths served as examples of effective care coordination, since the two women began treatment within the 60 day-period set by law. It was noted from the reports of those users that efforts have been made by the professionals to expedite their referral before the schedule controlling system. However, it is noteworthy that, in the case of M3, the referral was prioritized because the diagnosis was revealed after a surgical procedure required by a non-specialist professional, which worsened her medical condition.

The main issues related to the organization of health services from the knowledge of the cancer diagnosis involve both the waiting time for the carrying out of the diagnosis confirmation procedures by means of
the biopsy and the scheduling of the treatment initiation. The speech of M1 expressed the difficulties she faced:

*I was able to make the biopsy appointment two or three months later [...] so I had to go to Irajá. Because when you find out, you become in a hurry to have the treatment. I think the treatment had to start faster, because it takes too long. It was a very long trajectory, of months. I arrived here in February (2015) and began the treatment last week.* (interview given on 28/09/2015).

The results of the first part of the study reveal that the majority of cervix cancer treatments of women diagnosed with invasive cancer (88%) began after the 60-day period. Such a situation was verified by the trajectories of three women among the five interviewed. The late-onset treatment compromises the survival of women once the disease progression limits the possibilities of treatment\(^{11}\).

Another important issue highlighted by users M3 and M5 concerns the difficulty to go through radiation therapy and chemotherapy in different units. In the case of these two women, because of the waiting list, it was necessary to forward them to other partnership units of SUS network so to expedite the start of treatment with radiotherapy sessions. M3 path report revealed the burden to cross long distances in search for treatment. Frequently, she left the radiotherapy clinic around midnight, when the public transportation supply is scarce, to arrive home around two o’clock in the morning. However, M3 explained that it was the only option available to start the treatment the quickest possible.

Paths’ reports confirmed that access inequality is one of the major problems to be faced by SUS so to work in accordance with defined principles and guidelines\(^{25}\). Particularly, M3 and M5 narratives evinced as main difficulties of their path. Besides the diagnosis of locally advanced disease and the treatment prescription involving sessions of radiotherapy, chemotherapy and brachytherapy, they also had to go through each part of the treatment in different health units, far between each other and their homes. The treatment fragmentation compromises the care completeness and causes the trajectory of these women, already weakened by the disease diagnosis, to become even more painful.

**Comments**

The findings of this study reinforce a contradiction between tracing and controlling strategies concerning cervix cancer advocated by the MS and the organization structure of health services responsible for these actions. The users’ perceptions about access to preventive test and difficulties reported throughout the care path strengthen the paradox. The analysis carried out to verify the compliance with the 60-day time limit for treatment initiation proved pertinent to state that improvements are needed in the articulation of services within their different levels of complexity so to ensure that all diagnosed women have timely access to the forms of treatment they need.

The path description of the women under health care aroused thoughts about the difficulties observed in the care line of cervix cancer in the Municipality of Rio de Janeiro. It fulfilled the proposal of giving voice to the women affected by the disease, enabling the identification of the main issues that influenced their paths. The late diagnosis of the women who participated in the study revealed some factors that prevented early detection of the disease. These factors relate mainly to the difficulties in accessing preventive test in SUS due to the bureaucratisation of the services, and to UBS inflexible scheduling to service women committed with long working journeys. The users have the feeling that the services provided by SUS have low
resolution. Other findings are related to the lack of information about the disease and the purpose of the test, in addition to subjective factors as fear and embarrassment regarding the test itself.

Thus, to improve the prevention and early detection of the disease, efforts must also focus on AB strengthening, mainly ESF, a care model that emphasizes comprehensive care and stays closer to the community. ESF must take the responsibility for active search of asymptomatic women and for monitoring the preventive test frequency of the territory target population. In addition to the active search, it is also AB’s role to put into practice health education actions so to inform the female population about the tracing test objectives.

The ESF in the Municipality of Rio de Janeiro is still in expansion, although current coverage be around 50%. The implementation by MS of the Program to Improve Access and Quality of Primary Care (PMAQ-AB) in 2012 prompted the increasing in the population access to services, and the improvement of care quality by means of the transfer of resources linked to the performance of teams. The cytopathological test coverage is one of the care quality indicators covered by the Program. Thus, the trend is that the coverage among women in the target age range increases as ESF coverage increases in the Municipality of Rio de Janeiro. The expansion of AB is a challenging issue since the care network should be organized also to absorb the demand of a larger number of women subjected to tracing as to forward altered cases to appropriate and timely treatment, in order to decrease the incidence of cervix cancer.
References


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