Addressing outcome disparities – opportunities for Australian cancer nurses to make a difference

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CEO – Cancer Council Australia
President elect - UICC
Overview

• Outline global cancer burden
• Consider the question of equity in Australia
• Examine inequity in cancer outcomes from a population perspective
• Consider how a population perspective could shift our focus
• Explore some ways nurses might make a contribution
We have significant global equity issues in cancer outcomes
The global cancer burden

Currently, 8.2 million people die from cancer worldwide. Over 60% of deaths are in low- and middle-income countries.

- 30% preventable
- 30% curable with ED & treatment
The global cancer burden

Over the next 10 years, low- and middle-income countries will see a disproportionate increase in cancer deaths.
Global inequities in cancer outcomes

In 2015, the CONCORD-2 study provided data on five-year cancer survival trends and inequalities worldwide.

Five-year net survival for women diagnosed with breast cancer 2005-2009 varied from 50% in South Africa to 85% or higher in 17 high-income countries.

Five-year net survival for children diagnosed with acute lymphoblastic leukemia 2005-2009 varied from less than 50% to over 90%.
The case of childhood cancer

Even worse in Africa where < 20% of children survive!

Survival from childhood cancer varies internationally.
Five-year survival in children for select cancers diagnosed in select regions

- **Leukemia**
  - Australia, 1997-2006: 80.6%
  - China, Shanghai, 2002-2005: 52.2%
  - Thailand, 2003-2005: 57.4%
  - India, Chennai, 2002-2005: 36.3%

- **Neuroblastoma**

- **All Cancers**
  - 1997-2006: 79.6%
  - 2002-2005: 55.7%
  - 2003-2004: 54.9%
  - 1990-2001: 40.0%

THE CANCER ATLAS

CANCER.ORG/CANCERATLAS
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Cancer Is a Global Equity Issue

Over half of all new cases of cancer occur in LMICs

2/3\textsuperscript{rd} of all cancer deaths occur in LMICs
• Even in breast cancer 68\% of deaths are in LMICs

Tobacco accounts for 30\% of cancer deaths
• 80\% of smokers are from LMICs and rising

Cancer kills more people in LMICs than malaria, HIV and TB combined
Cancer Is a Global Equity Issue

Only 5% of global cancer spending is in LMICs despite having 80% of the global burden

Cancer drugs remain expensive in LMICs despite 26-29 key agents being off patent

• Lessons from HIV

150 countries have little or no access to morphine

• UICC GAPRI program
• McCabe Centre for Cancer & the Law
Much of the problem is to do with social determinants of health

The social determinants of health are the conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries.
While the earnings of a minority are growing exponentially, so too is the gap separating the majority from the prosperity enjoyed by the happy few …This imbalance is the result of ideologies that defend the absolute autonomy of the marketplace and financial speculation.

Pope Francis - 2013
This inequality is not just a problem for low and middle income countries.
The Problem of Inequity

- The Inverse Care Law – Julian Tudor Hart 1971

“The availability of good medical care tends to vary inversely with the need for it in the population served”
Equality

The degree to which all persons are treated as indistinguishable, thus treating them identically or granting them the same quantity of a good per capita.

Equity

How fairly and socially just resources are distributed throughout the population.

‘Equal resources for equal need’
We need solutions that increase equity

Equity: Improving Outcomes for All
But Australia is the lucky country”

We have Medicare – patients can access free health care!

Cancer outcomes in Australia are amongst the best in the world!
Appointment of Dr Meg O'Brien to work out of Washington

Policy work relating in to Commission on Narcotic Drugs meeting Vienna, March

Landmark resolution on access to opioid analgesics

ASCO presentation (June 2010)

Task Force meeting (June 2010)
Socio-economic disadvantage and cancer

- Socio-economic disadvantage
  - Incidence
  - Survival
  - Appropriate treatment
  - Advanced stage at diagnosis

- woods et al. ann oncol, 2006.
- abdoli et al. plos one, 2014.

tervonen, 2015
Our cancer system is not equitable in terms of outcomes

- Despite our best intentions getting timely, best cancer treatment is a lottery
- You are less likely to survive cancer if:
  - You are Aboriginal
  - You are poor
  - You live in outer suburban or rural and remote areas
  - You are unlucky enough to get the wrong referral
- Everywhere we look there are variations in outcomes

Trevonen 2015
Bone 2014
What is patient-centred care?

“...an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. Patient- and family-centred care applies to patients of all ages, and it may be practiced in any health setting”

ACSQHC Discussion Paper 2010
Dimensions of Patient-Centred Care

- Respect for patients’ preferences and values
- Emotional support
- Physical comfort
- Information, communication and education
- Continuity and transition
- Coordination of care
- Involvement of family & friends
- Access to care

ACSQHC Discussion Paper 2010
Overarching Focus

• Improve the patient and family’s experience of their interactions within the health care system.

• Laudable & Appropriate
• Individualistic
• Insufficient
  • No focus on outcomes
  • Misses the focus on systems
The Positives of Individual Thinking

• Better patient-professional relationships
  – Communication
  – Information provision
  – Patient and family support

• Improved care planning

• Focus on individual care coordination

• Improved patient experiences of care
  – UK Cancer Patient Survey shows CNC identified in care pathway as strongest predictor of positive patient experiences of care
The Down Side of Individual Thinking

- Positive patient experiences may mask poor treatment and care
- Focus on processes of care rather than outcomes
- The focus is on the patients you see – not those you don’t
  - The Breast Nurse database experience
We are blinded largely to the factors influencing outcomes that are beyond our view of an individual.
What does a population perspective mean in terms of patient-centred care?

From this perspective every individual would:

• Understand cancer risk factors and receive preventive health care focused on their situation
• Participate in screening and early detection
• Have timely diagnosis
• Access appropriate and best treatment
• Have an equal chance of survival when controlling for stage and other patient/disease factors

Not just those lucky enough to see the right provider!
Defining Access

Levesque et al, 2013
Conceptual Framework

Levesque et al, 2013

Figure 2 A conceptual framework of access to health care. 
• Outcomes for Individuals Need System Solutions for Populations
At a systems level we need to consider equity in:

- Prevention
- Timely diagnosis
- Appropriate treatment
- Supportive Care
- Psycho-social Impact
- Palliative Care
Pre-diagnosis & disparity

- At USA county level, socio-economic disadvantage related to screening resources and colorectal cancer outcomes (Faruque et al 2015)
- International review shows CRC screening related to SES, ethnicity, age and gender (Javanparast et al 2010)
- Racial & Socio-economic disparities in emergency colorectal cancer diagnosis & surgery (Pruitt et al 2014)
- Maori women report significantly more barriers to and delays in access to breast cancer care in NZ (Ellison-Loschmann et al, 2015)
- Medical personnel more likely to receive CRC treatment in higher volume hospitals, lower ER rates and lower mortality in Taipei (Liu et al, 2015)
Localised disease at diagnosis is the most critical factor influencing survival from cancer
### Rural and Regional Areas

- **Stage at presentation** - Odds of presenting with localised cancer by AHS after controlling for all factors

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<thead>
<tr>
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<th>Urban</th>
<th>Rural</th>
<th>odds of localised</th>
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<tbody>
<tr>
<td><strong>All</strong></td>
<td>1.00</td>
<td>0.93</td>
<td>-7%</td>
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<tr>
<td><strong>Breast</strong></td>
<td>1.00</td>
<td>1.03</td>
<td>NS</td>
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<tr>
<td><strong>Prostate</strong></td>
<td>1.00</td>
<td>0.96</td>
<td>-4%</td>
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<tr>
<td><strong>Bowel</strong></td>
<td>1.00</td>
<td>0.98</td>
<td>NS</td>
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<tr>
<td><strong>Lung</strong></td>
<td>1.00</td>
<td>0.77</td>
<td>-23%</td>
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Factors affecting odds of local disease

Rurality ↓ odds by 4-14%
• 4205 fewer cases than expected over 1980-2008

Aged 30-74 yr ↑

Aged >70 ↓

Areas of higher affluence ↑

Born in non-English speaking country ↓

More recent period of diagnosis ↑

Questions

• Whose role is it to advocate for enhanced preventive healthcare? E.g Liver Cancer Prevention

• How do we work more effectively with primary care to ensure cancer, as a diagnosis of exclusion, is adequately managed?

• How do we redesign our intake systems to reduce delay for all?
Getting treatment at the right place: e.g. Rare and Complex Surgery

Moving to greater benchmarking & public transparency
Rare and Complex Cancer Surgery

- First reported a volume-outcome relationship in NSW oesophageal and pancreatic cancer surgery in 2011

- NSW outcomes confirmed the magnitude and direction of this relationship evidenced in very large international analyses
  - p values in NSW difficult as despite seeing significant variation in outcomes at a system level, low volume centres would need 35 years of data to show significant variation.
NSW Hospitals performing these procedures at very low volume

Oesophagectomy for invasive oesophago-gastric cancer

2009, N = 123

2013, N = 126

N = 50

N = 22
Hospitals performing these procedures at very low volume

Pancreatectomy for invasive pancreatic and ampullary cancer

2009, N = 185
2013, N = 216
Who is getting surgery?

There is a two-fold difference across NSW by LHD* (post code of residence) of the percentage of people diagnosed with the cancer having surgery with curative intent

Oesophagus

Pancreas

* This excludes the LHDs with high rates of patient outflows
Percent resected by LHD with curative intent, 2010-2012

- For people with a first admission for cancer between 2010 and 2012:
  - 14-27% for oesophagus
  - 9-24% for pancreas

Northern NSW, Southern NSW and Far West LHDs are excluded.
Questions

• Is there an obligation to publically report cancer outcomes in ways that support patients to access best quality treatment?

• How can nurses use their skills in communication and information provision earlier in the diagnostic pathway?

• What do we know about our own health care choices that could be shared with the public? How?
## Public identification of services

<table>
<thead>
<tr>
<th>Oesophagectomy</th>
<th>Pancreatectomy</th>
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<td>Sydney Adventist Hospital</td>
<td>Royal North Shore Hospital</td>
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<td>St George Private Hospital</td>
<td>Westmead Hospital</td>
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<td>North Shore Private Hospital</td>
<td>Bankstown/Lidcombe Hospital</td>
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<tr>
<td>Concord Hospital</td>
<td>Royal Prince Alfred Hospital</td>
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<td>John Hunter Hospital</td>
<td>North Shore Private Hospital</td>
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<td>Gosford Hospital</td>
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<td>Westmead Hospital</td>
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<td>Nepean Hospital</td>
<td>Sydney Adventist Hospital</td>
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<td>Royal Prince Alfred Hospital</td>
<td>Concord Hospital</td>
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<td>Wagga Wagga Base Hospital</td>
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<td>Liverpool Hospital</td>
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<td>St Vincent's Hospital Darlinghurst</td>
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<td>Prince of Wales Hospital</td>
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<td>Wagga Wagga Base Hospital</td>
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<td>The Tweed Hospital</td>
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**Definition of higher-volume hospitals in NSW**

The Cancer Institute NSW has analysed NSW volume and outcome data and identified that for best outcomes, the minimum volume threshold for NSW hospitals is:

- At least 6 oesophagectomies per year

Or

- At least 6 pancreaticectomies per year

Higher-volume hospitals in NSW are those that meet this suggested minimum threshold. The most recent average annual procedural volume of the higher-volume hospitals are shown.
Empowering patients with information

Pancreatic cancer

**What I need to know**

Treatment of pancreatic cancer can involve complex surgery. It is recommended that you:

- See a specialist who is a member of a multidisciplinary team. You can ask your GP to refer you to one.
- Have your surgery at a recommended hospital.

**What is pancreatic cancer?**

The pancreas is a small organ that helps you digest food. Pan
What does a population perspective bring?

This perspective would help to ensure:

- Better use of administrative information showing system improvement opportunities
- Appropriate use of scarce health resources
- Delivery of treatment and care that enables greatest support for those who need it most
  - Redress the inverse care law
What can nurses do? - Clinicians

- Find the outcome data for the population you serve.
- Keep disadvantage top of mind in practice.
- Talk to the most disadvantaged patients in your care. Understand factors influencing their care experiences.
- Consider specific models of care that address disadvantage.
- Systematise the delivery of essential information to support patient decision making and care.
- Link with liaison staff in areas of specific need.
- Raise awareness about what quality treatment and care looks like. Measure that it happens for all.
What can nurses do? - Educators

- Build social determinants of health into the curriculum
- Partner with schools with expertise in disadvantage
- Ensure a focus on variations in outcomes
- Build disadvantage into frameworks for patient assessment and care planning
- Consider clinical experiences that focus on inequity
What can nurses do? - Researchers

- Include the social determinants of health as variables in your outcome assessment.
- Undertake research that explores disadvantage with a focus on outcomes.
- Examine the representativeness of your study samples using an equity lens.
- Partner with social science and epidemiology researchers with an interest in social disadvantage.
What can nurses do? - Advocacy

- Inform yourself about the relationship between outcomes and the social determinants of health.
- Get involved in conversations about reforming our taxation and health systems.
- Speak up about the rising costs of health care.
- Examine election promises and consider the impact of Government policies – are they likely to aid or worsen the equity gap in wealth and health?
- Vote for better health and welfare in Australia
And when there is a moment

Share what you learn, know and create with others.
Always think as a Global Citizen.
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