Your Experience Matters:
A Pilot to Evaluate Patient Education at a Provincial Level

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Background

Health information that is clear, easy to understand, and evidence-based empowers cancer patients and their families to better navigate the system and make well-informed decisions[123].

The ability for patients and families to receive quality health information is an important dimension of patient satisfaction and experience.

Currently, the success of information delivery at the Regional Cancer Programs (RCPs) is measured by the Ambulatory Oncology Patient Satisfaction Survey (AOPSS). While the AOPSS is a great starting point for quality improvement (QI), there are some disadvantages to the survey, such as:

- Questions are general in nature
- Question wording can be interpreted differently by patients
- Questions do not rate the helpfulness of information received

The Patient Education program at Cancer Care Ontario (CCO) identified a need for more detailed, region-specific data where the results could be used to create more specific, actionable QI initiatives.

This gap provided opportunities to:

- Develop a more regionally-specific survey to help RCPs improve delivery of patient education
- Create a new indicator to systematically measure patient education success on a regional and provincial level

Objectives

1. To develop a survey which can assess
    a) the type of information patients and families received and through what means; and
    b) how helpful the education and information was in understanding and managing their cancer journey
2. To determine whether the format and wording of the survey was patient friendly

Given this was a pilot, objective #2 was important to determine whether changes needed to be made before expanding the scope of the project.

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Methodology

Literature Review

- Targeted review of patient education program evaluation literature and relevant process and outcome indicators

Survey Development

- Working group: 3 RCP representatives and CCO staff
- 9 questions to assess patient education provision and helpfulness of information
- 8 questions on survey design

Survey Testing

- Draft survey tested at 2 RCPs between July-August 2013
- Focus group with 2 Patient and Family Advisors
- Draft postcard with link to online survey developed

Survey Pilot

- Survey updated based on feedback from testing phase
- Updated postcard as part of recruitment strategy
- Pilot deployed at 3 RCPs for 6 weeks in November and December 2013

Data Analysis

- Data collated through an online survey platform
- Qualitative and quantitative analysis

Results

Respondents

- n = 199
- 87% were patients; 10% were family members; 3% other

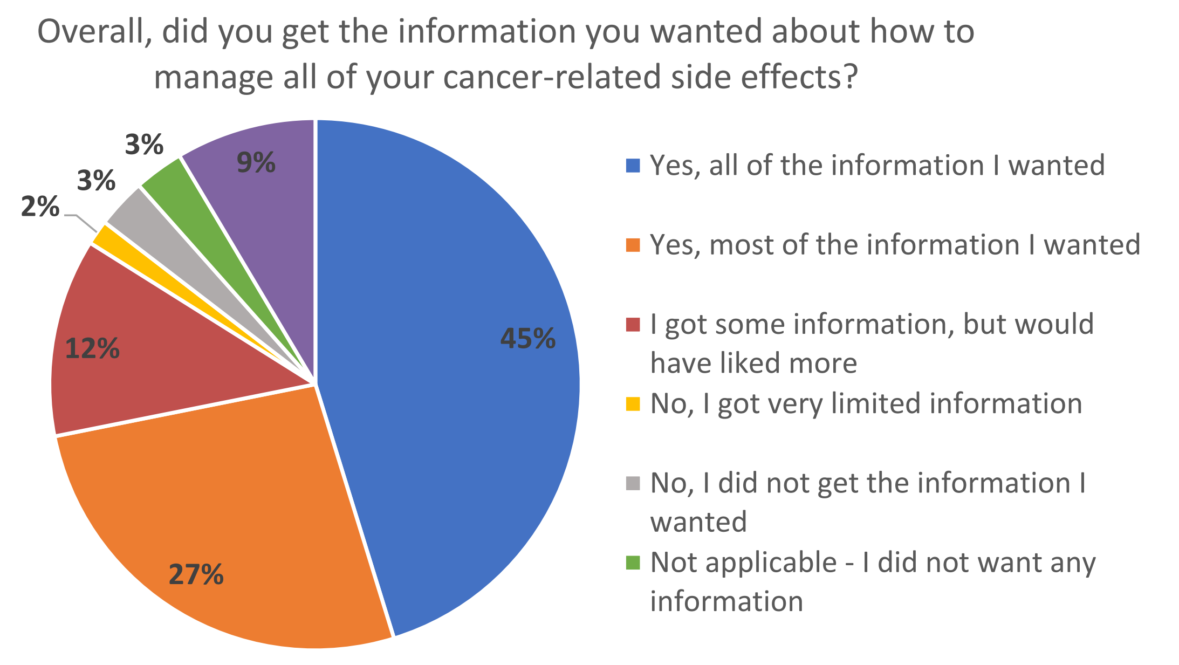
Sources of Patient Education/Information:

- Health care providers were the top providers of information across all three pilot sites, followed by education classes and resource areas (patient library, waiting room, etc.)

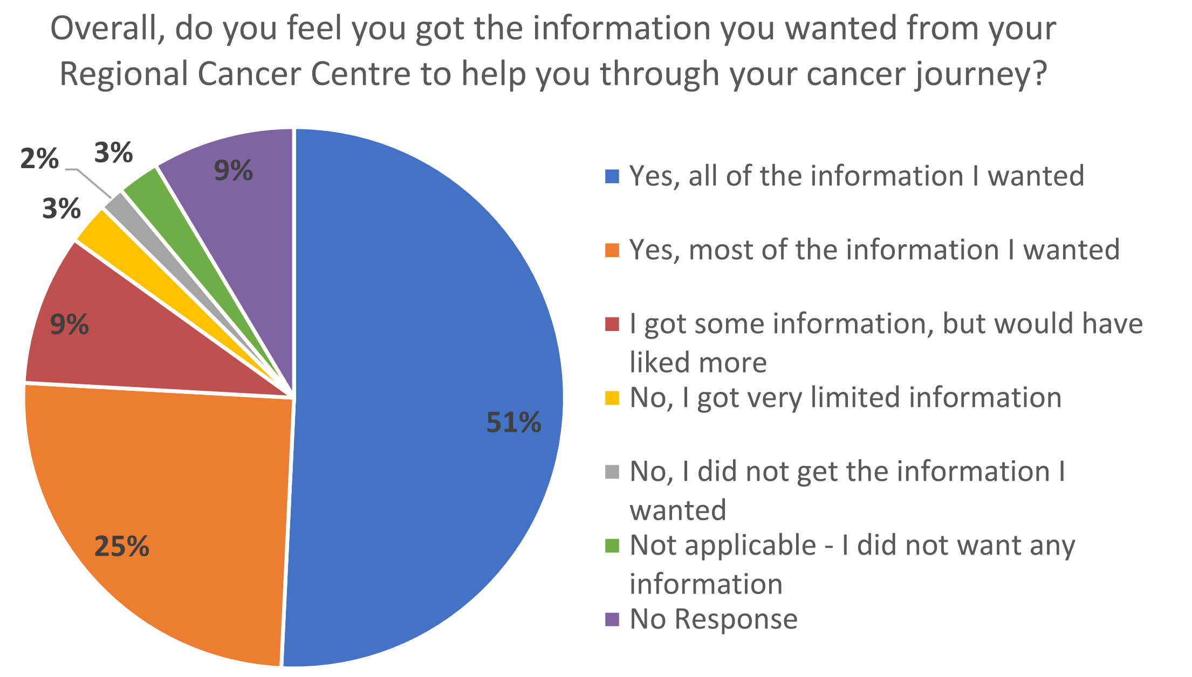
Survey Design

- 69% learned about the survey through a student/volunteer/health care provider
- 91% understood what the questions were asking
- 94% thought the survey was easy to read
- 93% knew how to answer the questions
- 79% liked the format of the survey

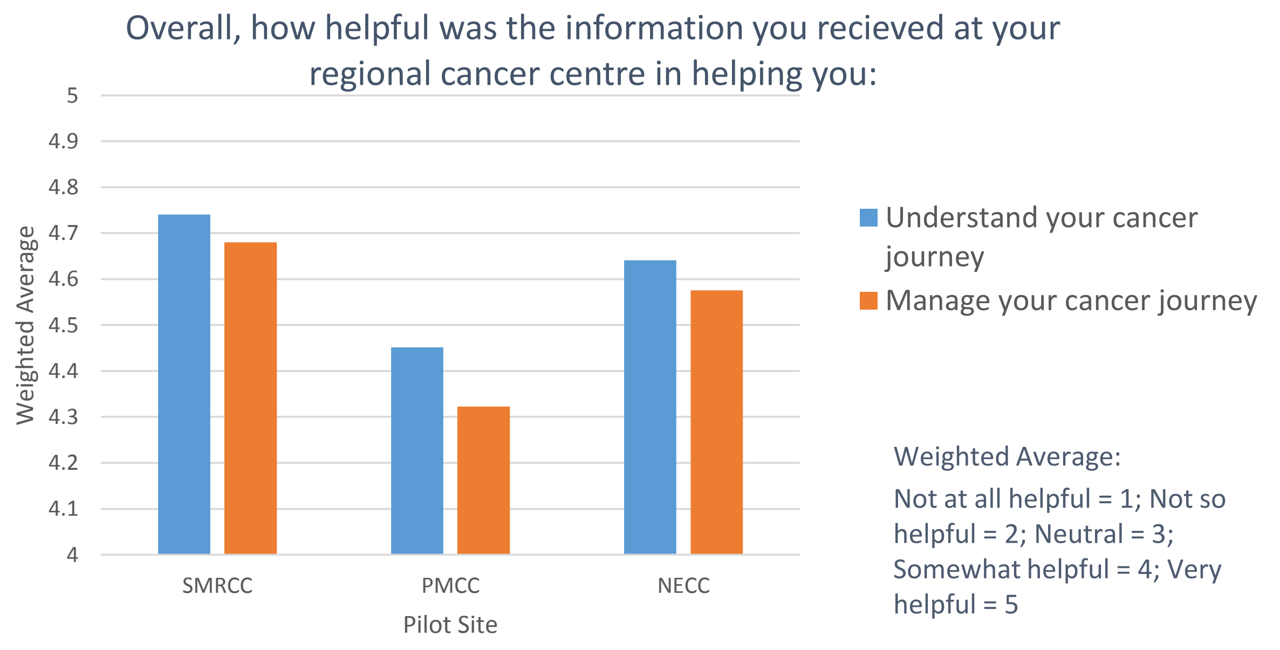
72% received all or most of the information they wanted on their cancer side effects



76% received all or most of the information they wanted to help them through their cancer journey



Patients from all pilot sites found information helpful in understanding and managing their cancer journey



Discussion

The Provision & Helpfulness of Information

- All 3 RCPs are doing well in providing helpful information to patients
- No significant difference between 3 pilot RCPs, except for how information is delivered

Survey Design

- Important to utilize both active and passive approaches when recruiting patients
- Overall, respondents understood the questions and found the survey easy to read. However many nuances were noted, including:
    - Certain words/phrases can be interpreted in different ways: e.g. cancer journey, helpful(ness), N/A, cancer-related side-effects
    - Questions which require the patient to refer to the choices in previous questions are confusing when survey is delivered on paper (vs. online)

Limitations

- There is no one-method of surveying which is suitable for all cancer patients
- In-person recruitment strategies were most successful but biases include sampling bias, end aversion bias, social desirability bias, etc.
- Online surveys exclude patients who are not tech-savvy or do not have a computer

Next Steps

- Revise survey to include patient preference for information delivery (including how, when, where and how much)
- Plan for provincial deployment of the survey to all RCPs
- Link survey results to regional and provincial QI initiatives
- Determine if these questions can be used as a meaningful indicator to measure the effectiveness of patient education programs

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