Factors that, in the view of Women, Impede the Early Diagnosis of Cervical Cancer

Fatores que, na Visão da Mulher, Interferem no Diagnóstico Precoce do Câncer do Colo do Útero

Factors that, in the View of the Woman, Interfere in the Diagnóstico Precoz del Cáncer del Cuello del Útero

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Abstract

Introduction: In Brazil, cervical cancer is the fourth leading cause of cancer death in women. It is estimated that there will be 16,370 new cases in 2018, translating to an incidence of 15.43 cases per 100,000 women. Objective: To identify the factors that, in the view of women, impede the early diagnosis of cervical cancer. Method: This was a descriptive quantitative and qualitative study consisting of an epidemiological approach anchored in the investigation of sentinel events and a qualitative approach based on content analyses of thematic categories. We interviewed women with advanced stage cervical cancer treated in January and February of 2012 at health care facilities operated by the Unified Health System in the city of Campo Grande, in the state of Mato Grosso do Sul. Results: The study included seven women between 37 and 54 years of age. The interviewees proved to be uninformed about the usefulness of preventive screening and reported that they do not see themselves as the target of specific health interventions. When faced with the diagnosis of cancer, they showed despair, pain, anger, fear, incapacitation, and denial. They also reported having made use of alternative treatments, having relied on their beliefs and on family members to deal with the effects of the disease, and having noted shortcomings of the health care facilities. Conclusion: Our results indicate the need for future studies on the subject. Such studies should focus on health care worker practices and on the educational process carried out in the context of comprehensive health care interventions for women.

Key words: Uterine Cervical Neoplasms; Early Diagnosis; Sentinel Surveillance; Qualitative Analysis.
INTRODUCTION

In Brazil, cervical cancer is the fourth leading cause of cancer death in women. It is estimated that there will be 16,370 new cases in 2018, translating to an incidence of 15.43 cases/100,000 women\(^1\). In the state of Mato Grosso do Sul, the estimate is for 20.49 new cases/100,000 women in that same year\(^2\). Between 2006 and 2015, the age-adjusted mortality rates in that state ranged from 4.58 to 8.55 cases/100,000 women, the proportion of women affected being highest (22.8%) in the 50- to 59-year age group -old women, followed by 20.3% in the 40- to 49-year age group and 19.1% in the 60- to 69-year age group\(^3\).

The World Health Organization\(^1\) estimates that mortality from cervical cancer could be reduced by 80% if women between 25 and 60 years of age were screened with the Papanicolaou (Pap) smear test and received appropriate treatment of precursor lesions with a high potential for malignancy or carcinoma in situ. The efficiency of those procedures depends on the organization of the health care network, the thoroughness of the care provided, the quality of the screening/follow-up of patients showing alterations in the cytopathology examination, and, above all, the conscious participation of the women.

It should be noted that the factors that reportedly cause women not to undergo a Pap smear have been consistent across various studies conducted in Brazil and are commonly related to low socioeconomic status, a low level of education, low family income, and youth\(^4\). However, in discussing the challenge of reducing mortality from cervical cancer, Zeferino\(^5\) added to that list factors related to health care services. According to that author, the most important factors related to health care services are those for which short-term interventions would be possible: maintaining quality to ensure correct diagnosis and accurate treatment; making access to services easy and rapid; having the flexibility to schedule and reschedule visits; and providing prompt treatment. In addition to ensuring 70-80% coverage for the Pap smear which is already the case in many parts of Brazil it is important that women who have abnormal Pap smear results receive appropriate treatment. Thuler\(^6\) stated that the diagnosis of cervical cancer at an advanced stage reflects problems in access to services, aggravated, mainly, by the scarcity of oncology centers outside the large metropolitan centers of the country. Osawa and Marcopito\(^7\) argued that impeded access is associated not only with the socioeconomic characteristics of individuals but also with the availability and organization of health care services. In addition to these factors, we should also highlight the erroneous referral to secondary services of patients in whom the cervical cytology is consistent with atypical cells of undetermined significance (reactive cells) or low-grade intraepithelial lesion who should undergo the examination again in six months thus overloading the health care services, which is contrary to the norms established by the Brazilian National Ministry of Health\(^8\). Within this context, the objective of the present study was to identify the factors that, in the view of women, influence the early diagnosis of cervical cancer.

METHOD

This was a descriptive, cross-sectional study, employing quantitative and qualitative analyses, anchored in the investigation of sentinel events and the content analysis of thematic categories. We interviewed women with advanced stage cervical cancer, with the objective of evaluating health care practices, as well as detecting flaws in the organization of services and in the relationship with the patients. We constructed a logic model of the Mato Grosso do Sul State Cervical Cancer Prevention Program, in accordance with the basic roadmap proposed by the Brazilian National Institute of Applied Economic Research\(^9\) and containing the following elements (Figure 1): resources; activities/actions; intermediate results; and final results. In addition, a content analysis of thematic categories was used in order to study the social representations; to identify the knowledge, information, and understanding of the feelings; the meanings that the disease can have; and the way in which women deal with it. To that end, we constructed operations to separate the text into units of meaning, according to the pre-established categories, consisting in identifying nuclei of meaning, describing them and quantifying them as to their significance.

The study was conducted at the Mato Grosso do Sul State Department of Health. In 2010, the state had a Municipal Human Development Index of 0.729, the second best in the region and tenth in the national ranking\(^10\). According to the Brazilian Institute of Geography and Statistics\(^11\), of the 2,449,024 inhabitants living in the state in 2010, 1,229,096 (50.2%) were female. The average life expectancy of women in the state (77.7 years) was the ninth highest in the nation.

Because of the study design, we decided to analyze an intentional sample in which women were included until the point of saturation had been reached; that is, when the discourses began to present elements in common, adding little to the information already collected, the
sample was finalized. The following inclusion criteria were applied: being between 25 and 59 years of age; having been treated in January and February of 2012 at a health care facility affiliated with the Unified Health System; being a resident of the state of Mato Grosso do Sul; and having a history of advanced stage cervical cancer. The interview was the only source of data, consisting of guiding, closed, and open questions. The data were collected by an interviewer who was trained and qualified for that purpose. The project was approved by the Research Ethics Committee of the Federal University of Mato Grosso do Sul, on October 19, 2011 (Reference no. 2195 CAAE 0289.0.0.049.000-11), and all of the participants gave written informed consent.

RESULTS AND DISCUSSION

Sociodemographic profile

We interviewed seven women between 37 and 54 years of age. Of those seven women, four (57.1%) were single, six (85.7%) were White, six (85.7%) worked in the domestic labor market, five (71.4%) were earning up to three times the Brazilian national minimum wage, five (71.4%) had < 9 years of schooling, and one (14.3%) had a college degree. It is important to emphasize that the level of education is an essential factor in adherence to health prevention measures, especially those related to early detection of cervical cancer. Various studies have shown that women with greater access to formal education take better care of their own health, as well as that of their families, and seek treatment more often. Three (42.9%) of the seven women interviewed in the present study had not had a Pap smear for more than three years. In a study conducted in the state of Roraima, Fonseca et al. found that 71.7% of women with cervical cancer or high-grade premalignant lesions had never had a Pap smear.

Mismatches between technical and popular knowledge

Each of the women interviewed had unique information and ideas regarding the concept of cervical cytology and its specificities. We found that none of the interviewees knew what the preventive exam is for, although 85.7% reported that they had received the results of the exam, as highlighted in the following statements, given in response to the question regarding the purpose of a Pap smear:

(housekeeper, age 44) – I don’t know, I just knew that my mother said she had to do it every year. I did it when I had some drainage.

(homemaker, age 43) – It lets you know everything, you know if you have any type of disease. To prevent a lot of problems.
develop their potential in the field of knowledge, as well as sensitizing, motivating, and supporting women in order to among health care workers, users, and health education practices centered on technical norms that do not perceive the disease. The same problem exists for others, as can be seen in the following statements:

The following transcripts show how much women are informed about cervical cancer prevention and from where they received this information:

This statement is revealing of the mismatches among perceptions, knowledge, attitudes, and educational practices centered on technical norms that do not motivate, do not offer subsidies or autonomy to the subject to act on their health problems, especially in the search for the prevention of cancer be it of the cervix, breast, or another location. This perception of the user in relation to health care services also reveals denial of the disease. The same problem exists for others, as can be seen in the following statements:

These perceptions demonstrate that the relationships among health care workers, users, and health education should give rise to strategies capable of empowering, sensitizing, motivating, and supporting women in order to develop their potential in the field of knowledge, as well as to deepen their knowledge about their health, their reality of life situation, social relationships established between the public power and between themselves, as well as providing them with guidance in learning how to change their attitude, values, and customs, as well as how to make choices related to living in society and participating in public affairs. From that perspective, it is worth mentioning the study conducted by Freire, Gadotti, and Guimarães\textsuperscript{14}, who argued that, in the case of the democratization of knowledge, two issues must be taken into account. The first is that citizens have a right to improve upon the knowledge they have already gained from their own experience. It is undeniable that each subject has a certain level of knowledge, and that health care workers, educators, and other social actors can provide the support needed in order to better that knowledge. The second issue is that citizens also have the right to know what they do not yet know; that is, they have the right to participate in the production of new knowledge, beginning by answering the questions producing what, for whom, against whom, and against what.

In the statements of the interviewees, another aspect that merits attention is that, despite being alerted to the need for follow-up after the detection of precursor lesions, some do not adhere to the recommendations, as can be seen below:

In the following statement, the interviewee presents her idea of how health care services should guide educational activities or social mobilization:

\textit{(university professor, age 37)} – Three years ago, when I was pregnant with my third daughter, my doctor took a Pap smear and it showed inflammation. I had no symptoms. I was healthy. I knew I had inflammation and should go back after giving birth, but I didn’t.

In the following statement, the interviewee presents her idea of how health care services should guide educational activities or social mobilization:

\textit{(university professor, age 37)} – It might be necessary to carry out a more targeted campaign, to increase the psychological pressure, a campaign that attracts attention, a strong one, that points out the responsibility that people have for themselves. We all think it will never happen to us . . . I knew that prevention was necessary, but no one emphasized it. We, especially those of us who have families and children, don’t pay enough attention.
In addition to using health care professionals as sources of information, the interviewees reported using the Internet as a major means of staying informed, as indicated in the following statements:

(cook, age 40) – I did an Internet search and learned everything about it. I saw that it’s really serious, you know?
(homemaker, age 43) – Yes, I had a lot of questions, a lot. I looked on the Internet. I don’t know if it’s good to know, it freaks you out. Ignorance is bliss.

RECTIONS, ATTITUDES, AND FEELINGS: DESPAIR AT THE DIAGNOSIS OF CERVICAL CANCER

The statements below demonstrate how the women felt when they learned the results of the cervical cytology examination. In general, they express despair, pain, indignation, fear, incapacity, and, often, denial of the disease. In addition, cancer is a disease that carries a strong stigma, to the point that the women often omitted its name or were unable to utter it. There is also the understanding that cancer is synonymous with premature death and suffering:

(university professor, age 37) – I thought about death. Cancer is death. It was very painful. I decided that it was the annihilation of the person. One day, I saw a friend, who said, ‘but you look fine!’ Yes, there is a cure for this disease, ok. Now I know, it can be controlled. I resisted, really resisted, being treated at the cancer hospital. I hated talking about the disease. I did everything, I looked for a private doctor. My doctor helped me as much as he could before referring me to the cancer hospital.
(cook, age 54) – I just told my daughter, I cried and said that it was no use doing the treatment. The only thing I knew was that it was an incurable disease. I got really bad. I thought there was no chance of a cure, that my life was over.
(housekeeper, age 44) – Very bad. It’s difficult. I still can’t believe I’m sick. I really don’t feel like I have this disease, malignant cancer of the uterus. The most difficult time is when you find out that you have this disease: malignant cancer of the uterus.

All the interviewees stated that they had received the positive test result from their doctors. The behavior, emotions, and feelings expressed at that moment answer some of the main questions of our study, in terms of having access to the feelings, reactions, and attitudes in relation to receiving the diagnosis of cervical cancer, as well as the significance that a diagnosis of cancer has for these women. According to Moscovici23, some cultures have norms that lead to individualization, whereas the norms of others lead to socialization. From that perspective, one can then say that the representations that develop in those cultures carry the traits, the roots of ambiguity, giving them meaning in relation to the health-illness continuum, death, and life.

Another important aspect of our study is the focus on sexuality and gender issues, a concept that can be grasped from the following statement:

(cook, age 41) – I didn’t feel it, I really felt nothing. For my husband I was a “real pain”, you know? I told him: we’re going to split up soon. If I were you, I’d be thinking: wait six years to heal. He doesn’t want to break up. It had been almost a year since we’d had sex. I was in a lot of pain. He drinks a lot. But when he’s not drinking he’s a good person . . . I think about leaving him. I can’t be his wife anymore, you know? The hardest part is when you get the diagnosis. People look at you differently, people abandon you. I think it’s because they’re afraid that you will ask for help or want something from them.

To understand this behavior, it is important to remember that cervical cancer, breast cancer, pleasure and sex life are directly linked to sexuality and gender issues, making up the elements of a woman’s body, which represents the “forbidden temple”. Therefore, talking about these issues is not easy at all and can entail some embarrassment.

STRATEGIES TO ACHIEVE A CURE: ALTERNATIVE TREATMENTS

When asked about the use of alternative treatments or herbal medicines, the women revealed their attempts, as follows:

(university professor, age 37) – I used several things: purple trumpet-tree tea, seaweed, chlorella. The chlorella is widely used. It is even used by astronauts as a supplement. It’s a very powerful algae, a very knowledgeable naturalist recommended it. I took soursop capsules for two months. Then all the symptoms came back.
(cook, age 40) – I drank teas of purple trumpet-tree, white rose, sheep bur, and other herbs. I used them before and after the medical treatment. When I started the radiotherapy I stopped. The most difficult thing now is buying the medications.
(farm cook, age 46) – When I had myoma, yes, pink trumpet-tree tea, I also put on the mate, Senna macranthera, for everything, virgins’ bark. Everything the people told me to take I took to ease
the pain. But when the pain was really tight, I came to [the town of] Corumbá.

(homemaker, age 43) – Yes, homemade tea: arnica with Croton urucurana. My mother made the tea.

In view of these choices of alternative medicines and teas and the belief in their power in relieving pain and curing disease, it can be said that, in general, the form in which the various medicines, whether chemical or natural, are presented is dependent on the population's idea of their nature and efficacy. Some authors, including Loyola, Boltanski, and Helman, state that the population orders and divides medications into hierarchical levels, ranging from the least effective to the most effective, from the least dangerous to the most dangerous, the weak to the strongest, and from the good to the bad.

**Hope for a Cure and Interpersonal Relationships**

The interviewees expressed themselves regarding expectations of a cure, beliefs, religiosity, and interpersonal relationships in the following statements:

(cook, age 40) – Now I’m better, thank God (laughs). I wasn’t religious, but I went to the evangelical church. Yesterday I received a holy card in the mail: Our Lady of Grace. I’m using it, and I gave them a donation. They say that this saint is miraculous. Well, it’s good to help people.

(university professor, age 37) – I told my husband, then my family. I had to overcome, to digest, because they were very shaken. More than I was. My family says that this disease is nothing. They don’t believe me or they tell me to stay calm.

(cook, age 40) – My family said: Oh! That’s nothing.

(cook, age 41) – I got the most support from myself. I once said: I’m going to get up. I stayed in bed nine days, lost seven kilos. I said: starting today nobody else is going to tell me what I have to do. Dad and mom just say it’s nothing. People that I thought would be on my side, were not, the ones I did not expect to be . . . My husband supports me. He talks to his boss whenever I need him for anything.

(Demand for health care services: a difficult crossing)

By following the recommended technique for studies of sentinel events, one can reconstruct the history of these women and of the attendances received, identifying possible existing flaws. We noted that some of the women made true pilgrimages, from clinic to clinic, without having their needs met, as can be seen in the following statement:

(cook, age 41) – Four and a half years ago, I took a preventive exam. Two years ago, I began to feel like my belly was swollen and had a lot of pain at the base of my belly. I took the test and the result was normal. I continued to feel a lot of pain in my belly. Pain like baby pain, you know? In my menstrual period, there was a lot of bleeding. Then, in February of 2011, the doctor diagnosed it as a family support as essential for individuals with cancer or other serious diseases, not all of the women interviewed had the same perceptions. Some have indicated that the reactions of relatives to the diagnosis of cancer constitute an additional element to be faced, because, despite the despair provoked by the disease itself, family members still had to support the individuals with cancer, as indicated in the following statements:

(cook, age 41) – Four and a half years ago, I took a preventive exam. Two years ago, I began to feel like my belly was swollen and had a lot of pain at the base of my belly. I took the test and the result was normal. I continued to feel a lot of pain in my belly. Pain like baby pain, you know? In my menstrual period, there was a lot of bleeding. Then, in February of 2011, the doctor diagnosed it as a
CONCLUSION

In the experiences of these women described here, it is evident that social representation must be understood and analyzed from its genesis and against the background of the social conditions that produce it. Social reality has specific meanings and a structure of great relevance for individuals who live, think, act, and interact. It cannot be denied that the perceptions of these women regarding prevention and the symptoms of the disease itself are linked to their relationships with the health care facilities, their family, and their friends, and that those perceptions are influenced by culture, work and vulnerability to social exclusion. Finally, our results indicate the need for future studies on the subject, covering other localities, focusing on the practices of health care workers, and examining the educational process carried out in the context of giving more complete attention to women’s health.

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AUTHOR CONTRIBUTIONS

Maria Aparecida da Silva and Hilda Guimarães de Freitas collected, analyzed, and interpreted the data; drafted the manuscript; and approved the final version for submission. Regiane Luiz Ribeiro; Maiene Nâdia Lopes Oliveira, and Fabiana Cavalcante de Araújo Sanches collected, analyzed, and interpreted the data; revised the manuscript; and approved the final version for submission. Luiz Claudio Santos Thuler conceived and designed the work; interpreted the data; revised the manuscript; and approved the final version for submission.

DECLARATION OF CONFLICTS OF INTEREST

Nothing to Declare.

REFERENCES


