Original Articles

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Integrality in cervical cancer care: evaluation of access

ABSTRACT

OBJECTIVE: To evaluate integrity of access to uterine cervical cancer prevention, diagnosis and treatment services.

METHODS: The tracer condition was analyzed using a mixed quantitative and qualitative approach. The quantitative approach was based on secondary data from the analysis of cytology and biopsy exams performed between 2008 and 2010 on 25 to 59 year-old women in a municipality with a large population and with the necessary technological resources. Data were obtained from the Health Information System and the Regional Cervical Cancer Information System. Statistical analysis was performed using PASW statistic 17.0 software. The qualitative approach involved semi-structured interviews with service managers, health care professionals and users. NVivo 9.0 software was used for the content analysis of the primary data.

RESULTS: Pap smear coverage was low, possible due to insufficient screening and the difficulty of making appointments in primary care. The numbers of biopsies conducted are similar to those of abnormal cytologies, reflecting easy access to the specialized services. There was higher coverage among younger women. More serious diagnoses, for both cytologies and biopsies, were more prevalent in older women.

CONCLUSIONS: Insufficient coverage of cytologies, reported by the interviewees allows us to understand access difficulties in primary care, as well as the fragility of screening strategies.

DESCRIPTORS: Uterine Cervical Neoplasms, prevention & control. Women's Health Services. Integrality in Health. Health Care Quality, Access, and Evaluation.

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INTRODUCTION

In step with worldwide trends, the most common types of cancer in Brazilian women are breast cancer and uterine cervical cancer (UCC). According to Brazilian Ministry of Health National Cancer Institute figures,[19] UCC is responsible for the deaths of around 230 thousand women annually. In developing countries, incidence is around two times higher than in more developed countries. At the same time, it is a type of cancer with higher potential for prevention and for cure if diagnosed early.

The high prevention and cure potential is explained by the of the disease, with well-defined stages, and the ease of early detection of changes, making quick diagnosis and efficacious treatment viable.

Effective early UCC detection, through Pap smear tests, associated with treating squamous intraepithelial lesions, can reduce the incidence of such cancers by 90.0%, with significant impact on morbidity and mortality rates.[16] However, such a reduction depends on quality screening covering at least 80.0% of the target population (25 to 59 years old). As recommended by the World Health Organization (WHO).[28] Effective screening programs can help to reduce incidence rates and, consequently, mortality from UCC.[17]

Despite improvements in the coverage of cytological testing in Brazil, it is still deemed insufficient to reduce UCC mortality.[16] Moreover, the quality of testing and the stages at which cases are diagnosed are other factors influencing this situation.[24]

Delayed diagnosis makes it more difficult to access services and, above all, reveals a lack of quantity and quality oncological services outside of the larger state capitals.[16] Other aspects which may contribute to delayed diagnosis are: poor professional training in oncological care, inability of health care units to meet demand and municipal and state administration difficulties in defining and establishing flow at different care levels.[20]

In one sense, integrality can refer to the population's access to different levels of care. Although universal access is a constitutional right and this has broken down formal barriers, difficulties in access to, and continuity of, care remain,[15] both in primary care and in more specialized services.[9,26]

Seeking to combat the disease effectively, the National UCC Control Program in Brazil provides access to different services for dealing with each phase of the illness. Early detection (screening) of UCC in asymptomatic women is this program's paramount initiative, with the following essential elements: defining the target population and screening method and interval; coverage goals; infrastructure in the three levels of care and guaranteed quality of the actions.[18]

Developing evaluative studies regarding UCC care integrality may encourage identification of this context, enabling bottle necks in the different levels of care to be identified.

Using tracers is one of the recommended strategies in developing evaluative research.[13,23] Using this technique enables foci to be more easily defined and means multiple care points involved in integrating services can be covered.[12]

UCC is a tracer[4,13,16] as it is a disease which meets the requisites: frequent event with scientifically well-defined etiology, diagnosis, treatment and prevention; the existence of a consolidated national program involving all levels of care; a disease that evolves slowly and for which there is an effective treatment.

Considering that integrality covers different dimensions,[6] the aim of this study was to evaluate integrality in the dimension of access to prevention, diagnosis and treatment services for uterine cervical cancer.

METHODOLOGICAL PROCEEDINGS

Evaluative research was conducted based on the sequential mixed methods design. Quantitative data were used, followed by qualitative data. This combination aimed to enable better understanding of the research problem by converging numeric trends from a quantitative approach and qualitative details.[8]

It was decided to use a case study. The location studied is one of the Brazilian cities with the highest number of registered health care establishments and available health care professionals, being the biggest health care reference center in the northeast of Sao Paulo state. It is a significant case [29] due to its coverage and capacity to provide UCC care, as well as for historical and political investment processes and advances in local SUS structuration. Given these details, this study denominated the location as a key-municipality.

As in other large urban centers, despite the provision of health care services, the location studied has limitations concerning the quality and capacity of responses at different care levels.[26] Although there are sufficient health care facilities to make integrality of UCC care viable, the place studied reflects the Brazilian reality of mortality from this type of cancer, with a rate of 4.5 deaths per 100 thousand women in 2008.

The focus of the study identified functional bottle necks in the UCC prevention, diagnosis and treatment process, using the capacity to provide services at different levels of technological complexity as a parameter in the search for integrality in care.

The first stage of investigation consisted of formulating the following hypotheses:

1. Pap smear coverage is insufficient in the key municipality;

2. There are difficulties in accessing levels of more technological density (biopsy and treatment).

To investigate these hypotheses, the different care levels were studied, aiming to quantitatively understand women's capacity to access different services, as well as their ability to meet users' needs.

The data were taken from Hygiaweb and the regional Siscolo. Hygia is the key municipality's health care secretariat's official information system in which procedures performed in municipal health care units are recorded. The data were generated in Excel spreadsheets, enabling access to cytopathology tests, diagnoses and possible referrals for women aged 25 to 59 and recorded in the system between January 2008 and June 2010.

To complement the data obtained from Hygia, the XIII Regional Health Department of the Sao Paulo State Health Secretariat (SES/SP) database was accessed regarding the UCC prevention diagnosis procedures that occurred under state administration in the key municipality. The data available in the state and municipal sphere were organized in a single database, enabling the procedures covering the local health care system to be visualized together in one place.

Secondary data were analyzed using PASW statistic 17.0 software to analyze frequency distribution and the study variables.

The variables studied concerning cytology (performed and with changes) and biopsies were: year test was performed, age group, type of change (diagnostic), health care service administration (state/municipal).

From these variables, cytology coverage in the key municipality was identified by year and age group as were the changes that most affected the women in the study and biopsy coverage where necessary.

Regarding data concerning treatment, a lack of records in the local health care information system was identified.

The qualitative approach involved selecting the two health districts (HD 3 and HD 4) that conducted the most cytological tests in the period studied, these having the greatest provision and, consequently, the greatest coverage of care activities for the condition traced. The key informants selected were: primary and/or specialist health care professionals involved in activities promoting, preventing, diagnosing and/or treating women with UCC; users aged between 25 and 59, registered with the health care unit and in need of referral to other levels of care due to changes detected in their cytology tests. In addition to the health care professionals directly involved, representatives of municipal administration with attributes identified as being relevant in the other interviews were also interviewed.

Individual, semi-structured interviews were conducted with ten health care professionals operating at different levels of the health care system; ten users and two representatives of the administration. The primary data were transcribed and underwent content analysis.[11] the data were categorized using NVivo 9.0 software.

Although the qualitative findings covered different dimensions of integrality, the results shown here only refer to the dimension of access, in dialogue with the quantitative findings of the research.

Thus, the categories presented are: rapid access to specialist services; difficulty in making appointments; and primary care spontaneous demand based care.

Names were changed to maintain participants' confidentiality. Users were given the first name "Maria" and administration representatives and health care professionals were given names related to weaving.

ANALYSIS OF RESULTS AND DISCUSSION

Preventing uterine cervical cancer

In the key municipality, the female population aged between 25 and 29 corresponded to a total of 146,868 women and the 30 thousand smear tests performed annually by SUS services for this population means coverage of around 20.0% per year, as can be seen in Figure 1.

Smear test coverage in the key municipality is, therefore, lower than WHO recommendations (80.0%) to have significant impact on morbidity and mortality rates for this kind of cancer.[28] However, the coverage observed in the key municipality exceeded that in the majority of Brazilian states, where the coverage was below 20.0% in 2008-2009 for women in the same age range.[19]
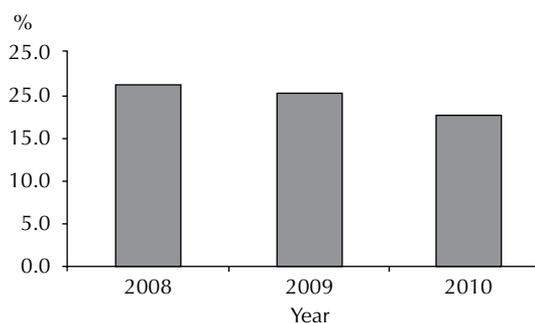
Figure 1. Annual coverage of cytological tests for women aged 25 to 59. Key municipality, SP, Southeastern Brazil, 2008-2010.

Pap smear screening is deemed to be the most effective approach for controlling UCC. Epidemiological studies have shown a higher risk of the disease in women who have never had the test done and a proportional rise in risk according to the time elapsed since the most recent smear test.[10,14]

Hypotheses regarding poor coverage in the key municipality include: underreporting of tests actually performed, the percentage of women having the test done in private health care services, insufficient supply of services/human resources making access to primary care services more difficult and/or insufficient active searching.

On the topic of private health care service use, it was noted in the interviews that many users used means of accessing health care other than the SUS, such as health care plans.

In addition to these hypotheses, the findings of Brenna et al[5] on factors associated with poor adherence to having a smear test done should also be taken into account; these include: embarrassment, distance, difficulty leaving children or dependents, getting time off work, as well as financial or transport-related difficulties.

Of the hypotheses listed above, difficulty in accessing primary care and insufficient active search were reported in the interviews.

> "In the health care center, there is only one day on which you can make appointments. It's the first of the month. When that day comes round, there are so many things going on that you end up forgetting. When you remember, it's too late". (Maria de Nazaré)

> "It is difficult to access the primary care unit (...). It takes users a long time to manage it. (...) in some units they are very strict about it. In the end, they only do what is very urgent. If not, no time is made for it". (Cotton)

> "From the moment I became strict about punctuality, the patients I saw dropped by 30.0% (...). Today, I don't squeeze them in. I only make room for emergencies. Miss your appointment? It's not my problem". (Fabric)

Based on the interviews, it can be stated that difficulty in accessing primary care is, above all, related to lack of flexibility in making appointments. The dynamic of attendance is restricted and bureaucracy contributes to making it difficult and to discouraging women from seeking to use the service, delaying them having a smear test done, as can be seen in Figure 1.

There are different studies that indicate a similar situation to that observed in the key municipality. Andrade et al[2] (2007) indicate critical access situations in family health care units in a municipality in Bahia, Northeastern Brazil, where it was common to arrive at the unit in the early hours of the morning and even then not be guaranteed an appointment. Cunha & Vieira-da-Silva[9] highlighted difficulties in accessing primary care in cities in the Northeast of Brazil, in both traditional units and family health care units, emphasizing the appointment making process as a significant obstacle to using the service.

Statements such as those of Fabric and Cotton portray the indifference of professionals who see themselves as spectators, without taking responsibility for the situation and ignoring users' rights.

Regarding the entrance policy for users, representatives from the three groups interviewed confirmed it was based on the logic of spontaneous demand:

> "I hadn't had one [smear test] for 20 years (...). Nobody ever talked to me about it. I did it now because I decided to look after myself". (Maria de Nazaré)

> "Our unit is very passive. It waits for people to come to it (...) we deal with whoever shows up and we have no idea who needs to have it done". (Fiber)

> "Units that don't have a community health worker don't have that type of focus: someone missed their appointment? Deal with the user who is there and no one looks into it any further". (Warp)

The way in which the health care services are organized to screen for cancer can be based on either organized or spontaneous provision.[27]

In the organized model, there are appropriate structure and resources to perform screening tests regularly, as well as to treat suspicious lesions. There are mechanisms to recruit the target population and systematic monitoring of individuals whose test results are positive.[3]

In the spontaneous model, screening is not a systematic part of the routine of health care services and is restricted to those who occasionally seek the health care service for different reasons, with no actions developed to actively seek cases, resulting in inequalities in access and inefficient use of resources.[27]

Organization based on spontaneous demand is a basic characteristic of the privatized care model traditionally found in health care services in this country.

Regarding prevention of UCC, various studies[21,25] have shown that having a Pap smear test done is predominantly associated with the women themselves seeking this, reaffirming what was stated above in the interviews and resulting in situations such as that of Maria de Nazaré, who reported not having the test done for more than 20 years.

Vale et al[25] emphasize the relationship between primary care based on spontaneous demand and poor coverage. Higher frequency of events, such as pregnancy, need for contraceptive methods or treating discharge, in younger women, means that they see the gynecologist more often than older women.[1] Thus, in addition to being insufficient, coverage is also concentrated on younger women and does not reach those in their 50s and 60s, the group with the highest cancer risk. Actively seeking cases, associated with monitoring and performing tests, are actions which could encourage increased Pap smear coverage, especially in women over 50.

As can be seen in Figure 2, in the key municipality, there is a trend for coverage to decrease with age group. Over the age of 40, coverage is below 15.0%.

The fact that women between 40 and 59 visit the gynecologist less often results in low frequency of having Pap smear tests and, consequently, in diagnoses being more serious than those observed in younger women. The concentration of cytopathology tests in women aged under 35 is a commonly observed situation in Brazil.

Amorim et al[1] deem it essential that health care services take advantage of older women using them for other health problems to perform a Pap smear.

Parada et al[21] suggest reorganizing reception in primary health care units using strategies such as: consultations without appointments, alternative opening hours (during the night or the weekend), actively seeking women within the program's age range, especially those who have never had a smear test, seeking to increase and facilitate women's access to these services.
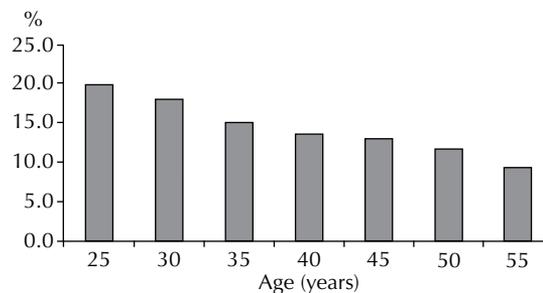
Figure 2. Cytology in women aged 25 to 59 by age group. Key municipality, SP, Southeastern Brazil, 2008-2010.

The urgent need to capture users aged over 50 can be seen in Figure 3, which shows the predominance of malignant changes in women aged over 50. Malignant changes (adenocarcinoma, carcinoma) were mainly diagnosed in women aged between 50 and 59, whereas benign and pre-malignant changes were concentrated in younger women (25-39) (Figure 3).

Ribeiro et al[22] identified that, for women aged between 46 and 74, gynecological examination is seen by many as a painful, embarrassing and disagreeable experience. According to the authors, this perspective is explained as they form part of a generation which suffered intense sexual repression, as well as having undergone negative experiences during impersonal, careless gynecological examinations without any explanation of the process given, which contributes significantly to these women's refusal to seek this form of caring for themselves.
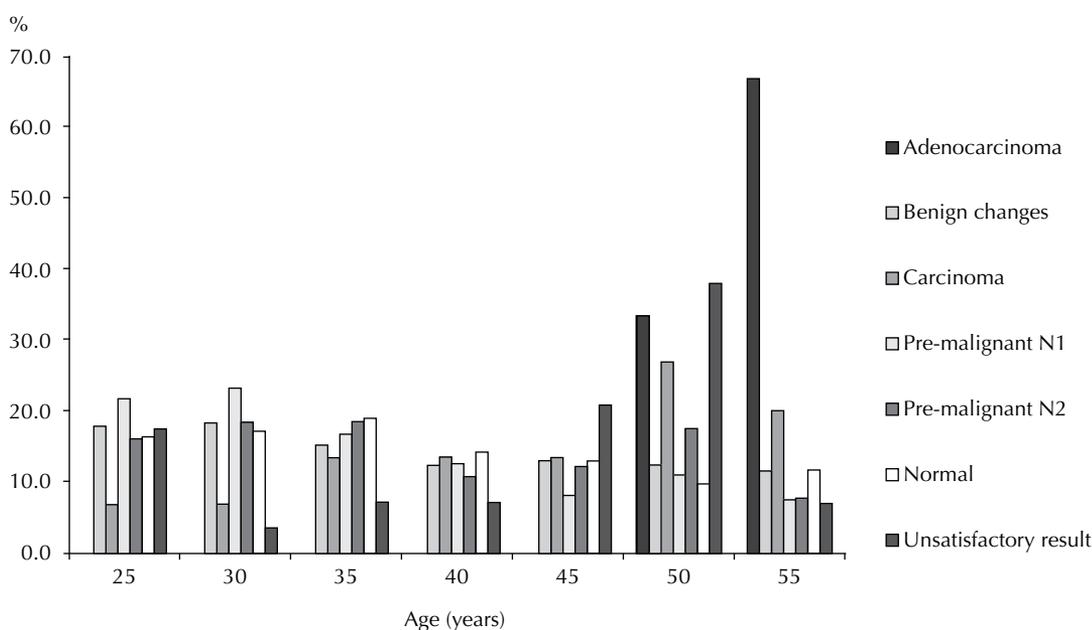
Figure 3. Diagnoses of cytology by age group. Key municipality, SP, Southeastern Brazil, 2008-2010.

Incorporating guidance by the health care team on the preventative role of the test in menopausal women's health is essential in encouraging it, contributing to reducing incidence and mortality in this population.

Diagnosing and treating uterine cervical cancer

The Brazilian Ministry of Health[20] recommends the following procedures for diagnoses obtained from Pap smear tests: normal cytology and benign changes should follow routine (annual) cytological screening: for pre--malignant changes, it is recommended that cytology is repeated every six months; in case of malignant changes, a colposcopy is immediately performed and, if lesions are found, a biopsy is recommended.

Thus, the aim is to identify equivalent coverage between the number of biopsies performed and the number of Pap smear results with changes that led to them being performed, by year and age group.

In Figure 4, it can be seen that the number of biopsies is equivalent to the number of cytological tests showing changes. In 2008, however, this was not the case, with the rate being around 80.0%. The years 2009 and 2010 had rates of 116.7% and 119.3%, respectively. This finding can be explained both by inappropriate referral in cases that did not require a biopsy, as reported by health care professionals from the specialist service, and by women having the smear test done in the private sector and then referred to have the biopsy done in the public sector.

> "I see that my colleagues have difficulty following the ministry guidelines. For example, when an NIC 1 cytology appears, they immediately refer this patient, when they should repeat the test after 6 months (…). In my outpatients' unit, around 50.0% of referrals are not appropriate". (Shuttle)

The qualitative data confirm that cases requiring a biopsy are referred to specialist services. From the interviews, it was observed that access to medium complexity care occurs quickly, which may favor the observed result.

According to the interviewees, it varies between one and two weeks to enter secondary level care when some change requiring more complex tests is identified in the cytology: the period between making an appointment and the result is between 15 and 20 days.

> "It didn't take long. It was really quick. Around 20 days". (Maria da Conceição)

> "It's around a week, at the most. The PHC (primary health care unit) itself calls and makes an appointment.
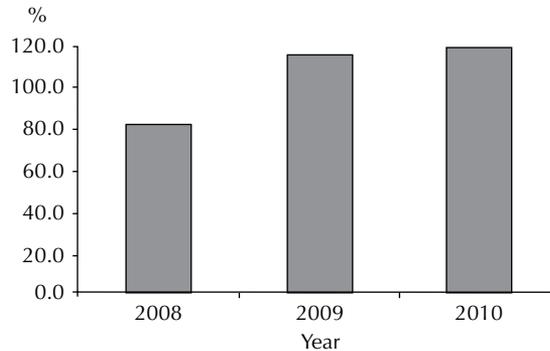
Figure 4. Coverage of biopsy by cytology with changes. Key municipality, SP, Southeastern Brazil, 2008-2010.

In a week, the patient has an appointment scheduled". (Needle)

It was not possible to obtain qualitative data on users' treatment. According to data from the UCC Information System,[a] the key municipality did not have follow up records of 99.98% of cases, as proposed by Siscolo. However, the qualitative approach identified issues such as making access to tertiary level care within a short space of time more viable:

> "Ah! It was really quick there. I was referred the same week". (Maria das Graças)

> "When someone needs to be referred to the university hospital, they have an appointment made to start treatment within 15 or 20 days". (Needle)

> "There is no difficulty making appointments with the university hospital for cervical cancer cases. None at all". (Loom)

Facilitated access to secondary and tertiary levels of care is not a commonly observed situation in this country. According to Parada,[21] guaranteeing appropriate actions in diagnosing and treating UCC is a key point in the organization of the care flow.

Cecílio & Merhy[7] state that "the care flow, thought of as a whole, crosses through countless health care services". According to these authors, there is no radical integrality without transversality within the system. UCC, specifically, depends on uniting different technologies to advance women's health care, considering the disease's different levels of evolution.

The situation observed in the key municipality is explained by the prioritization of immediate referral of service users when necessary. Ease of access to specialized services is a relevant investment in preventing secondary and tertiary UCC.

Using UCC as a tracer to assess integrality in the dimension of access enabled the principal strengths and weaknesses of the different care levels for this disease to be identified.

Ongoing insufficient cytological coverage, especially among older women, reflects users' problems in accessing primary care and the fragility of active searching for cases.

There are no access problems in the secondary level, which includes a higher number of women than expected. On the other hand, as well as portraying referrals from the private sector, professional insecurity concerning Pap smear results may mean that not all the cases they refer for biopsy are suspicious.

Regarding following up of positive cases, we found problems recording data, impeding a quantitative assessment of access to this level of care. The limitations found in the health care information systems consulted portrays a problem researchers often face when working with secondary data obtained using these tools.

It is difficult to find health care information systems being consulted in planning and assessing actions, with this instrument being underused in decision making. This underuse frequently results in incomplete, unreliable and out of date data, making their use for scientific studies or administration difficult. As administrators come to better understand the use of such data in decision making, their recording will gradually improve.

CONCLUSION

The findings of this study met the expectation to assess integrality in access to UCC care. Identifying bottle necks in the SUS encourages decision making by administrators aiming to improve UCC care quality as well as other health problems. However, in order for advances in SUS integrality to take place, complementary exploration of this care dynamic is needed.

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