

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

BRAZIL

Community Profile Executive Summary and References

Paraisópolis
São Caetano
Porto Alegre

March - July, 2008



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.

INSTITUTE OF
INTERNATIONAL
EDUCATION


susan g.
komen
FOR THE
cure.


ALBERT EINSTEIN
SOCIEDADE BENEFICENTE ISRAELITA BRASILEIRA
HOSPITAL • ENSINO E PESQUISA • RESPONSABILIDADE SOCIAL

Acknowledgements

Course for the Cure´s team in Brazil:

Luciana Holtz de Camargo Barros – Program Manager
 Maria Teresa Veit – Master Trainer

Course for the Cure´s participants:

<i>São Paulo</i>	<i>São Paulo</i>	<i>Porto Alegre</i>
Alba Fusco	Aline Ueda	Isabel Vargas
Alcina Meirelles	Ana Paula Silva	Marlene Soares Silveira
Claudia Toledo	Ana Paula S. Teixeira	Claudia Feldmann Gonçalves
Cristina Neder	Bethânia Neves	Claudia Mattia
Gilze Francisco	Bruno A. Ponce	Eliane Sá Brito
Joacira Dantas	Camila Alves	Márcia Santos Silva
José Luis Francisco	Camila F. Augusto	Marinês Lima Marconato
Lair Dias	Damila Trufelli	Marta Bitencourt Barcellos
Lise Cury	Elise Klettehofer	Nalda Vargas
Lola Andrade	Flávia D. Martins	Sara Jane da Costa de Souza
Mauricéia Souza	Franclen R. B. Carvalho	Virginie Fett
Meire Rebelo	Gabriela Rocco	Carlise Schneider
Patricia Melo	Genoveva R. C. Zillo	Altair Margarida de Conto
Soila Silva	Juliana P. Silva	Rita de Cássia Castro
Terezinha Cipriani	Karina Brunetti	Barbara Marçal
Thereza Ferraz	Lais Lois	Liane Araujo
Tiago Matos	Mayccon Alfredo	Lauren Caleffi
Vera Teruel	Natália Fraile	Larissa Brouwers
Vera Monari	Neiva Guarnieri	Ana Lucia Gomes
	Penélope Laranjeira	Karine Fabretti
	Rachel R. R. Gronch	Debora Cardoso
	Vinicius de Oliveira	Maria Beatriz Tagliari
	Fernanda Pajares	Jussara Pasquini
	Andresa Montorso	Flávia Boabaid
	Mateo Yaksic	Anke Wilms
		Ana Dutra
		Ademar Bedin Jr
		Julia Viegas
		Mônica Leal
		Rodrigo Ribeiro
		Eunice Domingues Olivo
		Giovana Paggiarin
		Karina Pertile
		Maria Angélica Linden
		Rosa Maria Rutta

Executive Summary

Introduction of the 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.

Goal of the Community Profile

This Community Profile Report details the findings of Course for the Cure™ participants in Paraisopolis, Sao Caetano and Southern of Porto Alegre. 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.

This Community Profile Report details the findings of Course for the Cure™ participants in the São Paulo low-income community of Paraisópolis and the city of São Caetano, as well as the southern region of Porto Alegre. 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.

Brazil is a continental-sized country with 26 states and one federal district where the capital, Brasília, is located. Brazil is divided into 5 regions by IBGE: North, Northeast, Central-West, Southeast and South.

From a socioeconomic point of view, the South and Southeast are the regions that have reached the greatest level of industrial development. This, however, generated migration movements from the less developed areas to these regions. The great number of migrants created at the same time an increased demand for new jobs and opportunities, new social policies and new health policies.

The importance of social policies in Brazil is directly proportional to the social indicators (population distribution by gender, age, race and ethnicity, population development degree, poverty, employment and unemployment, education and life and health conditions) that reflect a society dealing with inequalities.

The Brazilian federal government invests more than R\$200 / US\$ 127 billion per year in social programs. The main goal of Brazilian social policies is to eliminate poverty.

Public healthcare initiatives are directed towards reducing the prevalence and incidence of various diseases, the control of endemic and parasitic diseases, and improvement in health monitoring and overall quality of life of the Brazilian population.

In December 2005, the National Policy for Oncologic Attention (PNAO) was launched. Its purpose is to promote integrated actions between government and society towards the implementation of a new policy that recognizes

cancer as a public health problem and enables actions towards its control in Brazil, through the Oncologic Attention Network.

In Brazil, there will be an estimated 466,730 new cancer cases in 2008. 234,870 women will develop cancer, of which 49,400 will be breast cancer. Breast cancer currently is the leading cancer-related cause of death among Brazilian women. (INCA, National Cancer Institute of Brazil, 2008)

The concern with breast cancer has been gradually increasing, especially due to the fact that it may affect economically active women so this incites women to seek more information about breast cancer.

At this time in Brazil there are five Campaigns associated with breast cancer and thirteen breast cancer NGOs. A governmental resolution determined that, starting in the year 2009, all women aged 40-49 years should have a mammography in addition to the clinical exam that was previously recommended.

Community Profile

The Community Profile for each of the three communities includes:

- Demographic Findings
- Socioeconomic Data
- Breast Health and Breast Cancer Statistics
- Programs and Services
- Qualitative Data
- Identified and Prioritized Gaps
- Recommended Next Steps

Paraisópolis

Demographic Findings

Paraisópolis occupies an area of 84 hectares and the Union of Residents of Paraisópolis estimates that approximately 80,000 people live in the favela. The demographic density is 952 inhabitants/ hectare. Gender distribution indicates that men surpass women by 6%, and of the estimated total of inhabitants, 42,400 (53%) are men and 37,600 (47%) are women.

A total of 3,526 women are aged 40- to 59 years, and 646 are 60 years or older, totaling 4,172 women aged 40 years or older living in the Paraisópolis community.

Socioeconomic Data

The mean net family income is between 1 to 3 minimum wages (1 minimum wage in Sao Paulo / 2008 = US\$ 264). The estimated per capita income is R\$ 5,400 to R\$16,200 per year (US\$ 3,290 to 9,800 per year).

Breast Health and Breast Cancer Statistics

The medical services oriented towards breast cancer detection and diagnoses are limited to the UBS and to the Campo Limpo Municipal Hospital. There are no mammography machines or ultrasound equipment available in the Paraisópolis community. There is no specific breast cancer detection program in the community of Paraisópolis.

Programs and Services

Paraisópolis is presently served by public and private health services. There are also health programs developed in the community, that are essentially focused on primary health care and maternal (prenatal) and child care.

Basic Health Unit Paraisópolis II is a Family Health Program Unit, and is 100% administered by the Albert Einstein Hospital through a public-private partnership with the municipality of São Paulo; the program serves approximately 18,000 users, with an average of 400 appointments/ day.

Family Health Unit Paraisópolis I offers health services to the general community, with an average of 3280 appointments per month.

The Ponto de Luz Philanthropic Group provides prenatal care, general practice appointments and odontological care to the community.

Einstein Hospital has been providing health care services for children in this community for the last 10 years. It offers appointments and develops actions in the areas of General Medicine, Psychology, Speech Therapy, Physiotherapy, Psycho-Pedagogy, Social Service and Nutrition for children from 0 to 10 years.

The “Einstein at the Paraisópolis Community” Program serves 10,000 children that are registered in the Pediatrics Outpatient Clinic and 6,000 people at the Center for Health Care and Promotion.

Qualitative Data

Fifty seven interviews were conducted with the residents of the community using an interview guide developed by the group of participants for the assessment of qualitative data regarding the following topics:

- Women’s Health Problems in the Community
- Awareness About and Information on Breast Cancer
- Is there a support group
- Barriers to Breast Health Services

Identified and Prioritized Gaps

Quantitative and qualitative data analysis was conducted by a systematic review of the findings. The Course for the Cure™ group participated in the identification and prioritization of the main gaps by reporting their personal

experiences and impressions during the interviews, and by presenting their own suggestions concerning the identification of the gaps.

The following gaps were identified:

- Lack of complete official demographic data.
- Lack of official data on breast cancer
- Insufficient data about the existing breast health services available for this community.
- Inadequate or insufficient material resources - infrastructure
- Inadequate or insufficient human resources and equipment for breast cancer screening and treatment
- Residents lack information on breast health and breast cancer
- Insufficient number of health professionals and of the support network for breast cancer detection

Recommended Next Steps

- Create awareness, motivate and mobilize women towards breast self-care and general health issues, through the institution of a permanent program which addresses awareness among women on how to take care of their breast health and which motivates them to do so.
- Guarantee the access to early breast cancer screening for all the women aged 40 years or more who live in Paraisópolis.

São Caetano do Sul

Demographic Findings

São Caetano do Sul is a city in the state of São Paulo, located in the region of the Great ABC has the best social indicators in Brazil, being a model city in many aspects.

In 2007 the city had a population of 144,857 residents

The city of São Caetano do Sul covers an overall area of 15.3 km², and a demographic density of 9,467 inhabitants per km².

As to gender distribution, there are more women than men living in São Caetano - Women: 76,774 (53%) and Men: 68,083 (47%)

A total of 54.125 (70%) of the female residents of São Caetano are over 40 years.

Socioeconomic Data

The mean net family income in São Caetano is one of the highest in Brazil, reaching up to R\$2,300 (US\$ 1,400). The estimated per capita income is about R\$30,000/ year (US\$ 16,500).

Breast Health and Breast Cancer Statistics

The Municipality invests about 20% of the city's resources in the healthcare system. São Caetano has public and private health facilities and diagnostic equipment that are available to the community, among the diagnostic equipment there are 8 X-ray mammography systems and one stereotactic

mammography system. Hospital mortality data from São Caetano in the year 2007 shows that out of a total of 481 deaths 23 were women who died of cancer. The health department of the city of São Caetano estimates that there will 101 new breast cancer cases in 2008.

Programs and Services

Several health programs are carried out in the city of São Caetano:

- Family Health Program
- Chronic Disease Management Program
- School-Based Health Care Policy Program
- Prenatal Care Assistance Program
- Homecare Assistance Program
- Women's Health Program

Many health campaigns are carried out during the year aimed at preventing the most common diseases and interacting with programs carried out by the Ministry of Health. There are 8 Basic Health Units (UBS) and two reference hospitals in São Caetano. There also is the Women's Comprehensive Health Care Center (CAISM - Centro de Atenção Integral à Saúde da Mulher) that treats approximately 5,000 women a month.

Qualitative Data

Twenty one interviews were conducted using an interview guide developed by the group of participants for the assessment of qualitative data regarding the following topics:

- Women's Health Problems
- Information About Breast Cancer
- Presence of a support group
- Barriers

Identified and Prioritized Gaps

Quantitative and qualitative data analysis was conducted by a systematic review of the findings. The Course for the Cure™ group participated in the identification and prioritization of the main gaps by reporting their personal experience and impressions during the interviews, and by presenting their own suggestions concerning the identification of the gaps.

The following gaps were identified:

- Underused diagnostic equipment - mamographies
- Residents lack information on breast health and breast cancer
- No availability of chemotherapy and radiotherapy in the community
- Lack of information about specific training in breast cancer detection exams and breast health education for physicians and technicians
- Community agents are not trained and motivated towards breast health initiatives
- Large number of the education campaigns conducted have no outcomes assessment

- Psychological barriers for breast health care
- Low impact in the community of the current mobilization and awareness initiatives

Recommended Next Steps

- Create awareness, motivate and mobilize women towards overall health care and breast health in particular, by the institution of a permanent health program.
- Allow all women with breast cancer to have access to specialized psychological evaluation and treatment.

Porto Alegre - South Region

Demographic Findings

The state of Rio Grande do Sul had 10,582,840 inhabitants in 2007. The city of Porto Alegre had 1,420,667 inhabitants and an area of approximately 496.8 km², the demographic density corresponds to 2,859.5 hab/km².

The community selected has 121,550 inhabitants, as to gender distribution of this population, there are more women than men living in Porto Alegre's Southern Region- Women: 62,112 - 51.1% and Men: 59,437 - 48.9%. Women between 40 - 69 years total 16,358. The total area of the chosen community amounts to 205 km², with a demographic density of 1.073 inhabitants per km²

Socioeconomic Data

The mean income of the chosen community is 1.19 minimum wages (US\$ 264 in 2008) per capita and the mean number of residents per households is 4.6.

Breast Health and Breast Cancer Statistics

Breast cancer is the leading cause of death in women in Porto Alegre. The disease was responsible for 16.9% of the deaths of female inhabitants in the year 2006.

Programs and Services

The UBS are responsible for caring for most of the health problems identified by the community agents. Twenty UBS and PSF exist inside the community.

Porto Alegre has mammography machines that are distributed by type of service providers and by type of equipment. In the year 2008, there were a total of 39 X-ray mammography systems: 10 philanthropic, 2 public and 2 private; and a total of 20 stereotactic mammography systems: 9 philanthropic, 4 public and 7 private.

The program of the Breast Nucleus of Porto Alegre - NMPOA - was created in 2004 as a partnership between the Moinhos de Vento Hospital and the Municipal Department of Health. NMPOA's purpose is to offer free medical care, including screening, comprehensive follow-up, exams and surgeries, in addition to Nutrition and Genetics appointments to the patients, and counseling for their families.

Qualitative Data

Forty eight interviews were conducted using an interview guide designed by the group of participants for the assessment of qualitative data regarding the following topics:

- Women's Health Problems.
- Information About Breast Cancer
- Presence of a support group
- Barriers

Identified and Prioritized Gaps

The following gaps were identified:

- Lack of official data on breast cancer for this region
- Lack of motivation of the non-working women regarding their own health
- Lack of awareness on behalf of the residents of the community about: Screening routines, early detection, treatment, breast health resources, breast self-exam and rights.
- Psychological and educational barriers for breast cancer screening
- High rate of late diagnoses of breast cancer in advanced stages
- Problems to conduct mammography screening in this population
- Lack of specific training of mammography technicians
- Lack of specific training of the doctors in conducting clinical examination
- Insufficient Public health services to meet the needs of the population
- Low quality of the overall care provided to breast cancer patients
- Insufficient qualification of the health professionals
- Unavailable psychological support services
- The figure of the health agent and their work are not properly valued by the population
- Lack of qualification of the health agent in breast health issues

Recommended Next Steps

- Create awareness, motivate and mobilize women towards breast self-care and general health issues, by the institution of a permanent program addressing women's awareness of how to take care of their breast health and to be motivated do so.
- Health agents will be able to motivate and mobilize women to participate in the available breast health program.
- Guarantee the excellence - in equipments and human resources - of the mammographies performed in all the public services offered to this community.

COMMUNITY PROFILE REFERENCES AND RESOURCES

Brazilian Institute of Geography and Statistics (IBGE)
<http://www.ibge.gov.br/>

Campo Limpo Hospital

Feminine Network of São Caetano do Sul

General Health Coordination(Coordenadoria Geral de Saúde-CGVS)
<http://portal.saude.gov.br/saude/>

HAGAPLAN

Institute for Applied Economic Research (IPEA)
<http://www.ipea.gov.br/>

Instituto da Mama (Breast Institute)

Ministry of Economy
<http://www.fazenda.gov.br/>

Ministry of Health
<http://www.portal.saude.gov.br>

Mortality Information System, Municipality of São Paulo

National Cancer Institute (INCA)
<http://www.inca.gov.br/>

Population Based Cancer Registry

PSF Paraisópolis II

São Caetano Municipality Office

SIAB Basic Attention Information System 2008

State System of Data Analysis (SEADE)
<http://www.seade.gov.br/>

Union of Paraisópolis Residents

United Nations Children's Fund (UNICEF)
<http://www.unicef.org/infobycountry/brazil.html>

World Health Organization (WHO)
<http://www.who.int/countries/bra/en/>