

CANCER SURVIVOR FOCUS GROUP STUDY

PRESENTED TO:
VERMONT DEPARTMENT OF HEALTH
AND
VERMONTERS TAKING ACTION AGAINST CANCER

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"It's a journey".¹

INTRODUCTION

The Vermont Department of Health and Vermonters Taking Action Against Cancer (VTAAC) commissioned consultant Erica Garfin to conduct a focus group study to gather information from cancer survivors in Vermont about their experiences and needs. The focus group study grew out of VTAAC's recently-created state cancer plan, which identifies improving the quality of life for cancer survivors as one of its priorities. The information gathered by the study will be used to assist the state in developing strategies to meet the needs that have been identified.

This report describes the findings from six focus groups that were conducted in June 2006. As with all qualitative research, the findings are to be viewed as suggestive rather than definitive. Because the participants are not randomly selected and the sample sizes are small, the results are not statistically generalizable to the entire population of cancer survivors in Vermont.

A small advisory committee provided input and feedback on the development of the research design, recruitment plan, and discussion guide. Thanks go to David Cranmer and Ellen Fein, from the Vermont Cancer Survivors Network, and John Olson, from the Vermont Department of Health, who served in that capacity.

Without the help of the dedicated individuals who recruited participants for the focus group sessions around the state, this project could not have gone forward: Tracy Adams, Rose Colletti, David Cranmer, Ellen Fein, Leslie MacMurtry, Katie McGreevey, Erica Tamblini, and Amy Yavitz.

Special thanks go to the focus group participants for openly sharing their experiences and perceptions and for the support they provided to one another in the process.

Because this study's findings will be used to guide efforts aimed at meeting the needs of cancer survivors, the emphasis of the report is on the unmet needs and challenges that confront cancer survivors. It is important to note that focus group participants also told many positive stories about their experiences.

¹ Throughout the report, verbatim quotes from participants appear in *italics*.

STUDY DESIGN AND IMPLEMENTATION

The study design utilized six focus groups. Sites were selected in heterogeneous regions in an effort to learn how the experiences of cancer survivors may vary according to geographic region, urban or rural character, and level of medical and support services available.

Table 1. Focus Group Locations and Regional Characteristics

Location	Level of service available in region
Bennington	hospital-based community cancer center, including radiation service; previously—medical humanist
Colchester	comprehensive cancer center/academic medical center; urban
Montpelier	2 medical oncologists; cancer coach; no designated oncology beds; no radiation
Newport	part-time oncologist; nurse-coordinator; very rural; no radiation
Rutland	hospital-based community cancer center, including radiation service
VT Cancer Survivor Network	varied (statewide representation)

Fifty-one (51) individuals participated in the six focus groups. Eighty percent (80%) were female and 20% were male. Ages ranged from 21 to 83 years old. Time since initial cancer diagnosis ranged from 6 months to 22 years.

Table 2. Focus Group Composition

Location	Men	Women	Total no. of participants
Bennington	0	13	13
Colchester	1	6	7
Montpelier	1	7	8
Newport	2	6	8
Rutland	6	4	10
VT Cancer Survivor Network (statewide)	0	5	5
Total	10	41	51

A range of cancer diagnoses was represented among the participants, as well as a mix of stages of survivorship² (e.g., newly diagnosed; in remission; finished with

² The term cancer survivor refers to individuals from the time of diagnosis through the remaining years of life.

treatment; cancer considered permanently arrested; living with chronic disease or side effects; experiencing relapse, recurrence, metastasis, or secondary cancers; at the end of life). Thirteen (13) participants reported experiencing secondary cancers or metastases currently or in the past. A number of participants reported experiencing one or multiple recurrences of their primary cancer currently or in the past. Several participants also spoke about their experiences with their spouse's or children's cancers. Breast and prostate cancer survivors comprised the greatest numbers of participants. This is not surprising since they are the most prevalent cancers among women and men, respectively. These were followed by lung, melanoma, and colon cancer survivors. Those cancers are the next most prevalent cancers across both sexes.

Table 3. Cancer Diagnoses Represented

Cancer diagnosis	Primary diagnosis	Secondary diagnosis/metastasis
Breast	24	
Prostate	7	
Lung	3	2
Bone		4
Melanoma	3	
Colon	3	
Pancreatic	2	
Lymphoma, non-Hodgkins	2	
Ovarian		2
Liver		2
Anal canal	1	
Brain		1
Endometrial	1	
Leukemia, acute lymphoblastic	1	
Lymph		1
Lymphoma, Hodgkins	1	
Multiple myeloma	1	
Ureter		1
Uterine	1	
Uncertain	1	

The focus group study was designed to provide information about the following research questions. The research questions were developed in consultation with the advisory committee.

1. What are the needs of cancer survivors in Vermont in the following domains?
 - a. Treatment
 - b. Information and decision-support
 - c. Emotional, social, and spiritual
 - d. Physical
 - e. Activities and logistics of daily life

- f. Health and wellness
 - g. Economic and legal
 - h. Navigating service delivery systems
2. To what extent do cancer survivors feel that their needs are being met?
 3. Do demographic characteristics have an impact on the experiences of cancer survivors in Vermont?
 4. Do needs vary among cancer survivors by stage of survivorship?
 5. What are the barriers to receiving needed services and supports?

A discussion guide that was created with feedback from the advisory committee was used in all of the focus groups to elicit information relevant to the research questions. (*See Appendix.*) Participants generally had a great deal to say. As a result, the scope of the questioning frequently proved overly ambitious for the two-hour time frame available for each focus group session. Where that was the case, the consultant concentrated on eliciting responses on the topics that had been identified as priorities by the advisory committee.

The original recruitment plan was predicated upon using existing local cancer support groups and the statewide Vermont Cancer Survivor Network as the basis for the focus groups. After a number of dead ends were reached in pursuit of that plan, it became evident that no comprehensive list of support groups is maintained in Vermont. Where existing support groups could not be found, advisory committee members and cancer center nurses and social workers were called upon to recruit individuals to participate in the focus groups.

Participants were paid a \$40 stipend as an incentive to participate and refreshments were provided as an additional incentive. Participation on the dates of the focus groups was high, with 88% attendance among those who had agreed to participate.

The focus group sessions were tape recorded, with permission from the participants, and transcribed verbatim for the consultant's use in analyzing the findings.

FINDINGS

SUPPORT

The predominant theme across all of the focus groups is that support plays a critical role for cancer survivors, yet the need is not well met in many parts of the state.

Many participants talked about the support that had been provided by their families. Friends played an important role for many, and some survivors described networks of friends who rallied as a team and provided a variety of supports.

Participants described other cancer survivors as giving a kind of support that can only be provided by one who has been through it. Peers not only provide emotional support but were frequently identified as the best source of information about what to expect, side effects, resources, programs, and evaluating options. Connecting with other cancer survivors provided opportunities not only to receive but to offer support. An extremely high value was placed on this kind of support.

Participants who participated in support groups could not say enough about how important they are, and many of those who did not have access to support groups wanted them. A number of men in the focus groups were active participants in Man to Man prostate support groups, which are sponsored by the American Cancer Society and held around the state. It is interesting to note that even the men whose cancer was considered to be well under control or permanently arrested continued to participate in the Man to Man groups. Some of the support groups serve a social function in members' lives as well, and participants described outings and shared meals, as well as opportunities to learn from informational speakers.

- *What I've noticed about men, and all the beer drinking and bars...men tend not to talk about their physical health. Men, you know, we're too tough, right? Not going to happen to me. Cancer will never happen. But in the Man to Man group, it's amazing how the guys open up. They'll talk about anything and everything. It's very comforting to see a bunch of guys...*
- *Just listening to these ladies, it almost sounds to me that the state of Vermont could do a service to cancer people if they kind of helped organize and support these groups that do..this Man to Man that we go to—if they could do it for every type of cancer.*

One-to-one contact with survivors who had a similar diagnosis, before and after treatment, was highly valued and sought after for information as well as support. Participants spoke of the special quality of their relationships with doctors, nurses, social workers, and other health care professionals who were themselves cancer survivors. A few people were aware of the BeFriend Program at Dartmouth Hitchcock Medical Center that matches up individuals who share a common diagnosis. For some of the focus group participants who had had little contact with other cancer survivors, the focus group session itself seemed to serve as a support group. Particularly poignant was the

participant from a rural area who had never before had a conversation with another cancer survivor and was astonished to learn that her memory lapses and "flakiness" were so common that they are commonly referred to as "chemo brain." It was not uncommon for participants to linger at the end of sessions to continue talking with each other.

- *They [the BeFriend Program] hook you up with someone...they're a similar age, the same diagnosis, the same treatment. And you can talk to these people as a cancer buddy all through your treatment. I think it's fabulous.*

One participant noted that separate support groups are needed to address the needs of individuals with metastatic, recurring, and advanced cancers.

- *I do belong to two support groups. One support group I started very shortly after my diagnosis in '95. The other support group is for Stage 4 patients only. And there's two different sets of—we were talking about hospice and end-of-life care. In the Stage 4 group we talk about a lot of very different things than what we talked about [in the other group]. Most of the people in the other group have not had recurrences, so they don't want to hear about that.*

A number of participants talked about the need for support for caregivers. Other than Man to Man prostate groups, which welcome spouses and partners, no one was aware of support groups or peer support opportunities for caregivers.

Although this study tapped only a fraction of the state's counties, it is possible to generalize that the need for peer support for cancer survivors is being poorly met in the state. In addition to participant input, this conclusion is supported by the consultant's own efforts to recruit focus group participants through existing support groups. In some areas of the state there are no active support groups, and in many areas the support groups are restricted to the most common cancers, particularly breast and prostate. The consultant found the only statewide list of support groups to be incomplete and out of date, and efforts to locate support groups often took numerous phone calls and resulted in dead ends.

- *My doctor referred me to the breast cancer support group. I was told that I could not get in because I didn't have breast cancer, that I had uterine cancer. And I was left out on a limb.*
- *When I called the Cancer Society they had support groups for breast cancer, but no other cancer. And I had colon cancer, so I couldn't join...*

INFORMATION

Another prominent theme is that cancer survivors need information. Participants expressed a desire that information be offered to them rather than always having to search for it, but they reported that to be the exception rather than the rule for concerns other than diagnosis and treatment.

Access and Quality

There was wide variation among participants in their "need to know." At one end of the spectrum were individuals who did not want a prognosis, did not seek information, and did not question their doctors' advice. At the other end were aggressive information seekers who sought out additional information, "double-checked" doctors' advice, and sought second opinions. The majority of participants described a profound and ongoing desire for information.

There was a sense that if people went out looking for information and knew where to look and whom to ask, they generally found what they were seeking in the realm of diagnosis and treatment options. Doctors were the primary source of information and many people sought second opinions. People who were most successful were often those who had someone else to do the research and interpret the information for them, i.e., a friend or family member, particularly early on.

- *I have a sister who's an RN and another sister who's a researcher, so they kind of took over for me and stepped right in and got the information that was necessary.*
- *The people I know were sources of misinformation at times. It was difficult for me to get accurate information.*

A number of participants spoke of the helpfulness of having friends and family members present at medical appointments to ask questions and gather information which the survivors themselves were unable to absorb. This was cited as important in the decision-making process as well.

- *When I went to appointments -- and I am in the medical field, but this is different. I'm talking about me. I had people that were strategic being my ears and to catch the small things that when...you slam the door shut, because I'm not going to listen any more.*

Finding clear and accurate information about issues other than diagnosis and treatment was more problematic for participants, and participants often spoke of the distress they experienced as a result of not having been given information by their health care providers. Areas where participants reported being given inadequate or no information included the side effects of treatment; residual effects; nutrition; depression and anxiety, particularly at the end of treatment; and living life as a cancer survivor. A number of participants were uninformed or misinformed about benefit programs and insurance options that could have helped them. Access to information about services was mixed. Participants in Newport and Bennington, the far corners of the state, were less well-informed about cancer-related activities throughout the state; for example, very few outside central Vermont and Chittenden county knew about the Stowe Weekend of Hope. Some participants identified a need for information about how to talk to children about their cancers.

- *I didn't know you could get burnt with radiation. I got horribly, horribly burnt. I had no idea. I had no clue. I had no information.*
- *The worst things to find were nutritional information.*

- *I was told that it might be helpful to have, for instance, an acupuncturist to deal with nausea...I had to call probably ten different people to get that information [about an acupuncturist].*
- *The biggest obstacle I find right now is dealing with chemo brain. I think it's a huge issue that people need to know prior to treatment.*

In addition, participants noted that while information about breast and prostate cancer is abundant, information about other cancers, particularly less common cancers, is much less available. Younger participants noted the difficulty of finding information relevant to younger adults.

- *I would say the hardest thing was finding information relevant to my age group. I would say that some of the cancers that are more common – breast cancer and lung cancer, it's very easy, I'm sure, to get information about those if you're in the age group that typically gets it. But if you have an unusual cancer, it's hard to find information. And I found [by] myself on the Internet a group dedicated to women under 45 with breast cancer. So I ultimately found it...that was like my own volition. No doctor said, "Hey, by the way, there's the Young Survivor Coalition." [from a survivor diagnosed in her late 20s]*

Participants repeatedly described other cancer survivors as the best sources of information. Support groups were cited as invaluable sources of information and decision-support, as were one-to-one connections with individuals with similar diagnoses.

- *That's one of the things I would really love, is for everybody to be able to immediately contact others who have survived to know what they did.*
- *I know the nurses were great here and everything, but it's not a situation they had been through. And I think if I could have talked to a woman who had been through it, I think that would have made a lot of difference.*

Those who turned to the Internet at some point, by themselves or with help from others, were in the majority. They described very mixed results. Many spoke about getting conflicting information as well as information that proved to be inaccurate at best and terrifying at worst. The greatest frustration was finding reliable information about complementary and alternative medicine (CAM). At the other end of the spectrum, some individuals were able to find useful research on the Internet about their conditions and treatment options as well as clinical trials. That kind of information is largely found on research-based websites that are directed at the medical and scientific community, and may require a level of sophistication that is not within reach of many individuals.

- *There was just nothing available for me [information at a rural hospital] so I went on my own to the Internet which I now know was the biggest mistake I ever made. Because after I did this I thought they said I had a fifteen percent chance of survival. I had the meeting with the oncologist...and she said, "Who told you that?" I said I got it off the Internet and she said that is the worst place you could go for information.*
- *I'm the type of person that needs to know more than what I've been given, and I went on the Internet and made phone calls to different other organizations,*

and by the time I got back to [the oncologist] five days later I was a basket case. I said to him, how come you didn't tell me I was going to die within two years? He's like, where are you getting this?

Some participants noted that it is helpful to be given information in ways that they can understand it. This included visual representations and materials written in laypersons' terms.

Changing information needs over time

Many participants spoke of the need for information to be offered repeatedly and on an ongoing basis, as they are universally overwhelmed at the time of diagnosis and unable to take much in. In addition, their readiness for and ability to absorb information may change over time. Participants in some regions talked about being visited by a psychologist or social worker when they were first diagnosed, at a time when they were not ready for their services or the information they could provide, but not having received follow-up contact at a later point when they most needed it.

- *I need continual information.*
- *In the beginning one of my doctors went over a lot of the side effects, but not having experienced it, I really wasn't sure what it meant or how it would feel. Now I know, but it's so overwhelming at first, because they list all of the side effects, but what are you going to do about it?*
- *I found it to be a developmental process. And in the beginning I really couldn't process. I knew I had cancer. I knew it was a serious disease. I knew what I needed—I just needed to know what do I need to do next. I did what I call playing peek-a-boo with my disease. You know, I'd kind of look at it for a few minutes and be able to take in the information, then I'd have to look away. What I see over time is that I needed to grow before I could really see the whole picture, and I've had the people to help me do that. And then I found that I was willing to look at more and more, and so I wanted more information.*

Some participants described learning how to become full participants in decision-making over time, which went hand-in-hand with wanting more information and more detail.

- *I guess a lot of it does come from just wanting to be able to carry on that conversation with the doctor and wanting to know what he's talking about. I get all of my reports. I read all of my reports. I ask questions on my reports if I don't understand. if he kind of, you know, skims over something. And I think that comes with time, wanting to have the information.*
- *I think at first it's—you walk in the office and say, okay, I trust you to do whatever. and then you get to the point where you're like, okay, this is my life. And I tell my doctor, and he agrees with me, okay, you want me to do this drug, well, we'll do this drug if I want to do this drug.*
- *The second time I had cancer I was a little bit more savvy on how to talk to my doctors, and I said what are my options. I explained what I needed. I need to*

know details. I needed to know if he wants me to take this treatment, why he came up with that. And it worked. It was a whole lot better the second time around.

In addition, the kind of information survivors need changes over time. At some point, the information they need shifts to side-effects and residual effects of medications, surgery, chemotherapy, and radiation. Participants spoke of not knowing what information they need because they have not been advised in advance about what to expect. A number of survivors described their focus shifting to ways to heal themselves or stay well using complementary and alternative approaches once their treatment had ended. Although a number of participants spoke about the social and emotional aspects of being a cancer survivor, most reported not having been given information about the potential for depression and anxiety.

- *It could be a product of me waiting too long to get that information about what surviving is about. And for me, a lot of that had to do with more social, emotional, dare I say mental aspects of what it means to be in treatment, what it means to be out of treatment, what it means to have cancer in your life, or had cancer in your life, or is cancer always in your life...Information I don't feel like I was offered any of that by my doctors.*
- *The social and emotional piece became much more prominent the year after my treatments were over. I was anxious and was surprised by how depressed I got. And at that point I started looking for information that would help me deal with those emotional side effects.*

This issue was particularly acute for survivors who no longer see their oncologists on a frequent basis post-treatment but are still dealing with the ongoing impact on their lives.

- *...I think that is a problem you get, because the first year the information I was seeking I could get from my medical team. And then the year after, the information I sought they no longer could provide me, and no one was there to give it to me besides them.*

TRANSITIONS

The third prominent theme is that transitions are often difficult for cancer survivors.

Awaiting news about test results after completing a round of treatment was described as highly stressful. Some doctors were acknowledged for providing test results quickly. However, the more common experience was having to wait for test results, sometimes for days or weeks, a circumstance that compounded an already-stressful experience,

- *I think the worst time...was after the first chemotherapy...waiting for the next shoe to drop in the early stages of cancer. I had tremendous anxiety about what was coming next. I'm waiting for results and I would physically get ill*

when I went in to get the results of my CAT scan. At one point I was sitting in the parking lot throwing up....

Participants described treatment as a time when they were actively doing something to help themselves and to fight their cancer. Ending treatment was experienced by many participants as a difficult and sometimes frightening transition. Some noted that they missed the regular contact with the treatment team. A number of people described being blindsided by depression, anxiety, and "craziness" when their treatment ended, even though they had had positive results. Many of them reported being unprepared for things such as the residual effects of treatment, the time required to regain physical capacity and energy, and the need to find a "new normal."

- *I remember begging the doctor to please let me take an extra year of Tamoxifen because I'd been waiting for five years to get off, and when it was finally time it was like, you know what? I've been okay for five years, why would I want to stop taking it?*
- *When you finish a course of radiation or chemo, you've been coming on a regular basis...everybody is so supportive and so nice, and then it's like you graduate, you're done, and you feel like you're just hanging out there.*
- *There's a lot of mental things, and you really need to be told. People suggested that it would be hard, but no one said how hard.*

Ending a relationship with the oncologist, or even being out of touch with the oncologist during a pause or delay in treatment, was also singled out as a difficult emotional time. Participants described a loss of security when they are "cast adrift" from their primary resource and no resource has been provided to take their place. In essence, they described a pervasive lack of discharge planning that could smooth the transition to post-care by offering survivors guidance and information about what to expect emotionally and physically, and how to fill the medical and informational void they feel they are entering. One participant expressed it as a lack of facilitated, or gradual, closure.

- *I think that when you walk out of that office and you've been deemed well that you're scared, because how long and am I going to be well...when do I call again, what's the next step. They've been a lifeline for you.*

Participants offered several suggestions about how these transitional periods might be made easier:

- Provide follow-up contact a month or two out to check in and see how people are doing, either through an appointment or a phone call. Several participants had welcomed such follow-up calls from health insurance case managers.
- Provide "kinder curtailing of contact" through a gradual process.
- Build formal closure into the treatment plan, including referral to counseling if desired.
- Arm survivors with information about possible side effects.
- Advise survivors that a period of emotional adjustment is common.
- Offer connections to other cancer survivors.

SOCIAL AND EMOTIONAL WELL-BEING

In addition to the emotional challenges experienced during transitions, there were other common threads related to social and emotional well-being.

Doctors rarely open the door to discussion of emotional issues, and survivors would like them to do so.

- *Well, the support group helped, but it would also be nice if the oncologist's office..said, "This is typical." I mean, we've all fallen apart, but it wasn't anything the oncologist ever mentioned.*

Emotional support, like information, needs to be offered on an ongoing basis as individuals' needs change. Even those who were offered counseling support early on noted that such an offer would have been welcome later on.

- *Okay, there's a psychologist, but I don't have any issues that I need to talk to a psychologist about. ..Yes, she's available but that doesn't mean that you know what to do with her, or that you know you should do something with her, or how that works.*

Practices such as meditation, yoga, and spiritual practices were found to be helpful by a number of participants. As noted previously, peer support was cited as key. Dealing with other people's anxiety and well-meaning inquiries about one's condition can be emotionally and physically exhausting. Some survivors have addressed this successfully by sending out e-mail updates to a list of concerned others or maintaining a website with information about their progress.

MEDICAL CARE

Cancer care

With a few notable exceptions, participants generally seemed satisfied with the quality of the care they received. Many spoke very highly of their physicians, hospitals, and the quality of the care they received. Oncology nurses were identified as particularly important sources of information and support. To a great extent, those who had access to needed treatment "locally" may have gone outside the area for second opinions or consults, but chose to get their care close to home rather than traveling to a comprehensive cancer center.³ The most frequently cited reason for receiving care outside the local area was the unavailability of radiation therapy locally, and some people traveled many hours on a daily basis for their radiation. One participant chose an academic medical center at the other end of the state because local services were "not fat-people friendly." Some participants chose specialists or facilities because their own

³ In Vermont, "local" facilities may be as much as an hour away.

primary care providers (PCPs) or PCP's family members had received their care from them. Few cited quality concerns as their reason for seeking care outside the local area. However lack of choice and dissatisfaction with local oncologists in regions served by one, two, or a part-time "visiting" oncologist motivated some participants to travel some distance for their care.

- *Oncology nurses rock!*
- *I had my work done here. My surgeons were here, my surgery was here, my everything, right here. It's a wonderful, wonderful group.*
- *If they could have done it here, I would have done it here.*
- *[My gynecologist's] wife was seriously ill at the time with a gynecological cancer, and she was being treated in Burlington, and it was a no brainer. If this guy's good enough for your wife, then he's going to take care of me.*

Relationships with health care providers were identified by many as important components of healing and emotional well-being. The importance of touch and hands-on contact by providers was singled out by some as very important, and some frustration was expressed with doctors who do not seem to "do" anything.

- *I went to see him [an expert at a cancer center] a couple times. So he was sort of in charge, but he had me take—I think he asked me to breathe into the stethoscope once, but otherwise he's not—I don't know if he counts. He doesn't really do anything. He just, you know, goes through papers.*

While some participants spoke of having very good communication with their health care providers, others described doctors who were rushed, abrupt, and did not listen to their patients' concerns. Participants in Bennington spoke highly of a medical humanist at the community cancer center at Southwest Vermont Medical Center who had helped to bridge the communication gap between patients and providers.⁴

- *I had an experience where I was talking with [the medical humanist] one time about my treatment and how it was taken care of and what made me feel confident...One of them is that I love to hear [the doctor] whistle in the hallway. Well, the next time they came in he whistled himself to death. She had that little touch.*

Routine health care

A number of participants felt there was very good coordination and communication regarding cancer-related concerns between oncologists, specialists, and primary care providers. While this seems to be done as a matter of course in some areas and by some providers, the need for the individual to be "in the driver's seat" was a theme across the focus groups. One participant described a log she kept in order to make sure that all providers were fully informed. Some spoke of having assembled health care teams or selecting primary care providers who would work as part of a team.

⁴ One participant described the medical humanist's role as bringing the human experience to the medical experience. Participants noted that the position ended when grant funding ceased.

- *I see about six specialists and it took awhile, but they finally got all on the same page, and they do communicate. And now instead of having six different blood tests at different times we coordinate and we do one.*
- *I'm sort of the catalyst to make sure that all of the records get where they're supposed to so that they can keep in constant contact with one another.*
- *You really need to have some kind of control. You've got to be in the driver's seat.*

Knowing which doctor to consult about side effects, residual effects, and potentially non-cancer-related ailments was described as a greater challenge. While some oncologists play the role of primary care provider (PCP), not all are attentive to or knowledgeable about routine medical concerns and preventive tests. Some participants were not confident that PCPs were knowledgeable about post-treatment issues. The resulting fragmentation for survivors in those situations prevented them from being treated as whole persons. As noted previously, this also causes stressful transitions from one type of care to another. The ideal that was described was having PCPs who specialize in cancer survivors, oncologists who are also qualified as PCPs, or practices that include both oncologists and primary care practices. The two latter models, which were available to some participants, were well-liked by those who were served by them.

- *It gets very, very complicated... especially with things that are peripheral to cancer.*

Staying well and quality of life

Services and information related to staying well and maintaining quality of life as a cancer survivor were not consistently available to participants in all parts of the state. Some participants characterized this as a void. To some extent, this may fall through the cracks between cancer care, primary care, and CAM. Several participants spoke of the need for more than general messages about exercise, good nutrition, and not smoking; they asked for a personalized "prescription" that told them exactly what to do. Some participants described feeling cast adrift when they are discharged from the oncologist's care without guidance in these areas. Some participants described themselves as fortunate for having a relationship with one provider (oncologist, oncology nurse, radiologist, cancer coach⁵) who provided support and guidance about how to stay well.

- *...everybody's saying, "You're well, go out, live your life." And those are wonderful words to hear but it's almost like ... maybe your doctor to just say..."Let me tell you what I think you should do every day now. I think you need to take a one mile walk. I think you need to call a friend every day." And...write it on a little prescription that makes it look like it's official...[and you come back] in a year to make sure you've been doing it.*
- *I found this Lance Armstrong Foundation poll that asked if people felt their non-medical needs were met, which I think just meant, you know, outside of*

⁵ A cancer coach offers personalized assistance in identifying resources, practical problem-solving, advocacy, and activities to promote relaxation and activate the body's ability to heal.

standard medical care. And 50 percent of the cancer survivors polled said no, and of those 50 percent about half of them said that their physicians, their doctors, were unable to provide them with any information in regard to how they could promote their healing outside of what they were doing with their doctor...It's promoting your own healing by doing other things that will help you bring the joy to your life, the passion to your life, and having some help while you're doing that from your medical team.

Staying well through good nutrition was described as a high priority by many participants. It was also one of the main gaps in services that was identified across focus groups. Participants in some areas of the state had had consultations with nutritionists and dieticians, but with a few exceptions they noted that those consultations focused primarily on getting enough calories to keep weight on during treatment rather than on learning how to "eat healthy." Several participants had gained weight as a side effect of their medications, but noted that they had never been offered help with taking the weight off. Some were aware of nutritional seminars that were available at their hospitals, while others in the same regions were not. Stress management was also singled out as a need by a number of participants.

- *I have never had one doctor tell me anything about my diet except...a white diet for six weeks so I wouldn't have diarrhea really bad [during radiation]. But other than that, I've never been told how to eat healthy to prevent myself from getting any other cancer again. The information I get is from TV and radio and books and other people, but not from my doctors,*

Complementary and alternative medicine

A substantial number of participants had used various forms of complementary and alternative medicine (CAM). A number of those reported that they inform their conventional doctors that they use CAM; the responses they described ranged from resigned tolerance to neutrality to encouragement. Cost and lack of reliable information about the safety and efficacy of CAM were identified as barriers.

Several hospitals and oncology practices were described as having actively taken on an integrative medicine component; in these settings it seems that integrative medicine is not only accepted but promoted.⁶ At least two of those hospitals offer reiki on-site and participants were enthusiastic about its effectiveness in managing pain and stress. At least one hospital offers yoga classes for cancer survivors. One community-based practice includes a cancer coach and one hospital has a part-time holistic nurse consultant on staff. All of these were enthusiastically received by participants. Participants noted that doctors should take a more active role in promoting CAM where it is available.

⁶ "Integrative medicine combines the best practices of complementary and traditional medicine to maximize the body's innate potential for self-healing, and ideally involves a partnership in which patient and practitioner together address healing on physical, emotional, and spiritual levels."
<http://www.harthosp.org/IntMed/manual/chapter-I.asp>

FINANCIAL AND LEGAL CONCERNS

Discussions about financial concerns among focus group participants centered primarily on health insurance, employment, and the link between the two.

Almost all of the participants had health insurance of some kind. A number of participants reported being satisfied with the coverage and service provided by their insurance. A number described devoting time and energy to appealing denied claims, and a few had experienced delays in treatment because of insurance denials. For many others, the issue was underinsurance, primarily in the form of extraordinarily high deductibles, lack of prescription drug coverage, lack of coverage for CAM, limitations on coverage for certain therapies (e.g., chemotherapy that was covered in a hospital setting but not at home), and restricted networks of providers. For a few, these financial considerations affected their treatment decisions. For example, one woman had to forego costly diagnostic tests because she could not afford the high deductible.

The high cost of premiums and out-of-pocket costs were a tremendous burden for some participants, and some reported that they had used retirement savings or gone into debt to meet those expenses. One participant described having her credit rating ruined even after the hospital agreed to drop unpaid charges. Participants cited the experiences of other cancer survivors who had delayed or foregone treatment because they lacked transportation.

- *Cancer is expensive...they send you home [from the hospital] with a prescription. There's not money to buy your prescription because you haven't met your deductible yet...and then what do you do. Because you start your treatment but then you don't get the growth things your you don't get the antibiotics that you need.*
- *The drug that I've been put on now...I think it's going to be like \$300 a month. So I'm worth it, of course, but I call it a car payment in a bottle.*

Issues of equity were raised, specifically the ability of some individuals to pay out-of-pocket to undergo treatment at nationally known cancer centers in other states.

- *I chose to have all of my surgery, etc. down there [Memorial Sloan Kettering Cancer Center in New York]. But my insurance company doesn't consider it in the network, so we are paying a large bit of it, and we can afford it without hardship, and that infuriates me....I got that treatment, and there's a lot of people who don't get to make that kind of decision for themselves because they can't afford it, and that makes me crazy.*

A recurring theme was that cancer survivors and their spouses frequently continue to work through illness and beyond retirement age because it is the source of their health insurance. There is also a Catch-22 for part-time workers or workers whose jobs do not provide health insurance—as long as they keep working, their incomes are too high to qualify for Medicaid or VHAP.

- *It's not about the job, it's really about the insurance.*

- *If I wasn't working I could get help, but because I enjoy working and doing what I do, it puts me in an [income]category. But it's a struggle every day to think I've got to go to work. I've got to pay \$200 on this bill, I've got to pay \$100 on this bill.*

Some participants told of having "wonderful" and accommodating employers who allowed them to have flexible schedules while receiving treatment, held their jobs for them when they were unable to work, and worked with them to maximize paid leave time. Others had to continue to work throughout their illness in order to keep their jobs. A small number related experiences with being threatened with termination or actually losing their jobs when they were unable to work or had used up leave time. A few had foregone more aggressive treatment because they were unable to lose time from work.

Legal concerns were rarely mentioned by participants in any of the focus groups.

MAKING DECISIONS AND NAVIGATING SYSTEMS

Support for making treatment-related decisions

Many participants followed the advice and recommendations of their doctors in making decisions about treatment when their cancer was first diagnosed. This was particularly true for those whose situations were relatively straightforward or for whom the need to begin treatment was perceived as urgent. While this approach satisfied many, some wished in hindsight that they had known how to be more involved in making decisions, and a few noted that they believed their doctors had made the decisions for them.

- *My doctor made all of my decisions for me. When I went in the office he said this is what we're going to do, wham, bam, whang, and there was really not much of a question.*

Some participants described a sort of "information privilege" that is available to few; that is, being able to call upon friends and family who are medical professionals or connected to medical experts who can provide and sort through information and assist with decision-making. This not only helped them reach decisions but sometimes opened doors to being treated at cancer centers in other states.

- *So I called my brother-in-law, who is a retired surgeon, and I asked him to help me research this [a clinical trial]. Well, he in turn called two friends of his, a husband a wife who are gynecologists who are retired, and they checked into my doctor that I have at Dartmouth, and they checked into the protocol, and they told him tell her to go ahead with it.*
- *I would echo a family member with research background is huge, but not all of us are that blessed.*

Among those who were presented with more than one option or desired help in making decisions, support groups and conversations with individual survivors who had

confronted similar decisions were cited as being extremely helpful. This approach was particularly appealing to participants who had not had access to decision-support. A number of participants had sought second opinions, and participants were appreciative when their own doctors offered it as an option. A few had sought third and even fourth opinions and went with the majority opinion. Participants who had not had access to decision-support identified several additional approaches as potentially helpful: being given more time to consider their options; knowing they could seek a second opinion or change doctors; and having an algorithm (i.e., a formula) for looking at the options and likelihood of success.

- *I think the problem certainly for us with prostate is—we can define the options, but to evaluate the options is the most difficult in terms of our own cases.*
- *You don't necessarily have to be in a group, but it would have been nice if I could have called a person like XX or XX and "You've been through this, can you just kind of give me some input about what's going to happen here?" I think that would have helped a lot.*

Navigating systems

The need for assistance with service coordination, advocacy, and navigating service delivery systems was a theme across the focus groups, but few had received this type of assistance.

A clear need for coordination of medical care was identified.

- *I wish there was a person that was assigned to you to pull together your medical team. That's one of the first questions I asked my surgeon. Who was in charge of this? Who was going to coordinate all these things that you need—your mental health, your physical health, your dietary care...Nobody's doing this. You are doing it. Get someone to help you.*

Assistance is also needed with identifying and coordinating benefits, programs, supportive services, and post-treatment supports. This need had been addressed to a limited extent where there were hospital- or clinic-based social workers. However, these social workers were described as narrow in scope of service, available only on-site, and of limited usefulness for survivors who live some distance from those facilities. Some participants had been helped by case managers from their insurance companies.

Dealing with insurance issues and finances was described as overwhelming and burdensome for individuals when they are sick. Some participants expressed a wish to have someone who could take on that role.

- *When you're feeling sick, when you're really sick and they deny a claim, it makes you cry. I mean, I burst into tears. It's an awful burden when you're sick to do that, to fight with them. So it's nice to have a support person do it for you.*

Participants described a need for people who can advocate for them. This role was most often played by family or friends. Although participants described becoming more savvy and more assertive over time, some clearly needed coaching in self-advocacy as well as assistance in learning about their rights and roles as full participants in decision-making.

Participants in two regions described individuals who played newly emerging roles in the health care system. These were the medical humanistic in Bennington and the cancer coach in central Vermont. Both of these professionals had sought out the newly diagnosed survivors, offered their services, and provided individualized support to survivors. As described by participants, the medical humanist focused more on coordination of medical care, while the cancer coach focused more on the integration of non-medical care. Because one of these individuals was herself a cancer survivor, she provided a role model for self-advocacy to other survivors.

DEMOGRAPHIC AND REGIONAL DIFFERENCES

Demographic differences

Recruitment for the focus groups was designed to include individuals who reflected a range of ages, diagnoses, cancer diagnosis, time since diagnosis, and stage of survivorship. Several findings stand out.

Younger participants noted that there is little relevant information and few resources available for people who are diagnosed with cancers as young adults (in their cases, breast cancer and leukemia). A number of participants with less common cancers noted that the relative abundance of programs, support, and information for breast and prostate cancer is in sharp contrast with what was available to them.

The need for information and support is not static. As individuals move through the stages of survivorship, their needs change as well. This is true for the nature of the information they need, their readiness and ability to process information, and the way information is provided to them. The same is true for support, which may be different for someone who is newly diagnosed than for a long-term survivor or someone who is experiencing a recurrence or metastasis.

Regional differences

As reflected in the Table 2, the six sites that were selected for the focus groups were quite varied in terms of the level of medical and support services that were available, urban and rural character, and geographic setting. The most pronounced differences were found in the Newport area. Newport holds a unique place in the study in several ways:

- Newport is in the most rural area of Vermont.

- Its location in the Northeast Kingdom is far from urban centers and is at least a two-hour drive from a major medical center.
- It is served by an oncology nurse and a part-time oncologist from Dartmouth Hitchcock Medical Center (DHMC) who holds a clinic at the hospital one day a week.

The study found that:

- People are more isolated from other survivors than in other parts of the state. Female participants with other cancers were frustrated that they were not welcome in a breast cancer support group. The distance to DHMC is too far to travel to a support group. During the discussion, participants came up with the idea of creating a volunteer survivor registry that would enable the oncology nurse to match up survivors in a buddy system, and also expressed interest in attending an "all cancers" support group.
- Lack of transportation and distance to treatment sites creates substantial barriers to receiving treatment.
- Survivors told more stories of misdiagnoses and missed diagnoses than in other areas of the state.
- Fewer resources are available than in other areas of the state.
- Survivors who go outside the local area for treatment are even less likely to know about local resources.
- Survivors have little information about cancer-related activities around the state (this was also true of Bennington, which sits at the far southwest corner of the state).

SUMMARY OF KEY FINDINGS

Support

The most predominant theme throughout the various threads of the focus group study is that support plays a critical role for cancer survivors. Support from other cancer survivors is especially important. Connecting with other survivors, both through support groups and one-to-one contact, provides opportunities to give and receive emotional support and to exchange information. Despite its importance, the need for peer support is being poorly met in the state.

Information

The majority of focus group participants described a profound and ongoing desire for information. Information needs change over time as individuals move through the stages of survivorship. Survivors want to have information offered to them rather than always having to search for it. Survivors have concerns about the reliability of the information they find on their own, particularly on the Internet. Information about diagnosis and treatment options is more readily available than information about "everything else," and information and resources related to less common cancers can be hard to find.

Transitions and emotional well-being

Transitions frequently present emotional challenges for cancer survivors. The end of treatment was experienced as a difficult and sometimes frightening transition, even when outcomes are positive. The end of an active relationship with an oncologist often leaves survivors feeling that they have been cast adrift, a situation that is compounded by a lack of discharge planning that could smooth the transition to post-care. Survivors are generally surprised by the depression and anxiety that occurs during these transitions because they are rarely advised that a period of emotional adjustment is common. Survivors report that their doctors rarely open the door to discussion of emotional issues, and survivors would like them to do so. Emotional support and counseling, like information, needs to be offered on an ongoing basis as individuals' needs change. Practices such as meditation, yoga, and spiritual practices are found to be useful by many survivors.

Medical care

Survivors were generally satisfied with the quality of their cancer-related care. The challenge for many comes in the area of routine care and after-care. Lack of clarity about whether to be followed by an oncologist or primary care provider can result in fragmented care that does not treat the individual as a whole person. Services and information related to staying well and maintaining quality of life were not consistently available to survivors in all parts of the state. A substantial number of survivors used various forms of complementary and alternative medicine, and several hospitals and oncology practices have incorporated integrative medicine into their practices.

Financial concerns

While almost all participants had health insurance of some kind, cost and underinsurance in its various forms were major issues for many. The link between insurance and employment is also problematic, and some survivors and their spouses must continue to work through illness and beyond retirement age in order to retain their health insurance.

Decision-making and navigating systems

Many participants followed the advice and recommendations of their doctors in making treatment decisions following their initial diagnosis. Some wished in hindsight that they had known how to be more involved in making decisions. Conversations with individual survivors who had confronted similar decisions were cited as being extremely helpful. The need for assistance with service coordination, advocacy, and navigating service delivery systems was a theme across the focus groups, but few had received this type of assistance.

CONCLUSION

This report begins with the words of a cancer survivor. The words of two other survivors aptly capture the essence of the study's findings and the spirit of the survivors who participated in the focus groups.

I do feel the medical profession handles the physical parts of the disease very well, But there's always all those other things.

I'm really healthy, except for a touch of cancer every few years.

APPENDIX

Cancer Survivor Focus Group Study DISCUSSION GUIDE

Introductions

1. Earlier you heard me refer to cancer *survivors*. We use the term cancer survivor to refer to individuals from the time of diagnosis through the remaining years of life.

This includes

- people who are newly diagnosed
- people who are in remission or have finished their treatment
- people who are living with chronic disease or side effects
- those whose cancer is considered to be permanently arrested, and
- and those who are at the end of their lives.

Many of you have been through more than one of those stages, possibly even more than once. Your needs and experiences may be very different now than they were when you were first diagnosed. When you respond to our questions, we hope you'll also tell us about how your needs may have changed over time.

We know that no two survivors' situations and experiences are the same. Your experience and reactions may be quite different from another survivor at the same stage or with a similar diagnosis. We'd like to start by learning a little bit about you. Let's go around the table and have each of you tell us a little bit about yourself. Please tell us:

- your first name or name you like to be called by
- what town you live in
- what kind of cancer you've had
- how long ago you were diagnosed, and
- what the status of your cancer is now

I'm going to start by asking you some questions about getting information about things related to your cancer. We'll start with when you were first diagnosed, and then about how your needs may have changed over time.

HIGH

2. When you were first diagnosed, were you able to get the information you needed? If not, why not? What got in the way of your getting that information?

*probes: Didn't know enough to ask questions.
Didn't know where to look.*

3. Has the kind of information you need changed over time? How?
Have you turned to different sources for information as your needs have changed?

Now I've got some questions for you about how you've made decisions about things related to your diagnosis.

HIGH

4. When you have to make decisions about treatment options or other things related to your cancer, have you turned to anyone for help or support in making the decision? Who?

For those of you who have wanted support in making decisions, have you always been able to get it?

If not, why not?

HIGH

5. Are there circumstances that have affected your decisions about treatment? For example, these might be financial circumstances, or things like transportation, or your work schedule, or things about your life at home.

*Probes: insurance coverage – lack, inadequacy
ability to pay
transportation
child care
support at home
flexibility of work schedule*

Now I'm going to ask you some questions about medical care and treatment.

HIGH

6. First I'd like to go around the table and have everyone say whether you've gotten your cancer-related medical care close to home or whether you travel to a doctor or hospital farther away. For example, you might get your care in the town where you live, in some other part of Vermont, or in another state. If you do travel for care, please tell us approximately how far you travel and why. *Round robin.*

*probes: needed service not available locally (e.g., radiation, transplant)
no full-time oncologist
clinical trials*

7. I'd like you to think about the physical side of having cancer. Are there things that have been particularly helpful to you in dealing with physical issues such as managing symptoms, managing pain, changes in the way your body functions, or changes in your appearance. We're not asking you to go into detail about the physical issues themselves, but more about what was helpful in dealing with them.

Are there things you didn't get that would have been helpful?

*probes: Managing symptoms
Managing pain
Change in the way your body functions
Appetite and nutrition
Disability
Living with chronic illness, maybe for a lifetime*

Appearance

Palliative care (care directed at comfort rather than tx or cure

Finding out about and using CAM (complementary and alternative medicine) and integrating it with your conventional doctor

8. What about staying well in general and your more routine health care needs, like preventive screenings and other kinds of medical concerns that don't have to do with cancer? Who do you see for that -- your oncologist or a primary care doctor like an internist or family physician?

Has that changed over time?

probe/listen for: PCPs knowledgeable about the ongoing effects of cancer treatment?

Do you think there's good coordination between your oncologist and your primary care doctor or other specialists that you see, such as an ob/gyn? Do you think that's important?

probe: managed care facilitate this?

HIGH

9. Do you think that you're getting the help and information you need in order to stay well and have good quality of life—things like nutrition, physical activity, stress management, and figuring out how to live better during recovery or with ongoing disease?

If not, why not?

*probes: cost
not available/lack of access
transportation
other demands on time (family, work, etc)*

There's a lot more to all of us than just our bodies, and we know that cancer can have a big impact on other aspects of our lives as well. Now I'm going to ask you some questions about how cancer has affected other dimensions of your lives.

10. How many of you could have used some assistance with aspects of living your everyday life? What kind? Have you gotten the help you needed? If not, why not? What would have been helpful?

*probes: caring for yourself
housework, cleaning, chores
shopping, cooking
child care
support for family
paying bills*

HIGH

11. I'd like to ask you to think back to a time when you have gone through some kind of transition as a cancer survivor. Some examples might be when you finished treatment, when your cancer went into remission, or when you were adjusting to living with chronic side effects.

What kind of challenges did you face during those times or other times of transition? Based on your experience, is there something that could make those transitions easier for cancer survivors?

HIGH

12. According to national studies, many survivors report that cancer also affects their social and emotional well-being. When cancer has affected these aspects of life for you and other survivors you know, what kinds of support or activities have made a difference?

*probe for: Kinds of issues: fear/anxiety/stress/helplessness
family/relationship issues (dealing w/partner,
children)
depression
sexuality
body/self-image
isolation
loss of ability
concerns about end of life*

*What's helped: faith
spiritual practices
peer support
counseling
yoga, meditation
online support groups*

Could you get the support you were looking for? If not, why not?

Now I'm going to ask you about financial and legal issues.

HIGH

13. We know that a cancer diagnosis can cause financial and legal issues for individuals and their families. What have your experiences been about things like work, insurance, and the financial burden of having cancer?

*probes: employment, loss of employment
employment discrimination
access to reasonable employment accommodations
health insurance: uninsurance, underinsurance, inadequacy
reluctance to change jobs
reluctance to return to work/ lose benefits
financial planning
access to life insurance
disability insurance / SSDI
eligibility for Medicaid, Medicare, etc.
income supports/SSI
wills and advance directives*

14. How many of you have ever gotten help from anyone to work your way through the system and put all of the pieces together? Sometimes this can be a team of people who work with you or an individual.

Who? Was it helpful?

*probes: a.k.a. service coordinator or case manager
family member or friend
support organization like Amer. Cancer Society
home health
advocate
social worker
someone from the doctor's office
VR
insurance*

Do you think there are times when that kind of assistance would be especially helpful?

We've talked about what cancer survivors need, and about things that have been helpful to you as well as times when you haven't gotten what you need. We're getting towards the end of our time, and I want to ask a few questions to make sure we haven't left anything out.

MED

15. Are there any other things that haven't come up yet that get in the way of your getting services and supports that you need? Are there other barriers that have kept you from getting what you need?

*probes: transportation to appointments, radiation
nothing available in your part of the state
child care
payment for screening but not for treatment
unaware services exist
don't qualify
can't pay for it
disability access
other access issues*

16. If you could choose one thing that's been helpful to you that you wish all cancer survivors could have, what would that be? I'd like to go around and hear from everybody.

LOW

17. Are there ways that your life or circumstances have improved since you were diagnosed?

*probes: family/friends support
take better care of self/preventive care
relationship with personal doctor[have one]
opportunity for personal growth*

MED

18. What do you think is the biggest gap in the programs, services, or supports for cancer survivors? I'd like to hear from everybody on this question, too.

LOW

19. We know that it's not always easy for people to share their experiences as cancer survivors and we're very grateful to you and the other people who have been willing to talk with us in these focus groups. We'd like to understand more about why cancer survivors might choose not to participate in a survey or a focus group and I'd like to ask if you have any thoughts about this.

*probes: don't identify as a cancer survivor
want to move on
causes anxiety
privacy*

20. We've come to the end of our questions. Is there something you think we should know that we didn't ask you about?