Improving outcomes from breast cancer in Bangladesh: research, and global citizenry and diplomacy

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Breast cancer in Bangladesh: 87% STAGE III+ to Stage "H" at diagnosis Challenge or Opportunity?





Breast cancer descriptive epidemiology 2010

Projected Annual Cases

World	1,550,000
World-poor	1,000,000
Asia	800,000
Bangladesh	20-30,000
USA	200,000

Bangladesh:155 million people in an area the size of IOWA OR New York





Khulna

bangladesh quality of life

GDP per capita ~\$US 510

Living on < \$1 per day >30%

Illiteracy, Adult women 64%

Undernourished people 30%



GENERAL BACKGROUND

1

In low/middle income countries there is now an "epidemiologic transition" to major increases in the chronic disease and cancer burdens.

For breast cancer in Bangladesh, aging of the population, increased age at first full term pregnancy, and decreased parity each will contribute to a steady increased annual country case-burden.

See: The <u>Economist</u>: The global burden of cancerchallenges and opportunities. August 2009

BACKGROUND

#2

_"Bangladesh has received disproportionately limited health aid, relative to its disease burdens".

Lancet June 19, 2009

BACKGROUND

#3

Improving population health is a RESEARCH exercise. International academic partnerships are a critical mechanism for bringing these efforts to their highest and most rigorous levels.

Institute of Medicine Report, 2009

RESEARCH, NOT TECHNOLOGY TRANSFER

FOR CANCERS among POPULATIONS differences in:

- Tumors themselves
- The patients who react differently to medicines and treatments.
- Cultural traditions.
- Health systems.

Barriers --- in ALL countries Context is everything

Structural violence (Farmer): "The diffuse and indirect oppressive societal forces whose routine application limits individual choices in the extreme".

Political terrorism
Racism → genocide
Cultural extremism
Class discrimination

Gender discrimination → gendercide
Market terrorism
Religious terrorism
Poverty

Health systems issues--everywhere. Limited:

- Access to care
- Use of information technology
- Centralized and coordinated care
- Use of evidence-based, costeffective interventions

BACKGROUND

#4

LESSONS LEARNED

- *Disease-specific interventions should STRENGTHEN primary health systems.
- *Need for focus on RESULTS and VALUE.
- *Need for local leaders, capacity building, sustainability=business plan and exit strategy, and scalability.
- *Independence from pharmaceutical industry.

Finding the right point organization

*Field experience: over three years, seeking clinical trial sites, with multiple hospitals and one large non-governmental organization =>Complete failure.

- *Recruited in-country-experienced Bangla-speaking U.S. research program manager=>
- *Amader Gram ("our village") a successful, nongovernmental rural IT development organization, with a visionary, honest leader, Reza Salim.

The Amader Gram Program

 Due diligence in first observing, describing and understanding the problems with breast cancer in Bangladesh.

Development of a comprehensive "model" "search and research approach", sensitive, in particular to broad background issues.

Amader Gram-NCI In-country Experience





Women seeking care for breast problems in rural Bangladesh

Over 24 months, in free walk in clinics:

Women evaluated: 1565

Women with an objectively confirmed medical breast problem: 756

Women with breast cancer: 179

Data from Amader Gram Breast Care, 2009

BREAST CANCER IN RURAL BANGLADESH

238 CONSECUTIVE NEW CASES 2007-08 at Khulna Medical College and Hospital

Stage I/II (Local) 9 (4%) Curable

Stage III+ (Regionally advanced)
208 (87%) Cure unlikely

Stage IV (Distant metastatic) 21 (9%) Incurable

Data from Amader Gram Breast Care, 2009

Focus group meetings with breast problem-afflicted women





The Amader Gram assessment: Breast Cancer in Bangladesh

- 20,000-30,000 new cases each year
- 80% or more die (versus 25% in high-income countries)
- Most women first get evaluation when they have advanced, incurable disease, but 25% of women first present with a breast lump which is not diagnosed or treated as cancerous.
- Most specific care appears to be of poor quality-unneeded or impractical tests, and treatments which are ineffective or incomplete

Amader Gram Breast Care Program

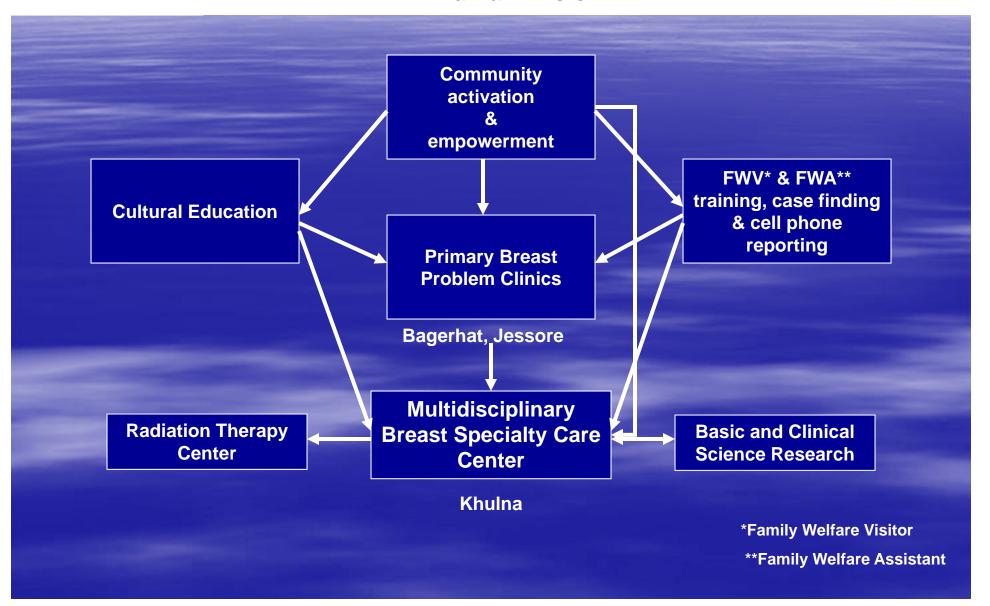
MISSION

Reduce morbidity and mortality from breast cancer and other breast diseases in the women residing in the Khulna Division of Bangladesh by sustainable and innovative social business(es)



AMADER GRAM BREAST CARE PROGRAM

Target Population 3.5 Million Women > 21 in the Khulna Division



Addressing silence: Community activation and empowerment: activities to date

- Created 3 district, 7-member committees
- Developed governance guidelines.
- Started process of creating specific flip chart educational materials for use in village meetings.
- Plans for division meeting, cultural education program, problem clinics, Family welfare visitor training course, and Multidisciplinary Center visits.



Cultural education: Rupantar Performance art "Pot Song" on Breast Problems

Cultural education: a research exercise

- Breast problem "Pot song" content developed based on communications theory model.
- Goal is to change 1. Perceptions of nature of serious breast problems and acceptability of taking action to address these; and 2. Behavior, by increasing numbers of women who seek help for breast problems.
- Evaluation will be in a village randomized trial of this and another "control" "Pot Song" with surveys of selected attendees and monitoring of Breast Problem Clinic and Specialty center visitor numbers and dates.

Breast Problem "Pot Song" performance: 700 attendees, May 31, 2009





Family welfare visitor (FWV) training case-finding and cell phone reporting

Train all Khulna division FWVs (n=3000) in:

- Recognition of breast cancer
- Breast examination
- Success in management of cancer
- Patient motivation and facilitation in seeking care
- * Operation of software reporting system on cell phone



Multidisciplinary Breast Care Center, Khulna: An outpatient "one stop", "medical home" facility providing:

- Access for all regardless of ability to pay
- Centralized and coordinated care
- Paperless system
- Care based on clinical practice, evidence-based guidelines
- International (US- NCI/CEC) telemedicine consultation



Breast Care Center, Khulna: an outpatient facility which out-sources:

- Diagnostic Xray, blood testing and pathology services
- Hospitalization for surgery
- Radiation therapy



Breast Care Center, Khulna: centralized and coordinated "one stop" "medical home" care means

For any serious breast problem responsibility will be taken for all arrangements and diagnostic and treatment activities – initial and long term – including services outsourced and the business payment parts of all care.



AMADER GRAM BREAST CARE

CLINICAL PRACTICE GUIDELINES

Version 5/2009; 27 pages

www. agbreastcare.org

www. ibcrf.org



Cost effectiveness of investments in three Amader Gram projects

- Cultural education-Rupantar : \$75,000-> \$100 per year of life saved
- FWV training for case finding/cell phone reporting: \$150,000->\$100 per year of life saved
- Breast care treatment center: \$50,000->\$50 per year of life saved

Usual return on health care investments in US: \$42,000 per year of life saved.

Framing or the goals of the Amader Gram Breast Care program

DECREASING POVERTY AND INCREASING SOCIAL STABILITY THROUGH SOCIAL CHANGE AND INNOVATION BY

- *Local governance
- *Empowerment of women
- *Job creation with IT expertise in health sector

IN THE PROCESS OF ADDRESSING

A serious chronic disease, with a "search and research" model, focusing on major issues.

16 COLLABORATING RESEARCHERS FROM 4 COUNTRIES

- Richard R. Love, Med Oncologist, National Cancer Institute, and Ohio State University.
- Bruce E. Hillner, Internist, health outcomes researcher and economist,
 Virginia Commonwealth University.
- Ophira Ginsburg, Med Oncologist/Epidemiologist, University of Toronto.
- Anthony Roberto, Communications researcher, Arizona State University.
- Han Chong Toh, Med Oncologist, National University of Singapore.
- Norman Coleman, Rad Oncologist/ CEC, National Cancer Institute.
- Sheikh Iqbal Ahamed, Computer scientist, Marquette University
- Rezwan Islam, Med Oncologist –telehealth researcher, Marshfield Clinic
- James Woods, Surgeon, Medical College of Wisconsin
- Katherine Nelson and Mary Houghton, Business developers, Northwestern University and Shore Bank
- Muhammad Yunus, Social entrepreneur and banker, Grameen Bank
- Habib Ahsan, Epidemiologist, University of Chicago.
- Hoon Eng Khoo, Acting Vice Chancellor, Asian University for Women
- Syed Mozammel Hossain, Surgeon, KMCH, Bangladesh
- Mohammad Golam Mostafa, Pathologist, NCRI&H, Bangladesh

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Basic and translational research in development

Tumor

- *Analysis and comparison of gene copy number and mutation heterogeneity in locally-advanced primary and metastatic breast cancers, including paired samples. (Norton, Hicks, MSKCC)
- *DNA methylation patterns in multiple "LABC" tissues (Sukumar, Hopkins)
- *Gene expression profiles in primary and metastatic "LABC" lesions (Teh, Van Andel Research Institute)

Host

- *Tamoxifen pharmacogenomics in Bangladeshi women (Flockhart, Desta, Indiana University)
- *Anthracycline pharmacogenomics in Bangladeshi women (Chowbay, National University Singapore)

Funding to date

- * For Research and Innovation:

 NCI (IPA for presenter)
 NCI- Office for International Affairs
 International Breast Cancer Research Foundation
 Breast Cancer Research Foundation
 United Nations Development Program
- * For Patient Care
 Government of Bangladesh
 Patient fees
 Corporate Social Responsibility/Philanthropy

Justifications for international collaborative efforts in health: personal perspectives

- Scientific: The need for much more efficacy, effectiveness and implementation research everywhere.
- Humanitarian: The ethical obligations (to increase quality and length of lives) and the rewards of giving.
- Diplomatic: Better health reduces poverty, builds economies, promotes peace, increases security, and increases mutual respect among peoples.

Other International collaborative research of the presenter

- Pre-laboratory tissue specimen management for breast cancer-Philippines and Bangladesh. (ASCO Guidelines for hormonal receptor testing, in press)
- Human Genome Atlas project (Provision of some of 700 frozen tumor samples +clinical data from Vietnam and Philippines)
- Luteal phase adjuvant oophorectomy (Clinical trial in 762 Vietnamese and Philipino women – RO1 CA 097375)



U.N. Declaration of Human Rights (1948)

Article 25...

(1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family.



A War To Peace Transition Hero

During the Vietnamese/American war Nguyen Cong Binh, MD served as a field surgeon in the central Vietnam DMZ from 1963-1975. He became chief of breast and gynecologic surgery at Hospital K, the NCI Hanoi, and has championed the presenter's oophorectomy / tamoxifen studies.

The Next Generation





Nguyen Khanh Linh, Dr Binh's daughter, works on a project in rural women's reproductive health. Her good friend Genevieve Laura Love, teaches English at Colorado College. Together the women are planning a course for American students on English literature about Vietnam and modern Vietnamese literature in translation, to be given in Vietnam.

Questions

- What in-house NCI or extramural mechanisms, in place or to be created, can facilitate increases in international collaborative basic, translational and clinical science cancer research?
- Specifically, further how can more public health-addressing cancer research be facilitated and funded?