Tailoring Strategies to Available Resources

Jordan Breast Cancer Program
A Bottom-up Model for Early Detection and Screening

Boston
November 2nd, 2009
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- Resources and Breast Cancer In Jordan
- Inception and Governance
- Strategy and Achievements to Date
- Maximizing Use of Resources through Partnerships
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  - Inception and Governance
  - Strategy and Achievements to Date
  - Maximizing Use of Resources through Partnerships
Breast cancer is the most common cancer among females and continues to grow on a yearly basis.

Ten Most Common Cancers Among Jordanian Females
JNCR 1996-2006

New Cases of Breast Cancer
JNCR 1996-2007

<table>
<thead>
<tr>
<th>Primary Site</th>
<th>Cumulative Number of Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>6018</td>
</tr>
<tr>
<td>Colorectal</td>
<td>1710</td>
</tr>
<tr>
<td>Leukemia</td>
<td>1228</td>
</tr>
<tr>
<td>Thyroid</td>
<td>954</td>
</tr>
<tr>
<td>Corpus</td>
<td>925</td>
</tr>
<tr>
<td>Uteri</td>
<td>953</td>
</tr>
<tr>
<td>N.M. Skin</td>
<td>674</td>
</tr>
<tr>
<td>Ovary</td>
<td>744</td>
</tr>
<tr>
<td>Brain&amp;CNS</td>
<td>629</td>
</tr>
<tr>
<td>N.H.L</td>
<td>525</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Cases</th>
<th>ASR</th>
<th>% from all cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>1996</td>
<td>448</td>
<td>29.4</td>
<td>28.5%</td>
</tr>
<tr>
<td>2000</td>
<td>554</td>
<td>35.2</td>
<td>32.7%</td>
</tr>
<tr>
<td>2004</td>
<td>646</td>
<td>39.2</td>
<td>35.3%</td>
</tr>
<tr>
<td>2007</td>
<td>817</td>
<td>45.6</td>
<td>36.2%</td>
</tr>
</tbody>
</table>

16 per 100,000
95%
Jordanian females are inflicted with the disease at a young age when they are at the peak of their productivity.

Distribution of Breast Cancer Cases by Age Group
JNCR 2005

Average Age Specific Incidence Rate (ASIR)
Per 100,000 Females 1996-2006
JNCR

*Median age in developed countries = 65 years

70% of Jordan population under age of 30 years
At the onset of JBCP, Breast Cancer used to be detected at late stages when the survival rate and treatment success are not promising

Stages of Breast Cancer in Jordan based on KHCC Experience before JBCP

- Stage 0, 0.50%
- Stage I, 6.70%
- Stage II, 23.70%
- Stage III, 56.20%
- Stage IV, 12.90%

N=550

Direct Correlation of Survival to Stage of Detection

<table>
<thead>
<tr>
<th>Stage of Disease at Detection</th>
<th>Percent of Survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>100%</td>
</tr>
<tr>
<td>I</td>
<td>98%</td>
</tr>
<tr>
<td>II a</td>
<td>88%</td>
</tr>
<tr>
<td>II b</td>
<td>76%</td>
</tr>
<tr>
<td>III a</td>
<td>46%</td>
</tr>
<tr>
<td>III b</td>
<td>49%</td>
</tr>
<tr>
<td>IV</td>
<td>16%</td>
</tr>
</tbody>
</table>

5 years relative rate of survival
There was no allocation of resources at federal, local or institutional levels to address the challenges facing breast cancer early detection.

**Capacity Building**
- Lack of female technicians trained in mammography and recruited to serve the facilities
- Absence of training facilities (other than KHCC) in Jordan to accommodate for training of technicians and radiologists
- Incomprehensive academic curricula that do not mandate mammography as a required course for technicians
- Training manuals have not yet been implemented

**Mammography Services**
- Lack of availability and accessibility to screening services
- Unequal distribution of services across the Kingdom
- No asymptomatic screening policy; only referred symptomatic patients accepted
- Cumbersome regulations to screening

**Quality Assurance**
- Lack of protocols and standard operating policies and procedures (SOPs) to run the units
- No certification program to set the standards for the mammography units
- No monitoring and evaluation of performance of health providers regarding guidelines for breast screening

**Public Awareness**
- Negative attitudes towards subject of breast cancer (many females prefer not to know) added to cultural barriers & social taboos that extend beyond the female herself leading to fears of being ostracized by husband, family or society
- Need for more individualized and one-on-one activities in order to change behavior that require large outreach efforts
- Lack of awareness, buy-in & action of key-informant & service providers supporting screening

**Non-exhaustive**
The Jordan Ministry of Health is the primary arm in Jordan for healthcare services, resources and legislation

<table>
<thead>
<tr>
<th>Provider</th>
<th>Basic Role</th>
<th>Description</th>
<th>Cancer Control</th>
</tr>
</thead>
</table>
| Ministry of Health              | Law, regulations, budget, health expenditure, insurance, | Reactive vs. Proactive  
Limited resources  
Focused on service delivery  
Public health influenced by Int'l arena | No full plan (under consideration)  
Divided activities  
Strong registry  
Covers all Jordanians  
Mediocre qty Rx services |
| Royal Medical Service           | Closed Military System with Insurance Scheme     | Independent budget  
Serves 20% of populations  
Quality Services | Prevention without outreach (clinic based)  
Rx (not comprehensive) |
| Private Sector                  | Regulated by MoH from Quality perspective not pricing | Business driven  
Varied quality (perceived by population as a higher quality sector than government) | Rx focused  
Not driven by unified protocols  
Very expensive  
Varied quality |
| Universities                    | Free of charge for enrollees or less privileged  | Limited budgets  
Acceptable quality  
Innovation limited | No oncology departments  
Rx available not comprehensive  
Varied quality (KAH vs. JU) |
| Non-for-Profit Sector           | Free of charge for enrollees or less privileged  | Limited budget  
High expertise and focused expertise  
Dependent on Fundraising | Only player to date KHCC  
Comprehensive 1st class center (2 accreditations)  
Outreach, control, diagnosis, Rx and Palliative care |
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Thus the Jordan Breast Cancer Program was set up in late 2006 to down stage the disease and decrease morbidity and mortality.

Program Objectives

- To improve availability and accessibility of screening services across Jordan, especially to less privileged;
- To increase the knowledge of the public on the benefits of breast cancer prevention and to change attitudes and behavior of target population to seek early detection services;
- To establish national unified protocols and guidelines that cover all processes of a comprehensive early detection and screening program including best practices & quality assurance guidelines on training, medical equipment, diagnosis, and referral systems;
- To improve healthcare personnel education and training; and
- To evaluate the impact of the program by collecting data for surveillance and epidemiological analysis to record and measure success.
The Program is governed by a National Committee and incubated by the King Hussein Cancer Foundation.

**National Steering Committee for Cancer**  
*Chair* by the Minister of Health

- **Breast Cancer Early Detection Committee**
  - **Chairperson** Dr. Mahmoud Sarhan (KHCC)
  - **Honorary Chairperson** HRH Princess Dina Mired (KHCF)

- **Treatment Protocols Committee**

**Secretary**

- **Private Sector**
- **PSP USAID**
- **KAH**
- **KHCC**
- **MoH**
- **WHO**
- **UNRWA**
- **RMS**
- **HU**
- **JU**

**Remarks**

- The National Board governs the overall goals and approach of the Program and ensures participation of several stakeholders.
- The Executive Board manages the daily activities of the program, provides guidance to the team, and oversees funding and expenditure.

Members of the National Board form the Executive Board.
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JBCP started with the pilot areas of Amman and Balqa targeting 50% of the female population ages 40-60 years

### Pilot Project Components

<table>
<thead>
<tr>
<th>Inception Phase</th>
<th>Pilot Project</th>
<th>Nationwide</th>
</tr>
</thead>
<tbody>
<tr>
<td>Starts June/July 2007</td>
<td>Starts January 2008</td>
<td>Starts January 2010</td>
</tr>
<tr>
<td>Duration 6 months</td>
<td>Duration 2 years</td>
<td>Duration 5 years</td>
</tr>
<tr>
<td>Establishment of National Coordination office</td>
<td>Covers Amman &amp; Balqa</td>
<td>Covers the whole Kingdom</td>
</tr>
<tr>
<td>Design of implementation plan</td>
<td>Includes both down staging and opportunistic screening approach</td>
<td>Includes both approaches</td>
</tr>
</tbody>
</table>

### Timeline

- **Initiation of Program**: June 2007
- **Beginning of Implementation**: Jan 2008
- **End of Pilot Project**: Dec 2009
- **Phase 3 Start**: Jan 2010
- **Phase 3 End**: Dec 2014
- **Phase 3**: Jan 2010 to Dec 2014
- **Nationwide**: Jan 2010 to Dec 2014
JBCP designed core strategic areas to work on and developed an action plan with prioritized activities.
In the past 3 years, JBCP has been implementing two approaches for raising awareness – mass campaigns and targeted outreach.

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Initiatives</th>
<th>Own</th>
<th>Sponsor</th>
<th>Support</th>
<th>Priority</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increasing Public Awareness</td>
<td>Targeted Awareness Activities</td>
<td>X</td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>March Campaigns</td>
<td>X</td>
<td></td>
<td></td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>October National Campaigns</td>
<td></td>
<td>X</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Development of Information &amp; Communication Toolkits</td>
<td>X</td>
<td></td>
<td></td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>SUPPORT = JBCP Hotline promotion + SANAD group</td>
<td>X</td>
<td></td>
<td></td>
<td>4</td>
</tr>
</tbody>
</table>
Provision of services is coupled with raising awareness among the public and driving the demand towards early detection.
JBCP works closely with all healthcare service providers to activate screening centers and improve the physical settings to suit early detection and accessibility.

<table>
<thead>
<tr>
<th>Objectives</th>
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<th>Sponsor</th>
<th>Support</th>
<th>Priority</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve Availability and Accessibility of Services</td>
<td>▶ Activation of Existing Mammography Units</td>
<td>X</td>
<td></td>
<td>X</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>▶ Cooperation with the Private Sector (continuation)</td>
<td></td>
<td></td>
<td>X</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>▶ New Mammography Units in MoH Healthcare Centers</td>
<td>X</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>▶ Acquisition of Mobile Mammography Unit</td>
<td></td>
<td>X</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>▶ Screening of Underprivileged Women</td>
<td>X</td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>▶ Model Center</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

**Before Program**
- Infrastructure and Equipment
- Waiting Area
- Changing room
- Mammography room

**After Program**
- Infrastructure and Equipment
- Waiting Area
- Changing room
- Mammography room

2

3

4

5

6

7

8

9

10

11

12

13

14

15

16
JBCP has been heavily focused on improving the skills of healthcare providers at all levels from primary to tertiary.

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Initiatives</th>
<th>Own</th>
<th>Sponsor</th>
<th>Support</th>
<th>Priority</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developing Human Resources</td>
<td>Capacity building of radiologists</td>
<td>X</td>
<td>X</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Capacity building of technologists</td>
<td>X</td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Developing skills of media for breast cancer awareness</td>
<td>X</td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Developing skills of gatekeepers and first line health providers</td>
<td>X</td>
<td></td>
<td></td>
<td>4</td>
</tr>
</tbody>
</table>

- Training of 4 radiologists with Dr. Tabar
- Oncology Nursing Training (35 nurses ToT)
- Clinical Breast Exam training for private sector
- Recruitment of RT
- Training of 4 radiologists – observer ship @ MDACC
- Training of 12 RT @ KHCC
- Training for 30 RTs with MDACC expert
- Screening Training (140 attendees)
- CBE Training ~ 1480 nurses & midwives
- Awareness Training – 148 health educators (ToT)
- Radiologist – Breast Imaging Training (150 attendees)
More importantly, JBCP has been working on developing standardized procedures and guidelines to ensure quality...

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Initiatives</th>
<th>Own</th>
<th>Sponsor</th>
<th>Support</th>
<th>Priority</th>
</tr>
</thead>
<tbody>
<tr>
<td>Setting Guidelines, Protocols and QA</td>
<td>Disseminating &amp; Implementing National Guidelines</td>
<td></td>
<td></td>
<td>X</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Disseminating and Implementing Registry</td>
<td></td>
<td></td>
<td>X</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Developing unit standard operational policies &amp; procedures</td>
<td></td>
<td></td>
<td>X</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Developing accreditation system (selecting criteria, developing process...)</td>
<td></td>
<td></td>
<td>X</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Developing referral and service monitoring system</td>
<td></td>
<td></td>
<td>X</td>
<td>4</td>
</tr>
</tbody>
</table>

Guidelines:

- Physical Examination
- Normal Risk, Negative Physical Findings
- Increased Risk, Negative Physical Findings
- Symptomatic, Positive Physical Findings
  - Mass, Age ≥30 Years
  - Mass, Age < 30 Years
  - Nipple Discharge, No Palpable Mass
  - Asymmetric Thickening/Nodularity
- Skin Changes
- Mammographic Evaluation
- Breast Screening Considerations
- Clinical Breast Examination Guidelines
- Mammographic Assessment Category Definitions

Priority:

1. Chart-1
2. Chart-2
3. Chart-3
4. Chart-4
5. Chart-8
6. Chart-12
7. Chart-13
8. Chart-14
9. Chart-15
10. Annex-A
11. Annex-B
12. Annex-C
...and ensure data collection for follow up and decision making

### Objectives

#### Developing Research and Data

<table>
<thead>
<tr>
<th>Initiatives</th>
<th>Own</th>
<th>Sponsor</th>
<th>Support</th>
<th>Priority</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conducting 2009 KAP study</td>
<td></td>
<td></td>
<td>X</td>
<td>1</td>
</tr>
<tr>
<td>Benefit from Omnibus to assess information on campaigns and tools</td>
<td></td>
<td></td>
<td>X</td>
<td>3</td>
</tr>
<tr>
<td>Develop automated database (at least the backbone design of the software)</td>
<td></td>
<td></td>
<td>X</td>
<td>4</td>
</tr>
<tr>
<td>Data Collection &amp; Reporting on Workload</td>
<td></td>
<td></td>
<td>X</td>
<td>1</td>
</tr>
<tr>
<td>Technical Assessment of MoH Mammography Units</td>
<td></td>
<td></td>
<td>X</td>
<td>2</td>
</tr>
</tbody>
</table>

- Patient Personal Data: Name, Address, Telephone, National No.
- Date of last Clinical Breast Exam & last Mammogram Exam.
- Information to cover main risk factors:
  - Age, Age of menarche, Age of menopause, Age of 1st child birth.
  - Personal & Family Medical History regarding cancer.
  - Intake of Hormonal Replacement Therapy
- Any Complaints / Symptoms / changes in the breast.
- Mammography result (According to BIRADS system)
- Any extra procedures needed / done.
JBCP is working on policy recommendations for MOH based on results of a feasibility study conducted in September 2008

Feasibility Study Findings

- The investment required to implement screening mammography is small when compared to overall government spending on health and considering the substantial benefits.
- Lower treatment costs and higher survival rates, and significant improvement in the quality and quantity of life would be derived from the early detection and treatment that result from screening mammography.
- The Ministry of Health (MOH) should adopt a policy that supports this program.
- The Impact on MOH budget for mammograms investigations would be relatively minimal (< 1 million JDs per year) assuming that other sources participate in funding screening if the ministry assumes the lead in screening.

KHCC
- Accredited twice (the only oncology-specific)
- Comprehensive protocols and guidelines with process and outcome indicators
- 105 full-time consultants
- Affiliated with 4 international organizations
- All-spectrum services
- Sees approximately 50% of cancer cases
- Training and residency

Ministry of Health
- Education
- Provide non-comprehensive services
- In the process of upgrading
- Varied quality

King Abdullah Hospital & Jordan University
- High quality
- No expansion
- No residency programs for oncology

Royal Medical Services
- Plan for expansion – oncology center
- Quality services

Private Sector
- Increased costs
- Varied quality
Despite the varied quality of treatment, Jordan has been achieving good results comparable to the developed nations.
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As a snapshot of JBCP’s costs, in 2008, the program spent only around 1.5 million USD.

**Cash Expenditure 2008**
- Total = 460,000 JOD
- International orgs: 38%
- MoH: 30%
- Public Sector: 4%
- Private Sector: 2%
- WHO: 2%
- USAID LC: 4%

**In-kind Expenditure 2008**
- Total = 580,000 JOD
- Private Sector: 63%
- MoH: 17%
- WHO: 9%
- KHCC/KHCF: 7%
- PSP: 4%

Jordan Breast Cancer Program
JBCP literally orchestrates the work of all partners and stakeholders towards one goal.
JBCP prides on its participatory approach in its work methodology

**Type of Initiatives**
- Public awareness campaigns
- Outreach to communities through existing groups
- Activation of existing or development of new mammography services
- Development of guidelines, protocols & SOPs
- Accessibility to mobile mammography services

**Role of JBCP**

**JBCP Supported Project**
- Not Involved
- Support
- Lead

**JBCP Sponsored Project**
- Not Involved
- Support
- Lead

**JBCP Owned Project**
- Not Involved
- Support
- Lead
So although two years ago Jordan faired poorly on screening and early detection, today we are at the enhanced level.

<table>
<thead>
<tr>
<th>Level of resources</th>
<th>Public Education and Awareness</th>
<th>Detection Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic</td>
<td>Development of culturally sensitive, linguistically appropriate local education programs for target populations to teach value of early detection, breast cancer risk factors and breast health awareness (education + self-examination)</td>
<td>Clinical history and CBE</td>
</tr>
<tr>
<td>Limited</td>
<td>Culturally and linguistically appropriate targeted outreach/education encouraging CBE for age groups at higher risk administered at district/provincial level using healthcare providers in the field</td>
<td>Diagnostic breast US +/- diagnostic mammography in women with positive CBE. Mammographic screening of target group*</td>
</tr>
<tr>
<td>Enhanced</td>
<td>Regional awareness programs regarding breast health linked to general health and women’s health programs</td>
<td>Mammographic screening every 2 years in women ages 50-69*. Consider mammographic screening every 12-18 months in women ages 40-49*</td>
</tr>
<tr>
<td>Maximal</td>
<td>National awareness campaigns regarding breast health using media</td>
<td>Consider annual mammographic screening in women ages 40 and older. Other imaging technologies as appropriate for high-risk groups†</td>
</tr>
</tbody>
</table>

SOURCE:

Key
Before JBCP
After JBCP
KHCC provides Jordan with 1st class comprehensive services across the whole spectrum.
In less than two year’s experience, preliminary indications from KHCC data already show a shift in staging of the disease.

**Stage III**
- Before JBCP: 56.20%
- After JBCP: 24.20%

**Stage II**
- Before JBCP: 23.70%
- After JBCP: 41.32%

**Stage I**
- Before JBCP: 6.70%
- After JBCP: 8.90%

**Stage IV**
- Before JBCP: 12.90%
- After JBCP: 17.35%

**Stage 0**
- Before JBCP: 0.50%
- After JBCP: 4.79%

3.42% unknown
Pink & the Pink Ribbon are the international symbols for breast cancer awareness across the world. Jordan has chosen the local hatta pattern and turned it to pink in the form of a ribbon to represent the

*National Jordanian Symbol for Breast Cancer Awareness*