Patient Navigation for Early Detection in Fragile or Fragmented Health Systems

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The problem and lessons
Discrepancies in HDI variation and Cancer Care outcomes

- Overall worldwide 5-10% ↑ cancer survival
- Highest survival are in high HDI regions
  - North America
  - Australasia/Oceania
  - Nordic countries
- Key drivers
  - Cancer registries
  - Cancer control plans
  - Political Will
  - Research
  - Strong Health systems
  - Dedicated Funds
  - Respect for Human rights
  - Accountability
- Many LIC/LMIC fall within low and medium HDI
- Difference in cancer outcomes between HDI regions other than paucity of the listed key drivers to success include (Schliemann 2018)
  - Competing health interest
  - Religious/Ethnic influence on health practices
  - High illiteracy rate – traditional beliefs
    - ↓ uptake of knowledge
    - mistrust of health system
- 15% ↓ breast survival between eastern and northern Europe (Eniu 2018)
- 50-75% of women in SSA present with LABC (Ginsburg 2018, Sutter 2017)
- Breast cancer OS 50% in SSA, 61% in India, > 85-90% in HIC (Ginsburg 2017)
- 20% ↓ in colorectal cancer survival - HIC, UMIC & LMIC
- Cervical cancer survival ↑ 10-20% in many UM& LMIC

(ALLEMANI 2018)
Evidence based recommendations for reducing impact of cancer

30-40% Preventable through risk reduction
- Tobacco
- Alcohol
- Diet
- Obesity
- Physical inactivity
- Pollution
- Infections

30% Curable if diagnosed at early stages
- Breast
- Cervix
- Colorectal
- Prostate
- Oral cancer
- Childhood

15-20% Treatable
- Locally advanced cancers
- Other cancers

Mass education through improved knowledge, ensuring community engagement and integration to ensure effectiveness

Enable increased case detection and management by improving knowledge and access to care at all referral levels

Capital intensive and success depends on health system infrastructure. Includes supportive and palliative care interventions
Translating knowledge into action

- Approx. 60% reduction in incidence/mortality.
- Dependent on societal behavioral change, which are in turn influenced by geographic, economic, sociocultural factors, ethnical and religious norms.
- Drivers - legislation, communication, incentive.
- NCD” best buys’ - obesity, cervix / breast VIA& vaccination and screening (CBE/SBE) respectively, alcohol, smoking, obesity control.

Achievable at ALL levels of Health system using existing structures and In relation to country specific context at low cost starting at community level.

Addressing disparities in high HDI regions

• In spite of the modest increase in early diagnosis/survival of many cancers in high HDI regions, there are shortcomings in health care delivery for ethnic minorities, immigrants, religious groups and other deprived societies. (Paskett 2011, Freeman 2006)

• Many in deprived communities carried over controversial, negative and heavily cultural dependent health seeking behaviors from country of origin or indigenous descent (Jones 2015)

• The social determinants of care are the rate limiting factors to effective implementation of early cancer detection programs (Smith 2018)

• Without comprehensively addressing social determinants of disease outcomes, disparities will prevail even in robust health systems (Askoy 2014, Rikard 2016)
Addressing disparities in high HDI regions II

- Community level interventions to address concerns associated with poor cancer outcomes in deprived populations is likely to tackle stigma, misconceptions, prevention, early detection, access to timely intervention is likely result in downstaging of cancer at presentation and improved outcomes. (Weber 2012, Braun 2012, Bensink 2014, Chowdry 2017)

- Patient navigation was introduced in the US in the 90:s to reduce breast cancer mortality in African-Americans living in Harlem N.Y. by Freeman (Freeman 1995)

- Reported improved cancer compliance, a 50% reduction in late presentation and mortality (Freeman 2005).

- This concept has been replicated in reproductive health / HIV, (Braun 2013, Jennings 2013) diabetes, renal dialysis, (Zeh 2012), cervical and colorectal cancer, (DeGroff 2017) cardiovascular disease (Spiro 2012)

  with improved outcomes in deprived populations within North America, UK, Australia (Shomu 2016, Carter 2018)
Typical patient journey

Raw and factual details

Simplified guided factual details

https://goo.gl/images/mqskdr
Improving cancer outcomes through patient navigation (PN)

- Navigation involves the intervention and steering of clients by local community member, survivor, volunteer, nurse or social worker who is familiar and associated with community norms through the complex health system.
- Navigators assess, understand, appraise, apply the situation in context of community culture, leading to timely diagnostic resolution by acting as an access entry point into an ambiguous and alien health care system.
- In effect they improve access to care, enhance coordination, galvanize and consolidate necessary actions.
- PN Impact is highest in:
  - uptake of screening services for breast, cervix, colorectal cancer in weak systems
  - positive behavior change
  - follow up of abnormal mammogram
  - short time to disease evaluation
  - decrease default rate
  - short time to treatment
  - increase # with early stage disease

Breast cancer treatment onset delay in Africa

Espina 2017
Making a case for PN in early detection of breast cancer in weak health systems

Factors contributing to poor outcomes amongst breast cancer patients in patient delays

- Advanced disease  - poor uptake of early detection practices
  - use of traditional medicine
  - poor cancer awareness
  - misconception
  - stigma
  - loss of income generation
- Fear of mastectomy  - educational gaps, beliefs, family structure
- Poor patient provider communications
- Lack of social support
- Poor knowledge of available health resources
- Denial

Making a case for patient navigation for early detection of breast cancer in weak systems II

System delays

• Lack of resources for screening and early detection
• Complexity of health system referral pathways
• Lack of patient care guidelines for follow up and recall
• Lack of cancer clinical knowledge and low level of suspicion amongst primary care personnel
• Reduced diagnostic capabilities
• Communication gaps
• Delayed diagnostic results
• Record keeping and scheduling delays

Logistical delays

• Uninsured
• Transport
Planning an early detection module for cancer

**Perform situation analysis of existing cancer services**

- **Early diagnosis capacity limited**
  - Screening absent
  - Provide basic diagnostic tests and treatment
  - Focus on early diagnosis capacity
  - Improve awareness
  - Ensure prompt diagnosis and referral

- **Early diagnosis capacity limited**
  - Unorganized or ineffective screening present
  - Focus on early diagnosis capacity
  - Reduce delays in care
  - Improve coordination between health facilities
  - Consider limiting screening activities to one demonstration project or stopping screening
  - Consider focus on cervical cancer screening depending on burden and resource availability

- **Early diagnosis capacity strong**
  - Unorganized or ineffective screening present
  - Devise programme to strengthen screening services focusing on regions with demonstration projects
  - Focus on meeting criteria for organized screening and high participation rates

*Note: Countries with weak health systems or low resources are likely to have limited early diagnosis capacity and absent or ineffective national screening programmes.*

Guide to cancer early diagnosis, WHO 2017
Planning early detection modules for breast ca in LMIC

- Mammographic Screening involves technical equipment, labor intensive, capital and human resource investments, set up systems for recall, follow-up and quality assurance algorithms.

- Many LMIC have shortage of trained health care personnel to meet needs

- Currently there is a modest survival benefit for mammography and most likely less for large palpable tumors as seen in LMIC

- Many of these countries do not have mammograms, established population or opportunistic screening modules

- CBE is a cost effective alternative as per data from Ghana, Egypt, India and therefore recommended for resource constrained regions. (Ginsburg 2017, Sutter 2016)

- Problem with both is poor follow through especially in LMIC without structured interventions and access to care

- Cancer awareness campaigns, CBE and follow up of abnormal masses can be executed by training of non health care personnel especially in hard to reach regions in an attempt to bridge the gaps (Jaganathan 2017)
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<th>Opportunities</th>
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<td>• CHW are the first point of call in most communities and entry point of health care, chance to downstage cancers</td>
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<td>• Identification with community promotes overcoming negative sociocultural and traditional hurdles</td>
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<td>• Able to triage abnormal breast presentations</td>
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<td>• Bridge communication gaps and literacy barriers</td>
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<td>• Many other factors contributing to delays can be mitigated or navigated to reduce barriers</td>
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<td>• Increased mobile technology enhances activities of health navigation (Malaysia, Bangladesh, Tanzania, Uganda)</td>
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<td>• Research coordinators and data collectors to improve implementation</td>
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<td>• Ability to increase exposure of primary care providers to cancer awareness</td>
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<td>• Provide valuable feedback for NCCP planning or evaluation</td>
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Challenges

• No legislation

• No funding available for remuneration

• Introduce religious, cultural bias

• Act in the capacity of medical personnel

• Burn out in very low resource settings

• Confidentiality issues

• Cost effectiveness

• Sustainability
### Setting up a patient navigation program for early detection

**Navigator Quality of Care Strategies and Objectives**

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<th>Strategy</th>
<th>Objective for specific community of focus</th>
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<tr>
<td>Understandable</td>
<td>• To provide education to improve knowledge, attitudes, and practices regarding cancer</td>
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<td>Available</td>
<td>• To map out the location of and identify contact individuals for cancer services and to advocate for services to fill service gaps</td>
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<tr>
<td>Accessible</td>
<td>• To remove structural and cultural barriers to services, assuring that what is available can be accessed</td>
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<tr>
<td>Affordable</td>
<td>• To assure that individuals are enrolled in insurance, free, and low-cost programs for which they are eligible so that cost is not a barrier</td>
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<tr>
<td>Appropriate</td>
<td>• To establish culturally competent services and staff at facilities and programs utilized by community members</td>
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<tr>
<td>Accountable</td>
<td>• To assure the sustainability, quality, cultural appropriateness, and responsiveness of the cancer services to and for the population(s) of focus</td>
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Braun Kl 2012
Setting up a patient navigator program for early detection

- Feasibility study and situational analysis
  health system strengths
  scan environment for cultural, ethnic, social peculiarities
  ability to integrate community care with existing health system
  integration of stakeholders
  develop criteria for engagement
  develop multidisciplinary training manual
  technical support and platform for mobile technology
  documentation or e-forms development

- Pilot
  Training
  resolve operational issues
  identify and resolve barriers to implementation
  validate algorithm

Monitoring and evaluation of PN program for early detection of cancer

- Patient / provider surveys at predetermined intervals (at least 100 per cancer site)

- Realistic targets based on geographical, socioeconomic and cultural community/country context

- Structure indicators i.e. logistics

- Important Process indicators
  - > 80% of community aware of signs and symptoms
  - < 1 month delay between detection and diagnosis
  - > 80% with curable disease
  - < 1 month delay between diagnosis and treatment

- Important outcome indicator
  - > 70% presenting early disease

Summary

• Investing in early detection is the most pragmatic and cost-effective means of cancer control with maximum return in investments, however the benefits may be unachievable in weak health systems without application of resource stratified approaches.

• Many countries within the low to middle human development index regions have common barriers to early detection of cancer and could learn from HIC using simple and low technology interventions such as patient navigation programs in deprived communities.

• In fragmented or dis-coordinated health systems, patient navigation integrates and enables various aspects of care interventions to promote a smooth, patient, friendly, culturally sensitive and timely journey through an otherwise complex and matrix required to improve cancer care outcomes most importantly at the beginning of the cancer care continuum.
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