

## Review Article

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# Research on the Situation of Breast Cancer in Kosovo

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"Raising Awareness of the Unmet Needs of Breast Cancer in Kosovo" Implemented by: GoldMinds for the "Renaissance" Association, Kosovo

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### Introduction

Breast cancer is the most common cancer in women - the fifth leading cause of death worldwide and the leading cause of death in Europe [1]. The possibility of developing breast cancer is a source of anxiety for many women. In this context, awareness of early detection of breast cancer in women and girls is very important, given that Kosovo has a population where young age is significantly predominant. Awareness campaigns are constantly organized in Kosovo for women to have frequent check-ups, so that the disease can be detected in time, because breast cancer, diagnosed at a later stage, can be more difficult to treat. These awareness campaigns, in addition to aiming to raise the awareness of the population about the risk of breast cancer, also make efforts to encourage the institutions responsible for creating conditions for early detection of the disease and its treatment. With the support of the Think Pink Europe umbrella organization, which includes about 30 European organizations, the 'Renesansa' Association, which is a member of this network, has joined the initiative to contribute to improving and accelerating the exchange of information and best practices for breast cancer health care. In the framework of Think Pink Europe activities, as in other European countries, the Race for the Cure marathon is organized in Kosovo every year, an activity which serves the awareness of the population about breast cancer and focuses on reducing inequalities in access to health care and closing the healthcare gap between European countries. The "Renesansa" Association continues to help women affected by breast cancer on a voluntary basis by providing them support to cope with treatment as easily as possible, psycho-social rehabilitation after medical treatment, support for the families of people affected by the disease, and material assistance needed after treatments such as wigs, prostheses, etc. The "Renesansa" Association is grateful to all the people of good will who have helped and continue to help a cause as sensitive and vital as breast cancer awareness and support in coping with such a disease.

### The Aim of the Research

This research aims to identify the (new) cases diagnosed with breast cancer in 2020 in Kosovo, compare these numbers with those of previous years in order to see if there is an increasing or decreasing trend; and identify the main challenges faced by people diagnosed with breast cancer as well as the difficulties faced by Oncologists and the Oncology Clinic in Prishtina in general.

The research also presents statistics on the prevalence of breast cancer in the world and the region and contains recommendations from Specialist Oncologists, women who have survived the disease and those who are currently being treated in Kosovo and abroad.

### Methodology

Combined methodology was used in this research. Firstly, relevant literature was researched to make comparisons of breast cancer prevalence in the world and region. In-depth interviews were conducted with Oncology Specialists of the Oncology Clinic at the University Clinical Center of Kosovo and a Focus Group was also conducted with women surviving breast cancer.

The data were provided by the Administration of the University Hospital and Clinical Service of Kosovo and the annual reports of the same institution.

\*\*\*The identity of the Focus Group respondents in this research remains protected in accordance with the code of ethics, namely the law on personal data protection [2].

The data collected in the field will be used for scientific purposes only.

### Acknowledgments

We cordially thank Dr. Ilir Kurtishin and Dr. Arben Bislimin for their contribution by participating in interviews. A special thanks goes to the Focus Group participants, who as respondents, breast cancer survivors provided very important information and recommendations for this research.

### Literature Review

Breast cancer is an uncontrolled growth of breast cells. Cancer occurs as a result of mutations, or abnormal changes, in the genes responsible for regulating cell growth and keeping them healthy [3].

In 2020, breast cancer surpassed lung cancer as the most diagnosed cancer in the world, with about 2.3 million new cases (11.7%) [4].

The survival rate for breast cancer is very high when the cancer is detected early and when treatment is available. Unfortunately, 50 to 80% of breast cancer cases are diagnosed at an advanced stage in [2]. many low- and average- income countries, when cancer is more difficult to treat, it is more costly to do so and is usually incurable [5].

The first country in the world that leads in the number of most frequent cases of breast cancer is Belgium, followed by Luxembourg, the Netherlands, France, Lebanon, Australia, etc.

Most of the literature studied states that the average age of onset of breast cancer in the world is after the age of 50, although in the past decade the average age has been around the age of 62.

The American Cancer Society recently published a “Facts and Figures” 2019-2020 [6]. study estimating that about one-third of postmenopausal breast cancer cases are associated with potentially modifiable factors, including postmenopausal overweight, physical inactivity, consumption of alcohol, non-breastfeeding, genetic factors etc.

The prevalence of breast cancer in the region in 2020

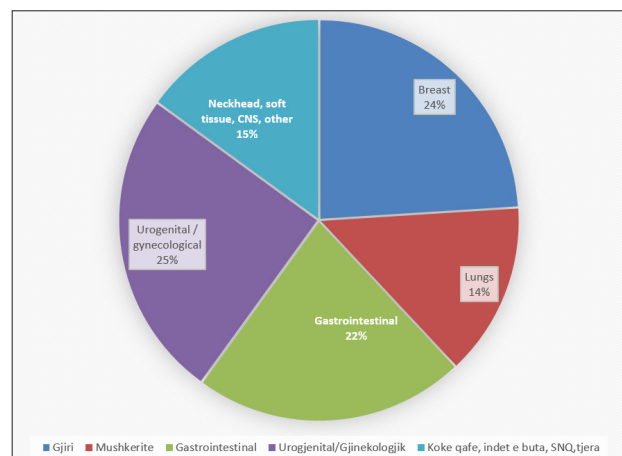
**Table 1: New cases diagnosed with breast cancer in the region in 2020 in numerical value and percentage in relation to the number of inhabitants**

	Number of inhabitants	New cases of Breast Cancer (year 2020)
Kosovo	1,873,000	332 (0.017%)
Albania	2,877,800	936 (0.032%)
Norht Macedonia	2,077,000	988 (0.047%)
Serbia	8,737,370	6,724(0.00007%)
Montenegro	628,062	378 (0.060%)
Bosnja dhe Hercegovina	3,280,815	1,554(0.047%)

As can be seen from Table 1, which shows the numbers of new cases diagnosed with breast cancer in the countries of the region in relation to the number of inhabitants, Serbia has the highest number, but that in percentage in relation to the population turns out to have the lowest number, compared to Montenegro which has 378 new cases but a significantly smaller population than Serbia.

Northern Macedonia and Bosnia and Herzegovina have the same percentage of new cases in relation to population, while Albania and Kosovo have approximate percentages in relation to population.

New cases affected by malignant diseases in Kosovo during 2019

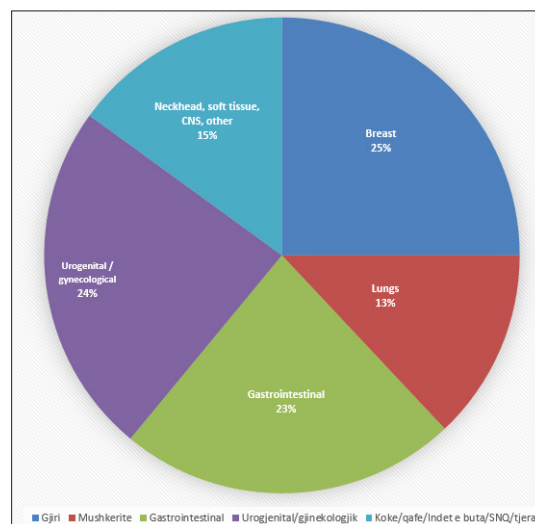


**Figure 1:** New cases affected by malignant diseases in 2019 expressed in percentage [7].

The chart above shows the total number of new cases affected by malignant diseases in 2019. According to the annual work report of HUCSK for 2019, new cases of breast cancer represent 24% of the total number of cases with malignant diseases.

According to this report, during 2019, a total of 1,586 cases of malignant diseases were registered, of which 376 of them were breast cancer.

New cases affected by malignant diseases in Kosovo during 2020



**Figure 2:** New cases affected by malignant diseases in 2019 expressed in percentage [8].

According to the annual work report of the HUCSK for 2020, new cases of breast cancer represent 25% of the total number of cases of malignant diseases.

According to this report, during 2020 a total of 1,336 cases of malignant diseases were registered, of which 332 of them were breast cancer.

If we compare the new cases of breast cancer from 2019 with those of 2020, we have a very slight decline where 2020 marks 45 new cases less than 2019, so it has suffered a decrease of 15%.

Undoubtedly the COVID-19 pandemic has reduced the number of new cases diagnosed with breast cancer because women have been reluctant to go for check-ups at the Oncology Clinic.

Referring to the materials and interviews of Oncologists Specialists of the Oncology Clinic at the University Clinical Center of Kosovo, it turns out that during 2020, in the period January-September there were 250 new cases of breast cancer, while last year there were about 15 percent more. As for breast surgeries, during the time of the pandemic they were delayed. The interventions were performed mainly in private hospitals. These operations have been suspended at the University Clinical Center of Kosovo due to the COVID-19 pandemic [9].

In a statement to Radio Free Europe, the Director of the Oncology Clinic, Dr. Ilir Kurtishi claims that breast control programs as well as breast surgery services were discontinued in March, as the University Clinical Center of Kosovo focused its resources on treating the pandemic. Only emergency cases were treated there. With the release of services in the last three months, as Kurtishi claims, there has been an increase in the number of women being reported as new cases.

### **Main Findings of the In-Depth Interviews**

In-depth interviews were conducted with Dr. Ilir Kurtishi, Director of the Oncology Clinic at the University Clinical Center of Kosovo and Dr. Arben Bislimin, President of the Association of Oncologists of Kosovo.

Regarding the prevalence of breast cancer in Kosovo, Dr. Ilir Kurtishi and Dr. Arben Bislimi, claim that in 2019 there were 365 cases of breast cancer, while in 2020 the number was lower, due to the pandemic. As for the stage in which patients find themselves when they are diagnosed, it turns out that, usually half of women are diagnosed in the third or fourth stage (50% or 55%) and the other half in the first or second stage (about 45%), which is better in terms of early detection of breast cancer.

Statistics globally show an increase in growth but in Kosovo based on new cases reported to the Oncology Clinic, this number is approximately the same in the last three years. Factors that increase the incidence of breast cancer start with lifestyle, followed by the impact of obesity, genetic factors and in addition it has been noted that at the same time the rate of diagnosis and awareness in relation to it has increased.

The level of awareness in our society regarding the early detection of breast cancer, according to Oncologists, is not satisfactory. However, various campaigns are always organized which affect the improvement of this condition. Oncologists claim that even we in Kosovo can detect cancer at stage zero if we are aware.

Compared to western countries that can diagnose the disease in the first or second stage (over 60 or 70% of cases), in our country the most common forms appear in the third stage and the fourth stage. Dr. Bislimi claims that recently there is a tendency to reduce the stage of presentation to approach the second stage of the disease, although there have been cases in very early stages.

The average age of women diagnosed with breast cancer is 48-54 years old.

Dr. Ilir Kurtishi claims that the biggest difficulties faced by doctors and the staff of the Oncology Clinic during the treatment of breast cancer cases are overload with patients, access to patients and the constant lack of medication. Approximately 200 to 250 patients receive services such as chemotherapy or other therapy and medications within a day. Both Oncologists claim that the daily work of an oncologist in the clinic has many difficulties, mentioning here the defects in the radiation equipment that directly reflects on the effectiveness of the work of doctors.

Kosovo is the only country in the region that does not have a palliative center and the management of these patients causes a lot of trouble in daily work, so it is very important to do something in this regard.

The Oncology Clinic has partially sufficient staff with 13 clinical oncologists and 7 radiotherapists. As for the middle staff, it is clear that there is a need for nurses who would be divided into separate wards and thus better manage patient overload.

The Municipality of Prishtina dominates with more patients, followed by the Municipality of Prizren and the Municipality of Peja. Gjilan, Mitrovica and Ferizaj are approximately the same in number. Regarding the cases that metastasize, unfortunately the Clinic does not possess those data but Dr. Arben Bislimit assumes that 30% of patients have the disease in the form of metastatic progression.

As for the advice for women in Kosovo regarding the early detection of breast cancer and those who have been diagnosed and are being treated, Dr. Kurtishi emphasizes performing routine check-ups, women over the age of 45 have ultrasound or mammography done, especially those who have had previous family cases with cancer. Whereas, Dr. Bislimi says that women are encouraged to seek the help of the nearest doctor for any changes they notice in the breast, avoiding taboos that have existed so far, because until there is no other prevention, the only way out is early diagnosis.

Oncologists' recommendations regarding the improvement of the working conditions of the Oncology Clinic are mainly related to the expansion of capacities and space. The Oncology Clinic has been requesting additional space for two years now. There is a need for special rooms for oncologists and radiotherapists. Although this year the supply of medicines, especially for breast cancer is at a satisfactory level, oncology patients need to have a greater institutional care.

### **Main Findings of the Focus Group**

This Focus Group consisted of six women from different municipalities of Kosovo who are breast cancer survivors. Some of them have recovered while some are being treated in Kosovo but also abroad.

As far as the question of how they were diagnosed, most respondents claim that they first noticed the changes with self-control and afterwards saw a doctor. One of the respondents claims that although she noticed a gland in the breast, she ignored this situation for about 3 months, but then went for an examination to the oncologist who gave the diagnosis. "Therefore, it is very important that these changes in the breast are never ignored because later there may be consequences," said the respondent.

Regarding the cooperation with the doctor, the Clinic, as well as the duration for the confirmation of the diagnosis and mammography,



the participants of the Focus Group claim that the cooperation had been very good, except for one who explains how the tests and controls performed in Kosovo unfortunately do not correspond with the correct diagnosis and for this reason she had been forced to seek treatment abroad. She claims that she understands that sometimes the tests may not be accurate so frequent check-ups and getting the opinion of various oncologists is vital.

In general, the medical staff are very friendly and sensitive when it comes to treating breast cancer patients, though certainly there are exceptions, because the respondents have had experiences where the diagnosis has been communicated to them in a very direct and harsh way, which had a negative effect by lowering their morale and sowing fear and anxiety about the future of their health.

A positive factor is that women who have to undergo surgery do not have to wait, which means the Oncology Clinic prioritizes not only surgery but also other treatments for breast cancer.

An issue of concern which is still present is the financial support for the treatment of breast cancer, given that this treatment has great financial costs.

Respondents claim that for a family with an average financial income, it is not financially unmanageable, but it is difficult for families living below average. "For each chemotherapy I had to give 100 EUR, then for some medicine 18 EUR, then the Liposomol vitamins are 40 EUR".

Fortunately, almost all the necessary drugs for the treatment of the disease can be found in Kosovo, sometimes offered by the hospital but often bought by the patients themselves.

As the way of receiving the necessary information about the disease, the participants of the Focus Group state that they have had some information before, especially those who have a family history with this disease. The media and the internet play a very important role in providing a load of information about the disease. Otherwise, information coming from civil society associations and organizations is always welcome, though not enough.

All the respondents agreed on the disappointment they experienced in terms of information coming from the medical staff. "We think that doctors do not give enough explanations. It's a disease you need willpower, good, motivating words that can make it easier to cope with the disease. We as patients had to get most of the information ourselves. In terms of nutrition and vitamins, we had to research and find out how to feed on healthily."

Although the overcrowding of patients in the Oncology Clinic is evident, and the working conditions of doctors are not satisfactory, the respondents compare the services of the Oncology Clinic in Kosovo with those of foreign countries such as Macedonia and Turkey, where doctors are more transparent and take time to take care of the patient's morale and also provide psychological advice to patients being treated for this disease.

Women's lives after being diagnosed with breast cancer change radically. The members of the Focus Group share the same opinion that after the diagnosis they understand the value of life, health care and things in life that need our time and care. "After being diagnosed I love life more, I avoid stressful people and I better manage the time I have to devote to myself."

One of the respondents claims that upon being diagnosed with cancer, she was closed to herself and did not cope well with the situation. "It seemed to me that everything was ending, but the support of my family and society made me change my mind and become a more combative person. Over time it just did not have much impact on me, as long as I felt well, I had the support of family and doctors and I saw that the way a person copes with the disease is very important in psychological terms."

While another respondent says that it was lucky for her that she did not have much information but only continued the treatment until recovery, taking it as a normal disease. "Shortly before the end of the therapy, I went online and received detailed information about the consequences of the disease and then I saw the kind of risk I was exposed to. Fortunately, everything went well and I recovered."

All Focus Group participants agree that the state should provide more support to breast cancer survivors and all other patients with malignant disease because breast cancer is a disease that costs both financially and morally. Organizations and associations working for women's rights should seek greater state support for the category of women affected by breast cancer.

## Conclusions

- The number of cases diagnosed with breast cancer in Kosovo in 2020 has a slight decrease of 15% compared to 2019.
- Breast cancer in Kosovo is diagnosed in most cases with self-examination and then continued with a doctor's examination to continue with other treatment procedures.
- Half of women in Kosovo are diagnosed in the third or fourth stage (50% or 55%) and the other half in the first or second stage (about 45%), which is better in terms of early detection of cancer of the breast.
- Factors that affect the increase of breast cancer cases start with lifestyle, then obesity, genetic factors and in addition it is emphasized that at the same time the rate of diagnosis and awareness in relation to it has increased.
- The Municipality of Prishtina dominates with more patients, followed by the Municipality of Prizren and the Municipality of Peja. Gjilan / Gnjilane, Mitrovica and Ferizaj / Uro .evac have approximately the same number of cases diagnosed with this disease.
- The Oncology Clinic lacks data on cases which metastasize but it is thought that 30% of patients have the disease in the form of metastatic progression.
- In Kosovo, the most common forms of breast cancer occur in the third and fourth stage.
- The average age of women diagnosed with breast cancer is 48 - 54 years old.
- The cooperation of patients with the doctor and the Clinic is generally good, but there is room for improvement, especially in terms of moral support of patients, the way of communicating the results of the disease, etc.
- Associations and civil society organizations provide sufficient information about the disease, its prevention and treatment, to some extent, though there is room for improvement here as well.

## Recommendations

- Performing routine visits; women over the age of 45 should have an ultrasound or mammogram, especially those who have had family history of cancer.
- Women are encouraged to seek the help of the nearest doctor for any changes they notice in the breast, avoiding the taboo

topics that have existed so far, because since there is no other prevention, the only way out is early diagnosis.

- Increase opportunities for diagnosis and have psycho-social and physiotherapeutic support.
- Aspects of breast cancer treatment should be regulated by Law.
- Increase the accountability of public officials and health institutions in addressing violations of women's rights in health care.
- Increasing women's access to quality health care.
- The number of support staff at the Oncology Clinic in Prishtina should increase.
- Expansion of capacities and space in the Oncology Clinic.
- Establishment of a palliative center because Kosovo is the only country in the region that does not have such a center.
- More work to be done on raising the awareness of the population for early detection of breast cancer.

Kosovo, as a young developing country in Europe, is facing breast cancer, like other developed countries, but it is a fact that Kosovo is facing breast cancer without health insurance, without new medicines in the essential list that prolongs life in metastatic cases, without a register of breast cancer, with job loss during treatment, especially in the private sector. There are as many issues and challenges as women with breast cancer and who have to fight their disease.

Despite the situation, there are tremendous demands to defeat breast cancer in Kosovo, as follows:

1. National cancer plan
2. Screening programs
3. Newer and more modern medicines that expand the life span of the patients
4. Timely and fair treatments according to International Guidelines (ESMO, ASCO, ABC, etc.)
5. Specialised breast cancer clinic based on UN standards
6. Counseling and genetic testing
7. Accreditation
8. Metastatic breast cancer care
9. Palliative care

We need to take giant steps and actions as soon as possible to start with:

- Prevention of Breast Cancer
- Early detection of breast cancer
- Adequate treatment, the right person, the right treatment, at the right time
- Quality of life of patients and survivors
- Life after breast cancer
- Educating patients / population about breast cancer

We must follow the vision of Europe, the Breast Cancer Plan, a plan that brings hope and together we can make a difference, we can change the lives and histories of so many families or citizens.

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