Assessing the Needs of Cancer Patients for Rehabilitation & Survivorship Services in Maine



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Assessing the Needs of Cancer Patients for Rehabilitation & Survivorship Services in Maine

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October 15, 2004

TABLE OF CONTENTS

Acknowledgements	i
Executive Summary	1
Project Overview	2
Introduction	2
Intended/Potential Use of Assessment Finding	2
Assessment Design/Location/Timeframe	2
Assessment Questions	2
Inclusion/Exclusion Criteria	3
Sampling	3
Consent Process	3
Study Instruments	3
Data Collection and Analysis	4
Results	5
Section I. Demographics and Overall Responses	5
Section II. Respondents who have used the Services	9
Section III. Respondents who did not use the Services	12
Study Limitations	15
Recommendations	15
Appendices	17
A. American College of Surgeons Commission on Cancer Facilities in Maine	18
B. Cancer Rehabilitation & Support Services Survey Consent	19
Cancer Rehabilitation & Support Services Survey Instructions	
Cancer Rehabilitation & Support Services Survey	
C. Maine Cancer Consortium's Rehabilitation and Survivorship Work Group	35
D Survey Responses by Unidentified Facilities	36

TABLE & GRAPHS

Table 1. Respondents by Age Cohort & Mean Age	5
Table 2. Respondents by Gender	5
Table 3. Age at Diagnosis and Length of Time (in years) with Diagnosis	6
Table 4. Have you used this service? Type of Responses	7
Table 5. Have you used this service? Responses by Facility Type	9
Table 6. Referral Sources	9
Table 7. Service Quality and Availability	10
Table 8. Payment of Services	11
Table 9. Respondents answering no to the question, "Have you used this service?" Reasons	12
Table 10. Awareness of Service – Have you heard about this service? (Respondents previously answering no to the question, "Have you used this service?)	13
Table 11. How did you hear about this service? "No" responders	14
Graph 1. Primary Care Diagnoses among Respondents	6
Graph 2. Percentage of No Responses by Service Domain	8

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Executive Summary

Currently, no published data exist regarding the type of rehabilitation and survivorship services that are being used or other services offered to cancer survivors in Maine. The findings of this assessment are the first statewide baseline data collected on cancer rehabilitation and survivorship services in Maine.

The assessment is designed to answer 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. Of the 18 facilities that returned surveys, six returned 50% or more of the surveys they received.

In order to get a representative sample, 2,160 assessments were disseminated during a two-month period (June and July 2004), with the goal of 1,200 completed surveys. Eight hundred and sixty one (n=861) or 40% of the 2,160 surveys were returned.

The assessment tool was developed by Ellen Sharp, M.Ed., a University of Maine graduate student intern with the Maine Comprehensive Cancer Control Program and CancerCare of Maine in consultation with the Maine Cancer Consortium's Rehabilitation and Survivorship Work Group and staff from the Maine Center for Public Health. Each site was given a coded group number so their individual site data can be compared in aggregate and assessed individually during data analysis. Hospital staff submitted the completed assessments to the Edmund S. Muskie School of Public Service for data entry and analysis.

Key Findings

- ➤ 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.
- > 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 means that at least 85% of respondents had either not used the service or left the question unanswered.
- ➤ 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.

October 15, 2004

Project Overview

This assessment provides an opportunity to gain critical information about the needs of those who are receiving cancer treatment or follow-up rehabilitative care and survivorship services in Maine. This assessment provides information on the usefulness, affordability, and helpfulness of cancer rehabilitation and survivorship services, such as transportation, speech therapy, and counseling. One of the intended outcomes of this project is to begin collection of baseline data on cancer rehabilitation and survivorship services across the state. To date, there has been no collection of such data, which has made it challenging to make data-driven program decisions.

The data collection method consisted of surveying people who receive cancer treatment or follow-up at select Maine hospitals during June and July 2004. Patients received a copy of the survey while they were at a participating Maine hospital receiving oncology, radiation, chemotherapy or follow-up services. Returned surveys were entered into an Access Database developed by the Edmund S. Muskie School of Public Service for data entry and analysis purposes.

Introduction

With the change in age demography, the nature of Maine's geographic terrain, and the patchwork nature of rural health service delivery, there is a great need for a statewide survey to assess the patient perspective on cancer survivorship. Currently, no published data exist regarding the type of rehabilitation and survivorship services that are being used or other services offered to cancer survivors in Maine. No data exist on the survivors' perspective on the accessibility of the services, how they discovered the services and if their health insurance covers the costs or if transportation is a barrier. Furthermore, no data exist at a statewide level as to the referral pattern for survivor services from providers for support groups, homecare, hospice or alternative medicine adjunctive treatments or rehabilitation including occupational, physical and speech therapy. The assessment intends to identify the gaps in perceived patient access to services as related to distance, finances, advertising, and general rates of use of particular services.

Intended/Potential Use of Assessment Findings

The findings of this assessment are the first statewide baseline data collected on cancer rehabilitation and survivorship services in Maine. The accompanying results will inform Maine's service providers and the Maine Cancer Consortium on the needs for and use of cancer rehabilitation and survivorship services. The findings will be used to make recommendations on how to enhance the system in order to reflect the reported needs of Maine residents living with cancer and seeking treatment or support services.

Assessment Design/Location/Timeframe

The study is a cross-sectional survey that utilized a convenience sample. The 90-item questionnaire was designed to be self administered to all participants who were receiving cancer treatment or follow-up services during June and July 2004. All hospitals which provide cancer treatment in Maine were invited to participate in the assessment, contingent upon approval of their internal IRB, if applicable. The questionnaire was piloted at two hospitals in the spring of 2004.

Assessment Questions

The assessment is designed to answer 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?

Inclusion/Exclusion Criteria

The inclusion criteria for participation in the assessment are:

- An adult (18-89)
- Living in Maine
- Cancer diagnosis
- Receiving cancer treatment or follow-up services
- During June and July 2004

Hospital representatives were responsible for screening study participants to assure that all respondents met the inclusion criteria.

Sampling

On average, there are 608 Mainers diagnosed with cancer each month. A sampling plan for each participating hospital was developed based on the number of individuals seeking treatment at a particular hospital on a monthly basis. All adults at participating hospitals who are receiving cancer treatment or follow-up services were given the assessment to complete. Hospitals serving at least 100 patients a month were given two weeks to return their allotted number of surveys. Hospitals treating less than 50 patients a month were given a month. In order to get a representative sample, 2,160 assessments were disseminated during a two-month period (June and July 2004), with the goal of 1,200 completed surveys.

Twenty hospitals/radiation oncology treatment centers took part in the survey. All but two of them returned completed surveys. Of the 18 facilities that returned surveys, six returned 50% or more of the surveys they received. Only one returned all the surveys it received. Nine of the 11 American College of Surgeons (ACoS) Commission on Cancer approved hospitals in Maine participated in the survey and eight of these returned surveys. Ten non-ACoS Maine facilities participated as well. Please see Appendix A for more information on ACoS facilities.

Consent Process

Passive consent was used for this assessment. A cover letter was attached to the survey with the following language, "Your participation is voluntary. By completing the survey, you are giving your consent to participate." Assessment forms did not contain any individual-identifying information.

Study Instruments

The assessment tool was developed by Ellen Sharp, M.Ed., a University of Maine graduate student intern with the Maine Comprehensive Cancer Control Program and CancerCare of Maine in consultation with the Maine Cancer Consortium's Rehabilitation and Survivorship Work Group and staff from the Maine Center for Public Health. Please see Appendix B for a copy of the assessment tool and Appendix C for a list of Rehabilitation and Survivorship Work Group members.

Assessing the Needs of Cancer Patients for Rehabilitation & Survivorship Services in Maine

The final survey protocols including the questionnaire and consent form were reviewed by representatives from the Maine Comprehensive Cancer Control Program, the Maine Center for Public Health, and Rehabilitation and Survivorship Work Group members. (Appendix C).

Data Collection and Analysis

Each site was given a coded group number so their individual site data can be compared in aggregate and assessed individually during data analysis. Hospital staff submitted the completed assessments to the Edmund S. Muskie School of Public Service for data entry and analysis. Data analysis was completed with SPSS software. Descriptive statistics were calculated to provide a general picture of the study sample with respect to demographics, including age, sex, date and type of cancer diagnosis, and name of hospital where treatment was received.

RESULTS

Section I. Demographics and Overall Reponses

Eight Hundred And Sixty One (N=861) Or 40% Of The 2,160 Surveys Were Returned

Age and Gender of Respondents

Eight hundred and forty-three (n=843) or 98% of the survey respondents provided their age. The mean age for respondents was 62.9. Fifty-two (52%) percent of the respondents were between the ages of 50-69.

Table 1. Respondents by Age Cohorts & Mean Age

	Frequency	<u>Percent</u>
20-39*	29	3.4%
40-49	98	11.6%
50-59	207	24.6%
60-69	228	27.0%
70-79	190	22.5%
80-89	91	10.8%
Total	843	100.00%
Non-responses		18
Mean Age		62.9

^{* =} No 18-19 year olds completed the survey.

Seven hundred and ninety-two (n=792) or 92% of the respondents indicated a gender. Of these, 64% were female and 36% were male (Table 2). Among American College of Surgeons (ACoS) Commission on Cancer approved hospitals in Maine, the breakdown was 61% female and 39% male, while 73% and 27% of non-ACoS respondents were female and male respectively. Please see the Appendix A for a listing of ACoS facilities in Maine.

Table 2. Respondents by Gender

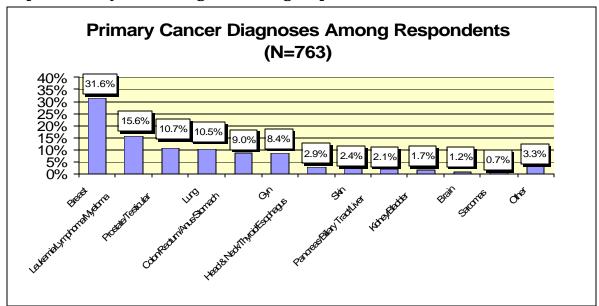
	Overall (n=792)	ACoS (n=629)	Non-ACoS (n=163)
Female	63.6%	61.2%	73.0%
Male	36.4%	38.8%	27.0%

Primary Cancer Diagnoses A mong Respondents

Seven hundred and sixty-three (n=763) or 89% of all respondents listed a cancer diagnosis or some type of diagnosis. A breast cancer diagnosis accounted for about a third (31.6%) of all primary diagnoses.

Females accounted for 65% of the 719 respondents who gave a diagnosis <u>and</u> selected a gender. A breast cancer diagnosis was the primary diagnosis for 49% of these women followed by gynecological (13%), leukemia/lymphoma/myeloma (12%), lung (9%), and colorectal (8%).

Prostate/testicular cancer (30%) was the leading primary cancer diagnosis for male respondents followed by leukemia/lymphoma/myeloma (22%), lung (15%), colorectal (10%), and head and neck/thyroid, and esophagus (5%).



Graph 1. Primary Cancer Diagnoses among Respondents

Age at Diagnosis

Eight hundred and two (n=802) or 93% of the respondents indicated their current age and year of diagnosis. This enabled the Muskie School to calculate a crude age at diagnosis. Since the month and date were not specified, the Muskie School determined the age at diagnosis by taking the current year and subtracting the diagnosis year. Then taking this difference and subtracting it from their current age.

For example, respondent X gives their current age as 41 (in 2004) and the year of their cancer diagnosis as 1993. The age at diagnosis is calculated as follows: current year (2004) - diagnosis year (1993) = 11. Current age (41) - year difference (11) = age at diagnosis (30).

The mean age when cancer was first diagnosed for the 802 respondents mentioned above was 59.5 years. Among these respondents the average length of time with a cancer diagnosis was 3.1 years. Length of time ranged from 0 (diagnosed this year) to 51 years. Please note that some people may have had a subsequent diagnosis.

Table 3. Age at Diagnosis and Length of Time (in years) with Diagnosis

	, 0
Mean Age at Diagnosis (n=802)	59.5
Mean Length of Time with Cancer Diagnosis	3.1
Length of Time with Cancer Diagnosis (range)	0 to 51 years
Year of Diagnosis	1953 to present

Cancer Treatment

Eight hundred and twenty-two (n=822) or 95% of the survey respondents answered the question whether they were currently receiving treatment for a cancer diagnosis. Of the 822, 66% and 34% answered "Yes"

and "No" respectively. Women (69%) tended to be currently receiving treatment more than men (62%). Among age cohorts (20-39, 40-49, 50-59, 60-69, 70-79, and 80-89), no age group reported large difference when it came to this question.

Returned Surveys by Facility Type

Among ACoS approved hospitals in Maine, the response rate was 45% compared to 28% for non-ACoS facilities. ACoS facilities returned 79% of all the surveys entered by the Muskie School. For more information on responses, please see Appendix D.

Service Use Domains

Respondents were asked to respond to the following question, "Have you used this service," to 15 different services (Table 4). The service used most often was nutrition counseling (15.1%) followed by education and support groups (14.4%). The services used least often were hospice (2.8%) and speech therapy (2.2%).

Table 4. Have you used this service? Type of Responses (in the order the question was asked) (n=861)

<u>Service</u>	% Yes	<u>% No</u>	<u>% NR*</u>
Transportation	9.5%	85.1%	5.3%
Lodging	6.4%	85.9%	7.7%
Financial Assistance	10.5%	80.0%	9.5%
Physical Therapy	10.5%	80.6%	8.9%
Lymphedema	5.0%	81.8%	13.2%
Occupational Therapy	5.7%	82.8%	11.5%
Speech Therapy	2.2%	85.5%	12.3%
Education & Support Groups	14.4%	74.7%	10.9%
Counseling	9.4%	78.7%	11.8%
Nutrition Counseling	15.1%	73.2%	11.7%
Pain Management	12.9%	74.4%	12.7%
Alt./Complementary Medicine	7.7%	79.7%	12.7%
Home Care	13.8%	74.9%	11.3%
Palliative Care	7.1%	78.2%	14.8%
Hospice	2.8%	84.1%	13.1%

^{*} NR = No Response

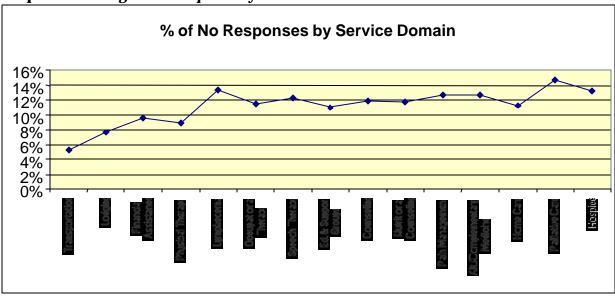
On average, each respondent used 1.3 of the 15 services. Among respondents who used at least one service, the average was 2.6 services. Almost half (49%) of the 861 respondents did not use any of the 15 services and only four respondents used all of them.

The non-responses to these questions are noteworthy. For the first four services (transportation, lodging, financial assistance, and physical therapy) on the survey, the no responses were less than 10%, even though they were not the most used services. With all subsequent services, the non-response rate was over 10%. Graph 2 on the next page charts the non-response rate in the order in which the service question was asked.

Non-ACoS respondents were <u>more</u> apt to have used rehabilitation and survivorship services than ACoS respondents. As table 5 on page nine indicates, non-ACoS respondents used the first nine services <u>more</u> than their ACoS counterparts. It should also be noted that non-ACoS respondents only make up 21% of all respondents. When the results are weighted to give ACoS and non-ACoS equal representation in the sample, education and support group services would be the most used service.

October 15, 2004

7



Graph 2. Percentage of No Responses by Service Domain

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Section II. Respondents Who Have Used the Services

Referral Sources

If respondents used a service they were then asked, "How did you hear about this service?" The respondents were given eleven choices including "other." They could check all that apply. Table 6 shows the referral sources for the various services.

Physicians were the most common referral source for all rehabilitation and survivorship services with the exception of alternative/complementary medicine. In this case they were second to family/friend. With all but three services - lodging, financial assistance, and alternative/complementary medicine - more than half of the respondents indicated that a doctor/physician was one of or the only referral source. Nurses were the next most common source of referral information followed by social worker and then family/friend.

Table 5. Have you used this service? Responses by Facility Type (in rank order) (n=861)

		-J	, (,
<u>Service</u>	% Yes (Overall)	<u>% Yes – Weighted*</u>	<u>% Yes (ACoS) – </u>	<u>% Yes – (Non-ACoS)</u>
		(Overall)	<u>(n=676)</u>	<u>(n=185)</u>
Nutrition Counseling	15.1%	15.5%	14.8%	16.2%
Educ. & Support Groups	14.4%	16.0%	13.2%	18.9%
Home Care	13.8%	15.3%	12.7%	17.8%
Pain Management	12.9%	13.3%	12.6%	14.1%
Financial Assistance	10.5%	11.6%	9.6%	13.5%
Physical Therapy	10.5%	12.3%	9.0%	15.7%
Transportation	9.5%	11.0%	8.4%	13.6%
Counseling	9.4%	10.5%	8.6%	12.4%
Alt./Complement. Medicine	7.7%	8.4%	7.1%	9.7%
Palliative Care	7.1%	6.5%	7.5%	5.4%
Lodging	6.4%	5.2%	7.2%	3.2%
Occupational Therapy	5.7%	5.6%	5.8%	5.4%
Lymphedema	5.0%	4.8%	5.2%	4.3%
Hospice	2.8%	2.8%	2.8%	2.7%
Speech Therapy	2.2%	2.0%	2.4%	1.6%

^{* =} Sample weighted to give ACoS and non-ACoS facilities equal representation

Table 6. Referral Sources

	Doctor	Family/ Friend	Nurse	Social Worker	Clergy	Brochure	Newspaper	TV	Phone help line	Web/ Internet	Other
Transportation (n=82)	54%	27%	16%	18%	0%	5%	1%	1%	0%	0%	9%
Lodging (n=55)	46%	26%	16%	18%	0%	4%	0%	2%	2%	0%	4%
Financial Assistance (n=84)	41%	23%	24%	37%	1%	5%	0%	1%	0%	1%	12%
Physical Therapy (n=88)	82%	10%	34%	23%	1%	5%	0%	0%	0%	1%	2%
Lymphedema (n=41)	90%	7%	24%	5%	0%	2%	0%	0%	0%	0%	2%
Occupational Therapy (n=48)	71%	15%	35%	38%	2%	4%	2%	0%	0%	2%	4%
Speech Therapy (n=19)	84%	26%	21%	26%	5%	0%	0%	0%	0%	0%	0%
Ed. & Support Groups (n=122)	57%	25%	50%	30%	2%	18%	4%	1%	2%	6%	7%
Counseling (n=77)	68%	20%	35%	42%	8%	7%	0%	0%	0%	4%	4%

October 15, 2004

Nutritional Counseling (n=127)	59%	9%	58%	15%	0%	6%	2%	2%	0%	2%	8%
Pain Management (n=107)	94%	9%	50%	10%	2%	5%	1%	0%	0%	1%	5%
Alt./Complement. Medicine (n=64)	39%	58%	28%	6%	0%	9%	5%	3%	2%	11%	14%
Home Care (n=117)	76%	9%	44%	21%	0%	3%	1%	1%	0%	0%	7%
Palliative Care (n=58)	86%	14%	48%	19%	2%	5%	3%	0%	0%	2%	3%
Hospice (n=22)	73%	32%	46%	23%	5%	0%	5%	5%	0%	0%	0%

(n is the number of people who answered yes to the previous question, "Have you used this service" and answered this question.)

Service Characteristics

If respondents used a service they were then asked a series of follow-up questions regarding their satisfaction with the services. The answers to these questions are in Table 7.

Among respondents answering "Yes" to the question "Have you used this service," transportation was the most helpful service (95%) followed by home care (93%). With the exception of hospice and speech therapy services, at least 75% of respondents found each of the services helpful.

With the exception of lymphedema services, a majority of respondents indicated that services were helpful to family members. Lodging services were the most helpful service for families.

A majority of respondents indicated that they were able to use most of services within 30 miles of their home, the exception being lodging services. This is not surprising since most people who reside less than 30 miles from a treatment facility probably commute and would not have a need for lodging services.

Table 7. Service Quality and Availability

	Did this service help you? (% Yes)	Did this service help your family? (% Yes)	Did you use this service within 30 miles of your home? (% Yes)
Transportation (n=82)	95%	74%	63%
Lodging (n=55)	87%	82%	34%
Financial Assistance (n=90)	83%	59%	60%
Physical Therapy (n=90)	83%	49%	72%
Lymphedema (n=43)	77%	19%	56%
Occupational Therapy (n=49)	82%	63%	55%
Speech Therapy (n=19)	68%	53%	53%
Ed. & Support Groups (n=124)	82%	52%	71%
Counseling (n=81)	82%	68%	68%
Nutritional Counseling (n=130)	84%	55%	63%
Pain Management (n=111)	84%	52%	64%
Alt./Complement. Medicine (n=66)	83%	53%	73%
Home Care (n=119)	93%	74%	85%
Palliative Care (n=61)	89%	67%	66%
Hospice (n=24)	63%	58%	54%

(n is the number of people who answered yes to the previous question, "Have you used this service" and answered this question.)

Payment for Services

For those who answered yes to the original question, "Have you used this service," respondents were asked to respond to the following question, "How did you pay for this service?" Respondents indicated that most clinical and rehabilitative services were covered by their health insurance coverage. For example, 91% of respondents who used home care services had this service covered by health insurance. The service least likely to be covered by health insurance was education and support groups. Nearly three-quarters of respondents stated that this service was free to them.

The services most likely to be out of pocket expenses were alternative/complementary medicine (55%) and lodging (48%). The services least likely to be an out of pocket expense were speech therapy and hospice.

Services most likely to be free were education and support groups (74%) and financial assistance (50%). Services least likely to be free were home care (4%), occupational therapy (7%), and physical therapy (8%).

Some service domains generated several additional "other" responses. With financial assistance, one in three people providing an "other" response said MaineCare or Medicare. Likewise, nearly half of the people who provided an "other" option with transportation services mentioned MaineCare or Medicare.

Table 8. Payment of Services (How did you pay for this service – check all that apply).

, and the second	Health Insurance (% Yes)	On my own (% Yes)	Service was Free (% Yes)	Other (% Yes)
Transportation (n=78)	41%	13%	44%	19%
Lodging (n=50)	32%	48%	22%	16%
Financial Assistance (n=80)	34%	14%	50%	39%
Physical Therapy (n=79)	85%	11%	8%	13%
Lymphedema (n=35)	83%	23%	9%	9%
Occupational Therapy (n=45)	87%	9%	7%	13%
Speech Therapy (n=15)	87%	0%	13%	0%
Ed. & Support Groups (n=104)	22%	5%	74%	3%
Counseling (n=70)	59%	17%	36%	6%
Nutritional Counseling (n=112)	52%	11%	36%	9%
Pain Management (n=93)	75%	14%	15%	9%
Alt./Complement. Medicine (n=60)	28%	55%	25%	7%
Home Care (n=111)	91%	3%	4%	12%
Palliative Care (n=52)	65%	8%	29%	6%
Hospice (n=16)	63%	0%	31%	6%

Section III. Respondents Who Did Not Use the Services

No Responses

Most people completing the surveys answered "No" to the question, "Have you used this service?" People responding no were given five choices to choose from to explain their answer. In many cases, the person responding no did not provide a reason.

Of those that did check a reason(s), most chose "I do not have a need for the service." Among those responding to this question, speech therapy (94%), lodging (93%), hospice (92%), and occupational therapy (90%) were checked the most often. Most people were aware of the various services, though 30% of responders answering no were not aware of alternative/complementary medicine services.

Most people did not provide an "other" response; however, the education and support group service domain was the exception. With this service, many people said it was inconvenient in their situation, too far, and/or not at the right time.

Table 9. Respondents answering no to the question, "Have you used this service?" Reasons – (check

all that apply).

un enac appropri	Number of Respondents answering "No"	Number of Respondents answering "No" who provided a reason*	I do not have a need for the service (% Yes)	The service was not available (% Yes)	I could not afford the service (% Yes)	I was not aware of the service (% Yes)	Other (% Yes)	Number of respondents not answering the question
Transportation	733	565	86%	1%	<1%	20%	3%	46
Lodging	740	532	93%	1%	1%	13%	1%	66
Financial Assistance	689	461	76%	1%	<1%	25%	6%	82
Physical Therapy	694	458	85%	1%	<1%	15%	3%	77
Lymphedema	704	426	88%	<1%	1%	12%	5%	114
Occupational Therapy	713	407	90%	<1%	<1%	13%	1%	99
Speech Therapy	736	460	94%	0%	<1%	9%	1%	106
Ed. & Support Groups	643	374	77%	1%	<1%	13%	11%	94
Counseling	678	404	81%	1%	1%	17%	6%	102
Nutritional Counseling	630	370	80%	1%	1%	18%	4%	101
Pain Management	641	400	86%	1%	<1%	15%	3%	109
Alt./Complement. Medicine	686	405	70%	1%	2%	30%	2%	109
Home Care	645	399	87%	1%	1%	13%	3%	97
Palliative Care	673	397	79%	1%	1%	21%	2%	127
Hospice	724	443	92%	<1%	1%	8%	2%	113

^{*} = Percentages are based on the number in this column.

<u>Awareness of Services – Respondents Answering "No"</u>

Respondents who answered no to the question, "Have you used this service," were subsequently asked if they heard about the service. The percentage figures below are based on those answering yes, no, or left in unanswered.

The services respondents answering no had heard the most about were education and support groups (33%), transportation (31%), and hospice (30%). The services these responders had heard the least about were lymphedema (10%), alternative/complementary medicine (11%), and palliative care (11%).

With the exception of education and support groups, more people had not heard of the particular service than those that did.

Table 10. Awareness of Service – Have you heard about this service? (Respondents previously answering no to the question, "Have you used this service?")

5	Number of Respondents who did not use service	Have you heard about this service? (% Yes)	Have you heard about this service? (% No)	Have you heard about this service? (% NR*)
Transportation	733	31%	50%	19%
Lodging	740	22%	47%	31%
Financial Assistance	689	19%	50%	31%
Physical Therapy	694	19%	43%	38%
Lymphedema	704	10%	49%	41%
Occupational Therapy	713	14%	45%	41%
Speech Therapy	736	12%	44%	43%
Ed. & Support Groups	643	33%	29%	39%
Counseling	678	26%	35%	39%
Nutritional Counseling	630	24%	37%	39%
Pain Management	641	24%	37%	39%
Alt./Complement. Medicine	686	11%	48%	41%
Home Care	645	19%	39%	42%
Palliative Care	673	11%	48%	41%
Hospice *NP - No response	724	30%	31%	40%

^{*}NR = No response

If a responder answering no had heard about the service they were asked, "How did you hear about this service?" They could check all that apply.

The answers below differ with those in Table 6. The responses in Table 6 are based on people who have used the 15 services. The answers below reflect respondents who did not use the service(s) and their awareness, or lack thereof, of the rehabilitative and survivorship services and how they obtained that information. The sources of information for the 15 services are fairly evenly spread among doctors, family/friends, nurses, social workers, and brochures with doctors and nurses leading the way.

October 15, 2004

Table 11. How did you hear about this service? (Check all that apply) – People who did not use services

	Doctor	Family/ Friend	Nurse	Social Worker	Clergy	Brochure	Newspaper	TV	Phone help line	Web/ Internet	Other
Transportation (n=204)	25%	26%	28%	14%	0%	17%	6%	1%	1%	1%	12%
Lodging (n=147)	20%	29%	27%	18%	0%	19%	6%	13%	0%	1%	13%
Financial Assistance (n=108)	18%	15%	35%	22%	0%	19%	3%	4%	0%	2%	13%
Physical Therapy (n=110)	38%	25%	33%	10%	0%	23%	4%	3%	0%	1%	13%
Lymphedema (n=63)	56%	19%	29%	3%	0%	19%	0%	0%	0%	0%	13%
Occupational Therapy (n=81)	32%	22%	40%	10%	0%	28%	7%	9%	0%	1%	11%
Speech Therapy (n=72)	31%	19%	29%	11%	0%	32%	10%	6%	0%	3%	14%
Ed. & Support Groups (n=173)	40%	26%	46%	17%	1%	36%	6%	4%	0%	5%	7%
Counseling (n=145)	41%	24%	56%	21%	3%	29%	3%	2%	1%	3%	6%
Nutritional Counseling (n=124)	42%	18%	60%	12%	1%	29%	2%	2%	1%	2%	6%
Pain Management (n=127)	64%	21%	57%	9%	1%	23%	5%	4%	0%	2%	6%
Alt./Complement. Medicine (n=68)	21%	29%	32%	7%	3%	28%	16%	13%	0%	7%	9%
Home Care (n=101)	35%	34%	46%	17%	0%	17%	11%	5%	0%	4%	11%
Palliative Care (n=62)	39%	18%	50%	11%	0%	24%	7%	3%	0%	7%	11%
Hospice (n=177)	24%	53%	31%	15%	7%	28%	20%	15%	6%	1%	11%

October 15, 2004

14

Study Limitations

- 1. The "Yes" results on the 15 services are based on relatively few respondents. On average, about 9% of the entire sample answered yes to the question, "Have you used this service," for each of the 15 services.
- 2. Some of the service use categories may have been beyond the comprehension of some respondents. Some completed surveys indicated that some respondents did not understand a particular service or did not understand what the term meant. Definitions of terms were somewhat brief and may not have helped the respondents.
- 3. Some people wrote down multiple cancer diagnoses. The instructions do not specify whether to list the first and/or subsequent diagnoses. Multiple diagnoses make it difficult to do cross-tabulations.
- 4. Some respondents were confused about the survey's skip patterns and the sequence of questions. Some early questions were skipped and then later ones, dependent on the earlier ones, were answered.
- 5. Many respondents left the latter pages of the survey blank. The length of the survey and the redundancies may have contributed to "survey fatigue."
- 6. Many hospitals did not submit a large number of completed surveys. The results may not reflect an adequate understanding of patient needs at various hospitals.
- 7. Females appear to be over-represented in the study sample, especially at non-ACoS facilities.
- 8. Some hospitals distributed surveys that were returned unanswered. Some of these surveys were not returned to the Muskie School. Hence we do not have a true sense of the overall number of distributed surveys.

Recommendations

- 1. More in-depth information is needed to understand why respondents do or do not use certain services. Conducting focus groups, with adequate age and gender representation, at both ACoS and non-ACoS facilities would help uncover some of these reasons.
- 2. If this or another similar survey is undertaken, a better sampling strategy is needed. Many hospitals returned less than 50% of the surveys allocated to them. Perhaps more time is needed or a different time of the year is better. A better process/criteria for hospitals estimating the number of surveys they can distribute is needed.
- 3. The differences in responses among ACoS and non-ACoS facilities need further investigation. As Table 5 indicates, a higher percentage of non-ACoS respondents used the 15 rehabilitative and survivorship services.
- 4. If this survey is repeated, it should be shortened and/or reformatted. Based on the responses (in many cases the lack of responses), respondents did not adequately complete the instrument. If repiloted, respondents should be questioned about the instruments after completing it.

October 15, 2004

Assessing the Needs of Cancer Patients for Rehabilitation & Survivorship Services in Maine

- 5. The referral source data in Table 6 point to the need for expanding sources of information for various support services. The results indicate that doctors/physicians are the leading source of information for a variety of services. Given how busy doctors are and the limited time they have with patients, it may be appropriate to explore other ways of conveying support services information to patients.
- 6. Most questions dealing with the quality of rehabilitation and survivorship services are based on relatively few responses. The data in this report do not adequately address this issue. Further study is warranted.
- 7. The same as above for payment of services.

Appendix A

American College of Surgeons (ACoS) Commission on Cancer Facilities in Maine

American College of Surgeons Commission on Cancer (ACoS) approved hospitals ensure quality cancer care through the availability of state of the art technology, access to multi-disciplinary consultation and treatment, and ongoing quality assessment that monitors treatment effectiveness and outcomes. Every approved cancer program must provide a host of basic services. These services are provided on-site at the facility, by referral, or are coordinated with other facilities or local agencies. Services include: Diagnostic, Treatment, Pain management, Rehabilitation, Support, Counseling, Hospice care, Nutritional support, Pastoral care, Patient and family support, and Prevention and early detection.

Facilities in Maine

Central Maine Medical Center

Eastern Maine Medical Center

Goodall Hospital

MaineGeneral Medical Center

Maine Medical Center

- Maine Center Radiation Oncology Portland
- MMC Radiation Oncology -Scarborough
- Coastal Cancer Treatment Center
- o MMC Outpatient IV Scarborough

Penobscot Bay Medical Center

Redington Fairview General Hospital

Southern Maine Medical Center

Stephens Memorial Hospital

St. Mary's Regional Medical Center

Togus VA Medical Center

October 15, 2004

Appendix B

Cancer Rehabilitation & Support Services Survey

About the Survey:

The survey focuses on support and rehabilitation services you may have used or needed so far during your cancer treatment, care and/or recovery. The survey is sponsored by the Maine Comprehensive Cancer Control Program/Maine Bureau of Health/Department of Human Services, the Maine Cancer Consortium Rehabilitation and Survivorship Work Group and Eastern Maine Medical Center's CancerCare of Maine. Whether you are newly diagnosed, actively receiving treatment or here for a follow up appointment, we could use your input. Patients at hospitals throughout the state are being asked to participate. Responses will provide information from people, like you, across Maine about what is needed, used, helpful and how easy it is to access and learn about available services. Your responses will help in statewide planning.

Participation:

Your input is voluntary. By filling out the survey, you are giving your consent to participate. **Completing the survey will not keep you from being on time for your appointment.** After reviewing the survey if you decide you do not want to complete it, simply return it to the box marked **SURVEY RETURN** without filling it out.

Confidentiality:

This is an anonymous survey. Please **do not put your name anywhere**. All responses will be kept confidential and results will be reported in a group format.

Survey Completion Instructions:

- If you want to participate in the survey, follow the instructions on the next page
- ◆ Again, if you decide you do not want to complete the survey, please place it in the box marked SURVEY RETURN without filling it out.

Resources:

For more information related to the survey, contact Anita Ruff at 207-287-5358 or Anita.Ruff@maine.gov At CancerCare of Maine, if you have questions, ask for Nadine Bullion, LCSW, Support Service Manager or call 973-7476 or 1-800-987-3005 or e-mail nbullion@emh.org

Service Use Survey Instructions

- ♦ This survey will take about 10 minutes to complete.
- ♦ Completing the survey will NOT delay your care.
- ♦ Please read every question.
- On the <u>last page</u> there are <u>two additional questions</u> <u>numbers 87 & 88</u>, please be sure to answer these too!

Please complete the following:		
Age:	Male or Female (circle one)	
Year cancer was diagnosed:		
Cancer diagnosis:		
Are you currently receiving treatment for this canc	er? Yes No (circle one)	

Transportation
(Help with rides or with the cost of getting to your health care.)

1.	Have you used this service? Yes (please skip to question 2)	No (check all thatI do not have a neeThe service was noI could not afford tI was not aware ofOther: (please specify)	ed for the service. ot available. the service. the service.
		Have you heard about this ser Yes	vice? No
1			(Go to the next page)
2.	How did you hear about this s Doctor Friend/family Nurse Social worker	Brochure Web	phone help line o/Internet er (specify):
	If you did	not use this service, go to	the next page.
3.	Did this service help you? Yes	No	
4.	Did this service help your fan Yes	nily? No	
5.	Did you use this service withi Yes	n 30 miles of your home? No	
6.	. How did you pay for this serv Health insurance		
	On my own	Other financial support (spe	cify):

Lodging
(Help with a place to stay while getting care.)

7. Have you used this service?			
Yes (please skip to question 8)	No (chec	k all that ap	oply)
I			ed for the service.
		rice was no	
	I could	not afford t	he service.
	I was no	ot aware of	the service.
	Other: (please specify)	
	** 1 1 1	1 •	
	Have you heard abo	out this serv	
•	Yes	•	No
	(Go to question	on 8)	(Go to the next page)
			<u></u>
	. 0 / 1 1 11 41	. 1)	
8. How did you hear about this s			مام المام المام
Doctor	Clergy	-	phone help line
Friend/family Nurse	Brochure		/Internet
	Newspaper		r (specify):
Social worker	Television		
9. Did this service help you? (It	f vou did not use this	service go	to the next page)
Yes	No	561 (166 80	to the hold page)
10. Did this service help your fa	mily?		
Yes	No		
11. Did you use this service with	nin 30 miles of your h	ome?	
Yes	No		
10 II 11 6 41	. (1 1 11 1	1 \	
12. How did you pay for this serv	-		
Health insurance	Service was free		
On my own	Other financial s	support (snec	eify):
		II . C.L.	• /

Financial Assistance

(Help with finding ways to pay for your care.)

13. Have you used this service	?		
Yes (please skip to question)			
	The service was not available.		
	I could not afford the service.		
	I was not aware of the service.		
	Other: (please specify)		
	Have you heard about this service?		
•			
	(Go to question 14) (Go to the next page)		
14 How did you hear about f	his service? (check all that apply)		
Doctor	Clergy Telephone help line		
Friend/family			
Nurse	Newspaper Other (specify):		
Social worker	Television		
Social Worker			
15. Did this service help you Yes	? (If you did not use this service go to the next page) No		
46 5000			
16. Did this service help you	·		
Yes	No		
17. Did you use this service Yes	within 30 miles of your home? No		
	service (check all that apply) Service was free		
On my own	Other financial support (specify):		

Physical Therapy (Help with recovery from cancer surgery or treatment.)

19. Have you used	this service?			
Yes (please skip t		No (ch	eck all that app	ly)
		I do n	ot have a need	for the service.
		The se	ervice was not a	vailable.
		I could	d not afford the	service.
		I was 1	not aware of the	e service.
		Other:	(please specify)	
	Цо	wa wan baard ah	out this convice	. 9
1	110	ive you heard ab Yes	out this service	No
•			- (an 20)	
		(Go to questi	IOII 20)	(Go to the next page)
20 11 1:1	1 1		4141	
•	hear about this serv			ona halm lina
Doct	0f d/fam:1	Clergy		
Frien		Brochure		
Nuis	e .l worker	Newspaper	Other (s	pecify):
5001	ı worker	Television		
21 Did this servi	ce help you? (If yo	ou did not use th	is service on to	the next nage)
Yes	ce help you. (If yo	No	is service go to	the next page)
105		110		
22. Did this servi	ce help your family	₁ ?		
Yes	or mark how remaining	No		
		<u> </u>		
23. Did you use t	his service within 3	30 miles of your	home?	
Yes		No		
_		_		
24. How did you	pay for this service	(check all that	apply)	
Healt	th insurance	Service was fre	ee	
On m	ny own	Other financial	support (specify)	:

Please continue to next page $\hat{\mathbf{O}}$

Lymphedema (Help with management of lymphedema.)

25. Have you used this service?		
Yes (please skip to question 26	No (check all that a	pply)
		eed for the service.
	The service was r	
	I could not afford	
	I was not aware o	
	Other: (please specify	2)
	Have you heard about this ser	vice?
+	Yes	No
	(Go to question 26)	(Go to the next page)
26. How did you hear about this	s service? (check all that apply	
Doctor	Clergy Te	lephone help line
Friend/family		eb/Internet
Nurse	Newspaper Otl	ner (specify):
Social worker	Television	
27. Did this service help you?	(If you did not use this service ;	go to the next page) —
Yes	No	go to the next page)
1cs	140	
20 Did this samples halp your f	omily9	
28. Did this service help your fa	-	
Yes	No	
29. Did you use this service wit	•	
Yes	No	
30. How did you pay for this se	ervice (check all that apply)	
Health insurance	Service was free	
On my own	Other financial support (s	pecify):

Occupational Therapy (Help with recovery related to cancer diagnosis.)

31. Have you used this service?	
Yes (please skip to question 32)	No (check all that apply) I do not have a need for the service The service was not available I could not afford the service I was not aware of the service Other: (please specify) Have you heard about this service? Yes No (Go to question 32) (Go to the next page)
32. How did you hear about this Doctor Friend/family Nurse Social worker	service? (check all that apply) ClergyTelephone help line BrochureWeb/Internet NewspaperOther (specify): Television
33. Did this service help you? (I Yes	If you did not use this service go to the next page) No
34. Did this service help your far Yes	mily? No
35. Did you use this service with Yes	nin 30 miles of your home? No
36. How did you pay for this ser Health insurance	vice (check all that apply) Service was free
On my own	Other financial support (specify):

Speech Therapy (Help with recovery from cancer diagnosis or care.)

37. Have you used this service?	
Yes (please skip to question 38)	No (check all that apply) I do not have a need for the service The service was not available I could not afford the service I was not aware of the service Other: (please specify) Have you heard about this service? YesNo (Go to question 38) (Go to the next page)
38. How did you hear about this s Doctor Friend/family Nurse Social worker	service? (check all that apply) Clergy
39. Did this service help you? (I Yes	f you did not use this service go to the next page) No
40. Did this service help your far Yes	mily? No
41. Did you use this service with Yes	in 30 miles of your home? No
42. How did you pay for this ser Health insurance	
On my own	Other financial support (specify):

Educational & Support Groups (Help with learning more about your cancer & gaining support.)

43. Have you used this service?	
Yes (please skip to question 44)	No (check all that apply)
	I do not have a need for the service.
	The service was not available.
	I could not afford the service.
	I was not aware of the service.
	Other: (please specify)
	Have you heard about this service?
↓	Yes No
	(Go to question 44) (Go to the next page)
	(Go to question 44) (Go to the next page)
44. How did you hear about this	
Doctor	Clergy Telephone help line
Friend/family	Brochure Web/Internet
Nurse	Newspaper Other (specify):
Social worker	Television
45. Did this service help you? (I	f you did not use this service go to the next page)
Yes	No
46. Did this service help your far	mily?
Yes	No
103	110
47 Did way was this samples with	in 20 miles of years home?
47. Did you use this service with	•
Yes	No
48. How did you pay for this ser	
Health insurance	Service was free
On my own	Other financial support (specify):

Counseling
(Help with coping with diagnosis, treatment and recovery.)

49. Have you used this service?	
Yes (please skip to question 50)	No (check all that apply) I do not have a need for the service The service was not available I could not afford the service I was not aware of the service Other: (please specify) Have you heard about this service? Yes No (Go to question 50) (Go to the next page)
50. How did you hear about this Doctor Friend/family Nurse Social worker	service? (check all that apply) Clergy Telephone help line Brochure Web/Internet Newspaper Other (specify): Television
51. Did this service help you? (Yes	If you did not use this service go to the next page) No
52. Did this service help your fa Yes	mily? No
53. Did you use this service with Yes	nin 30 miles of your home? No
54. How did you pay for this ser Health insurance	rvice (check all that apply) Service was free
On my own	Other financial support (specify):

Nutritional Counseling (Help with nutritional needs.)

55. Ha	ave you used this service?				
	please skip to question 56)	No (check	all that app	ly)	
`		I do not have a need for the service.			
		The service was not available I could not afford the service I was not aware of the service Other: (please specify)			
		Have you heard about this service?			
\		Yes	No		
		(Go to question	on 56)	(Go to the next page)	
56. I	How did you hear about this			1 1 1 1	
	Doctor	Clergy	_	hone help line	
	Friend/family Nurse	Brochure	Web/		
	Nuise Social worker	<pre> Newspaper Television</pre>	Other	(specify):	
	Social worker	Television			
57. I	Oid this service help you? (I Yes	f you did not use this No	service go	to the next page)	
58. I	Did this service help your far Yes	nily? No			
59. I	Oid you use this service with Yes	in 30 miles of your h No	ome?		
60. I	How did you pay for this ser Health insurance		oply)		
	On my own	Other financial s	upport (speci	ify):	

Pain Management (Help with coping with pain related to cancer diagnosis.)

61. Have you used this service?
Yes (please skip to question 62) No (check all that apply) I do not have a need for the service. The service was not available. I could not afford the service. I was not aware of the service. Other: (please specify) Have you heard about this service? Yes (Go to question 60) (Go to the next page)
62. How did you hear about this service? (check all that apply) Doctor Clergy Telephone help line Friend/family Brochure Web/Internet Nurse Newspaper Other (specify): Social worker Television
63. Did this service help you? (If you did not use this service go to the next page) Yes No
64. Did this service help your family? Yes No
65. Did you use this service within 30 miles of your home? Yes No
66. How did you pay for this service (check all that apply) Health insurance Service was free
On my own Other financial support (specify):

Alternative/Complementary Medicine (Included but not limited to, herbal medicine, acupuncture, Reiki, homeopathy & massage)

67. Have you used this service?				
Yes (please skip to question 68)No (check all that apply)				
1	I do not have a need for the service.			
	The service was not available.			
	I could not afford the service.			
	I was not aware of the service.			
	Other: (please specify)			
	Have you heard about this service?			
↓	Yes No			
	(Go to question 64) (Go to the next page)			
68. How did you hear about this s				
	Clergy Telephone help line			
Friend/family	Brochure Web/Internet			
	Newspaper Other (specify):			
Social worker	Television			
69 Did this service help you? (If	you did not use this service go to the next page)			
Yes	No			
_	_			
70. Did this service help your fam	nily?			
Yes	No			
71 P.1 4				
71. Did you use this service within	•			
Yes	No			
72. How did you pay for this serv	ice (check all that apply)			
· - ·	Service was free			
On my own	Other financial support (specify):			

Home Care

(Help with chemo therapy infusion at home or other healthcare at home.)

73. Have you used this service?		
Yes (please skip to question 74)	No (check all that apply)	
I do not have a need for the service.		
The service was not available.		
	I could not afford the service.	
	I was not aware of the service.	
	Other: (please specify)	
	Have you heard about this service?	
*	YesNo	
	(Go to question 70) (Go to the next page)	
_, _, .,		
74. How did you hear about this		
Doctor	ClergyTelephone help line	
Friend/family	BrochureWeb/Internet	
Nurse	Newspaper Other (specify):	
Social worker	Television	
75 Did this sarvice help you?	If you did not use this service so to the next page)	
Yes	If you did not use this service go to the next page) No	
1es	140	
76. Did this service help your fa	milv?	
Yes	No	
77. Did you use this service with	in 30 miles of your home?	
Yes	No	
78. How did you pay for this ser	vice (check all that apply)	
Health insurance	Service was free	
On my own	Other financial support (specify):	

Please continue to next page $\mathbf{\hat{O}}$

Palliative Care

(Help with management of a range of symptoms related to a cancer diagnosis.)

79. I	Have you used this service?
	No (check all that apply) I do not have a need for the service. The service was not available. I could not afford the service. I was not aware of the service. Other: (please specify) Have you heard about this service? Yes No (Go to question 76) (Go to the next page)
80.	How did you hear about this service? (check all that apply) Doctor Clergy Telephone help line Friend/family Brochure Web/Internet Nurse Newspaper Other (specify): Social worker Television
81.	Did this service help you? (If you did not use this service go to the next page) Yes No
82.	Did this service help your family? Yes No
83.	Did you use this service within 30 miles of your home? Yes No
84.	How did you pay for this service (check all that apply) Health insurance Service was free
	On my own Other financial support (specify):

Hospice Care

(Help coping with a limited life expectancy - may include volunteer support and/or a range of in home services.)

85.	Have you used this service?				
Yes	s (please skip to question 86)	,	all that ap	• • •	
Ī		I do not	have a ne	ed for the service.	
		The serv	vice was n	ot available.	
		I could i	not afford	the service.	
		I was not aware of the service.			
		Other: (I	please specify))	
		TT 1 1 1 1	1 •	: 0	
1		Have you heard abo	ut this ser		
•		Yes	0.0	No	
		(Go to question	on 82)	(Go to question 87)	
	'				
86.	How did you hear about this	,	11 .		
	Doctor Friend/family Nurse	Clergy		phone help line	
	<pre> Friend/family</pre>	Brochure	Web	/Internet	
	Nurse	Newspaper	Othe	er (specify):	
	Social worker	Television			
87.	Did this service help you? (1	If you did not use this	service, 2	to to question 87)	
	Yes	No	, c	<u> </u>	
				V	
88.	Did this service help your far	mily?			
00.	Yes	No			
	1cs	110			
00	5		2		
89.	Did you use this service with	· · · · · · · · · · · · · · · · · · ·	ome?		
	Yes	No			
2.0					
90.	How did you pay for this ser		oply)		
	Health insurance	Service was free			
	On my own	Other financial s	upport (spe	ccify):	
91. W	as this survey easy to compl	ete? Yes	No		
	ow many minutes did it take				
74. II(ow many minutes did it take	you to complete:			
		Thank yo	u very mı	ich for your time & help!	

Assessing the Needs of Cancer Patients for Rehabilitation & Survivorship Services in Maine

Appendix C

Maine Cancer Consortium's Rehabilitation and Survivorship Work Group

Michaele Bailey UMO Social Work Intern

Terry Baker American Cancer Society

Nadine Bullion, LCSW CancerCare of Maine

Paulette Burbank New England Rehabilitation Hospital

Doug Dieckmann American Cancer Society

Melanie Feinburg Maine Medical Center

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Michael Reesman Beth C. Wright Cancer Resource Center

Holly Richards Maine Comprehensive Cancer Control Program

Anita Ruff Maine Comprehensive Cancer Control Program

Ellen Sharp UMO Social Work Intern

Cheryl Tucker American Cancer Society

Appendix D

Responses by Hospital

Hospitals are not identified by Name or Code. They have been assigned a random number in this chart.

	# of Returned			
Number	Responses	% Returned	# Distributed	% Returned/Distributed
1	0	0.0%	0	0.0%
2	0	0.0%	20	0.0%
3	14	1.6%	70	20.0%
4	40	4.6%	40	100.0%
5	7	0.8%	70	10.0%
6	20	2.3%	50	40.0%
7	9	1.0%	100	9.0%
8	0	0.0%	70	0.0%
9	27	3.1%	40	67.5%
10	24	2.8%	100	24.0%
11	13	1.5%	20	65.0%
12	50	5.8%	250	20.0%
13	336	39.0%	500	67.2%
14	32	3.7%	200	16.0%
15	27	3.1%	120	22.5%
16	183	21.2%	320	57.2%
17	3	0.3%	20	15.0%
18	17	2.0%	35	48.6%
19	30	3.5%	75	40.0%
20	0	0.0%	0	0.0%
21	1	0.1%	20	5.0%
22	28	3.3%	40	70.0%
Total	861	100.0%	2,160	39.9%
ACoS facilities	676	78.5%	1,500	45.1%
Non-ACoS facilities	185	21.5%	660	28.0%

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