Cancer Survivorship in India

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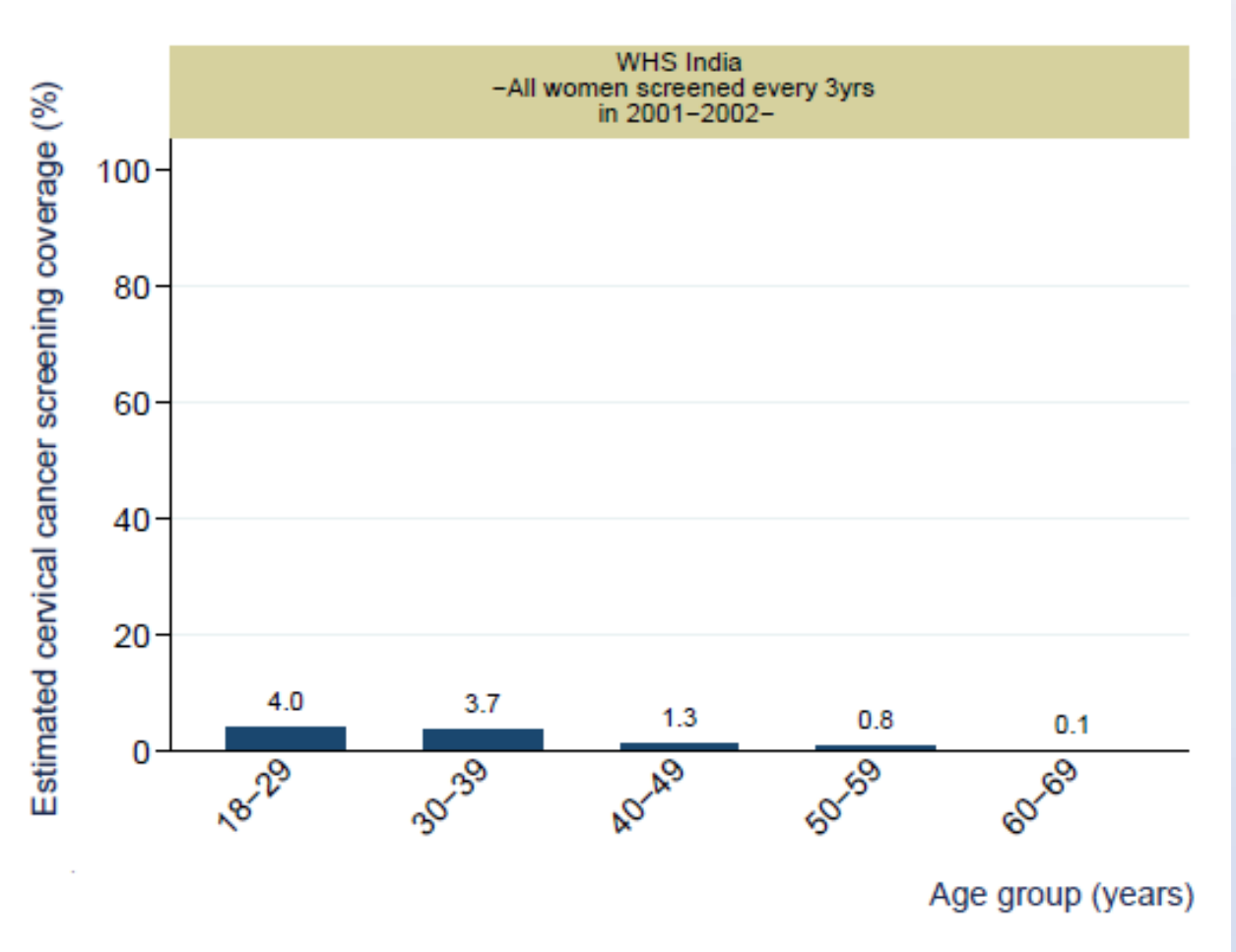
Women's Cancers in India

	India	Mexico	USA
Risk of cervical cancer, 2010	1 in 53	1 in 36	1 in 116
Cases	79,159	12,940	16,486
Risk of breast cancer, 2010	1 in 30	1 in 22	1 in 8
Cases	143,000	20,912	241,249
Ca Cx Mortality to incidence ratio, 2010	27 to 100	21 to 100	13 to 100
BC Mortality to incidence ratio, 2010	32 to 100	40 to 100	24 to 100

Source: IHME. The Challenge Ahead: Progress and Setbacks in Breast and Cervical Cancer.

Few Women Get Screened for Ca Cx in India.



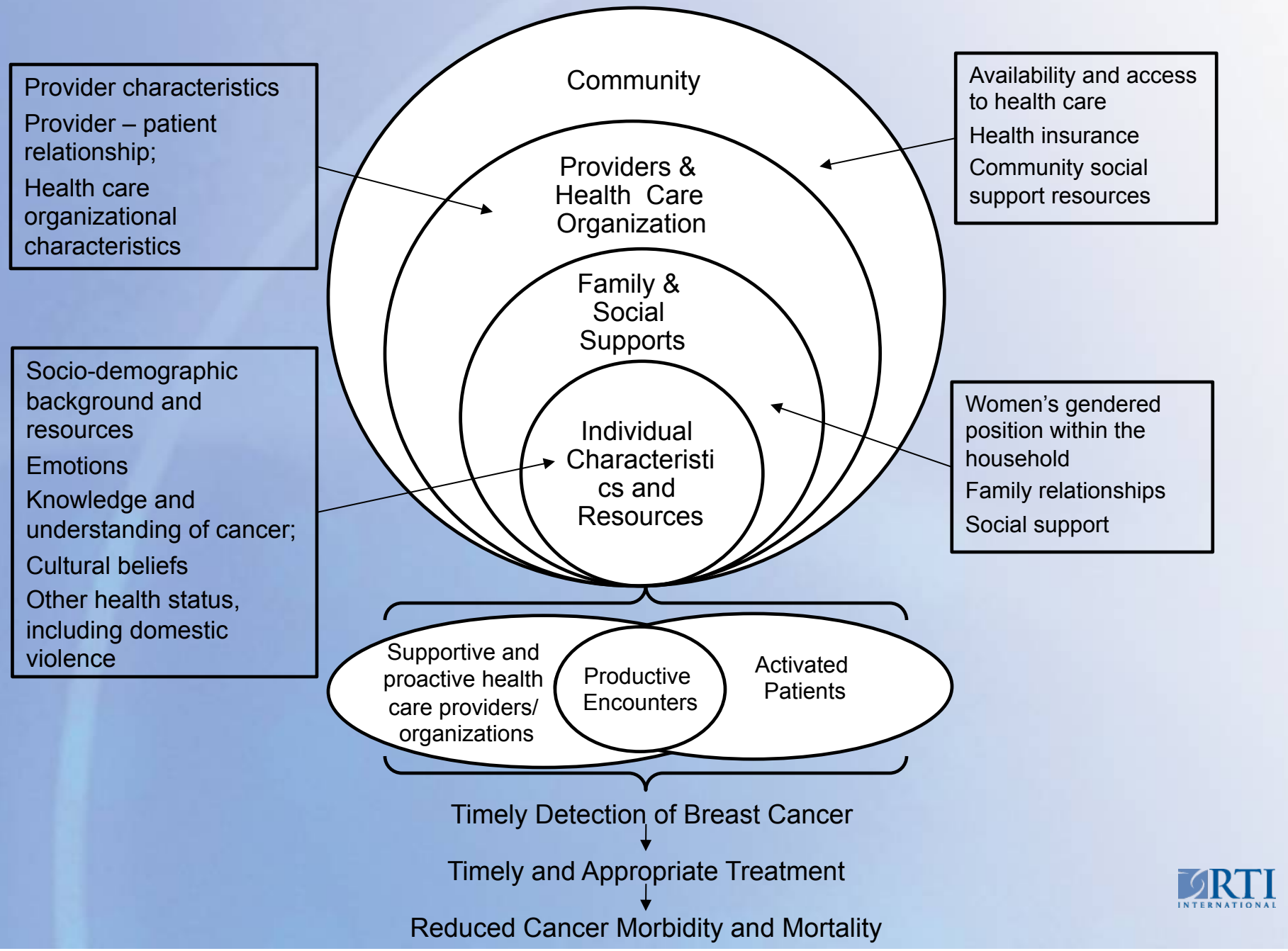
WHO/ICO Information Centre on HPV and Cervical Cancer (HPV Information Centre). Human Papillomavirus and Related Cancers in India. Summary Report 2010. [26 August 2012] Avaliable at www.who.int/hpvcentre

Survivorship in Context

- Majority of women's cancers are diagnosed at advanced stages.
  - 70% of ca cx are diagnosed at advanced stages.
  - <30% of women diagnosed with Stage III ca cx survive first 5 years post-diagnosis.
  - Survival is as low as 6% among women with stage IV ca cx.
- Only about half of Indian women with breast cancer survive the first 5 years post-diagnosis, compared to 90% of women in the United States.

Using a Social Ecological Framework to Understand the Cancer Care Continuum

- Hypothesize that factors at the level of the individual, family, provider/health care organization, and community will facilitate or impede cancer diagnosis, treatment and survivorship.


Provider characteristics
Provider – patient relationship;
Health care organizational characteristics
Socio-demographic background and resources
Emotions
Knowledge and understanding of cancer;
Cultural beliefs
Other health status, including domestic violence
Community
Providers & Health Care Organization
Family & Social Supports
Individual Characteristics and Resources
Availability and access to health care
Health insurance
Community social support resources
Women's gendered position within the household
Family relationships
Social support
Supportive and proactive health care providers/ organizations
Productive Encounters
Activated Patients
Timely Detection of Breast Cancer
Timely and Appropriate Treatment
Reduced Cancer Morbidity and Mortality

Evidence suggests that cervical cancer diagnosis and disease prognosis are shaped by individual, household, community and health systems factors.

Majority of CIN2+ cases are likely to be missed due to "program failures."

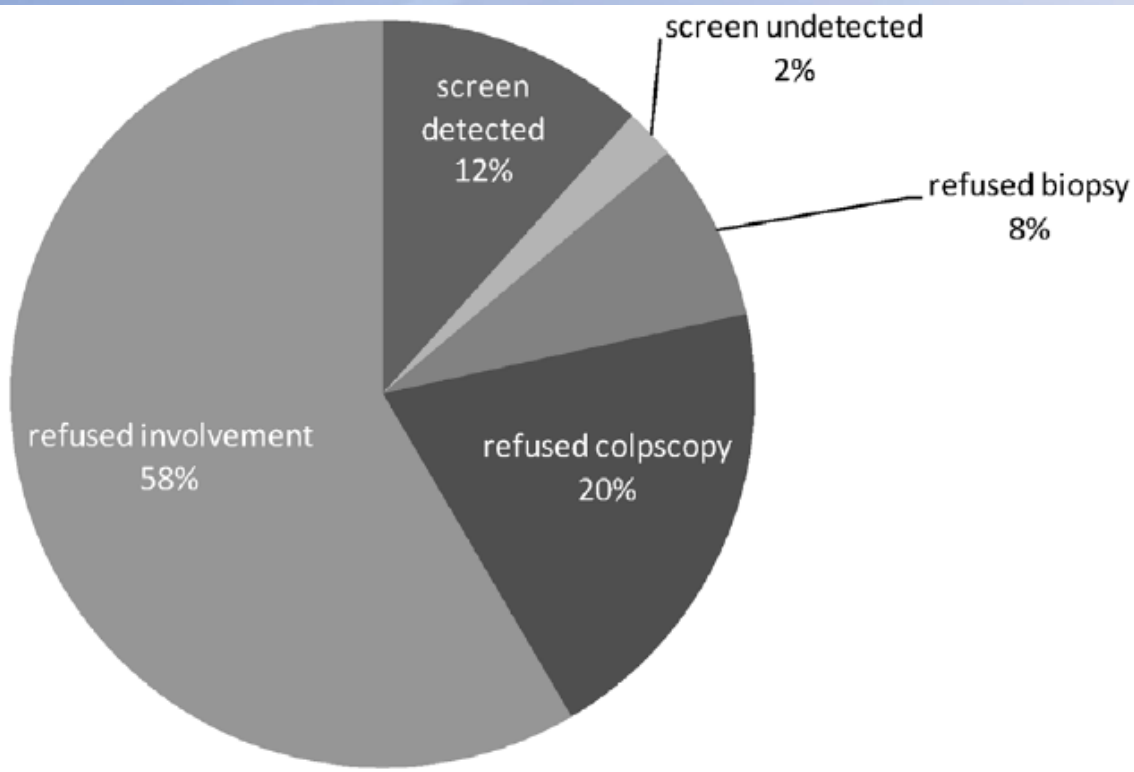


Figure 2. Estimated proportion of cases of CIN2+ observed and estimated via population weighting for verification bias adjustment. *Screen detected* indicates proportion of cases of CIN2+ detected by hc2, and *screen undetected* indicates the proportion of CIN2+ cases detected through the screening program, but missed by hc2. *Refused biopsy* indicates the proportion of CIN2+ cases estimated among those who refused biopsy, *refused colposcopy* indicates the proportion of CIN2+ cases estimated among those who screened positive, but refused colposcopic exam, and *refused involvement* indicates the proportion of CIN2+ cases estimated among those who refused participation in the program (i.e., not screened).
doi:10.1371/journal.pone.0013711.g002

Source: Gravitt et al. 2010. Plos One

Lack of participation is a key barrier to screening & detection

- Nearly 3 in 5 women invited to participate in a ca cx screening study in AP refused screening.
- Among those who screened positive and were advised colposcopy,
  - 27% refused when offered immediate colposcopy (along with screening)
  - 44% refused to return for colposcopy

Source: Gravitt PE, Paul P, Katki HA, Vendantham H, Ramakrishna G, et al. (2010) Effectiveness of VIA, Pap, and HPV DNA Testing in a Cervical Cancer Screening Program in a Peri-Urban Community in Andhra Pradesh, India. PLoS ONE 5(10): e13711. doi:10.1371/journal.pone.0013711

Discomfort and fear of screening procedures are reasons for refusals.

- Specific reasons reported by women include:
  - No reason to be screened (asymptomatic)
  - Fear of the test; misconceptions about screening process
  - Adverse effects of test reported by neighbor/relative
  - Feeling shy to have the exam
  - Fear of community gossip and speculation
  - Fear of cancer diagnosis
  - Lack of familial support
  - Poor quality of public care

Krishnan et al. 2013. The Oncologist. In press.

There is a dearth of evidence on breast cancer survivorship issues.

Qualitative interviews with women diagnosed with breast cancer, family members, and health care service providers, are being conducted to explore:

- Women's knowledge and emotions associated with cancer diagnosis, treatment, and survivorship
- Cultural beliefs about illness and survival
- Role of socioeconomic and gender–related factors in shaping treatment outcomes and survivorship
- Steps and activities involved in each type of care (detection, diagnosis, treatment, survivorship) as well as the transitions from one type of care to the next.

Emerging survivorship challenges include:

- Fear and denial.
- Limited social and economic resources for care provision
- Limited information regarding survivorship: psychological and social issues, risk of recurrence, etc.
- Lack of systems to support communication and coordination across levels of care.
- Inadequate knowledge of survivorship care among primary care providers.
- Inadequate communication regarding course of treatment: providers unprepared for disclosure.
- Overburdened tertiary care centers; limited access to palliative care.

Scale up of HIV/AIDS care and support services in India provide key insights for provision of cancer care.

- External advocacy, civil society-led demands
- Investments in health facilities – human resources, infrastructure, linkages across levels
- Extensive community outreach and support – community link workers, NGOs, CBOs, health system
- Affordable screening and diagnostic technologies and treatments
- Financial protection

Promoting Survivorship in India