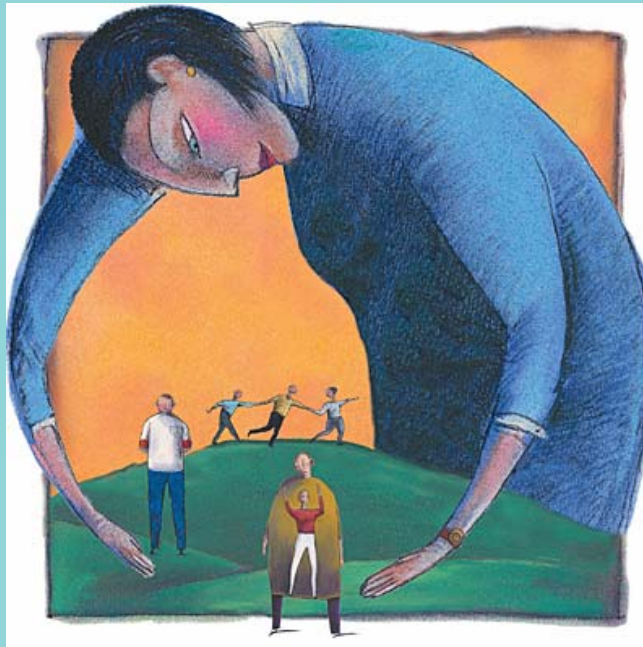


Uncovering the Gaps

An Inquiry of Breast Care in British Columbia



The Journey to Supportive Care

February 2005



The Canadian Breast Cancer Foundation BC/Yukon Chapter

- ❖ Established in 1992, the BC/Yukon Chapter is located in Vancouver with branches in Victoria and the Fraser Valley
- ❖ With a National office in Toronto and Chapters in British Columbia, Alberta, Ontario and the Atlantic Provinces, the Canadian Breast Cancer Foundation is the leading, national, volunteer-based organization dedicated to working towards a future without breast cancer



The Canadian Breast Cancer Foundation BC/Yukon Chapter

The CBCF works collaboratively to fund, support and advocate for:

- ❖ Relevant and innovative breast cancer research
- ❖ Meaningful education and awareness programs
- ❖ Early diagnosis and effective treatment
- ❖ A positive quality of life for those living with breast cancer



The Canadian Breast Cancer Foundation BC/Yukon Chapter

To fulfill this mandate, CBCF released in April 2002 the Gap Analysis – a study which examined the state of breast care in British Columbia

The purpose of the study was to discover the state of breast health care, from prevention to palliation, and to determine how the CBCF could focus its time, effort and dollars to best assist women.

This is the first piece of consumer-based research of its kind conducted in Canada on the topic of breast cancer



Collaborating Partners

- ◆ BC Cancer Agency
- ◆ Canadian Cancer Society
- ◆ Vancouver Foundation
- ◆ Ipsos Reid Group

There was consensus on the approach and the findings amongst the collaborating partners.



Leading Questions for Newly Diagnosed Women

- ❖ *What would improve Breast Care?*
- ❖ *What priorities?*
- ❖ *What gaps do women experience?*



Methodology

Quantitative Research:

- ❖ Interviews with 20 key informants in health care – health care professionals across disciplines
- ❖ Series of focus groups involving women with recent experience of the breast cancer treatment system

Qualitative Research:

- ❖ Ipsos-Reid Group telephone survey with 750 BC women who have never had breast cancer treatment



"We do a pretty good job of actually finding the abnormality in the mammogram. But after that it's a free-for-all in my mind. I see a lot of that in my practice."



Qualitative Findings

From key informants...

"The gaps are everywhere."

A 'maze', a 'run-around' and a 'free for all'.

Little perceived 'system' at all.



Qualitative Findings

From focus groups...

- ❖ Barriers to Information
- ❖ Difficult Decisions Under Stress
- ❖ Loss of Control
- ❖ Insensitivity of Providers
- ❖ Excessive Waiting
- ❖ Inconsistencies & Errors
- ❖ Financial Issues
- ❖ Rural Access



"I felt I needed to be my own project manager. I was the only common linkage between my GP, my surgeon and the oncologist."



Qualitative Findings

- ❖ Women feel unsupported
- ❖ Experience loss of trust
- ❖ Self only continuity in delivery
- ❖ Control anxiety:
 - hyper-alert to mistakes
 - felt need to manage own care



“If everybody had sat down together and said, ‘she’s probably going to need this, this and this,’ it might have been an easier year and things would have turned out better.”



CBCF's Response:

- ❖ Education
- ❖ Navigation
- ❖ Integrated Breast Health Services
- ❖ Partner Initiatives – BC Cancer Agency; Canadian Cancer Society; Screening Mammography Program of BC



Initiatives: Navigation

- ❖ Navigation is a set of tools and/or roles that assist people with breast cancer to access the information they need to make informed decisions and make their way in a timely fashion through the complex services of health professionals and treatments
 - Case management
 - Communication systems
 - Care navigator



Initiatives: Navigation

- ❖ Victoria Breast Health Clinic
- ❖ Partnering with BC Cancer Agency, the Canadian Breast Cancer Initiative and the Canadian Cancer Control Strategy to investigate current navigation programs and develop a best practice model



Initiatives: Navigation

- ❖ Alliance Information Kits For The Newly Diagnosed (2700 per year) distributed through surgeons and some radiologists
- ❖ Creation of treatment and services “road map”



I felt that along the way, information was only given to me on a need-to-know basis. Basically, when I discovered a problem with the treatment; some kind of after-effect, and I would mention it, it would be "Oh yes, a number of people have that happen."



- ❖ “What appears to be a gap in services may actually be a gap in linkages between them.”
- ❖ “I think the biggest Achilles heel to cancer systems in terms of reaching out to community partners is information systems and the lack of getting consistent, easily accessible information to the people in the community.”



A FUTURE WITHOUT BREAST CANCER →

