Cancer in Global Perspective

Joana D. Ramos, M.S.W.

http://ramoslink.info/
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Personal Motivation for Cancer Activism
Cancer is a Critical Public Health Issue
Cancer Deaths Worldwide

Year 2000:

Cancer killed more than 6.2 million people around the world

Cancer deaths

Cancer knows no borders. It is the second leading cause of death in developed countries and is among the three leading causes of death for adults in developing countries.

12.6% of all deaths are caused by cancer. That’s more than the percentage of deaths caused by HIV/AIDS, tuberculosis, and malaria put together.

Cancer is a public health problem worldwide. It affects all people: the young and old, the rich and poor, men, women, and children.

North America
- 308,000
- 286,500
- 269,000

Southern Europe
- 245,000
- 210,000
- 180,000

Eastern Europe
- 245,000
- 210,000
- 180,000

Northern Europe
- 245,000
- 210,000
- 180,000

South America and the Caribbean
- 236,200
- 236,200
- 236,200

North-Western Europe
- 236,200
- 236,200
- 236,200

Sub-Saharan Africa
- 316,300
- 455,000
- 615,000

Latin America
- 455,000
- 555,000
- 655,000

South-Eastern Asia
- 324,000
- 394,000
- 494,000

Western Europe
- 394,000
- 494,000
- 594,000

Southern Africa and Western Asia
- 394,000
- 494,000
- 594,000

Europe
- 494,000
- 594,000
- 694,000

Asia
- 494,000
- 594,000
- 694,000

Percentage of deaths due to cancer in 2000

- <5%
- 5-10%
- 10-15%
- 15-20%
- 20-25%
- >25%

Global Action Against Cancer, © WHO/UICC 2003
Future Cancer Crisis?

By 2020, cancer could kill

Trends
The biggest rates of increase are in developing and newly industrialized countries.

The relative increase is smallest in some Western countries where populations are rejecting tobacco and adopting healthier lifestyles.

10 million people per year unless we act

Percentage increase in cancer deaths since 2000

0-25% 25-50% 50-75% 75-100%

Global 2000 BMC
Causes of Cancer

43% of cancer deaths are due to tobacco, diet and infection.

Sub-Saharan Africa
Total: 37%

Europe (Northern, Southern and Western)
Total: 49%

From a global perspective, there is strong justification for focusing cancer prevention activities on these three main cancer-causing factors.
Huge Global Disparities in Two Types of Cancer

- Cervical Cancer
- Childhood leukemia
- Success stories in developed world, killers in developing world
Childhood ALL

- In developed world, 70% of children are now cured
- In developing world, at least 80% of children die, most without treatment
Cancer Awareness Campaign in South Africa

**SAINT SILUAN**

**WARNING SIGNS FOR CANCER IN CHILDREN**

- **S:** Seek: Medical help early for persistent symptoms
- **E:** Eye: White spot in the eye, new squint, blindness, bulging eyeball
- **L:** Lump: Abdomen and pelvis, head and neck, limba, testes, glands
- **U:** Unexplained: Fever, loss of weight and appetite, pallor, fatigue, easy bruising or bleeding
- **A:** Aching: Bones, joints, back, and easy fractures
- **N:** Neurological signs: Change in behaviour, balance, gait, and milestones, headache, enlarging head

*Saint Siluan was a Russian monk who died on Mount Athos in 1906. He prayed ceaselessly for all humanity.*

This list has been compiled by the South African Children’s Cancer Study Group

Children’s Cancer Help Line: toll-free 0800-333-555 (weekdays 08h00 - 16h00)
Cervical Cancer

- 80% of cases in Latin America, sub-Saharan Africa, South Asia, parts of Oceania & Asia
- Almost 290,000 annual deaths
- HPV + system & cultural barriers
- Prevention possible - public health investment needed
- Condom use could prevent cervical cancer + HIV
Confronting Cervical Cancer

- Without detection & early treatment, almost always fatal
- HPV infection begins early, cancer develops mostly in women age 35+
- Low-cost screening methods now developed, vaccine in progress
- Alliance for Cervical Cancer Prevention
Focus on Selected Issues

- Access to treatment
- Clinical trials
- Bioethics
Treatment Must Include

- Screening & diagnosis
- Medical treatment
- Practical & supportive care for patient & family
- Pain control & palliation
Treatment Depends on Access to Medicines

- Need for affordable medicines critical
- Cancer care means drugs to treat disease and effects of therapy
- Need to understand role of international trade agreements & patent laws
  - WTO & TRIPS & regional & national treaties
  - Doha Declaration
Who owns my polio vaccine? The people! Could you patent the sun?

Jonas Salk
Drug Prices

- Pharma claims on drug pricing to support R&D unfounded
  - Recent research shows more spent on marketing
  - NIH R&D = US public pays twice
  - Pricing issues worldwide
- Patients in many countries must purchase own drugs & supplies even if medical care may be available
# Cancer Drug Prices Compared

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Peru</th>
<th>USA</th>
<th>MSH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tamoxifen*</td>
<td>$49.20</td>
<td>$37.99</td>
<td>$1.55</td>
</tr>
<tr>
<td>Prednisone*</td>
<td>$9.66</td>
<td>$2.70</td>
<td>$1.50</td>
</tr>
<tr>
<td>Methotrexate*</td>
<td>$156.66</td>
<td>$32.99</td>
<td>$2.67</td>
</tr>
<tr>
<td>Doxorubicin</td>
<td>$13,038.60</td>
<td>$272.09</td>
<td>$20.00</td>
</tr>
<tr>
<td>Cytarabine</td>
<td>$2,862.34</td>
<td>$45.30</td>
<td>$4.06</td>
</tr>
<tr>
<td>Heparin</td>
<td>$833.00</td>
<td>$8.39</td>
<td>$0.75</td>
</tr>
<tr>
<td>Vincristine</td>
<td>$2,986.66</td>
<td>$23.45</td>
<td>$1.58</td>
</tr>
</tbody>
</table>

Peru: prices paid by MINSA (Ministerio de Salud) FY 2003  
USA: average retail price 2004-5  
MSH (Management Sciences for Health) - supplier listing for non-profit sector  
*price for 30 tablets
New Drug Case Example: Glivec

- Unique cancer therapy-unique global price
- Novartis promised no pt. would be denied access for financial reasons
- Cultivated pt. support via PR campaigns
- Access reality quite different
Global Price of Glivec

- $30,000 USD/yr. for average dose of 400mg/day
- Price per country varies somewhat
- Some pts. need 600 or 800mg daily
- Controls disease, does not cure
- Must take indefinitely
South Korea

- Leukemia patients protest price of Glivec
- Korean Federation of Activists Fighting for Health Rights arrested at Novartis Korea HQ, February 2003
Glivec Donation Program

- GIPAP offers free medicine IF:
  - Pt. “properly diagnosed”
  - Not reimbursed or insured
  - No generics in-country
  - Pt. meets per-country income & tx criteria
GIPAP Inequities

- Diagnostics often unavailable
- Argentina vs. Brazil criteria example
- Prior tx requirement
- Income to qualify:
  - in US, <$43,000/yr.
  - in China, <$250/yr. (lowest 10% bracket)
- Application process web-based, in English
Lessons From GIPAP

- Drug donation programs not the answer
- Complex & costly overhead
- Discourages local solutions
- Sustainability in question
- Pending EMR case in India
WHO Model List of Essential Medicines

- Excludes drugs for cancer therapy from priority list
- Oncology drugs now only on complimentary list
- Price is factor in selecting essential drugs
- 2004 Letter of request from pediatric cancer specialists: Ponte di Legno & SIOP
Perspective on WHO Role Re: Drug Access

- Challenge of PPP influences?
- World Cancer Report (2003) seems apologist on pharma pricing
- IARC now transparent & pro-active re: cancer causes?
- WHO 2004 Resolution on cancer prevention & control
Pharma Influences

- Awareness: relation to price of drugs
- Physicians & other health professionals
- Patient groups
- Ethical dilemmas
DTCA Situation & Challenge

- Allowed only in US & NZ
- Biopharmas try to bypass bans
- Role of the Internet & e-media
- Learn their strategies
Clinical Trials

- Outsourced to developing countries to lower costs & possibly reduce oversight
- “tx naïve” patients being recruited
- Need for protections
- Complaints have surfaced re: recent cancer trials in Argentina, India & other countries
Global Clinical Trials

- Clinical trials have become a worldwide business
  - Example: CenterWatch
Trial Sites Extend to these Areas

- Central & South America
- Eastern Europe
- Africa
- Asia
Declaration of Helsinki

- World Medical Association decree of 1964
- Paragraph 30 upholds right of research subjects to receive continuing health care
- WMA currently upholding & reviewing Paragraph 30
Bioethics

Why do we need to be concerned?
Little-known Saga of Abbott’s Urokinase

- Blood clot-buster for cardio, lung, & cancer tx
- FDA recall in 1999 re: manufacturing practices dangers and infection risks
- Collected from kidneys of deceased neonates at one hospital in Cali, Colombia
- Questions on informed consent of mothers
Stem Cells are Big Business

Value of Cell-based Therapies Market Estimated to Reach $26.6 billion in 2005, with Largest Expansion in Diseases of Central Nervous System and Cancer

Source: Research & Markets Feb. 2005
http://www.researchandmarkets.com/reports/c10806/
Umbilical Cord Blood Stem Cells

- Hope or hype?
- Potential of CBSCT for unrelated BMTs
- Public vs. private cord blood banking
- Potential for exploitation
Cord Blood Banking in Peru?

- Expectant parents of child with leukemia request advice
- 3 cord blood “banks” in Lima
- Reality: not CB banks, but branch offices of foreign firms
- Unrelated BMTs not done in Peru, related BMTs quite rare
- So why presence of CB industry?
Ad for Private Cord Blood Banking Company

- Baby Cord – Banco de Cordón Umbilical de Chile
- Hay decisiones que se pueden tomar una sola vez en la vida. La Conservación del cordón umbilical implica una "esperanza de vida" para su hijo.
- http://www.babycord.cl/
CB Banking Consumer Concerns

- Need for objective, accurate information
- Position of medical societies
- Who protects mothers, babies, and recipients?
- Politics & profits
- Control of CB program for USA presently being contested
Work in Progress

- UNESCO Declaration on Universal Norms on Bioethics–International Bioethics Committee & Intergovernmental Bioethics Committee
- World Marrow Donor Association Working Group on Ethics
- National Bioethics entities
- UN Interagency Committee on Bioethics
US Cancer Issues Are Global Issues Too

- Cancer disparities are a social justice issue
- Everywhere in the world, cancer disparities mean more suffering & more deaths
- In the USA resources exist; will to make them available is needed!
Cancer Health Disparities

“The unequal burden of disease in our society is not just a scientific and medical challenge. It also represents a moral and ethical dilemma for our Nation”

Scope of the Problem

- 1 in 3 non-elderly uninsured = 82 million
- 33% of adults & 36% of children uninsured
- Worse cancer outcomes due to late diagnosis
- Sociodemographic inequalities persist
- Pts. in rural & remote areas fare worst
Examples of Disparities

- Prostate cancer 60% higher among African-American men than among whites
- Cervical cancer among Latinas & Vietnamese-Am. women 2X rate among Anglos
- Native Americans have poorest survival rate from all cancers than any other group in USA
- National Breast & Cervical Cancer Health Program only serves 15-18% of eligible women
- Uninsured & Medicaid pts. cannot get urgent dental care mandatory to receive cancer tx
Medicaid Patchwork

- 51 different programs
Care Delayed or Denied for Some Cancer Pts. In the USA

- Uninsured & those with Medicaid coverage often face long delays if not denials
- Denials for pts. waiting for public benefits
- Denials for children & adults with undocumented immigration status
- Noncitizens may be wrongly denied coverage by Alien Emergency Medicaid Program (AEMP)
AEMP & Cancer in WA

- Provisions often misunderstood—not just for undocumented.
- Care must be provided for conditions or diseases that threaten life.
- Includes tx that will prevent the state of emergency from recurring.
- Cancers requiring therapy by surgery, radiation, and/or chemotherapy may be included.
International Patients Often Seek Cancer Care in USA

- Today’s information age means more global awareness of tx possibilities
- So more pts. & families seek care
- Access impossible for most, even among transnational families
- US entities need to help create local solutions
Meeting the Challenge

- Current piecemeal efforts inadequate
- Public & private sectors need to move beyond identifying problems: plan + action
- Genuine efforts need to be made to offer culturally & linguistically appropriate services
- Go beyond fragmented & divisive cancer site/disease specific focus
Actors In International Cancer Control

- WHO World Health Organization
- International Agency for Research on Cancer
- UICC International Union Against Cancer
- National Institutes of Health-USA
- International Network for Cancer Treatment and Research
- World Cancer Research Fund International
Some US Cancer Venues with Global Focus

- National Cancer Institute
  - Office of International Affairs
- NIH Fogarty International Center
- St. Jude CRH International Outreach Program
- Action on Smoking & Health
Who’s Who In Pediatric Oncology

- SIOP International Society of Pediatric Oncology
- ICCCPO International Confederation of Childhood Cancer Parent Organizations
- St. Jude Children’s Research Hospital
- NCI Ped-Onc Branch
Role of Agencies & NGOs

- Worldwide, most conduct or support research
- Mostly awareness activities, not pt. care or support
- Historical “Cancer Establishment”
- Corporate model of charities
- Reliance on industry support can impact agendas
Power of the Internet

- Computers & the internet serve as tools to help patients worldwide get disease & treatment information, and work for better care.

Photo from: asiaone.com
Internet as Community Organization Tool

- Case study: global access to Glivec
- Community members contacted Internet users, who translated messages & sought help
- Patient & caregiver e-networks already in place served as conduits
- Patients in wealthy countries had tracked Glivec development, got help; some worked for equity
Reality Check re: Internet

- Recognize it as tool, not answer
- Digital Divide persists
- Genuine personal global linkages promote transparency & local solutions
- Beware illusions of action
Solving the Cancer Crisis

- Micro- & macro-level changes needed
- Create progressive cancer advocacy constituency
- Integrate cancer control into health promotion
- Build prevention focus = dividends on multiple fronts
Fresh Approaches to Education and Training Needed

- Understand sponsorship risks
- Break dependence on pharma resources
- CO techniques & training skills
- Lessons from the past
Grassroots Action Examples

- In WA, activists got cancer restored as covered under AEMP, March, 2004
- European peds cancer groups “twin” with developing countries, e.g. Italy-Nicaragua
- JD Ramos
  - drug price work in Peru & Philippines
  - contribute content to Spanish childhood cancer website
  - end-of-life care planning in Brazil
  - provide English translations for articles & web sites
  - member of patient & professional discussion lists
Work in Progress

- **5/03** - Framework Convention on Tobacco Control adopted at WHA, ratified, to take effect 27 Feb. 2005
- **9/04** - Declaration by SIOP on right of all children to cancer treatment
- **12/04** - Canada-Chile Glivec compulsory license case, facilitated by Essential Inventions
- **1/05** - Pres. Vicente Fox declares that all Mexican children with cancer will have right to treatment at no cost
- **5/05** - Cancer will be on WHA agenda for 1st time
Get Involved

- Health workers, individually & in groups, can
  - play an important role in cancer policy & practice
  - build global collaborations & training opportunities
  - promote culturally & linguistically appropriate services
  - participate in international cancer programs
The good we secure for ourselves is precarious and uncertain until it is secured for all of us and incorporated into our common life.

Jane Addams