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# Potentialities and weaknesses in access to cancer treatment: perspective of mastectomized women

Potencialidades e fragilidades no acesso ao tratamento oncológico: perspectiva de mulheres mastectomizadas

Potencialidades y debilidades em el acceso al tratamiento del cáncer: perspectiva de las mujeres mastectomizadas

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**Abstract:** Objective: identify potentialities and weaknesses in the health care network for access to treatment (surgical, chemotherapy and / or radiotherapy) of mastectomized women Method: exploratory descriptive study with a qualitative approach with ten mastectomized women. Data collection was performed through semi-structured interviews, analyzed according to content analysis. Results: the lack of qualified professionals to meet this demand and information about the disease were cited as problems. As potentialities, women referred to the offer of free treatment by the Unified Health System and the follow-up performed by the multi-professional team. Conclusion: professional care and breast reconstruction stood out as potentialities in cancer treatment, while the lack of information and qualified professionals were weaknesses, and the multi-professional team and managers recognize the needs of this public for qualification of care.

Descriptors: Comprehensive health care; Unified health system; Mastectomy; Mammoplasty; Patient Care Team

Resumo: Objetivo: identificar potencialidades e fragilidades na rede de atenção à saúde para o acesso ao tratamento (cirúrgico, quimioterápico e ou radioterápico) de mulheres mastectomizadas. Método: estudo exploratório, descritivo, com abordagem qualitativa, com dez mulheres mastectomizadas. A coleta de dados



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realizou-se por meio de entrevistas semiestruturadas, analisadas conforme a análise de conteúdo. **Resultados:** a falta de profissionais qualificados para atender essa demanda e de informações sobre a doença foram citadas como problemas. Como potencialidades as mulheres referiram a oferta do tratamento gratuito pelo Sistema Único de Saúde e o acompanhamento realizado pela equipe multiprofissional. **Conclusão:** o atendimento dos profissionais e a reconstrução mamária destacaram-se como potencialidades no tratamento oncológico, enquanto a falta de informações e de profissionais qualificados foram fragilidades evidenciadas, cabendo a equipe multiprofissional e gestores reconhecerem as necessidades deste público para qualificação da assistência.

**Descritores:** Assistência integral à saúde; Sistema único de saúde; Mastectomia; Mamoplastia; Equipe de assistência ao paciente

**Resumen:** Objetivo: identificar las potencialidades y debilidades en la red de atención médica para el acceso al tratamiento (quirúrgico, quimioterapia y / o radioterapia) de mujeres mastectomizadas. **Método:** estudio exploratorio descriptivo con enfoque cualitativo con diez mujeres mastectomizadas. La recopilación de datos se realizó através de entrevistas semiestructuradas, analizadas de acuerdo con el Análisis de Contenido. **Resultados:** la falta de profesionales calificados para satisfacer esta demanda y la información sobre la enfermedad se mencionaron como problemas. Como potencialidades, las mujeres se refirieron a la oferta de tratamiento gratuito por parte del Sistema Único de Salud y al seguimiento realizado por el equipo multiprofesional. **Conclusión:** la atención profesional y la reconstrucción mamaria se destacaron como potencialidades en el tratamiento del cáncer, mientras que la falta de información y profesionales calificados fueron debilidades, y el equipo multiprofesional y los gerentes reconocen las necesidades de este público para la calificación de la atención.

Descriptores: Atención integral de salud; Sistema único de salud; Mastectomía; Mamoplastia; Grupo de Atención al Paciente

# Introduction

Cancer incidence and mortality are growing rapidly worldwide.<sup>1</sup> In Brazil and most countries, breast cancer is the leading cause of death among women<sup>2</sup> and with regard to incidence, the estimated for 2019 is 59,700 new cases or 29.5% of the total cancers.<sup>3</sup> Worldwide, new cases reach nearly 25% of all recent cancers in women.<sup>2</sup>

In Brazil, breast cancer is usually diagnosed at more advanced stages, which worsens the prognosis, compromising patient survival.<sup>3</sup> In 2016, the gross mortality rate in Brazil was 15.4 deaths / 100,000 women and between 1980 and 2016, there was a 33.6% increase in the standardized mortality rates of women with this cancer.<sup>3</sup>

The control of breast cancer has been one of the priorities in the National Health Policy Agenda in Brazil, with strategies for early detection and identification of the disease in early stages, which requires screening and early diagnosis actions.<sup>4</sup> Screening consists of a biennial mammogram for women aged 50 to 69 years. Early diagnosis involves: alert population for suspicious signs and symptoms, trained health professionals to assess suspected cases, and health systems and services prepared to ensure timely and quality diagnostic confirmation.<sup>4</sup>

Law No. 12.732 provides for the first treatment of symptomatic users of malignant neoplasia, diagnosis and initiation of treatment within 60 (sixty) days.<sup>5</sup> However, studies with women diagnosed with breast cancer reveal that the time between symptom and treatment is longer than recommended by the Ministry of Health (MH).<sup>6-7</sup> Factors that hinder early detection include: sociocultural issues, lack of information about the disease and organizational obstacles, such as waiting lists for appointments, examinations and treatments.<sup>6</sup> In addition, it is essential that health teams have human resources prepared for effective, humanized and qualified care, especially regarding screening actions for early diagnosis.<sup>6</sup>

In this context, the problem of this research was: What are the potentialities and weaknesses in the health care network for access to treatment (surgical, chemotherapy and or radiotherapy), in the perception of mastectomized women? It aimed to identify potentialities and weaknesses in the health care network for access to treatment (surgical, chemotherapy and / or radiotherapy) of mastectomized women.

## Method

This is an exploratory-descriptive study of qualitative approach, developed in Basic Health Units (BHU) of a municipality in the western region of Santa Catarina. Ten mastectomized women participated in the study, selected according to the inclusion criteria: having had a mastectomy between 2012 and 2018 and having received treatment (especially chemotherapy or radiotherapy) by the Unified Health System (UHS).

The period from 2012 to 2018 was proposed considering the Law No. 12.732 of 2012, which establishes a period of 60 days after the diagnosis to start treatment. The public was selected due to the epidemiological situation of breast cancer in the female population, demanding different forms of treatment, in addition to breast reconstruction surgery.

To identify and contact the women, they had the help of the Community Health Agents (CHA) of the BHU of the municipality. Sixteen women were contacted, but ten met the inclusion criteria established, with no refusals. The final number of participants was defined by data saturation, that is, when the collected material presented absence of new elements.<sup>8</sup>

Data collection took place in the first half of 2018, in a pre-arranged semi-structured interview at each participant's home. Initially, the research was presented to women and their doubts were answered. Afterwards, they were invited to participate by signing the Free and Informed Consent Term (FICT). A script of questions was used to guide the interview, which were recorded on smartphone, fully transcribed. The average duration of each was 30 minutes. The anonymity of the participants was respected, identifying them by the names of heroines of children's stories, considering that to overcome the disease and the difficulties encountered throughout the trajectory of breast cancer, they fought bravely, becoming heroines of their own lives.

Data analysis was performed based on interview transcripts and using the content analysis method. Initially, pre-analysis was performed with fluctuating reading of the data extracted in the interviews, construction of a table with the collected data and choice of documents for the constitution of the data for the analytical procedures. Then, the analysis material was explored, organizing the data into two categories: "Potentialities in the care of mastectomized women" and "Weaknesses in the care of mastectomized women", which will be presented and discussed based on the literature review.

This study was approved on May 3, 2018, by the Ethics Committee on Research with Human Beings of a Public University of Southern Brazil, under opinion number 2.634.165 and Certificate of Presentation for Ethical Appreciation (CAAE) number 86982318.5.0000.5564.

# Results and discussion

The study included ten women users of UHS, aged between 42 and 79 years. Regarding color, seven were white and three brown. Regarding marital status, seven women were married, two widows and one separated. Most lived with their families, including husbands and / or children; two participants lived alone. Regarding occupation, five declared themselves as housewives, three pensioners and two retirees, with family income ranging from zero to four minimum wages.

Regarding the level of education, four had incomplete elementary school, one participant had completed elementary school, two of them completed high school, one completed higher education and two women were illiterate. Regarding mastectomy, one of the women had it in 2012, four of them in 2014, two in 2016, two in 2017 and one in 2018. Four women underwent breast reconstruction.

## Potentialities in assisting mastectomized women

The women participating in this research identified several potentialities in care. Among them, we highlight the assistance received from UHS, which expressed feelings of gratitude to the system and the good care of health professionals.

I am very grateful to the health professionals, I thank UHS, who gave me support at these times, because it is very difficult. (Gamora)

Doing free treatment for us is already a plus point and the nurses are very dear, the doctors too, we are all well treated. (Raven)

The service was very good, everywhere I went [...] I think they have a lot of consideration, a very special attention [...] to this type of person and this disease. (Supergirl)

UHS is the main financier of "cancer treatment in the country, responsible for 75% of the attendances in chemotherapy, radiotherapy, hemotherapy and hemodialysis". <sup>10:31</sup> To qualify the demand and care, the MH advocates equity in access to the actions and services offered and care for cancer patients. <sup>5</sup> In order to put into practice the principles of UHS in the daily routine of health services, the National Humanization Policy (NHP) brings the concept and the need for humanization. Humanizing means including differences in management and care processes, with a view to stimulating the production of new ways of caring and organizing work in a collective and shared manner. <sup>11</sup>

According to the NHP, humanized care demand multidisciplinary team work.<sup>11</sup> The multi-professional care was declared by the interviewees as a positive aspect in the disease trajectory. Among the various professionals who provide health care, the nursing staff was positively highlighted.

The nurses are very dear to [...] chemo, the nurses always there, caring, helping. (Raven)

I was well attended yes. The chemo girls are very good people, that helps a lot. There are some nurses who just look at you know what you need. (Scarlet Witch)

The role of the nurse is configured in the provision of humanized care manifested in welcoming, therapeutic communication and all responsibilities based on theoretical and scientific knowledge. Appropriate care requires the ability to perceive and identify the needs of others, which is an attribute of the nursing staff, arising from experience and practice in the profession and the time spent with the user and their family throughout the disease process. In addition to these attributes, the nurse has a fundamental role due to the practice of nursing consultation, promoting the individualization of care and effectiveness of treatment for each individual.

All women who underwent chemotherapy and radiotherapy attended nursing consultations, which was emphasized as a positive aspect of care:

They explain everything that can happen and what cannot in the first chemo [...] Before starting the radio also had a consultation, I had a prescription of what to do, what to use in the burn, all explained well. (Raven)

Once a week the nurse would talk to people about the guidelines they needed to take care of the burns. You felt comfortable and had a hand that held you, a shoulder that listened to you. It's like a security guard, I felt good and I liked it. (Batgirl)

Nursing consultation, a private nurse activity based on the scientific method, aims to identify health / disease situations, prescribe and implement measures to promote, prevent and protect the health of the individual, family and community. Before starting chemotherapy and radiotherapy treatments, users go through nursing in order to be informed about the purpose, objectives and schedule of treatments, the importance of attendance and routine of the service, as well as to establish a link between the triad health-user-family team.<sup>13-14</sup>

Consultations minimize problems through guidelines and nursing actions planned and developed by considering the needs of each individual and advocating comprehensive care. It is up to the nurse to provide systematic and humanized care. Thus, nursing care is recognized as the articulator and integrator of different knowledge and the constant presence with the patient. 13,15

The participants of this study also referred the follow-up with other professionals of the multidisciplinary team as a potentiality of the system. Among them, they mentioned the social worker, psychologist, nutritionist and the physical therapy performed by UHS:

I went through nutritionist, psychologist, very good that they refer you to all this. (She Hulk)

Social worker and psychologist talked to me and my husband. And the physiotherapies I got all by UHS! (Wonder Woman)

The social worker can answer questions, identify difficulties and needs, supporting and directing the user when necessary. The performance of the nutritionist is important due to the metabolic changes and body composition resulting from the treatments. The psychologist is responsible for supporting and guiding women and their families, considering the feelings experienced during and after the disease. The physiotherapist is essential to assist women after mastectomy, aiming to minimize and / or prevent sequelae due to immobility time of the upper limbs.<sup>15</sup>

Multidisciplinary follow-up assists in orientations, referrals and treatment, in order to achieve positive results, as the problems of the user and their families are multifaceted, which highlights the importance of care. Therefore, in the integral care of women who experience cancer, it is relevant to observe the problems from different perspectives, defining a singular, uniform care with common goals.<sup>15</sup>

Another point considered favorable to care was breast reconstruction:

I had the surgery and already implanted the prosthesis. (She Hulk)

I did the reconstruction along with the surgery [mastectomy]. (Supergirl)

Supergirl and She Hulk performed breast reconstruction at the same time as mastectomy by UHS. Wonder Woman also rebuilt the breast at the same time, however, through the private health sector. According to Law No. 13,770 of 2018, breast reconstruction should be performed during mastectomy surgery, when necessary technical conditions exist. In the event that immediate reconstruction is impossible, the patient will be referred for follow-up and will be guaranteed surgery immediately after reaching the required clinical conditions.<sup>16</sup>

Sexuality and body image are important elements of identity, self-concept and affective relationships. These aspects are usually compromised in breast cancer. In this context, breast repair can restore a woman's self-esteem and assist in rebuilding her self-image, giving her the feeling of being whole again. In this regard, a study that aimed to evaluate the quality of life and satisfaction with the aesthetic outcome of mastectomized patients undergoing breast reconstruction, concluded

that surgery well performed by a trained and specialized team can bring excellent results, favoring the reestablishment of the role social status and promote their quality of life.<sup>17</sup> Thus, breast repair surgery can be considered as a potential for UHS.

Of the participants in this study, Stellar and Storm had the opportunity to have restorative surgery, but chose not to perform:

I do not intend to do. I, at this age, will suffer again for what? (Starfire)

I didn't want to do the surgery, I'm fine. (Storm)

In Starfire's speech, there is the fear of suffering again with another surgery, which together with the age (70 years) led her to not perform plastic surgery. This result corroborates the research obtained with mastectomized women in a city of Alagoas, according to which the fear of a new surgery discourages women, leading them to think about the possibility of rejection, relapse of the disease and even death.<sup>18</sup>

However, even though age has contributed to the decision not to rebuild the breast, it is important to consider the possibility that many women choose not to rebuild for other reasons, such as lack of breast does not affect their self-esteem and continue to feel complete despite the mutilation, as significant people in their lives do not value the physical change in their relationship. For some women, lack of breast, aesthetics and vanity do not influence their quality of life, especially for older women. For them, healing and survival are essential for their well-being.<sup>18</sup>

All participants mentioned several positive points of health care, such as the good care received and the follow-up by the multidisciplinary team in times of fear and longing for the future, overcoming the disease and healing. The positive points were related to UHS as a public and free system. However, participants also found and reported weaknesses in care, which are discussed below.

#### Weaknesses in the care of mastectomized women

The MH guides the implementation of early breast cancer awareness strategies, based on guiding the female population about the usual changes in different moments of the life cycle, stimulating self-knowledge and dissemination of the main signs and symptoms of this cancer. In addition to a lump in the breast, neck, or armpits, this disease may present in other forms, such as changes in the skin, nipple, or shape of the breast, redness, wrinkling, bulging or retraction, and spontaneous discharge, signs and symptoms that demand immediate investigation.<sup>4</sup>

The first weakness evidenced by the participants was the lack of information about the disease. Although MH advocates the above methods and promotes the annual "Pink October" campaign, there is still a lack of information:

As I was breastfeeding, I thought it was blistered milk, [...] it took me another two or three months to go to the doctor. (Raven)

There was no lump, [...] the pout was coming in, says it's a symptom, that there are some, was running out of that pout, but as I did not know [...] (Phoenix)

In this sense, multimedia-based interventions to promote breast and cervical health, as well as culturally relevant and linguistically appropriate educational materials can more effectively disseminate information about cancer and accessible preventive measures.<sup>19</sup> The statements reveal the lack of knowledge of possible signs and symptoms of breast cancer, which led to delay in seeking care in the health service, resulting in late diagnosis and treatment.

Another negative factor highlighted about the assistance was the difficulty and the delay for breast reconstruction. One study participant was able to do it four years after mastectomy, while others are still waiting for the procedure:

Now it's been three months since I did the reconstruction. (Scarlet Witch)

I have an appointment in October [2018], the doctor will see when it will be rebuilt, could not rebuild because it had a few problems at the time of surgery. (Gamora)

# I am in line since 2014 waiting. (Phoenix)

Still, there is the case of another study participant who, despite wishing to perform breast reconstruction, the doctor did not put her on the waiting list, believing that such procedure was not a priority in treatment:

I didn't do breast reconstruction. I went to see if I got in line, but the doctor didn't want to put me in the queue. I said that doing the reconstruction was not a priority and was in the background, in my case. (Raven)

The lines indicate delayed breast reconstruction, which for many women is a problem that affects their well-being. However, it is important to consider that breast reconstruction is not always possible at the time of mastectomy, as in those situations that will require combination of chemotherapy and radiotherapy in adjuvant treatment. In the Netherlands, mastectomy is performed in 33% to 40% of women with breast cancer, and only 20% of these patients want breast reconstruction. However, patients undergoing breast reconstruction after mastectomy have better sexual function, better body image and fewer depressive symptoms than those undergoing mastectomy alone. <sup>21</sup>

Raven's statement above is revealing, in that she has received no clarification on the reasons for not performing the reconstruction and suggests a vertical and one-way relationship with her controller, which excludes her from decisions about her own body. Although Law No. 12.802 / 2013 determines that breast repair surgery for women with mastectomies due to cancer is performed by UHS, less than 10% of Brazilian women under these conditions have access to immediate breast reconstruction by UHS, mainly due to the lack of qualified professionals for onco-plastic surgeries.<sup>22</sup>

The lack of qualified and committed professionals influences the care of women with breast cancer. The lack of acceptance, mainly related to the devaluation of the complaint and the overvaluation of the exams, without due complementation with the physical exam and the history, were reported by the study participants as negative points:

The result of the mammogram came saying that it was to be repeated in a year, which was probably a benign cyst. The gynecologist looked at my exams and he said it would be nothing [...] I did not settle for it, I told him if he was available to examine me, because it was not what the exam showed that I felt. When he examined me, he saw that it was not the exam that was beating, he referred me urgently to make the resonance, to go to the mastologist. (She Hulk)

Just as She Hulk had to ask the doctor to be examined, other participants pointed to the difficulty and the delay in diagnosis due to lack of attention with complaints reported in the consultations:

I was about two years with this pain, I was going to consult and they said it was from the spine. (Phoenix)

I found the lump in my breast, I went to talk to the doctor, he said it was nothing. (Supergirl)

Reception serves as a technological tool for intervention in the qualification of listening, bond building, ensuring access with accountability and resoluteness in services. The lack of care can suggest the lack of preparation and lack of training of staff, characterized as barriers in access to the health system and delayed early detection of the disease. Thus, the lack of commitment, respect and attention of professionals cause dissatisfaction in patients.<sup>11</sup>

The delay in performing exams, procedures, mastectomy and breast reconstruction surgeries and the beginning of chemotherapy and / or radiotherapy treatment were also pointed out as weaknesses by the research participants:

*Much delay to start chemotherapy.* (She Hulk)

The delay of waiting for an exam. Many people end up unable to beat the disease because of this wait. (Raven)

The surgery should be faster, the consultations are very long, you are waiting for the treatment and it is really long. (Gamora)

Regarding the initiation of treatment, reports suggest that the UHS cannot meet the 60-day interval between diagnosis and initiation of treatment, as required by law. Likewise, the delay and waiting time for confirmation of the diagnosis point towards the need for prioritization of suspected cases of breast cancer in consultations and examinations, because the entire treatment process depends on it and, in this disease, waiting may represent the difference between life and death.

Different studies conducted in Brazil identified a time interval greater than 90 days between the first visit, the biopsy and the start of treatment.<sup>6-7</sup> In addition, the average time may be shorter in a private institution than in a public institution.<sup>7</sup> In this context, given the weaknesses emphasized in the interviews, women were asked about their recommendations for improving health care. Thus, the participants in this study suggested quickness of care, more professionals and availability of information about the disease:

Decrease waiting time for both exam and surgery to begin treatment. (Storm)

They should have two waiting lists, one with the normal disease lists and one for those with cancer, for these cancer people to get tested faster. (Batgirl)

The statements presented above reinforce the need for rapid confirmation of the diagnosis, which is essential for the definition and continuation of treatment, since, according to article 2 of Law No. 12.732, of November 22, 2012,<sup>5</sup> that provide for the first treatment of a patient with proven malignancy, sets a deadline for its onset.

The individual with malignant neoplasia has the right to undergo the first treatment in SUS within 60 days from the day the diagnosis is made in pathological report or shorter, according to the therapeutic need of the case, recorded in a single medical record. The time lapse between

mammography and biopsy results increases the risk of disease-related mortality<sup>23</sup> and reducing this time is important for a better prognosis <sup>8</sup>, especially for those women diagnosed in late stages of the disease.<sup>24</sup>

There are, however, two types of delay: the delayed woman seeking care and the delayed system delay from the first consultation to the start of therapy, which may lead to poor prognosis.<sup>25</sup> In this study it is possible to perceive the first type of delay in the speech of Raven and Phoenix, as well as the second in the reports of Storm and Batgirl.

The agility in performing examinations, consultations and surgery was unanimously emphasized by the participants. One woman also recalled that the State is also responsible for the time between diagnosis and treatment initiation because, although the MH has instituted the 60-day time to start treatment, support must be provided for this to be achieved in practice by passing on resources with adequate investments in the health sector.

I think it doesn't just depend on people's health. It's the government itself, it's speeding up, because a serious illness like that can't wait too long in between exams. (Raven)

Among the investments, there is a need for more qualified professionals to meet this demand:

Have more professionals available. (Wonder Woman)

Another noteworthy observation was the importance of disseminating more information about the disease to encourage breast self-examination and mammography, through campaigns beyond the "Pink October", which prioritizes women's health care and prevention of breast and cervical cancer.

Spreading more for women to take care of themselves, encouraging more women, they do the pink October campaign, for example, the preventive once a year, but there are women who do not, even if it is free. It would have to be at least four times a year that women would take better care of themselves. (Wonder Woman)

Results from a study aimed at developing and evaluating multimedia interventions to promote breast and cervical health in Hong Kong women suggest that the use of socio-culturally and linguistically appropriate educational materials will effectively disseminate information about cancer and cancer prevention measures.<sup>19</sup>

It is necessary to expand the care network by facilitating access to the system and improving the quality of care for women who experience cancer. From the results obtained in this research, it is observed that access to the care network was not equal for users, as some women started treatment exclusively by UHS, as recommended by the MH, including reparative surgery, while others took a long time, which led them to seek the private system to expedite the start of treatment.

#### Final considerations

The women in this study cited as weaknesses in access to health care, the lack of information about the disease, which may be associated with the reduced number of qualified professionals for holistic care of women with cancer, which may influence the difficulties of diagnosis and onset of the timely treatment of the disease, as well as obstacles to breast reconstruction.

It is noteworthy that the lack of information and the reduced number of qualified professionals are generated by the scarce investments in the health sector. From this perspective, it is recognized the cascade of events generated by the lack of financial resources and committed managers, resulting in the suffering of women who experience breast cancer.

However, women also identified potentialities in the care network that helped them in the experience of cancer such as good care of professionals, breast reconstruction and the monitoring provided by the multiprofessional team, showing the feeling of gratitude to UHS for enabling free treatment. Regarding the assistance of the multiprofessional team, the study participants emphasized the work of the nursing team because they are the professionals who spent more time with women in cancer treatment and for humanized attention when considering each individual in a unique way. Also, they emphasized the prescription and the nursing consultation. Thus, the contribution of nursing in care in all stages of the cancer trajectory, especially the nursing process, is highlighted, in order to pay attention focused on the needs of each user.

Emphasizes the importance of greater investments by the public sector in actions for screening and early detection of breast cancer, training health professionals for qualified attention and providing more information about the signs and symptoms of the disease, encouraging women to self-knowledge, as timely initiation of treatment contributes to the reduction of mortality in the female population and the reduction of morbidity risks.

The main difficulty encountered in the development of this study was the absence of specific records on women living in territories who had breast cancer and used the public system for treatment. This made the initial selection of potential participants difficult and required greater participation from CHAs who, with their knowledge of their micro-area users, helped locate women and facilitated their first contact with them.

Another aspect to be highlighted is the age variation between the participants (42 to 79 years old), which raises the possibility that the perceptions about the potentialities and weaknesses of health care in the process of diagnosis and treatment of breast cancer are different in different ways, a group of women with greater homogeneity of age. In particular, access to the breast reconstruction procedure deserves further studies with women of the same age group.

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