Population Perspectives on Patient-Centred Care in Cancer

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Overview

• Consider the meaning of patient-centred care
• Examine inequity in cancer outcomes
• Consider how a population perspective could shift our focus
• Explore some ways nurses might make a contribution
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
THE PEOPLE AFFECTED BY CANCER

IN THE WORLD

IN YOUR COUNTRY

IN YOUR TOWN

IN YOUR HOSPITAL

WHO YOU DIRECTLY CARE FOR
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!
Yet this isn’t what happens!

• Despite our best intentions getting timely, best cancer treatment and care is a lottery:
  • Everywhere we look there are variations in outcomes
  • You are less likely to survive cancer if:
    • As an Australian you are poor, Aboriginal and live in a rural area
    • As a global citizen if you live in a low or middle income country
  • There is post-code variation even in non-rural areas
  • Some evidence of poorer care experiences for those who are non-white, or with chronic illness, learning disabilities or mental health conditions (NHS Pt Experience Survey)

Trevonen 2015
Bone 2014
We have significant global and local equity issues in cancer outcomes
Cancer Facts and Figures

Each year

• 12.7 million people learn they have cancer
• 7.6 million people die from cancer
  • This will rise to 13.1 million by 2030
• 30% of cancers can be avoided through prevention
• 30% can be cured through early detection and treatment
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
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.
5-year relative survival for cancer by integrated services region

North-Eastern - 64 (63,65)
Southern - 62 (61,63)
Loddon-Mallee - 60 (58,62)
Grampians - 59 (57,62)
Hume - 59 (57,62)
Western & Central - 58 (57,60)
Barwon - 58 (56,60)
Gippsland - 57 (55,60)

Victoria - 61% (60,61)

Relative survival by region of residence

Melbourne - 62%
Rest of Victoria - 59%

* Period survival
Socio-economic disadvantage and cancer

Incidence ↓↑

Survival ↓

Socio-economic disadvantage

Appropriate treatment ↓

Advanced stage at diagnosis (↑)


Tervonen, 2015
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
Defining Access

Accessibility of:
- Providers
- Organisations
- Institutions
- Systems

Ability of:
- Populations
- Communities
- Households
- Individuals

Access
(defined as the opportunity to have health care needs fulfilled)

Health care needs
Perception of needs and desire for care
Health care seeking
Health care reaching
Health care utilisation
- Primary access
- Secondary access
Health care consequences
- Economic
- Satisfaction
- Health

Figure 1 A definition of access to health care.

Levesque et al, 2013
Figure 2: A conceptual framework of access to health care.

Levesque et al, 2013
• Outcomes for Individuals Need System Solutions for Populations
“Perhaps the defacto organising principle for (US) healthcare – approaching each patient strictly as an individual – is obsolete”

“Social factors, especially poverty, education, and social networks, are stronger determinants of the health of a population than healthcare”
Artificial Distinction between Research and Practice

Two defining features of research

- Designed to develop generalizable knowledge
- Requires a systematic investigation

Three empirical assumptions that clinical research:

- Presents less net benefit & greater overall risk than practice
- Introduces burdens or risks from activities not otherwise part of the patients clinical management
- Uses protocols to dictate which therapeutic or diagnostic intervention a patient receives

Kass et al 2013
“Requiring only what is classified as research to undergo the burdens and costs of extensive oversight…creates disincentives to rigorous learning, thereby increasing the likelihood that interventions will continue to be introduced into clinical practice and health care systems in the absence of scientific efforts to evaluate their effects”
Traditional separation of research & practice is blurring as “... a model of healthcare emerges in which practice and learning are integrated, where a central goal of the health care system is to collect, aggregate, analyze, and learn from patient-level data, and where clinicians are expected to make evidence-based decisions guided by the general knowledge of structured learning”
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

<table>
<thead>
<tr>
<th></th>
<th>Urban</th>
<th>Rural</th>
<th>Odds of localised</th>
</tr>
</thead>
<tbody>
<tr>
<td>All</td>
<td>1.00</td>
<td>0.93</td>
<td>-7%</td>
</tr>
<tr>
<td>Breast</td>
<td>1.00</td>
<td>1.03</td>
<td>NS</td>
</tr>
<tr>
<td>Prostate</td>
<td>1.00</td>
<td>0.96</td>
<td>-4%</td>
</tr>
<tr>
<td>Bowel</td>
<td>1.00</td>
<td>0.98</td>
<td>NS</td>
</tr>
<tr>
<td>Lung</td>
<td>1.00</td>
<td>0.77</td>
<td>-23%</td>
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</table>
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

Hospital (public and private)
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* (postcode 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

**Higher-volume hospitals** (even if surgery does not seem likely at the time of referral to ensure optimal assessment and care):

<table>
<thead>
<tr>
<th>Oesophagectomy</th>
<th>Pancreatectomy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sydney Adventist Hospital</td>
<td>Royal North Shore Hospital</td>
</tr>
<tr>
<td>St George Private Hospital</td>
<td>Westmead Hospital</td>
</tr>
<tr>
<td>North Shore Private Hospital</td>
<td>Bankstown/Lidcombe Hospital</td>
</tr>
<tr>
<td>Concord Hospital</td>
<td>Royal Prince Alfred Hospital</td>
</tr>
<tr>
<td>John Hunter Hospital</td>
<td>North Shore Private Hospital</td>
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<tr>
<td>Gosford Hospital</td>
<td>John Hunter Hospital</td>
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<tr>
<td>Westmead Hospital</td>
<td>St George Private Hospital</td>
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<tr>
<td>Nepean Hospital</td>
<td>St George Hospital</td>
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<tr>
<td>Royal Prince Alfred Hospital</td>
<td>Liverpool Hospital</td>
</tr>
<tr>
<td>Wagga Wagga Base Hospital</td>
<td>St Vincent’s Hospital Darlinghurst</td>
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<tr>
<td></td>
<td>Prince of Wales Hospital</td>
</tr>
<tr>
<td></td>
<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 pancreatectomies 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 data about the population you serve and examine your own practice?
• Talk to the most disadvantaged patients in your care and understand the 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
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 assessment 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.
- Examine the representativeness of your study samples.
- Partner with social science and epidemiology researchers with an interest in social disadvantage
And when there is a moment

Share what you learn, know and create with others.
Always think as a Global Citizen.
• Liu et al, Outcome disparities between medical personnel and nonmedical personnel patients receiving definitive surgery for colorectal cancer: a nationwide population based study. Medicine, 2015, 94(4): pe402.
• Ellison-Loschmann et al, Barriers to and delays in accessing breast cancer care among New Zealand women: disparities by ethnicity. BMC Health Services Research, 2015, 15:394
• Levesque et al, Patient-centred access to health care: conceptualising access at the interface of health systems and populations. Int J Equity in Health, 2013, 12:18
• Trevoren et al, Cancer Survival and summary stage among Aboriginal and Torres Strait Islander peoples – the impact of socio-economic disadvantage and remoteness. (Under review)
• Tracey, E. et al, What factors affect the odds of NSW cancer patients presenting with localised as opposed to more advanced cancer? Cancer Causes and Control, 2012.
• Kass et al, The research-treatment distinction: a problematic approach for determining which activities should have ethical oversight. Hastings Center Report, 2013, Jan-Feb.
• Javanparast et al, How equitable are colorectal cancer screening programs which include FOBTs? A review of qualitative and quantitative studies. Preventive Medicine, 2010, 50: 165-172.