

SUPPORTING DOCUMENTS



Kamloops Cancer
Supportive *Care* Society



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SUPPORTING DOCUMENTS

KAMLOOPS CANCER SUPPORTIVE CARE CENTRE COMMUNITY FORUM FEBRUARY 22, 2020

WHAT CANCER PATIENTS AND SURVIVORS ARE TELLING US

REPORT PREPARED BY KAMLOOPS CANCER SUPPORTIVE CARE CENTRE ADVOCACY GROUP

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BACKGROUND

THE VISION

The Kamloops Cancer Supportive Care Centre is a not-for-profit organization serving adults in Kamloops who have had a diagnosis of cancer. The Centre works in partnership with patients to help with navigation of the medical and other support systems. Every person with cancer can get help to self-manage their physical, mental, and emotional health as well as financial, legal and work place challenges.

WHAT IS CANCER SUPPORTIVE CARE?

Supportive cancer care “is better and earlier access to expertise in managing the “range of” adverse effects of cancer and cancer treatments.” (Berman, et al., 2017)

KAMLOOPS CANCER SUPPORTIVE CARE CENTRE - ORGANIZATIONAL OBJECTIVES

Currently, the Advocacy Group for the KCSCC are working on four main objectives towards the development of the Centre.

1. Fundraising
2. Research
3. Development of a Not for Profit Organization to run the Centre
4. Community Engagement and Awareness

RESEARCH METHODOLOGY

As part of the Community Engagement and Awareness campaign for the KCSCC, a series of community forums were scheduled for the Spring and Summer of 2020. We held one forum on February 22, 2020, before the series was interrupted by the onset of Covid-19. The forums are designed to call together a small group of 30 people selected for their particular experience and knowledge related to cancer care.

In addition, 16 people who indicated an interest in participating, but who were unable to attend the forum, completed the questionnaires only and submitted their responses through email.

Forum Recruitment: Participants were recruited through word of mouth, and through emails sent out from Kamloops Cancer Connections, the Spirit Warriors Dragon Boat Team, and Kamloops Breast Cancer Support Group. Forum #1 was focussed on Cancer Patients and Survivors – those with Lived Experience. Over 65 people responded, 28 people attended the forum, and a further 16 people completed the questionnaire only.

Questions: All participants received a 10-question questionnaire ahead of time, they then shared their thoughts in the small group settings. The questions focussed on support received, support needed, gaps and activities undertaken by patients to improve healing and state of mind. A copy of the questionnaire is included as an addendum to this report. The results are summarized and retained as data for the development of the Centre and delivery of services and are contained in the body of this report.

RESULTS

General Observations from 65 cancer patients or caregivers responded. The responses are organized according to responses to each of the ten questions.

CONCLUSIONS

Our overall conclusion from this forum is that there is room for a Cancer Supportive Care Centre 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 on 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. As one respondent stated, ‘the paper beats you down, when you’re already down’.

RECOMMENDATIONS

The Advocacy Group for the formation of a Kamloops Cancer Supportive Care Centre recommend the following:

Continuation of the Community Engagement and Awareness process by holding more forums (in person or virtually) across the summer of 2020. Other stakeholder groups will be invited: Medical practitioners, the Business Community, Caregivers, Politicians, and the general public. Results will be gathered and collated with the results of the February 22 forum. Upon completion of the forums, the resulting report will be added to the body of evidence from the TRU research in order to build a complete picture for the development of a Kamloops Cancer Supportive Care Centre.

SURVEY QUESTIONS:

1. *What support or resources were provided to you, and your caregivers, to help you to understand your diagnosis?*

General Observations:

A summary of responses shows that most patients got information and support about their Diagnosis and Treatment, but that most received no support whatever in the Emotional, Financial, Physical, Care, Work, Legal, and Caregiver Support categories.

Two respondents received their cancer treatments outside of Kamloops; one in Brampton Ontario, and one in the United Kingdom. Their responses are included in the numbers above but it should be noted that both these patients responded ‘yes’ to almost every item. Note: McMillan Nurses are cancer-specific nurses assigned to patients upon diagnosis of cancer in the UK.

Several patients that were union members responded ‘yes’ to most supports received. In general union members received more supports than non-union members. Many respondents were self-employed, and worked in the ‘gig’ economy; these people reported fewer institutional supports available to them.

Patients responded that family support was crucial, and in most cases, was the only support they received for emotional and financial well-being.

Not one respondent said they received information about palliative care, even patients with metastatic disease. One stage IV patient sought out palliative care help through Interior Health, but was told she was ‘not advanced enough’. She then went to Hospice, and was told to come back when her disease was more advanced.

Almost all respondents wanted, but did not receive, holistic symptom management help.

Many respondents sought out and received supports in various categories only by diligent, assertive, and vigorous searches on their own. Many got information through friends and word-of-mouth. Nobody received information about Kamloops supports from the Kelowna Cancer Clinic. Many respondents expressed surprise that there was a social worker at the Kamloops Cancer Clinic who may have been available to help them.



2. What additional supports or information do you wish had been made available to you and your caregivers?

General Observations:

Most respondents reported needing more information and support in the area of Navigation of the medical system, Advocacy, and Support during Transition from treatment back to 'normal life'.

Exceptions to this included one person who had been diagnosed and treated for her cancer in the UK, where she was assigned a McMillian Nurse immediately upon diagnosis. This nurse was her navigator, advocate, and medical liaison for the duration of her treatment.

Many respondents mentioned needing extra supports in their interactions with the medical community throughout their treatment. Some of the help required, but not available, was: information about CBD and Cannabis for pain relief, Naturopathic/Holistic options, and information about the trajectory of their disease.

3. Do you have any lasting effects from your cancer experience? If yes, please briefly explain.

General Observations:

Participants were asked to identify if they had lasting effects from their cancer experience in each of the following categories: Physical, Emotional, Social, Professional, Financial, Legal. Caregiver Burnout, and other. In general, forum participants replied "Yes" to at least one lasting effect from their cancer experience. Most people ticked 'yes' to lasting physical, emotional and social effects. Many people indicated there were ongoing detrimental effects professionally.

In the category of "other", of the 8 people who responded 'yes', 4 people mentioned chronic pain, 2 people mentioned lasting emotional effects on children, 1 person mentioned the stress of having to be a self-advocate, and 1 person mentioned a marriage breakdown.

4. What do you do to manage these effects and

5. What resources or supports have been provided to you to help you manage these effects?

General Observations from Questions 4 and 5:

Every one of the respondents reported lasting effects from their cancer treatment, and when asked these questions – what do you do to manage these effects, and what resources have been provided to you to help you manage these effects, many of them responded with comments such as "live with it!" and "Nothing has been provided".

However a large number of respondents also availed themselves of various resources and supports available in Kamloops, many of which have been mentioned in the comments.

Overwhelmingly, respondents said that they had found these resources/people on their own, and stated that their 'journey' would have been made easier if they had known 'where to go for help' right from the start.

Only one person reported being referred to, and using, the services of Allied Health.

Some of the resources mentioned by participants are:

- Spirit Warriors Breast Cancer Survivor Dragon Boat Team
- Kamloops Breast Cancer Support Group (KBCSG)
- The Kamloops Run Club
- Melanoma Network of Canada
- Save Your Skin Foundation
- Sensational Survivors Cancer Survivors Exercise program run by the City of Kamloops (Jen Edgecombe)
- DR Leia-Stephens Survivorship Program
- Tracy Waddington, Social Worker, Kamloops Cancer Clinic
- Kamloops Cancer Connections – practitioners in Massage Therapy, Physiotherapy, Yoga, Acupuncture, and Counselling



**6. Following your treatment, what was your experience returning to your previous life?
Did you receive any support? If so, what?**

General Observations:

Interestingly, all participants interpreted this question as being about return to work. A couple of people said it didn't relate to them because they were already retired. Almost all participants reported feeling adrift after treatment was over. Nobody at all reported any BCCA-, Interior Health-, or family doctor- provided Transition Support after finishing treatment. During the forum, many participants expressed bewilderment as to what Transition Support might look like besides return-to-work support from their employers.

Only one survey respondent mentioned Transition Support. She found that through her own Internet searching at an organization called Callanish (www.Callanish.org) in Vancouver, which provided a week-long retreat, and provided what she called 'help with re-entry'.

7. During your cancer experience, list the things that were done well by the medical community.

General Observations:

Generally, with only a couple of exceptions, respondents were pleased with the treatment and services they received from BC Cancer and Interior Health providers. There were people who were without a family doctor whose experiences were not as positive as those with their own doctors. The fact that a lot of services were provided in Kelowna caused hardship financially. Respondents also reported that it was more difficult to build a relationship with doctors in another city.

8. During your cancer experience, what were the things that you feel were important and could have been done better?

General Observations:

Some patients reported not knowing about the future treatments and timelines and finding it difficult to get precise information from their medical teams. One patient fought for 6 months to be taken seriously by her doctor, because she was young and healthy. Another patient was essentially diagnosed by her dentist, because of signs of cancer manifesting in her gums. As well as these examples, there were other examples given of incidents that seemed to relate to the lack of communication between doctors and 'systems' as well as singular incidences of bad timing, poor communication, and lack of support with system navigation.

Overall, however, most respondents claimed that their medical treatment was excellent. Several people mentioned specific doctors by name for the exemplary care they received.

In general, many of the difficulties experienced by respondents during treatment can be traced to lack of personal support and navigating complex systems whilst undergoing treatments.

9. During your cancer experience, list the things that were done well by the medical community for your CAREGIVERS.

General Observations:

Two respondents who received their treatment in Brampton, Ontario and the UK stated that their own care was excellent and that their caregivers also received personal supports through the medical system.

Patients in Kamloops and Kelowna reported no caregiver support whatsoever. One person mentioned receiving help through the Bounce Back program, and another said the Chemo nurses was where he got the most help and information.

Many people expressed surprise that there might have been help available through the Social Worker at the Kamloops Cancer Clinic.

Almost all respondents stated that support for caregivers was essential but missing in the system.

10. During your cancer experience, what were the things that you feel were important for your CAREGIVERS, and could have been done better?

General Observations:

Some respondents wanted, and were unable to access help for their children during their treatment. Again, many people were not aware that there was a Social Worker available in the Kamloops Cancer Clinic.

Most people said that family and caregivers would have made their cancer experience so much easier. One person commented, 'the cancer patient ends up being the caregiver for the caregivers'.



Kamloops Cancer
Supportive *Care* Society

KAMLOOPS CANCER SUPPORTIVE CARE SOCIETY COMMUNITY FEEDBACK SURVEY MARCH 27, 2021

WHAT ALLIED HEALTH PROFESSIONALS ARE TELLING US

**REPORT PREPARED BY
KAMLOOPS CANCER SUPPORTIVE CARE SOCIETY**



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BACKGROUND

THE VISION

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RESEARCH METHODOLOGY

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This forum, scheduled for March 27, 2021 was aimed at Allied Health Professionals. Twenty nine (29) questionnaires were sent out via survey monkey to Allied Health Care Professionals, such as Physiotherapists, Counsellors, etc. 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.

Twenty one (21) questionnaires were completed and received back. Of the 21 questionnaires which were completed and received, 10 people responded yes to attending the Forum on Mar 27. It was decided to postpone the forum until a larger representative group could be assembled. However, there was still some important information to be gleaned from the survey responses, included below.

Questions: All participants received a questionnaire ahead of time, a mix of factual questions about their professional status, as well as questions asking them to share their thoughts, and their patients' feedback, about cancer supportive care. The questions focussed on support provided, support needed, gaps and activities undertaken by patients to improve healing and state of mind. The results are summarized and retained as data for the development of the Centre and delivery of services and are contained in the body of this report.

RESULTS

General Observations in this document are organized according to responses to each of the questions, but overall, 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

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.

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 can not 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?

Our conclusions from the responses to this survey suggest that there is room for a Cancer Supportive Care Centre 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.

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."

RECOMMENDATIONS

The Kamloops Cancer Supportive Care Society recommends the following:

Continuation of the Community Engagement and Awareness process by holding more forums (in person or virtually) across the summer of 2021. Other stakeholder groups will be invited: Medical practitioners, the Business Community, Caregivers, Politicians, and the general public. Results will be gathered and collated with the results of this survey, as well as the results of the February 22, 2020 forum. Upon completion of the forums, the resulting report will be added to the body of evidence from the TRU research in order to build a complete picture for the development of a Kamloops Cancer Supportive Care Centre.

SURVEY QUESTIONS

Q1. CONTACT INFORMATION – CONFIDENTIAL

Q2. WHAT IS YOUR OCCUPATION/PROFESSIONAL STATUS?

Acupuncturist	0	Breast Cancer Support Group Facilitator.	3
Alternative Energy Modalities Practitioner	2	Alternative Health Practitioner	1
Counsellor.	0	Kinesiologist	1
Massage Therapist	3	Nutritionist / Dietician	0
Occupational Therapist	0	Radiation Therapist	1
Respiratory Therapist.	0	Speech Therapist.	0
Physiotherapist	1	PT & Certified Lymphedema Therapist.	1
Specialty Garment Fitter	1	Yoga Instructor	1
School Psychologist.	1	Pilates Teacher	1
Naturopathic Physician	1	"Other" not specified	1



Q3. WOULD YOU LIKE TO RECEIVE UPDATES ON THIS PROJECT?

21 people replied yes.

Q4. WHAT KIND OF SERVICES DO YOU PROVIDE FOR CANCER PATIENTS AND/OR THEIR CAREGIVERS?

All 21 respondents provide care to cancer patients

16 respondents provide services to caregivers

Q5. HOW LONG HAVE YOU BEEN PROVIDING THESE SERVICES FOR?

Approximately 50% of respondents have provided care for more than 10 years in Kamloops

The other 50% have provided care for between 1-10 years

Q6. DO YOU CHARGE FOR YOUR SERVICES?

Q7. IF SO, HOW? CHECK ALL THAT APPLY:

Almost 70% of respondents charge directly for their services, the others are reimbursed through:

Direct payment from patient. 13

Direct payment through an insurance
or benefits company 5

You charge the patient, and they then get
reimbursement from another provider 7

Another 19 responses were shown including the following:

- ICBC, WorkSafeBC, Veteran's Affairs
- "I was employed as a contractor with the City of Kamloops. Participants paid through the City for program and the contractors were paid by the City. Subsidies are available for the program participants if needed."
- "Would love to volunteer and teach more classes to caregivers."
- "I have also worked for trade. If a patient cannot afford treatment, I have offered trade incentives where I am then allowed to use their medical file as a case study (keeping all personal information confidential)."
- "Don't charge for my services. I am employed by PHSA, BCCA"

Q8. HOW DO PEOPLE FIND YOU?

Family Doctor referral 13

Other Specialist Physician referral. 5

Canadian Cancer Society website 3

Word of mouth ("a friend told me"). 15

Other Responses: 9

Including:

- Through other local practitioners
- Information directory booklet
- City of Kamloops Activity Guide
- Their journey through the healthcare system
- Facebook
- Referrals from physics, osteopaths, chiropractors
- BC Lymphedema Association; other professionals - typically garment fitters, but also other RMT and PT colleagues.
- Employed by PHSA

Oncologist or Cancer Clinic referral. 11

BCCA website 1

Support Group referral. 7

Your own website or marketing efforts 13



Q9. DO YOU THINK THERE ARE ANY OTHER WAYS FOR CANCER PATIENTS AND CAREGIVERS TO FIND THEIR WAY TO YOU THAT DOES NOT EXIST RIGHT NOW? PLEASE EXPLAIN.

- Yes, it would be lovely to have a more centralized site, walking patients through the options available to them.
- I don't know- probably.
- Yes, straight from GP, surgeon or oncologist and hospital staff
- No
- Directory at the hospital, hospice or cancer clinic
- Not sure massage is very well utilized in regards to cancer. Would love to see that change
- Maybe networking with naturopaths, oncologists and other health care providers who deal with cancer patients
- We would love to have more promotion through all outside services. We would like to reach as many women who are recovering from or struggling with breast cancer treatments and outcomes.
- Providing a comprehensive list of contact information for current community-based resources that cover medical, emotional, social, legal, recreational needs
- I believe there should be a primary prevention cardiac group for post cancer treatment patients that are at higher risk for cardiac events.
- I keep it pretty low-key as I have over a year-long waitlist for new clients. My practice is focused on chronic pain and psychosomatic issues in the body related to trauma etc.
- Yes. 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.
- Through word of mouth
- Pre-operatively if oncologists could refer for screening would be ideal, secondly at the hospital post operatively to be at least provided with some education and signs and symptoms to watch for.
- It is probably more difficult to find us since the beginning of pandemic. Cannot meet in person for the last year. Zoom meetings monthly.
- Probably but not well known
- N/A
- Patient navigators
- Yes, straight from GP, surgeon or oncologist and hospital staff
- No

Q10. WHAT DO YOU THINK ARE THE DIFFICULTIES, IF ANY, THAT PREVENT CANCER PATIENTS AND CAREGIVERS FROM ACCESSING YOUR SERVICES?

- | | |
|---|--|
| • Transportation7 | • Too ill to come to your place of business 7 |
| • Lack of funds.7 | • Lack of benefits to cover the cost of services 12 |
| • Lack of knowledge that your services exist . . . 12 | • Lack of understanding about the benefits of your services . 17 |

Other responses included:

- Social stigmas around mental health, lack of understanding how cancer will impact one's mental health, focus on physical health . . . 1
- The program is currently not running due to COVID2
- I would say all of the above would be applicable when looking at allied health care services outside of Interior Health . . . 1
- Lack of dedicated (and educated) programming for this population 1



Q11. GIVEN YOUR UNDERSTANDING OF THE RANGE OF SERVICES PROVIDED TO CANCER PATIENTS AND CAREGIVERS IN KAMLOOPS, ARE THERE ANY GAPS IN CARE AND/OR POTENTIALLY BENEFICIAL SERVICES THAT ARE NOT CURRENTLY PROVIDED?

- Definitely an integrative clinic - somewhere patients can go where all the different modalities are located under one roof.
- Increased awareness for importance to access social/emotional support during treatment and recovery
- Gaps in care are referral program- education of oncologist and surgeons about benefits exercise rehab should be mandatory for those with cancer and available to those going through treatment- hugely =beneficial to quality of life and reduction of disability
- I find when patients arms are starting to swell with lymphedema, it does not seem of a great importance and the doctor often lets it go undiagnosed
- The siloed approach to cancer care is difficult to navigate as a patient. Mixed messages, conflicting information, lack of awareness of available services add to the frustration and isolation of an already terrifying experience. Over the years participants have reported: mixed messages with respect to post surgical recovery, lack of access to prehab and rehab post surgery, missed and conflicting information from different health care providers, lack of awareness of available services, and long waits between tests and treatment plans.
- Services vary and are dependent on many of the factors in the question above. I would also add a persons geographical location as many services are not available to folks who live in the surrounding areas. I often see occupational rehabilitation has a missing piece and is a much needed service to this population.
- Insurance coverage
- I think classes to assist caregivers in giving some relief to their loved ones would be very beneficial. I don't believe that happens? Always been interested and have taken continuing education in this also but haven't had (or made) the time to reach out and find a way to offer it. Also for palliative care I think would be amazing too
- Naturopathic doctors who specialize in oncology to help patients' immune systems respond better during and after treatments (I just recently moved to Kamloops so I'm not aware of any naturopaths who specialize in oncology or do IV therapy)
- Would like to see all services for cancer patients and their caregivers centrally located. Therapy, peer support, adjuvant services in one location would ease difficulties for persons struggling with their diagnoses.
- A coordinated, collaborative and inclusive approach to identifying on-going needs, publicizing supports within the community as well as problem-solving to eliminate obstacles would be so beneficial to patients and caregivers.
- As mentioned above there is a gap for cardiac primary prevention for post cancer treatment.
- More services available in Kamloops, I have many clients that have had to travel to Kelowna daily for treatments. Also, more mental health supports would be beneficial.
- Educational classes and support groups for caregivers. They are often overlooked and very often in need of care themselves. Knowledge is powerful, feeling useful and being able to physically help is powerful, but remembering to continue with self care is most important. They often overlook their own health issues while caring for their loved one. Best case scenario - they could simply remain the loved one and not have to facilitate "care".
- There should be a health professional managing the health care needs. Preventative and prescreening processes are overlooked. For example the best time to catch lymphedema is early. Treatment has the best chance when lymphedema is caught early. Prescreening would give the therapist a baseline to work from as cancer treatment progresses; it would take some of the guess work out. Educational seminars regularly run with repeating information, or progressive phases, on what to expect during and after cancer treatments. We don't know what we don't know and often in seminars questions get asked that we didn't know to know. There can be a lot more clarity in a professionally run seminar where the group can ask questions that benefit everyone than a simple piece of informational paperwork. Understanding the research. Understanding the value of good vs bad research. Learning to check your source and weed through the results from Dr. Google searches. It would be nice if there were a place to get help on dissecting valuable from worthless information. For example, it is highly unlikely that fat/grease from a black bear when applied to your scalp will increase hair growth rate. We could save people a lot of time, heart ache, and messy applications as well as one more black bear's life. The biggest gap comes in transition back to daily life (as you were) once all medical intervention is complete. There is no mechanism in place for true Return-to-Life. We have Return-to-Work mechanisms, but work was not the only thing in a person's life. To go from appointments and full-time observational care to no care once cleared of cancer is disjointed enough, but then there is no guidance or mental/emotional support mechanisms other than patients helping patients. Medical intervention is dropped cold-turkey style with no transitional support. Understanding between medical and naturopathy interventions. There is a feeling of competing professions instead of respectful collusion. Science based medicine should always remain the standard, but people are afraid and will try many things and even possibly postpone life-saving interventions because they fear them. If they turn to a ND for help, there should be automatic collusion with that patient's medical team. Supportive and collaborative care.



- A holistic approach to treating the person and not just the disease. There are more supportive measures and options when you live near a major cancer Center.
- Big gaps from treatment completion to survivorship or long term palliative care. Patients are often left feeling no support and GPS don't necessarily have the time and knowledge to support people to the fullest extent.
- The services are available but the issue is lack of knowledge they exist especially within the medical community (nursing, GP's, oncologist), as well as lack of understanding of the substantial benefit.
- Need an umbrella of care that is easily accessible to cancer patients and their caregivers. This is needed during active treatment and afterwards. E.g. a cancer support center
- Not sure
- DON'T THINK I CAN REALLY ADD TO THIS.
- Navigator Services to increase awareness of supportive care

Q12. PLEASE CHECK BELOW IF CANCER PATIENTS AND CAREGIVERS THEMSELVES HAVE INDICATED TO YOU THAT ANY OF THE SUPPORT SERVICES LISTED BELOW ARE REQUIRED. CHECK ALL THAT APPLY: NOTE: 20 PEOPLE RESPONDED TO THIS QUESTION. THE NUMBERS REPRESENT THE # OF PEOPLE WHO RESPONDED YES, THEY HAVE HEARD THIS PARTICULAR NEED FROM THEIR PATIENT(S).

- | | | | |
|---|----|--|----|
| • Help looking for Alternative Therapies. | 15 | • Help with understanding and interpreting medical information . | 15 |
| • Physical side effects & limitations of cancer & treatment . . . | 14 | • Emotional support (such as counselling) | 13 |
| • Pain management | 13 | • Massage Therapy | 12 |
| • Finding support groups | 11 | • Travel and accommodation costs to cover treatments . . | 11 |
| • Medication costs | 11 | • Nutrition and Dietetics | 11 |
| • Caregiver support for emotional needs | 10 | • Finding information about Clinical Trials | 10 |
| • Acupuncture | 9 | • Help with accessing medical records | 9 |
| • Physiotherapy | 9 | • Meditation | 9 |
| • Recreation for health. | 9 | • Peer support for caregivers | 9 |
| • Financial help to cover income loss. | 9 | • Workplace challenges and accommodations | 9 |
| • Assessment off post-treatment abilities to work | 8 | • Information on disability coverages | 8 |
| • Help with understanding Pharmacare & Prescriptions . . | 8 | • Help with understanding tax implications of health costs . . | 8 |
| • Workforce re-entry supports. | 7 | • Legal and financial resources for caregivers | 6 |
| • Help applying for Federal EI & Disability Benefits . . | 5 | • Obtaining spiritual support | 5 |
| • Fertility Support / Information | 5 | • Home and community care | 5 |
| • Palliative care | 5 | • Hospice care | 4 |
| • Help looking for a new job | 4 | • Speech Therapy | 4 |
| • Completion of Power of Attorney documents | 4 | • DNRs (Do Not Resuscitate) orders and/or No CPR forms . . | 3 |
| • Finding legal help for Representation Agreements . . | 3 | • Will creation / advice on updating wills | 2 |

Q13. IN YOUR OPINION, HOW EASY IS IT FOR CANCER PATIENTS TO NAVIGATE THE HEALTH CARE SYSTEM TO ACCESS AVAILABLE SUPPORT SERVICES?

- VERY EASY: information and referrals are provided by the GP or Oncologist 0
- EASY: as long as the patient understands where to find the information for referral 1
- DIFFICULT: it is not clear what information is available and/or how too access it in a timely manner 13
- VERY DIFFICULT OR IMPOSSIBLE: the patient does not have the wherewithal (energy, time, well-being or funds) to research options and seek out the services they require. 7



Q14. IN YOUR OPINION, WHAT ARE THE DIFFERENCES BETWEEN PATIENT SITUATIONS WHERE ONE PATIENT FINDS IT EASY TO ACCESS THE SUPPORTS THEY NEED, AND OTHERS FIND IT DIFFICULT OR IMPOSSIBLE?

- Severity of their condition, financial situation (greater flexibility in this regard makes it more feasible an option to look for further supports), individual knowledge prior of varying types of supports (for cancer specifically and otherwise)
- Previous knowledge of the medical system and/or a close family/friend who has knowledge of the medical system.
- Education level, SES status, family support, access to internet, belief that health and movement is important, not everyone can access the internet and search google or websites and needs additional support if they do not have a family member to help them.
- Patients with confidence, determination, a willingness to independently research their diagnosis and possible treatments, willingness to ask questions and have a great relationship with their primary HCP find the most ease in accessing supports they need.
- This is dependent on many of the determinants of health. Economic barriers, education, social supports, geographical location, where they are in their trajectory and their own understanding of their illness and openness to receive services, who is on their care team and their knowledge/understanding of cancer care and ability to advocate.
- Their ability to advocate for themselves
- Some are more resourceful and will seek it out. Others get overwhelmed by their diagnosis and just basic treatment can be enough for them.
- I think most resources are found online so the patients who usually are unable to find what they need are elderly and don't necessarily have access to a computer or understand how to find the information online.
- Some patients are excellent researchers and advocates for their own health or have family/friends that can do it for them. Others have neither the knowledge, funds, nor ability to locate available services.
- Mental and physical energy level, response to medication side effects, confidence in importance as a patient to question medical staff, medical staff response to patient questions, perseverance, perception of options available and/or offered, presence or lack of other significant life events and supports, access to others who have gone through cancer and can share stories of hope and recovery, as well as stories of medical complications and lessons learned
- Generally age of patient and whether or not they are technically savvy. Having a large circle to gather info from helps. If someone is on their own, it is up to them only to do the leg work and many don't know where to start.
- Supportive primary healthcare providers, education, self management and self advocacy.
- I think healthcare could do with trauma-informed workshops, some people are completely overwhelmed and do not retain the information when given, also how tech savvy someone seems to affect their access to services and information.
- Fatigue - the more fatigued, the less inclined to search. Education - the more education, be it on internet searching or ability to filter through government websites/jargon, the easier it flows.
- Finances - if finances are at-the-ready, they can access what they need, but that doesn't mean they are willing to part with their retirement savings to receive the treatments they require...so even if they have the finances, it doesn't mean they get the treatments.
- Extended Health Coverage - if they have it, they will use it.
- A few reasons. Ones own intellectual level of understanding. Literacy level. Cognitive changes/confusion due to disease and also medications etc.
- Often it seems to be luck. If a person knows someone that has accessed care they will likely get word of mouth referral to one of the community practitioners. From there we all refer around as needed quite well. Sometimes a GP will send for a compression garment and this is another way into the circle of cancer care services.
- Help from GP and specialists, having a supportive caregiver, education level and comfort level researching diagnosis and treatment
- Everyone faces a unique challenge caused by age, knowledge, understanding, emotional readiness, family/friend supports etc.



Q15. AS WE CONTINUE TO ADVOCATE FOR A CANCER SUPPORTIVE CARE CENTRE IN KAMLOOPS, WHAT CAN YOU TELL US FROM YOUR PERSONAL AND PROFESSIONAL EXPERIENCE THAT WILL HELP INFORM OUR MODEL OF CARE AND SERVICE PROVISION?

- I think it needs to be centralized - either with one building housing the services being offered or having a central person (s) to provide that guidance- of all of the practitioners in town focused on this type of care, the services they provide, access to financial supports if available, etc. Something that patients are directed to as soon as they're diagnosed so it removes the obstacle of having to try to find it themselves.
- Continuity of care, clarity around accessing care, importance of accessing supports for physical/emotional/social supports
- This 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.
- Those who have had support have a better outcome and attitude about living with cancer. This is a life altering diagnosis and is filled with anxiety and fear. It should absolutely be included in their program of care to have a nurse navigator and network of community supports.
- Patients need a one stop shop to help them navigate their cancer journey. A CSCC in Kamloops would offer a place to go, a contact for patients to help them get a sense of the process, understand what comes next, a contact to reach out to for support in any capacity (counselling, post surgery rehab, exercise, medication information, clinical trials...). ONE place, a constant contact to have access to information, to answer questions, to direct the patient to appropriate and available services.
- The biggest factor in ensuring success would be to establish good communication systems with internal/external care partners, establish and streamline processes to allow easy navigation, access and equitably to the various services while using a person centered approach to care. The model would be to ensure care is active and that people are companioned through each stage of illness and recovery.
- Would be lovely to have all the resources and support in one place so everyone knows how to find the information. And all health practitioners. Alternative or not would have the information to share with their clients as well.
- As a former patient that did not know where or how to find services, I believe that the first line must be our physicians and specialists. They need to know where services can be found and at this time these are very scattered or lacking. This information should be available in one place, preferably a brick and board building, that is known as the place to access all information for all types of cancer. It would also have space to offer therapy, peer support, massage, etc. at no cost to the patient.
- The ultimate experience I wish for myself and others is that of an individualized and wholistic approach, where patient time and energy can go into healing much more than in chasing down answers to concerns. A cancer diagnosis, and in the cases of re-diagnosis, is typically preceded and followed by a flurry of medical testing and treatment. This can easily overwhelm other aspects of life. It is my hope that a Cancer Supportive Care Center in Kamloops will help provide services to complement and balance the patient medical needs with the many other important slices of life for overall wellness.
- I think having more services in Kamloops so that people from the surrounding area do not need to travel as far every day would make a large impact.
- The number one thing that would help in all areas would be a nurse navigator. Best case scenario, the Model of Care includes body, mind and soul; links to all supports available within our community; inclusion of medical and allied health supports. There needs to be support pre-, during, and post-cancer treatment with transitional support assisted by a medical professional (nurse navigator) for all stages while being the role model for how medical and allied medical can work together in the best interests of the patients.
- This is a much needed service even as Kamloops cancer services expand to radiation therapy. As patients move through the BCCA system, they are also moved out once active treatment is completed. Oncologists don't necessarily have the time to review things with patients who aren't on active treatment. So regardless we NEED this service. But we also need to be willing to provide care from a holistic approach and include all different types of allied health professionals, fee for service or not. This is truly a team centred approach, with the patient as the Center of care.



- Personally, I found it very difficult to understand what services my family member would even need outside of the typical chemo, surgery and radiation. I believe that all cancer patients have the right to be educated on the entire disease process and this includes what happens after the medical portion is complete. I believe education sessions should be offered monthly for people diagnosed so that they can learn more and have a connection to access supportive services available.
- There is support available during active treatment, but afterwards the patient is left alone to navigate their “new normal” including side effects and complications of treatment
- There is a wide gap in the personal services that are available and the patients. Patients are not able to find out about the services and then obtain access to them.
- Remember to be “patient/family centered”. Each diagnosis of “cancer” can be different, so not every approach will be the same.