

**Determining the Use of Cancer
Rehabilitation & Survivorship Services in Maine:
Findings from a Focus Group Study**



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**Determining the Use of Cancer Rehabilitation & Survivorship Services in Maine:
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George Shaler, MPH, Evaluation Coordinator

The author is on the staff of the
Edmund S. Muskie School of Public Service
Institute for Public Sector Innovation

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Executive Summary

In an effort to learn more about the needs and attitudes of Maine cancer survivors, the Maine Center for Disease Control (Maine CDC) and Prevention's Comprehensive Cancer Control Program (CCCP) and the Maine Cancer Consortium's Rehabilitation and Survivorship Work Group (MCC) partnered to explore some of the findings from a 2004 statewide assessment on cancer rehabilitation and survivorship services in more detail through the use of focus groups. The aim of the focus group study concentrated on learning why cancer survivors¹ do not readily access available rehabilitation and survivorship services in the state. In addition, focus groups were also conducted with providers and cancer survivor advocates/family members to discern what barriers exist that prevent cancer survivors from accessing services.

This qualitative study explored in detail among a small group of cancer survivors, their family members/advocates, and health care providers their experiences with rehabilitation and survivorship services. The study design called for two focus groups in each of Maine's six epidemiological planning areas. The focus groups were held from June through August 2005.

For the focus groups, the facilities that hosted the focus groups received 102 responses to the more than 500 recruitment letters that were mailed. Of the 102 responses, 65 (64%) confirmed that they would attend. Of this number, 54 (83%) actually attended. Of the 54, nearly two-thirds (65%) were female. The average focus group size was 5, with a high of nine and a low of one. The five cancer patient/survivor focus groups averaged 7.2 participants, while the advocate/family members and health care provider focus groups both averaged 3.0 people.

Findings:

Among the major findings are:

- The theme mentioned most often was the need for more information regarding rehabilitation and survivorship services. Many survivors said a list or booklet of rehabilitation and survivorship services was needed for each area of the state.
- Hospital and treatment center staffs were identified by cancer survivor and advocate focus group participants as the primary source of information on rehabilitation and survivorship services.
- Cancer survivors and advocates both requested more communication with members of the health care teams providing their treatment.
- Many cancer survivor and advocate focus group participants cited the lack of support groups as the most important rehabilitation and survivorship service missing in their communities.
- Advocates and survivors also stated that services for caregivers were needed.
- Church/prayer groups are important sources of support for some cancer patients/survivors.
- With information fragmented and some rehabilitation and survivorship services lacking, some focus group participants maintained that cancer survivors need to be their own advocates.
- Provider focus group participants were asked what barriers they experience in discussing treatment and follow-up with patients. The barrier cited most often was a provider's lack of comfort in discussing the topic with patients or a patient being unprepared to discuss treatment.
- Insurance issues were cited as a barrier to accessing some rehabilitation and survivorship services.
- The criterion considered most often by health care provider focus participants in making referrals for rehabilitation and survivorship services is family concerns.

¹ In this paper, the term cancer survivor means any person diagnosed with cancer.

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Introduction

In 2000, there were an estimated 9.6 million Americans with a history of cancer that were alive.² Of significance is that the five-year survival rate for all cancers is now 63%, up from 50% just 25 years earlier.³ While the five-year survival rates are promising, they do not tell us at what stage a person was diagnosed or other factors that influence survival. However, the rate can generally be seen as encouraging. The rates signify that more and more people diagnosed with cancer are living longer. With more cancer survivors living longer, issues pertaining to quality of life and daily functioning are increasingly important ones.⁴

In an effort to learn more about the needs and attitudes of Maine cancer survivors, the Maine Center for Disease Control and Prevention's Comprehensive Cancer Control Program (CCCP) and the Maine Cancer Consortium's Rehabilitation and Survivorship Work Group (MCC) partnered in 2004 to assess rehabilitation and survivorship services that are being used or other services offered to cancer survivors in Maine. Prior to this assessment, no published data existed regarding the type of rehabilitation and survivorship services being used in Maine.

As a follow-up to the 2004 study, CCCP and MCC decided to explore some of the findings from the initial assessment in more detail through the use of focus groups. The aim of the focus group study concentrated on learning why cancer survivors do not readily access available rehabilitation and survivorship services in the state. In addition, focus groups were also conducted with providers and cancer survivor advocates/family members to discern what barriers exist that prevent cancer survivors from accessing services.

The focus group study built upon the findings from the 2004 assessment study. Briefly, the 2004 assessment focused on answering the following questions:

- What are the cancer treatment and follow-up needs of cancer patients seeking rehabilitation and survivorship services in Maine?
- What rehabilitation and survivorship services do cancer patients use in Maine?
- Are these services useful, affordable, and helpful?
- How did those living with cancer learn about these services?

All hospitals which provide cancer treatment in Maine were invited to participate in the assessment. Twenty hospitals/radiation oncology treatment centers took part in the survey. All but two of them returned completed surveys. A total of eight hundred and sixty one (n=861) individuals seeking treatment at one of these 18 facilities completed a survey.

Some of the key findings from "*Assessing the Needs of Cancer Patients for Rehabilitation and Survivorship Services in Maine*" include:⁵

- The respondents' mean age was 62.9.
- Fifty-two (52%) percent of the respondents were between the ages of 50-69.
- Females made up 64% of the respondents.

² *Cancer Facts & Figures: 2004*, American Cancer Society, 2004, p.1.

³ *Ibid*, p.18.

⁴ Maine Cancer Consortium web site, <http://www.maineccconsortium.org/welcome.html>

⁵ *Assessing the Needs of Cancer Patients for Rehabilitation and Survivorship Services in Maine*, George Shaler, University of Southern Maine, Edmund S. Muskie School of Public Service, 2004.

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- The mean age at diagnosis was 59.5.
- The mean length of time with a cancer diagnosis was 3.1 years.
- Among 15 rehabilitation and survivorship services respondents were asked about, nutrition counseling (15.1%) services were used most. This indicates that at least 85% of respondents had either not used the service or left the question unanswered. (For a list of the 15 services, please see Appendix).
- Physicians were the most common referral source for all rehabilitation and survivorship services with the exception of alternative/complementary medicine.
- Among respondents who had used certain services, transportation services was the most helpful.
- The service most likely to be out of pocket expense was alternative/complementary medicine. The service least likely to be an out of pocket expense was speech therapy.

Methodology

CCCP and MCC contracted with the University of Southern Maine's Edmund S. Muskie School of Public Service's Institute for Public Sector Innovation (Muskie School) to conduct a series of focus groups on why cancer survivors do not access rehabilitation and survivorship services in greater numbers. Three Muskie School employees conducted focus groups and audiotaped the hour-long sessions.

This qualitative study explored in detail among a small group of cancer survivors, their family members/advocates, and health care providers their experiences with rehabilitation and survivorship services. The study design called for two focus groups in each of Maine's six epidemiological planning areas.

The six regions comprise the following counties:

Region 1 (South)	Cumberland and York
Region 2 (West Central)	Androscoggin and Kennebec
Region 3 (Coastal)	Knox, Lincoln and Sagadahoc
Region 4 (West)	Franklin, Oxford, Piscataquis and Somerset
Region 5 (East Central)	Hancock, Penobscot, and Waldo
Region 6 (North East)	Aroostook and Washington

Six cancer survivor focus groups (one in each of the six regions) along with three health care provider and three advocate/family member focus groups were scheduled. The criteria listed below were chosen because these groups indicated on the previous statewide assessment survey that they use survivorship services less or more often than other survivors. The six cancer survivor categories were assigned to one of the six regions. The hospitals within each region that generated the most survey responses to the initial assessment were selected as host sites for the focus groups.

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Table 1: Focus Groups by Region, County and Type

Region	Counties	Focus Group Types
1	Cumberland and York	Cancer survivors and Advocates
2	Androscoggin and Kennebec	60+ male cancer survivors and Providers (RN/Social worker)
3	Knox, Lincoln and Sagadahoc	Older cancer survivors and Advocates
4	Franklin, Oxford, Piscataquis and Somerset	Survivors diagnosed 3+ years ago and Providers (Physicians)
5	Hancock, Penobscot, and Waldo	Providers (Physicians)
6	Aroostook and Washington	Survivors newly diagnosed (within past 1-2 years) and Advocates

The focus groups were held from June through August 2005. It was the intent of this project to conduct 12 focus groups; however, due to recruitment difficulties the female cancer survivor focus group was not held.

Study Population

In April 2005, the MCC sent each of the hospital/treatment facility host sites a letter informing them that the Muskie School would be contacting them shortly to discuss how their facilities could help in identifying possible focus group participants for this project. For the survivor focus groups, each of the host hospitals/treatment facilities were asked to select cancer patients meeting the criteria listed above (e.g., Coastal Cancer Treatment Center selected cancer survivor patients who were 60 years of age or older). To protect patient confidentiality the Muskie School developed a letter of invitation for the hospitals/treatment facilities to send to cancer survivors. Subsequently, the hospital/treatment facility sent letters inviting potential participants to the focus groups. In addition, each hospital/ treatment facility assisted in recruiting for either an advocate/family member or health care provider focus group. At the suggestion of the Region 6 hospital, Muskie drafted an ad that the hospital placed in a local newspaper asking for advocates/caregivers to participate in a focus group. Health care provider participants (Primary Care Providers, Oncologists, and Osteopaths) were selected from a database maintained by the Maine CDC. Social Workers and Nurses were recruited from lists purchased from the Maine State Board of Nursing and Board of Social Workers. In some cases, the focus groups were not held at the host site.

Cancer survivors and advocates/family members who participated received a \$40 stipend. Health care providers received \$250 for taking part in the focus groups.

For the 11 focus groups, the host hospitals/treatment facilities received 102 responses to the more than 500 recruitment letters that were mailed. Of the 102 responses, 65 (64%) confirmed that they would attend. Of this number, 54 (83%) actually attended. Of the 54, nearly two-thirds (65%) were female. The average focus group size was 5, with a high of nine (Older cancer patients – Bath) and a low of one (Advocates – Houlton). (Due to low turnout, the Houlton advocate focus group was more of an interview/discussion). The five cancer patient/survivor focus groups averaged 7.2 participants, while the advocate/family members and health care provider focus groups both averaged 3.0 people. The table below summarizes the recruitment and attendance figures.

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Table 2: Cancer Survivorship and Rehabilitation Focus Group Recruitment and Attendance Figures

Group	Location	Date	Letter Sent	Respond	Confirm	Male Attend	Female Attend	Total Attend
Region 1 Portland: Patient	USM Portland Campus	08/16/05	100	15	12	3	5	8
Region 1 Portland: Advocate	USM Portland Campus	08/16/05	NA	5	5	2	3	5
Region 2 Waterville: 60+ male	Thayer Hospital, Waterville	06/27/05	82	10	7	6	0	6
Region 2 Augusta: RN/SW	UMA, Augusta	06/28/05	32	4	3	1	2	3
Region 3 Bath: Older patients	YMCA, Bath	08/17/05	96	15	9	3	6	9
Region 3 Bath: Advocates	YMCA, Bath	08/17/05	NA	7	4	0	3	3
Region 4 Farmington: Patients diagnosed 3+ years	Farmington Public Library	07/28/05	96	26	10	1	7	8
Region 4 Farmington: Providers	Franklin Memorial Hospital, Farmington	07/26/05	33	5	5	1	1	2
Region 5 Bangor: Female cancer patients	EMMC Campus, Bangor	Not Held						
Region 5 Bangor: Providers	EMMC Campus, Bangor	08/24/05	37	4	4	1	3	4
Region 6 Houlton: Patients newly diagnosed or past 1-2 years	Houlton Regional Hospital	08/25/05	44	8	4	1	4	5
Region 6 Houlton: Advocates	Houlton Regional Hospital	08/25/05	NA	3	2	0	1	1
TOTALS			520	102	65	19	35	54

NA = Not available

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Survey Instrument

Muskie School staff worked in conjunction with MCC members and CCCP staff in developing the focus group guide. Both the cancer survivors and advocates/family members were asked similar questions while health care providers (e.g. physicians, specialists, nurses, social workers, etc.) received a different set of questions. All focus groups consisted of six questions. See the Appendix for a list of questions.

All focus group questions along with the study design were submitted for review and approval to the University of Southern Maine's Institutional Review Board prior to the study's start. All focus group participants signed an "Informed Consent for Participation as a Subject in a Research Study" form before each focus group commenced. The consent form spelled out the following:

- The focus groups will be audio-recorded for transcription and analysis
- The transcripts of the sessions will not contain any names or any information that could identify participants
- All research data will be stored in a locked file cabinet and audio tapes will be destroyed after the research analysis is completed
- The tapes will be turned over to the Muskie School employee conducting the focus groups
- The employee will destroy them once the final report is completed
- The participant could ask that the tape be turned off at any time during the focus group session

Data Collection Procedures

The 11 focus groups were facilitated by Muskie School employees. With the exception of one of the focus groups, all sessions were taped and transcribed verbatim. In one instance, the tape recorder failed to operate correctly at the beginning of the session. In this case, the facilitator took detailed notes.

A Muskie School researcher, who was not involved in facilitating any of the groups, read all of the transcripts. After an initial reading, the researcher developed a theme or code list. The researcher then re-read and coded the transcripts. The transcripts and meeting notes were entered verbatim into N6, a qualitative data analysis software program developed by QSR. The transcripts were then coded in N6. This enabled the researcher to query all 11 focus group transcripts by theme(s) at one time.

Results

Of the 11 focus groups, eight were either cancer survivor or advocate/family members with the other three being health care providers. Since cancer survivor and advocate/family members were asked similar questions, the results from these eight focus groups were analyzed together.

In the following section, the results from the cancer survivor and advocate/family member focus groups will be presented first followed by the health care provider focus groups results. Themes that emerged in response to the focus group questions are presented. A table is presented with each question detailing the following:

1. Number of coded comments
2. The top five themes⁶

⁶ To be considered in the top five themes, a theme had to have more than four responses. In some cases, a question did not have five themes that met this criterion.

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3. A column indicating the percentage of total comments generated by the particular theme
4. A column indicating on a percentage basis whether the theme was raised in any of the eight survivor/advocate or the three provider focus groups

With the top two themes, direct quotes are included that are representative of the particular theme.

Cancer Survivor and Advocate/Family Member Results

Question 1. *How did you learn about rehabilitation/survivorship services for your family?*

Overall, participants provided 79 coded comments to this question. The answers were categorized into one of 13 themes resulting in 6.1 comments per theme. The top five themes, presented below, accounted for 73% of all responses.

Table 3: How survivors/advocates learned about rehabilitation and survivorship services

Theme	Number of Comments (N=79)	% of all Comments	% Theme mentioned in each of the 8 focus groups
1. Hospital/treatment center staff gave out information and contacts for various services/advocate	17	21.5%	75%
2. Medical professional (generalist or specialist) provided list of services/helpful	15	19.0%	75%
3. Not aware of list or services on the list, I need a list	7	8.8%	50%
4. Fragmented information, too much information – no coordination	7	8.8%	50%
5. Self advocacy	6	7.6%	50%
6. Support groups	6	7.6%	50%
Other	21	26.6%	NA

As the table shows, physicians, both generalist and specialists, and hospital/treatment center staff are the leading sources of information on rehabilitation and survivorship services. Medical professionals pertain to physicians not necessarily located in or affiliated with a hospital. Hospital/treatment center staff includes nurses, practice managers, and sometimes physicians.

Also of note is the focus by Region 6 cancer survivor focus group participants on one service in particular – lodging. Given the rural nature of Aroostook and Washington counties this should not come as a surprise. Region 2 cancer survivor focus group participants mentioned on a number of occasions that hospital and health care practice employees were uninformed when it came to providing information about rehabilitation and survivorship services.

Hospital/treatment center staff gave out information and contacts for various services/advocate

“Most of ‘em on the list ... we were told about mostly by ... the nursing staff. You know, things that may be, well we may need help with this some.” (Region 1 – Survivor)

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“See in our case it was the surgeon who was the biggest help, I think for us and then we did receive a packet also when we went to the radiation place and um . . . and I actually learned a lot from that . . .” (Region 3 – Advocate)

Medical professional (generalist or specialist) provided list of services/helpful

“I actually got a packet of information from my urologist. . .with pretty comprehensive information actually.” (Region 1 – Advocate)

“We got information from the oncologist.” (Region 3 – Advocate)

Question 2. What types of rehabilitation and survivorship services are not available in your area?

Overall, participants provided 119 coded comments to this question. The answers were categorized into one of 24 themes resulting in 5.0 comments per theme. The top five themes, presented below, accounted for 53% of all responses.

Table 4: Types of rehabilitation and survivorship services not available

Theme	Number of Comments (N=119)	% of all Comments	% Theme mentioned in each of the 8 focus groups
1. Support Groups – all types and survivor networks	24	20.2%	50%
2. Services for Caregivers – emotional support and information support	19	16.0%	50%
3. Gratitude for doctor/hospital/nursing staff assistance with services	9	7.6%	38%
4. Financial assistance	6	5.0%	63%
5. No person coordinates/explains services in a comprehensive way	5	4.2%	38%
Other	56	47.1%	NA

As the table shows, comments on the lack of support group and services for caregivers predominated. The request for more support groups was strongest among Region 1 cancer survivors, Region 3 advocates, and Region 4 cancer survivor focus group participants. Nearly all the requests for caregiver support came from Region 1 patient advocate focus group participants. The third theme actually does not reflect a lack of service, but participants praise for health care providers in their respective areas.

Also of note is that several Region 4 cancer survivor focus group participants mentioned that no services were needed in their area.

Support Groups – all types and survivor networks

“Well I will speak for a man. It would be nice to be able to meet with other men who might have similar issues.” (Region 1 – Survivor)

“...we had a surgeon in Portland that removed the esophagus but there are no support groups for esophageal cancer patients/survivors. Like I said, you can get on the Internet and it’s chat room type thing, but it’s not face-to-face...” (Region 3 – Advocate)

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Services for Caregivers – emotional support and information support

“I want something, you know, if I can get together with a group and they, you know, could give us some indoctrination, have answers, you know? Your wife is going through this ...you’re the person... caring for is going through this, but a-a-a-h, you know, this what you’re gonna ...have to deal with. ... This is the mental state you can get yourself into, you know, you know. So if I knew to expect, I think I can manage it better. I had a lot of surprises.” (Region 1 – Advocate)

“I mean, sometimes that [treatment] was two hours! That would be a good time to be watching a video or, you know . . . I mean there was a lot of people there who were care givers, I mean there’s a real opportunity to [provide caregivers with support and information].” (Region 1 – Advocate)

Question 3. What information or services did you want or would you have liked for family member or friend?

Overall, participants provided 116 coded comments to this question. The answers were categorized into one of 20 themes resulting in 5.8 comments per theme. The top five themes, presented below, accounted for 59% of all responses.

Table 5: Services wanted for a family member or friend

Theme	Number of Comments (N=116)	% of all Comments	% Theme mentioned in each of the 8 focus groups
1. More communication with doctors, nurses – regarding the type of treatment they are receiving	18	15.5%	50%
2. More information on steps being taken and what to expect in the future	14	12.1%	63%
3. Doctor/practice treatment – great	13	11.2%	63%
4. Support groups for various types of cancer	12	10.3%	38%
5. Family and caregiver support/counseling	11	9.5%	50%
Other	48	41.3%	NA

As the table indicates, cancer survivors and their advocates want more communication with the health care team regarding the type of treatment they are receiving and what to expect. The request for more communication with the health care team was mentioned most among Region 4 cancer survivors and Region 6 advocates. Of interest is that most of the comments dealing with theme #4 (Support groups for various types of cancer) were generated by Region 3 advocates. Also more than half the comments for theme #5 (Family and caregiver support/counseling) were made by Region 1 patient advocates.

Also of note is that several Region 6 cancer survivor focus group participants brought up financial and leave assistance as services they would like for a family member or friend.

More communication with doctors, nurses – regarding treatment

“I’d like to talk to a doctor a little more than one minute at a time. He gave me a shot in the belly and ah the bill was up to \$75 ... and the radiation is up to over \$10,000 and ... you’re in, you’re out and you can’t talk with the people that administer it.” (Region 3 – Survivor)

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“And I think it would have been nicer for the doctor to say, you know, I’d like for you and your husband to come into my office, or for you to come to the hospital and talk with instead of calling me at my office and telling me that my husband had cancer and I’m, like, right in the middle of everything, so that wasn’t pleasant.” (Region 6 – Advocate)

More information on steps being taken and what to expect

“I think something along the counseling line, too. I don’t know if it’s exactly counseling, but um somebody that would be able to explain what, what you’re going through and what you are going to go through and stuff like that. Because a lot of times, I found I didn’t know what questions I should be asking.” (Region 1 – Survivor)

“...I would like to see them give you a pamphlet on, you know, anyone who’s going to have chemotherapy, on the things that might happen to be aware of and to get on it right away...” (Region 4 – Survivor)

Question 4. Did you or your family member/friend encounter any barriers to accessing services?

Of the six questions asked of patients and their advocates/family members, this question evoked the fewest responses. Overall, participants provided 59 coded comments to this question. The answers were categorized into one of 17 themes resulting in 3.5 comments per theme. The top two themes, presented below, accounted for 32% of all responses. No other theme generated more than four responses.

Table 6: Barriers to accessing services

Theme	Number of Comments (N=59)	% of all Comments	% Theme mentioned in each of the 8 focus groups
1. Issue is not knowing services exist – no centralized location – need a list explaining services	10	16.9%	63%
2. Problems with insurance/no coverage for alternative care	9	15.3%	38%
Other	40	67.8%	NA

Cancer survivors and their advocates feel that the biggest barrier to accessing services is not knowing what services exist in the first place. This was especially true for cancer survivors in Region 3 who contributed half of the comments to this theme. Insurance problems were raised most often among Region 1 advocates.

No other theme generated more than four comments.

Issue is not knowing services exist – no centralized location – need a list explaining services

“That’s the point I’m trying to get at, is that none of us really know about what these services are and where they’re available.” (Region 3 – Survivor)

“...On the other hand I would have appreciated a list in case I needed something like that [rehabilitation and survivorship service]...” (Region 1 – Survivor)

Problems with insurance/no coverage for alternative care

“Insurance... need to have too many referrals from [the] primary care provider...” (Region 3 – Survivor)

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“... like, my husband would have an appointment on Friday and on Monday he would be getting a letter from the insurance saying okay, it’s okay for you to have gone in and done that or it’s okay for you to go, but he had already gone. What if they had said it’s not okay and he had done it.” (Region 6 – Advocate)

Question 5. What would have helped you or your family member /friend access or learn about these services?

Overall, participants provided 92 coded comments to this question. The answers were categorized into one of 17 themes resulting in 5.4 comments per theme. The top five themes, presented below, accounted for 64% of all responses.

Table 7: What would have helped you/family member access services

Theme	Number of Comments (N=92)	% of all Comments	% Theme mentioned in each of the 8 focus groups
1. Booklet on services available in the area, updated periodically, more detailed	22	23.9%	88%
2. Caseworker/someone/advocate to sift through the information for you	15	16.3%	50%
3. Information in plain language/not deceptive/what to expect	9	9.8%	38%
4. Need to be an advocate	7	7.6%	50%
5. Having access to support groups/survivors	6	6.5%	25%
Other	33	35.9%	NA

Of the eight focus groups for patients and their advocates, all but one mentioned the need for a booklet outlining available services in their communities. Nearly two-thirds of the comments on the need for a booklet were made by cancer survivors and their advocates in Region 1. The need to have an advocate or caseworker was mentioned in four of the focus groups. In three of the focus groups, participants requested that cancer information be written in plain language so that it was discernible for all types of survivors.

Also of note is that several Region 1 survivor advocates requested information on stress management and the “mind/body connection”. In Region 6, many newly diagnosed cancer survivors wanted information on support group services.

Booklet on services available in the area, updated periodically, more detailed

“...Typically more detailed information. I mean I came away after one of my first visits with this ... this brief case full of paperwork, papers and information, but most of the information that was in it was kind of vague...” (Region 1 – Survivor)

“...here’s a guide book to help you work through it, here’s the kind of services that are available, and there’s who provides...” (Region 1 – Advocate)

Caseworker/someone/advocate to sift through the information for you

“I think while you’re accessing services, you know, it’s always good to have somebody else with you.” (Region 2 – Survivor)

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“Once again, I think the caseworker would help out here. You have enough to deal with having the cancer. You don’t know what to ask.” (Region 6 - Advocate)

Question 6. Who or what agency did you or your family member /friend turn to for support?

Of the six questions asked of patients and their advocates/family members, this question evoked the most responses. Overall, participants provided 131 coded comments to this question. The answers were categorized into one of 22 themes resulting in 6.0 comments per theme. The top five themes, presented below, accounted for 51% of all responses.

Table 8: Turn to for Support

Theme	Number of Comments (N=131)	% of all Comments	% Theme mentioned in each of the 8 focus groups
1. Cancer support groups/survivors	24	18.3%	100%
2. Physician	12	9.2%	38%
3. Church, prayer groups	11	8.4%	75%
4. Dealt with it on own	11	8.4%	13%
5. Need more information, especially from hospitals, early on in the process/throughout various phases	9	6.9%	25%
Other	64	48.9%	NA

Of the eight focus groups for patients and their advocates, all of them mentioned cancer support groups or talking with survivors at least once. Almost a third of the comments were made by survivors in Region 1. Physicians were a source of support for many, especially advocates in Region 3. Church or prayer groups were a source of support for many as well. Not surprisingly, many advocates in Region 3 mentioned that men deal with cancer on their own and do not avail themselves of support groups. In Region 6, especially among advocates, focus group participants maintained that they need more information throughout the various stages of surviving cancer.

Cancer support group/survivors

“I went down to the [treatment center] in my case. The support group I have been involved with for the past eight months has helped me immensely.” (Region 1 – Survivor)

“It helps who you talk to... she [another survivor] is so upbeat, you know. She’s had a double mastectomy but, you know, she’s a great one to have...” (Region 6 – Survivor)

Physician

“At least my, I know, my husband asked, I think he got a lot from his ... radiation doctor. He would ask him anything and everything.” (Region 3 – Advocate)

“It sounds like the physician was their primary support system.” (Region 3 - Advocate)

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Health Care Provider Results

In this section, the results from the three health care provider focus groups will be presented. Since only three focus groups fall into this category, caution is warranted in interpreting the results. The results from one focus group can easily distort the overall results.

Question 1. Which of these (rehabilitation and survivorship) services are not available in your area? Why not?

Of the six questions asked of health care provider focus group participants, this question evoked the most responses. Overall, participants provided 80 coded comments to this question. The answers were categorized into one of 24 themes resulting in 3.3 comments per theme. The top five themes, presented below, accounted for 51% of all responses.

Table 9: Rehabilitation/Survivorship Service not Available in your Area

Theme	Number of Comments (N=80)	% of all Comments	% Theme mentioned in each of the 3 focus groups
1. Improved provider-patient care coordination	9	11.3%	33%
2. Alternative therapies – doctors not accepting of them	8	10.0%	33%
3. Pain management	7	8.8%	67%
4. Have a list of services available in hospital	7	8.8%	33%
5. Health care workers need to provide more information	5	6.3%	33%
6. Support groups	5	6.3%	33%
Other	39	48.8%	NA

The first theme is not one of the 15 services that participants were asked to consider. However, it was a topic of conversation at the Region 5 health care provider focus group. Among the 15 services, the one service that generated the most comments was alternative therapies. Again, all the comments were generated by Region 5 health care provider focus group respondents.

Of note is that several Region 2 health care providers addressed the lack of a resource directory in the hospital for cancer patients. Also of note is that Region 4 health care provider focus group providers mentioned that support groups were lacking in their area.

Improved provider-patient care coordination

“...they’ll (hospital physicians) only work on an inpatient setting because they believe – they [patients] use the hospital ... and many of them have never worked in an outpatient setting and have no concept of what is ...available...”
(Region 5 – Health Care Provider)

“...I had a patient who was very nicely regulated on pain medications which were provided by a palliative care physician in the hospital. He went home, was in good shape, came back to the hospital and his oncologist took him off all of the drugs and put him on what the oncologist was comfortable with and lo and behold, the patient didn’t do well.” (Region 5 – Health Care Provider)

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Alternative therapies – doctors not accepting of them

“You have a bunch of things under alternative therapies the medical staff...has clearly taken a stand that there [are] no alternative therapies going on in this hospital.” (Region 5 – Health Care Provider)

“There are several oncologists who have never made a hospice referral in their lives.” (Region 5 – Health Care Provider)

Question 2. Have you ever considered the level of influence you have with your patients when it comes to recommending/suggesting activities that might influence their quality of life? If so, how would you describe its’ impact on your practice? If not, why?

Of the six questions asked of health care provider focus group participants, this question evoked the fewest responses. Overall, participants provided 23 coded comments to this question. The answers were categorized into one of 10 themes resulting in 2.3 comments per theme. Only one theme generated more than four responses. The top theme, presented below, accounted for 22% of all responses.

Table 10: Level of Influence Health Care Provider has with Cancer Patient/Survivor

Theme	Number of Comments (N=23)	% of all Comments	% Theme mentioned in each of the 3 focus groups
1. Should have a Social Worker meet with patient and family	5	21.7%	33%
Other	18	78.3%	NA

Region 2 health care provider focus group participants responded to this question by stating that a social worker should meet with the patient and family to recommend activities that might influence their quality of life.

Should have a Social Worker meet with patient and family

“...I think the nurses are great, but then you’re a patient, you don’t see them that often... there’s no continuity. I think that is a role that there should be a social worker that definitely meets with both the [patient] and the family.” (Region 2 – Health Care Provider)

“...So it would be really helpful if there was a social worker there that could, ...that’s familiar with this, can relate, I’ve dealt with a lot of people who’ve gone through the same thing...” (Region 2 – Health Care Provider)

Question 3. What criteria do you use in making referrals for rehabilitation and survivorship services?

Overall, participants provided 43 coded comments to this question. The answers were categorized into one of 15 themes resulting in 2.9 comments per theme. The top two themes, presented below, accounted for 35% of all responses. No other theme generated more than four responses.

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Table 11: Criteria Used to Make Referrals

Theme	Number of Comments (N=43)	% of all Comments	% Theme mentioned in each of the 3 focus groups
1. Family concern/their ability to handle it/ family wants service	10	23.3%	100%
2. Patient care coordination - poor	5	11.6%	33%
Other	28	65.1%	NA

Of the three health care provider focus groups, all of them addressed family concerns as being a criterion for referral. This criterion was mentioned most among Region 2 health care provider focus group participants. The second theme mentioned above is not a criterion but more a practice problem. This problem was voiced by health care providers in Region 5.

Family concern/their ability to handle it/family wants service

“...I just had a lady that had a mastectomy and her family did not want her going home because they live on an island far away and there was no one to care for her...” (Region 2 – Health Care Provider)

“We have to look at the quality of life of those around them ‘cause sometimes it’s um the support is really needed for the daughter or the family member um that’s not for the patient sometimes...” (Region 4– Health Care Provider)

Patient care coordination – poor

“Then we have a major problem with referral to rehabilitation services because those get done by the oncologist. They’re the one...disconnected from these patients...” (Region 5 – Health Care Provider)

“...we’ve been seeing your patient for a cancer that you have not yet been informed they have. This is what has happened to them, this is where they are now, and here are what their future needs are anticipated to be. ...I am routinely embarrassed by a patient that comes in ... I say ... it’s been a year and – since I’ve seen you.” (Region 5 – Health Care Provider)

Question 4. Whose role is it within the healthcare setting to refer patients to rehabilitation and survivorship services?

Overall, participants provided 31 coded comments to this question. The answers were categorized into one of 10 themes resulting in 3.1 comments per theme. The top four themes, presented below, accounted for 71% of all responses. No other theme generated more than four responses.

Table 12: Whose Role it is to Refer Patients to Rehabilitation and Survivorship Services

Theme	Number of Comments (N=31)	% of all Comments	% Theme mentioned in each of the 3 focus groups
1. Primary Care Provider	6	19.3%	67%
2. Social Services	6	19.3%	33%
3. Health Care Team	5	16.1%	67%
4. Hinges on patient/family’s wishes/needs	5	16.1%	33%
Other	9	29.0%	NA

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The primary care physician and social services were cited most as the health care workers that should refer patients to rehabilitation and survivorship services. Region 2 focus group participants (nurses and social workers) indicated that social services should take the lead; Region 5 participants (physicians) indicated that primary care physicians should make the referrals.

Primary Care Providers

“...This is what family practitioners do [refer]. We are part of the team. These questions are established.” (Region 5 – Health Care Provider)

“There are many good internal medicine trained physicians who know how to access rehab, who know how to pay attention to nutritional problems. I would not take that away from them.” (Region 5– Health Care Provider)

Social Services

“Well because they [social services] seem to have all the answers in terms of questions that you might have...knowing what’s available...” (Region 2 – Health Care Provider)

“...I would say social services would probably have the majority of the information.” (Region 2 – Health Care Provider)

Question 5. When you think about the exchange that you have with patients during treatment and follow-up, what are the types of barriers you experience to discussing points about survivorship issues?

Overall, participants provided 28 coded comments to this question. The answers were categorized into one of 10 themes resulting in 2.8 comments per theme. The top two themes, presented below, accounted for 61% of all responses. No other theme generated more than four responses.

Table 13: Barriers to Discussing Survivorship Issues

Theme	Number of Comments (N=28)	% of all Comments	% Theme mentioned in each of the 3 focus groups
1. Personal comfort with discussing topic/not ready	12	42.9%	100%
2. Need standard assessment evaluation form for people diagnosed with cancer/as to what services they need/are available	5	17.9%	33%
Other	11	39.3%	NA

Of the three health care provider focus groups, all of them indicated that a barrier to discussing survivorship services was the patients’ readiness to discuss it. Some of these focus group participants also mentioned that health care providers also avoid this topic. This was especially true for participants in regions 2 and 4. Region 4 health care provider focus group participants believed that a standard assessment evaluation form for people diagnosed with cancer should be developed. The results would help the health care teams make the appropriate referral for survivorship services.

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Personal comfort with discussing topic/not ready

“Well for me, . . . I’m in a critical care environment for the most part . . . Very few patients want to discuss survivorship issues when they are just waking up from a general anesthetic.” (Region 2 – Health Care Provider)

“It hurts to say, my own inner barriers of initiation and comfort with these topics.” (Region 4– Health Care Provider)

Need standard assessment evaluation form for people diagnosed with cancer/as to what services they need/are available

“ . . . that maybe even if there was some sort of a needs assessment, that provider doctors could do with a patient . . . but if there was a questionnaire designed to help determine what, what was already in existence for the family in terms of support systems . . . , based on what it’s [assessment] telling me . . . it seems like . . . a cancer support group would work really well . . . ” (Region 4 – Health Care Provider)

“Yes, I see that a needs assessment evaluation being very important.” (Region 2 – Health Care Provider)

Question 6. What would help you in facilitating the referral process?

Overall, participants provided 36 coded comments to this question. The answers were categorized into one of 12 themes resulting in 3.0 comments per theme. The top two themes, presented below, accounted for 47% of all responses. No other theme generated more than four responses.

Table 14: Facilitators for the Referral Process

Theme	Number of Comments (N=36)	% of all Comments	% Theme mentioned in each of the 3 focus groups
1. List/packet of information regarding rehabilitation/survivorship - More detailed where to access throughout state	10	27.8%	67%
2. Oncological nurse/counselor in hospital who provides support/coordinates referral services	7	19.4%	100%
Other	19	52.8%	NA

Nearly all the comments addressing the need for a list/packet of information regarding rehabilitation and survivorship services were generated by the Region 2 health care provider focus group participants. Noteworthy is that all three health care provider focus groups mentioned the need for someone in the hospitals to be coordinating/facilitating the referral process.

List/packet of information regarding rehabilitation/survivorship – More detailed where to access throughout state

“The only other thing that I could think of that could help would be to get this list of social services . . . all the places in Maine . . . you know, like we said where services are available.” (Region 2 – Health Care Provider)

“ . . . So I think that there might be a lot of services that we’re not aware of. And I worked as a nurse so [I should be] aware of that particular thing. So I think definitely a more detailed list and then where in their area to access it throughout the State.” (Region 2 – Health Care Provider)

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Oncological nurse/ counselor in hospital who provides support/coordinates referral services

“...but if hospitals could have care support or nurse counselors who really ...the whole care management thing is the person who connects the person from one service to the next service and make sure...making sure nobody falls through the cracks. That would be ideal...” (Region 4 – Health Care Provider)

“...Like under the admissions process...the patient had cancer...That something like this would come up to social services so that...either the nurse or the social service, talk to the patient or maybe I could just grab a sheet, more detailed, give it to the patient, you know, take a look at that and then we can discuss it later.” (Region 2 – Health Care Provider)

Analysis

Information Dissemination

The theme mentioned most often was the lack of information or the need for more information regarding rehabilitation and survivorship services. This subject area was mentioned at seven of the eight cancer survivor and advocate focus groups. It was also discussed at two of the three health care provider focus groups. When presented with a list of rehabilitation and survivorship services, many focus group cancer survivors were unaware that many of the services were available to them or even existed. Many survivors said a list or booklet of rehabilitation and survivorship services was needed for each area of the state. Further, the booklet should be updated regularly and written in “plain” language that is easily understood.

Hospital and treatment center staffs were identified by cancer survivor and advocate focus group participants as the primary source of information on rehabilitation and survivorship services. Physicians (generalists and specialists) were also identified as sources of information as well. Outside the treatment setting, cancer support groups/networks were recognized as places to get information on services.

Communication with the Health Care Team

Cancer survivors and advocates both requested more communication with members of the health care teams providing their treatment. This topic was addressed at half of the survivor and advocate focus groups. It was mentioned most often during the Region 2 and 4 cancer survivor focus groups. Survivors voiced concerns about not having much interaction with the physicians overseeing their treatment. Some of these survivors wanted more information from their physicians on the steps being taken in their treatment and what to expect.

Patient Care

When asked about which rehabilitation and survivorship service is not available in their area, health care focus group participants in Region 5 instead focused on patient care. Some focus group participants mentioned that care coordination between the primary care provider, various specialists, and rehabilitation services was not well coordinated. In addition many focus group participants claimed that many hospitals and treatment facilities did not coordinate rehabilitation and survivorship services adequately. Some survivors said they would have liked someone to help them sift through the information on various services and explain the specifics to them in a comprehensive way while they dealt with their illness. Health care provider focus group participants differed on whose role within the hospital it is to provide such a service, but most agreed that the facilities should be doing more.

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Alternative Therapies

Another service mentioned often as not being available was alternative therapies. This topic was mentioned more by health care providers than survivors. The transcripts reveal that many focus group participants indicated that health care providers in the area do not allow or condone such services at local hospitals. In addition, one respondent indicated that some oncologists do not make referrals for other services such as hospice.

Support Groups

While cancer support groups were mentioned as sources of information and/or support for some participants, other cancer survivors and advocates cited this rehabilitation and survivorship service most often when it came to services not available in their communities. This was true in both urban and rural areas of the state. Health care providers also mentioned that support groups were lacking in their respective areas. Some participants did say that support groups for breast cancer patients and survivors were more readily available, but groups for other types of cancer, especially those needed by men, were not as readily available. Advocates and survivors also stated that services for caregivers were needed. This was especially true among focus group participants in southern Maine. Some said that advocates needed emotional support themselves as they helped a family member or friend cope with their illness.

Other Sources of Support

For some focus group participants, church or prayer groups are an important source of support as they grapple with cancer or while their illness is in remission. Many of the comments about church and prayer groups were generated during the Region 1 advocate focus group. These respondents attended church or prayer groups not only for their family member or friend's benefit – the person with cancer, but for their benefit as well.

Self-Advocacy

While many people cited physicians, other health care workers, and support groups as places to get information on treatment issues, some focus group participants maintained that cancer survivors need to be their own advocates. They claim with information fragmented and some rehabilitation and survivorship services lacking, survivors need to look out for their own self-interest. This issue was raised in four of the survivor/advocate focus groups with most of the comments coming from the Region 2 survivor focus group. Participants at this focus group urged other survivors to ask more questions of their health care providers, get second opinions, visit their public libraries and use the internet to get more information, and when possible bring a support person with you when receiving treatment.

Barriers to Treatment

Health care focus group participants were asked what barriers they experience in discussing treatment and follow-up with patients. The barrier most often cited was a provider's lack of comfort in discussing the topic(s) with patients and/or a patient being unprepared to discuss treatment. This theme was mentioned during all three health care provider focus groups. Since some cancer survivors are too ill at the time of treatment, some providers opt not to discuss these issues. Since patient/provider interaction can be limited in some circumstances, not discussing these issues at treatment means they do not get discussed.

Insurance Coverage

Insurance issues were cited as a barrier to accessing some rehabilitation and survivorship services. This subject emerged in three of the cancer survivor and advocate focus groups. It generated the most discussion

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among advocates at the Region 1 focus group. Some focus group participants lamented changes in health insurance coverage by employers as exacerbating the situation. Other focus group participants showed concern about the many referrals needed to get a referral for rehabilitation and survivorship services. Some others said the approval process for treatment and/or rehabilitation and survivorship services was lengthy and either delayed treatment or caused some to seek treatment before approval was granted.

Life insurance was also raised as an insurance problem. Some survivors mentioned that they could not afford coverage or that their rate had jumped markedly.

Family Concerns

The criterion considered most often by health care provider focus participants in making referrals for rehabilitation and survivorship services is family concerns. This criterion was raised at all three health care provider focus groups, but most often at the Region 2 health care provider focus group. Some focus group participants iterated that some are unable to care for family members in the advanced stages of the illness. Compounding this issue is that often family members and friends need support of their own to deal with impending loss and cannot manage to adequately care for a loved one.

Study Limitations

The findings in this report are based on a relatively small sample of 54 Maine cancer survivors, advocates, and health care providers. When advocates and health care providers are subtracted, the number of cancer survivors who attended a focus group is 36. The people who attended the focus groups do not necessarily represent a cross-section of Mainers by age, race or income who have or have had cancer other than they come from different regions of the state.

As mentioned earlier, one of the focus groups – Region 5 cancer survivors - was cancelled. Also, the cancellation meant only one focus group was held in the East Central region of the state. It was this region that generated the majority of the 2004 assessment surveys referenced earlier in this report.

Four of the focus groups had three or fewer participants. One of the groups was not actually a group since it only attracted one participant. As Table 1 illustrates, the number of people who responded to the recruitment letter was nearly twice that of the number of participants. For cancer survivors, one's comfort level in discussing their illness may have played a part in their decision not to attend. Even after agreeing to participate in one of the sessions, some survivors may have decided they were not comfortable recounting their struggles with their illness before a group of strangers.

In addition, since these four groups were poorly attended, the level of discussion was much more limited. Focus groups tend to work best with anywhere from six to ten individuals. With a group this size, a good back and forth discussion can ensue. In a smaller group, as was the case in couple of focus groups conducted for this study, if there are one or more people who do not talk, the discussion becomes more of an interview between the focus group facilitator and a more loquacious individual(s).

Recruiting advocates was especially challenging. Whereas the host hospital sites had lists of cancer survivors, none of them had actual lists of advocates. The hospitals that hosted advocate focus groups sent letters to survivors asking them to refer family members and friends to the focus groups. As mentioned earlier, one host hospital offered to run an ad in the local newspaper asking for interested participants to contact the Muskie School.

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Recruiting health care providers for the provider focus groups was arduous as well. Understandably, health care providers, especially physicians, are very busy. They have patients scheduled throughout day and finding time in their day to sit down and talk for an hour can be problematic. Even with the financial enticement and Muskie staff flexibility to hold sessions at times convenient to physician schedules, getting health care providers to attend such a session is difficult. As a result, this study includes the opinions of only nine health care providers.

As discussed earlier, just one researcher identified all the themes. Different researchers may or may not have identified other themes or categorized the responses differently. In addition, the researcher may have categorized the focus responses somewhat differently had he actually attended the focus group sessions. Due to time and budget constraints, the researcher could only review the transcripts.

Conclusion

The survivors, advocates, and health care workers who participated in the study focused on the need for improved information and communication. The findings from this study reveal that cancer survivors and advocates want more easy to understand information on cancer, treatment options, and what to expect in the future from a centralized and accessible source. Further, they want to be better informed about rehabilitation and survivorship services in their communities. In addition, survivors want more communication with their health care/treatment team.

Some survivors and health care provider focus group participants addressed provider-patient care and the poor coordination between providers and rehabilitation and survivorship service providers. Further some participants felt that the hospitals/treatment facilities needed a cancer care coordinator/gatekeeper that could help cancer patients negotiate the myriad systems of care. A further exploration of how a gatekeeper would fit within the current system of care deserves some consideration.

Another area meriting further study is the issue of support services for family members/advocates. Cancer can take a toll on the individual both physically and emotionally. The transcripts from the advocate focus groups revealed that many of them endure a great deal of emotional duress providing care to the family members and friends. While some advocate participants suggested they needed counseling services themselves, a future study might probe deeper by looking at what other services they need to provide the support to their family members and friends.

Alternative therapies generated a lot of discussion, especially among the health care provider focus group participants. As discussed, some reported that health care workers in their area were unreceptive to these treatment options. The lack of insurance coverage for some of these treatments prevents referral. Also, some physicians may be reluctant to refer patients for some alternative treatment if they are not evidence-based. More information needs to be gathered as to the reasons why some physicians do not refer patients for these types of treatment.

Lastly, some survivors and practitioners raised health care providers' lack of comfort in discussing treatment and follow-up with patients, especially among patients who might be terminal. This lack of comfort may reduce the chances that someone with end-stage cancer is referred to the appropriate end of life care service. A possible next step might be to pursue this topic area with cancer specialists

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Appendix

A. Rehabilitation and Survivorship Services Listed in the 2004 Assessment Study

B. Focus Group Questions by Group Characteristic

Appendix A

Rehabilitation and Survivorship Services Listed in the 2004 Assessment Study

1. Transportation
2. Lodging
3. Financial Assistance
4. Physical Therapy
5. Lymphedema
6. Occupational Therapy
7. Speech Therapy
8. Education and Support Groups
9. Counseling
10. Nutritional Counseling
11. Pain Management
12. Alternative/Complementary Medicine
13. Home Care
14. Palliative Care
15. Hospice

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Appendix B

Focus Group Questions by Group Characteristic

Questions	Cancer Survivors Advocates/Family members	Health Care Providers
How did you learn about rehabilitation/survivorship services for your family member or friend?	*	
What types of rehabilitation and survivorship services are not available in your area?	*	
What information or services did you want or would you have liked for family member or friend?	*	
Did your family member/friend encounter any barriers to accessing services?	*	
What would have helped your family member/friend access or learn about these services?	*	
Who or what agency did your family member/friend turn to for support? Prompt: If not why?	*	
Which of these services are not available in your area? Prompt Why not?		*
Have you ever considered the level of influence you have with your patients when it comes to recommending/suggesting activities that might influence their quality of life? If so, how would you describe its impact on your practice? Prompt: If not why?		*
What criteria do you use in making referrals for rehabilitation and survivorship services? Prompts: Severity of illness, life expectancy		*
Whose role is it within the healthcare setting to refer patients to rehabilitation and survivorship services?		*
When you think about the exchange that you have with patients during treatment and follow-up, what are the types of barriers you experience to discussing points about survivorship issues?		*
What would help you in facilitating the referral process?		*

Muskie School of Public Service

MUSKIE SCHOOL OF PUBLIC SERVICE
96 Falmouth Street
PO Box 9300
Portland, ME 04104-9300

TELEPHONE (207) 780-4430
TTY (207) 780-5646
FAX (207) 780-4417
www.muskie.usm.maine.edu



UNIVERSITY OF
SOUTHERN MAINE