

Breast and colorectal cancer survivors' experiences with and perspectives on their follow-up care

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- **Our study participants**

Our NS-based research

- **Study various survivorship issues & used multiple methods**
 - Health services utilization: linked administrative databases, systematic review/meta-analysis
 - Family physician- (FP) led follow-up: randomized controlled trials
 - Preferences for and experiences with follow-up care: qualitative methods

Purpose

To deepen our understanding of:

- 1. Breast cancer (BC) and colorectal cancer (CRC) survivors' perspectives on their routine follow-up care and**
- 2. Their views on cancer specialist versus FP-led follow-up care**

Methods

- **Methodology:**
 - **Phenomenology:** to provide a description of human experience as it is experienced or lived by the person
- **Data collection procedures**
 - **Focus groups (BC and CRC)**
 - **Semi-structured interviews (CRC)**

Participants

- **BC and CRC survivors receiving routine follow-up care after completing primary treatment (tx)**
 - **Inclusion criteria: diagnosed with invasive BC or CRC within 12-48 (72) months; without evidence of disease; free of primary tx complications**
 - **Exclusion criteria: primary tx not completed at least 3 months previously**

Participants cont'd

- **Recruitment**
 - **Identification in cancer centres (Halifax and Sydney)**
 - **Surgeons**
 - **Cancer Patient Family Network**
 - **Posters distributed to cancer support groups and organizations throughout Nova Scotia**

Analysis

- **All focus groups/interviews were audiotaped, transcribed, and audited**
- **Coding, constant comparison, categorizing, and theme identification**
 - **Two independent analyses**
 - **Third researcher compared analyses**
 - **Discrepancies resolved through team discussion**

Findings

- **N = 23 (13 BC, 10 CRC)**
 - All BC were female; 4 CRC were female
 - Majority received follow-up care from both specialists and FPs

- **6 main themes identified**

My care is my responsibility

Description	Representative quotations
<ul style="list-style-type: none">• Shift from doing nothing to doing everything• Guilt (self care, bothering professionals)	<p>“It’s shocking that you had to be, like, you had to constantly be on alert. You had to be the one seeking people rather than people coming.” [CRC]</p>
	<p>“I cried because I was abandoned. I got use to somebody making my appointments, my tests and my mammograms ... my family doctor ... he wasn’t really that aware of my problems ... Who was going to find more cancer? ... Are there tests that I had to look for, for myself?” [BC]</p>
	<p>“... and then I’m saying, ‘oh my god, what are you complaining about?’ It could be so much worse and I’m lucky that I have these options but it’s still an adjustment.” [CRC]</p>

How I receive information on follow-up care

Description	Representative quotations
<ul style="list-style-type: none">• Issues with language, overload, and timing• Written info does not replace conversation	<p>“Well, the information that I received about after care was during my final meetings with my oncologist and surgeon, and I thought that was the appropriate time to be told about this information because, for one thing, I was feeling great that I was declared cancer free so I was ready to listen.” [CRC]</p> <p>“[On healthy eating] “You have read it yourself ... you need somebody ... to sit down and explain it to me, ‘you need to eat so many vegetables a day because’ ... of what they do for me and how they help me rebound from cancer.” [BC]</p>

I have many care needs

Description	Representative quotations
<ul style="list-style-type: none">• Physical, psychological, emotional, supportive• Ostomy (CRC)	<p>“The radiation messed me up. Basically, I’m probably one step away from Viagra. The sex drive just isn’t there.” [CRC]</p>
	<p>“Tell me what I have to do to get all the way back to the happy person that I once was.” [BC]</p>
	<p>“I have more issues with this [ostomy] than with the cancer. It’s stupid but I think it’s just, it’s a reminder of what I went through. If I had surgery and just a scar and that would have been it, I think it would have been a lot better.” [CRC]</p>

I want to be prepared and informed

Description	Representative quotations
<ul style="list-style-type: none">• How does follow-up care work?• What needs might I have?• Mapping, tracking of care	<p data-bbox="548 339 1812 696">“Can you tell me what to expect? Can you tell me, you know, what would be some normal things? You know, and I’m smart enough to recognize that this is just a guideline, but could you tell me something because this is all new to me and I have no idea where to even begin.” [CRC]</p> <p data-bbox="548 739 1812 953">“I would like to have like a tracking, like for a courier package, you can go online and see, okay, your test is here ... and this is when you can expect it.” [BC]</p>

The role of my FP in my cancer experience and follow-up care

Description	Representative quotations
<ul style="list-style-type: none">• Comfort in specialist care• FPs are not specialists• Confidence in FP's knowledge• Being in the 'system'	<p>"[My FP is] not a surgeon. That's about the only thing ... As far as my other ailments ... he takes excellent care of me." [CRC]</p>
	<p>"In a family physician setting ... it depends on, you know, what your family doctor has read recently." [BC]</p>
	<p>"If something happened, I would feel like I could get in. That's my sense and I don't even think about it, but just the fact that I, like, if I have to go through my family doctor, it would take longer because I would be out of the system." [BC]</p>

The role of media (BC only)

Description	Representative quotations
<ul style="list-style-type: none">• Guilt• Reminder of their cancer	<p data-bbox="523 354 1812 596">“If you pay attention to the media...it is like okay, I worked out and look I still got cancer and your people are on the radio saying ... now do this and it won't come back.” [BC]</p> <p data-bbox="523 615 1812 772">“With October being breast cancer month, you can't go anywhere without the reminder. It is everywhere.” [BC]</p>

Challenges & Limitations

- **Recruitment**
 - CRC survivor recruitment was *difficult*
 - Led team to revise methods, inclusion criteria
 - Related to disease, physician/provider, context of care, socio-historical context?
- **Generalizability**
 - Provides a patient-centered perspective
 - Adds context to other (quantitative) work

Implications

- **Transition to FP-led care requires assurances related to FP competencies and rapid re-entry into the “system”**
 - Expanding FP role during diagnosis & tx, thorough discharge planning, just-in-time consults
- **Need to implement strategies that better prepare survivors for post-treatment care**
 - Tools to map care, exit interviews, survivorship care plans

Thank you
Questions?