



Cancer Services of New Mexico
Providing Services to Reduce Cancer Suffering in New Mexico

P.O. Box 51735
Albuquerque, NM 87181-1735

(505) 259-9583
www.CancerServicesNM.org

New Mexico Cancer Services Survey

Final Report

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*The first statewide survey to understand gaps in
New Mexico's cancer-related services, from the perspective
of cancer patients/survivors and their loved ones*

December, 2004



Contents

- Acknowledgements 3**
- Executive Summary..... 5**
- Background..... 7**
 - *Why Did New Mexico Need a Cancer Services Survey?*
 - *Objectives of the New Mexico Cancer Services Survey*
- About Cancer Services of New Mexico..... 9**
- 1. Study Approach 11**
 - *Sampling Approach*
 - *Survey Instrument*
 - *Data Collection Approach*
 - *Completed Questionnaires*
 - *Criteria for Including Questionnaires in the Study*
 - *Data Analysis Approach*
- 2. Respondent Demographics 15**
 - *Respondent Relationship to the Cancer Patient/Survivor*
 - *Breakdown by Patient Status*
 - *Breakdown by Patient’s County of Residence*
 - *Breakdown by Type of Cancer*
 - *Breakdown by Patient’s Gender*
 - *Breakdown by Patient’s Age at Diagnosis*
 - *Breakdown by Patient’s Ethnic/Racial Group*
 - *Breakdown by Patient’s Insurance Coverage During Treatment*
- 3. Importance of Different Cancer-Related Services..... 23**
- 4. Satisfaction with New Mexico’s Cancer-Related Services 25**

5. Perceived Gaps in New Mexico’s Cancer-Related Services 27

- *Calculation of “Gap Ratings”*
- *Relative Satisfaction/Importance Gaps for Cancer-Related Services*

6. Sources of Information for Patients and Their Loved Ones 31

- *Factors Limiting Access to Cancer-Related Services*
- *Helpfulness of Different Types of Information Providers*
- *Organizations and Individuals Respondents Found Particularly Helpful*

7. Differences Among Demographic Groups 35

- *Comparisons by Tumor Type*
- *Comparisons by Region of Residence*
- *Comparisons by Ethnic/Racial Group*
- *Comparisons by Patient Gender*
- *Comparisons by Insurance Type*
- *Comparisons by Age When Patient Was Diagnosed*
- *Comparisons by Patient Status*
- *Comparisons by Length of Time Since Diagnosis*

8. Discussion..... 57

- *Key Findings and Implications*
- *Limitations of the Study*
- *Next Steps*

Appendices 61

- *Appendix A: Survey Questionnaire*
- *Appendix B: Comments on Services Where Respondents Were Not Satisfied/Somewhat Satisfied*
- *Appendix C: Comments on Services That Did Not Exist to Support Respondents*
- *Appendix D: Comments on Services Respondents Would Focus on Improving*
- *Appendix E: Comments on Factors Limiting Access to Important/Very Important Services*
- *Appendix F: Organizations, Individuals, and Other Resources Respondents Found to Be Particularly Helpful*
- *Appendix G: Additional Comments*



Acknowledgements

The New Mexico Cancer Services Survey would not have been possible without the help of the many people who were willing to share their personal experiences with us. We thank the nearly 900 New Mexican cancer patients/survivors and their loved ones who took the time to tell us what they think about New Mexico’s cancer-related services and provide suggestions for improving services for future New Mexicans coping with cancer.

Major funding for this study was provided by grants from the Con Alma Health Foundation and the McCune Charitable Foundation. We thank these organizations for their commitment to improving cancer-related services throughout our state.

Cancer services organizations across New Mexico helped us reach survey participants throughout the state. During Phase I, People Living Through Cancer (PLTC) helped us distribute our survey to thousands of individuals in its mailing database. PLTC’s generosity made it possible for us to complete Phase I of the study quickly and cost-effectively. During Phase II, many other organizations helped us mail questionnaires to their clients and invited our interviewers to spend time in their clinics collecting data from patients and their loved ones. Thanks go to the Prostate Cancer Support Association of New Mexico (PCSANM), the UNM Cancer Research & Treatment Center, the Cancer Institute of New Mexico, San Juan Oncology, Southeastern NM Internal Medicine Hematology & Oncology, and the New Hope Cancer Center for their support during Phase II of this program.

Research & Polling, Inc., provided the team that conducted on-site data collection at oncology clinics across the state. Special thanks to Jeanie Emery for the warmth and compassion she showed during the many hours she spent talking to cancer patients/survivors and their loved ones about their journey through the cancer process.

Charles Key, MD, PhD, former Medical Director of the New Mexico Tumor Registry, provided invaluable suggestions regarding questionnaire design, sampling approach, and many other aspects of the study design. We thank him, and the many others who reviewed early versions of the study questionnaire and provided suggestions for improving it.

Cancer Services of New Mexico’s Board of Directors provides tremendous support and guidance to all aspects of our organization. I greatly appreciate the assistance of the individuals who served on our Board during this program, including: Laurie Bowman; Gary Eisenberg; Richard Larson, MD, PhD; Gena Love; Jerry Lujan; Steve Nakamura; Laurie Roach; Deborah Schwartz; and Stuart Winter, MD.

Our deepest thanks go out to everyone who supported this effort!

Blaire Larson
President
Cancer Services of New Mexico



Executive Summary

The New Mexico Cancer Services Survey is the first statewide effort to understand gaps in New Mexico’s cancer-related services, from the perspective of adult cancer patients/survivors and their loved ones. Findings from this study will assist cancer services providers across the state in better customizing their offerings to meet the needs of New Mexicans coping with cancer.

The survey was conducted in two phases. During Phase I, we distributed a survey questionnaire to 3,200 people in People Living Through Cancer’s mailing list. The major advantage of using PLTC’s database was that we had immediate access to a large population of New Mexican cancer patients/survivors and their loved ones. The disadvantage is that we knew our Phase I results would not be statistically representative of the entire New Mexican population coping with cancer. During Phase II, we ensured a more representative sample by working with oncology groups and other cancer services providers across the state to distribute surveys to patient populations that were not sufficiently represented during Phase I.

A total of 888 questionnaires were completed and returned during this program. For analysis purposes, we opted to focus on the subset of respondents that we believed would provide the most relevant information for guiding efforts to improve future cancer-related services in New Mexico – specifically, the 471 respondents who described the experiences of patients/survivors who had been diagnosed since 2000 and had lived in New Mexico during treatment.

Several analyses were conducted to understand the demographic breakdown of respondents and to compare these demographics to those of all New Mexicans coping with cancer. Our respondents represented a wide variety of tumor types, disease stages, geographic locations, ages, levels of insurance coverage, and ethnic/racial groups. A few groups were somewhat over-represented in the study: ethnic/racial groups other than non-Hispanic whites; breast cancer patients/survivors; women; and younger patients/survivors.

Statistical analyses were conducted to understand the relative importance of a variety of cancer-related services, to understand respondents’ satisfaction with each of these services, and to uncover gaps between respondents’ importance ratings and satisfaction ratings for each service. Additional analyses were conducted to understand how patients and their loved ones get information on managing the disease process. Highlights of our findings include:

- Medically-oriented services (early detection/screening services, traditional medical treatments) were the most important services to respondents, followed by assistance with paperwork/reimbursement for treatment costs; emotional services (support programs for patients and caregivers), and day-to-day assistance services (hospice/end-of-life services, training in day-to-day management skills, in-home care, and transportation services to/from appointments). Housing/lodging services and alternative/integrative therapies were less important to respondents.
- There is substantial opportunity to improve New Mexicans’ experiences with cancer-related services. The average satisfaction rating was below “satisfied” for five of eleven services evaluated: emotional support programs for caregivers;

alternative/integrative therapies; emotional support programs for patients; transportation services to/from medical appointments; and training in day-to-day management skills. Respondents were most satisfied with traditional medical treatments (e.g., radiation, chemotherapy).

- For each of the eleven cancer-related services evaluated, respondents indicated a gap between the importance of the service and their satisfaction with the service. Services with the largest gaps may indicate the greatest opportunities for improvement. These include transportation services to/from appointments; emotional support programs for caregivers; emotional support programs for patients; early detection/screening services; training in day-to-day management skills; and assistance with paperwork/reimbursement for treatment costs.
- There appear to be substantial opportunities to improve the way information is disseminated about New Mexico's existing cancer-related services. Over 30% of respondents indicated they were unable to access needed services because they were not aware that services were available.
- In open-ended comments regarding cancer-related services that didn't exist to support respondents and/or services they would focus on improving, respondents were most concerned about a lack of information and education to help them manage the cancer journey. Concerns cited inadequate information on the disease process and treatment options, along with insufficient information on what cancer-related services are available to assist patients and their loved ones. Gaps in emotional support services for patients and caregivers came a close second. These areas are potential targets for significant improvement.
- There are opportunities to refine service offerings to better meet the needs of different patient demographic groups. For example, non-Hispanic white respondents reported a significantly smaller gap for emotional support programs for patients than other respondents did, suggesting that future efforts to expand these types of programs should particularly focus on other ethnic/racial groups.

This report is being distributed to cancer services providers throughout New Mexico, in the hope that our findings will provide some guidance for how they might continue to improve the services offered to New Mexicans coping with cancer. It will also serve as a major input to Cancer Services of New Mexico's strategic planning process, to ensure our programs and services continue to be focused on the areas of greatest need.

There are many additional ways that we could mine the data in our survey database, and we would welcome the opportunity to work with other groups to help them answer specific questions not covered in this report. Please contact us at (505) 259-9583 or info@CancerServicesNM.org if you are interested in learning more.



Background

Why Did New Mexico Need a Cancer Services Survey?

Over 54,000 New Mexicans are currently living with cancer and over 6,000 more are diagnosed each year. While many are satisfied with the care they receive, stories abound about the frustrations and difficulty that cancer patients and their loved ones face in gaining access to the services and support they need.

In 2001, Cancer Services of New Mexico (CSNM) conducted over 25 interviews with representatives from a wide range of organizations and agencies (including the NM Department of Health, the Indian Health Service, the American Cancer Society, the UNM Cancer Research & Treatment Center, and representatives from a variety of hospitals and other service providers) to get their perspectives on current gaps in cancer-related services in New Mexico. One important finding was that **there had never been an in-depth effort to ask New Mexico's cancer patients/survivors and their loved ones how cancer-related services should be modified or improved to better meet their needs.** While there had been limited attempts to understand patient perspectives (e.g., focus groups to support development of the state's cancer plan, small-scale surveys conducted by individual oncology groups), no one had invested the time and effort to undertake a comprehensive study of needs. Yet, this perspective is critical to ensure the appropriate set of cancer-related programs and services are available in our state. **A clear understanding of needs is necessary to optimize the allocation of state, federal, and private funds for cancer care in New Mexico.**

Cancer Services of New Mexico has received tremendous encouragement from New Mexico's cancer services community about the value of conducting this survey.

Objectives of the New Mexico Cancer Services Survey

By surveying people across New Mexico who have been treated for cancer or who have helped close relatives and/or friends through the cancer process **we are able, for the first time, to understand people's experiences with New Mexico's cancer services and identify needs that are not being adequately met.**

Survey findings will be used to guide development of Cancer Services of New Mexico's future programs. In addition, we are distributing this report to cancer services providers across the state, to assist them in improving their services. Our intended results are that:

- New Mexico's cancer services providers will be able to allocate their resources more effectively towards needed services; and
- Future New Mexican cancer patients and their loved ones will have significantly better experiences during the difficult treatment and recovery period.

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About Cancer Services of New Mexico

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Cancer Services of New Mexico (CSNM) is an independent, non-profit, 501(c)(3) organization that focuses on addressing gaps in cancer-related services in our state. Formed in 2001, our mission is to reduce cancer suffering in New Mexico by providing services that are not available through other organizations. We work closely with other cancer services providers to ensure coordination and avoid duplication of effort. We are the **only** non-profit organization that looks broadly at addressing gaps in cancer-related services, while maintaining a 100% focus on New Mexico.

In addition to conducting the New Mexico Cancer Services Survey, our other programs currently include:

- **Family Cancer Retreat** – a free, three-day, educational program held twice each year for New Mexico’s adult cancer patients/survivors and their loved ones that provides families with the tools and information they need to better manage the survival process. While only entering its fourth year, the Family Cancer Retreat has become the largest general cancer education program in New Mexico and the largest program of its type in the U.S.
- **Zoo Night for Kids with Cancer** – a free evening of fun and education for New Mexico’s current and former pediatric cancer patients and their families, held at the Albuquerque BioPark each year.
- **Outreach to Kids Whose Parents Have Cancer** – distribution of free “information kits” to parents who are newly diagnosed with cancer. The kits contain materials to help these parents and their children cope with the impacts of the disease on their family.

For more information on our programs and services, please contact:

Blaire Larson
President
Cancer Services of New Mexico
P.O. Box 51735
Albuquerque, NM 87181-1735

Phone: (505) 259-9583
Email: info@CancerServicesNM.org
Website: www.CancerServicesNM.org



1. Study Approach

Sampling Approach

A major challenge in conducting this study involved determining how to get a large, representative group of New Mexico's cancer patients/survivors and their loved ones to share their experiences with us cost effectively and in a reasonable timeframe. To address this challenge, we opted to conduct the survey in two phases.

During Phase I, People Living Through Cancer (PLTC), an organization that coordinates support groups and other services for New Mexicans coping with cancer, helped us distribute our survey questionnaire to individuals in their mailing list. The major advantage of using PLTC's database is that we had immediate access to a large population of New Mexican cancer patients/survivors and their loved ones. The disadvantage is that we knew the results from Phase I would not be statistically representative of the entire New Mexican population coping with cancer (for example, there is a higher percentage of Albuquerque residents and breast cancer survivors in PLTC's database than in the general cancer population). However, we felt the benefits of gaining an early, preliminary, perspective on patient needs/concerns outweighed the expected sampling issues. We produced a report summarizing our Phase I findings in September, 2003.

During Phase II, we worked with oncology groups and other cancer services providers across the state to distribute surveys to patient populations that were not sufficiently represented during Phase I. For this phase, we focused on collecting data from patient/survivors residing outside of the Albuquerque area; uninsured/under-insured patients/survivors; and patients/survivors coping with tumors other than breast cancer.

Survey Instrument

A two-page questionnaire was developed to collect information from New Mexican cancer patients/survivors and their loved ones on their experiences with cancer and cancer-related services in New Mexico. A preliminary version of the questionnaire was tested with a small group of cancer patients/survivors and refined to better capture the perspectives of the target audience. An English-language version of the survey was used for mailings. Both English- and Spanish-language versions were available during on-site data collection in oncology clinics. A copy of the English-language version of the questionnaire is included in Appendix A of this report.

Data Collection Approach

In Phase I, survey questionnaires were distributed by mail, with postage paid return envelopes, to 3,200 people in PLTC's database. (This Phase was conducted in two parts – an initial mailing to 200 people in November, 2002, and a follow-up mailing to an additional 3000 people in January, 2003). Completed questionnaires were mailed back to Cancer Services of New Mexico's post office box.

Phase II included mailed surveys and on-site visits to oncology clinics throughout New Mexico. For on-site data collection, patients were given a flyer when they arrived for their oncology appointments explaining that Cancer Services of New Mexico was in the clinic that day conducting a survey. A Cancer Services of New Mexico researcher approached patients in clinic waiting areas, asked them if they would take a few minutes to complete the survey questionnaire, and reviewed a consent document with them. Respondents could choose to fill out the survey questionnaire themselves or be interviewed by the researcher.

In August, 2003, survey questionnaires were distributed by mail, with postage paid return envelopes, to 597 people in the Prostate Cancer Support Association of New Mexico's (PCSANM) database. Completed questionnaires were mailed back to Cancer Services of New Mexico's post office box.

On-site interviews were conducted at the following oncology clinics during 2004:

- UNM Cancer Research & Treatment Center (UNM CRTC), Albuquerque – January 9, 12, and 16, 2004
- Cancer Institute of New Mexico –
 - Santa Fe clinic – March 4, 23, and 25, 2004
 - Espanola clinic – March 5, 2004
 - Taos clinic – March 22, 2004
 - Las Vegas clinic – March 24, 2004
- San Juan Oncology, Farmington – March 16-18, 2004
- New Hope Cancer Center, Las Cruces – September 20-23, 2004
- Southeastern NM Internal Medicine Hematology & Oncology, Roswell – October 4-6, 2004

Throughout the study, we took significant precautions to ensure patient confidentiality. For mailed surveys, a third-party mailing service handled the physical distribution of the survey questionnaires so that Cancer Services of New Mexico did not have access to the names or addresses of individuals receiving the survey. During on-site data collection, survey participants were never asked to provide their names or contact information.

Completed Questionnaires

888 questionnaires were completed during the New Mexico Cancer Services Survey:

Data Source	Completed Surveys
PLTC pilot	53
<u>PLTC large mailing</u>	<u>221</u>
Total PLTC	274
PCSANM	168
UNM CRTC	104
CINM-Santa Fe	77
CINM-Espanola	6
CINM-Taos	17
<u>CINM-Las Vegas</u>	<u>13</u>
Total Cancer Institute of NM	113
San Juan Oncology	53
New Hope Cancer Center	83
SENM Internal Medicine Hematology & Oncology	93
Overall	888

Criteria for Including Questionnaires in the Study

Information from the 888 respondents to the New Mexico Cancer Services Survey was sorted based on where the cancer patient/survivor resided during treatment and the year when cancer was diagnosed. For individuals who listed more than one date of cancer diagnosis, the most recent date of diagnosis was used. 38 respondents did not indicate their date of diagnosis. The breakdown by diagnosis date and residence for the remaining 850 respondents is shown in Figure 1.

Figure 1: Breakdown by Most Recent Diagnosis Date and Residence

Year of Most Recent Diagnosis	Patient's State of Residence		Total
	New Mexico	Other States	
2000-2004	471	9	480 56.5%
1995-1999	228	9	237 27.9%
1990-1994	92	0	92 10.8%
Before 1990	40	1	41 4.8%
Total	831 97.8%	19 2.2%	850 100.0%

For subsequent analyses, we opted to focus on the group of respondents that we believed would provide the most relevant information for guiding efforts to improve future cancer-related services in New Mexico. Responses from patients diagnosed many years ago may not effectively represent the experiences of current patients. Similarly, responses about the experiences of non-New Mexicans may not reflect people's experiences with New Mexico's cancer-related services. Thus, **the findings presented throughout most of this report focus only on the 471 questionnaires that described the experiences of New Mexican patients/survivors who were diagnosed since 2000.** An analysis of the differences in responses between these patients/survivors and longer-term survivors is included in Section 7: Differences Among Demographic Groups.

Data Analysis Approach

Survey responses were analyzed using STATPAC statistical software, running on a desktop PC. Responses were analyzed to understand a variety of respondent perspectives, including the relative importance of various cancer-related services, satisfaction with these services, and barriers to receiving outstanding service.

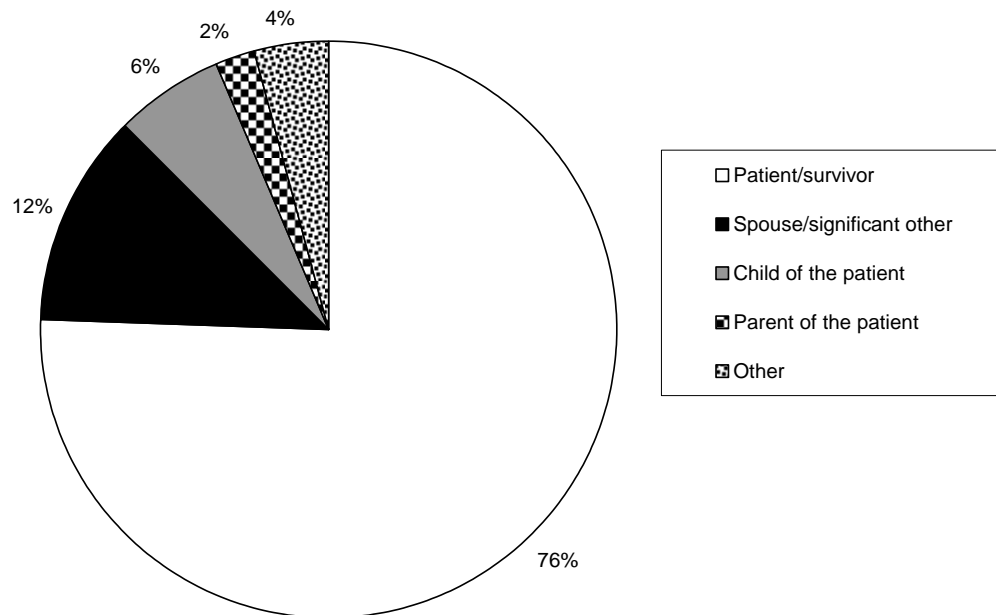
2. Respondent Demographics

Several analyses were conducted to understand the demographic breakdown of respondents and compare respondent demographics to those of all New Mexicans coping with cancer. This section summarizes demographic information for the 471 respondents who described the experiences of New Mexican patients/survivors who were diagnosed with cancer from 2000-2004.

Respondent Relationship to the Cancer Patient/Survivor

Approximately 3/4 of the individuals who completed and returned the New Mexico Cancer Services Survey were cancer patients/survivors. Respondents also included spouses/significant others, children, parents, and other family members and loved ones. Figure 2 provides an overview of the respondent group.

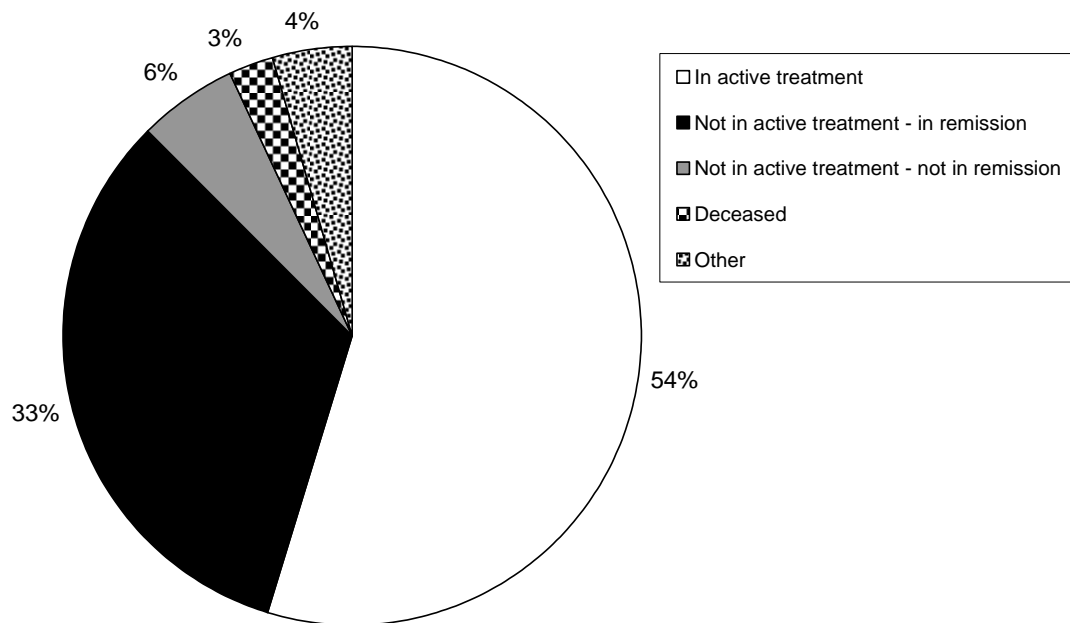
Figure 2: Relationship of Respondent to Cancer Patient/Survivor



Breakdown by Patient Status

Most of the questionnaires were completed for individuals who were in active treatment. Figure 3 provides an overview of the current status of the cancer patients/survivors participating in the survey.

Figure 3: Current Status of the Cancer Patient/Survivor



Breakdown by Patient's County of Residence

The patients/survivors represented in this study came from all around New Mexico. Figure 4 provides details on where these individuals lived during treatment.

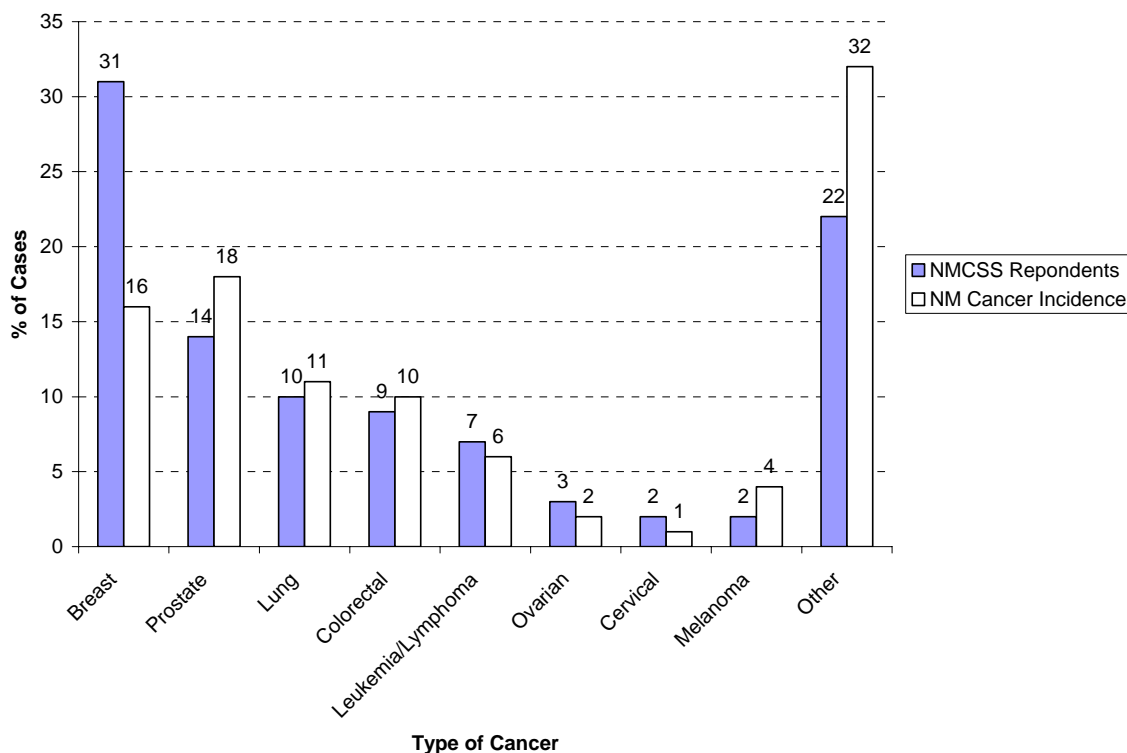
Figure 4: Patient's County of Residence

County	Breakdown by County	Total for Region
Santa Fe	47	
San Juan	45	
Taos	14	
Rio Arriba	7	
McKinley	6	
Los Alamos	2	
<i>Total Northern NM</i>		121
Bernalillo	151	
Sandoval	10	
Valencia	10	
Mora	3	
Cibola	2	
Guadalupe	2	
Macintosh	1	
<i>Total Central NM</i>		179
Chaves	59	
Dona Ana	45	
Eddy	14	
Otero	6	
Luna	6	
Lincoln	2	
Sierra	1	
Curry	1	
Hidalgo	1	
<i>Total Southern NM</i>		135
<i>NM – county not specified</i>		36
Total		471

Breakdown by Type of Cancer

Breast cancer patients/survivors were represented in this study at a substantially higher rate than they appear in the overall population of New Mexicans coping with cancer. Patients/survivors with prostate cancer, lung cancer, colorectal cancer, leukemia/lymphoma, ovarian cancer, cervical, and melanoma were represented at rates similar to overall New Mexican incidence rates for these tumor types. Over twenty additional types of tumors were listed by respondents. Several of the respondents were coping with more than one form of cancer. Figure 5 provides information on the types of cancer our survey respondents were facing, with comparisons to overall cancer incidence rates in New Mexico.¹

Figure 5: Comparison of Cancer Types to Overall NM Cancer Incidence

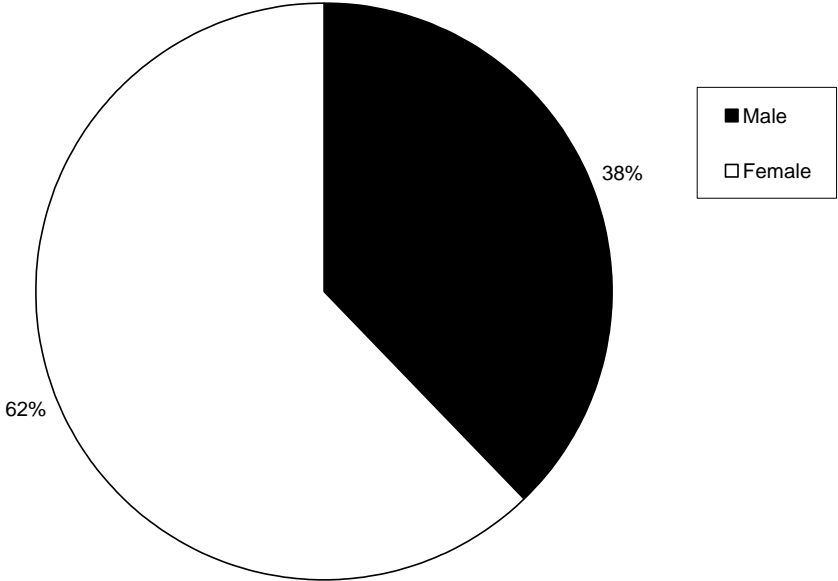


¹ All references to New Mexican cancer incidence rates in the report are based on statistics found in “New Mexico Cancer Facts and Figures: 2000-2001,” American Cancer Society, 2000.

Breakdown by Patient's Gender

Not surprisingly, given the high incidence of breast cancer patients/survivors participating in the survey, the respondent group was skewed towards female patients/survivors. Figure 6 provides a breakdown of respondents by patient/survivor gender. By contrast, the overall New Mexican population diagnosed with cancer is 47% female and 53% male.

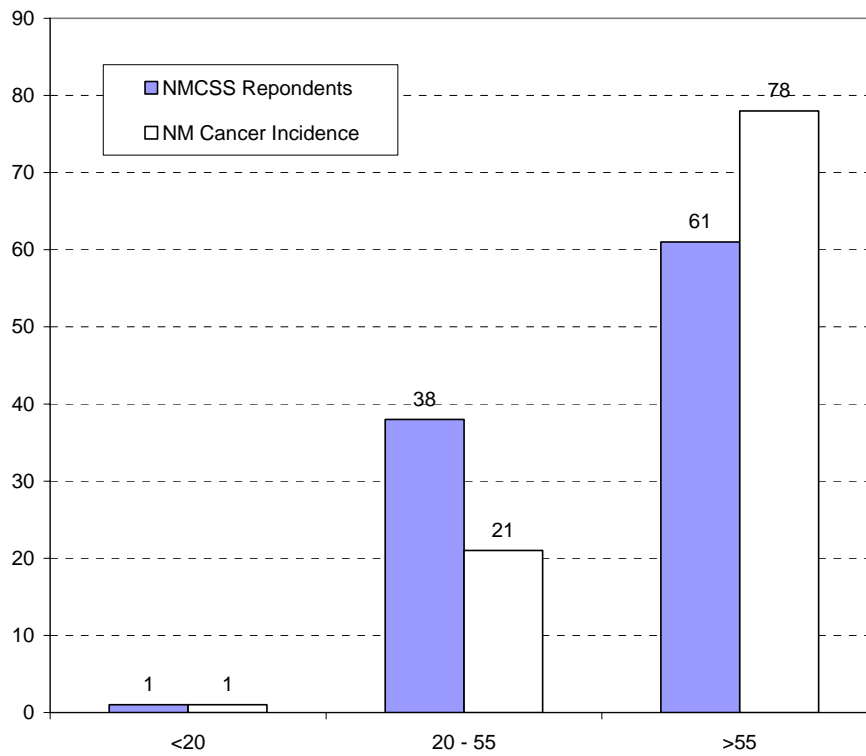
Figure 6: Patient's Gender



Breakdown by Patient's Age at Diagnosis

The New Mexico Cancer Services Survey focused solely on patients/survivors who were diagnosed with cancer as adults. The patient/survivor group we studied is skewed somewhat younger than the overall New Mexican adult cancer patient population. Figure 7 compares the age distribution of the patients/survivors in our survey to the broader population of New Mexicans coping with cancer.

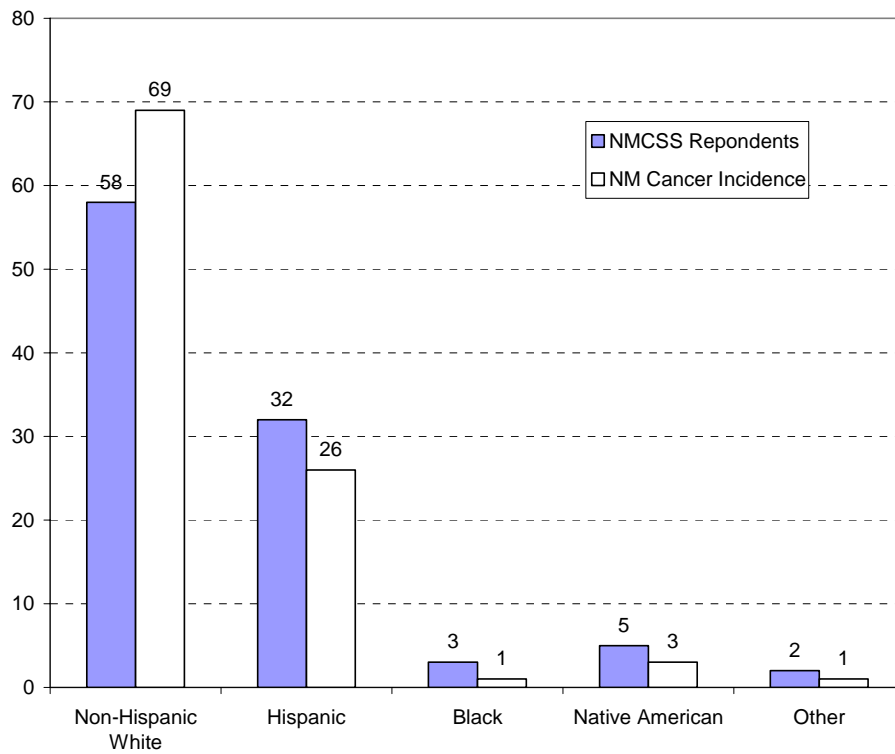
Figure 7: Comparison of Patient Age at Diagnosis to Overall NM Cancer Incidence



Breakdown by Patient's Ethnic/Racial Group

Figure 8 compares the ethnic/racial mix of the people in our study group to statewide statistics for cancer patients. The patient/survivor group we studied had a somewhat lower representation of Non-Hispanic White New Mexicans than the overall New Mexican cancer patient population.

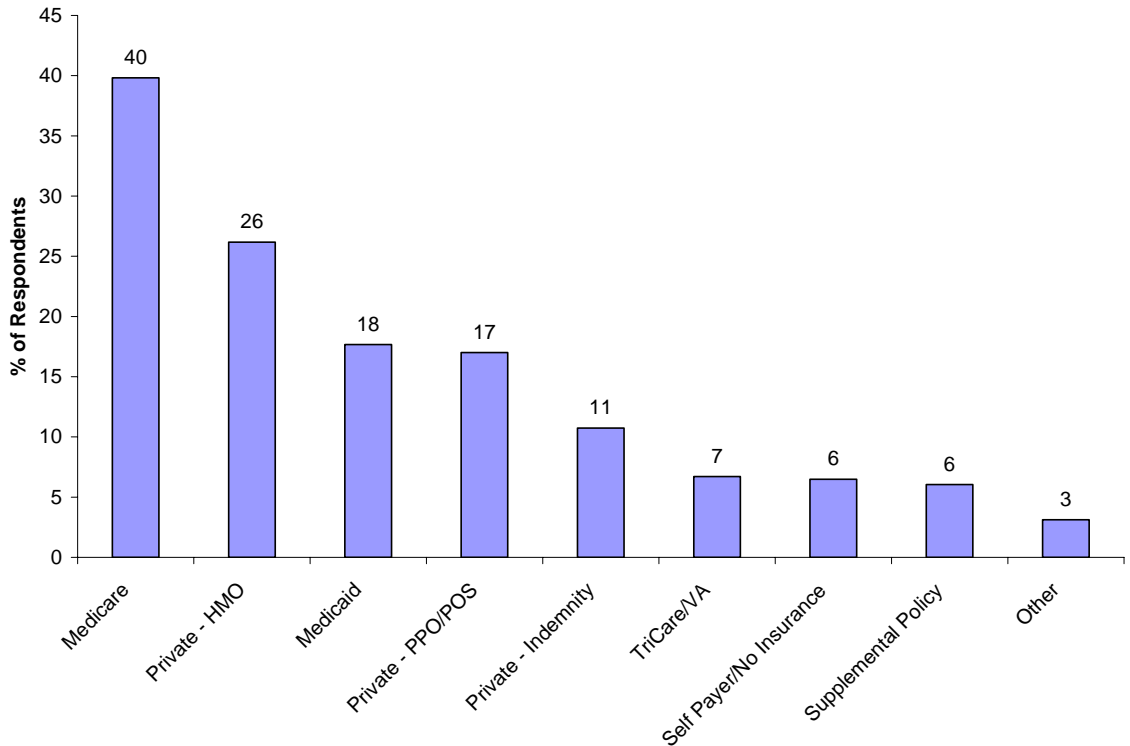
Figure 8: Comparison of Respondent Patient Ethnic/Racial Group to Overall NM Cancer Incidence



Breakdown by Patient's Insurance Coverage During Treatment

The majority of survey responses were for patients/survivors who had healthcare insurance through Medicare and/or an HMO. Figure 9 provides information on the type of insurance coverage that patients/survivors had during treatment. The percentages sum to more than 100% because some individuals had more than one form of insurance coverage during treatment. On average, respondents listed 1.3 types of insurance coverage during treatment.

Figure 9: Patient's Insurance Coverage During Treatment



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3. Importance of Different Cancer-Related Services

Respondents were asked to rate the importance of various cancer-related services to them, on a scale where 1=Not Important; 2=Somewhat Important; 3=Important; and 4=Very Important. Figure 10 summarizes their responses.

Figure 10: Relative Importance of Cancer-Related Services

Service	Average Importance	# Respondents
Early detection/screening services	3.79	421
Traditional medical treatments (e.g., radiation, chemotherapy)	3.76	423
Assistance with paperwork/reimbursement for treatment costs	3.47	297
Emotional support programs for patients	3.42	333
Hospice/end-of-life services	3.37	151
Emotional support programs for caregivers	3.37	256
Training in day-to-day management skills (e.g., administering medication, stress management)	3.30	256
In-home care	3.19	177
Transportation services to/from medical appointments	3.14	198
Housing/lodging services (for those who received treatment away from home)	2.98	131
Alternative/integrative therapies (e.g., herbs, acupuncture, imagery)	2.72	243
Other (described by respondent)	3.62	26

T-tests were conducted to determine statistically significant differences between ratings of importance for these services. In making comparisons between services, responses were only included if a respondent rated both services. The following differences were identified to be statistically significant at the level of $p=.05$:

- **Early detection/screening services** and **traditional medical treatments** were significantly more important than all other services
- **Assistance with paperwork/reimbursement for treatment costs** was significantly more important than transportation services and in-home care
- **Emotional support programs for patients** were significantly more important than transportation services, in-home care, and training in day-to-day management skills
- **Emotional support programs for caregivers** were significantly more important than transportation services
- **Alternative/integrative therapies** and **housing/lodging services** were significantly less important than all other services

Additional T-tests were conducted to determine statistically significant differences in service importance based on various demographic criteria (tumor type, residence region, insurance type, gender, ethnic/racial group, etc.). Results from these additional tests are included in Section 7: Differences Among Demographic Groups.

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4. Satisfaction with New Mexico’s Cancer-Related Services

Respondents were asked to rate their satisfaction with the same set of cancer-related services that they rated for importance, on a scale where 1=Not Satisfied; 2=Somewhat Satisfied; 3=Satisfied; 4=Very Satisfied. Figure 11 summarizes their responses.

Figure 11: Respondent Satisfaction with Cancer-Related Services

Service	Average Satisfaction	# Respondents
Traditional medical treatments (e.g., radiation, chemotherapy)	3.48	391
Early detection/screening services	3.19	392
In-home care	3.16	119
Assistance with paperwork/ reimbursement for treatment costs	3.15	240
Hospice/end-of-life services	3.13	76
Housing/lodging services (for those who received treatment away from home)	3.04	73
Training in day-to-day management skills (e.g., administering medication, stress management)	2.94	192
Transportation services to/from medical appointments	2.94	113
Emotional support programs for patients	2.89	270
Alternative/integrative therapies (e.g., herbs, acupuncture, imagery)	2.86	150
Emotional support programs for caregivers	2.82	185
Other (described by respondent)	2.64	22

T-tests were conducted to determine statistically significant differences between satisfaction ratings for these different services. In making comparisons between services, responses were only included if a respondent rated both services. The following differences were identified to be statistically significant at the level of $p=.05$:

- Respondents were significantly more satisfied with **traditional medical treatments** than with all other services
- Respondents were significantly less satisfied with **emotional support programs for caregivers** and **emotional support programs for patients** than with early detection/screening services and assistance with paperwork/reimbursement for treatment costs
- Respondents were significantly less satisfied with **training in day-to-day management skills** than with early detection/screening services
- Respondents were significantly less satisfied with **housing/lodging services** than with assistance with paperwork/reimbursement for treatment costs

Additional insight into respondents' satisfaction with New Mexico's cancer-related services were gained through a review of narrative responses to Question 6 of the survey, which asked respondents to comment on any services where they were "not satisfied" or "somewhat satisfied."

Respondents provided **more comments about dissatisfaction with early detection/screening services** (33 comments) **than any other service**. In most of these cases, respondents complained about late or missed diagnoses. There were also **numerous comments about dissatisfaction with emotional support programs for patients** (25 comments); **assistance with paperwork/reimbursement for treatment costs** (25 comments); **traditional medical treatments** (19 comments); **transportation services to/from medical appointments** (18 comments); **emotional support programs for caregivers** (16 comments); **training in day-to-day management skills** (15 comments); and **alternative/integrative therapies** (14 comments). A full listing of responses to Question 6 is included in Appendix B.

Additional T-tests were conducted to determine statistically significant differences in service satisfaction based on various demographic criteria (tumor type, residence region, insurance type, gender, ethnic/racial group, etc.). Results from these additional tests are included in Section 7: Differences Among Demographic Groups.



5. Perceived Gaps in New Mexico’s Cancer-Related Services

Calculation of “Gap Ratings”

To understand perceived gaps in New Mexico’s cancer-related services we compared each respondent’s ratings of the importance of each cancer-related service with his or her satisfaction with that service. Specifically, the “gap rating” for each service was calculated as:

$$\text{Gap Rating} = \text{Satisfaction Rating} - \text{Importance Rating}$$

An individual’s “gap rating” for a service was only computed if the respondent rated both the importance of the service and his or her satisfaction with the service. Negative “gap ratings” indicate that the average satisfaction rating for the service was lower than the average importance rating for the service. Larger gaps indicate greater discrepancies between the importance of a particular service offering to respondents and their satisfaction with that service offering.

Relative Satisfaction/Importance Gaps for Cancer-Related Services

Figure 12 summarizes the “gap ratings” computed for this study. Respondents’ satisfaction ratings were lower than their importance ratings for every service, resulting in negative “gap scores” for every service. Services with the largest gaps may indicate areas with the greatest opportunity for improvement

Figure 12: Difference Between Importance of Cancer-Related Services and Respondent Satisfaction with Cancer-Related Services

Service	Average Gap	# Respondents
Transportation services to/from medical appointments	-0.65	112
Emotional support programs for caregivers	-0.65	180
Emotional support programs for patients	-0.64	267
Early detection/screening services	-0.62	385
Training in day-to-day management skills (e.g., administering medication, stress management)	-0.54	189
Assistance with paperwork/reimbursement for treatment costs	-0.51	235
Hospice/end-of-life services	-0.45	71
Housing/lodging services (for those who received treatment away from home)	-0.35	71
Alternative/integrative therapies (e.g., herbs, acupuncture, imagery)	-0.34	141
Traditional medical treatments (e.g., radiation, chemotherapy)	-0.30	385
In-home care	-0.29	115
Other (described by respondent)	-1.14	21

T-tests were conducted to determine statistically significant differences between “gap ratings” for these different services. In making comparisons between services, responses were only included if a respondent provided importance and satisfaction ratings for both services. The following differences were identified to be statistically significant at the level of $p=.05$:

- **Transportation services to/from appointments, emotional support programs for caregivers, emotional support programs for patients, and early detection/screening services** had a significantly larger gap between satisfaction and importance than traditional medical treatments and alternative/integrative services
- **Training in day-to-day management skills and assistance with paperwork/reimbursement for treatment costs** had a significantly larger gap between satisfaction and importance than traditional medical treatments

- **Emotional support programs for caregivers** had a significantly larger gap between satisfaction and importance than assistance with paperwork/reimbursement for treatment costs
- **Emotional support programs for patients** had a significantly larger gap between satisfaction and importance than in-home care and training in day-to-day management skills
- **Early detection/screening services** had a significantly larger gap between satisfaction and importance than in-home care and housing/lodging services

Additional insights into respondents' perceptions of gaps in New Mexico's cancer-related services were gained through a review of narrative responses to Questions 10 and 11 of the survey, which asked respondents to comment on what cancer-related services are needed that didn't exist to support them, what cancer-related services they would focus on improving, and how they would improve these services.

Respondents cited gaps in receiving adequate information (54 comments for the two open-ended questions) **more than any other area**. Concerns focused primarily on lack of information on the disease process and treatment options, along with insufficient information on what cancer-related services are available to assist patients and their loved ones. **Gaps in emotional support services** came a close second (43 comments). There were also many comments about the need for **better access to medical personnel** (19 comments) and the **need for improved research and treatment protocols** (16 comments). A full listing of responses to Question 10 and 11 is included in Appendices C and D.

Additional T-tests were conducted to determine statistically significant differences in gap ratings based on various demographic criteria (tumor type, residence region, insurance type, gender, ethnic/racial group, etc.). Results from these additional tests are included in Section 7: Differences Among Demographic Groups.

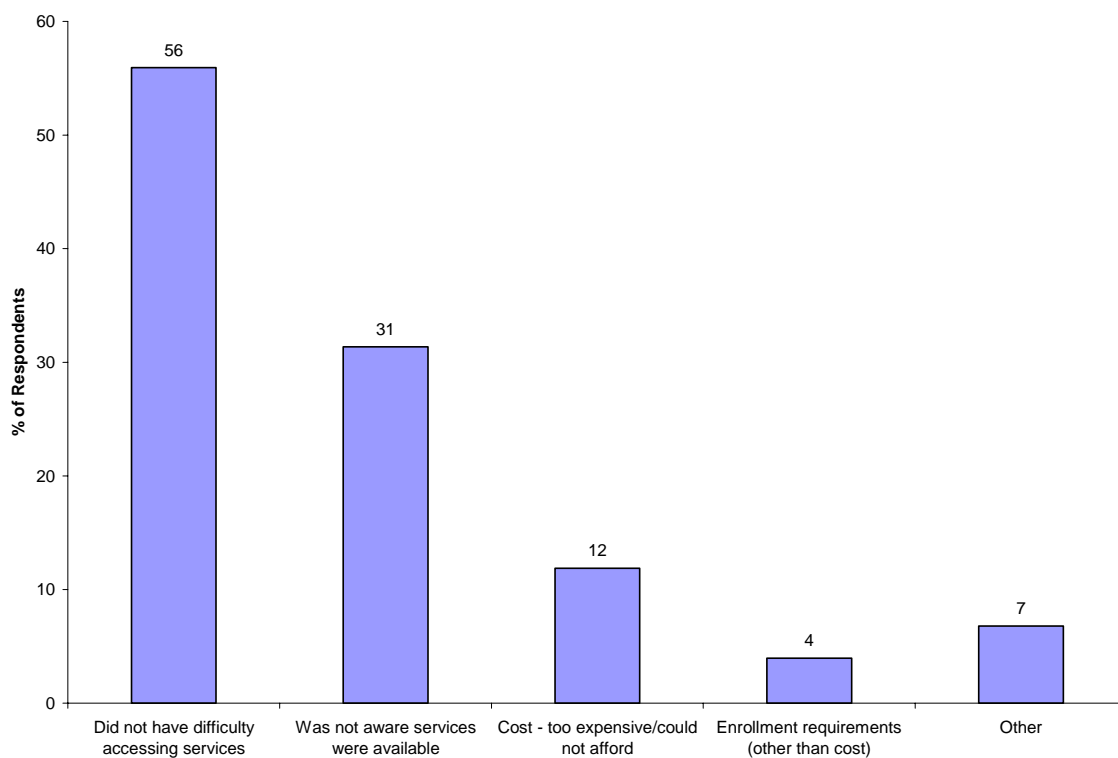
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6. Sources of Information for Patients and Their Loved Ones

Factors Limiting Access to Cancer-Related Services

Respondents were asked to indicate what factors, if any, limited their access to cancer-related services that were important to them. Respondents could list multiple factors, if necessary. Figure 13 summarizes their responses.

Figure 13: Factors Limiting Access to Important/Very Important Services



While over half of the respondents indicated that they did not have difficulty accessing critical services, nearly 1/3 of respondents said they were not aware that services were available to help them. We are unable to determine from our survey data whether this is due to the actual absence of necessary services, or due to an absence of information on the respondents' part of how to access existing services, but **it is clear that cancer patients/survivors and their loved ones are hungry for more information on how to manage the disease process.** As mentioned in Section 5, in response to Questions 10 and 11 which asked respondents what

services didn't exist to support them and what cancer-related services they would focus on improving, **respondents cited lack of adequate information more than anything else.**

A review of open-ended comments in response to Question 7 revealed that within the “other” category several respondents felt their access to services was limited due to delays in diagnosis, treatment decisions, and/or being able to make appropriate appointments. A listing of open-ended comments to Question 7 is included in Appendix E.

Helpfulness of Different Types of Information Providers

Respondents were asked to rate how helpful various groups were in providing information on what cancer-related services were available, with a rating scale of 1=Not Helpful; 2=Somewhat Helpful; 3=Helpful; 4=Very Helpful. Figure 14 summarizes their responses.

Figure 14: Helpfulness in Providing Information on Availability of Cancer-Related Services

Information Source	Average Helpfulness	# Respondents
Independent reading/internet searches	3.36	299
Nurses	3.35	400
Physicians	3.33	431
Cancer support group(s)	2.97	237
Cancer agencies/organizations	2.87	237
Social Workers	2.77	171
Other	3.52	42

T-tests were conducted to determine statistically significant differences between helpfulness ratings for the different information sources. The following differences were identified to be statistically significant at the level of $p=.05$:

- **Independent reading/internet searches** were significantly more helpful than all other sources except nurses
- **Nurses and physicians** were significantly more helpful than social workers, cancer agencies/organizations, and cancer support groups
- **Cancer support groups** were significantly more helpful than cancer agencies/organizations

Additional T-tests were conducted to determine statistically significant differences in service satisfaction based on various demographic criteria (tumor type, residence region, insurance type, gender, ethnic/racial group, etc.). Results from these additional tests are included in Section 7: Differences Among Demographic Groups.

Organizations and Individuals Respondents Found Particularly Helpful

In Question 9, respondents were asked to share the names of any organizations or individuals that they found particularly helpful. In response, they provided the names of over 30 cancer research and support organizations and programs; 12 medical groups; 5 hospice organizations; nearly 80 physicians; nearly 50 other individuals; and a variety of other resources. Several respondents listed more than one individual/group. Figure 15 summarizes the list of organizations, individuals, and other resources receiving more than two mentions.

Figure 15: Organizations/Individuals/Other Resources that Respondents Found Particularly Helpful

Organization/Individual/Resource	Number of Mentions
• People Living Through Cancer/PLTC support groups	38
• Prostate Cancer Support Association of New Mexico	26
• American Cancer Society	16
• Friends	11
• Family	8
• Cancer Institute of New Mexico (CINM)	7
• Doctors – in general	7
• Church friends/groups	6
• Dr. Lee	6
• Receptionists	6
• Chemo staff	5
• Colleen Sullivan Moore - Lovelace Breast Health Specialist	5
• Cancer support group -- specific group not identified	4
• Dr. Rauth	4
• Dr. Scott Timperley	4
• Dr. Wong	4
• Internet – in general	4
• Leukemia & Lymphoma Society	4
• Mayo Clinic	4
• Radiation staff – in general	4
• UNM CRTC	4
• Christine - UNM Joint Clinics	3
• Doctors at UNM CRTC	3
• Dr. Mitchell Binder	3
• Dr. Douglas Clark	3
• Dr. Jeff Neidhart	3
• Dr. Pitcher	3
• Doreen	3
• Independent reading – in general	3
• Joe Nai – PCSANM	3
• Nurses – in general	3
• Nurses at San Juan Oncology	3
• Staff – in general	3

People Living Through Cancer (PLTC) and the Prostate Cancer Support Association of New Mexico (PCSANM) received by far the most mentions. While this is not overly surprising, given that the survey questionnaire was mailed to members of these groups, it is still notable that so many respondents thought highly enough of these organizations to list them by name. A full listing of responses to Question 9 is included in Appendix F.

7. Differences Among Demographic Groups

Responses to the New Mexico Cancer Services Survey were analyzed to identify differences in responses by different demographic groups. These findings may be helpful as cancer services providers seek to customize their offerings to best meet the needs of the different segments of the patient population that they serve.

This section summarizes differences among respondents by tumor type, region of residence during treatment (e.g., Northern, Central, or Southern New Mexico), ethnic/racial group, gender, insurance type, age at diagnosis, patient status, and length of time since diagnosis. In each case we list the top three areas of importance, the three largest “gap rating” areas, and the three most helpful information sources for each group. In addition, T-tests were conducted to determine statistically significant differences in importance ratings, “gap ratings,” and helpfulness ratings for each demographic group.

As in the rest of this document, for most of these analyses we analyzed responses from the 471 questionnaires that described the experiences of New Mexican patients/survivors who were diagnosed since 2000. In the final section (Comparisons by Length of Time Since Diagnosis) we included responses from the 831 respondents that described the experiences of New Mexican patients/survivors (regardless of their date of diagnosis), so we could compare the experiences of recently diagnosed respondents to longer-term survivors.

Comparisons by Tumor Type

Figure 16: Most Important Services by Tumor Type

Tumor Type	Most Important Services	Average Satisfaction	# Respondents
Breast	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.87	141
	• Early detection/screening services	3.84	139
	• Emotional support programs for patients	3.49	114
Prostate	• Early detection/screening services	3.92	60
	• Traditional medical treatments	3.67	51
	• Hospice/end-of-life services	3.57	14
Lung	• Early detection/screening services	3.63	41
	• Traditional medical treatments	3.61	46
	• Hospice/end-of-life services	3.61	23
Colorectal	• Emotional support programs for caregivers	3.79	24
	• Early detection/screening services	3.75	36
	• Traditional medical treatments	3.70	43
Leukemia/ Lymphoma	• Early detection/screening services	3.84	32
	• Traditional medical treatments	3.68	31
	• Hospice/end-of-life services	3.67	12
Ovarian	• Early detection/screening services	3.92	13
	• Traditional medical treatments	3.88	16
	• Emotional support programs for patients	3.85	13
Cervical	• Early detection/screening services	3.70	10
	• Traditional medical treatments	3.70	10
	• Assistance with paperwork/reimbursement for treatment costs	3.57	7
Melanoma	• Hospice/end-of-life services	4.00	2
	• Traditional medical treatments	3.88	8
	• Emotional support programs for caregivers	3.80	5

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Breast cancer** respondents rated traditional medical treatments as significantly more important than other respondents did
- **Prostate cancer** respondents rated transportation services to/from appointments, training in day-to-day management skills, and emotional support programs for caregivers as significantly less important than other respondents did
- **Colorectal cancer** respondents rated emotional support programs for caregivers as significantly more important than other respondents did
- **Melanoma** respondents rated early detection/screening services as significantly less important than other respondents did

Figure 17: Largest Gap Ratings by Tumor Type

Tumor Type	Services with Largest “Gap Ratings”	Average Gap	# Respondents
Breast	• Emotional support programs for caregivers	-0.84	55
	• Transportation services to/from appointments	-0.82	39
	• Housing/lodging services (for those who received treatment away from home)	-0.69	16
Prostate	• Early detection/screening services	-0.41	58
	• Emotional support programs for patients	-0.35	37
	• Alternative/integrative therapies	-0.27	15
Lung	• Assistance with paperwork/reimbursement for treatment costs	-1.05	22
	• Emotional support programs for caregivers	-0.91	22
	• Emotional support programs for patients	-0.88	25
Colorectal	• Transportation services to/from appointments	-1.00	10
	• Early detection/screening services	-0.54	35
	• Emotional support programs for caregivers	-0.28	18
Leukemia/ Lymphoma	• Housing/lodging services	-1.00	6
	• Training in day-to-day management skills	-1.00	16
	• Transportation services to/from appointments	-0.80	10
Ovarian	• Emotional support programs for patients	-1.73	11
	• Early detection/screening services	-1.36	11
	• Emotional support programs for caregivers	-1.11	9
Cervical	• Emotional support programs for patients	-0.83	6
	• Training in day-to-day management skills	-0.83	6
	• Emotional support programs for caregivers	-0.80	5
Melanoma	• Early detection/screening services	-1.00	9
	• Emotional support programs for caregivers	-1.00	4
	• Housing/lodging services	-0.25	4

The following differences in “gap ratings” were determined to be statistically significant at the level of $p=.05$:

- **Prostate cancer** respondents reported a significantly smaller gap for training in day-to-day management skills than other respondents
- **Colorectal cancer** respondents reported a significantly smaller gap for emotional support programs for patients than other respondents
- **Lung cancer** respondents reported a significantly larger gap for assistance with paperwork/reimbursement for treatment costs than other respondents
- **Ovarian cancer** respondents reported a significantly larger gap for early detection/screening services and emotional support programs for patients than other respondents

Figure 18: Most Helpful Information Sources by Tumor Type

Tumor Type	Most Helpful Information Sources	Average Rating	# Respondents
Breast	• Nurses	3.55	139
	• Physicians	3.39	143
	• Independent reading/internet searches	3.34	94
Prostate	• Independent reading/internet searches	3.69	52
	• Cancer support group(s)	3.31	52
	• Physicians	3.17	63
Lung	• Physicians	3.40	43
	• Nurses	3.40	43
	• Independent reading/internet searches	3.09	23
Colorectal	• Nurses	3.56	41
	• Physicians	3.48	42
	• Independent reading/internet searches	3.36	28
Leukemia/ Lymphoma	• Physicians	3.52	33
	• Independent reading/internet searches	3.24	21
	• Nurses	3.23	31
Ovarian	• Independent reading/internet searches	3.38	13
	• Nurses	3.20	15
	• Physicians	3.13	15
Cervical	• Nurses	2.89	9
	• Physicians	2.89	9
	• Cancer agencies/organizations	2.88	8
Melanoma	• Physicians	3.36	11
	• Nurses	3.36	11
	• Independent reading/internet searches	3.22	9

The following differences in helpfulness ratings were determined to be statistically significant at the level of $p=.05$:

- **Breast cancer** respondents found nurses significantly more helpful than other respondents did
- **Prostate cancer** respondents found cancer support groups and independent reading/internet searches significantly more helpful than other respondents did
- **Leukemia/lymphoma** respondents found cancer support groups significantly less helpful than other respondents did
- **Cervical cancer** respondents found independent reading/internet searches significantly more helpful than other respondents did

Comparisons by Region of Residence

Figure 19: Most Important Services by Region of Residence

Region	Most Important Services	Average Importance	# Respondents
Northern NM	• Early detection/screening services	3.83	103
	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.77	110
	• Assistance with paperwork/reimbursement for treatment costs	3.40	80
Central NM	• Early detection/screening services	3.83	163
	• Traditional medical treatments	3.75	158
	• Hospice/end-of-life services	3.49	49
Southern NM	• Traditional medical treatments	3.76	124
	• Early detection/screening services	3.73	120
	• Assistance with paperwork/reimbursement for treatment costs	3.65	89

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Southern New Mexicans** rated assistance with paperwork/reimbursement for treatment costs as significantly more important than other respondents did

Figure 20: Largest Gap Ratings by Region of Residence

Region	Largest Gap Ratings	Average Gap	# Respondents
Northern NM	• Early detection/screening services	-0.61	95
	• Transportation services to/from appointments	-0.59	27
	• Emotional support programs for patients	-0.54	63
Central NM	• Emotional support programs for caregivers	-1.00	76
	• Transportation services to/from appointments	-0.89	37
	• Emotional support programs for patients	-0.82	116
Southern NM	• Emotional support programs for caregivers	-0.54	46
	• Transportation services to/from appointments	-0.52	42
	• Early detection/screening services	-0.50	105

The following differences in gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Northern New Mexicans** reported a significantly smaller gap for in-home care and emotional support programs for caregivers than other respondents did
- **Central New Mexicans** reported a significantly larger gap for in-home care, training in day-to-day management skills, emotional support programs for patients and emotional support programs for caregivers than other respondents did
- **Southern New Mexicans** reported a significantly smaller gap for traditional medical treatments and training in day-to-day management skills than other respondents did

Figure 21: Most Helpful Information Sources by Region of Residence

Region	Most Helpful Information Sources	Average Rating	# Respondents
Northern NM	• Nurses	3.52	111
	• Physicians	3.42	113
	• Independent reading/internet searches	3.25	72
Central NM	• Independent reading/internet searches	3.49	129
	• Nurses	3.24	144
	• Physicians	3.17	167
Southern NM	• Physicians	3.43	121
	• Nurses	3.30	118
	• Independent reading/internet searches	3.16	76

The following differences in helpfulness ratings were determined to be statistically significant at the level of $p=.05$:

- **Northern New Mexicans** rated nurses as significantly more helpful than other respondents did
- **Central New Mexicans** rated physicians as significantly less helpful than other respondents did, and rated cancer support groups and independent reading/internet searches as significantly more helpful than other respondents did
- **Southern New Mexicans** rated independent reading/internet searches as significantly less helpful than other respondents did

Comparisons by Ethnic/Racial Group

Figure 22: Most Important Services by Ethnic/Racial Group

Group	Most Important Services	Average Importance	# Respondents
Non-Hispanic White	• Early detection/screening services	3.78	230
	• Traditional medical treatments	3.75	231
	• Assistance with paperwork/reimbursement for treatment costs	3.30	157
Hispanic	• Early detection/screening services	3.81	123
	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.76	127
	• Emotional support programs for patients	3.69	98
Native American	• Emotional support programs for patients	3.89	19
	• Assistance with paperwork/reimbursement for treatment costs	3.86	21
	• Housing/lodging services (for those who received treatment away from home)	3.85	13
Black	• Early detection/screening services	3.92	12
	• Traditional medical treatments	3.91	11
	• Assistance with paperwork/reimbursement for treatment costs	3.40	5

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Non-Hispanic White** respondents rated alternative/integrative therapies, transportation services to/from appointments, assistance with paperwork/reimbursement for treatment costs, emotional support services for patients and caregivers and training in day-to-day management skills as significantly less important than other respondents did
- **Hispanic** respondents rated alternative/integrative therapies, transportation services to/from appointments, assistance with paperwork/reimbursement for treatment costs and emotional support services for patients and caregivers as significantly more important than other respondents did
- **Native American** respondents rated in-home care, housing/lodging services (for those who received treatment away from home), emotional support programs for patients and assistance with paperwork/reimbursement for treatment costs as significantly more important than other respondents did

Figure 23: Largest Gap Ratings by Ethnic/Racial Group

Group	Largest Gap Ratings	Average Gap	# Respondents
Non-Hispanic White	• Transportation services to/from appointments	-0.81	48
	• Early detection/screening services	-0.66	216
	• Training in day-to-day management skills	-0.56	98
Hispanic	• Emotional support programs for patients	-0.79	78
	• Emotional support programs for caregivers	-0.68	62
	• Early detection/screening services	-0.57	107
Native American	• Emotional support programs for patients	-1.14	14
	• Emotional support programs for caregivers	-0.92	12
	• Assistance with paperwork/reimbursement for treatment costs	-0.88	17
Black	• Hospice/end-of-life services	-1.00	3
	• Emotional support programs for patients	-0.83	6
	• Emotional support programs for caregivers	-0.80	5

The following differences in gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Non-Hispanic White** respondents reported a significantly smaller gap for emotional support programs for patients than other respondents did

Figure 24: Most Helpful Information Sources by Ethnic/Racial Group

Group	Most Helpful Information Sources	Average Rating	# Respondents
Non-Hispanic White	• Independent reading/internet searches	3.39	174
	• Nurses	3.30	210
	• Physicians	3.29	231
Hispanic	• Nurses	3.40	128
	• Physicians	3.35	134
	• Independent reading/internet searches	3.31	86
Native American	• Nurses	3.24	21
	• Physicians	3.22	23
	• Independent reading/internet searches	3.21	14
Black	• Physicians	3.75	12
	• Nurses	3.67	12
	• Independent reading/internet searches	3.00	9

The following differences in helpfulness ratings were determined to be statistically significant at the level of $p=.05$:

- **Non-Hispanic White** respondents rated social workers as significantly less helpful than other respondents did

Comparisons by Patient Gender

Figure 25: Most Important Services by Patient Gender

Gender	Most Important Services	Average Importance	# Respondents
Female	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.80	268
	• Early detection/screening services	3.79	263
	• Assistance with paperwork/reimbursement for treatment costs	3.51	186
Male	• Early detection/screening services	3.80	150
	• Traditional medical treatments	3.68	147
	• Assistance with paperwork/reimbursement for treatment costs	3.41	106

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Men** rated alternative/integrative therapies and emotional support programs for patients as significantly less important than women did

Figure 26: Largest Gap Ratings by Patient Gender

Gender	Largest Gap Ratings	Average Gap	# Respondents
Female	• Emotional support programs for patients	-0.78	174
	• Emotional support programs for caregivers	-0.76	112
	• Transportation services to/from appointments	-0.74	72
Male	• Early detection/screening services	-0.61	140
	• Emotional support programs for caregivers	-0.47	64
	• Transportation services to/from appointments	-0.47	38

The following differences in gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Men** reported a significantly smaller gap for emotional support programs for patients than women did

Figure 27: Most Helpful Information Sources by Patient Gender

Gender	Most Helpful Information Sources	Average Rating	# Respondents
Female	• Nurses	3.39	255
	• Physicians	3.33	262
	• Independent reading/internet searches	3.27	182
Male	• Independent reading/internet searches	3.48	113
	• Physicians	3.32	164
	• Nurses	3.27	140

The following differences in helpfulness ratings were determined to be statistically significant at the level of $p=.05$:

- **Men** rated independent reading/internet searches as significantly more helpful than women did

Comparisons by Insurance Type

Figure 28: Most Important Services by Insurance Type During Treatment

Insurance Type	Most Important Services	Average Importance	# Respondents
Private Insurance	• Early detection/screening services	3.78	220
	• Traditional medical treatments	3.76	212
	• Hospice/end-of-life services	3.43	74
Medicare	• Early detection/screening services	3.75	159
	• Traditional medical treatments	3.73	157
	• Assistance with paperwork/reimbursement for treatments costs	3.41	111
Medicaid	• Early detection/screening services	3.89	70
	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.76	75
	• Assistance with paperwork/reimbursement for treatments costs	3.53	62
Self-Pay/Uninsured	• Assistance with paperwork/reimbursement for treatments costs	3.83	24
	• Early detection/screening services	3.79	24
	• Traditional medical treatments	3.74	27
Supplemental Insurance	• Traditional medical treatments	3.92	24
	• Early detection/screening services	3.84	25
	• Assistance with paperwork/reimbursement for treatments costs	3.50	16
VA/TriCare	• Early detection/screening services	3.83	24
	• Housing/lodging services (for those who received treatment away from home)	3.75	4
	• Traditional medical treatments	3.71	28

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Private insurance** respondents rated assistance with paperwork/reimbursement for treatment costs as significantly less important than other respondents did, while **self-pay/uninsured** respondents rated this service as significantly more important than other respondents did
- **Medicare** and **supplemental insurance** respondents rated alternative/integrative therapies as significantly less important than other respondents did

Figure 29: Largest Gap Ratings by Insurance Type During Treatment

Insurance Type	Largest Gap Ratings	Average Gap	# Respondents
Private Insurance	• Transportation services to/from appointments	-0.83	46
	• Emotional support services for caregivers	-0.79	96
	• Emotional support services for patients	-0.68	148
Medicare	• Emotional support services for caregivers	-0.72	53
	• Transportation services to/from appointments	-0.60	40
	• Emotional support services for patients	-0.59	85
Medicaid	• Emotional support services for patients	-0.77	52
	• Early detection/screening services	-0.73	64
	• Transportation services to/from appointments	-0.53	38
Self-Pay/Uninsured	• Early detection/screening services	-0.83	24
	• Assistance with paperwork/reimbursement for treatment costs	-0.82	22
	• Emotional support services for caregivers	-0.53	15
Supplemental Insurance	• Transportation services to/from appointments	-0.75	4
	• Emotional support services for caregivers	-0.75	4
	• Emotional support services for patients	-0.58	12
VA/TriCare	• Housing/lodging services (for those who received treatment away from home)	-1.50	2
	• Early detection/screening services	-0.67	21
	• In-home care	-0.50	4

The following differences in gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Medicare** respondents reported a significantly smaller gap for assistance with paperwork/reimbursement for treatment costs than other respondents did
- **Supplemental insurance** respondents reported a significantly smaller gap for hospice/end-of-life services than other respondents did

Figure 30: Most Helpful Information Sources by Insurance Type During Treatment

Insurance Type	Most Helpful Information Sources	Average Rating	# Respondents
Private Insurance	• Independent reading/internet searches	3.42	179
	• Physicians	3.23	225
	• Nurses	3.18	205
Medicare	• Physicians	3.36	162
	• Nurses	3.33	149
	• Independent reading/internet searches	3.20	102
Medicaid	• Nurses	3.45	71
	• Physicians	3.38	74
	• Independent reading/internet searches	3.20	44
Self-Pay/Uninsured	• Nurses	3.63	27
	• Physicians	3.56	27
	• Independent reading/internet searches	3.06	18
Supplemental Insurance	• Physicians	3.30	23
	• Nurses	3.13	23
	• Independent reading/internet searches	3.00	13
VA/TriCare	• Independent reading/internet searches	3.55	20
	• Nurses	3.54	24
	• Cancer support group(s)	3.53	17

The following differences in helpfulness ratings were determined to be statistically significant at the level of $p=.05$:

- **Private insurance** respondents rated physicians, nurses, and social workers as significantly less helpful than other respondents did
- **Medicare** respondents rated independent reading/internet searches as significantly less helpful than other respondents did
- **VA/TriCare** respondents rated cancer support groups as significantly more helpful than other respondents did

Comparisons by Age When Patient Was Diagnosed

Figure 31: Most Important Services by Age When Patient Was Diagnosed

Age	Most Important Services	Average Importance	# Respondents
Under 20	• Early detection/screening services	3.33	3
	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.33	3
	• Assistance with paperwork/reimbursement for treatment costs	3.33	3
20-40	• Early detection/screening services	3.89	44
	• Traditional medical treatments	3.84	43
	• Assistance with paperwork/reimbursement for treatment costs	3.68	37
41-55	• Early detection/screening services	3.82	117
	• Traditional medical treatments	3.81	125
	• Assistance with paperwork/reimbursement for treatment costs	3.52	86
Over 55	• Early detection/screening services	3.77	249
	• Traditional medical treatments	3.74	245
	• Assistance with paperwork/reimbursement for treatment costs	3.40	166

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Patients diagnosed between ages 20-40** rated alternative/integrative therapies as significantly more important than other respondents did
- **Patients diagnosed over age 55** rated alternative/integrative therapies as significantly less important than other respondents did

Figure 32: Largest Gap Ratings by Age When Patient Was Diagnosed

Age	Largest Gap Ratings	Average Gap	# Respondents
Under 20	• Alternative/integrative therapies	-1.00	1
	• Hospice/end-of-life services	0.00	1
	• Training in day-to-day management skills	0.00	2
20-40	• Housing/lodging services (for those who received treatment away from home)	-0.93	14
	• Emotional support programs for caregivers	-0.83	29
	• Training in day-to-day management skills	-0.79	29
41-55	• Transportation services to/from appointments	-0.95	38
	• Emotional support programs for caregivers	-0.78	63
	• Emotional support programs for patients	-0.78	85
Over 55	• Early detection/screening services	-0.57	223
	• Emotional support programs for patients	-0.56	140
	• Emotional support programs for caregivers	-0.51	81

The following differences in gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Patients diagnosed between ages 20-40** reported a significantly larger gap for housing/lodging services than other respondents did
- **Patients diagnosed over age 55** reported a significantly smaller gap in assistance with paperwork/reimbursement for treatment costs than other respondents did

Figure 33: Most Helpful Information Sources by Age When Patient Was Diagnosed

Age	Most Helpful Information Sources	Average Rating	# Respondents
Under 20	• Physicians	4.00	3
	• Social workers	4.00	2
	• Nurses	3.67	3
20-40	• Independent reading/internet searches	3.55	29
	• Nurses	3.45	40
	• Physicians	3.44	43
41-55	• Independent reading/internet searches	3.42	93
	• Nurses	3.35	119
	• Physicians	3.25	123
Over 55	• Nurses	3.34	237
	• Physicians	3.34	260
	• Independent reading/internet searches	3.31	175

No significant differences in helpfulness ratings were identified by age group.

Comparisons by Patient Status

Figure 34: Most Important Services by Patient Status

Status	Most Important Services	Average Importance	# Respondents
In Active Treatment	• Early detection/screening services	3.79	226
	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.76	237
	• Assistance with paperwork/reimbursement for treatment costs	3.50	171
Not in Active Treatment – In Remission	• Traditional medical treatments	3.79	132
	• Early detection/screening services	3.78	141
	• Assistance with paperwork/reimbursement for treatment costs	3.48	90
Not in Active Treatment – Not in Remission	• Early detection/screening services	3.74	19
	• Traditional medical treatments	3.65	20
	• Assistance with paperwork/reimbursement for treatment costs	3.53	15
Deceased	• Hospice/end-of-life services	4.00	10
	• Emotional support services for patients	3.80	10
	• Emotional support services for caregivers	3.80	10

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- Respondents completing the survey on behalf of **deceased** patients rated traditional medical treatments as significantly less important than other respondents did

Figure 35: Largest Gap Ratings by Patient Status

Status	Largest Gap Ratings	Average Gap	# Respondents
In Active Treatment	• Early detection/screening services	-0.64	209
	• Emotional support programs for caregivers	-0.62	107
	• Emotional support programs for patients	-0.61	140
Not in Active Treatment – In Remission	• Transportation services to/from appointments	-0.89	28
	• Emotional support programs for caregivers	-0.67	45
Not in Active Treatment – Not in Remission	• Emotional support programs for patients	-0.57	84
	• Early detection/screening services	-1.00	17
Deceased	• Emotional support programs for patients	-0.87	15
	• Assistance with paperwork/reimbursement for treatment costs	-0.85	13
	• Early detection/screening services	-2.00	7
	• Assistance with paperwork/reimbursement for treatment costs	-1.67	3
	• Housing/lodging services (for those who received treatment away from home)	-1.50	2

The following differences in gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Patients in remission** reported a significantly smaller gap for early detection/screening services and traditional medical treatments than other respondents did, while respondents completing the survey on behalf of **deceased** patients reported a significantly larger gap in these areas than other respondents did
- **Patients not in active treatment/not in remission** reported a significantly smaller gap for emotional support programs for caregivers than other respondents did

Figure 36: Most Helpful Information Sources by Patient Status

Status	Most Helpful Information Sources	Average Rating	# Respondents
In Active Treatment	• Physicians	3.42	229
	• Nurses	3.41	223
	• Independent reading/internet searches	3.31	153
Not in Active Treatment – In Remission	• Independent reading/internet searches	3.43	103
	• Physicians	3.28	142
Not in Active Treatment – Not in Remission	• Nurses	3.27	125
	• Physicians	3.00	22
Deceased	• Independent reading/internet searches	2.93	14
	• Nurses	2.89	18
	• Nurses	3.63	8
	• Cancer support group(s)	3.20	5
	• Independent reading/internet searches	3.00	7

The following differences in helpfulness ratings were determined to be statistically significant at the level of $p=.05$:

- **Patients not in active treatment/not in remission** rated nurses, social workers, cancer support groups and cancer agencies/organizations as significantly less helpful than other respondents did

Comparisons by Length of Time Since Diagnosis

Figure 37: Most Important Services by Length of Time Since Diagnosis

Year Diagnosed	Most Important Services	Average Importance	# Respondents
2000-2004	• Early detection/screening services	3.79	421
	• Traditional medical treatments (e.g., radiation, chemotherapy)	3.76	423
	• Assistance with paperwork/reimbursement for treatment costs	3.47	297
1995-1999	• Early detection/screening services	3.83	204
	• Traditional medical treatments	3.68	191
	• Hospice/end-of-life services	3.42	72
1990-1994	• Early detection/screening services	3.90	81
	• Traditional medical treatments	3.74	78
	• Hospice/end-of-life services	3.68	31
Pre-1990	• Early detection/screening services	3.65	34
	• Assistance with paperwork/reimbursement for treatment costs	3.64	25
	• Hospice/end-of-life services	3.60	20

The following differences in service importance ratings were determined to be statistically significant at the level of $p=.05$:

- **Patients diagnosed from 2000-2004** rated transportation services to/from appointments as significantly more important than other respondents did
- **Patients diagnosed from 1995-1999** rated transportation services to/from appointments, traditional medical treatments, and assistance with paperwork/reimbursement for treatment costs as significantly less important than other respondents did
- **Patients diagnosed prior to 1990** rated traditional medical treatments as significantly less important than other respondents did

Figure 38: Largest Gap Ratings by Length of Time Since Diagnosis

Year Diagnosed	Largest Gap Ratings	Average Gap	# Respondents
2000-2004	• Transportation services to/from appointments	-0.65	112
	• Emotional support programs for caregivers	-0.65	180
	• Emotional support programs for patients	-0.64	267
1995-1999	• Early detection/screening	-0.69	186
	• Emotional support programs for caregivers	-0.63	98
	• Emotional support programs for patients	-0.54	147
1990-1994	• Hospice/end-of-life services	-0.67	18
	• Housing/lodging services (for those who received treatment away from home)	-0.60	10
	• Training in day-to-day management skills	-0.58	45
Pre-1990	• Housing/lodging services	-1.17	6
	• Transportation services to/from appointments	-1.00	10
	• Early detection/screening	-0.90	31

The following differences in gap ratings were determined to be statistically significant at the level of $p=.05$:

- **Patients diagnosed from 2000-2004** reported a significantly smaller gap for traditional medical treatments and a significantly larger gap for transportation services to/from appointments than other respondents did
- **Patients diagnosed from 1995-1999** reported a significantly smaller gap for transportation services to/from appointments than other respondents did
- **Patients diagnosed from 1990-1994** reported a significantly smaller gap in emotional support programs for patients than other respondents did
- **Patients diagnosed prior to 1990** reported a significantly larger gap in traditional medical treatments than other respondents did

Figure 39: Most Helpful Information Sources by Length of Time Since Diagnosis

Year Diagnosed	Most Helpful Information Sources	Average Rating	# Respondents
2000-2004	• Independent reading/internet searches	3.36	299
	• Nurses	3.35	400
	• Physicians	3.33	431
1995-1999	• Independent reading/internet searches	3.39	158
	• Cancer support group(s)	3.27	146
	• Nurses	3.20	187
1990-1994	• Independent reading/internet searches	3.41	64
	• Cancer support group(s)	3.15	67
	• Nurses	3.10	72
Pre-1990	• Cancer support group(s)	3.16	25
	• Independent reading/internet searches	3.12	26
	• Physicians	3.00	36

The following differences in helpfulness ratings were determined to be statistically significant at the level of $p=.05$:

- **Patients diagnosed from 2000-2004** rated nurses and physicians as significantly more helpful than other respondents did and rated cancer support groups as significantly less helpful than other respondents did
- **Patients diagnosed from 1995-1999** rated physicians significantly less helpful than other respondents did and rated cancer support groups as significantly more helpful than other respondents did

8. Discussion

Key Findings and Implications

The New Mexico Cancer Services Survey yielded several important observations and implications about the experiences of New Mexico’s cancer patients/survivors and their loved ones. Highlights include:

- Medically-oriented services (early detection/screening services, traditional medical treatments) were the most important services to respondents, followed by assistance with paperwork/reimbursement for treatment costs; emotional services (support programs for patients and caregivers), and day-to-day assistance services (hospice/end-of-life services, training in day-to-day management skills, in-home care, and transportation services to/from appointments). Housing/lodging services and alternative/integrative therapies were less important to respondents.
- There is substantial opportunity to improve New Mexicans’ experiences with cancer-related services. The average satisfaction rating was below “satisfied” for five of eleven services evaluated: emotional support programs for caregivers; alternative/integrative therapies; emotional support programs for patients; transportation services to/from medical appointments; and training in day-to-day management skills. Respondents were most satisfied with traditional medical treatments (e.g., radiation, chemotherapy).
- For each of the eleven cancer-related services evaluated, respondents indicated a gap between the importance of the service and their satisfaction with the service. Services with the largest gaps may indicate the greatest opportunities for improvement. These include transportation services to/from appointments; emotional support programs for caregivers; emotional support programs for patients; early detection/screening services; training in day-to-day management skills; and assistance with paperwork/reimbursement for treatment costs.
- There appear to be substantial opportunities to improve the way information is disseminated about New Mexico’s existing cancer-related services. Over 30% of respondents indicated they were unable to access needed services because they were not aware that services were available.
- In open-ended comments regarding cancer-related services that didn’t exist to support respondents and/or services they would focus on improving, respondents were most concerned about a lack of information and education to help them manage the cancer journey. Concerns cited inadequate information on the disease process and treatment options, along with insufficient information on what cancer-related services are available to assist patients and their loved ones. Gaps in emotional support services for patients and caregivers came a close second. These areas are potential targets for significant improvement.

- There are opportunities to refine service offerings to better meet the needs of different patient demographic groups. While some of the findings for different demographic groups were to be expected (e.g., it is not surprising that patients in remission reported smaller gaps in service satisfaction than others, since they had a relatively good outcome), others provide interesting insights into the needs of different patient groups. For example, non-Hispanic white respondents reported a significantly smaller gap for emotional support programs for patients than other respondents did, suggesting that future efforts to expand these types of programs should particularly focus on other ethnic/racial groups.

Limitations of the Phase I Study

As explained in Section 1: Study Approach, the population targeted through the New Mexico Cancer Services Survey was not a randomized sample of New Mexicans coping with cancer. This was due to two major factors: a desire to maximize patient confidentiality, and the need to conduct the program within a relatively modest budget. Our sampling approach was designed to generate a pool of respondents whose demographics closely matched that of the entire New Mexican population coping with cancer, and we were relatively successful in meeting this goal. Our respondents represented a wide variety of tumor types, disease stages, geographic locations, ages, levels of insurance coverage, and ethnic/racial groups. A few groups were somewhat over-represented in the study: ethnic/racial groups other than non-Hispanic whites; breast cancer patients/survivors; women; and younger patients/survivors.

Because a portion of the study involved mailings to clients of People Living Through Cancer (PLTC) and the Prostate Cancer Support Association of New Mexico (PCSANM), a relatively high percentage of individuals who responded had had some interaction with these organizations. It is possible the our data reflects a group of New Mexicans that is more active in seeking assistance/support than average, particularly with respect to the type of emotional support and educational services these organizations provide.

Most of our data on Albuquerque-area patients came from respondents to the PLTC and PCSANM mailings and from on-site interviews at the UNM CRTC. There are several other Albuquerque-area oncology groups that are not well represented in the study. Similarly, our interviews in Northern and Southern New Mexico were conducted in a subset of the existing oncology clinics outside of Albuquerque. It is possible that findings would shift somewhat if respondents had been evenly distributed across all of the different oncology practice groups in the state.

Next Steps

This report is being distributed to cancer services providers throughout New Mexico, in the hope that our findings will provide some guidance for how they might continue to improve the services offered to New Mexicans coping with cancer. It will also serve as a major input to Cancer Services of New Mexico's strategic planning process, to ensure our programs and services continue to be focused on the areas of greatest need.

There are many additional ways that we could mine the data in our survey database, and we would welcome the opportunity to work with other groups to help them answer specific questions not covered in this report. Please contact us at (505) 259-9583 or info@CancerServicesNM.org if you are interested in learning more.

Our experiences so far have given us tremendous hope that this study will positively impact the experiences of New Mexico's cancer patients/survivors and their loved ones. Throughout the study, we have developed interim reports for the many organizations that have collaborated with us on this program. These reports summarize data from clients of each partnering organization, and have been extraordinarily well received. In each case, we have discussed several specific modifications or enhancements the group could make to better meet the needs of its clients. Several of these changes are already being implemented.

Several of our collaborators have asked if we plan to repeat this study in the future. We are exploring the possibility of conducting a follow-up survey that would enable us to track changes in ratings of cancer-related services over time. We will make a decision based on the feedback we receive from New Mexico's cancer services providers on the value the current study and an assessment of our organizational capacity to execute a follow-up survey effectively. We welcome comments on the value of conducting the New Mexico Cancer Services Survey on an ongoing basis, along with suggestions for improving this program in the future.



Appendices

- Appendix A: Survey Questionnaire
- Appendix B: Comments on Services Where Respondents Were Not Satisfied/Somewhat Satisfied (Question 6)
- Appendix C: Comments on Services That Did Not Exist to Support Respondents (Question 10)
- Appendix D: Comments on Services Respondents Would Focus on Improving (Question 11)
- Appendix E: Comments on Factors Limiting Access to Important/Very Important Services (Question 7)
- Appendix F: Organizations, Individuals, and Other Resources Respondents Found to Be Particularly Helpful (Question 9)
- Appendix G: Additional Comments (Question 19)

Appendix A: Survey Questionnaire



The New Mexico Cancer Services Survey

The first-ever statewide survey of cancer patients/survivors and their loved ones

Please take a few minutes to complete this confidential survey. Survey findings will be shared with providers of cancer-related services throughout the state, in an effort to improve New Mexico's cancer-related services. Completed surveys should be sent to: Cancer Services of New Mexico, P.O. Box 51735, Albuquerque, NM 87181-9970. Questions? Call us at (505) 259-9583.

Section I: Background

- | | | |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------|
| <p>1. Your Relationship to the Cancer Patient</p> <p>a. Patient/survivor</p> <p>b. Spouse/significant other</p> <p>c. Parent of the patient</p> <p>d. Child of the patient</p> <p>e. Other (describe) _____</p> | <p>2. Current Status of the Cancer Patient</p> <p>a. In active treatment (e.g., chemo, radiation)</p> <p>b. Not in active treatment – in remission</p> <p>c. Not in active treatment – not in remission</p> <p>d. Deceased</p> <p>e. Other (describe) _____</p> | <p>3. Year Diagnosed</p> <p>_____</p> |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------|

Section II: Your Experience with Cancer-Related Services in New Mexico

For each of the services listed below, circle the appropriate responses to questions 4 and 5

- | | |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>4. How important are/were each of these services to you:</p> <p>1. Not important</p> <p>2. Somewhat important</p> <p>3. Important</p> <p>4. Very important</p> <p>NA Not applicable</p> | <p>5. How satisfied are/were you with each of these services?</p> <p>1. Not satisfied</p> <p>2. Somewhat satisfied</p> <p>3. Satisfied</p> <p>4. Very satisfied</p> <p>NA Not applicable</p> |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

a. Early detection/screening services	1	2	3	4	NA	1	2	3	4	NA
b. Traditional medical treatments (e.g., radiation, chemotherapy, etc.)	1	2	3	4	NA	1	2	3	4	NA
c. Alternative/integrative therapies (e.g., herbs, acupuncture, imagery, etc.)	1	2	3	4	NA	1	2	3	4	NA
d. Transportation services to/from medical appointments	1	2	3	4	NA	1	2	3	4	NA
e. Housing/lodging services (for those who received treatment away from home)	1	2	3	4	NA	1	2	3	4	NA
f. In-home care	1	2	3	4	NA	1	2	3	4	NA
g. Training in day-to-day management skills (e.g., administering medication, stress mgmt, etc.)	1	2	3	4	NA	1	2	3	4	NA
h. Emotional support programs for patients	1	2	3	4	NA	1	2	3	4	NA
i. Emotional support programs for caregivers	1	2	3	4	NA	1	2	3	4	NA
j. Hospice/end-of-life services	1	2	3	4	NA	1	2	3	4	NA
k. Assistance with paperwork/reimbursement for treatment costs (e.g., insurance, Medicare, etc.)	1	2	3	4	NA	1	2	3	4	NA
l. Other (describe) _____	1	2	3	4	NA	1	2	3	4	NA

6. Please comment on any services where you circled "Not satisfied" or "Somewhat satisfied" in response to Question 5.

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Section II: Your Experience with Cancer-Related Services in New Mexico (continued)

7. For those services you described as Important or Very Important in Question 4 what, if anything, limited your access to these services? (circle all that apply)
- a. Cost – too expensive/could not afford
 - b. Enrollment requirements (other than cost)
 - c. Was not aware services were available
 - d. Other (describe): _____
 - e. Did not have difficulty accessing services
- Comments: _____

8. How **helpful** were each of the following in providing information on what cancer-related services were available to assist you and your family/loved ones?
1. Not helpful 3. Helpful NA Not applicable
 2. Somewhat helpful 4. Very helpful

a. Physicians	1	2	3	4	NA	e. Cancer agencies/ organizations	1	2	3	4	NA
b. Nurses	1	2	3	4	NA	f. Independent reading/ internet searches	1	2	3	4	NA
c. Social Workers	1	2	3	4	NA	g. Other (describe): _____	1	2	3	4	NA
d. Cancer support group(s)	1	2	3	4	NA						

9. Please share the names of any organizations or individuals that you found particularly helpful

10. What cancer-related services are needed that didn't exist to support you?

11. What cancer-related services would you focus on improving? How would you improve them?

Section III: Demographic Information

12. Type of Cancer
- a. Lung
 - b. Colorectal
 - c. Breast
 - d. Prostate
 - e. Melanoma
 - f. Cervical
 - g. Other (describe): _____
13. Patient's Insurance Coverage (during treatment)
- a. Medicaid
 - b. Medicare
 - c. Private – HMO
 - d. Private – PPO/POS
 - e. Private – Indemnity
 - f. Self payer/No insurance
 - g. Other (describe): _____
14. Patient's Sex
- a. Male
 - b. Female
15. Patient's Age at Diagnosis
- a. Under 20
 - b. 20 – 40
 - c. 41 – 55
 - d. Over 55
16. Patient's Ethnic/Racial Group
- a. Hispanic
 - b. Non-Hispanic White
 - c. Black
 - d. Native American
 - e. Other (describe): _____
17. Patient's County of Residence: _____
18. Oncology Group or Hospital: _____

Section IV: Other Comments

19. Is there anything else you would like to add?

Thank you for taking the time to complete this survey! All responses will be kept confidential. However, if you would like to speak with someone from Cancer Services of New Mexico about this survey, please provide your name and phone number below.

 Name (optional)

 Phone Number (optional)

Appendix B: Comments on Services Where Respondents Were Not Satisfied/Somewhat Satisfied

Summary of open-ended responses to Question 6: "Please comment on any services where you circled 'Not satisfied' or 'Somewhat satisfied' in response to Question 5," for the 471 respondents that described the experiences of New Mexican patients who were diagnosed from 2000-2004. Responses have been organized by type of cancer-related service.

A. Early Detection/Screening (33 comments)

- Lump diagnosed as a cyst was cancer a year later.
- Mammogram did not detect cancer at 2cm size
- Though I had yearly exams and frequent blood tests, my cancer was not caught. NM Aging Process Study Group caught my cancer (blood test)
- Tumor did not show on mammogram
- Not detected in NM. Detection made at Mayo Clinic.
- No good detection of ovarian cancer
- I was misdiagnosed on my mammogram
- I think at not quite 47, having had recurrent breast cancer 4 times in less than 7 year, I should have been given other tests (aside from the 3 mo. CTs, labs) which would have assisted me from having a "brain tumor" cancer today. I should have been given a head to knee annual checkup. I had original lumpectomy with radiation, then bilateral w/ chemo., and then a right lung dissection and now a brain surgery
- I was examined by a surgeon at about 4 mo. intervals for two years with a "suspicious" area in my breast - and 6 mos. after I was told I did not have to return I had an 8 cm tumor. Never showed up on a mammogram. I only had one ultrasound and no biopsy (prior to diagnosis biopsy)
- My gynecologist did not tell me that "spotting" during menopause could mean cancer. Luckily, after 6 months of spotting I made an appointment. Uterine cancer was detected. Gynecologists should educate patients about early signs of uterine cancer (I thought it was routine menopause)
- My sister went to a clinic in Moriarty the nurse practitioner kept telling her it was arthritis. She never had the medical doctor look at her until a knot the size of an egg came up.
- I feel when people complain of pain all the time they doctor should really try to find out why they have pain. Besides my sister a friend of mine complained of pain - then finally too late she had lung cancer
- PSA test was not stressed
- My cancer took almost 10 years to diagnose; even the urologist contended he was sure I had it but couldn't find it.
- Initial detection could have been earlier
- I was diagnosed with a tumor in May when I had a turp, but not told until December when I was moving to NM
- It took 3 months to diagnose her lung cancer from the time she became ill, by that time it had spread to her bones
- Mom had ovarian cancer which is difficult to detect early enough. I wish there was more education available via OB/Gyn's in NM so patients would be more aware of symptoms
- Mom had lung x-rays for pneumonia which did not detect the lung cancer - had CT scan, etc. been used it could have saved her life. Tests which would detect lung cancer should be used, especially with history of cancer (as in this case)
- Not diagnosed early as I am an inmate and scheduling was delayed on behalf of the Grants CCA facility
- Mammogram did not detect growth; work-related (should have gone for exam in Aug 2002, postponed until January because of work expectations)
- My father's primary physician ignored all signs of his cancer. Finally took him to different doctor and they found it immediately
- Mammogram never detected lump
- No form of test (early detection). No referral to doctor until very late in time of health of patient.
- Not diagnosed for two years
- Despite regular screening, cancer was not detected until large lump surfaced.
- My condition is rare and hard to diagnose. If it had been discovered earlier, it would have been easier to handle
- Primary physician did not diagnose cancer in spite of months of office visits and complaints about pain and a strange growth (tumor) in the stomach
- Clinic should have done more tests
- Need early detection, better understanding from physicians (not oncologists) that people at younger age have cancer (under 30 years old)
- First facility presented problems with follow-up in early detection and suggested follow-up after metastasis occurred.

Satisfied with second facility

- After I was diagnosed it took a long time to meet with any doctors
- My husband was diagnosed very late

B. Traditional Medical Treatments (19 comments)

General Comments about Traditional Medical Treatments

- Chemo may not have been effective; may not do it again if offered.
- Tumor was so rare that there have been no clinical trials. Hence, the chemo had no effect. She had three different regimens, one right after the other. Died in 18 months.
- Treatments (chemo and medications) were ineffective
- Chemo not working so far
- They should never have offered "treatment" because it gave my mother a false hope.
- Not available surgically in New Mexico - laparoscopic adrenalectomy
- My Dr. said I should undergo radiation and would not even discuss any alternate treatments. I don't see him any more
- Prostate seems to be new - where can I get more info on alternatives to surgery
- Practicing doctors need to learn about alternative therapies as well as Profou treatment. Keep up with improved radiation therapy
- Not enough info on alternative strategies before having to commit to RP and radiation; lots of unknowns, few clear answers - frustrating and scary
- After extensive research and interviews with several doctors in various specialties, it was my belief that the expertise required for the treatment I sought was not available in Albuquerque so I selected to obtain treatment out of state. - surgery, radioactive "seeds", external beam, etc.
- First doctor not sure of himself or treatment
- Not satisfied because not offered any other alternatives
- Treatment for blood clots was impersonal. Blood tests were painful, no one really qualified to take blood.
- I feel my doctor failed to let me know the cancer was back when he diagnosed the lymphodema

Comments on Post-Treatment Effects

- Have some bad side effects
- I am now dealing with chemotherapy's side effects on my body.
- Better awareness of symptoms of lymphoma in medical community could make diagnosis process quicker!
- I was not properly protected against damaging side effects of radiation

C. Alternative/Integrative Therapies (14 comments)

- Alternative services are rarely covered or talked about by HMO.
- Alternative therapies not covered by insurance.
- I am not aware of any multiple myeloma support group to discuss alternative treatments and their effectiveness
- Alternative/integrative therapies are not available to me
- I circled "not satisfied" to "c" because although I'm very interested in alternative therapies, none were offered to me by my physician or the hospital - any alternative therapy I had I found on my own at a time when I was too ill to do much searching/researching
- Alternative therapies - I'm more interested in studies about how diet, etc. effect cancer. Also, it would be interesting to know of positive herbal remedies where they exist. In many cases they probably don't exist but info. about resources, things to read to find out if alternatives exist would be useful.
- Not much alternative/integrative care offered
- Have only been given info on alternative therapies if I asked.
- No support, no help
- Very important; not yet used, are very much needed
- Not suggested
- Alternative medication in most cases doesn't seem to work.
- I don't believe in these therapies
- HMO treated only disease - no alt/integrative therapies

D. Transportation Services To/From Appointments (18 comments)

- Transport services were entirely unsatisfactory.
- I was always needing rides home and sometimes had trouble finding them.
- Transportation is needed.
- We were not told about transportation services at all. This could be extremely valuable to patient and family members with work obligations on days when taking time off is difficult.
- No transportation program
- From my house to the clinic was 250 miles one way. Traveled and lodged in personal RV. Most RV parks are fairly expensive. Drove up every Sunday afternoon, came home every Friday afternoon
- I had no transportation to my appointments, had very hard time getting rides to and from appointments. Missed appointments/was late because I didn't have rides half the time. The one who was supposed to help with that was never in his office and never returned calls. If it wasn't for volunteers I would not have made it to any of my appointments.
- Patient was not aware of transportation
- These services were not discussed with me or my husband who has to drive me from Las Cruces to Albuquerque for treatment
- No support, no help
- Transportation services have been non-existent
- Wait time for transportation from services provided by state.
- Very important; not yet used, are very much needed
- Travel distance from home - 60 miles, one way
- Provided all of my own transportation
- Transportation provided by family.
- Transportation from Artesia to Roswell is up to patient.
- Needed transportation

E. Housing/Lodging Services (5 comments)

- No support, no help
- Very important; not yet used, are very much needed
- Need to expand
- At MD Anderson Rotary house is very accessible but very expensive. Need more housing of this kind for out of town patients
- No housing/lodging services available that I am aware of.

F. In-Home Care (9 comments)

- More detailed home health care is needed, along with assistance with home maintenance
- Not told that a nurse would come into the home and help with drainage tube, etc.
- Home nursing was poor. Thank god for friends/family.
- In-home care was a real problem. We always ended up in the emergency room even for "standard" procedures (e.g., catheter issues).
- VA - no home care offered (1996, colon cancer); prostate cancer - none needed
- No support, no help
- Home care services have been non-existent
- Very important; not yet used, are very much needed
- Need care for folks not on Medicaid

G. Training in Day-to-Day Management Skills (15 comments)

- No training at all for day to day management of stress and life problems, only medical management of surgery, etc.
- I'd like to see nutrition counseling support group meetings, etc. where I receive treatment
- Never received any day to day coping training.
- There was no proactive care in nutrition resulting in a 30 lb. loss without nutritional counseling, no recommendation to use a pump with the feeding tube, and related problems
- There should be better "pre-chemo" information and stress management.

- No support, no help
- Very important; not yet used, are very much needed
- Really don't know if these services are provided by my home health care provider
- We had no contact with day-to-day management skills, stress mgmt., etc.
- Have never been offered any information
- Re: support for prostate cancer - not enough available for incontinence and impotency after surgery
- Explanation of medication was too fast for patient to understand
- I would like to see more programs for stress management, diet, and exercise
- Not much day-to-day education
- We were not offered any dietician services.

H. Emotional Support Programs for Patients (25 comments)

Comments about emotional support from health care providers:

- It seems the medical staff is very competent in dealing with healing the body itself but do not have the time or maybe don't have the skills to deal with the patient's emotional pain.
- The head nurse was rude and uncaring. Family member was kept out while I lay there for hours before surgery
- HMO treated only disease - no empathy, no support
- Oncologists not honest about the severity. Practice "hope" not reality. No good explanations.
- They haven't really asked about depression

General comments about emotional support programs:

- PLTC needs a group that focuses on initial diagnosis of breast cancer only -- I couldn't tolerate hearing about relapses and people dying the first time I got there. Short workshops on dealing with fear would be helpful.
- There is a need for emotional support programs for patients
- No one mentioned any support group or came to see me or phone me -- felt all alone
- Reach for Recovery never contacted me even though I called twice
- Support group focused too much on death and not emotional support.
- I am not currently involved in any support activities
- The support group is comprised of much older men and it makes becoming involved very depressing as these individuals have other issues compounding their health that make it difficult to create a connection
- Patient was not aware of any support groups or other services available to cancer patients
- Emotional support programs are not offered
- Have not been offered emotional support. Just diagnosed recently.
- Very important; not yet used, are very much needed
- No satisfactory support program
- No emotional support discussions, which patient feels is important
- There were not support services for cancer patients out of the clinic. There are some groups at St. Vincent's
- Emotional support provided by family and extended family
- No emotional support programs for patients in our area
- Have never been offered any information
- I could never get a hold of any emotional support program
- No support, no help
- I really do not have anyone to talk to

I. Emotional Support Programs for Caregivers (16 comments)

- My husband never went to any caregiver programs.
- Groups for spouses of breast cancer patients - none for lesbian patients
- Not enough "male" oriented support groups for husband caregivers.
- There is a need for emotional support programs for patients caregivers and significant others.
- My mother needed much more help with my 87 year old father who was diagnosed with lung cancer and survived < 4 mos.
- Need more emotional support/literature for caregivers.

- There was little emotional support programs for caregivers
- They have never asked about how my husband felt or if he needed help
- Emotional support programs are not offered
- No support, no help
- Very important; not yet used, are very much needed
- Support - even blood pressure reading -- needed for family, caregivers
- Family and church are very supportive
- Our family has always come together in crisis situations
- No emotional support programs for caregiver in our area
- Have never been offered any information

J. Hospice/End-of-Life Services (5 comments)

- Initially, the in-hospital hospice was disappointing, if not indifferent. The volunteers came regularly, but their services were not needed. When we changed to Zia Hospice and took my husband home hospice support was terrific.
- Very important; not yet used, are very much needed
- No hospice discussion, which patient feels is important
- We have had no contact with hospice
- Have never been offered any information

K. Assistance with Paperwork/Reimbursement for Treatment Costs (25 comments)

- Assistance with paperwork is important.
- I continue to receive incorrect bills and I can't get them to stop
- Never received any assistance with paperwork for insurance - still fighting that.
- No help with paperwork for reimbursement
- I didn't have any help with insurance
- The process used by my employer for partial disability pay was not adequately explained the first time I applied
- Few problems with Medicare - not serious
- A constant chore you have to do this yourself if you expect any results. People without family assistance will not be able to do this. Insurance companies are totally uncooperative.
- There was one bill that became a problem. The way it was coded caused the insurance company to deny the claim. It took a lot of time and several people were involved to get this corrected
- I didn't have a lot of paperwork, but changing insurance in a move complicated it. "Single payer" with no paperwork would be better
- Can not get reports for personal files
- The assistance for medicare or costs are the worst I have seen. The person who does this is very rude and inconsiderate
- The costs of treatment are overwhelming. I wasn't aware that the Cancer Center had a hospital financial assistant until midway through treatment, and purely by chance
- No support, no help
- Very important; not yet used, are very much needed
- Assistance is often a forced labor for the attendants
- Some difficulty working with my insurance company. Problems on both ends.
- Dealing with insurance has been a nightmare
- No specific "channel" for medical costs. Seems to be referrals to systems that don't necessarily apply
- I was diagnosed with a terminal illness, am a single parent, can not work, and was denied Medicaid. There needs to be more support services!
- Billed on lab, Xray, all services and then turned in to collections
- Very poor handling of insurance forms and records
- Medicare won't cover him because he has not been on disability for at least 2 years. A lot of good it does us when he won't be alive in two years.
- Have never been offered any information
- Terrible time getting the correct SSN on forms

L. Other Areas of Dissatisfaction

- Felt there was very little support for anything
- While the medical care was very good, there was a lack of coordination between providers.
- I am not getting much help. No educational material, not a lot of questions asked about my condition, not enough information given to me
- Pain management was extremely important in this case and I felt it was completely inadequate. I was overall not satisfied with my mother's care. She had very severe pain that would take over 15 hrs. in the ER to deal with while she was screaming in pain. There seemed to be nobody that believed her that her pain was actually real. I felt helpless as did she. She was in extremely severe pain in the hospital for the last 30 hours of her life.
- Besides dr's follow-ups, someone should be checking on patient's continued health.
- Need more information as to what to expect and what next step I would want
- My scheduled appointments both in Dr. visits and surgery were often messed up, as in...charts were not where they were supposed to be before surgery, and for my first chemo treatment which made me very uneasy
- Not informed of treatments or prognosis since chemo, radiation in July, 2004 - now September
- Not many good sources of help around Las Cruces
- Appointments usually take a little longer than time given. Example: 9:00 appointment, dr. does not see patient until 1 hour later
- I did not care for one of my doctors
- Parking - limited, terrible. Employees and/or non-cancer autos parked. I wrote to chief at the hospital to no avail. Facilities did not appear pleasant. My first appearance like a morgue - prison - basement. It grew on me.
- I'm not receiving any of these treatments. Had surgery to remove cancer, no treatment
- There need to be more services to help the patient, especially in the early weeks
- No support services offered
- Have not been offered support
- Many services not offered
- I was not made aware of services being offered
- I haven't had much help. My mom did most of the helping.
- None was offered

Other Comments

Compliments

- I'm actually satisfied with the treatments I have had to help me get well.
- Services and medications much improved over past 20 years
- The nurses at UNM in oncology were terrific, kind, helpful, caring.
- Sandia Hospice at Kaseman was wonderful
- Drs. and technicians were great.
- Dr. Wong and staff were outstanding and supportive.
- If "traditional medical" includes surgery I'm satisfied; surgery worked for me
- Just having a supportive medical staff plays a big role on the care given. Auntie always has a smile when leaving her treatment
- Had diagnosis and surgery in California but everyone here have been wonderful with smiles and warmth
- Great care
- Very satisfied
- Very satisfied, thank you
- Very satisfied with doctor and nurses. Care has been exceptional
- All services and personnel were excellent
- Went through proton radiation therapy in University Hospital at Loma Linda 5/20/02-7/20/02. Very satisfied with treatment at Loma Linda hospital.
- My prostate cancer was discovered when I was 84 year of age. I was treated at the VA and had excellent care

General Comments

- Just starting treatment
- Have just had one chemo treatment. Don't know exactly what to expect
- I have only just begun my medical care for this illness. I have not yet had treatment
- First time here
- Support groups are not a necessity for me
- Many of the services offered I/we did not use
- HMO did paperwork
- For my cancers, meditation, imagery, and self-evaluations were helpful as was the support of immediate family (wife and daughter). I am a retired psychiatrist and my psychoanalysis during training was helpful.
- I am taking Tamoxifen - I have had care and support from drs., nurses, family, friends and a lot of spiritual support
- At the present time I am receiving radiation locally. My wife drives me and I stay at my home.
- I was in hospital 1 day 6am to 6pm and used the nuclear seed type of treatment. Present PSA is 0.1 as of Aug 2003

Appendix C: Comments on Services That Did Not Exist to Support Respondents

Summary of open-ended responses to Question 10: “What cancer-related services are needed that didn’t exist to support you?” for the 471 respondents that described the experiences of New Mexican patients who were diagnosed from 2000-2004. Responses have been organized by type of cancer-related service

Emotional Support Services (25 comments)

- Support group/emotional support group – in general (9 comments)
- More caregiver support – in general (3 comments)
- Counseling (2 comments)
- Emotional support exist but I was afraid to go - don't know why. I wish I had raised my fears w/ my doctor
- Emotional support group or social worker for patient
- Emotional support groups in Artesia
- Need to have a support group here in Roswell - someone that can pray and talk to patients
- Support group closer to home and at an earlier time
- Support group for young prostate cancer patients
- Specific breast cancer support
- Specific dealing with fear about cancer
- Local phone contacts with other patients would be helpful
- Family support/counseling
- Young children were scared after surgery, teenagers required counseling at 4 months after surgery

Information/Education (19 comments)

- Truthful information was not readily available
- Clear assessment of alternatives with mortality stats
- Info and knowledge on lymphedema
- Information for children who have parents hit with cancer
- More info on colon and prostate cancer
- Ovarian cancer chat group, preferably doctor/nurse practitioner led
- More information regarding rides and support groups
- I don't know what is available in Las Cruces
- Be given support group info/not have to search for it on my own
- More patient/caregiver information
- No one let me know about PLTC or Cancer Services. I found a newly formed support group through the Clovis newspaper and through our group I learned about PLTC and you!
- More information about services being provided
- Information on various treatments are just not available to the general public in this part of the state (Eddy County)
- Information and education on chemotherapy and radiation prior to therapy
- Information
- Clearinghouse
- Help in obtaining cancer information when you are too tired to search anymore. When you're in treatment you don't have stamina to research answers.
- I felt like I didn't know what to expect at different points along this journey and still don't really know what to expect as the disease progresses. I would also like information about what it is like for a person as they approach death. Again, I am sure there is variation but having some info about the range of experience would be helpful. Also, how to help your loved one who is suffering.
- More could be done after diagnosis/before treatment to educate and prepare family members and friends who will be acting as caregivers on what to expect as far as the effects of treatment and how to respond

Research/Treatment Protocols (7 comments)

- Proton bombardment in NM
- Clinical trials in Las Cruces, NM
- Specialists with expertise in specific types of treatment
- I had to fight to be tested for HER2NEU gene - and I tested positive (1 of 3 women do). It should be standard protocol because it affects treatment and coping.
- We went to MD Anderson in Houston for surgery because their equipment was better and their surgeons specialize in brain cancer
- Pet scan - covered by Medicare for ovarian cancer
- Treatments and clinical trials for mixed müllerian tumors

Transportation Services (6 comments)

- I found transportation is not readily available
- Reliable counselor to help with rides
- Transport to treatment may be very useful
- Transportation services - have not been approached for need
- Transportation for patients that live a distance from the doctors, hospitals
- Transportation from Artesia to Roswell

Coordination of Care/Information About Patient Status (6 comments)

- I envision a team that works together, seeing the patient in person rather than shuffling papers. The human factor seems missing. My hospital's vision "to be the best place to get care, and the best place to give care" falls short!
- Most patients might appreciate more specific info - like a contact name and phone #. A better consistent point of contact might be like a case manager - could be a nurse.
- Physician needs to keep patient and relatives informed of treatments and prognosis
- Honest facts from doctors. No wishy washy.
- Personally I would like to see more services that support a holistic approach to me as a "person with cancer" and not just a walking diagnosis
- A bridging group into the medical world. PCSANM is a watchdog group - need an access support system too

Training in Day-to-Day Management Skills (5 comments)

- I live alone, with no family in town. When I was incapacitated during cancer treatment, there was no service to assist in day-to-day living activities
- Meals - after surgery - very weak
- Post operation problems, i.e. impotence
- Stress management, diet, exercise programs
- Support services for incontinence and impotence after surgery

Assistance with Paperwork/Insurance (5 comments)

- Expert information on insurance data, more clear instructions
- I was taken off Medicaid because I turned 65
- Insurance-related administrative help
- Reimbursement requests - too many delays in getting reimbursement
- Paperwork assistance

Alternative/Integrative Therapies (3 comments)

- Meditation techniques and coaches
- Physicians recommending alternative treatments along with traditional
- Information on vitamins, dietary, and naturopathic information

Access to Medical Personnel (3 comments)

- Surgical oncologists
- Shortage of cancer physicians, shortage of chemotherapy nurses and facilities
- No social workers available

Other Services That Did Not Exist to Support Respondents

- Early hospice
- Help with care of children for single parents w/ cancer, especially during vomiting bouts after chemo.
- Better nursing service after operation
- Homecare - have not been approached for need.
- More services related to lung cancer
- Private room for treatments
- Services that help patient out when traveling in from a long distance where breakfast, lunch, and dinner are served for patient and family while waiting
- I do not know. But, I believe a follow-up consultation appointment would be in order. My PSA at this time decreased from thirteen to six - which I believe should be zero. What next?
- None - just needed them sooner
- None in area of residence
- Anything at all
- I didn't get any support during my treatments

Other Comments

Compliments

- I had access to everything needed
- All the services needed were provided
- I received what I needed
- I'm happy about all my care
- In my case, I received what I needed
- Everything is great! Many services are available, but I do not use them due to the distance of my treatment center from my home.
- Boulder County did not have a support group. Los Cruces has a good support group

General Comments

- Just began treatments
- I'm not sure - I don't know about the services but have had support of family, friends, and churches

Appendix D: Comments on Services Respondents Would Focus on Improving

Summary of open-ended responses to Question 11: "What cancer-related services would you focus on improving? How would you improve them for the 471 respondents that described the experiences of New Mexican patients who were diagnosed from 2000-2004. Responses have been organized by type of cancer-related service.

Information/Education (35 comments)

- Education on all aspects - detection, treatment, insurance
- When a person is first diagnosed give them the names of organizations that will help
- When someone is diagnosed with cancer I would like to have the patient be given a list of "cancer- related services" and someone to tell you your options before surgery.
- Prior to treatment, have Oncology Social Worker or nurse meet with primary and secondary caregivers to educate them on treatment, effects, and available resources
- Everyone should keep informed of how new improvements might effect them. The support group in Albuquerque does an excellent job of keeping up with new info.
- Dissemination of information and support groups
- Giving information about cancer support groups
- Information on services available
- Increased awareness of available facilities in the community
- Make patients aware of any new services
- More information available on your cancer
- Literature on CMML! Patient is blind, so anything that you have tape and print also.
- Knowing more about pancreatic cancer/having pamphlets
- Someone should contact and inform folks with cancer problem
- Someone to explain all options of treatment that are available
- Still not familiar with all services available
- More information to public where groups are in dealing with depression, anxiety, etc.
- More information with more instructions
- "Flow chart" system so that all know who and where to go for funding
- Classes, not just support group, for caregiver
- Inform people. Hardly any of these "services" have been mentioned
- Information
- Information - a list of websites and phone numbers should be made available to patients when they are diagnosed and to high risk individuals. There is a huge amount of information available if you research and have access to larger bookstores and Internet. For a small region like we live in, a list of website and 1-800 numbers should be compiled and made available.
- More info on cancer before you get it. Put more info on internet
- Internet access to latest information
- Knowledge base of all possible treatments
- Website needs work!
- Information-based services geared toward prevention and early diagnosis. Perhaps more education of primary physicians.
- Information - my aunt just died of cancer and didn't even know what chemo was. If you are not savvy you can not even address treatment options
- I would encourage more physicians to be aware of cancer related services and make referrals to care coordinators
- Information given to individual by providers. They almost always recommend and push for their particular service.
- Physicians had no time to provide information
- Educate drs. (PCPs), nurses, and patients more about MM
- Encourage gynecologists to educate patients regarding signs of uterine cancer. Mine discussed signs of breast cancer, but never uterine cancer.
- Train urologists to share more fully and balanced information. Not just argue for their particular "truth"

Emotional Support Services (18 comments)

- Support groups/emotional support groups – in general (7 comments)
- Support groups for younger individuals
- Counseling for caregivers is needed and very important!
- Better one on one support
- Ask us about emotional support needs
- Being more friendly with first-time people and companions
- Cancer support groups were too depressing - we started our own group
- Group therapy for patients and caregivers provided at the hospital
- Counseling to address stress and emotional problems associated with having cancer
- Doctors need to ask about your emotions, sleeping
- Emotional aspects of dealing with cancer. Being able to discuss with a doctor or chemo nurse how you are feeling
- Maybe to let people know more about them, but I am sure if I had needed a support group all I had to do was ask

Access to Medical Personnel (16 comments)

- More physician options. I don't know how to improve them.
- More doctors who specialize in particular types of treatments for prostate cancer
- 2nd opinions from physicians - make easier to schedule in timely manner
- Referral service for oncologists, with physician's certifications
- Long waits for chemotherapy and oncologists
- Doctor visits - the doctor should schedule his appointments where we don't have to be here till the "wee hours". Don't overbook
- Doctors are too busy. Increase the number of specialists in this area and then have doctors limit their practices to what they can handle
- Fewer patients per doctor
- There do not seem to be enough doctors in our area for the number of patients
- Don't keep patients waiting so long
- Wait time to see doctor is long.
- Wait time, additional nurses
- Possibly better nursing or having more available after operation
- Hospital social workers
- All social workers missed the mark. At best, they were not helpful; at worst, they made it more difficult
- Have treatments in Deming

Research/Treatment Protocols (9 comments)

- Radiation - mom received burns
- Side effects
- When port was put in and taken out patient was very uncomfortable
- Research
- Research, research, research!
- Continue research
- Experimental/new treatment approaches
- Still need interventions and treatments - would rather just be able to take a pill
- I have great care. Just keep on with research so may help all cancer patients

Financial Assistance (6 comments)

- Financial support where insurance is inadequate
- Financial, by having bills passed for terminally ill patients
- Helping with housing and children
- More help for people with no insurance. Would like more help for medications and formula feedings.
- Government help for 19 year olds that lost their medicaid. The government should give these people all the money they need.
- Social Security Disability should help until full recovery

Early Detection/Screening (6 comments)

- Early detection
- Early detection - all "cysts" biopsied (especially if palpable)
- Early detection - it should be part of everyone's annual
- Early detection for prostate cancer
- Early detection, more emphasis on esophagus and danger-related diseases
- Detection/avoiding HMO and PCP delay pitfalls due to financial HMO rules

Coordination of Care/Information About Patient Status (5 comments)

- Doctors need to go over tests and any changes in patient's overall progress or lack of progress, what's available out there, etc.
- Doctors should spend more time familiarizing themselves with patient case and explaining things.
- More organization, communication, and professionalism
- Much more organization in appointment making
- Explanation of treatments for Spanish speaking patients

Improved Treatment Facilities (5 comments)

- Private room for treatments
- Individual/private rooms for patients who are more critical or not feeling well at time of treatment
- Have a separate chemo room for younger patients where they can be treated so they would feel comfortable about asking each other questions about their experience with treatment
- Better facilities
- Cancer patient parking only - have a permanent attendant verifying valid cancer passes. Doctors and other workers should not be allowed. I spent time checking for valid cancer patient parking

Alternative/Integrative Therapies (5 comments)

- Alternative therapies - physician discussions
- Alternative/integrative therapies
- More alternative treatments recommended to patients
- More free massage sessions
- More alternative therapies included in insurance

Training in Day-to-Day Management Skills (3 comments)

- Training in day-to-day management skills
- Better help with diet
- More help with shopping...daily activity sort of things that are so hard to do

Transportation Services (2 comments)

- I would improve transportation services to and from treatments
- More volunteer services needed for rides

In-Home Care (2 comments)

- Home nursing - more of them, more accessible - we and our loved ones need their knowledge and skill and respite.
- In house care for someone living alone

Other Services Respondents Would Focus on Improving

- Insurance reimbursement
- Long term care for patients
- Hospice
- Better equipment
- Provide needed supplies.
- Nurse practitioner phone line - help renewing prescriptions
- Providing assistance to cancer patients who don't have caregivers
- Have organizations talk to family
- Expanding services to other counties if possible
- Have them available at diagnosis of cancer in doctor's office
- Get HMO's and doctors off the payroll of pill makers
- More funding, fundraisers
- I hope we have more support in every way

Other Comments

Compliments

- Everything is good!
- Every hospital needs as good a Breast Education Program like Lovelace for families, loved ones. It's excellent!
- I am satisfied with all the services I got here
- I can't think of any! This cancer center is great! The doctors and nurses are great!
- I have been treated extremely well since my diagnosis with cancer
- I think it was all covered
- They are very nice
- Information and services seemed to be available

General Comments

- Cancer is new to us even though my brother died from liver cancer. Now my husband is dealing with it.
- For my cancer and surgery, physical therapy and exercises are very important!.
- I think my problem is with my hospital
- In treatment
- Patients must be very active in self care, assertive.
- Too new to know

Appendix E: Comments on Factors Limiting Access to Important/Very Important Services

Summary of open-ended responses to Question 7: “Comments on Factors Limiting Access to Important/Very Important Services,” for the 471 respondents that described the experiences of New Mexican patients who were diagnosed from 2000-2004. Responses have been organized by factor limiting access.

A. Cost – Too Expensive/Could Not Afford (10 comments)

- Before I got the Medicaid I could not afford anything
- Cost is very difficult to pay - retired
- First option was too expensive
- I couldn't get second opinion after treatment started. I would have to pay for medical records for the second opinion
- I have tried to find just a little help to pay some of my deductibles. Insurance premium is high to pay and so much after really makes it tough
- I was going to a different doctor; he was pretty expensive, so I was able to go to UNM. I am with Tricare - didn't cover enough
- Insurance - mammogram once/year
- It really hurts to pay \$10 a pill, so don't blame retirees for going across
- Having difficulty accessing financial services
- Penasco clinic B&CC program for screening financing doesn't advertise - word of mouth

B. Enrollment Requirements Other Than Cost (2 comments)

- Training in day-to-day management skills - no one appeared to have effective skills
- I need a driver to get to these services. My children take me, but they also hold jobs and are unable to take me at times

C. Was Not Aware Services Were Available (17 comments)

- Am not aware of most of the services!
- Any kind of seminars about what to expect, how treatment generally proceeds, etc. would be useful. I understand there is case by case variation but as much as possible, such info. is helpful. Also, book lists of suggested titles would be helpful
- Did not know in-home care was available
- Had to do own research to make sure care was complete
- We were not informed of any local cancer services and have researched our doctors ourselves
- When a patient is new, there should be some info packet which includes services offered as well as specific info re: type of cancer and background of key staff members
- If they are available we don't know about it
- I have to use VA and there may be other options
- Not being on Medicaid, not aware which services I could qualify for
- I don't think there's enough emphasis given to the mental/psychospiritual aspects of healing
- I have not talked to any social worker
- Not aware of support groups or other services available to patients. If was aware would have used them
- Support group is not offered in small towns and state programs require minimum incomes
- Was not and still am not very knowledgeable about cancer support groups
- Was not aware emotional support services were available
- Unaware of transportation available to patients - when?where? Lodging for family - where?how?
- Hospice was offered too late. He died in the hospital before hospice could come into the home

D. Other (16 comments)

Timing of Diagnosis/Service Availability (15 comments)

- The 6 week delay between seeing the oncologist and starting treatment harmed
- PCP could not believe diagnosis (made by patient) due to rarity and did not do tests needed for months. HMO foot dragging
- Took 3 weeks to get biopsy scheduled and 2 weeks to get blood pre-donation scheduled
- It took the doctor a few weeks to decide what to do
- Need to seek others on 2nd opinion
- Speed in service important once cancer is diagnosed; should be first on list for appointments
- Pet scan - ovarian cancer not covered by Medicare - \$2000 test out of pocket
- Closest treatment of choice was 250 miles one way. Not offered any treatment but surgery by local urologist
- Clinical trials - away from home
- Some available treatments were in trial stages; if you had prior chemo you could not try. Need FDA to approve more chemotherapy drugs

Other Barriers (5 comments)

- Knowledge of earliest symptoms might help people seek earlier diagnosis
- Billing from office not correct
- Charged too many times
- Home nursing: they need to come around and do the job. Not rush in/rush out and leave family to their job.
- Patient cooperation not good

E. Did Not Have Difficulty Accessing Services (25 comments)

- All services exceptional
- All services were covered through my insurance.
- All services were great
- Because I have M/C and Champ VA, but what about people that don't have insurance?
- Did my own search for surgeon and oncologist and very happy with both
- Did not need any of the services. Drove myself from Carlsbad
- Did not need at this time
- Didn't need at this time
- Dr. Rauth spotted immediately
- Due to very concerned staff at this facility
- Everyone answered questions I had when I was ill
- Hospice was excellent and professional
- I am at the VA and have excellent service from Dr. Wilson. I am a member of PCSA
- I had access to all since we have cancer center in Farmington and Durango
- I have had excellent care and services at Roswell Oncology Center
- I went to the internet "Breast Cancer Resource Center" first
- If I had to endure the cost on my income I would be in grave trouble
- Insurance made everything available
- My family and friends helped me
- My wife and I took care of all paperwork and details. Without her I would never have made it through the program
- Not needed at the present time
- Not yet used but hope when we need them will be able to use without too much trouble
- Once cancer was diagnosed, all went well
- Very happy with SafeRide
- We have not had a need for most services. We are able to take care of them. We worry about people that don't have anyone to assist at home with daily living activities

Appendix F: Organizations, Individuals and Other Resources Respondents Found Particularly Helpful

Summary of open-ended responses to Question 9: “Please share the names of any organizations or individuals that you found particularly helpful,” for the 471 respondents that described the experiences of New Mexican patients who were diagnosed from 2000-2004.

Cancer Research and Support Organizations & Programs

- People Living Through Cancer/PLTC support groups (38 mentions)
- Prostate Cancer Support Association of New Mexico (26 mentions)
- American Cancer Society (16 mentions)
- Cancer support group -- specific group not identified – (4 mentions)
- Leukemia & Lymphoma Society (4 mentions)
- Connelly House (2 mentions)
- Comadre a Comadre Project (2 mentions)
- International Multiple Myeloma Foundation (2 mentions)
- Look Better, Feel Better program (2 mentions)
- Lovelace education programs (2 mentions)
- Reach to Recovery program (2 mentions)
- St. Vincent's support group (2 mentions)
- Women's cancer support group (2 mentions)
- All cancer organizations (2 mentions)
- Breast and Cervical Cancer program
- Breast Cancer Forum - Nova Scotia
- Caminando Juntos
- Cancer Charitable Foundation of California
- Cancer Services of NM
- Carcinoid Foundation
- Casa Esperanza
- Colon Cancer Coalition
- Delta Sky Wish Program
- Lance Armstrong Foundation
- Lovelace Spirit of Women
- The Kitchen Angels in Santa Fe
- Neurofibromatosis Foundation
- NCI
- Social services from Memorial Medical Center
- Why Me? - National Cancer Society
- Women's Resource Center

Medical Institutions

- Cancer Institute of New Mexico (CINM) (7 mentions)
- UNM CRTC (4 mentions)
- Mayo Clinic (4 mentions)
- MD Anderson-Houston (2 mentions)
- San Juan Oncology (2 mentions)
- SENM Internal Medicine Hematology & Oncology (2 mentions)
- St. Vincent's
- San Juan home health
- Taos Medical Group
- Taos Pueblo Clinic
- UNM Pediatric Oncology
- VA Hospital

Hospice Organizations

- Hospice – in general (2 responses)
- Sandia Hospice (2 mentions)
- Lovelace hospice
- Presbyterian Hospice - Kaseman
- Zia Hospice

Medical Providers (in general)

- Staff – in general (3 mentions)
- Staff at CINM (2 mentions)
- Staff at Lovelace (2 mentions)
- Staff at Dr. Ampuero's office (SW Gyn Onc, ABQ)
- Staff at Kaseman Treatment Center
- Staff at New Hope
- GI clinic

- Doctors – in general (7 mentions)
- Doctors at UNM CRTC (3 mentions)
- Doctors at San Juan Cancer Center (2 mentions)
- Doctors at CINM
- Doctors at ENMMC
- Doctors at NCS
- Doctors at Mayo clinic
- Doctors at San Juan Oncology

- Nurses – in general (3 mentions)
- Nurses at San Juan Oncology (3 mentions)
- Nurses at SENM Internal Medicine Hematology & Oncology
- Surgical nurses at ENMMC
- Nurses at NM Oncology & Hematology

- Radiation staff – in general (4 mentions)
- Radiation techs at ENMMC

- Chemo staff (5 mentions)

- Laboratory staff (2 mentions)

- Receptionists (6 mentions)
- Admin/financial staff – in general (4 mentions)
- Dr. Rauth's financial staff
- People in Medicaid
- Chief parking attendant and assistant

- La Familia Care Center - wound nurses
- In-home health care

Specific Physicians

- Dr. Lee (6 mentions)
- Dr. Rauth (4 mentions)
- Dr. Scott Timperley (4 mentions)
- Dr. Wong (4 mentions)
- Dr. Binder – Lovelace (3 mentions)

- Dr. Douglas Clark (3 mentions)
- Dr. Jeff Neidhart (3 mentions)
- Dr. Pitcher (3 mentions)
- Dr. Bagwell (2 mentions)
- Dr. Dayao (2 mentions)
- Dr. James Liebman (2 mentions)
- Dr. Rivas (2 mentions)
- Dr. Harriet Smith (2 mentions)
- Dr. Snyder (2 mentions)
- Dr. Amy Tarnower (2 mentions)
- Dr. Adler
- Dr. Ampuero
- Dr. Anderson
- Dr. Anthony
- Dr. Baker
- Dr. Bergdorf - former chief of Dermatology at VA
- Dr. E. Diane Bowers - Lovelace Surgeon
- Dr. Bush - NMOHC
- Dr. Cathcart
- Dr. Cetrub
- Dr. Stephen Cetrullo, Outreach Surgeon
- Dr. Elizabeth Cunningham
- Dr. Richard Davis
- Dr. Robert Desko, Durango, Colorado
- Dr. Dudley
- Dr. Duncan
- Dr. Joel Elconin
- Dr. Endres
- Dr. Taylor Floyd
- Dr. Gopalan
- Dr. Hoekenga
- Dr. Michael Hopkins
- Dr. Khorsand
- Dr. La Porte
- Dr. Larson and his wife, Blaire (Cancer Services of New Mexico)
- Dr. Libby
- Dr. Lopez
- Dr. Lou
- Dr. Martinez
- Dr. McMillen
- Dr. McNeely, Denver VA
- Dr. Kathryn Miller (Breast Imaging)
- Dr. Miller at IHS
- Dr. Don Morris
- Dr. James Neidhart, MD
- Dr. Neidhart
- Dr. Newmann
- Dr. Mary Ochadlik - Lovelace Urology
- Dr. Ortelano
- Dr. Rabinowitz
- Dr. Rader
- Dr. Raes
- Dr. Rehallard - Carlsbad
- Dr. Reid
- Dr. Lorraine Sanchez

- Dr. Sanyal
- Dr. School
- Dr. Scott Schomer
- Dr. Sklar
- Dr. Anthony Smith
- Dr. Graham Smith
- Dr. Snider
- Dr. David Snyder, oncologist
- Dr. Jerome Snyder
- Dr. Paul Snyder
- Dr. Spafford
- Dr. Jeffrey Stanley
- Dr. Steitzman
- Dr. William Talbot, surgeon
- Dr. Thompson
- Dr. Claire Verschraegen
- Dr. Whitwarm
- Dr. Wright
- Dr. Melanie Yeats

Other Individuals

- Colleen Sullivan Moore - Lovelace Breast Health Specialist (5 mentions)
- Christine - UNM Joint Clinics (3 mentions)
- Doreen (3 mentions)
- Joe Nai – PCSANM (3 responses)
- Carmen Angel (2 mentions)
- Christina (2 mentions)
- Aaron
- Alice (social worker at UNM)
- Ann Parson
- Bernie Lash
- Blanche - nurse
- Carol Jordan (social worker)
- Debbie – nurse
- Edith Deleon, Discharge Planner at Northern Navaho Medical Center in Shiprock
- Fran Robinson
- Frances
- Ilene
- Jackie Casteel of Patients Services, Lovelace
- Jamie McDonald, Pres. Support Group head
- Josie H.
- Juan
- Kathy Legg
- Kathy Lencon
- Leigh Knox (nurse at Sandia hospice)
- Linda (physical therapy)
- Linda Turner
- Linda Wolcott
- Lorraine LaPlante (breast cancer group)
- Louise
- Lourdes - nurse
- Lucy
- Lyle Ware - PCSANM
- Marian Bruce, PCSANM

- Marit (Dr. Hamsi's nurse, Deming)
- Mary Roach, RN
- Mrs. Trenehy at the Cancer Foundation
- Nurse McDuffey
- Pat Harrington - Reach for Recovery
- Robert Neel - PCSANM
- Shauna
- Shirley Ann
- Stephanie at chemo hospital
- Susan – nurse
- Susan @ doctor's office helped get medications
- Tracy
- Wendy Hines, Social Worker at UNMH
- Yvonne

Other Resources

- Friends (11 responses)
- Family (8 mentions)
- Church friends/groups (6 mentions)
- Other survivors

- Internet – in general (4 responses)
- American Cancer Society-internet
- Angelfoundation.org
- Drugs.com
- WebMD-internet
- www.BreastCancerCareForums.com

- Independent reading – in general (3 responses)
- Book by John Link, MD, "The Breast Cancer Survival Manual"
- Books by Bernie Siegel, MD, such as "Love, Medicine, and Miracles"
- Cancer Coalition's booklet of services
- U.S. govt cancer-related materials
- Pamphlets

- Breast cancer grant – Wendy
- Hospital sanctuary
- Interpreter program
- State Human Services
- Truman Street clinical staff in pursuant to my condition -- HIV/AIDS services

Appendix G: Other Comments

Summary of Open-Ended Responses to Question 19: "Is there anything else you would like to add?" for the 471 respondents that described the experiences of New Mexican patients who were diagnosed from 2000-2004.

Compliments

- All care has been great!
- All doctors and nurses are awesome! They listen to me. They make you feel important
- All of the staff were wonderful to me always with a smile and very happy
- Cancer Society was so supportive and informative. They helped by sister-in-law and I to communicate with each other and understand. They helped me so much as a support person with correct usable info.
- Day surgery and radiation was all I required. Received excellent care
- Don't know of anything right now. I have been pleased with treatment.
- Everyone has been wonderful and helpful
- Everyone here at San Juan Oncology have been very helpful and supportive. It is a very difficult time.
- Excellent support staff and facility
- Getting connected to Art Street was wonderful! There should be more of this.
- God bless you and the cancer center
- Great that you are doing this!
- Here at the Cancer Center at UNM we found the most professional people, with the biggest heart - there are no words to describe how wonderful doctor, nurses, and all all the employees are
- I am very pleased with all your help. Thank you.
- I am very pleased with my treatments. My cancer was found at a very early stage and treatments have gone very well
- I am very thankful for all the help they gave me and support. Everything was really perfect.
- I appreciate all that has been done by Dr. Smith and Dr. Neidhart, as well as the San Juan Regional to provide a cancer center in Farmington so we don't have to travel to Albuquerque and can stay in Farmington for treatment.
- I appreciated all the prayers offered for me.
- I can't say enough about the staff in every department here. They have all made my illness and treatment as easy as is possible and always with smiles and efficiency.
- I feel so fortunate to have Dr. Snyder as my oncologist. And Dr. Elizabeth Cunningham is my surgeon- so special!
- I had wonderful care and support here.
- I have just moved to Santa Fe in February so I am not familiar with everything yet. However, I am pleased with all aspects of treatment and info I have needed so far.
- I just recently had breast reduction (on non-cancerous breast) and lift on both at Presbyterian Hospital by Dr. Luis Cuadros. All were caring and my surgery and during my 2 day hospital stay I felt kindness respect and caring!
- I was treated very well. Cancer in remission. Thanks.
- I was very satisfied with the procedure and PSA has remained at either 0.1 since procedure
- I would like to thank all the staff. They were very supportive with me. They had a lot of compassion with me, even the one that didn't know Spanish. Thank you.
- Rehab at St. Joseph's was outstanding as were the folks giving the radiation treatments.
- I'm very grateful that these services exist. This is a very scary illness to deal with.
- Keep up the good work. Dealing with Dr. Wong and all his staff including his cancer tech was a rewarding experience. The chief of parking service - outstanding - should be commended also.
- My PLTC support group is a wealth of information, compassion, and hope.
- Nurse practitioners are quick to meet needs and address them - they have been a life line
- Oncology group is very supportive, kind, treat patients like family, never impatient - can call them any time of day or night
- Our doctor is taking very good care of us here. We are very happy with our services here.
- Service has been phenomenal. Doctors and staff very informative; honest, either good or bad
- She is lucky that she is with UNM CRTCC
- Techniques have improved substantially in 20 years. I am most indebted to the wonderful professionals and volunteers who helped me.
- Thanks for asking
- Thanks for the assistance toward recovery

- Thanks for the survey!
- Thanks so far
- Thanks!
- The doctors, nurses, hospital staff were all wonderful. I was blessed that they were here for me.
- The entire staff are wonderful people, can't even think of any complaint
- The people and doctors at this center have all been wonderful. They have put my faith back in the medical field.
- This cancer center has been terrific. I don't see any problems. The doctors, nurses, etc. are top notch and I feel safe and secure here.
- University Cancer Center - very supportive and loving
- UNM Cancer Center was very professional and I don't have anything bad to say about the Cancer Center
- Very satisfied with treatment I received at Loma Linda hospital in California. Proton radiation. Would recommend to everyone. So pinpoint they can do a brain tumor or a bleeding eye.

Areas for Improvement

- 1) Surgeon - no follow up - cause of infection after surgery. 2) Had port - very little explanation of placing in or removing - very painful. 3) Rad. oncologist left patients
- A misdiagnosis in Albuquerque cost time and agony - had to go to Mayo in Scottsdale to receive correct diagnosis
- Also, people need to know the different testing that can be given, especially blood testing
- Although this is not only cancer-related, I was appalled at the lack of sensitivity, care, and common sense in patient interaction that I experienced during by hospital stay. Thank heavens I had a great doctor!
- Doctors should explain alternative methods of treatment before surgery. Patients need to take an active role
- Dr's seemed overworked
- Early detection is important
- Enhance education and support groups
- Fear that assistances won't be available
- For doctors to be honest when a person gets cancer to say if they are getting better or if not to better prepare for the worst
- I am a student, therefore difficulty for time management. What steps, if any, could be taken for allowable in-home/dormitory assistance for time constraints due to class time and duration of treatment?
- I am BRCA positive - I would like to have the very latest information available on latest research.
- I have to be very patient and wait sometimes for hours
- I opted for mastectomy/chemotherapy. I would have found it very helpful if the surgeon or my primary care provider had suggested contact with PLTC or a similar group at the time of diagnosis
- I realize it may be an unrealistic suggestion, but regular transportation to support group meetings would have been welcome. I do not drive. Transportation for medical needs is excellent.
- I wish I knew about the NM prostate group before having any treatment done. A very good and information organization, especially Lyle Ware
- I would say the doctors were slow in their diagnosis. In the main in-hospital care varied depending on who was on the shift. The surgeon seemed so clinical and impersonal. We were disappointed in oncologist who didn't seem interested in my husband's illness.
- If there was a way for post-surgery patients who live alone to have help with meals. I had help from friends.
- Instead of wasting money doing surveys you should be doing something like helping people pay for the exorbitant costs of cancer treatment
- Insufficient information and treatment facilities in New Mexico
- Is there anyone that can provide financial help?
- It was extremely important to me to obtain treatment from the best doctor I could locate who not only specialized in the procedure I decided to have but also had an excellent "track record" in that procedure. It was like "pulling teeth" to obtain this type of information in New Mexico.
- Let the patient and family know what to expect with each phase of the disease, complications of medications, etc.
- More support services for elderly and cancer patients
- My physician was so clinical he came across as cold and cruel. There should be educational programs for doctors so they understand the importance of empathy
- Need more nurses in chemo suite and lab, at times
- Oncologists who were aware of the importance of alternative medicine i.e., massage, acupuncture, and who supported and recommended this along with Western medicine.

- Overall I think the services provided are outstanding, however, more could be done "up front" to give practical advice on day-to-day struggles and how a friend or family member can best support the patient, both physically, psychologically, and emotionally
- People need more answers. My aunt had a PhD from John Hopkins and didn't understand treatments at all. Also people need to understand the genetic branch of cancer
- Telephone # for patients to call is a bad idea - couldn't reach anyone. Call returned four days later - was admitted to hospital by then.
- There are no services in Otero County to help cancer patients. I have received more help from UNM.
- They (dr.) told us she had lung cancer but never did tell us if she had bone cancer. They never told us or talked to us about how long she might live. It felt we needed to know.
- Through a personal contact I was able to find out who did "LOTS" of prostatectomies in Albuquerque. This is probably the most important factor in selecting a surgeon. It should be available before selecting a surgeon.
- Use much more care with the patient. She was poked many times by nurses who were trying to find her vein.
- We were provided with very good information on brain cancer at MD Anderson. However, our own diagnosing doctor in Albuquerque provided no information at all nor did he provide any compassion. He did however share with us how overworked he was
- Would like help in starting a support group in the Lake Arthur - Hagerman - Dexter area
- Would like medical community to provide info on non-medical services (nutrition, for example)

General Comments

- A lot has to do with the patient and family reaching out to the community - but that is so difficult if the patient doesn't want to do so. Cancer is a very isolating disease. Cancer patients have no control over the illness and do rely on support.
- Doing fine. I was at surgery, went very well. Went to one chemo session - went as well as expected.
- God and his son Jesus Christ, bless all the organizers that help cancer patients who have this disease or have suffered from this disease in the past
- Found early, taken care of early
- Helpful (1) being an MD; (2) Reservist Army and served in WWII, Korean conflict and Vietnam. Retired in 1982
- I am a physician so I had somewhat of an advantage in knowing options, accessing resources, researching treatments, etc.
- I had an annual physical for over 40 years. My PSA was elevated in 2000. After much study and research, went to Scottsdale, AZ - Dr. Gordon Grado - had brachtherapy - seed implant - outpatient - remarkable results. PSA as of Aug. 2003 is 0.1
- I had my surgery and treatment in Stuart, FL. Some of these I can not answer
- I have learned that a patient needs to become an active part of the healing process and not rely solely on the medical profession for treatment.
- It's very scary when you find out you have cancer. I wanted to go out and hide but my family gave me a lot of support
- Support is important! Sure was for me