

**Susan G. Komen for the Cure® Global Initiative for
Breast Cancer Awareness**

ROMANIA

Community Profile Executive Summary and References

Constanta
Cluj
Bucharest

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The information contained in this Community Profile has been compiled by Course for the Cure™ participants and comes from a variety of sources. Participants have attempted to obtain the latest and most reliable data available and to accurately reflect breast cancer challenges and resources in their city at the time of the profile. Susan G. Komen for the Cure does not recommend, endorse or make any representations or warranties of any kind with respect to the accuracy, completeness, timeliness, quality, efficacy or non-infringement of the information contained in this summary.

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Executive Summary

Goal of the Community Profile

This Community Profile Report details the findings of Course for the Cure™ participants in Bucharest, Cluj, and Constanta. The goal of the community profile is to assess breast health needs and resources, define the priorities and objectives for future action, and inform the work of breast health organizations and activists in their fight against breast cancer.

As part of the course's follow-up activities, participants have collaborated with Global Initiative staff to apply the community profile skills they are learning. Demographic, statistical, and program and service provider data - as well as data from formal and informal leaders in the community - are included to provide a multifaceted picture of breast health. After collecting and analyzing available data on breast health and services, participants identified and prioritized the community's current unmet needs or "gaps" in breast health. These prioritized gaps form the basis for developing plans for education outreach, awareness programs and advocacy efforts to improve breast health outcomes.

The Community Profile should be made widely available to the community and used on an on-going basis to inform strategic planning around breast health and to strengthen existing programs and services. As a living document, it also needs to be updated on a regular basis as circumstances change and new information becomes available.

Introduction of Susan G. Komen for the Cure Global Initiative for Breast Cancer Awareness

An estimated 25 million women around the world will be diagnosed with breast cancer over the next 25 years, and up to 10 million could die without a cure. With this in mind, Susan G. Komen for the Cure® - the world's largest grassroots network of breast cancer survivors and activists - launched the Komen for the Cure Global Initiative for Breast Cancer Awareness. The Institute of International Education (IIE) - one of the world's most experienced global higher education and professional exchange organizations - designed and manages the Initiative through its West Coast Center, in collaboration with local partners in eight pilot countries: Brazil, Costa Rica, Jordan, Mexico, Romania, Saudi Arabia, Ukraine and United Arab Emirates.

The goal of the Initiative is to create a dynamic global network of dedicated activists with the skills, knowledge and vision to play a strategic role in shaping their countries' response to breast cancer. This is accomplished by (1) empowering diverse stakeholders with the training, tools and support needed to influence strategic, locally-appropriate programming and funding decisions around breast cancer; and (2) strengthening individual and organizational capacity to launch effective education, awareness and advocacy campaigns to increase early breast cancer detection and reduce mortality.

At the core of the program is Course for the Cure™, a series of training modules based on Komen's 25 years of experience in breast cancer awareness and advocacy. The training modules, which have been customized in each country, cover five key topics: Community Assessment, Volunteer and Organization Development, Awareness and Education, Fundraising, and Advocacy.

Country Overview

With a population of 21,680,974 (according to the last Census in 2002), Romania ranks as the seventh largest country in the European Union. 51% of the population is female and 49% male; 53% of the population resides in rural areas and 47% in urban communities.

Breast cancer is an important public health problem in Romania, as statistics show that it is the most frequent cancer among females in the country. At present the medical system in place does not include screening for breast cancer, but only diagnosis services within the Institutes of Oncology (2), District Hospitals, and private clinics. Only a few non-profit organizations are active in the area of breast cancer and therefore several gaps are present in different areas: awareness, early detection through regular screening, and support services for survivors.

The program - and this Profile - included the capital city (Bucharest) and two districts: Cluj and Constanta.

Constanta

Demographics

The district's population in 2007 was 718,330 inhabitants, 51% female and 49% male. 70.4% of the general population resides in urban areas. Out of total female inhabitants, 69% reside in urban and 31% in rural communities. Constanta district is a model of diversity and peaceful cohabitation among 17 ethnic groups; however 91.95% are Romanians. Over 85% of the population is Christian (Orthodox, Catholics, Pentecostals, Reformed), and the rest are Muslim.

Breast cancer statistics

In 2006 the incidence of breast cancer was 76.48 per 100,000 women, higher than the national average (50.56 per 100,000 women). The prevalence in Constanta is higher than the national prevalence, as well - 690.78/100,000 women versus 509.32/100,000 women.

The incidence is double in urban area (48.93/100,000 persons) versus rural area (20.03/100,000 persons); this situation may be due to easier access to specialized medical diagnosis services in urban areas. The mortality is almost one fourth higher in urban areas (14.21/100,000 persons) than rural areas (10.01/100,000 persons).

Program and services

At this point the district does not have screening services for breast health in place; however diagnosis services are provided free of charge for patients referred by a doctor to one of the 4 Governmental facilities which perform mammography and ultrasound exams. In addition, the district has several private medical facilities which may also diagnose breast issues, but services are not free of charge. Treatment of breast tumors is available within one hospital, which is the main district hospital located in the capital city. The team identified only two support groups for survivors. The district has not had any consistent long-term programs for increasing of population's awareness on breast health and cancer.

Qualitative data

The Constanta team interviewed 10 Key Informants for identification of the main gaps among rural women in the area of breast health. Questions were grouped to collect targeted information on health (general and breast, information and services), barriers (in access, cost, fears, education/awareness and cultural/behavioral) and the health care system - namely in screening and treatment.

The main barriers were related to access, costs, fears, but also lack of awareness and existence of cultural and behavioral obstacles.

The key informants revealed the facts that medical community services are not satisfactory and that screening is not available anywhere in the district. They identified family doctors and nurses as best source for information and education.

The following gaps were identified based on collected data and on personal and institutional knowledge:

- Low level of awareness on breast cancer in the district
- Lack of a screening program
- The Family Doctors (who are the only medical service providers in rural communities) do not perform breast clinical screening on a routine basis
- Lack of support groups for survivors.
- Lack of services of counseling and rehabilitation for breast cancer patients.
- Failure of existing medical legislation to ensure free prosthesis for patients with mastectomy
- Insufficient specialists in oncology and breast health

Prioritized gaps, goals and objectives

Out of five strategic goals identified by Constanta team, it was decided to pursue the following two during the next three years: 1) increase level of awareness on breast cancer for rural women in the district; 2) improve the quality of life of survivors and co-survivors through increasing the number of support groups for women with breast cancer.

The team selected as population segment to be targeted within awareness programs the 15-65 years of age residing in rural areas. The wide limits of the age group are due to the wish of the team to start as early as possible building healthy preventive behaviors among population.

Cluj

Demographics

The district's population in 2007 was 692,316 inhabitants, 52% female and 48% male. 67% of the general population resides in urban areas. Out of total female inhabitants, 69% reside in urban and 31% in rural communities. The ethnic structure is the following: Romanians -79.4 %, Hungarians - 19%, Roma - 1.0 %, German - 0.2 %, Jew - 0.1 % and other 0.3 %. The majority of the population is Orthodox (69.2%), the rest being shared between Reformed -12.2 %, Roman-Catholic-5.5%, Greek-Catholic-5.8%, Pentecostals-2.6% and others-5.2%; 0.2% declared to be without religion and 0.2% were Atheist.

Breast cancer statistics

In 2006 the incidence of breast cancer was 71.90/100,000 persons, higher than the national average (50.56/100,000 persons). The mortality is comparable with the national average: 30.63/100,000 persons in Cluj versus 27.79/100,000 persons nationally. The distribution of breast cancer incidence between rural and urban residences shows that the number of cases diagnosed in urban areas is higher than the number of cases diagnosed in rural areas (88.06/100,000 persons versus 58.18/100,000 persons in 2006)

Program and services

Cluj district benefits from the services and expertise of an Institute of Oncology located there. At this point the district does not have screening services for breast health in place; however diagnosis services are provided free of charge for the patients that are referred by a Family Doctor or another medical specialist to one of the Governmental facilities which perform mammography and ultrasound exams: the Institute of Oncology, the Radiology Clinic and CFR Hospital. In addition the district has several private medical facilities which may also diagnose breast issues, but services are not free of charge. Treatment and surgery of breast tumors is available within two hospitals and at the Institute of Oncology. The Romanian Society for Cancer, a local NGO, provides support for cancer survivors, but not specifically for breast cancer patients. The district has not had any consistent long-term programs for increasing the population's awareness of breast health and cancer, but the Romanian Society for Cancer, based in Cluj, has developed some programs there.

Qualitative data

The Cluj team opted for the focus group technique in order to identify main gaps among rural women in the area of breast health. Two focus groups were organized in two locations, and 14 women aged 15-55 years attended. The

Focus Group Guides were structured as to cover several levels: individual (awareness and practices), institutional (services) and information sources.

Breast health and especially breast cancer is a topic of great interest for rural women in the Cluj community; their need and desire for information are high, and thus the receptivity of rural women to an educational program tailored to meet their needs is expected to be high. Rural women trust the medical staff in the primary medical care network within their communities as facilitators of informative sessions on breast health, including correct BSE.

Several barriers have been identified, related to transportation, cost, culture and behaviors (fear of finding out a bad diagnosis, fear of pain during procedure, shame/modesty of being examined by a male doctor, prohibitive costs associated with mammography provided in a private clinic, cost of transportation, and the attitude tending to postpone the examination).

The following gaps have been identified based on collected data and on personal and institutional knowledge:

- Low level of awareness on breast cancer of the target population (including prevention/early detection, BSE ,alarm signs, etiology, connection with stages of woman's life, possibility of recurrences,)
- Lack of awareness of rural women on existing services in breast diagnose within the district
- Lack of a breast screening program
- Lack of inclusion in the routine of the Family Doctors of the breast clinical screening

In conclusion it results that awareness about breast cancer and breast self examination is vague, BSE is not practiced, the services existing within their communities are not sufficient, women are unaware of locations in the district where they may access diagnosis services and they face several barriers in accessing those services.

Prioritized gaps, goals and objectives

Out of four strategic goals identified, the Cluj team decided to pursue during the next three years the following: raising awareness in rural women regarding breast self examination and on diagnosis services available in the district.

The team decided to target with awareness programs the segment of women 15-55 years of age residing in rural areas. The wide limit of the age group is due to the wish of the team to start as early as possible building healthy early-detection and risk-reduction behaviors among the population.

Bucharest

Demographics

The population of the city in 2005 was 1,9249,59 inhabitants, 53% female and 47% male. The ethnic structure of the Bucharest city is: 97% Romanian and the following important ethnic groups: 1.4% Roma, 0.3% Hungarians, 0.1% Germans, Turks, Russians, Greeks, and Chinese and under 0.1% Ukrainians, Tartars, Slovaks, Bulgarian, Italian, Czechs, Polish, Armenians, Croatians and Serbians. Similar to the national level, the biggest religious community in Bucharest is Orthodox - 96.1%, distantly followed by Roman and Greek - Catholics with 1.6%; Muslims represent 0.5%, Baptists and Adventists 0.2% each and the following religious communities make up 0.1% or less: Reformed, Unitarians, Evangelist, and Mosaics.

Breast cancer statistics

In 2006 the incidence of breast cancer was 54.47/100,000 persons and the mortality was 24.85/100,000 persons, comparable with the national average 50.56/100,000 persons in incidence and 27.79/100,000 persons in mortality.

Program and services

Bucharest also benefits from the services of an Institute for Oncology located there. Like everywhere in Romania, Bucharest city does not have screening services for breast health in place; however diagnosis services are free of charge for the patients referred by a doctor either to the Governmental facilities that perform mammography and ultrasound exams or to one of the two NGOs providing these type of services (Renasterea Foundation and the Romanian Association for Cancer Prevention). In addition there are many private medical facilities which may also diagnose breast issues, but services are not free of charge. Treatment of breast tumors is available within at least five hospitals. The city benefits from Renasterea Foundation's programs of diagnosis and awareness on breast cancer. Avon Company is also implementing a breast cancer awareness campaign at national level.

Qualitative data

The Bucharest team chose to use the technique of focus groups in order to identify main gaps existing among 40-59 years of age urban women. Two focus groups have been organized and 11 women attended. The Focus Group Guides were structured as to cover several levels: individual (awareness and practices), institutional (services) and information sources.

Breast health and especially breast cancer are topics of interest for women in Bucharest. Women have lots of knowledge on breast health/cancer in theory but they did not perform BSE. Also, women in Bucharest have a significant level of distrust in the quality of care existing in primary care network and seemed to be interested in accessing the best professionals.

Bucharest women mainly trust the medical staff in the secondary network (Gynecologists, Oncologists, Endocrinologists) of medical care but would also accept to be held informative sessions by Family Doctors.

The women in Bucharest participating in the focus groups recognized cost as a potential barrier to accessing services. They did not identify transportation as a barrier, but it is possible for women in the periphery of the city to face the transportation challenges. Also, cultural barriers were not identified among the groups of women who responded. Fears appear to be a barrier (diagnosis of breast cancer, unknown proceedings, dangers due to radiation dose during mammography and not being able to get the best medical opinion). Listed fears show that women in Bucharest are preoccupied by the quality of services (realized lack of medical advising, would want best experts to diagnose them), risk factors (radiation due to mammograms) and the natural fear of finding breast cancer.

The following gaps have been identified based on collected data and on personal and institutional knowledge:

- Lack of behavior of women in proactive early diagnosis of breast issues through breast self examination
- Lack of a breast screening program which will allow periodical and free mammography (at this point private clinics and few Governmental facilities provide the service but it targets diagnosis, not screening)
- Lack of counseling on breast examination, diagnosis and prognosis in medical facilities.
- Lack of inclusion in the routine of the Family Doctors and of other specialists of the breast clinical screening.

In conclusion it results that awareness on breast cancer and breast self examination exists but is insufficient and disorganized; there is no BSE behavior and women would be glad to be informed through sessions held by doctors and by media methods (TV and radio shows, written media and Internet).

Prioritized gaps, goals and objectives

Out of the four strategic goals identified by Bucharest team, in the end it was decided to pursue during the next three years the following: behavioral change towards preventive health in women 40 to 59 years old determining them to practice BSE and to be aware on the need for periodical clinical and mammography screening

COMMUNITY PROFILE REFERENCES AND RESOURCES

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European Commission

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GLOBOCAN

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Local Health Authority, Cluj

Local School Authority in Constanta and Cluj

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National Agency for Labor Market

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