Better Outcomes for Breast Cancer Patients in New Zealand

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“Outcome”

The way things turn out
Breast Cancer Diagnosis & Treatment Pathway

Presentation
- Clinical
- Screening

Diagnosis / Staging

Treatment Planning

Treatment
- Surgery +/- Reconstruction
- Radiation
- Oncology

Surveillance

Terminal Care
Multiple Drivers Affecting Care in General Practice

- Stress on secondary care services
- Value “in” primary care
- “Better-Closer-Sooner”
- Increasing involvement in public health initiatives
- Performance payments – management by measurement
Patient Centred Care

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

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

- Well woman?
- Not a uniform disease
- Course not always predictable
- Complex treatment 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 pressure with the increasing need for cancer care services
- Limited resources
- No consistency of provision and access to services nationally
- Multiple models of care co-ordination
- Insufficient funding and infrastructure support (both clinical and supportive)
- Siloed working practices and poor or no communication from others involved in patient care
- Multiple charities and support services involved – 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

• Significant uncertainty – over or under treatment? Surviving? Dying?

• Waiting – adds to suffering and loss of control

• Loss – time / money / psychological / social / physical

• Treatments more, not less, demanding
  For example, even with fewer mastectomies the array of therapies and follow-up monitoring significantly demanding – multiple professionals, appointments, and procedures

• Needs change over time
The Way a Thing Turns Out ...

- Cure
- Waiting
- Fear
- Fertility
- Death
- Self-esteem / confidence

- Depression
- Sexuality
- Intimacy
- Lymphoedema

- Menopause
- Nausea
- Menopause
- Sleep disruption
- Loss of income
- Scaring

- Hair loss
Greatest Concerns of Cancer Patients

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- Lack of consideration of patient’s circumstances in treatment planning
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Greatest Concerns of Cancer Patients

- Information insufficient or confusing
- Lack of consideration of patient’s circumstances in treatment planning
- Need for emotional support unmet
- Satisfaction with care improves when nurses have time and resources
Do you want to speak to the Doctor in charge ...

**OR**

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

Stephen Covey
Circles of Concern & Influence – Proactive Focus

Stephen Covey
Strategies / Opportunities to Improve Care of Breast Cancer Patients

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

- Accept we cannot solve or will fully understand
- Develop a sense of purpose
- Increase your knowledge / skills
- Protect time
- Invite support
- Be motivated to understand
- Demonstrate this – authentic, careful, appreciative, comforting, and honest
Understand & Appreciate the Context of Your Patient

• Protect time / create opportunities / formalise contact

• Get inside the patients paradigm (the context that give meaning and relevance)

• Understand the whole person and the experience
Be Aware

that sometimes our thinking can separate us
How Can We Do Better?

• Listen carefully – 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 – seek mutual understanding

• Establish priorities – first things first

• Help create pockets of certainty
Legitimise Concerns & Help-seeking

- Questioning / information seeking
- Practical
- Spiritual
Harvest Collective Wisdom & Support

- **Creative co-operation** – physical, mental, spiritual, and emotional

- **Identify the best and most appropriate support**
  - Provide knowledge of national, regional and local resources, covered services, and self-help groups
  - Help others understand what is happening and what is needed
Appropriate & Timely Information Can ...

- Affect behaviour, 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