

# Positive Cancer Experiences: Perspectives From Cancer Survivors

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## Abstract

The purpose was to review the perspectives of cancer survivors about what they perceive constitutes positive cancer experiences. A national survey was conducted in collaboration with 10 Canadian provinces to identify experiences and unmet needs for cancer survivors between 1 and 3 years of posttreatment. The survey included open-ended questions designed to allow the respondents to add topics and details of importance. This publication presents the analysis of quantitative data and open-ended questions regarding cancer survivors' perspectives about positive experiences and gaps in care during their cancer journey. Of the 13 534 unique adult survey respondents, 7794 (57.6%) responded to the positive experiences question and 6434 (47.5%) to the question about gaps in care. Elements of positive experiences included the compassionate health care workers, maintaining a positive outlook and the support of family and friends. Gaps in care included a lack of access to services, information, and support. Respondents were able to identify positive aspects of their cancer experiences and where improvements were needed. These findings assist in determining how health care professionals can address the needs of cancer patients based on what survivors have identified as helpful.

## Keywords

patient perspectives, positive cancer experiences, transitions in care, integrated care, survivorship care

## Introduction

More than 2.1 million Canadian cancer survivors are alive today, and this number is expected to grow in the coming years (1–3). Advances in science and treatments have changed the face of cancer survivorship and herald renewed hope for the future.

Cancer survivors possess a wisdom about cancer and the cancer care system that comes from having lived through the process of being diagnosed, treated, and followed after treatment. Capturing such wisdom has the potential to help cancer service planning. These individuals can provide insight into what constitutes a “positive” experience during the cancer journey and where there is room for improvement in services. Additionally, there is a growing consensus that recipients of care must provide input into what constitutes quality and effectiveness of care (4,5).

Several investigations have begun to shed light on what constitutes “positive” patient experiences during cancer from the patient perspective. Findings are similar across investigations and suggest there are consistent views on this topic from patients in different parts of the world. Wagland et al described themes regarding positive cancer care based

on qualitative analysis from 5634 comments (25% of UK colorectal respondents surveyed): timely diagnosis, emotional support, coordinated care, patient preparation and sign-posting, and good quality treatment follow-up care (6). Appleton et al reported interview-based findings with 30 Australian lung, colorectal, and head and neck cancer patients concerning what contributes to positive well-being (7). The overarching theme described *being in safe hands* and contained subthemes of interactions with staff (emotional support and rapport), navigating unfamiliar environments, organizational routines, solidarity with other patients, and feeling informed. Fitch et al identified themes concerning positive experiences from written comments of 6232 Canadian cancer patients (8). Respondents cited being

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treated as a person with respect and dignity, clear communication, access to relevant and timely information, and taking their needs into account as important. Communication, consistency, and ongoing consistent interactions with staff were highlighted as essential elements of a positive experience, yet areas where improvements are necessary. Similarly, it would be valuable to have survivors comment on what they perceive as positive and helpful about their cancer experiences.

## Purpose

The Canadian Partnership Against Cancer explored experiences of cancer survivors 1 to 3 years following primary cancer treatment (9). Respondents were asked to identify 1 positive experience and 2 suggestions for improvement in their care. This paper will report results from these questions with a view to sharing cancer survivor perspectives about what they perceive contributes to a positive cancer experience. We anticipated the information would add to understanding what cancer survivors consider important and where we can make improvements that would enhance the patient experience.

## Methods

The Canadian Partnership Against Cancer undertook to explore cancer survivors' experiences 1 to 3 years following completion of cancer treatment. Detailed description of the rationale and methods is available in a previous publication (9). In brief, a survey was distributed to a randomly selected sample of 40 790 cancer survivors across 10 Canadian provinces. The sample included adults survivors (aged 30+) of breast, prostate, colorectal, and melanoma diseases with no metastatic spread and selected hematological cancers and adolescents and young adults (18-29 years) with all nonmetastatic cancer types except testes, where the metastatic disease was included. The survey was designed to assess experiences of cancer survivors, identify their needs, and explore transitioning to follow-up care. The experiences could draw from their attending cancer care facilities in hospitals, ambulatory cancer clinics, and primary care practitioners. Ethics approval was given by the respective ethics boards of the 10 provincial cancer agencies participating in survey distribution. Participants provided consent prior to completing the survey.

This paper focuses on 2 open-ended survey questions. One asked the respondents to identify and describe an experience during their follow-up care they perceived as positive and would benefit other patients or survivors. The other question asked the respondents to identify the 2 most important things that could have been done, that were not done, to help them deal with their needs after cancer treatment. Taken together, the observations from both questions pinpoint what contributes to a positive cancer experience.

## Analysis

The work utilized a mixed quantitative/qualitative approach (10). First, responses to open-ended questions were tabulated to determine the number of comments for each question. The written comments for each question were then subjected to standard content and thematic analysis (11). After reading through 10% of the comments in each question, a coding framework was developed specifically to the question. Subsequently, all the written comments were reviewed and coded according to the respective framework categories. Coding was completed by 1 investigator with expertise in qualitative methods (M.I.F.) and reviewed by another investigator (I.N.). The comments coded into each category were reviewed and the key messages or themes were identified within the categories for each question. All investigators reviewed and discussed the themes. Finally, data from both questions were reviewed to identify common perspectives about aspects constituting positive experiences.

It should be noted that although respondents were asked to respond to the questions about the time period following the completion of treatment, many wrote comments about the intervals related to diagnosis and receiving treatment. Consequently, the analysis evolved themes with applicability across the cancer trajectory related to what constitutes a positive experience. Where comments concerned the survivorship interval specifically, these are noted.

## Results

### Sample

In total, 13 534 surveys were completed. This differs from the published report (9) because additional surveys received after data collection were closed for the initial analysis. The additional surveys were added for this study to maximize the amount of open-ended data. Of the 13 534 unique survey respondents, 7794 (57.6%) responded to the positive experience question and 6434 (47.5%) responded to the question about what could have happened to meet their needs that did not occur. In total, 8936 respondents are included in this report.

Respondents included in this report were predominantly adults aged 30+ years (97%) and were 55 years of age or older (80%; Table 1). Fifty-five percent were female. Fifty-two percent indicated their cancer treatment had occurred between 1 and 3 years previously. Breast cancer (30%) and prostate cancer (25%) patients accounted for the largest respondent groups. The profile of this sample was largely similar to the full sample of surveys received (Table 1).

### Positive Examples—Frequency of Responses

The 7794 respondents who answered this question generated a total of 9606 answers regarding instances they perceived as positive as many cited more than 1 instance (Table 2).

The most frequently cited positive example concerned having health care professionals whom respondents thought were knowledgeable about what was happening to them as

**Table 1.** Respondent Characteristics.

Variable	Respondents included in this report (n = 8936)		All respondents to survey (n = 13 534)	
	Number	Percentage	Number	Percentage
Sex				
- Male	3987	45.1	6411	48.5
- Female	4853	54.9	6820	51.5
- No answer	96		303	-
Age				
- 18-29	262	3.0	329	2.5
- 30-54	1478	16.7	1802	13.6
- 55-74	5300	59.9	7853	59.2
- 75 +	1815	20.5	3274	24.7
- No answer	81	-	276	-
Disease site <sup>a</sup>				
- Breast	2832	32.9	3780	30.2
- Prostate	1916	22.3	3079	24.6
- CRC	1583	18.4	2595	20.7
- Hematological	827	9.6	1153	9.2
- Melanoma	974	11.3	1527	12.2
- Other	467	5.4	661	5.3
- Missing	337	-	1016	-
Metastases				
- No metastases	6940	81.7	10 192	81.2
- Living with metastases	847	10.0	1223	9.7
- Unsure	703	8.3	1136	9.1
- Missing	446	-	983	-
Time since treatment				
- <1 year	1045	12.1	1,519	11.9
- 1 year to <3 years	4453	51.6	6148	48.0
- 3 years or more	2274	26.3	3242	25.3
- Did not receive treatment	863	10.0	1888	14.8
- Missing	301	-	737	-

Abbreviation: CRC, colorectal cancer.

<sup>a</sup>Percentages more than 100% because patient/survivors can be included in more than 1 site. Other category contains those who chose site(s) not of 5 shown.

survivors (n = 2074). These health care providers showed an understanding of what the survivor was experiencing and did not dismiss their concerns. The second most frequently cited positive example was described as the survivor maintaining a positive outlook throughout the cancer experience (n = 1626). This positive outlook was a function of the individual working to hold such a viewpoint or hearing “good news” about their treatment results (eg, *my cancer is cured*). The other frequently identified positive examples included support from family and friends (n = 1241) and organized follow-up care from selected health care providers (n = 1042).

Despite the request to describe a positive experience, 10.8% of the respondents wrote negative comments, indicated *there was nothing positive about the experience* or wrote they could not think of anything to describe. However, very few actually added details about significant negative aspects.

### Gaps in Care—Frequency of Responses

Of the 6434 respondents who answered this question, 9651 responses were generated (Table 3). These included 7331 specific suggestions regarding the most important things that

could have been done, that were not done, to help the survivors deal with concerns after cancer treatment. Many respondents wrote *no suggestions* (n = 700) or solely offered praise for the health care professionals or cancer center (n = 1620). Their comments emphasized the value of compassionate, caring and knowledgeable staff members, and the importance of taking time for personalized communication.

The most frequently cited topics focused on gaps in relevant information/personalized communication (n = 2424) and follow-up care (n = 1379). The next highest number of responses concerned the need for access to support/programs (n = 744), access to selected health care providers (n = 690), and changes in clinic/hospital service organization (n = 616).

### Contributions to Positive Experience—Themes

The written comments from both questions offered insight regarding what constitutes a positive experience from the survivors’ perspective. The descriptions about what was experienced as positive and the descriptions about what did not happen that would have been helpful were often about the same topics. Therefore, the major themes described

**Table 2.** Responses When Asked to Describe a Positive Experience.

Province Category	Subtotal	Total
Positive experiences		
Health care providers knowledgeable about what was happening to the survivor	2074	
Able to maintain a positive outlook	1626	
Support from family and friends	1241	
Organized/scheduled follow-up care	1042	
Support (various types—emotional to practical)	745	
Relevant Information/personal communication	698	
Support from cancer survivors/peers	481	
Access to alternative therapies	415	
Health care provider support (care and compassion) for survivors as individuals	379	
Regaining personal health/wellness	264	
Participating in research/trials/tests	250	
Clinic/hospital services organized and coordinated; short wait times	145	
Other—comments about an individual’s situations/status	94	
Positive general comment about the care being good	64	
Not being afraid to ask for help	56	
Financial support available	30	
Transportation support	2	
Total positive comments		9606
Negative responses		
Negative comment (ie, experience difficult; care poor, HCP who was non-supportive)	531	
Nothing positive experienced/ no examples of positive experiences	267	
No follow-up care occurred/still waiting for something to happen	46	
Total negative/blank responses		844
Total responses		10 450

Abbreviation: HCP, health care provider.

below draw from the responses to both questions. Examples of respondents’ comments are shown in Table 4.

*Caring and compassionate health care providers.* Respondents described health care providers who showed compassion and caring and whom respondents perceived were knowledgeable about what was happening with them. This was evident in how providers listened and responded to their concerns. Specifically, providers were praised who used an open communication style, accepted any question, engaged in discussion about the patient’s concerns, and were accessible. Negative comments about non-supportive health care providers focused on how these attributes were absent.

*Benefits of a positive outlook.* Many respondents wrote about the importance of maintaining a positive outlook throughout the cancer journey. They took this upon themselves to work on and felt that other cancer patients would benefit from

**Table 3.** What Would Have Been Helpful But Was Not Provided.

What did not happen but could have been helpful to meet needs Category	Subtotal	Total
Identified gaps in care		
Need for more information/personal communication	2424	
Follow-up care (eg, plans, schedules, tests expected)	1379	
Support (lack of access to programs, especially for mental health issues)	744	
Health care providers (eg, availability of various providers)	690	
Efficiency of clinic/hospital services (eg, test results, appointment scheduling, access to treatments, coordination between departments)	616	
Financial support (eg, information, programs, return to work assistance)	342	
Emotional support (eg, professional services, support groups)	268	
Posttreatment programs (eg, access to rehabilitation/support programs)	196	
Need for compassionate and caring health provider interactions	137	
Timely, easy access/scheduling for procedures	135	
Support for family and friends support programs, counselling	129	
More timely referrals/access to specialists	92	
Self-care/well-being	62	
Other (comments related to an individual’s status or condition)	56	
Practical needs (assistance with household chores, personal care, yard work, grocery shopping)	44	
Access to nutrition/diet services	8	
Access to alternative therapies	5	
Negative comments (eg, experience difficult, poor/non-supportive health team)	3	
Research (more clinical trials and participation)	1	
Total negative comments		7331
Neutral/positive responses		
Positive comment (comments about the care being excellent/satisfying)	1620	
Wrote: “No suggestions”/“nothing to add”	700	
Total neutral/positive comments		2320
Total		9651

holding a similar perspective. Survivors perceived that holding a positive outlook allowed them to move through the cancer experience more easily and look forward to the future. It helped them avoid some of the distress and upset they observed in others. In particular, regaining their energy and well-being following cancer treatment contributed to their positive outlook. As they found they were able to engage in former activities, they felt renewed.

*Importance of family and friends.* Respondents found that a very positive part of their cancer experience was receiving

**Table 4.** Examples of Positive Cancer Experiences: Major Themes.

Positive experiences	Positive comments What was noted as helpful:	Negative comments What would have been helpful (but what did not happen):
Caring and compassionate health care providers	<ul style="list-style-type: none"> <li>• <i>I continue to have excellent, accessible and open communication with my oncologist and my primary care physician. Being able to ask questions and receive answers in a reasonable time frame is very helpful</i></li> <li>• <i>My doctor . . . was a very wonderful person, she somehow knew what I needed to hear without asking the obvious questions</i></li> <li>• <i>The cancer navigation nurse is an indispensable position that was available should the need arise. I always knew she was on my side</i></li> <li>• <i>Easy access to family doctor who took the time to listen and share</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>I should have been told of the lasting effects of cancer/chemotherapy treatments</i></li> <li>• <i>My first oncologist was not forthcoming about possible side effects. I had to research what was wrong with me!</i></li> <li>• <i>Surgeon and nurse had no time to address my concerns; appointments were very rushed</i></li> <li>• <i>I would have liked to have had some interest in my well-being</i></li> </ul>
Maintaining a positive outlook	<ul style="list-style-type: none"> <li>• <i>Keep close contact with doctor/surgeon and people who are positive in attitude!</i></li> <li>• <i>I would recommend to anyone going through treatment to always remain positive, attitude is everything, and to be pro-active in all aspect of their cancer treatment</i></li> <li>• <i>I always felt very fortunate that my cancer was treatable and curable, so never felt sorry for myself and this helped me have a positive outlook, which I think is very important</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>None reported</i></li> </ul>
Importance of family and friends	<ul style="list-style-type: none"> <li>• <i>Having a good husband, friends and family is very important. I have a sister I called on every day</i></li> <li>• <i>SPOUSE was the most important support</i></li> <li>• <i>The positive emotional backing of family and friends</i></li> <li>• <i>I had a very close group of friends that could call, visit and take me for coffee</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>None reported</i></li> </ul>
Access to relevant support and posttreatment programs	<ul style="list-style-type: none"> <li>• <i>If there is someone that is going through the cancer at the same time as you, it is nice to compare notes and be supportive to each other</i></li> <li>• <i>Being set up with a physiotherapy program to work on getting my body fit</i></li> <li>• <i>Dietary and fitness workshops offered post-treatment. Ongoing workshops to learn about eating and fitness</i></li> <li>• <i>Understanding from practitioners of the devastating fear and your need to reach out to them</i></li> <li>• <i>A one-on-one caseworker (social worker) assigned to connect with me from day one, and routinely follow-up with ongoing issues and challenges</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>There should be some support for family members as it greatly affects everyone in the family. They go through the fear of losing their loved ones</i></li> <li>• <i>Would have appreciated more supports, from a nurse practitioner or a support group</i></li> <li>• <i>Though counselling is offered after treatment, consider one mandatory one-on-one session. Not always recognizing that one may need it</i></li> <li>• <i>No support group was available in [city] for my age group that had similar diagnosis</i></li> <li>• <i>I should have had more counseling and more regularly, like once a week to deal with going back to my life and with my relationship issues that arose from my illness</i></li> </ul>
Knowing what to expect/ having access to relevant information	<ul style="list-style-type: none"> <li>• <i>I was always well informed and provided with lots of information regarding cancer/treatment and support services available</i></li> <li>• <i>As I was involved in trial treatment, follow-up was/is ongoing every three months. This is very reassuring emotionally</i></li> <li>• <i>Telephone support group provided me with excellent information</i></li> <li>• <i>Clear explanation from dermatologist as to why cancer should not likely return</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>More info on treatment, downsides upsides of treatment, future treatments, impacts on life style</i></li> <li>• <i>Everyone reacts differently, I understand, but I did not realize the amount of pain/discomfort and fatigue that would remain</i></li> <li>• <i>I went weeks thinking I would never be able to dress myself or walk due to neuropathy</i></li> <li>• <i>In my case—it has taken two years to feel more “normal”—I needed to know it would/could take that long—I didn’t</i></li> </ul>

(continued)

**Table 4.** (continued)

Positive experiences	Positive comments What was noted as helpful:	Negative comments What would have been helpful (but what did not happen):
Efficiency of Clinic/ Hospital Services/ Organization	<ul style="list-style-type: none"> <li>• <i>The appointment times were held very reliable by Cancer Clinic</i></li> <li>• <i>Knowing I could call my cancer clinic at any time and have my problems dealt with. The staff there are awesome!!!</i></li> <li>• <i>There was good communication at the Cancer clinic—among the staff and the client</i></li> <li>• <i>I was offered counseling, both for me and my family. Dietary help, pain management, financial assistance and information, details about surgery and what to expect, a plan for radiation and chemo</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>Higher quality, timely response from the general staff working in the local cancer center</i></li> <li>• <i>No access to cancer clinic on weekends and holidays.</i></li> <li>• <i>Coordination between all the doctors and related parties dealing with your case. I had to do a lot of follow-up on my own and seemed not a priority after treatment</i></li> <li>• <i>Appointments could have been better coordinated. Gene testing time could have been improved</i></li> </ul>

support from their family and friends. They saw this support as invaluable and making a huge difference in their ability to cope. The support took many forms from accompanying them to appointments, providing emotional support, and offering tangible assistance such as drives and personal care. Many respondents noted that family members also require support and recommended tailored programs to help them cope.

**Support from peers and programs.** Respondents described receiving support from peers, in formal support programs, or community-based support groups, as critically important. Being able to share experiences and stories with others was most helpful, either one-on-one or in group settings. Additionally, many respondents indicated that access to professional support was helpful.

Respondents made many suggestions regarding access to support programs and groups to help with adjustment during treatment as well as following cancer treatment. One respondent wrote “Every cancer patient should be provided with a list of services”. Both professionally led and peer-based programs were cited as useful, and access to psychology, social work, or other counselling professional was seen as important. It was positive to have these services considered part of cancer care and available locally at no/low cost.

Posttreatment access to physiotherapy and nutrition for regaining strength and recovering from treatment was emphasized. Nutrition was seen as an important strategy in the prevention of recurrence. Many survivors wanted to make lifestyle adjustments and required help to learn what they ought to do. It was seen as positive to have programs such as yoga, massage, general exercise, and wellness designed for cancer survivors and available locally.

**Knowing what to expect.** Respondents described the value of knowing what to expect and not being *caught off guard*. Knowing about tests and appointment schedules, what will happen after surgery and treatments, what side effect can

occur, the recovery process, and who was in charge of their care was helpful. In particular, survivors who knew about transitioning to survivorship care ahead of time found the information invaluable. Some attended programs about survivorship and found it helped to prepare for transition. They appreciated clarity regarding follow-up plans and schedules, what tests they needed and respective time frames. Monitoring reflected a safeguard for them in reference to recurrence.

Many survivors found themselves surprised following cancer treatment when new symptoms or side effects emerged and they had not been warned to expect them or where to turn for help with them. Additionally, if something should occur and recurrence was suspected, they wanted assurance they would be able to access the cancer specialist quickly. Survivors indicated it was helpful when providers shared relevant information and discussed its potential impact on them specifically.

**Improving clinic/hospital organization of services.** Suggestions respondents made regarding clinic and hospital services focused on organization and communication throughout the cancer experience. Respondents felt confident in their care when appointment scheduling was efficient, access to specialist appointments and test procedures occurred without extensive wait times, and departments coordinated their efforts. Cancer center communication was considered positive when the centers contacted patients proactively about changes, especially in scheduling. Follow-up appointments or telephone calls to check-in with survivors and determine any issues was helpful. Access to telemedicine and videoconferencing were important as patients did not have to travel for appointments, especially during the follow-up period when appointments tend to be brief.

## Discussion

Analysis of open-ended questions provides opportunity to understand what respondents consider positive or helpful

during their cancer experience. The large sample of respondents across the country offered perspectives about experiences within a range of cancer programs. Many responses for these 2 questions (ie, what was positive, what was helpful) covered similar topic areas and reflected aspects of patient-centered care (12,13). The topics have also been reported as important in other investigations regarding patient experiences (4,6,14–19).

Descriptions regarding positive and negative experiences emphasize the variation which currently exists in practice. One could argue descriptions reflect pockets of excellence in patient-centered care as well as places where there are ongoing gaps and improvements could impact patient experience. Consideration of the perspectives from this study provides opportunities for cancer centers to identify gaps in care delivery or service.

Data provide insight regarding improvements which could be made during the diagnosis and treatment and survivorship care that would enhance the patient experience. Some of the ideas respondents shared about improvements during the diagnosis and treatment have been cited in previous reports: caring and compassionate communication with health care professionals, access to relevant information and personalized support, and coordinated efforts with appointment scheduling and tests (6–8,20–22). Newer insight about positive experiences emerged from the commentary about patients being able to maintain a positive outlook and receiving support from family and friends. This observation raises questions about how these aspects could be supported and enhanced/enlarged by health care professionals.

Three suggested areas of improvement emerged that could have significant impact on experience for survivors: communication with knowledgeable health care professionals, provision of relevant information, and availability of services designed for survivors that focus on healing and recovery. Ensuring health care professionals are knowledgeable about the needs of survivors, skilled in person-centered communication, and have opportunities to discuss plans for follow-up with survivors have been recommended (14,19). Instruction in self-care management has also been emphasized as important in helping survivors know what to expect to be prepared for handling emergent symptoms and side effects following treatment (23). Finally, innovation is needed to develop services which assist survivors in transitioning to survivorship and recovery (24–26). Specifically formalized steps to identify those most in need of intervention could be taken within cancer programs as individuals near the end of their treatment and survivorship preparation training offered (27,28).

This work has the potential to contribute to the development and design enhancement of instruments to assess patient experience or patient satisfaction. Gathering such data using standardized measures could assist with quality improvement initiatives and incorporating patient perspectives in care (29).

## Limitations

Although the survey focused on 1 to 3 years following cancer treatment, authors cannot verify whether respondents' answers about positive experiences or gaps in care focused on this period only or situations experienced during cancer treatment.

## Conclusion

Clearly, respondents were able to identify experiences they perceived as positive including compassionate communication, access to relevant information, and access to services. These findings can inform cancer care providers understanding about what survivors believe would be helpful and be able to focus improvement efforts on interventions to influence positive aspects of cancer patient experience.

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