

# EVIDENCE OF GAPS IN THE SYSTEM



Kamloops Cancer  
Supportive *Care* Society





## TABLE OF CONTENTS

WHAT KAMLOOPS PATIENTS ARE TELLING US - PATIENTS AND CAREGIVERS FORUM . . . . .	3
WHAT ALLIED HEALTH PROFESSIONALS ARE TELLING US – Surveys . . . . .	4
WHAT THE MEDICAL COMMUNITY IS TELLING US . . . . .	5
WHAT THOMPSON RIVERS UNIVERSITY RESEARCHERS ARE TELLING US . . . . .	6
WHAT OTHER RESEARCH IN CANADA IS TELLING US . . . . .	6
WHAT OTHER RESEARCH IN KAMLOOPS IS TELLING US . . . . .	7
WHAT BC CANCER AGENCY’S OWN RESEARCH IS TELLING US . . . . .	8



## EVIDENCE OF GAPS IN THE SYSTEM

KCSCS has engaged in academic research, community dialogue with Allied Health Professionals, and patient feedback forums to study the Kamloops community's lived experiences and has verified the need for cancer supportive care services. Patients, caregivers, and service providers have relayed their experiences and challenges in continuity of care and lack of access to necessary services and support.

### WHAT KAMLOOPS PATIENTS ARE TELLING US - PATIENTS AND CAREGIVERS FORUM

As part of the KCSCS Community Engagement and Awareness campaign, a community forum was held on February 22, 2020. All participants received a 10-question questionnaire ahead of time, then brought it to the forum. They then shared their thoughts in the small group settings. The results are summarized in a full report which is included with the questionnaire in Supporting Documents.

**KCSCS has engaged in academic research, community dialogue with Allied Health Professionals, and patient feedback forums to study the Kamloops community's lived experiences and has verified the need for cancer supportive care services.**

#### GENERAL FINDINGS

- Patients were generally satisfied with the quality of their medical experience with almost all people indicating satisfaction with the amount of information they received about their diagnosis and treatment options.
- Patients were generally dissatisfied with the amount of information they received about the trajectory and timeline of their disease.
- Patients were unhappy with the level of support in the transitions from cancer patient back to 'normal life'. Patients reported receiving little to no support services in the transition and afterwards.
- Patients who received support services were assertive advocates or had an assertive caregiver. However, most patients reported having absolutely no services provided at all for caregivers, family, and dependents.
- Almost all patients reports that their MDs were not equipped, nor had time to refer or connect patients with support services. Many forum participants stated that they themselves took this information back to their doctors.
- Patients reported receiving little to no support for issues other than medical oncology from the Kamloops Cancer Clinic. In fact, most forum participants expressed surprise at hearing that there is a Social Worker attached to the clinic. Some people felt that the Kamloops Cancer Clinic is not equipped to assist patients in accessing needed support services.
- Knowledge about availability of support services was very low. Many forum participants recounted long and tiresome searches for support services on their own after their diagnosis.
- Patients were not able to access support services quickly, ie. Counselling, support groups, peer support. Patients who were successful in accessing services often say they found it through 'word of mouth' or by accident. Disconnected networks caused delays and distress for many patients. One forum participant reported getting all her support and information from the Spirit Warriors Breast Cancer Survivor Dragonboat Team.
- Patients reported a variety of lasting effects from their cancer and its treatment. Most people reported physical and emotional side effects as being the most persistent and disabling. Yet, most patients report not being referred to, or informed of, adequate resources such as physiotherapy, massage, and counselling services.
- Patients reported needing, and not finding, assistance with financial resources, return to work and counselling during their treatment and survivorship. Most people stated that they were financially compromised, and 'poorer' after their treatment. Additional costs during treatment included transportation, accommodation, and living expenses associated with trips to Kelowna and elsewhere. Many reported reduced income potential after treatment.

#### CONCLUSIONS

Our overall conclusion from this forum is that there is a dire necessity for Cancer Supportive Care Services to increase the potency of current service provision. As allies of BC Cancer Agency, Interior Health, Family Doctors, and Allied Health, the Cancer Supportive Care Centre can assist patients in many ways.



Responses from participants at the forum and respondents to the questionnaire suggest the following:

**Navigation Services** would greatly increase the ability of cancer patients to heal, deal with medication problems, spend less time on fruitless “Dr Google” searches, and mitigate the stress that comes with finding their way around a complex, opaque medical system whilst also dealing with cancer. A one-stop-shop approach seemed to appeal to all people.

**Transition Services** are non-existent, or at least were non-existent to our respondents. Most people did not even understand the nature of what they might look like, but did respond with positive comments when transition services which were available in other jurisdictions were shown to them.

**Lack of Emotional Support** was a crucial need, according to respondents, and yet almost no-one was able to easily access appropriate emotional support while on their cancer journey. Finding emotional support mostly came through family and friends, and professional emotional supports, while available in the community were often out of financial reach, a ‘poor fit’, and when found, was the result of exhausting personal research and internet time.

**Lack of Caregiver Support** came up time and again for respondents. In most cases, the patient is often the caregiver of the caregivers, with negative consequences to their own health and healing.

**Lack of Access to Financial and Legal help** was also problematic for respondents. Many forum participants reported severe financial problems arising from their cancer diagnosis, and many people stated that the paperwork, forms, online research and applications, were stressful and exhausting.

*“The paperwork beats you down, when you’re already down.”*

*~ Forum Participant*

## WHAT ALLIED HEALTH PROFESSIONALS ARE TELLING US – Surveys

As part of the Community Engagement and Awareness campaign, the KCSCC surveyed Allied Health Professionals. Questionnaires were sent to Allied Health Care Professionals, such as Physiotherapists, Massage therapists, Counsellors, and Yoga Instructors. The survey asked for feedback about patients from the practitioners themselves. It also asked about what their patients were saying to them about cancer supportive care in Kamloops. The questionnaire and results are summarized in a full report which is included in Supporting Documents.

### GENERAL FINDINGS

From the responses provided to this survey from a small but diverse group of allied health professionals, it is clear that many cancer patients and their caregivers find the services provided are appropriate and helpful during both the treatment and survivorship stages.

- Many patients find their way to these service providers through other health care professionals, as well as through traditional means such as health directories and word of mouth.
- Our concurrent conversations with patients attest to the fact that once connected with supportive care, patients’ physical and emotional health, and quality of life are improved.
- However, there are questions arising from this survey: Over 60% of providers are paid directly by patients, the rest are often covered by some form of public benefits or funded by PHSA and BCCA directly. Who is providing service to those who cannot afford to pay, or have no benefits? Who pays for caregiver support? Where do treating doctors, nurses, and social workers get their information about cancer supportive care providers in the city?
- The responses can be summed up in the words of one person who commented in the questionnaire:

*“(The Cancer Supportive Care Centre) “is so important and is a much-needed resource. It could help people focus on healing and their health rather than stressing about what comes next and how to access it. I find people have so many unmet needs during treatment and during survivorship.”*



## CONCLUSIONS

Allied Health Professionals say that the Cancer Supportive Care Centre could:

“Provide a comprehensive list of contact information for current community-based resources that cover medical, emotional, social, legal, recreational needs.”

“Not all oncologists or their nurses are aware of therapies available to their patients. That would be the best place currently for patients to be given contact information for rehabilitation. But because there is typically an information overload in those appointments, it would be better if there was a one-stop-shop for information on all cancer rehabilitation options found within a community that a patient could access when they are ready for a little more information.”

## WHAT THE MEDICAL COMMUNITY IS TELLING US

### 1. Dr Maureen Leia Stephen SURVIVORSHIP Program

Beyond Breast Cancer is a program offered to anyone who has been diagnosed with breast cancer and completed active treatment. Early in her career as a general surgeon, Dr. Leia Stephen recognized that following treatment, breast cancer patients often had gaps in the services and supports they needed. This program is intended to close those gaps and offer support and assistance to patients once they've been released from their cancer care team.

As part of Beyond Breast Cancer Society, there is also a no-cost Speaker Series. These 2-hour presentations cover various topics relevant to survivors and their support persons and consist of education, resources, and question periods. Often, a specialist in the area of discussion is a presenter.

### 2. KCSCS is currently engaged in the planning stages of collaborative projects with members of the medical community to collaborate on the enhancement of cancer supportive care needs, identification of gaps in the current care system, and delivery challenges.

- a. The Thompson Region Division of Family Practice
- b. Orchards Walk Health Centre - STEPS

### 3. Royal Inland Hospital Foundation observations:

- 85% of surgical work at RIH in Kamloops is related to cancer care.
- “Statistics demonstrate that if a cancer patient lives more than 90 minutes away from treatment, patient mortality rises significantly.” (Source – Dr. Ross Halperin, BC Cancer Agency)  
Many cancer patients who travel to Vancouver or Kelowna for surgery often end up in the Emergency Room at Royal Inland Hospital because of complications (mostly clotting issues) related to travel and are being treated by doctors who were not involved in their treatment and care previously. The cost of this ER care vs the cost of prophylactic care is currently being researched by Dr Ehsan Latif at Thompson Rivers University, on behalf of KCSCS.
- Informal reports from the Kamloops Cancer Clinic at RIH suggest a significant need for another Social Worker, a psychologist, and Cancer Supportive Care Services. In lieu of another Oncologist, 2 more General Practitioners, Oncology, would be needed.
- In 2017, BCCA published a report that said only 17% of its frontline workers dealing with cancer patients had sufficient training and experience in psychosocial issues.





## WHAT THOMPSON RIVERS UNIVERSITY RESEARCHERS ARE TELLING US

Currently, there are two research projects in progress at Thompson Rivers University. The Kamloops Cancer Supportive Care Society are Community Partners with these researchers. These research projects are due to wrap up in summer, 2021.

### **Name of Projects: Two Part Study - (Quantative and Qualitative elements)**

### **Financial Burden of Acute Oncology Emergencies versus the Cost of Prophylactic Patient Engagement (Quantatative study), and**

### **Care - The Case of Breast Cancer (Qualitative Study - 99 participants).**

The Principal Investigator for the study is Dr. Ehsan Latif, Health Economist and Chair, School of Business and Economics. The Co-Investigator is Dr Melba D'Souza, Assistant Professor, Faculty of Nursing.

The specific objectives of the study are as follows:

1. To develop a model for a prophylactic patient engagement and care system using a literature review of relevant models and integrated with priorities via an environmental scan.
2. To provide a cost analysis of the proposed model vis a vis the status quo, ie. Treating the majority of post therapy cases acutely in hospital, ER visits, admissions and associated treatments.
3. Exploring the perceptions, knowledge, practises, and experiences among women diagnosed and treated with breast cancer in the community.

Both research projects are scheduled to be completed by September, 2021. From interim results, Dr D'Souza concludes that, anecdotally, three areas of concern for patients arise out of her research:

- Continuity of Care
- Support for Caregivers
- Support for Immigrants.

In summary, TRU research is continuing, and also presenting opportunities for further study. Most importantly, these research projects will reflect the local Kamloops situation with regard to the economics of present care, as well as the journeys of local Kamloops residents with regard to their experiences with the present system of care. In future, further studies may explore how the local Kamloops picture of cancer care reflects Provincial priorities, compares with care provided in other jurisdictions, and also demonstrate how care gaps persist, despite the excellence of treatment in the health care system. The Kamloops Cancer Supportive Care Society will continue to support TRU's research, along with other community research ventures, in its mission to advocate for local cancer supportive care.

## WHAT OTHER RESEARCH IN CANADA IS TELLING US

Associate Professor Doris Howell is a co-lead on the Improving Patient Experience and Health Outcomes Collaborative (iPEHOC), along with Dr. Madeline Li and Dr. Zeev Rosberger at the UNIVERSITY OF TORONTO LAWRENCE S. BLOOMBERG FACULTY OF NURSING, Centre for Professional Development – Research Program.

**"Research shows that cancer treatment negatively impacts patients' physical and psychosocial well-being. These impacts are under-reported by physicians and patients alike, which can lead to higher costs for the healthcare system as patients attempt to address poorly-controlled symptoms."**

*~ Associate Professor, Doris Howell*

The mandate of this three-year project is to develop and implement a standardized patient-experience and patient-reported outcomes measurement system. This will screen for emotional distress and the symptom levels of those diagnosed and undergoing cancer treatments.

The goal is to develop a common and sustainable patient experience measurement system that could be used across Canada.



## WHAT OTHER RESEARCH IN KAMLOOPS IS TELLING US

### TRANSITION SERVICES

Bridging the gap from the oncology setting to community care through a cross-Canada environmental scan. Canadian Oncology Nursing Journal, Volume 28, Issue 1, Winter 2018.

Author: D. M. Wittal

#### General Findings

In British Columbia, there is no provincial standard and transition service varies by regional cancer center, oncologist and disease site. The oncologist is responsible for discharge letter that is sent to the primary care physician. Future work includes exploring the transition of care from oncology to the community. There is no Survivorship Care Plan currently in practice.

#### Conclusion

Most interviewees were clearly aware of the growing needs and demands for high-quality follow-up cancer care. Several interviews ended with, 'I wish we did more', and 'our current system is not good enough; however, we are/ may be working towards something better.'

### LEARNING NEEDS OF PATIENTS

Evaluating the learning needs of women with breast cancer in Kamloops, British Columbia

Author: Jennifer Edgecombe, November 1, 2019

#### General Findings

The purpose of this proposed education initiative is to engage the women as partners in their own survivorship care by supporting their information needs for confident and informed treatment decisions and self-management of disease or treatment side effects.

#### Conclusion

Their Health Care Provider (HCP) and the women found that there is a local need for this type of education initiative.

### RETURN TO WORK AND VOCATIONAL REHABILITATION NEEDS

Exploration of Services for Cancer Survivors Returning to Work

Authors: Precious Livedotte, Jaylene Stewart, & Imara Rahim

#### General Findings

No agency that was surveyed had dealt with a patient returning to work after surviving cancer.

#### Conclusion

It is not the agencies themselves that stand in the way of cancer survivors utilizing these agencies, but that patients lack the ability to finance them on their own that stands in the way of vocational rehab and return to work services for cancer patients.



## WHAT BC CANCER AGENCY'S OWN RESEARCH IS TELLING US

On June 8, 2016, Presenters: Betty Lam, Shaun Lorhan, Andrea McIntosh, BC Cancer Agency – Care and Research, presented “Patient transition after active cancer treatment - How do we share care?” at a Survivorship Forum. Part of their presentation is shown below, demonstrating the identified gaps and needs from their stakeholder analysis, as well as recommended solutions.

As shown below, BC Cancer’s own research and the research undertaken by the Kamloops Cancer Supportive Care Society align in many areas.

### STAKEHOLDER ANALYSIS: IDENTIFIED GAPS/NEEDS

NEEDS	FREQUENCY OF REPORT
Coordination/continuity of care	83
Psychosocial support	63
Access/awareness of resources	39
Access/reliable information	27
Prevention: exercise/nutrition	17
Return to work/Finances	17
Other	6

### STAKEHOLDER ANALYSIS: CONTENT FOR RECOMMENDED SOLUTIONS

NEEDS	FREQUENCY OF REPORT
Psychological/emotional support – coping strategies	34
Lifestyle: wellness, nutrition, complimentary therapies, exercise	30
Resource information – who to contact when and for what	23
Long term side effects: pain, fatigue, memory loss	13
Practical: return to work, finances, transportation	12
Relationships: family, friends, sexual	9
Spiritual: death and dying	5