Better Outcomes for Breast Cancer Patients in New Zealand

Dr Phyllida Cotton-Barker, GP
“Outcome”

The way things turn out

Multiple perspectives from which “outcome” can be viewed
Breast Cancer - Diagnosis & Treatment Pathway

Presentation
- Clinical
- Screening

Diagnosis / Staging

Treatment Planning

Treatment
- Surgery +/- Reconstruction
- Radiation
- Oncology

Surveillance

Terminal Care
Improving “Outcomes” for Breast Cancer Patients

- No single parameter captures “outcome”
- Multiple perspectives from which “outcome” can be viewed
- Efforts to improve one “outcome” can have unexpected consequences for another
Multiple Drivers Affecting the role of General Practice in the “Care” of Breast Cancer Patients

- Stress on secondary care services
- Value “in” primary care - “Better-Closer-Sooner”
- Increasing involvement of primary care in public health initiatives with associated performance payments and “management” by measurement
Patient Care Models NZ - 2015

Ecological and/or Patient Centred?
Ecological Model

“Shared goal that unites the interests and activities of all stakeholders”

Patient Centered Model

“An atmosphere where patients can seize opportunities and solve problems in an increasing self-reliant way”
Barriers to both “Ecological” and “self-management” care models are multiple …..
Breast Cancer – the Disease

- Not a uniform disease - Course not always predictable
- Complex treatment requirements with multi-disciplinary teams each with a range of modalities
- “Survivorship” – 80% require ongoing treatment, surveillance, and support
Current Providers / Stakeholders in New Zealand

NZMOH 2010 - 2011

- **Increasing need for and pressure** on cancer care services. Limited resources, insufficient funding and infrastructure support (both clinical and supportive)

- **Multiple models of care co-ordination - No consistency** of provision and access to services nationally

- **Siloed working practices** and **poor or no communication** from others involved in patient care

- **Multiple charities and support services** – many developed in an ad hoc way

- **Disparities** in cancer-related health outcomes notably Maori and people in lower socioeconomic groups - **Lack of flexible funding** to address problems
Breast Cancer – the Illness

“When you fall into the river you are no longer a fisherman, you are a swimmer”
Breast Cancer – the Illness

- **Uncertainty**... Over or under treatment? Surviving? Dying?

- **Waiting**... *Waiting and uncertainty add to suffering and loss of control*

- **Loss**... Time / money / psychological / social / physical

- **Increasingly demanding treatment pathways**... *Even with fewer mastectomies the array of therapies, follow-up and monitoring are increasingly demanding – multiple professionals, appointments, and procedures*

- **Needs that change over time**
The Way Things Turns Out ...

- Depression
- Cure
- Death
- Self-esteem / confidence
- Nausea
- Hair loss
- Sex??
- Sleep disruption
- Waiting
- Intimacy
- Fear
- Loss of income
- Lymphoedema
- Scaring
- Fertility

Treatment SE
Greatest Concerns of Cancer Patients

Information insufficient or confusing
Greatest Concerns of Cancer Patients

- Information insufficient or confusing
- Lack of consideration of patient’s circumstances in treatment planning
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- Need for emotional support unmet
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Greatest Concerns of Cancer Patients

- Information insufficient or confusing
- Need for emotional support unmet
- Lack of consideration of patient’s circumstances in treatment planning
- Satisfaction with care improves when nurses have time and resources
The Role of Primary Care in the Care of Patients with Cancer

- Help with decisions around treatment
- Provide education
- Manage and co-manage disease progression / treatment complications
- Provide psychosocial support to patients (families)
- Address preventative care and health maintenance needs

Am Fam Physician. 2007 Apr 15;75(8):1207-1214
Do you want to speak to the Doctor in charge ...  

OR

the Nurse who actually knows what’s going on?
Circles of Concern & Influence
Reactive Focus

Circle of Concern

Circle of Influence

Stephen Covey
Circles of Concern & Influence
Proactive Focus

Circle of Concern

Circle of Influence

Stephen Covey
Improving Care of Breast Cancer Patients in NZ Primary Care 2015

- Develop a ‘context’ for you
- Understand and appreciate the ‘context’ of your patient
- Understand roles
- Find common ground
- Establish priorities
- Harvest collective wisdom
- Legitimise concerns, self care and help-seeking
- Minimise risk of further illness
Develop a Context for You

• Develop a sense of purpose
• Increase your knowledge / skills
• Accept we cannot solve or will fully understand and
• Protect time and invite support
• Authentic, careful, appreciative, honest and comforting
Be Aware

sometimes our thinking can separate us
Understand & Appreciate the Context of Your Patient

Get inside the patient's paradigm - the context that gives meaning and relevance

- Work to understand the whole person and their experience
- Protect time / create opportunities / formalize contact
How....

• Listen first with the intent to understand.

Then ...

• Strategic questioning
  – What can I do for you?
  – If I was sitting where you are and you were me what advice would you be giving me?
  – Note: cancer-related pain, depression, and fatigue are often under-diagnosed and under-treated (CRAP ST: Concentration – Relationships – Appetite – Pain – Sleep – Tiredness / Fatigue

• Roll with resistance
Find Common Ground...

- Understand process and roles – capacity, resources, time, timing
- Define problems
- Establish priorities – first things first
- Help create pockets of certainty
Legitimise Concerns & Help-seeking

- Questioning / information seeking
- Practical
- Spiritual
Identify the best and most appropriate support
- Provide knowledge of national, regional and local and personal resources, covered services and self-help groups

Help others understand what is happening and what is needed

Creative co-operation – physical, mental, spiritual, and emotional
Offer Truth & Maintain Hope ...

Challenging ...

• What **patients wish to know**, and what patients (and their family) **do not want to hear** (right now) and ......

• What **you think** a patient or their family should know
Be Realistic ….

“Ensnared by positivity ...”

- A positive approach is the normative way to talk about cancer
- Positively appraised by nurses
- Can be meaningful and therapeutic
- Can be good patient persona – protecting others
- Can be oppressive for some
- Positive outlook = positive outcome?
Appropriate & Timely Information Can ...

- Affect behavior, a decision, or an outcome
- Increase understanding, decrease uncertainty, and help people cope and find meaning in their experience of illness
The Majority of Patients Want to be “Informed”

However ...

- There is significant variation in the what, when, why, and how
- There are many reasons why patients and their families may not want information
- Advice and information may be avoided or ignored (regardless of expectations with respect to education and occupation)
Information – Hearts & Minds

- **Presented within a context that gives it meaning and relevance**
  - with a connection – trust, empathy
  - authentic – careful listening, appreciative, comforting, honest

- **Information needs to be**
  - regular
  - timely
  - accurate
  - specific
  - organised for a purpose
• The resources represented by Nurses in General Practice are increasingly influenced by drivers associated with measurement

• Consider the opportunity cost and lost of this

• Experts in care first listen to understand and then harvest collective wisdom ...... over and over .....
For information about breast cancer, check out the website www.nzbcf.org.nz or freephone: 0800-902-732

We’re here to help