Southwest Riverside County
Cancer Care Needs Assessment

by

HARC
HEALTH ASSESSMENT AND RESEARCH FOR COMMUNITIES

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for
Southwest Riverside County
Cancer Care Task Force

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About This Report

This report was created by HARC, Inc. (Health Assessment and Research for Communities), a nonprofit research organization, for the Southwest Riverside County Cancer Care Task Force. The content was written by two HARC staff members, Dr. Jenna LeComte-Hinely and Chris Morin.

If you have any questions or concerns about the report, please contact Dr. Jenna LeComte-Hinely, HARC's CEO, at jlecomte-hinely@HARCdata.org.

The Southwest Riverside County Cancer Care Task Force is made up of individuals representing the following entities:

- American Cancer Society
- City of Canyon Lake
- City of Lake Elsinore
- City of Menifee
- City of Murrieta
- City of Temecula
- City of Wildomar
- Inland Empire Health Plan (IEHP)
- Loma Linda University Medical Center
- Menifee Valley Medical Center
- Michelle's Place
- Riverside County
- Riverside University Health System, Public Health
- Scripps Health
- Temecula Valley Hospital
- UC Riverside School of Medicine
- UC San Diego Health

Additionally, the following local medical doctors were also active members of the Task Force:

- Dr. Amy Bremner
- Dr. Arun Kalra
- Dr. David Horner
- Dr. Evelyn Mendoza
- Dr. Julie Schwenka
- Dr. Mark Spicer
- Dr. Richard Chinook

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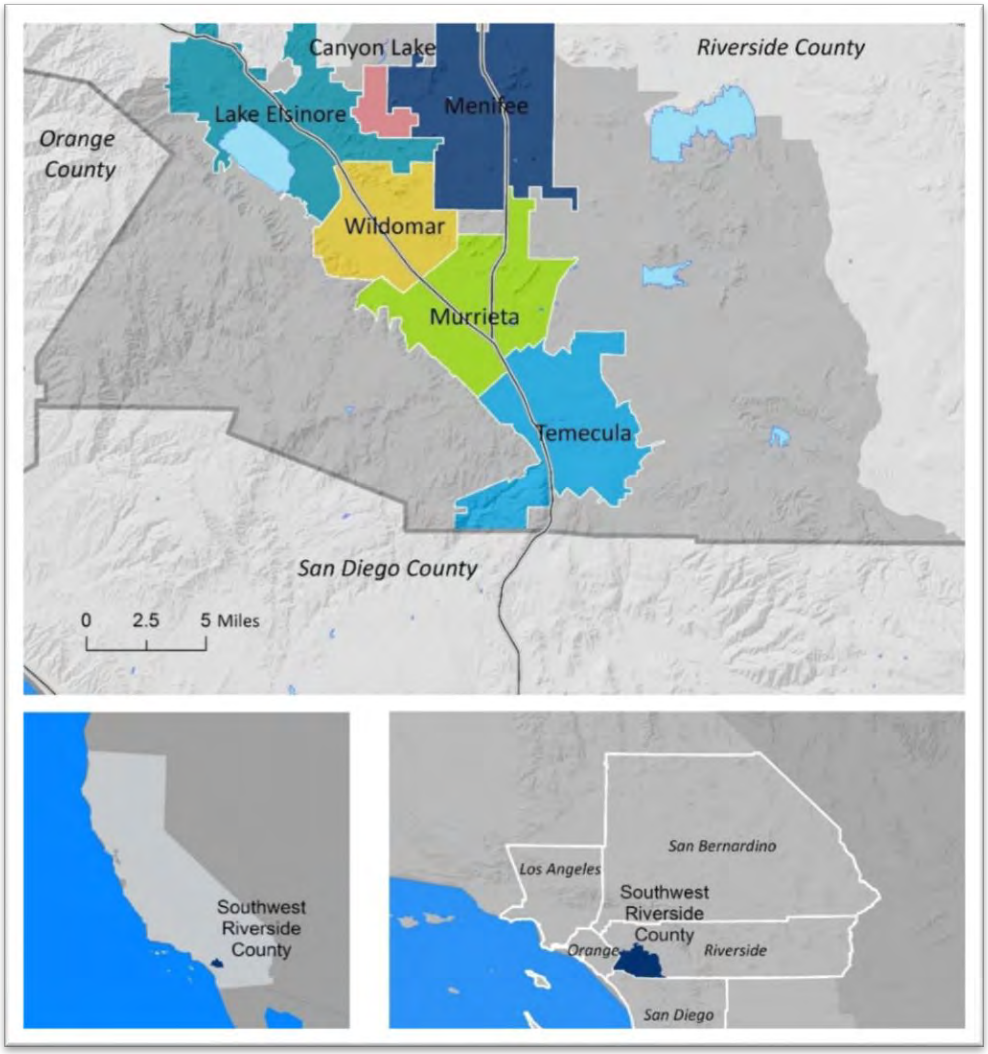
- City of Lake Elsinore
- City of Menifee
- City of Murrieta
- City of Temecula
- County of Riverside
- Inland Empire Health Plan (IEHP)

Thank you to all of the Task Force members who helped to distribute the survey. Thank you also to Paul Bandong, Vice President of Sales and Marketing for So Cal News and Marketing, Reeder Media group, for helping us publicize the survey and recruit participants.

Finally, thank you to all the participants who took the survey—your input is invaluable, and none of this work could be done without you.



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EXECUTIVE SUMMARY

Introduction

The Regional Cancer Treatment Task Force was created in November 2016 to assess the state of cancer-related services and treatment options in Southwest Riverside County and to develop a plan that promotes existing cancer care services and attracts additional services and resources to the area. The objective is to reduce the need for the region's cancer patients to travel to Orange, Los Angeles, or San Diego Counties for cancer treatment. The ultimate goal of the Task Force is to ease the burden of those suffering from cancer in the region by promoting comprehensive treatment options, resources, and support services closer to home.

In April 2017, the Task Force hired HARC, Inc. (Health Assessment and Research for Communities), a nonprofit research organization, to conduct a community health needs assessment. This report summarizes the findings of that needs assessment.

Methods

Working with a subcommittee of Task Force members, HARC designed a survey for cancer patients/survivors and their caregivers, and a second survey for healthcare providers who work in cancer prevention or treatment. Participant recruitment was conducted via Task Force partners, newspaper ads, and Facebook ads. This resulted in collecting 533 valid participants for the cancer/survivor and caregiver survey (385 patients/survivors, 148 caregivers) and 44 healthcare providers for the healthcare provider survey.

Patient/Survivor Results

Demographics

Most patients/survivors were female (74.9%), white/Caucasian (88.3%), and in their 50s or beyond (82.7%), with an average age of 60. Patients/survivors were also well-educated with only 9.4% having high school education levels or lower. The median household annual income was $79,000. The majority are from Temecula (38.6%) or Murrieta (22.9%).

Cancer Diagnosis

Most patients were diagnosed one to five years ago (40.6%). The three most common cancer diagnoses reported include breast (44.9%), skin (14.3%), and prostate (8.8%). About half of patients (49.1%) went to see a provider within a month of thinking something was wrong. For most people, the time from that first visit to the actual cancer diagnosis was less than two months. About a quarter of cancer patients/survivors (25.3%) were misdiagnosed on their first visit. After diagnosis, about a third (31.6%) took more than two weeks to see a specialist. This was usually due to appointment availability/scheduling conflicts.

Cancer Treatment

A quarter of patients (24.4%) are currently receiving cancer treatment, while 68.8% have completed their treatment. Nearly all (98.0%) have health insurance, however 8.5% have been denied health insurance at some point due to their cancer. The most important factor in selecting a course of treatment was trust that the treatment would be effective. Only 6.2% of participating patients/survivors participated in a clinical trial as part of their treatment. About 19.6% sought out complementary/alternative medical (CAM) treatment.

Geographic Cancer Treatment

In Southwest Riverside County, most patients went to Hematology Oncology Consultants, Breastlink, or Kaiser Permanente. Elsewhere in Riverside county, again, mostly included Kaiser Permanente facilities (e.g., Kaiser Riverside or Kaiser Moreno Valley). Those who left the county for treatment typically went to Loma Linda Medical Center or UC San Diego. About a quarter of patients/survivors (25.6%) traveled 50 or more miles to get to their treatment. Most drive themselves to treatment, or have family and friends drive them. The #1 reason for choosing treatment at that particular facility was because their insurance would cover it (44.2%).

Issues/Problems/Areas for Improvement

Household chores were the most commonly needed type of assistance; 37.3% of patients/survivors needed help with this, and many did not get assistance. The top three unmet needs for assistance included household chores, financial assistance, and utility assistance. The top three cancer care issues included a lack of accredited cancer centers (42.1%), lack of specialized care (33.2%), and the high cost of treatment (32.7%). Patients would like help with finding advice about community resources (32.2%), paying for treatment (24.2%), and applying for benefits (23.9%). Very challenging and common problems experienced by patients included worries about family (42.6%), side effects of the treatment (39.7%), uncertainty about the future (38.3%), and their emotional state (37.2%).

Support Systems

Most patients (61.6%) get all the help they need from family/friends at home. However, 22.2% need additional assistance. In terms of help from organizations, the most commonly cited source of support was Michelle’s Place (28.6%) followed by the American Cancer Society (12.5%). Common types of support received included support groups/group therapy (9.1%) and counseling/individual therapy (8.8%), but overall relatively few patients/survivors accessed these sources of support. .

Media/Distribution

For future dissemination of information, patients are best reached by emails (31.0%) or printed materials sent to their homes (20.1%).

Caregiver Results

Demographics

Most caregivers were female (77.3%), white/Caucasian (82.6%), and in their 40s (27.6%) or 50s (26.8%) with an average age of 51. Caregivers were also well-educated with only 6.3% having high school education levels or lower. The median household annual income was $95,000. The majority are from Temecula (49.2%) or Murrieta (26.6%).

Caregiving Relationship

Caregivers typically cared for one patient (86.8%), and care was usually being delivered to a spouse/significant other (34.9%) or parent (33.1%). Most participating caregivers were either the only caregiver for the patient (24.0%) or the main caregiver (34.7%). Three-quarters of these patients (75.0%) had no paid caregivers, relying entirely on volunteers to support them. Most caregivers (53.6%) provided care for one year or less. Only 16.6% are still caring for a patient.

About the Patient

Caregivers reported that their patients typically had breast cancer (24.0%) or lung/bronchus cancer (15.4%), and were diagnosed in the fourth stage of cancer (38.6%).

Caregiver Responsibilities

The greatest responsibility for caregivers was emotional support and encouragement (92.6%), followed by going to doctor appointments (84.0%), chores around the home (77.1%), and transportation (75.4%). Over three-quarters (79.2%) did not prepare for their role as a caregiver. Only 8.4% of caregivers accessed caregiver resources, but an additional 41.6% would've been interested. The #1 thing that unpaid caregivers would've liked help with was information about additional resources they may have been able to get like transportation programs or meal assistance; 54.3% wanted this type of help.

Issues/Problems/Areas for Improvement

The top three reported major local cancer care issues include a lack of cancer centers (53.7%), lack of specialized care (52.0%), and the high cost of treatment (43.4%). These are the same top three identified by cancer patients/survivors. Services that would have been beneficial for patients include help with understanding diagnosis and treatment options (45.7%), advice about community resources (43.4%), and help in applying for any benefits (39.4%).

Healthcare Provider Results

Demographics

Providers included nurses (50.0%), patient care coordinators (9.1%), and physicians (4.5%). A fair amount of "other" (36.4%) providers were listed and included positions such as hospital staff, technicians, etc.

Cancer Care Continuum

More than half are involved in treatment (68.2%), post-cancer treatment (59.1%), and diagnosis (54.5%) of patients with cancer. The majority of providers practice in Murrieta (47.7%).

Quality/Availability of Care

In regard to quality of care, 15.9% gave excellent ratings and another 31.8% gave very good ratings. However, a several gave less than desirable ratings; average (15.9%), fair (9.1%), and poor (9.1%). When asked about the availability of care, most provided an average rating (39.5%), followed by either below average (20.9%) or very good (20.9%).

Common Problems for Patients

Providers reported that common screening problems include access to screening and a lack of knowledge in what to do. Common problems for diagnoses include delays in getting results. Treatment problems include authorization and insurance problems. Common post-cancer care problems included a lack of support and a lack of patient compliance.

Services and Support

Most providers provide services related to obtaining pre-authorization for diagnostic studies (84.8%), coordinating insurance (81.8%), applying for SSI/SDI or other benefits (75.8%), and applying for public medical assistance (69.7%). The most common support programs include having a library of materials for cancer patients (69.4%) and dietician/nutritional services (51.4%). Providers that do not have support programs of their own refer out to other programs, such as Michelle's Place.

Issues with Beginning Care

Providers were asked if they had any issues beginning care locally for their patients. In response, 34.3% said they had no issues, while 65.7% had one or more issues. Most common problems included distance to and from treatment location (56.5%) and lacking enough cancer specialists (47.8%). A total of 86.5% of providers have referred their patients outside of the area, usually due to the availability of clinical trials (68.8%), more therapeutic options (46.9%), or a rare type of cancer (46.9%). Patients typically seek care outside of the area due to surgery (38.6%), pediatric cancer services (29.5%), and targeted therapy (27.3%).

Issues with Treatment

The #1 issue that providers identified as interfering with patients' cancer treatment was lack of financial resources, followed by accessibility/transportation issues. The most common difficult service for providers to set up included setting up transportation and home healthcare and/or caregiving.

Conclusion

The report ends with several recommendations for next steps based on these findings. Recommendations include local hospitals forming cancer care centers and seeking accreditation; bringing more clinical trial opportunities to the region; working to attract, retain, and grow our own providers; communicating available resources to the community at large; developing a foundation to defray patient costs; and providing some additional sources of support.

INTRODUCTION

Today, cancer is the second-leading cause of death in America. Treatment can be expensive, time-consuming, exhausting, and can have serious side effects. Thus, the burden on cancer patients and their loved ones is substantial.

To address this locally, in November of 2016 the Southwest Riverside County Regional Cancer Treatment Task Force was created to assess the state of cancer-related services and treatment options in Southwest Riverside County, California.

The Task Force is comprised of representatives from a number of jurisdictions and organizations, including the American Cancer Society, City of Canyon Lake, City of Lake Elsinore, City of Menifee, City of Murrieta, City of Temecula, City of Wildomar, Inland Empire Health Plan (IEHP), Loma Linda University Medical Center, Menifee Valley Medical Center, Michelle's Place, Riverside County, Riverside University Health System, Public Health, Scripps Health, Temecula Valley Hospital, UC Riverside School of Medicine, UC San Diego Health and local healthcare providers.

The Task Force's mission is to ease the burden of those suffering from cancer in our region by promoting comprehensive treatment options, resources, and support services closer to home. Specifically, the Task Force strives to:

- Identify and promote existing cancer care resources within the region
- Identify and address any barriers to accessing those existing resources
- Identify and address any gaps in resources, including: the pipeline of care facilities and providers, prevention, diagnosis, treatment, and post-treatment.
- Create a plan to promote, foster, and maintain desired cancer care resources within the region

In April 2017, HARC, Inc. (Health Assessment and Research for Communities) was hired to conduct a community needs assessment of the region in support of those goals. This report details the findings of cancer patients/survivors, caregivers of people with cancer, and healthcare providers.

METHODS

HARC worked with a subcommittee of the Task Force to develop two surveys: one for cancer patients, survivors, and/or caregivers of people with cancer (see Appendix A), and a second for healthcare professionals involved in the prevention and treatment of people with cancer (see Appendix B).

Articles about the Task Force and the data collection ran in Valley News on May 18[1], June 4[2], and September 7[3].

Newspaper ads were placed in the Riverside Press Enterprise (Sunday September 10, 2017) and in the Valley News on Friday September 8, 2017 and Friday September 15, 2017. See Appendix C for the advertisements. In addition to the print ads, Valley News also ran online ads.

HARC also ran several Facebook ad campaigns targeting people living in the Southwest Riverside County area. The reach (number of unique people who saw the ad at least once) of these efforts was nearly 9,000 people, as illustrated in Table 1.

Table 1. Participant Recruitment

Type	Survey	Link Clicks	Reach	Dates
Boosted post	Both	57	808	8/21 to 8/28
Ad	Provider	66	1,532	8/21 to 9/20
Ad	Patient/ Survivor/ Caregiver	144	2,550	8/21 to 9/20
Ad (targeting caregivers)	Patient/ Survivor/ Caregiver	27	658	8/28 to 9/20
Ad (targeting survivors)	Patient/ Survivor/ Caregiver	92	1,754	8/28 to 9/20
Ad (targeting healthcare providers)	Provider	95	1,618	8/28 to 9/20
Total		**481**	**8,920**	

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[1] http://myvalleynews.com/health/regional-cancer-services-task-force-moves-forward-hires-health-assessment-research-communities/

[2] http://myvalleynews.com/local/regional-cancer-task-force-releases-initial-data/

[3] http://myvalleynews.com/health/regional-cancer-task-force-aims-increase-accessibility-cancer-care-southwest-riverside-county/

RESULTS

A total of 689 people responded to the community survey. Those who did not live in Southwest Riverside County and those who were not either a cancer survivor or a caregiver for someone with cancer were removed, leaving a total of 533 valid participants.

In total, 385 cancer patients/survivors participated in the survey, and 148 caregivers participated in the survey. It is important to note that participants could qualify as both, and take both parts of the survey.

A total of 93 people responded to the healthcare provider survey. Those who did not treat patients in Southwest Riverside County were removed, leaving a total of 44 valid participants on the healthcare provider survey.

Results are separated into three sections here:

1. Cancer Patients/Survivors
2. Caregivers
3. Healthcare Providers

Cancer Patients and Survivors

Demographics of Cancer Patients/Survivors

The majority of the participating cancer patients/survivors were White/Caucasian (88.3%), as illustrated in Table 2. The second most common race was other (6.8%). Here, participants listed responses such as Hispanic, Latino, Mexican, and multi-race.

Table 2. Race

Type	Percentage
White/Caucasian	88.3%
Asian	4.2%
Black/African American	2.9%
American Indian/Alaska Native	1.2%
Native Hawaiian/Pacific Islander	1.0%
Other	6.8%

Note: *n* = 309.

Most of the cancer patients/survivors were not of Hispanic, Latino, or Spanish origin (86.1%), as illustrated in Table 3.

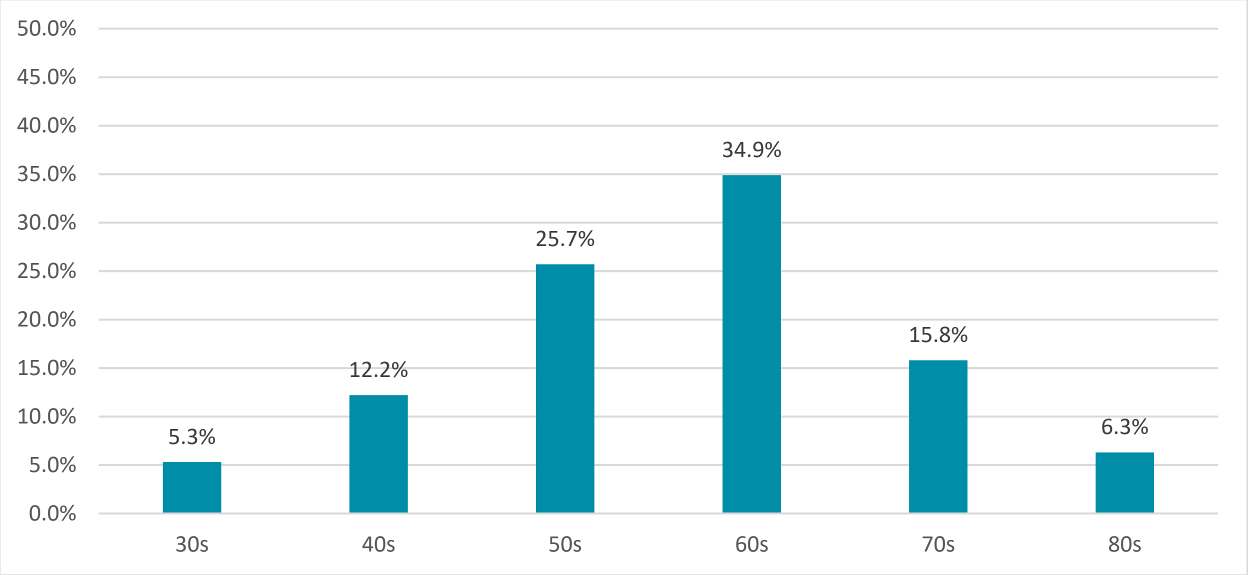
Table 3. Hispanic, Latino, Spanish Origin

Type	Percentage
Not Hispanic, Latino, or Spanish	90.1%
Yes, Mexican, Mexican American, Chicano	6.6%
Yes, another Hispanic, Latino, or Spanish origin	3.3%

Note: *n* = 303.

As illustrated in Figure 1, most of the participating cancer patients/survivors were in their 50s (25.7%) or 60s (34.9%). The average age of participating cancer patients/survivors was 60, with the youngest being 30 and the oldest being 89.

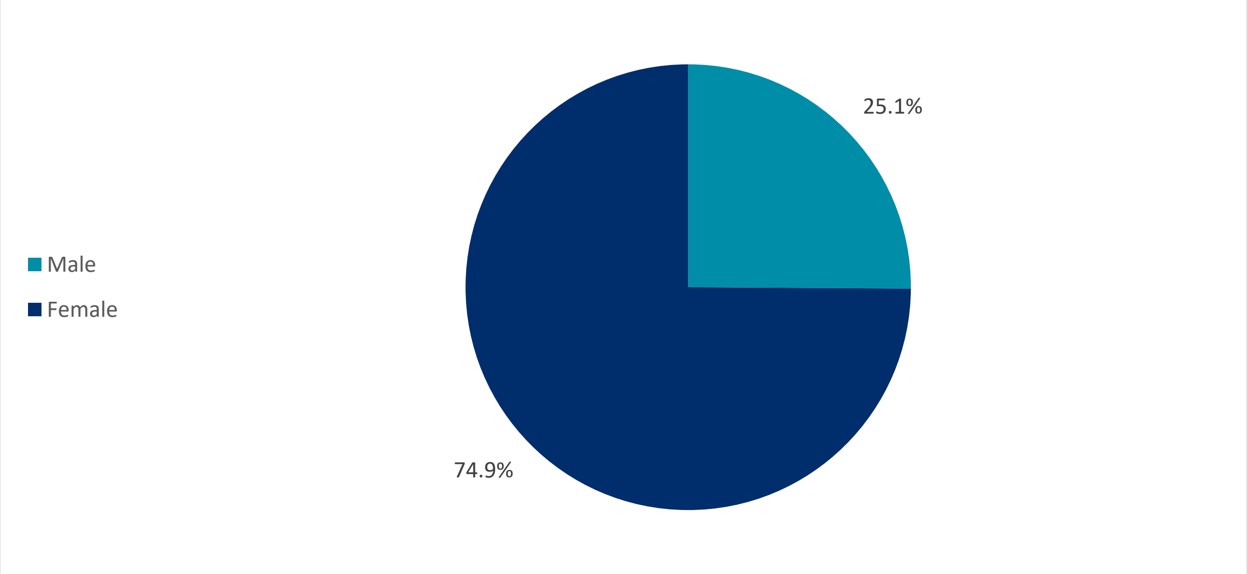
Figure 1. Age



Note: *n* = 304.

About three-quarter of participating cancer patients/survivors were female (74.9%), as illustrated in Figure 2.

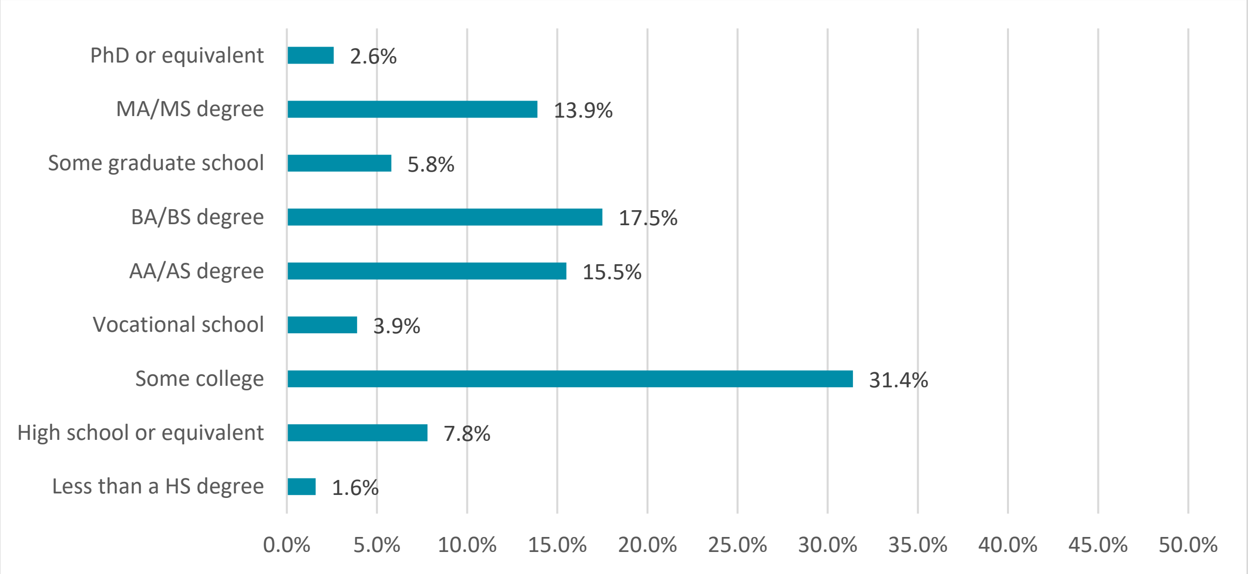
Figure 2. Gender



Note: *n* = 311.

Participating cancer patients/survivors were fairly well-educated; a little over half (54.4%) have some type of college degree, as illustrated in Figure 3.

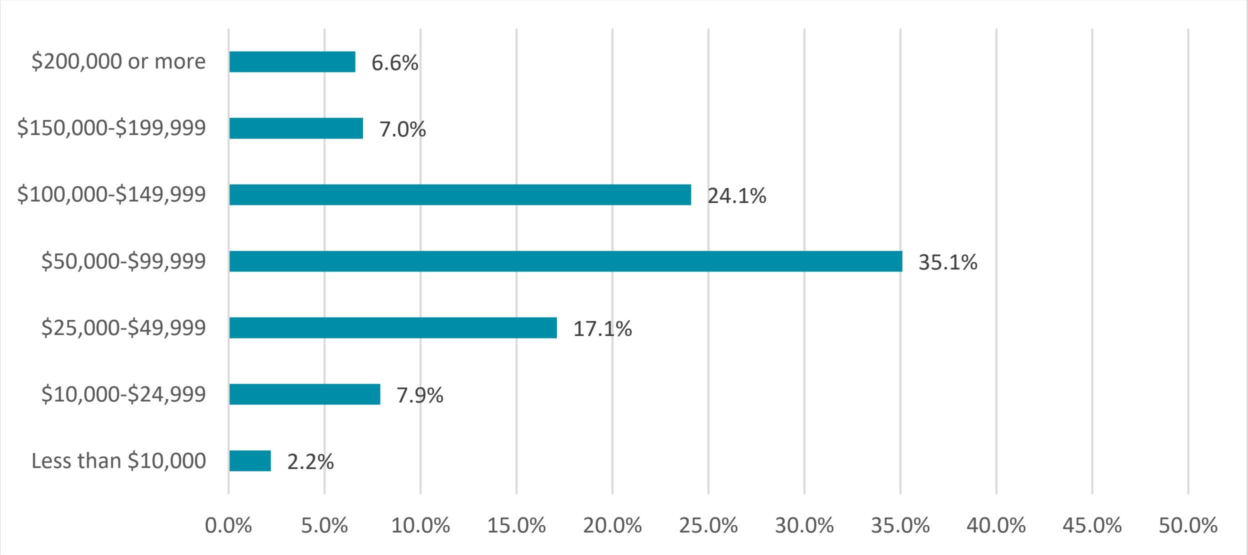
Figure 3. Education



Note: *n* = 309.

The median annual household income for participating cancer patients/survivors was $79,000. As illustrated in Figure 4, the income levels of participating cancer patients/survivors were relatively varied. About half of cancer patients/survivors fall between $50,000 and $150,000 per year.

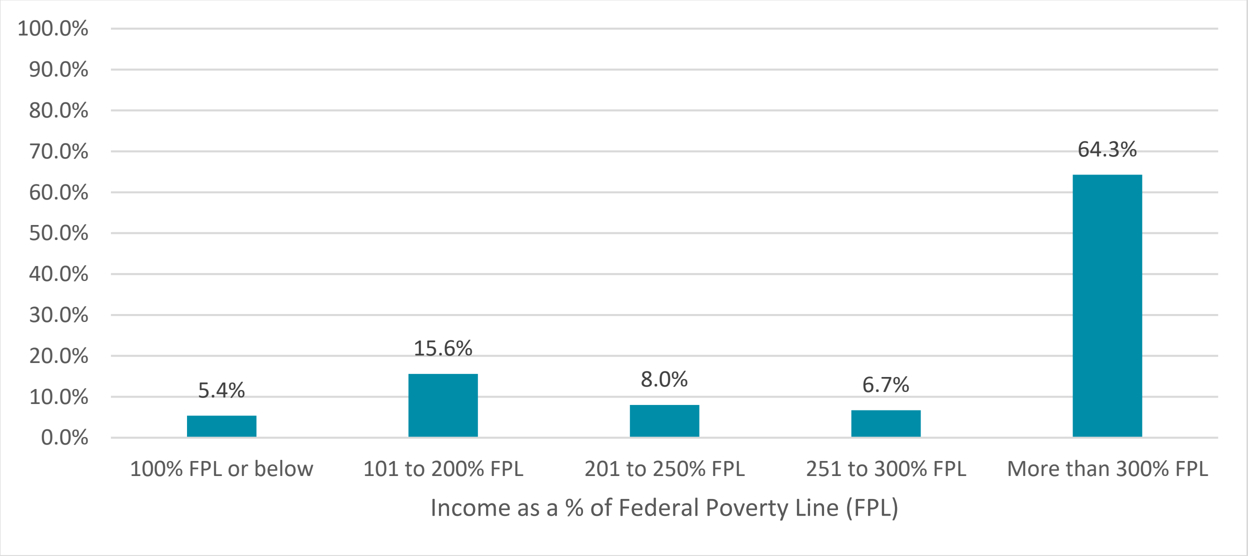
Figure 4. Household Income



Note: *n* = 228.

Participants were asked, “How many people live in your household in addition to yourself?” This information was used with the income information to calculate poverty using the federal poverty level guidelines. As illustrated in Figure 5, most participating cancer patients/survivors lived in households that fall above 300% of the federal poverty line.

Figure 5. Poverty Level

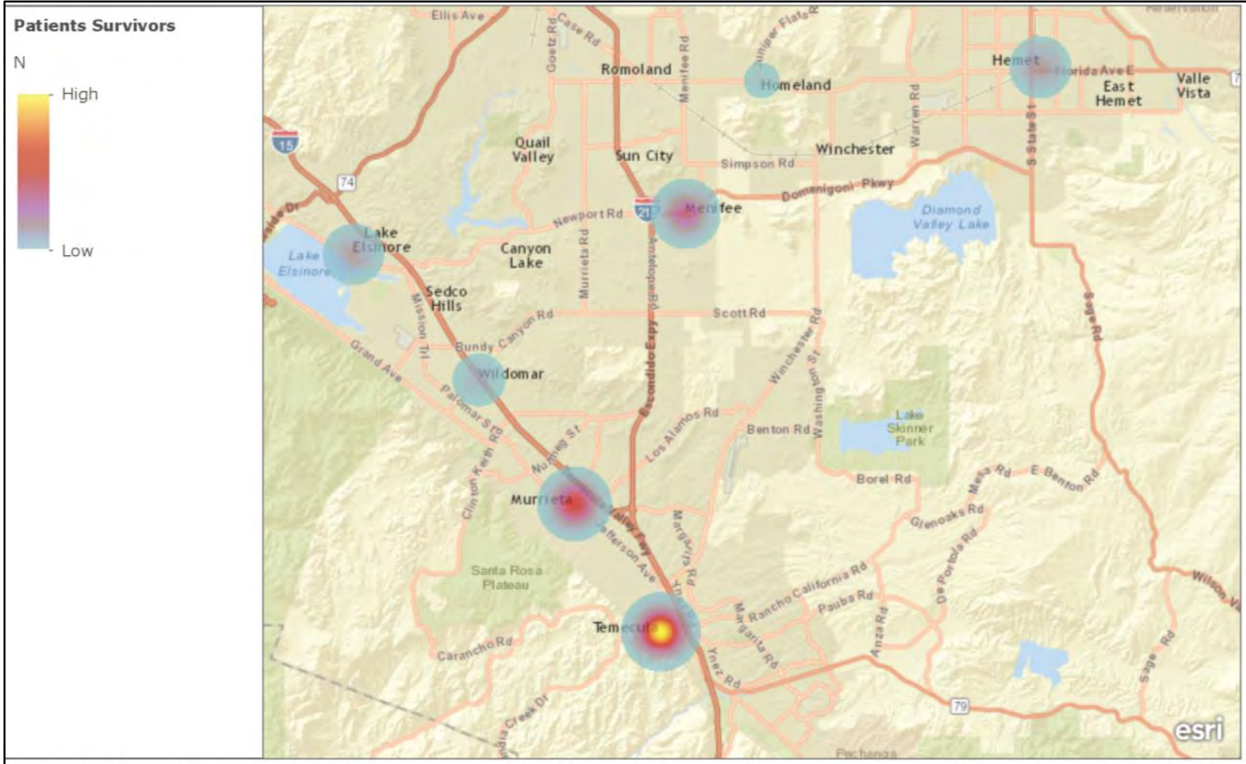


Note: *n* = 224.

As illustrated in Table 4, most participating cancer patients/survivors are from Temecula, Murrieta, and Menifee. The following cities had only one listing from each, and thus, are captured under "other cities": Anza, Mead Valley, Nuevo, San Jacinto.

Table 4. Location

Name of City	N	%
Temecula	118	38.6%
Murrieta	70	22.9%
Menifee	44	14.4%
Hemet	20	6.5%
Lake Elsinore	18	5.9%
Winchester	11	3.6%
Wildomar	9	2.9%
Canyon Lake	7	2.3%
Homeland	3	1.0%
Perris	2	0.7%
Other cities	4	1.3%
Total	**306**	**100.0%**



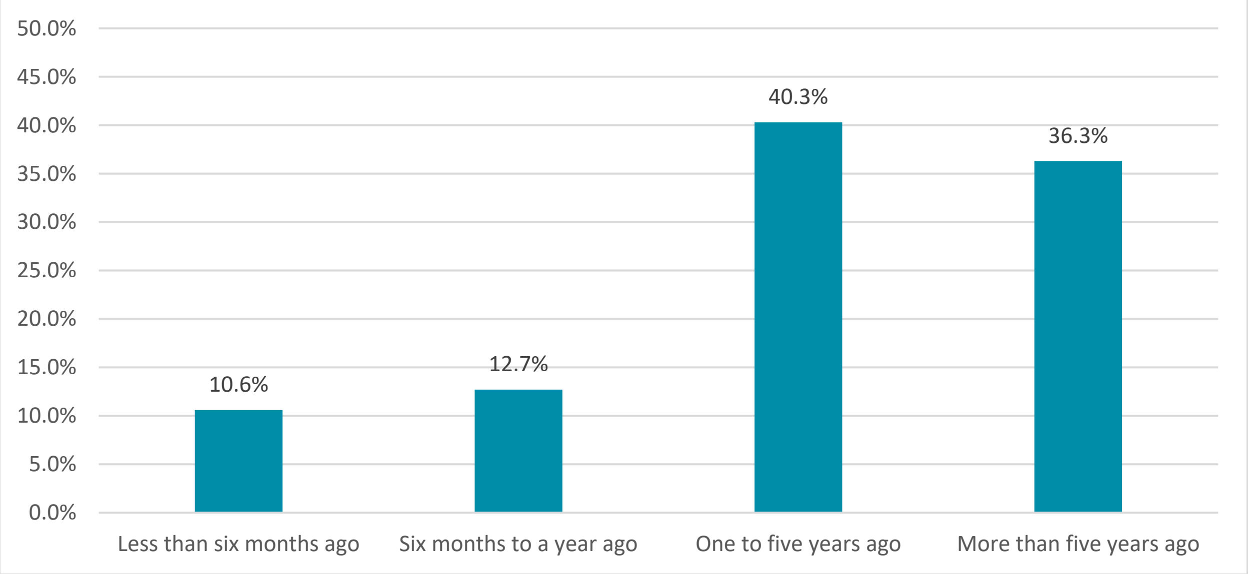
This map illustrates where cancer patients/survivors live who participated in HARC's community health needs assessment for cancer patients/survivors in Southwest Riverside County in 2017.

City of Riverside, County of Riverside, Bureau of Land Management, Esri, HERE, Garmin, NGA, USGS, NPS

Cancer Diagnosis

To assess how recent their experience was, participants were asked, "How long ago were you told you had cancer?" As illustrated in Figure 6, most participants are referencing a diagnosis that occurred within the past five years.

Figure 6. Time Since Cancer Diagnosis



Note: *n* = 377.

The most common type of cancer among patients/survivors was breast cancer (47.4%), as illustrated in Table 5. This may be because Michelle's Place, which primarily serves women with breast cancer, was a very active participant in the recruitment phase.

Table 5. Type of Cancer

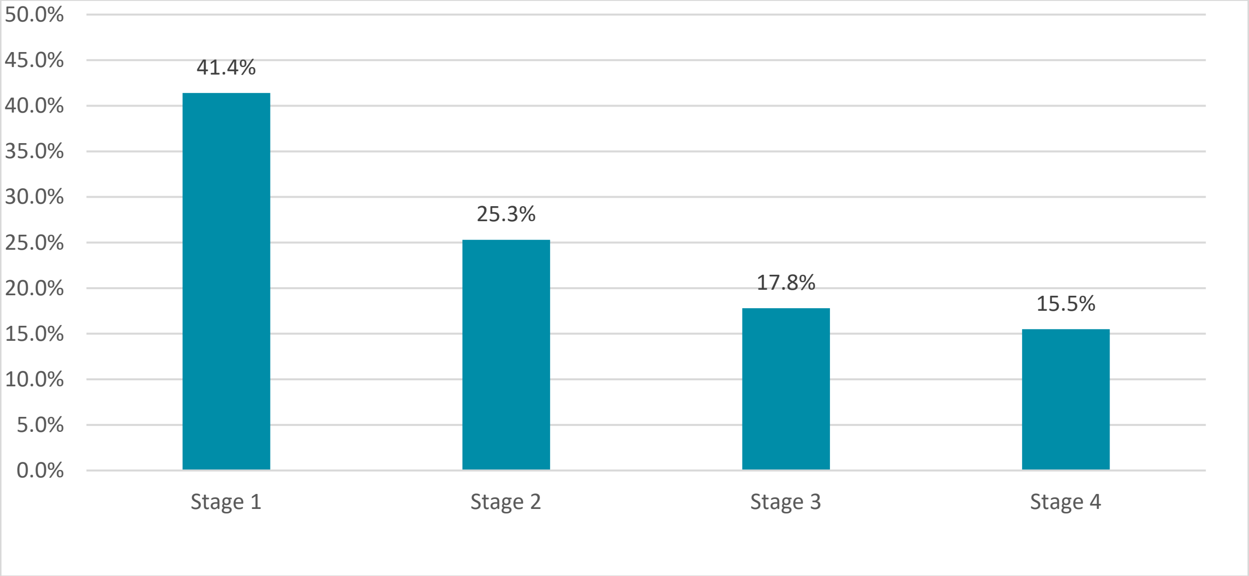
Type of Cancer	Percentage
Breast	44.9%
Skin	14.3%
Prostate	8.8%
Lymphoma	5.2%
Lung and bronchus	3.6%
Bladder	3.4%
Uterus	3.4%
Colon and rectum	2.9%
Leukemia	1.8%
Kidney and renal pelvis	1.0%
Other	24.6%

Note: *n* = 385.

Those who reported "other" most commonly listed cancers such as thyroid (*n* = 17), cervical (*n* = 11), ovarian (*n* = 8), melanoma (*n* = 8), myeloma (*n* = 6), and brain (*n* = 6). The remaining other listings included rarer cancers such as throat, tongue, blood, lymph nodes, liver, pancreas, testicular, spine, etc.

Most patients/survivors (41.4%) were initially diagnosed during stage 1 or stage 2 (25.3%), as illustrated in Figure 7. Relatively few were diagnosed in the late stages.

Figure 7. Stage of Cancer

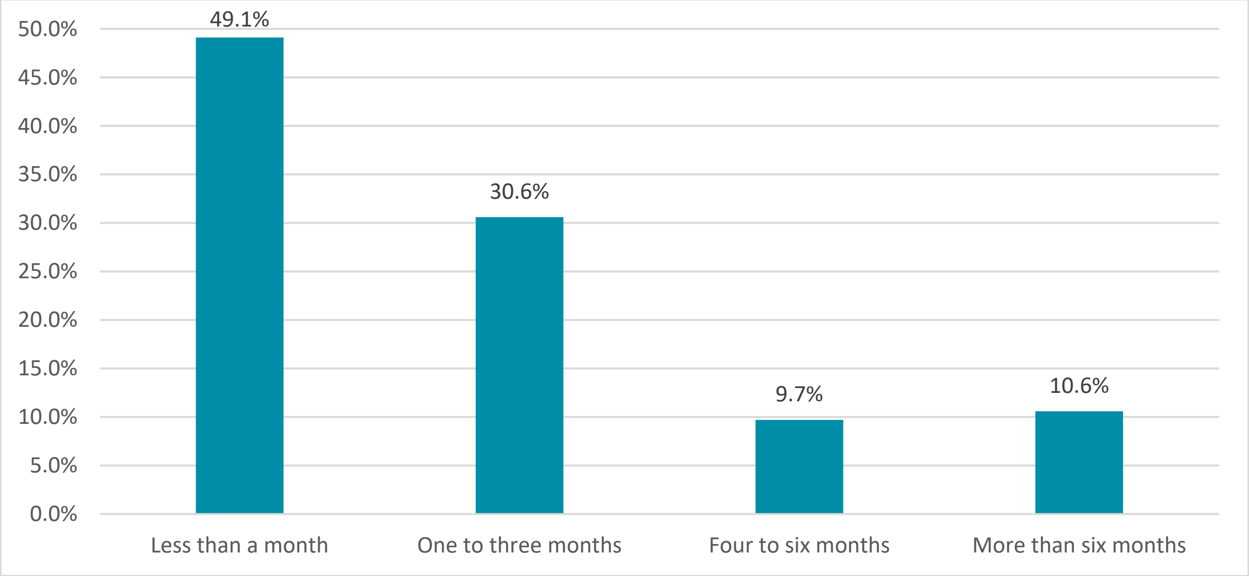


Note: *n* = 297. An additional 75 could not recall.

Patients/survivors were asked, “How long was it from the time you first thought something might be wrong with you until you saw a healthcare provider about it?”

About half of participating patients/survivors sought treatment within the first month, as can be seen in Figure 8. However, some patients took four to six months (9.7%) and more than six months (10.6%).

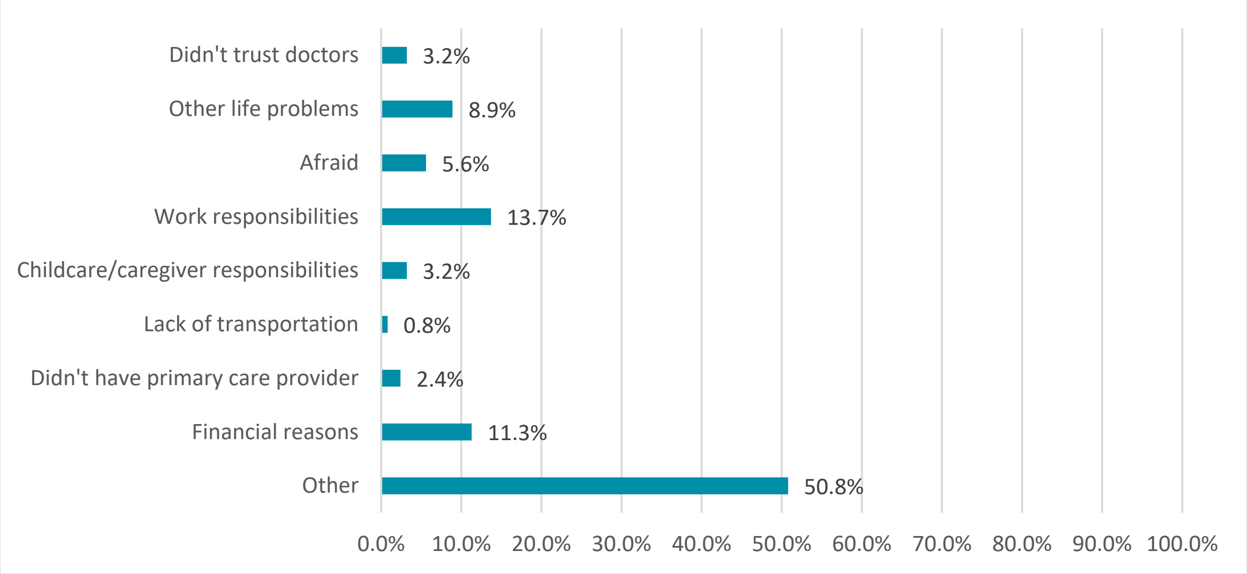
Figure 8. Time from Issue Noted to Care Sought



Note: *n* = 330. An additional 37 could not recall.

Patients/survivors were also asked, "If you delayed seeking care, why?" Most patients/survivors (*n* = 225) did not delay in seeking care. Of the 124 who did delay seeking care, common reasons included work responsibilities (13.7%), financial reasons such as lack of insurance or a high deductible (11.3%), and other life problems that were more important at the time (8.9%), as illustrated in Figure 9.

Figure 9. Reasons for Delaying Care



Note: *n* = 124.

"Other" reasons for delaying care are provided in Table 6. The most common reason for waiting to seek healthcare for the issue was thinking that the issue was not serious.

Table 6. Other Reasons for Delaying Care

Reason	Frequency
Didn't think it was something to worry about	22
Waiting for appointment/care/coverage	14
Mistakes by healthcare providers	10
Distance	3
Couldn't get care/no specialists	2
Other responsibilities	2

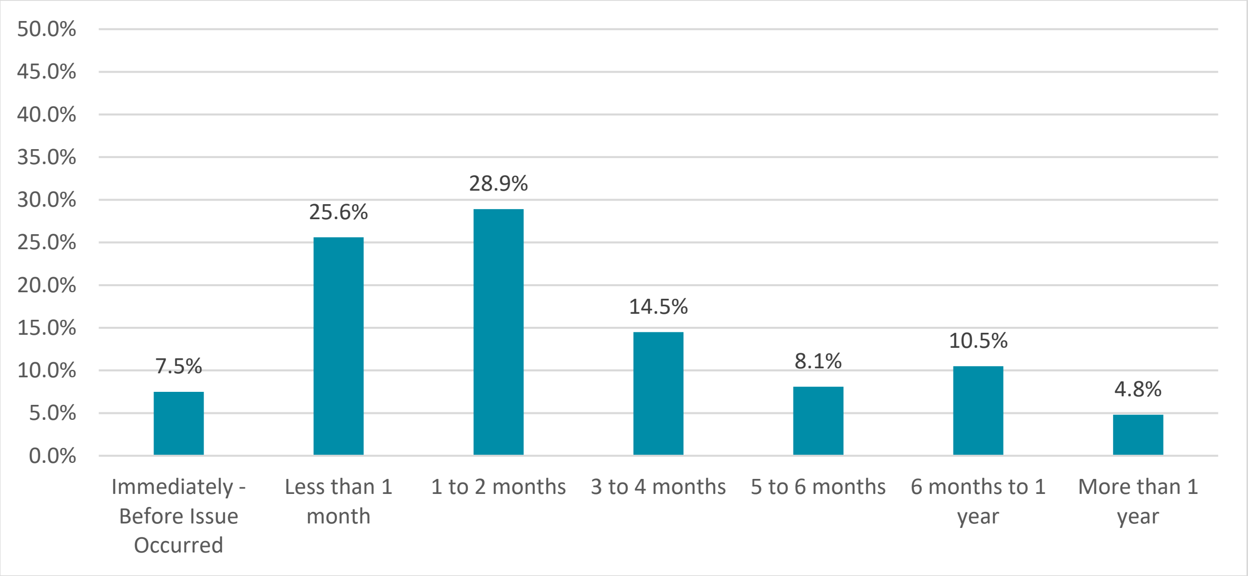
The following were also mentioned one time: bad choice in doctors, following doctor's instructions, and receiving other types of care at the time.

> *"I didn't think the small bump on my cheek was anything to worry about."*

Patients/survivors were asked to report the length of time from when they first thought something was wrong to when they were affirmatively diagnosed with cancer. Responses ranged from those who never thought anything was wrong ("I was diagnosed before I thought something might be wrong") all the way to one individual who went 26 years before being diagnosed.

The median amount of time was 42 days; meaning that most people were diagnosed about a month and a half after thinking something was wrong. As illustrated in Figure 10, about half of participants were diagnosed within 2 months of thinking something was wrong.

Figure 10. Time from Issue Noted to Cancer Diagnosis



Note: *n* = 325.

> *"I did not think anything was wrong. No symptoms. Cancer was found on my mammogram and then by biopsy."*

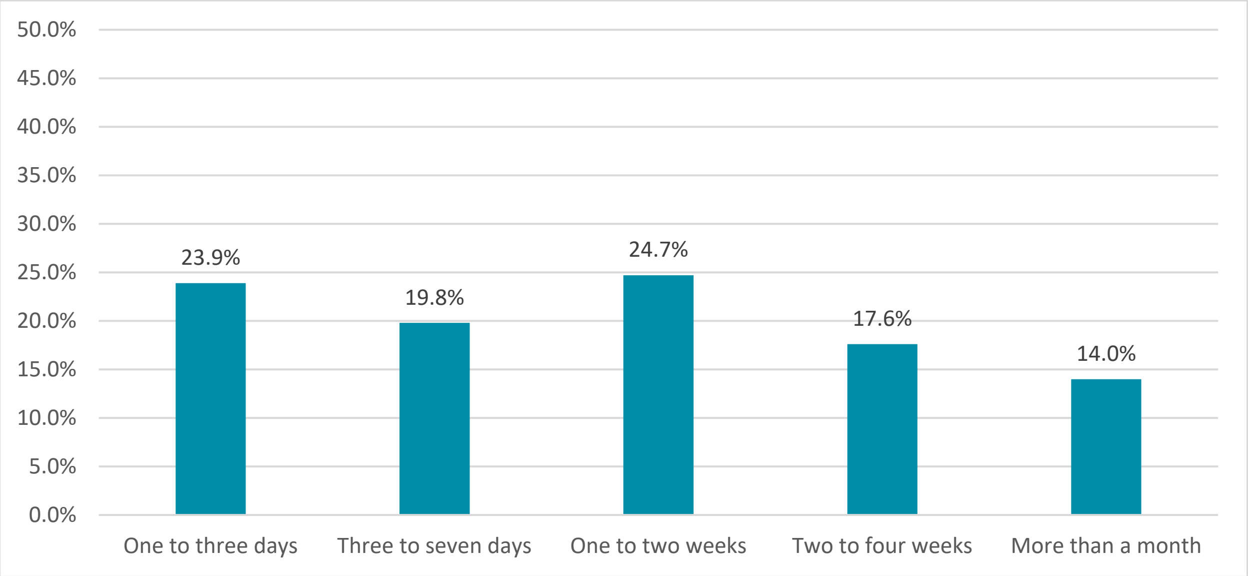
> *"4 long months from the time I sought care until I got a diagnosis."*

Participants were asked, “When you first went to the doctor for your issue, was it ever misdiagnosed?” Results indicate that 25.3% experienced a misdiagnosis, while 74.7% did not.

> *“[It took] 8 months [to be diagnosed because] I was misdiagnosed and then they lost the biopsy results”*

Following this, patients/survivors were asked, “How long did it take for you to see a cancer care specialist?” Results showed that most patients (68.4%) were able to see a cancer care specialist within two weeks of their diagnosis, as illustrated in Figure 11.

Figure 11. Time to See Cancer Care Specialist



Note: *n* = 364.

Patients/survivors were asked the following, “If seeing a specialist took longer than two weeks, why?” A total of 104 participants responded. The most common reason by far was due to issues with appointment availability and scheduling, as illustrated in Table 7.

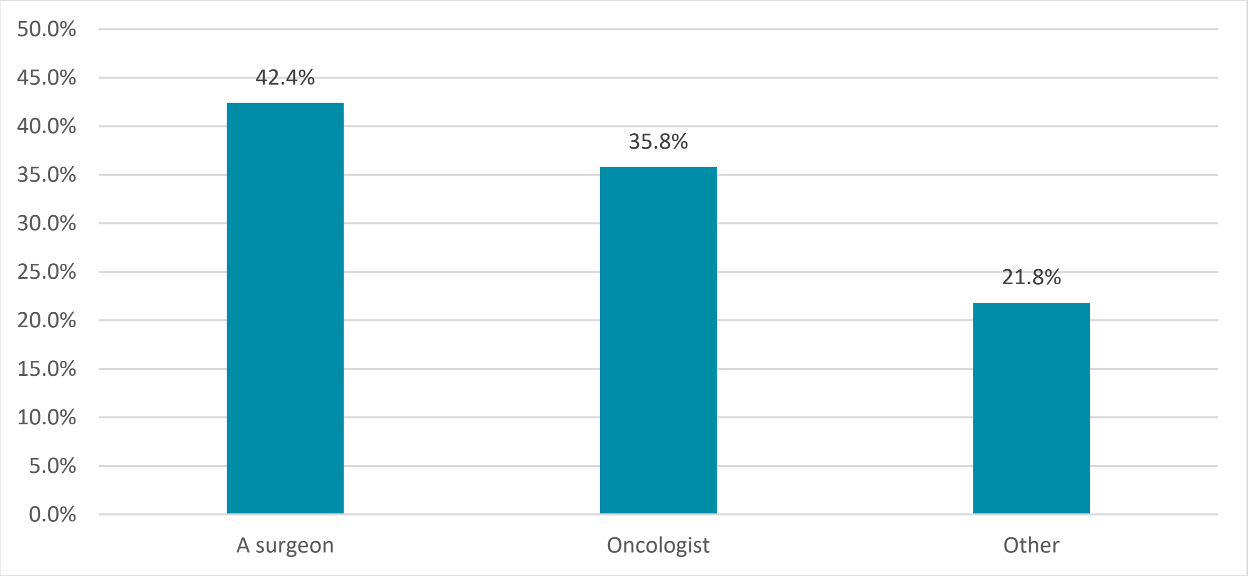
Table 7. Reasons for Seeing a Specialist Beyond Two Weeks

Reasons	Frequency
Appointment availability/scheduling	32
Referral	13
Lack of insurance/coverage	10
Additional testing/misdiagnosis	10
Delays in results/waiting for doctor	9
Limited specialist in area/finding doctor	9
Hesitation/scared/denial	5
Approval	3
Recovery time	3
Lost my results	3
Other life circumstances	2
Make sure right treatment/kept an eye on it	2

> *“They were booked. I called 3 days after prelim path report and first available appt w onc. was over 1 month out.”*

Patients/survivors were asked, “What type of specialists were you referred to?” About 42% were referred to a surgeon, while 36% were referred to an oncologist, as illustrated in Figure 12.

Figure 12. Type of Specialist Referral



Note: *n* = 363.

Of the 79 participants who specified what type of other provider they were referred to, the most common was a urologist, as illustrated in Table 8. The following also had one reference each: derma pathologist, obstetrician, epidemiologist, general practitioner, gynecology, gynecology oncologist, pulmonologist, radiation oncologist, and transplant specialist.

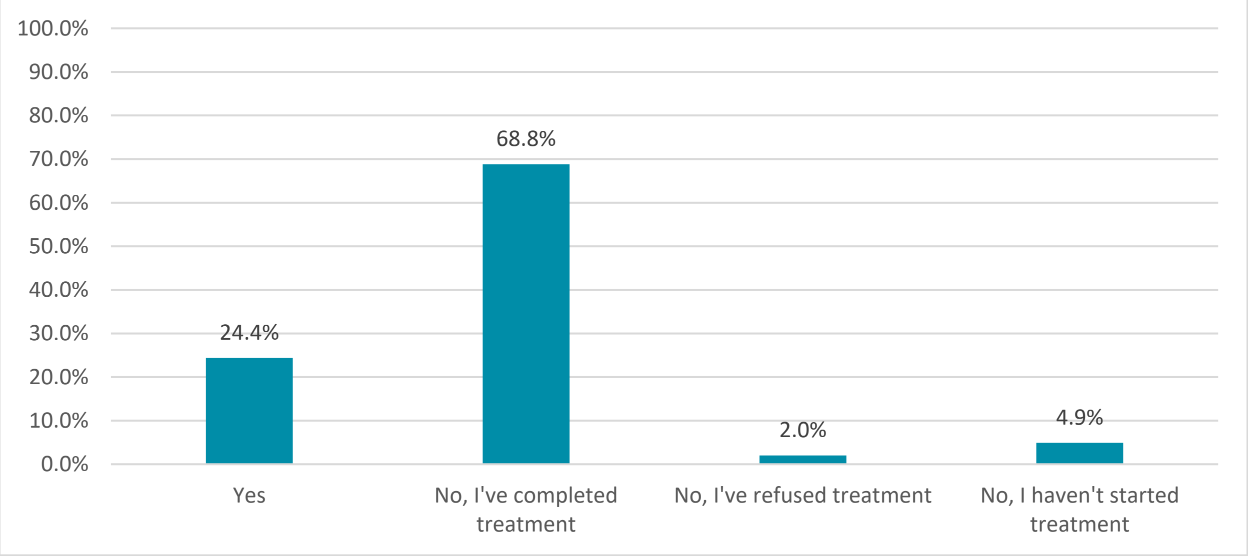
Table 8. Other Types of Specialists Referrals

Specialist	Frequency
Urologist	17
Both surgeon and oncologist	15
Dermatologist	12
Surgeon	8
Radiation	7
Oncologist	7
Plastic surgery specialist	7
Ear/nose/throat specialist	3
Hematology oncologist	3
Skin specialist	3

Cancer Treatment

As illustrated in Figure 13, a quarter of patients/survivors (24.4%) are currently receiving treatment for cancer. The majority, however, have already completed treatment (68.8%), while almost 5% have not yet begun their treatment.

Figure 13. Cancer Treatment Status

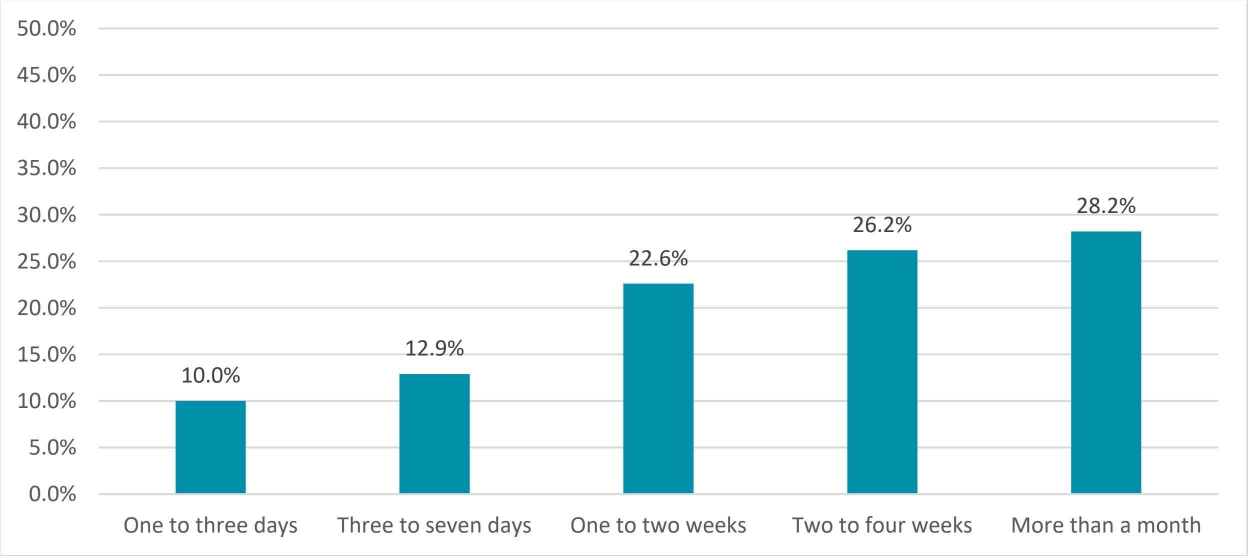


Note: *n* = 349.

Patients/survivors were asked, "After your first consultation with your cancer care specialist, how long did it take to begin your treatment?"

As illustrated in Figure 14, most patients (71.8%) began their treatment within one month of their first visit to a cancer specialist.

Figure 14. Length of Time to Begin Treatment



Note: *n* = 340.

Those who indicated that it took more than 2 weeks to begin treatment were asked to explain the delay. Responses fell into several general categories, as illustrated in Table 9.

One of the most common responses was that the issue was caused by lack of availability and scheduling issues. For example,

- "They told me it took that long to order the chemo made for me and that they did not have enough chairs for all the patients."
- "There is only one surgeon here so it took 3-4 weeks to schedule the surgery."

Many had to address other health issues—some cancer related, some relating to other issues—before they could commence treatment. For example,

- "Got pneumonia and was in ICU for a month and then pulmonary rehab for a month and to get better before full treatments could start."
- "I had other issues caused by the cancer, like compressed fractures in my spine."

Many had to wait for the results of their cancer-related tests, or to receive proper authorization to move forward. For example,

- "Scans needed to be performed that took a long time for results"
- "Waiting for insurance to approve chemotherapy treatment"

Some took the time to consider other treatment options or get second opinions. For example,

- "Discussing alternatives; consultation with complimentary doctor that is only in area 2x per month"
- "Researching alternative treatments"

Some chose to delay surgery due to other life circumstances. For example,

- "I had a vacation out of state planned that I wanted to do before I started chemo"
- "Had a charity function I needed to attend before surgery"

For some, the treatment was not yet necessary. For example,

- "It was not a rush, as the cancer was spreading slowly. I probably had 3 to 4 years before a decision would have been necessary."
- "Dr. said did not need to hurry so waited until after the holidays. Sept – Jan."

Table 9. Reason for Delaying Treatment

Reason	Frequency
Waiting for appointments and scheduling	51
Waiting for to heal and/or for after surgery	34
Waiting for tests, results, and/or authorizations	39
Choosing treatment options	14
Other life circumstances	13
Treatment wasn't needed yet	12
My own decision	6

Note: $n = 170$.

Patients/survivors were asked, “What sources of information did you use to decide what cancer treatment to select?” Participants could rate factors level of importance, or indicate “not applicable” if the person/source of recommendations was not relevant to them.

As illustrated in Figure 15 and Table 10, recommendations from oncologists were by far the most important source of information to consider when deciding on a course of treatment. Complementary and alternative medicine (CAM) professionals’ recommendations, along with those from friends and family, were the next most important sources of information.

Figure 15. Importance of Recommendations in Selection of Treatment

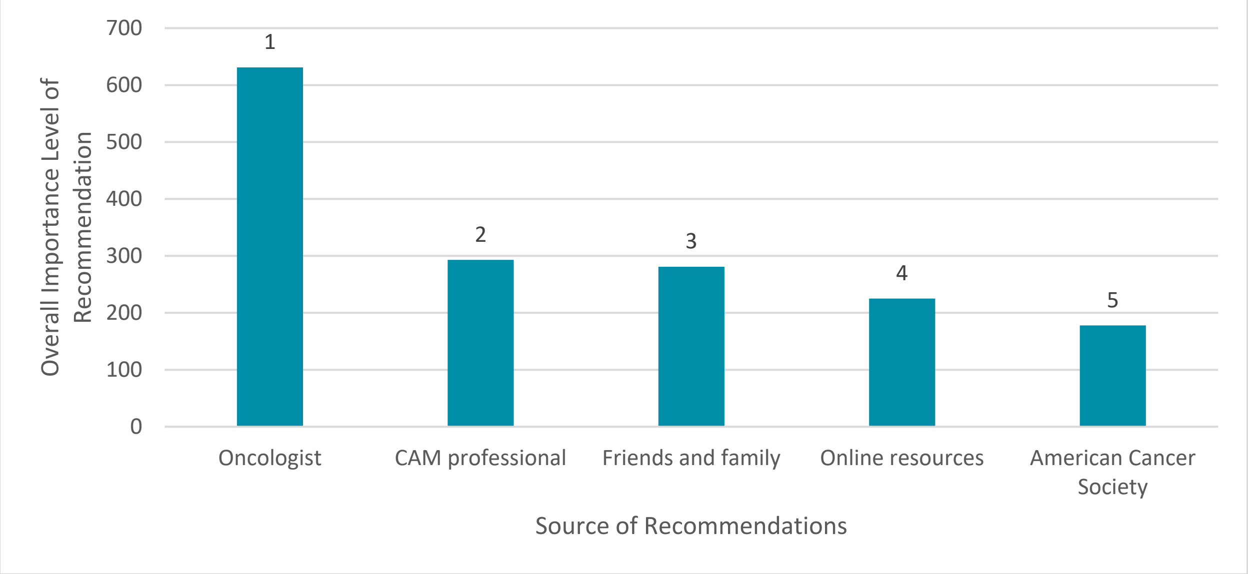


Table 10. Importance of Recommendations in Selection of Treatment

Source of Recommendations	**Level of Importance of Information from Source**				***n***
	Very Important	Somewhat Important	Not Very Important	Not at All Important	
Oncologist	90.4%	8.3%	1.0%	0.3%	303
CAM Professional	54.6%	26.4%	11.1%	7.9%	216
Friends and family	37.8%	35.0%	17.3%	9.8%	254
Online resources	24.5%	47.6%	19.3%	8.6%	233
American Cancer Society	25.6%	40.0%	20.5%	13.8%	195

Participating patients/survivors were asked, “What factors influenced your decision about which treatment to choose?” Participants could rate factors as most important, somewhat important, not at all important, or not applicable (if said factor was not relevant to them).

As illustrated in Figure 16 and Table 11, the most important factor in selection of treatment was trust that the treatment would be effective. This far outweighed all other factors when selecting a course of treatment. Thus, it is clear that cancer patients will select a course of treatment that they believe will be effective, with less consideration for things like where the treatment will take place or how to pay for it.

Figure 16. Importance of Factors in Selection of Treatment

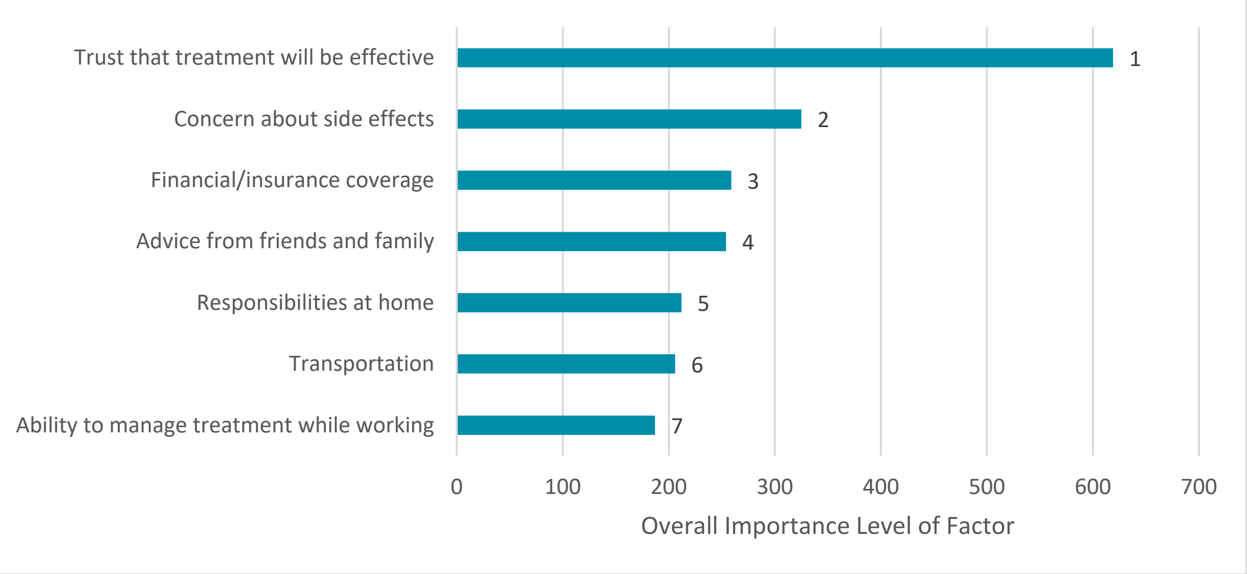


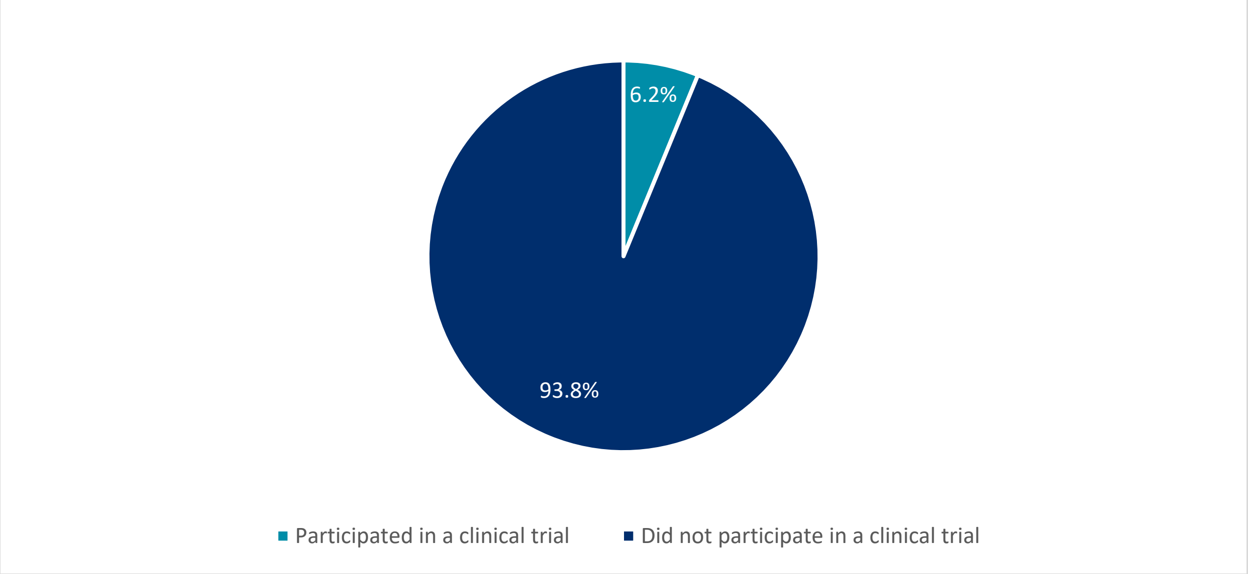
Table 11. Importance of Factors in Selection of Treatment

Factor	**Level of Importance**			***n***
	Most Important	Somewhat Important	Not Important	
Trust that the treatment would be successful	90.8%	8.9%	0.3%	325
Concern about side effects	35.4%	40.9%	23.7%	291
Financial/insurance coverage to pay for the costs	33.3%	27.2%	39.5%	276
Advice from friends and family	24.4%	45.0%	30.6%	271
Responsibilities at home	24.0%	38.2%	37.8%	246
Geographic proximity/ transportation to and from the treatment	19.9%	36.2%	43.9%	271
Ability to manage treatment while working	26.2%	36.7%	37.1%	210

Clinical Trials

Patients/survivors were asked, “Did you participate in a clinical trial as a part of your cancer treatment?” As illustrated in Figure 17, 6.2% of participants were a part of a clinical trial

Figure 17. Clinical Trial Participation



Note. *n* = 355.

The 22 participants who were a part of a clinical trial were then asked which hospital or healthcare facility they went to for their clinical trial. Results were as follows:

1. City of Hope (*n* = 5)
2. UCLA (*n* = 4)
3. Breastlink, Orange County (*n* = 2)
4. Kaiser (*n* = 2)
5. Loma Linda (*n* = 2)
6. UCSD (*n* = 2)

The following also had one reference each: Cedars Sinai Hospital, Houston, Texas Presbyterian, Orange City, and Orange County.

Complementary and Alternative Medicine

Patients/survivors were asked if they sought out treatment from complementary and/or alternative medical (CAM) providers. Results indicate that 19.6% of participating patients/survivors (n = 67) sought out CAM treatment.

Those who used CAM providers were then asked to specify what type of CAM care they sought out. As illustrated in Table 12, most patients listed “other” (49.3%). Aside from “other”, the most common types were nutritional counselor (34.3%), naturopathic/homeopathic doctor (26.9%), and counselor/stress management (20.9%).

Table 12. Type of Complimentary/Alternative Care

Type of Care	Percentage
Nutritional counselor	34.3%
Naturopathic/homeopathic doctor	26.9%
Counselor/stress management	20.9%
Therapeutic massage	14.9%
Acupuncturist	13.4%
Other	49.3%

Note: *n* = 67.

Patients/survivors who selected “other” CAM treatment listed things such as medical cannabis, acupuncture, yoga, herbalist, etc. However, it is worth noting that many of the responses under “other” do not fall within the general definition of CAM (e.g., “radiation oncologist”, “oncologist at Loma Linda”, “MD Anderson Phoenix”, etc.), and thus, participants’ understanding of what CAM is may not be strong.

Patients/survivors were asked where they received most of their CAM treatment. A total of 32 participants said that they got their CAM treatment outside of Riverside County. Many of these mentioned San Diego County, Orange County, and Los Angeles County. However, very few specified the actual place where they received their CAM treatment.

A total of 29 participants said they got their CAM treatment within Riverside County. For example,

- “Physical therapy in Murrieta”
- “Temecula Center of Integrative Medicine”
- “Nutritionist thru Loma Linda, Menifee, where I had radiation. Has since closed.”

Geography and Location

In order to assess geographic cancer treatment, patients/survivors were asked, "When you were seeking treatment for your cancer, where did you get the MAJORITY of your cancer treatment?" Options included in Southwest Riverside County, elsewhere in Riverside County, and outside of Riverside County, with "fill-in-the-blank" options for participants to specify their treatment facilities.

Overall, 140 participants indicated that they got treatment in Southwest Riverside County, while 69 others got treatment elsewhere in Riverside County, such as the cities of Riverside or Moreno Valley. A total of 168 received most of their treatment outside of the county.

Of those who were able to seek treatment locally, most were treated at Hematology Oncology Consultants (*n* = 18), Breastlink (*n* = 16), or Kaiser Permanente (*n* = 12), as illustrated in Table 13.

Table 13. Location of Treatment in Southwest Riverside County

Response	*n*
Hematology Oncology Consultants	18
Breastlink	16
Kaiser Permanente (city not specified)	12
Loma Linda (city not specified)	8
Loma Linda Murrieta	8
Murrieta	8
Inland Valley Medical Center	7
Vantage Oncology	6
Hemet	4
Southland Hematology Oncology	4
Dermatology	3
Dermatology Specialists, Inc.	3
Dr. Mendoza	3
Dr. Seghal	3
Dr. Schinke	3
Dr. Tsai	3
Temecula	3
Temecula Valley Hospital	3
Tri-Valley Urology	3
Wildomar	3

Note: Only those with 3 or more responses in each category are included in this table.

The following local doctors were mentioned by name: Dr. Bremner, Dr. Greek, Dr. Hayton, Dr. Jacobs, Dr. Lau, Dr. Martin, Dr. Mendoza, Dr. Mudge, Dr. Schinke, Dr. Seghal, Dr. Tsai, and Dr. Washington.

For those who received the majority of their treatment elsewhere in Riverside County, Kaiser Permanente was the most common provider, as illustrated in Table 14.

Table 14. Location of Treatment Elsewhere in Riverside County

Response	*n*
Kaiser Permanente Riverside	21
Kaiser Permanente (city not specified)	7
Riverside	6
Riverside County Regional Medical Center	4
Kaiser Permanente Moreno Valley	3
Moreno Valley	3

Note: Only those with 3 or more responses in each category are included in this table.

Of the patients who sought treatment outside of the County, many received treatment at Loma Linda (*n* = 19) or UC San Diego (*n* = 17), as illustrated in Table 15.

Table 15. Location of Treatment Outside Riverside County

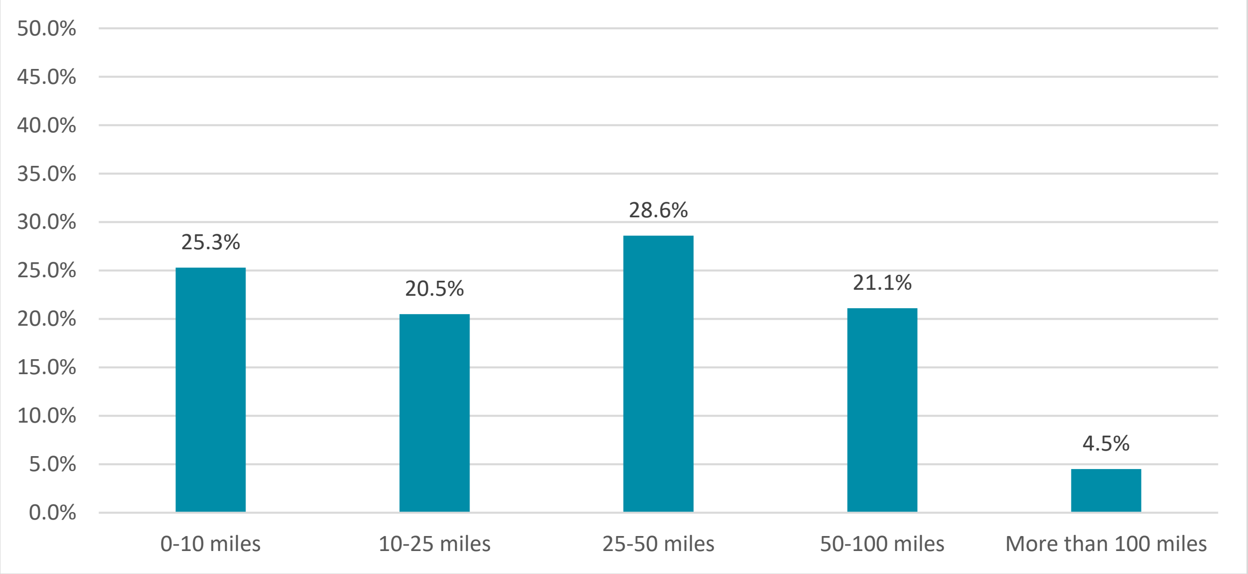
Response	*n*
Loma Linda	19
UC San Diego	17
Kaiser Permanente Ontario	9
Breastlink Orange	8
Fallbrook Hospital	7
Scripps (no city specified)	6
UC Irvine	6
UC Los Angeles	6
City of Hope	5
Orange County	5
San Diego	5
Los Angeles	4
Scripps La Jolla	4
Cedars Sinai Hospital	3
Los Angeles County	3
Ontario	3
San Diego County	3
Scripps San Diego	3

Note: Only those with 3 or more responses in each category are included in this table.

> *"Had to go to OC cuz after 2 1/2 months in RC, still no biopsy scheduled. Took way too long, despite begging and pleading. Usually took about 3 weeks for each next appointment and no one was as friendly as Hoag staff. Hoag did it all same day. Great place and worth the drive. Still go there for my routine cancer follow ups."*

Patients/survivors were asked how far their cancer treatment was from home. About a quarter of patients/survivors (25.3%) had to travel less than 10 miles to their cancer treatment location, as illustrated in Figure 18. However, a similar proportion must travel for 50 or more miles to get their treatment, and likely are burdened by the commute.

Figure 18. Treatment Distance from Home



Note: *n* = 336.

Patients/survivors were asked to indicate how they got to their treatment location. Most patients reported by a vehicle (driver not specified, *n* = 121) or drove themselves (*n* = 110), as illustrated in Table 16. The following also had one reference each: walking, boat, motorcycle, and plane.

Table 16. Mode of Transportation

Mode	Frequency
Vehicle	121
Drove myself	110
Family drove me	105
Friend drove me	20
Other drivers	6
Bus	5
Other services (e.g., Uber, medical transportation, etc.)	4

Patients/survivors were asked why they sought care at the facilities they went to. Nearly half of patients/survivors reported the reason was because their insurance would cover it (45.0%), as illustrated in Table 17.

Table 17. Reason for Choosing Facility

Type of Reason	Percentage
My insurance would cover it	44.2%
That's where my doctor is	36.4%
It was well-known as high-quality	32.7%
Treatment not available closer to home	19.7%
It was convenient	12.7%
Other	15.8%

Note: *n* = 385.

"Special radiation needed only [available] at UCSD and UCLA"

A fair number of patients/survivors (15.8%) reported "other" as their reason for choosing a facility. "Other" reasons for choosing this facility are provided in Table 18.

Table 18. Other Reasons for Choosing Facility

Reason	Frequency
Advised/recommended to go there	15
Facility had what I needed	10
Insurance reasons	9
Good quality/comfortable with it	6
Didn't like the local services/care	5
Lived nearby the facility	3
Referred there	3

The following each had one reference: needed help from family and friends, had no choice, didn't know about other alternative care options, and my doctor was there.

"My urologist in Murrieta felt that the level of surgery I required would be available outside of our region"

"The clinic that I would visit for yearly exams is in San Diego co because the wait time was shorter and they had better programs for people with no insurance."

Issues/Problems/Areas for Improvement

Patients/survivors were asked, "During your cancer treatment and recovery, did you need assistance with any of the following?" As illustrated in Table 19, the most commonly type of help needed was help with household chores; 37.3% of cancer patients/survivors needed help with household chores.

The most common unmet needs were for assistance with household chores (13.5%), financial assistance (12.6%), and utility assistance (10.3%).

Table 19. Need for Specific Assistance

Type of Help	Level of Need			*n*
	I did not need this type of help	I needed help, but didn't get it	I needed help and received it	
Household chores	62.7%	13.5%	23.8%	311
Financial assistance	69.5%	12.6%	17.9%	318
Home care	70.0%	7.7%	22.3%	310
Transportation assistance	71.2%	7.1%	21.8%	312
Utility assistance	85.5%	10.3%	4.2%	310
Lodging assistance	87.6%	5.7%	6.7%	314

Those who needed help and received it were then asked to specify where they received their assistance from. This helped to identify existing resources in the region.

Most participants relied on family and friends to help them with their household chore needs, as illustrated in Table 20.

Table 20. Sources of Household Chore Assistance

Source of Assistance	Frequency
Family	73
Friends	16
House cleaner/maid	5
Cleaning company	2
Social services	2
Homecare insurance	1
Homecare	1
Inland regional	1
Live in assistance	1

> *"My son was 15 at the time. We did the best we could [with chores]."*

Financial assistance was commonly provided by private organizations, charities, and pharmaceutical companies. Other common sources of financial support included friends and family, state disability, and Michelle's Place, as illustrated in Table 21.

Table 21. Source of Financial Assistance

Source of Assistance	Frequency
Private organizations/pharmaceuticals/charities	14
Friends and family	11
State disability	8
Michelle's Place	8
Insurance company	6
Clinic office/provider	4
Medicare/Medi-Cal	4
SNAP or food assistance	2
GoFundMe Campaigns	2
Payment plan was set up	2

> *"Pharmaceutical company provided assistance on newly FDA approved drug."*

> *"My oncologist's office arranged financial help to pay for chemo and meds, and Michelle's Place gave me a $100 grocery card"*

Family members were the most common source of assistance for home care, as illustrated in Table 22.

Table 22. Sources of Home Care Assistance

Source of Assistance	Frequency
Family	45
Home-healthcare	14
Friends	10
Hospitals/universities	3
Insurance Company	2
Center for Healthy Living	1
Social services	1
Live in assistance	1

> *"Home nurse visited twice, my sister was there for the whole time."*

Once again, family and friends stood out as the major providers of transportation assistance, as illustrated in Table 23.

Table 23. Source of Transportation Assistance

Source of Assistance	Frequency
Family	51
Friends	23
Insurance company/medical transportation	6
Transportation service	4
American Cancer Society	2

> *"This was a problem... I put people to great inconvenience to drive me and got rides from friends of friends... Sometimes I ended up driving myself, which wasn't safe, but I felt too vulnerable and overwhelmed by grogginess and exhaustion to find another way home."*

Few patients/survivors that did receive help reported a few sources of utility assistance. These included family (*n* = 4) and electricity discounts (*n* = 2). There was also a reference for water discounts, gas discounts, Murrieta Chamber of Commerce, friends, and the Home Energy Assistance Program.

> *"I belong on med baseline, somehow SCE booted me off, difficult to get back on KP and HMO's not good at filing paperwork out, really need help with utility costs"*

Again, few patients/survivors reported receiving lodging assistance. Sources of lodging assistance mostly included family (*n* = 11), friends (*n* = 3). The following each had one reference: City of Hope, American Cancer Society, Kaiser, and a VA Medical Center.

> *"Family could have used assistance so could get a motel/hotel to stay in the area during my operation and hospital stay. Also needed to stay in area when MRI and doctor's visits were not on same day."*

To assess patient perceptions of local cancer issues, patients/survivors were asked, "What do you think are the most critical cancer healthcare issues in Southwest Riverside County?"

As illustrated in Table 24, participating patients/survivors believe that the most pressing cancer issues in the region are a lack of accredited cancer centers (42.1%), a lack of specialized care (33.2%), and the high cost of treatment (32.7%).

Table 24. Major Local Cancer Issues

Type of Issue	Percentage
Lack of cancer centers	42.1%
Lack of specialized cancer care	33.2%
High cost of treatment	32.7%
Lack of awareness in where to go	29.9%
Appointments take too long	28.8%
Lack of health insurance/finding providers who accept my insurance	22.3%
Lack of clinical trial opportunities	17.9%
Lack of cancer screening opportunities	14.3%
Lack of transportation	11.7%
Other	19.7%

Note: *n* = 385.

Patients/survivors that reported "other" were asked to specify what other major local cancer issues exist. As illustrated in Table 25, the most common issues include a lack of good doctors (*n* = 17), and a lack of good facilities (*n* = 7).

Table 25. Other Types of Issues

Type	Frequency
Lack of good doctors	17
Lack of good facilities	7
Lack of specialties/treatment options	6
Insurance coverage problems	5
Large distance between services	4
Lack of general help	3
Waiting for appointments	3
Lack of alternative medicine	3
Lack of counseling/support groups	3
Lack of cancer awareness	2
Help finding resources/overwhelmed	2
Earlier cancer screening	2

> *"Lack of doctors that we can trust in this area. The ERs here are always full, the hospitals here are over burdened and the quality of care here is not as good as it is in San Diego county."*

Patients/survivors were asked the following, "What areas, if any, would you have liked help with during your illness?"

As illustrated in Table 26, the most desired types of assistance include advice about community resources (32.2%), paying for treatment (24.2%), applying for benefits (23.9%), and understanding diagnosis and treatment options (23.4%).

Table 26. Areas of Help Needed

Type of Help	Percentage
Advice about community resources	32.2%
Paying for treatment	24.2%
Applying for benefits	23.9%
Understanding my diagnosis and treatment options	23.4%
Arranging care at my home	11.7%
Coordinating my care	11.4%
Transportation	10.9%
Insurance and billing paperwork	10.1%
Childcare or other care responsibilities	6.0%
Scheduling and tracking appointments	4.9%
Other	14.8%

Note: *n* = 385.

The majority of those who listed other types of help included finding more options for treatment (*n* = 5) and better continued care/support (*n* = 5), as illustrated in Table 27.

Table 27. Other Help Needed

Type	Frequency
Help finding more options for treatment	5
Better continued care/support	5
Financial assistance (monetary, food)	3
More alternative treatments (counseling, nutrition advice, etc.)	3
Help with home maintenance	3
Faster referrals/treatment starting	3
Better quality healthcare	2
Patient advocates needed	2
More counseling/support	2
Help with transportation	1

> *"Help seeking quality care. Riverside county hospitals are horrible"*

Patients/survivors were asked the following, “What problems are you/did you experience during your cancer treatment?”

Most participants experienced issues with their emotional state and feelings, worries about their family, side effects of treatment, and uncertainty about their future, as illustrated in Table 28.

Table 28. Problems Experienced During Treatment

Problems	Not an issue	Somewhat Challenging	Very Challenging	*n*
My emotional state and feelings	23.7%	39.1%	37.2%	312
Worries about my family	24.8%	32.6%	42.6%	310
Side effects of treatment	25.3%	34.9%	39.7%	312
Uncertainty about my future	26.5%	35.1%	38.3%	313
Paying my bills	50.5%	28.9%	20.6%	311
Keeping track of medical records	56.6%	32.7%	10.7%	309
Keeping track of my insurance/bills	58.7%	27.1%	14.2%	310
People’s reactions to my illness	58.8%	27.8%	13.4%	313
Shopping and preparing meals	62.6%	25.2%	12.3%	310
My need to keep my job	64.7%	17.6%	17.6%	306
Keeping track of appointments	69.1%	26.1%	4.9%	307
Transportation to treatment	69.6%	23.3%	7.1%	309
Keeping track of medications	70.5%	24.6%	4.9%	305
Spiritual concerns	76.0%	16.7%	7.3%	300
Other transportation	76.3%	16.7%	7.0%	300

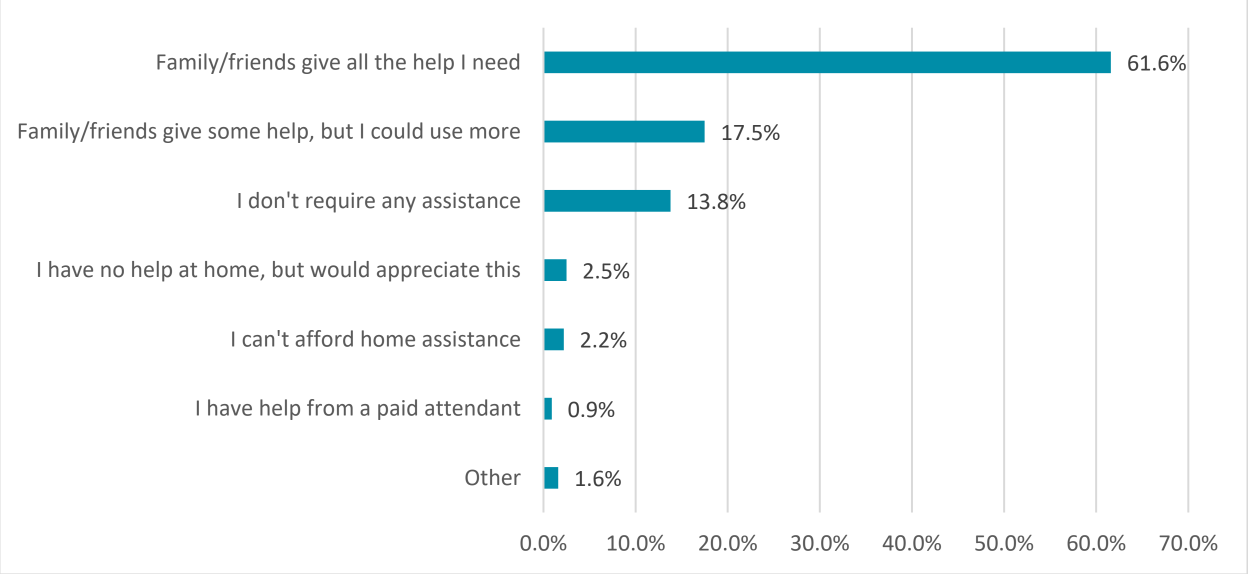
Support Systems

In order to assess existing support systems, patients/survivors were asked, "Did you/do you have help at home to assist you during your recovery?"

The majority of participating patients/survivors (61.6%) reported that family/friends give all the help that they need, as illustrated in Figure 19. There were some patients/survivors that have help but could use more (17.5%), some with no help (2.5%), and some who can't afford assistance (2.2%). All of these individuals would likely benefit from additional assistance in the home with their recovery.

Those who reported "other" (1.6%) provided responses such as needing occasional help (n = 1), wife helping (n = 2), not needing help (n = 1), and husband and wife only (n = 1).

Figure 19. Help at Home for Recovery



Note: n = 320.

> *"Kaiser was extremely helpful understanding my situation; and I was blessed with family and friends who helped with home care"*

Patients/survivors were asked, “Did you/do you now receive support from any of these organizations?”

As illustrated in Table 29, the most common organization for support was Michelle’s Place (28.6%), followed by the American Cancer Society (12.5%). The other possible support organizations were generally not utilized.

Table 29. Support from Organizations

Organization	Percentage
Michelle’s Place	28.6%
American Cancer Society	12.5%
Susan G. Komen	1.8%
Cleaning for a Reason	1.6%
Pink Ribbon Place	1.0%
Cancer Care Co-payment Assistance Foundation	1.0%
Other	18.2%

Note: $n = 385$.

Those who listed other organizations included church ($n = 2$) and OASIS ovarian cancer support group ($n = 2$). The following organization had one reference each: Addario Lung Cancer Foundation, Armstrong Foundation, breastcancer.org, Children’s Neuroblastoma Cancer Foundation, Colon Cancer Fund, Counseling in Walnut Creek, Firefighter Cancer Support Network, Gilda’s Club, Moore’s Cancer Center, an insurance company, Night of Hope, pharmaceutical foundations, Good Days Foundation, Patient Advocate Network, Redondo Beach Cancer Support Center, Relay for Life, and the Green Foundation.

Patients/survivors were asked, “Did you/do you now receive any of these types of support?” and then given a list to choose from. As illustrated in Table 30, support groups (9.8%) and counseling (9.5%) were the most common types of support received, although even these are relatively uncommon.

Table 30. Support

Type	Percentage
Support groups/group therapy	9.1%
Counseling/Individual therapy/stress management	8.8%
Home healthcare	5.2%
Patient navigators	4.2%
Financial assistance	3.9%
Hotlines or live chats	2.6%
Housekeeping or meal prep	2.6%
Occupational therapy	2.3%
Other	14.8%

Note: *n* = 385.

Those who provided “other” mostly listed receiving various types of support from Michelle’s place (*n* = 9). These included receiving hair pieces, hats, yoga classes, and retreats to name a few. The remaining patients reported receiving help from other organizations.

> *“I volunteer at Michelle's Place where I have lots of support.”*

> *“I joined Bladder Cancer Advocacy network online and received mountains of support and advice from other people who had already walked my path. I would love the opportunity to be able to direct people to patient navigators! There are so many people out there with Cancer and don't know what to do next. They assume their doctor will lead them by the hand and this is not the case.”*

Medi-Cal Eligible Cancer Patients/Survivors

California's Medicaid program, Medi-Cal, is available for individuals who fall below 138% of the federal poverty line. This means that individuals who are eligible for Medi-Cal are low-income individuals, who may experience more barriers to treatment, such as a lack of money for copays, a lack of providers who accept Medi-Cal, or a lack of transportation options, to name a few. In order to examine this high-needs population, this section presents some selected measures for only those who are 138% of the poverty line or less.

A total of 40 cancer patient/survivors were eligible for Medi-Cal by this measure. Of these individuals, nine were dual-eligible (i.e., eligible for Medi-Cal and Medicaid) for also being over the age 65.

The top three common locations that Medi-Cal eligible cancer patients/survivors are coming from includes the cities of Temecula (23.1%), Menifee (20.5%), and Murrieta (20.5%). This is somewhat similar to cancer patients/survivors overall, as Temecula, Menifee, and Murrieta were the top three common locations.

Table 31. Location of Medi-Cal Eligible Patients/Survivors

Name of City	Percentage
Temecula	23.1%
Menifee	20.5%
Murrieta	20.5%
Hemet	10.3%
Lake Elsinore	7.7%
Canyon Lake	5.1%
Homeland	5.1%
Perris	5.1%
San Jacinto	2.6%

Note: *n* = 39.

As illustrated in Table 32, the most common cancer type among eligible Medi-Cal participants was breast cancer (27.5%). This is similar to cancer patients/survivors overall as breast cancer was the most common type for them as well. “Other” responses included cervical (*n* = 3), multiple myeloma (*n* = 2), and one each for thyroid, melanoma, brain, and tongue.

Table 32. Cancer Type Among Medi-Cal Eligible

Cancer Type	Percentage
Breast	27.5%
Uterus	7.5%
Lymphoma	5.0%
Prostate	5.0%
Skin	5.0%
Bladder	2.5%
Colon and rectum	2.5%
Lung and bronchus	2.5%
Other	22.5%

Note: *n* = 40.

As illustrated in Table 33, most reported driving themselves (*n* = 15), or having family drive them (*n* = 9) to their treatment. These were common responses for cancer patients/survivors overall as well.

Table 33. Mode of Transportation for Medi-Cal Eligible

Mode	Frequency
Drove myself	15
Family drove me	9
Vehicle	8
Friend drove me	1
Bus	1
Car service	1

Note: *n* = 29.

As illustrated in Table 34, 17.2% took two to four weeks to see a specialist, while about a quarter (24.1%) took more than a month to see a specialist. This rate, for taking more than a month to see a specialist is comparatively higher than cancer patients/survivors overall at (14.0%).

Of those who took more than two weeks to see a cancer care specialist, reasons included scheduling issues (*n* = 5), insurance issues (*n* = 3), and one each for repeated testing, referrals, provider losing patient's paperwork, and the area not having a gynecological oncologist available.

Table 34. Time to See a Cancer Specialist – Medi-Cal Eligible

Amount of time	Percentage
One to three days	31.0%
Three to seven days	20.7%
One to two weeks	6.9%
Two to four weeks	17.2%
More than a month	24.1%

Note: *n* = 29.

As illustrated in Table 35, the majority of Medi-Cal eligible patients/survivors took either two to four weeks (27.6%) or more than a month (37.9%) to begin treatment. This length of time, for taking longer than a month, is higher than the rate for cancer patients/survivors overall (28.2%).

Those who took more than two weeks reported this happened because of scheduling issues (*n* = 5), waiting on insurance approvals (*n* = 4), needing to work on another health issue first (*n* = 4), and one each for misdiagnosis, referral issues, needing more tests, and his/her doctor said surgery wasn't needed yet.

Table 35. Time to Begin Treatment – Medi-Cal Eligible

Amount of time	Percentage
One to three days	10.3%
Three to seven days	17.2%
One to two weeks	6.9%
Two to four weeks	27.6%
More than a month	37.9%

Note: *n* = 29.

Of those who were eligible for Medi-Cal, nearly all of them did not participate in a clinical trial (93.1%). These are very similar rates compared to cancer patients/survivors overall, in which 93.8% did not participate in clinical trial.

Table 36. Participation in Clinical Trials – Medi-Cal Eligible

Participation	Percentage
Participated	6.9%
Did not participate	93.1%

Note: *n* = 29.

When asked what was their reason for choosing the facility they sought treatment, the most common reason was that their insurance would cover it (40.0%). Again, this is very similar to cancer patients/survivors overall who also reported choosing a facility because their insurance would cover it (44.2%).

Table 37. Reason for Choosing Facility – Medi-Cal Eligible

Type of Reason	Percentage
My insurance would cover it	40.0%
That's where my doctor is	27.5%
High-quality	25.0%
Treatment was not available closer to home	22.5%
Other	15.0%
It was convenient	12.5%

Note: *n* = 40

As illustrated in Table 38, about half of these patients/survivors (44.8%) travel 25 to 50 miles to their treatment. This is substantially higher than the rate of cancer patients/survivors overall who travel 25 to 50 miles (28.6%).

Table 38. Treatment Distance from Home – Medi-Cal Eligible

Distance	Percentage
0 to 10 miles	27.6%
10 to 25 miles	17.2%
25 to 50 miles	44.8%
50 to 100 miles	3.4%
More than 100 miles	6.9%

Note: *n* = 29.

Patients/survivors that are eligible for Medi-Cal most commonly reported local cancer care issues are the lack of cancer centers (32.5%), lack of awareness in where to go (32.5%), and the lack of specialized care (25.0%), as illustrated in Table 39. These rates were approximately equal to cancer patients/survivors overall.

Table 39. Major Local Cancer Issues – Medi-Cal Eligible

Type of Issue	Percentage
Lack of cancer centers	32.5%
Lack of awareness in where to go	32.5%
Lack of specialized care	25.0%
High cost of treatment	22.5%
Lack of clinical studies	20.0%
Appointments take too long	20.0%
Lack of health insurance	17.5%
Lack of transportation	15.0%
Lack of cancer screening	15.0%
Other	17.5%

Note: *n* = 40.

Patients/survivors that are eligible for Medi-Cal most commonly reported that they need help with applying for benefits (35.0%), advice about finding community resources (30.0%), and help in paying co-pays/out-of-pocket costs (25.0%), as illustrated in Table 40.

Table 40. Help Needed – Medi-Cal Eligible

Type of Help	Percentage
Help in applying for benefits	35.0%
Advice about community resources	30.0%
Help paying co-pays/out-of-pocket costs	25.0%
Help understanding diagnosis/treatment options	20.0%
Help coordinating care	17.5%
Help arranging care services at home	15.0%
Help arranging childcare or other care	15.0%
Help with transportation	12.5%
Help with insurance/billing paperwork	10.0%
Help scheduling/keeping track of appointments	2.5%
Other	12.5%

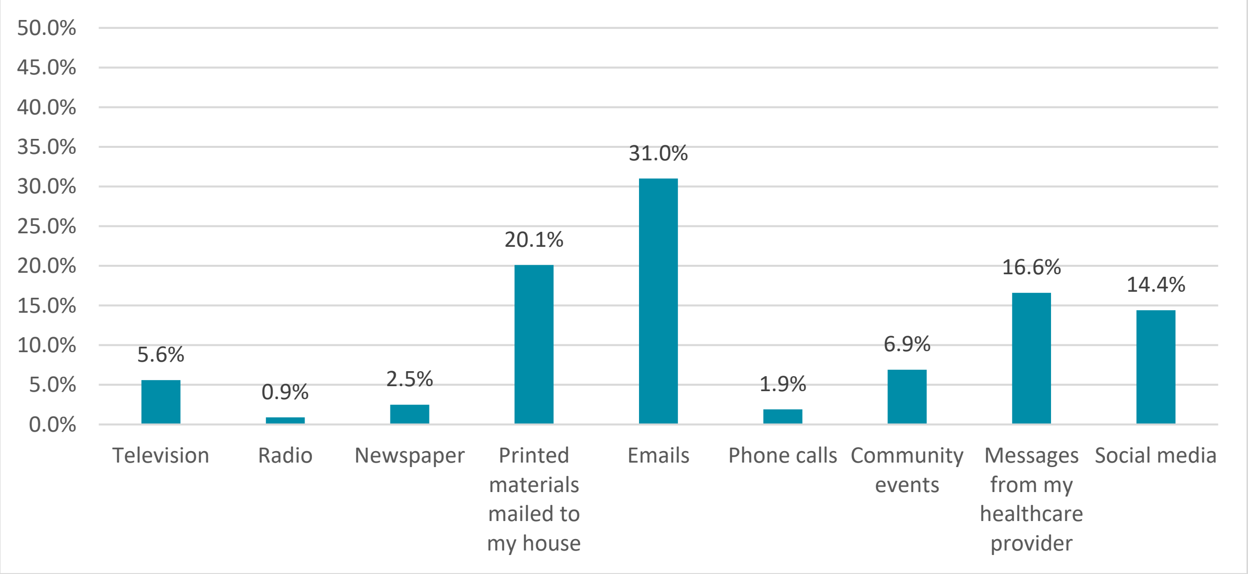
Note: *n* = 40.

Media/Dissemination

To help the Task Force in reaching cancer patients, patients/survivors were asked, “What method of communication would be most likely to reach you?”

As illustrated in Figure 20, the best methods of reaching these patients include emails (31.0%), printed materials sent to their homes (20.1%), and messages from their healthcare providers (16.6%).

Figure 20. Best Method of Communication



Note: *n* = 319.

Caregivers

Demographics of Caregivers

The majority of the participating caregivers were White/Caucasian (82.6%), as illustrated in Table 41. The second most common race was other (12.6%). Here, participants listed responses such as Hispanic, Latino, Mexican, and mixed.

Table 41. Race

Type	Percentage
White/Caucasian	82.6%
Asian	3.9%
Black/African American	1.6%
American Indian/Alaska Native	2.4%
Native Hawaiian/Pacific Islander	0.8%
Other	12.6%

Note: *n* = 127.

Most participating caregivers were not of Hispanic, Latino, or Spanish origin (86.1%), as illustrated in Table 42.

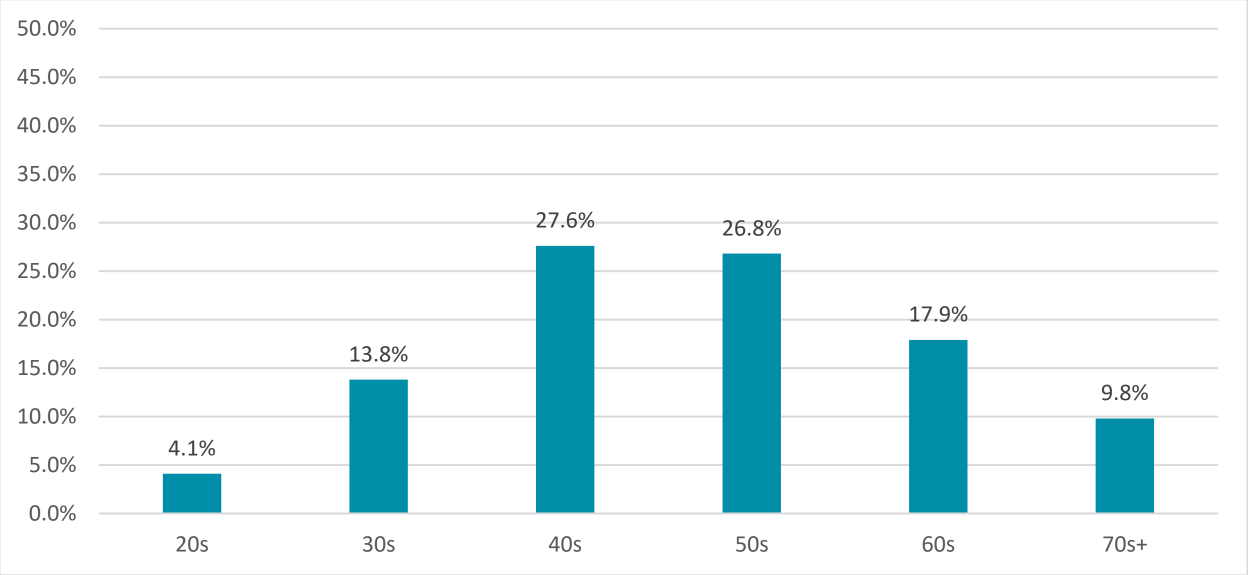
Table 42. Hispanic, Latino, Spanish Origin

Type	Percentage
Not Hispanic, Latino, or Spanish	82.0%
Yes, Mexican, Mexican American, Chicano	13.1%
Yes, another Hispanic, Latino, or Spanish origin	4.9%

Note: *n* = 303.

As illustrated in Figure 21, most of the participating caregivers were in their 40s (27.6%) or 50s (26.8%). The average age of participating cancer patients/survivors was 51, with the youngest being 23 and the oldest being 83.

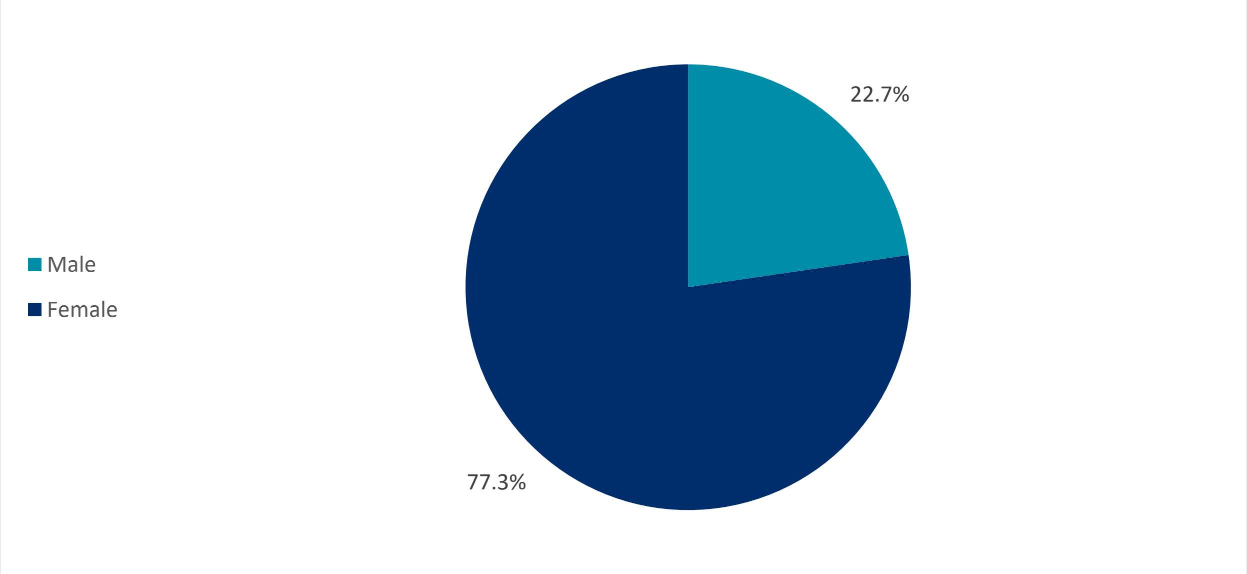
Figure 21. Age



Note: *n* = 123.

About three-quarters of participating caregivers were female (77.3%), as illustrated in Figure 22.

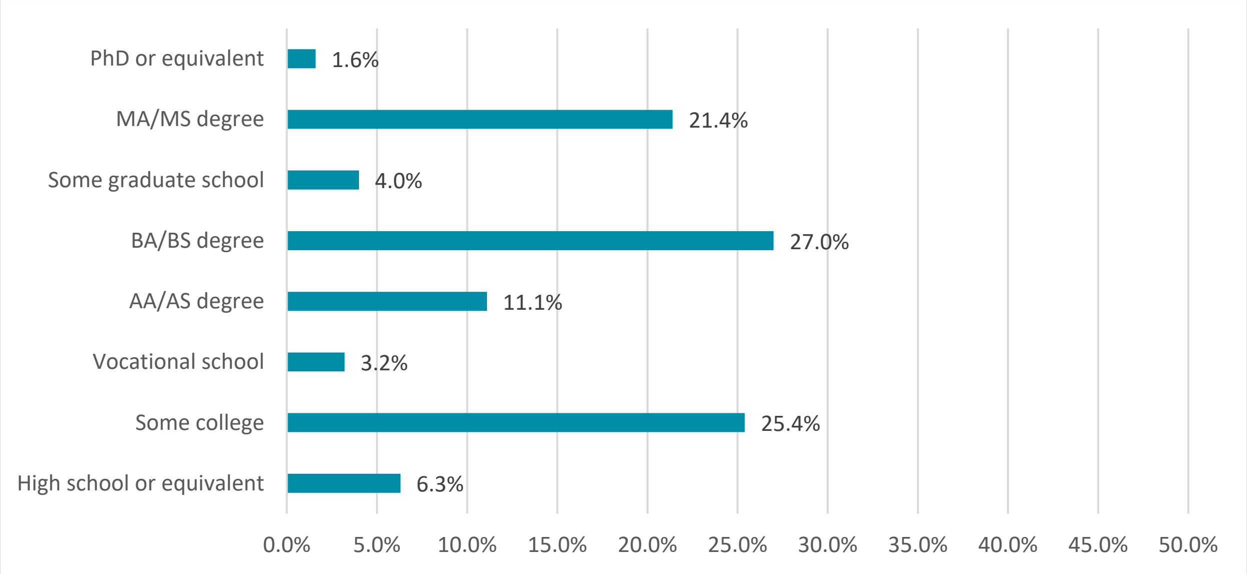
Figure 22. Gender



Note: *n* = 128.

Participating caregivers were fairly well-educated; the majority (65.1%) have some type of college degree, as illustrated in Figure 23.

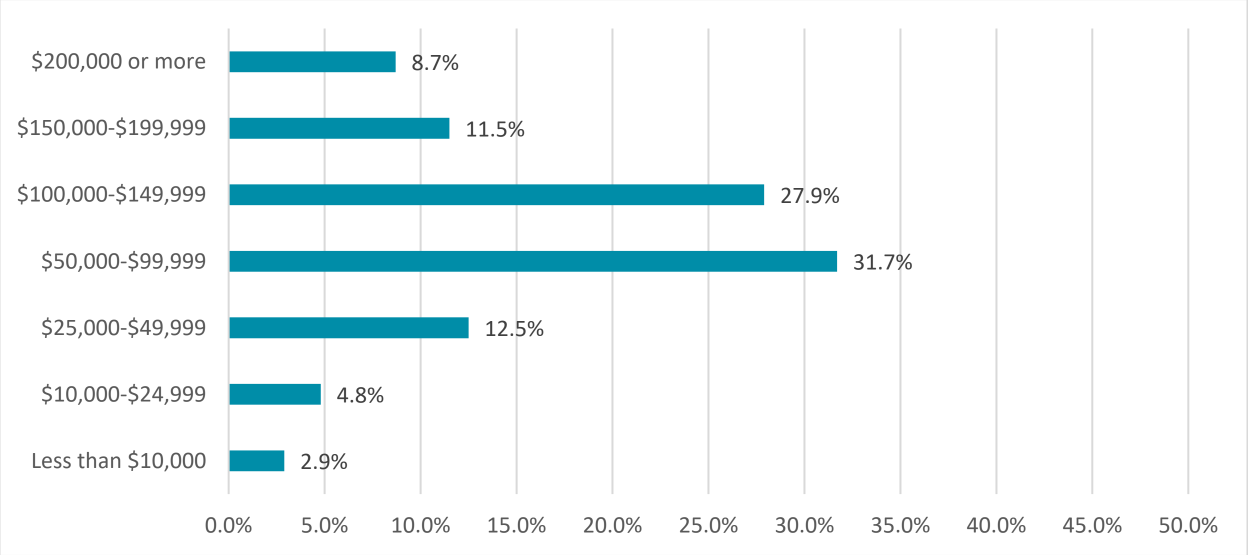
Figure 23. Education



Note: *n* = 126.

The median annual household income for participating caregivers was $95,000. As illustrated in Figure 24, the income levels of participating caregivers were relatively varied, although skewed high. About half of caregivers fall between $50,000 and $150,000 per year.

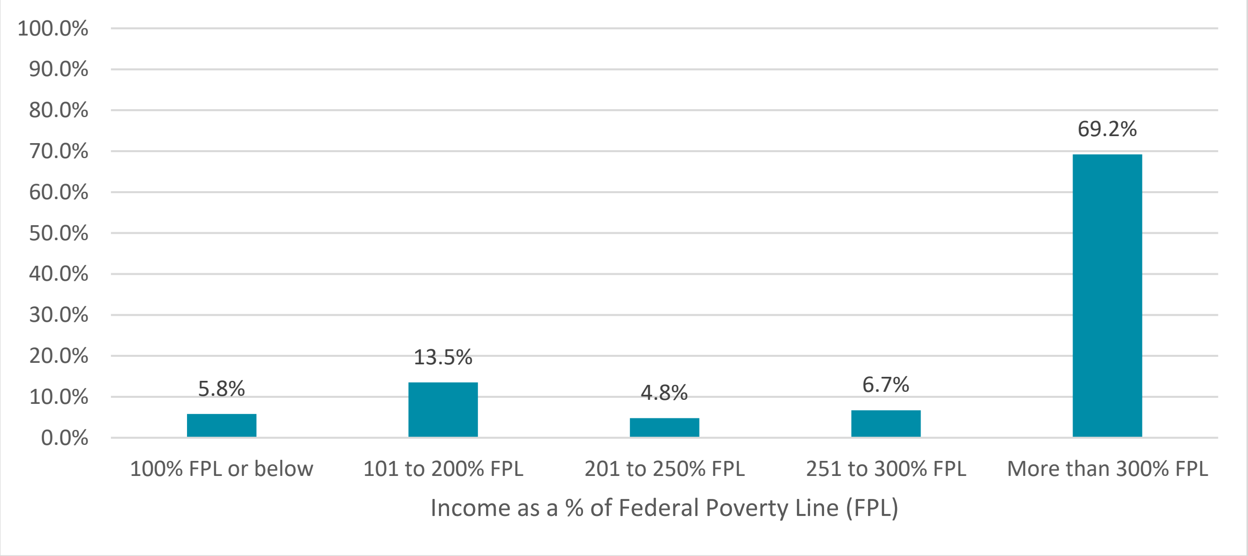
Figure 24. Household Income



Note: *n* = 104.

Participants were asked, “How many people live in your household in addition to yourself?” This information was used with the income information to calculate poverty using the federal poverty level guidelines. As illustrated in Figure 25, most participating caregivers (69.2%) lived in households that fall above 300% of the federal poverty line.

Figure 25. Poverty Level



Note: *n* = 104.

As illustrated in Table 43, most participating caregivers are from Temecula, Murrieta, and Menifee. The following cities had only one listing from each, and thus, are captured under "other cities": Aguanga, French Valley, Perris, and San Jacinto.

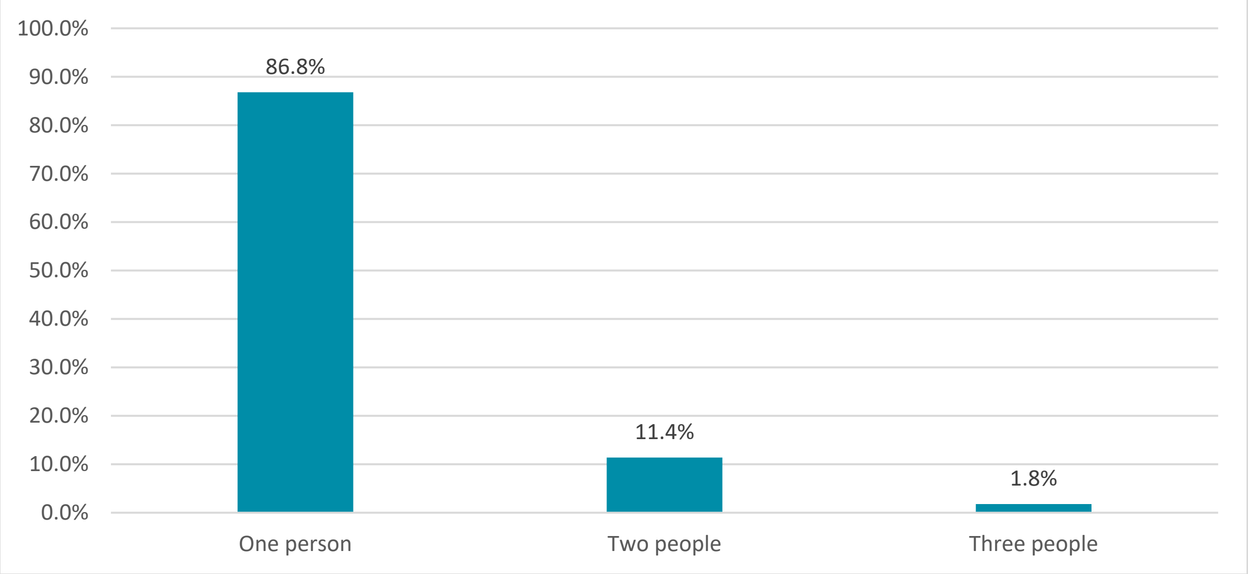
Table 43. Location

Name of City	N	%
Temecula	63	49.2%
Murrieta	34	26.6%
Menifee	9	7.0%
Wildomar	6	4.7%
Lake Elsinore	4	3.1%
Hemet	3	2.3%
Winchester	3	2.3%
Canyon Lake	2	1.6%
Other cities	4	3.1%
Total	**128**	**100.0%**

Caregiving Relationship

Caregivers were asked how many people with cancer they had cared for in Southwest Riverside County. The majority of caregivers (86.8%) have been a caregiver to one person, as illustrated in Figure 26.

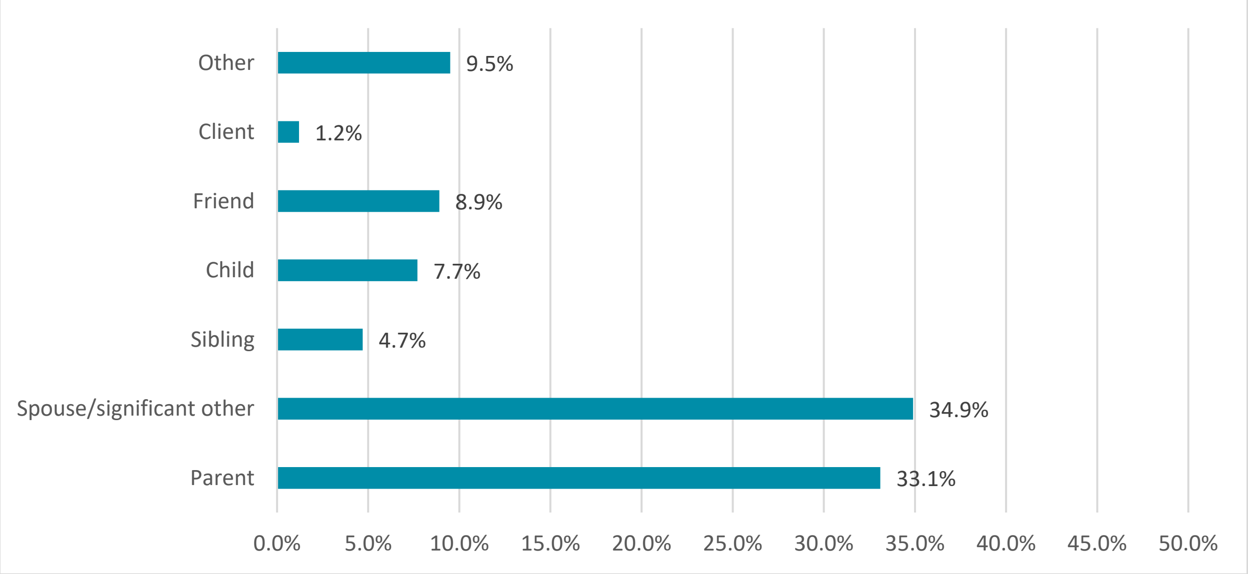
Figure 26. Amount of People Cared For



Note: *n* = 167.

As illustrated in Figure 27, most caregivers were providing care for a spouse/significant other (34.9%) or a parent (33.1%). Those who reported other (9.5%) provided care for in-law family (*n* = 5), extended family (*n* = 5), friends (*n* = 2), clients (*n* = 1), previous husband (*n* = 1), fiancée (*n* = 1), and strangers being referred (*n* =1).

Figure 27. Patient's Relationship to Caregiver



Note: *n* = 169.

Caregivers were also asked about their role on the patient's caregiving team. As illustrated in Table 44, the majority of participating caregivers played a key role in the caregiving team, either as the only caregiver (24.0%) or the main caregiver (34.7%) for the patient.

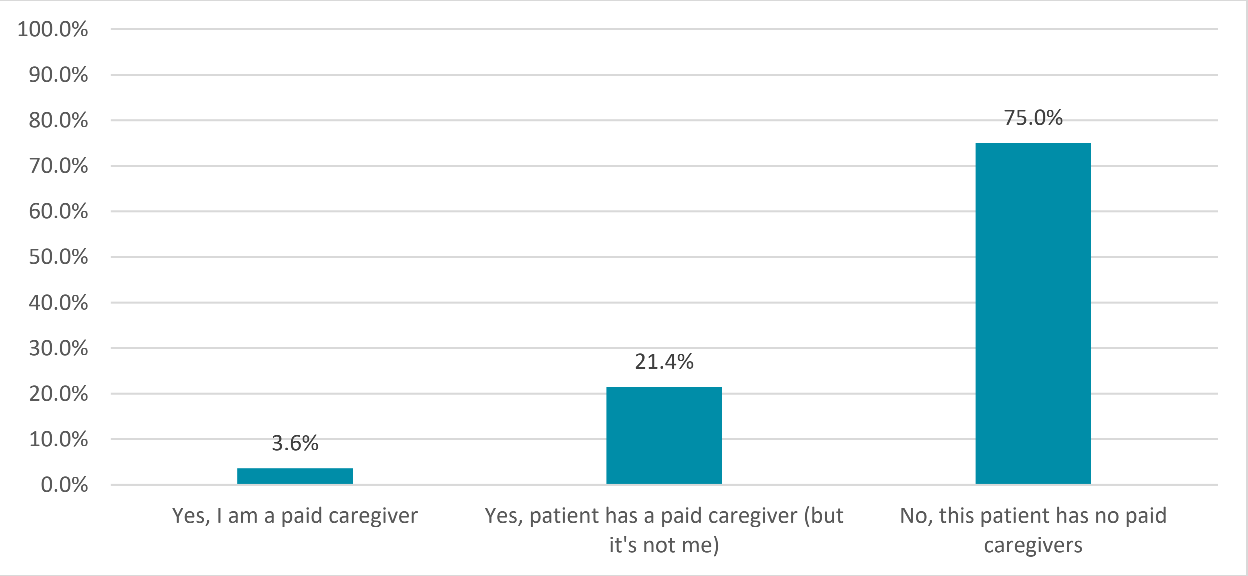
Table 44. Caregiver's Role for the Patient

Role	Percentage
I was the main caregiver during their treatment/recovery	34.7%
I was one of several caregivers during their treatment/recovery	29.3%
I was the only caregiver during their treatment/recovery	24.0%
I played a relatively minor role, mostly supporting other caregivers	12.0%

Note: *n* = 167.

Caregivers were asked, "Did this patient have any paid caregivers?" As illustrated in Figure 28, most participating caregivers reported that the patient had no paid caregivers, indicating that the care was supplied entirely by volunteers. It is worth noting that six participants were paid caregivers.

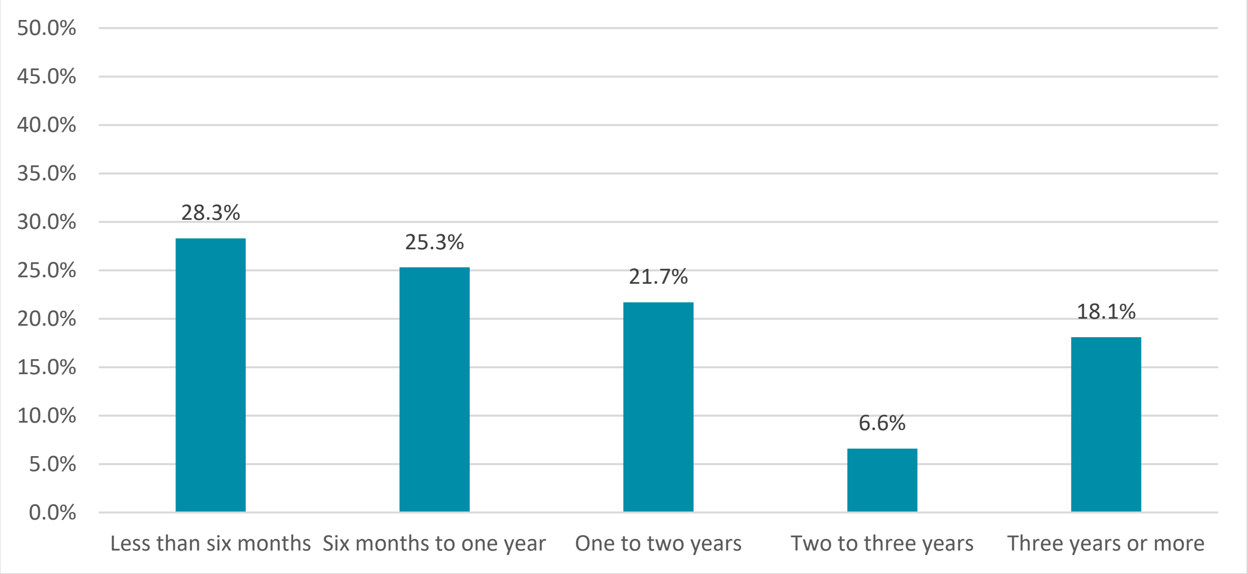
Figure 28. Paid Caregivers



Note: *n* = 168.

Caregivers were asked how long they provided care for their patients. As illustrated in Figure 29, time providing care was quite varied. About half of participating caregivers have spent one year or less providing care to a cancer patient.

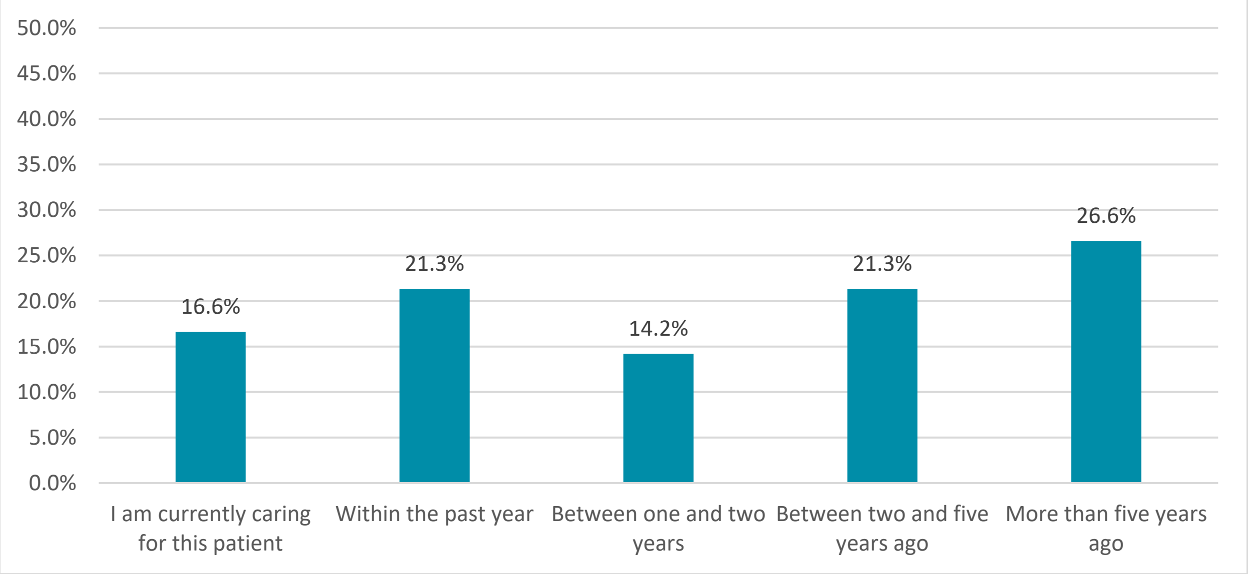
Figure 29. Time Providing Care



Note: *n* = 166.

Caregivers were also asked how recent their caregiving was. As illustrated in Figure 30, 37.9% of caregivers are either current caregivers, or have been a caregiver within the past year. This timeliness means that the data is likely well-representative of the current state of caregiving in Southwest Riverside County.

Figure 30. Time Since Providing Care



Note: *n* = 169.

About the Patient

Caregivers were asked what type of cancer the patient had. As illustrated in Table 45, the three most common types of cancer were breast (24.0%), lung and bronchus (15.4%), and colon and rectum (8.0%).

Table 45. Patient Cancer Diagnosis

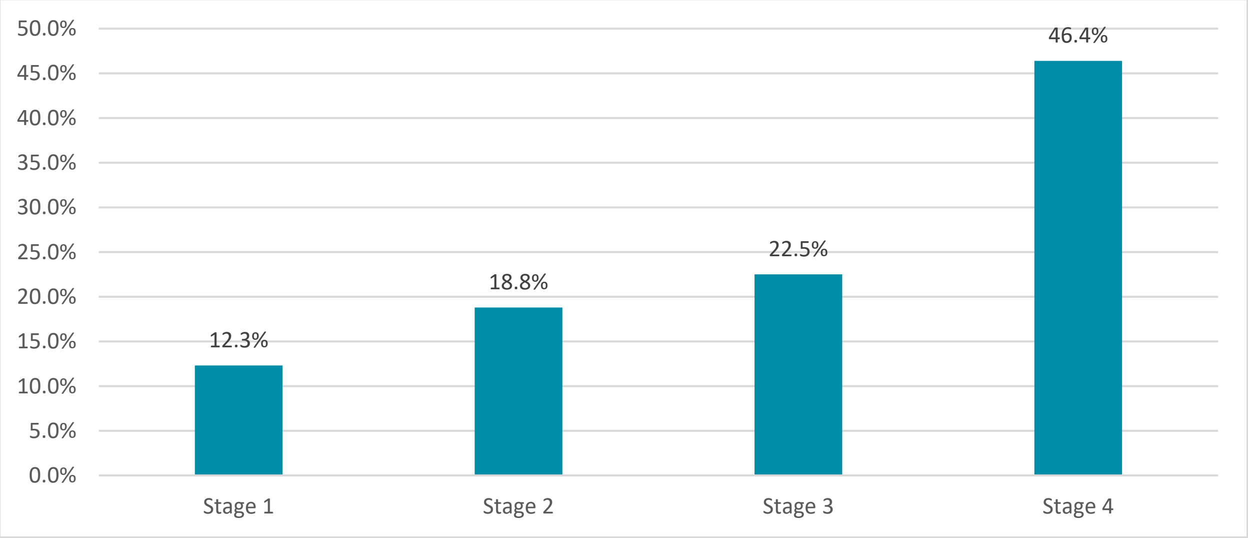
Type of Cancer	Percentage
Breast	24.0%
Lung and bronchus	15.4%
Colon and rectum	8.0%
Prostate	6.3%
Bladder	5.1%
Lymphoma	4.6%
Leukemia	4.6%
Skin	4.0%
Uterus	4.0%
Kidney and renal pelvis	3.4%
Other	36.0%

Note: *n* = 175.

Those who reported "other" reported other types of cancer such as brain (*n* = 15), pancreatic (*n* = 6), tongue/mouth/throat (*n* = 6), thyroid (*n* = 5), bone (*n* = 4), cervical (*n* = 4), liver (*n* = 4), lung (*n* = 2), melanoma (*n* = 2), multiple myeloma (*n* = 2), and stomach (*n* = 2). Other less common forms of cancer were also listed and included responses such as endometrial, glioblastoma, neuroblastoma, etc.

Caregivers were asked at which stage of cancer the patient was in when he or she was diagnosed. About half of these patients (46.4%) were diagnosed when they were already in Stage 4, indicating very advanced cases of cancer, as illustrated in Figure 31.

Figure 31. Stage of Cancer during Diagnosis



Note: *n* = 138. An additional 28 could not recall.

Caregiver Responsibilities

Caregivers were asked what they helped the patient with, and then given a range of options to choose from. As illustrated in Table 46, nearly all caregivers provided emotional support and encouragement (92.6%). Other common responsibilities included going to doctor appointments (84.0%), chores around the home (77.1%), and transportation (75.4%).

Table 46. Responsibilities

Type of Responsibility	Percentage
Emotional support and encouragement	92.6%
Going to doctor appointments with the patient	84.0%
Chores around the home (e.g., cooking, cleaning, laundry)	77.1%
Transportation	75.4%
Coordinating medical appointments	65.7%
Managing symptoms or side effects	62.9%
Giving medications	59.4%
Handling insurance and/or billing issues	44.0%
Financial support	36.0%
Caring for the patient's children	17.7%
Other	9.7%

Note: n = 175.

"Other" responses included responsibilities such as changing bandages/dressings (n = 3), end of life care and transition (n = 3), and staging treatment and finding care (n = 2). The following had one reference each: transferring medical records, meal-prepping, access to and education on cannabis, daily care/bathing, exercise, and praying with the patient.

Caregiver Resources

Caregivers were asked, “How did you prepare for your role as a caregiver?” Over three-quarters reported not preparing at all (79.2%), as illustrated in Table 47. Those who did prepare mostly search online (24.7%) and talked to healthcare professional (23.0%).

Table 47. Preparation for Caregiver Role

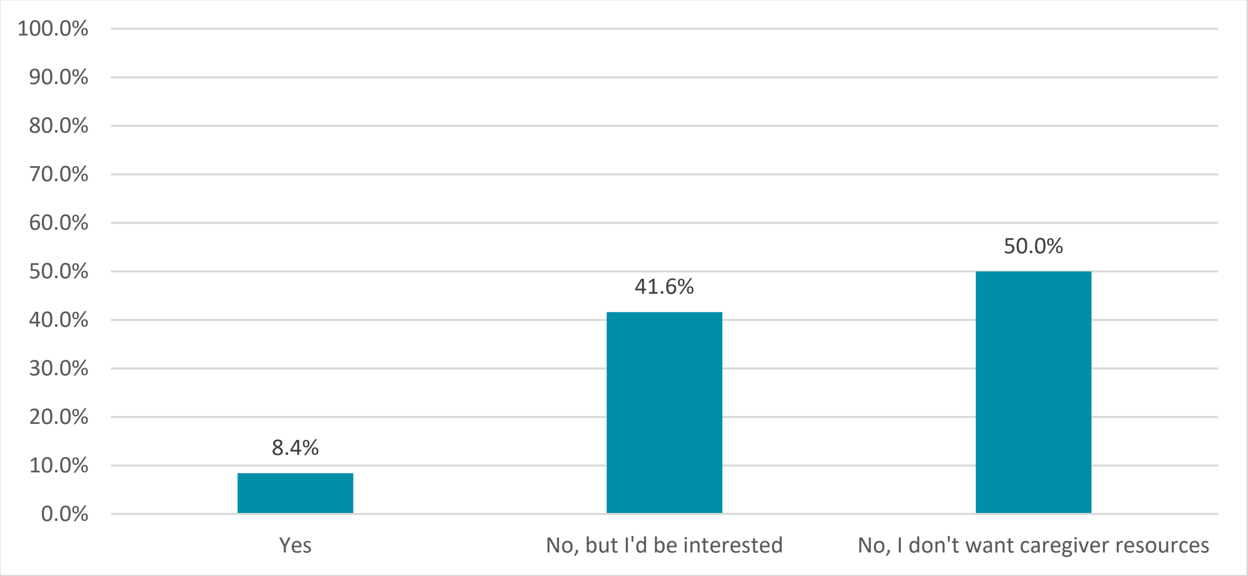
Type of Preparation	Percentage
I just jumped right in, no preparation	79.4%
I researched cancer on the internet	25.1%
I talked to healthcare providers to better understand cancer	23.4%
I talked to other cancer patients/survivors/caregivers to get a better understanding of what it would take	8.0%
I’m a professional caregiver	4.0%
Other	12.0%

Note: *n* = 175.

Those who reported “other” (12.0%) stated they were healthcare professionals (*n* = 6), had experience caring for others (*n* = 3), did additional research (*n* = 2), had the same type of cancer (*n* = 2). There were also single references to attended conferences, attended a caregiving class, hospice counseling, and knowing someone with the same cancer.

Caregivers were also asked if they ever accessed caregiver resources, such as the Cancer Hope Network’s caregiver volunteer match system or AARP’s “Caregivers in the Community” connection program. As illustrated in Figure 32, about half of caregivers don’t want caregiver resources (50.0%). Very few participating caregivers (8.4%) actually accessed caregiver resources.

Figure 32. Ever Accessed Caregiver Resources



Note: *n* = 166.

Caregivers were asked, "If you are an unpaid caregiver, what would you like help with?"

As illustrated in Table 48, more than half of caregivers (54.3%) would like information about additional resources that the patient might be eligible for.

Table 48. Desired Help for Unpaid Caregivers

Type of Help	Percentage
Information about additional resources we may have been able to get (e.g., transportation programs, meal assistance, etc.)	54.3%
Time off work to be a caregiver	30.3%
A support group for caregivers	28.6%
Respite care/paid caregivers so I could get a break	25.1%
I am a paid caregiver	1.7%
Other	8.0%

Note: n = 175.

Those who reported, "other" included a range of options. Some reported needing respite care again (n = 2), while others reported help with self-care, speech services, help with hospice care, more information regarding diseases and treatment side effects, meals for patients with compromised immune systems, and spiritual encouragement/assistance from churches.

> *"Help in learning what are the different treatment options and finding expert doctors performing the treatment. Help in finding expert doctors in monitoring the cancer after 1st treatment is complete"*

Issues/Problems/Areas for Improvement

To assess caregiver perceptions of local cancer issues, participating caregivers were asked, "What do you think are the most critical cancer healthcare issues in Southwest Riverside County?"

As illustrated in Table 49, the top three major local cancer care issued reported by caregivers include a lack cancer centers (53.7%), lack of specialized care (52.0%), and the high cost of treatment (43.4%).

As illustrated in Table 39, participating caregivers believe that the most pressing cancer issues in the region are a lack of accredited cancer centers (53.7%), a lack of specialized care (52.0%), and the high cost of treatment (43.4%). These are the same exact top three issues identified by cancer patients/survivors.

Table 49. Major Local Cancer Care Issues

Type of Issue	Percentage
Lack of accredited cancer centers in the region	53.7%
Lack of specialized cancer care	52.0%
High cost of treatment	43.4%
Lack of awareness of where to go to seek treatment	38.3%
Takes too long to make an appointment to see a provider	33.1%
Lack of clinical trial opportunities	30.9%
Lack of health insurance/finding providers who accept my insurance	25.1%
Lack of screening opportunities	22.3%
Lack of transportation	21.7%
Other	16.6%

Note: *n* = 175.

Those who reported "other" (16.6%) stated major local cancer care issues include a lack of skilled clinicians/doctors (*n* = 4), a lack of good specialists (*n* = 3), a lack of good hospitals (*n* = 3), a lack of help in home/lifestyle change (*n* = 2), and financial burdens (*n* = 2). There were also references to not having enough holistic treatments, a lack of coordination of services between providers, a lack of confidence in medical care in the area, and not having enough facilities.

> *"Patients travel to LA or San Diego for specialized treatment"*

Caregivers were asked, “In your opinion, what service/support system would’ve been most beneficial for this patient in his/her treatment and recovery?”

As illustrated in Table 50, three most common services that caregivers believe would have been most beneficial for patients include help with understanding diagnosis and treatment options (45.7%), advice about community resources (43.4%), and help in applying for any benefits (39.4%). This is slightly different than the responses from patients/survivors, where “help paying for treatment” was in the top three instead of “help understanding diagnosis and treatment options”.

Table 50. Services that Would Have Been Beneficial

Type of Service	Percentage
Help understanding diagnosis and treatment options	45.7%
Advice about community resources	43.4%
Help in applying for any benefits	39.4%
Help paying for treatment	28.6%
Help arranging care services at home	29.1%
Help with transportation	26.3%
Help coordinating care	25.1%
Help with insurance and billing paperwork	20.0%
Help scheduling and keeping track of appointments	9.7%
Help arranging childcare or other care responsibilities	9.7%
Other	13.7%

Note: *n* = 175.

“Other’” services that would have been beneficial included more supplemental care options/information (*n* = 3), having healthcare professionals who take the time to give individual and focused care (*n* = 2), more specialists (*n* = 2), help in learning about treatment options/finding care (*n* = 2), and more help for patients in Hospice (*n* = 2). There were also references to needing more/better doctors, more help for patients during all phases of diagnosis/treatment, more awareness of pediatric cancers, and more psychological support for the family.

Healthcare Professionals

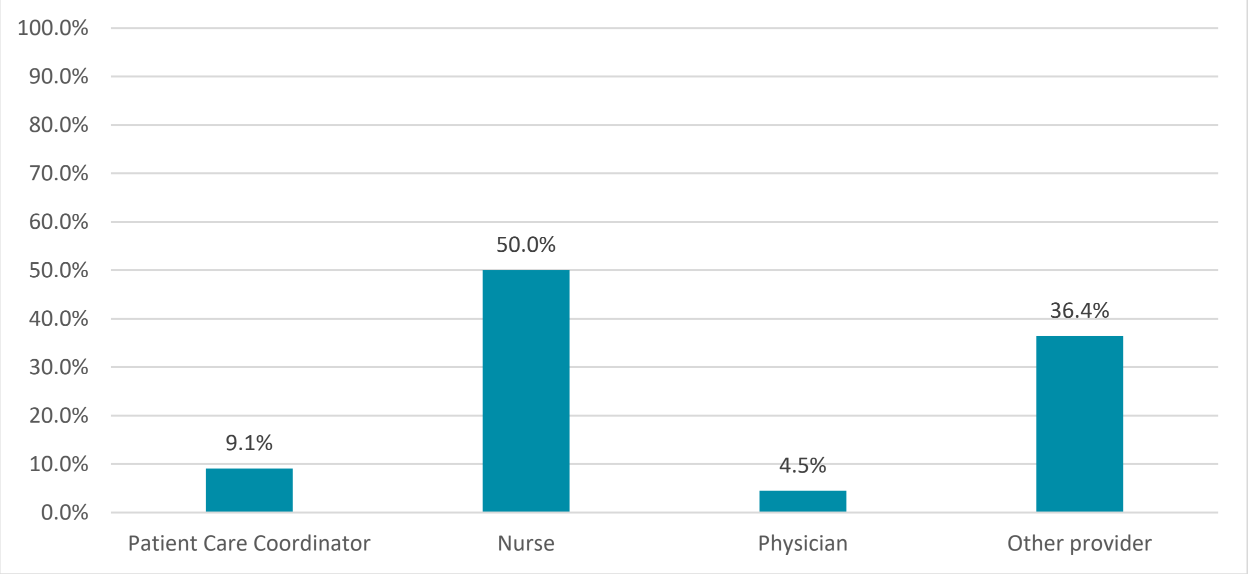
Healthcare Provider Demographics

A total of 93 people responded to the healthcare provider survey. Those who did not treat patients in Southwest Riverside County were removed, leaving a total of 44 valid participants on the healthcare provider survey.

Provider Type

As illustrated in Figure 33, most of the sample (50.0%) consisted of nurses, followed by other (36.4%) types of providers. Fewer patient care coordinators (9.1%) and physicians (4.5%) took part in the survey.

Figure 33. Type of Provider



Note: n = 44.

The other types of providers that were listed included hospital staff/administrators/executives (*n* =3) and lab/x-ray technicians (*n* = 2). The remaining types of providers all each had one reference: certified nutritionist, certified nursing assistant, nonprofit staff, physical therapist, practice manager, retired oncology nurse, speech pathologist, and a tumor registrar.

Providers were also asked to indicate their specialty. The most common specialties reported included oncology (*n* = 10), hematology oncology (*n* = 10), and pediatric hematology oncology (*n* = 4). A few responses also included acute care (*n* = 2), critical care (*n* = 2), and home care (*n* = 2). The following only had one mention each: cancer, cardiology, catheterization laboratory, family practice, geriatric occupational therapy, lymphedema management, MRI imaging, nurse paralegal, nursing, orthopedics, radiation, radiation oncology, general surgery, and speech therapy.

Level of Experience with Cancer

Providers were asked, "What percentage of your patients have been diagnosed with cancer?" Responses ranged from 1% of patients all the way to 100% of patients. On average, 59% of these providers' patients have been diagnosed with cancer, indicating that these respondents are extremely focused on cancer patients, and that they specialize in cancer patients specifically. Thus, these providers are likely to be very knowledgeable about cancer in the region.

Providers were also asked, "How many patients with cancer do you see each year?" Results ranged from only three patients with cancer per year all the way to 3,600 per year. On average, participating providers saw 587 cancer patients per year. Once again, this indicates high levels of expertise in the area.

Practice Location

As illustrated in Table 51, the most common practice locations include Murrieta (47.7%), other (29.5%), and Hemet (25.0%). "Other" locations included Beaumont, Fallbrook, Loma Linda, Moreno Valley, San Diego, and Riverside in general.

Table 51. Practice Location

Location	Percentage
Murrieta	47.7%
Hemet	25.0%
Wildomar	15.9%
Menifee	13.6%
Temecula	9.1%
Canyon Lake	9.1%
Lake Elsinore	6.8%
San Jacinto	4.5%
Other	29.5%

Note: *n* = 44.

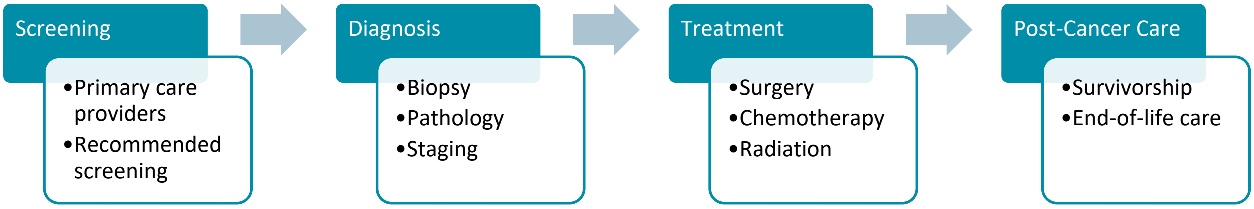
Cancer Care Continuum
Providers were asked where they fall on the cancer care continuum in terms of screening, diagnosis, treatment, and post-cancer treatment. Participating providers were free to select more than one phase, as many are involved with a patient throughout multiple phases.

The cancer care continuum begins with screening: are people getting the recommended screening appropriate for their age and gender and familial history? This is typically the purview of primary care providers.

Next in the continuum is diagnosis. This requires biopsy capabilities, pathology reporting, histological assessment, and staging.

Once someone is diagnosed with cancer, the next phase is treatment, which can include surgery, radiation, chemotherapy, or hormone therapy, among others. The providers involved in this stage have expertise in hematology, oncology, and surgery.

The next phase is post-cancer care. For some, this is related to survivorship, including screening for recurrences, counseling, plastic surgery, prosthetics, and more. For others, this is end-of-life treatment, including advance directors, hospice care, and bereavement.



Most participating providers were involved in diagnosis, treatment, and post-cancer treatment, as illustrated in Table 52.

Table 52. Cancer Care

Type of Care	Percentage
Screening	34.1%
Diagnosis	54.5%
Treatment	68.2%
Post-cancer treatment	59.1%
Other	18.2%

Note: *n* = 44.

“Other” responses included supportive roles such as education and support, in-home patient support/care, and help with maintaining functioning. Additional roles included lymphedema management, diagnosis and evaluation, swallowing therapy, and triage treatment.

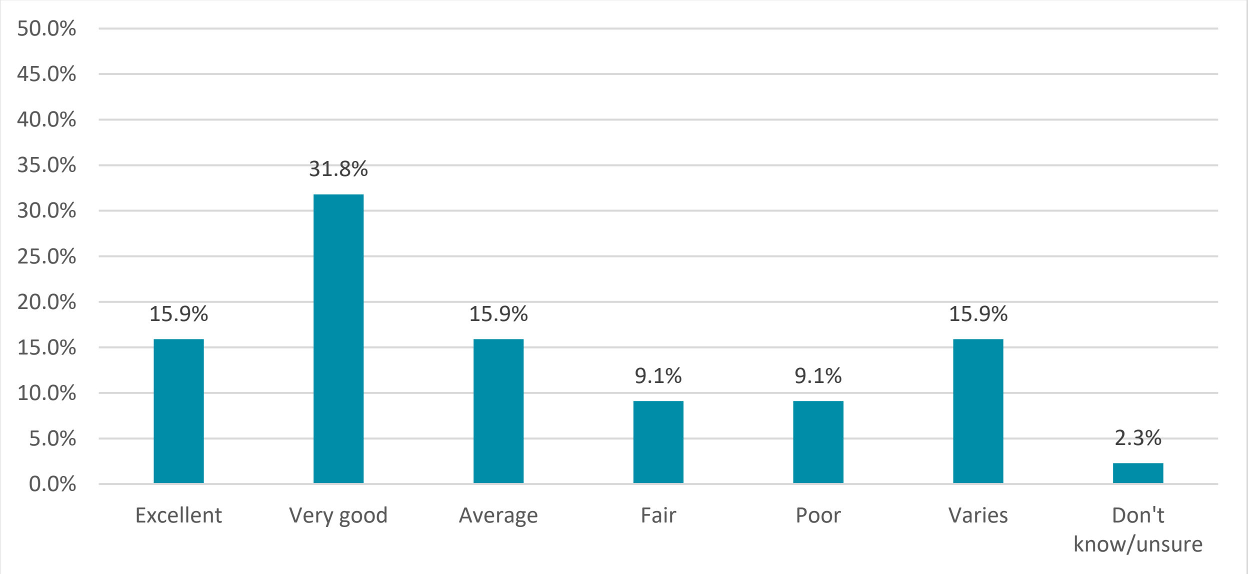
Quality and Availability of Care in SW Riverside County

Providers were asked to rate the quality of care for cancer patients in the Southwest Riverside County area. Participants were given the following options for rating:

- Excellent, state of the art
- Very good for most patients
- Average, standard or typical care
- Fair, but there are a few areas that need to be improved
- Poor quality, such that I advise most of my patients to seek treatment options outside of the area
- Variable depending on factors such as type of cancer or patient's life circumstances
- Don't know, unsure

As illustrated in Figure 34, responses were quite varied.

Figure 34. Perceived Quality of Care



Note: *n* = 44.

Providers were asked to elaborate on their ratings for quality of care. Those who rated the quality of local cancer care as "excellent" reported they provide quality and evidence based care (*n* = 4). For example,

> *"We have treated all cancers here locally and provide the same and as I believe better more personal service to the patient than a larger tertiary care center. Only a minimal amount of pts referred out of the area, for Bone marrow transplant or complicated onc surgery, but most all of those pts return to us for the remainder of their care."*

Those who stated that the quality of cancer care was “very good” reported having very good services (*n* =4), having good oncologists (*n* = 3), and being based on patient responses (*n* = 1). For example,

> *“I think we have a good share of excellent oncologists and treatment centers, however, I believe it is limited in this area and is most likely related to the fact that we do not have the bigger teaching hospitals and state of the art facilities as are present in San Diego and Orange Counties.”*

Those who believe that the quality of cancer care was “average” reported not having enough comprehensive care (*n* = 2) and one reference for each of the following: hospice services are too late, limited transportation services, no family education, lack social services, and not having enough specialty treatment.

> *“There is no specialty treatment in the area, merely traditional chemotherapy and radiation.”*

Those who rated the quality of local care “fair” described the following: difficulty getting authorization for patients, lack of chemotherapy locally, no gynecology oncology services in the area, having to rely on community care, and a lack of coordinating information between healthcare providers.

“Poor” ratings included one reference for each of the following: the Medicaid population having little resources, lack of access to chemotherapy, poor quality healthcare, and finally, one stated chemotherapy was a scam.

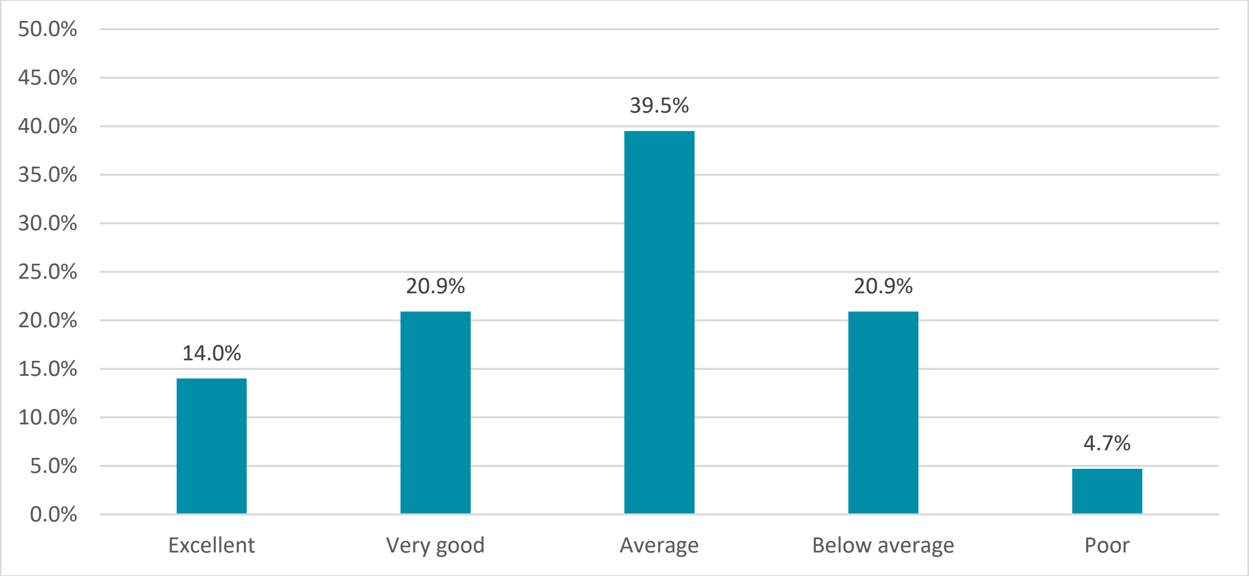
> *“I find the healthcare here is not supervised and the care I have seen is not even within standard of care.”*

“Varies” ratings mentioned the following reasons: not having affordable immediate access, limitations with insurance, restrictions on imaging available, difficulty with understanding prognosis, treatment options, and assistance options, lack specialized care, lack of doctors, little emphasis on prevention.

> *“There are few Oncologist and Hematologist in Riverside County. There also is really no Hospital that helps that many Patients of different types of cancers in Riverside County. Most patients get sent to Orange or San Diego Counties for treatments. The Oncologist out here do the best they can do with the small hospitals they have to work with. There does not seem like much financial help with some cancer situations, possibly due to lack of facilities in the area.”*

Providers were also asked to rate the *availability* of care in the Southwest Riverside County area, as compared to other areas in Southern California. As illustrated in Figure 35, most participants selected the mid-range ratings.

Figure 35. Availability of Care



Note: *n* = 43.

Providers were asked to elaborate on their ratings for availability of care in the Southwest Riverside County area. Those who provided "excellent" ratings stated having excellent care (*n* = 3), based on personal relationships with clients (*n* = 1), and distance being an issue (*n* = 1).

> *"90% of cancer patients can be successfully treated in our area with current state of the art treatment options in both Medical Oncology as well as Radiation Oncology. Plus, we know our patient's names and they see the same doctors and nurses every visit."*

Those who rated availability of care as "very good" reported a lack in cancer care services (oncology surgeons, gynecology oncology) (*n* = 3), lack of clinical trials (*n* = 1), and a lack of general services in the area (support groups, transportation, nutritional support) (*n* = 1).

> *"Not as much access to clinical trials and limited on oncology surgeons and gyn onc in the area"*

Those who stated that availability of care was “average” reported distance to services being an issue ($n = 2$), a need for more facilities and doctors ($n = 1$), there being limitations in subspecialized providers ($n = 1$), and there being issues with affordability, accessibility, and insurance restrictions ($n = 1$).

“There are always limitations to subspecialized providers for tertiary services when one is out of the big cities.”

Those who rated the availability of care as “below average” reported not having enough resources/lack of treatment ($n = 5$), and too much traveling time to treatment centers ($n = 1$).

“We have not built up our cancer resources in this community. Yes, we may be smaller (less densely populated), but we are heart and stroke focused. Most of my patients travel to San Diego, Orange County, and San Bernardino County for treatment. If there is a great availability of care, it is not well advertised. We also do not have providers who accept the Blue Shield PPO so all of those patients are being referred out of the area because the one physician who accepts the insurance is too saturated with patients right now.”

“Poor” ratings included one of each of the following: few local specialized facilities, poor technology available, and a lack of Center of Excellence.

“To find even quality supportive care you have to go to San Diego or LA”

Common Problems for Patients

Providers were asked, “What do you think is the most common problem that patients face when seeking screening, diagnosis, treatment, and post-cancer care?”

As illustrated in Table 53, providers most commonly reported that screening problems include access to screening (*n* = 6) and a lack of knowledge in what to do for the screening phase (*n* = 6).

Table 53. Common Screening Problems

Type	Frequency
Access to screening	6
Lack of knowledge in what to do	6
Lack of funds for screening	5
Lack of insurance coverage	3
Busy doctors causing delays in care	2
Not receiving roper orders from referring doctor	1
Not being able to take time off work	1

“Access and Awareness. Being proactive to care for one's self.”

When asked about common diagnosis problems, providers most frequently reported delays in getting test results (*n* = 7), as illustrated in Table 54.

Table 54. Common Diagnosis Problems

Type	Frequency
Delays in getting results	7
Getting authorization for treatment	3
Poor diagnostics	3
Poor access to care	2
Not enough doctors	2
Delays in referrals	2
Limited understanding in plan of care	2
Lack of support/care management	2
Overly busy screening facilities	1
Limited insurance	1

“Delays due to HMO auth, surgical delays, path reports and radiology testing delays in staging”

When providers were asked about common treatment problems, authorization/insurance problems (*n* = 8) and financial costs of treatment (*n* = 6) were frequently reported, as illustrated in Table 55.

Table 55. Common Treatment Problems

Type	Frequency
Authorization and insurance problems	8
Financial costs of treatment	6
Distance to treatment	4
Delays in test results	3
Lack of available resources/specialists	3
Lack of treatment options available	3
Lack of care support systems	3
Personal life issues	1
Coordinating appointments	1
Bad hospital treatment	1

"Can't afford co-pays, insurance companies not approving treatment"

Providers reported that common problems experienced for post-cancer care included a lack of support (*n* = 4), lack of patient compliance (*n* = 3), and no survivorship clinics/plans (*n* = 3), as illustrated in Table 56.

Table 56. Common Post-Cancer Care Problems

Type	Frequency
Lack of support	4
Lack of patient compliance	3
No survivorship clinics/plans	3
Access to post-cancer care	2
Insurance coverage/authorization problems	2
No formal follow-up facilities	2
Lack of care/side-effect management	2
Costs of post-cancer care	1
Busy doctors/facilities	1
Lack of exercise	1
Providers referring to physical/occupational/counseling therapy	1

"Side effect management and need for complete survivorship care plans."

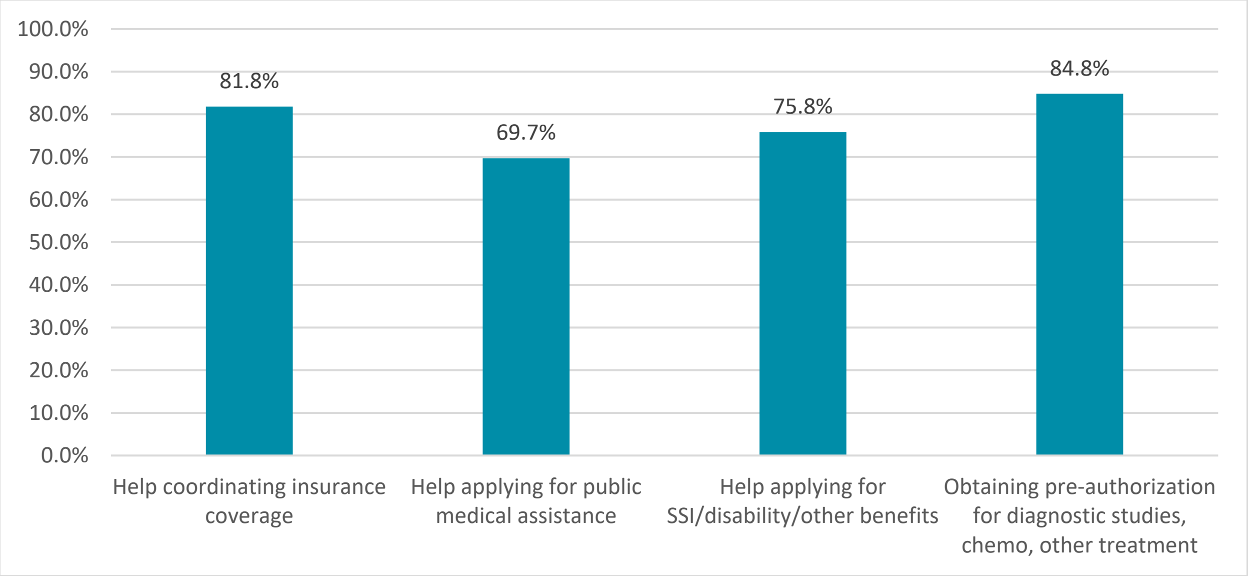
Financial Assistance for Patients

Cancer patients often have financial concerns about their care costs, insurance coverage, loss of employment and income, applying for social security/disability, or paying for their housing and transportation. As such, participating providers were asked, "Do you have trained staff in your office to assist patients with financial issues?"

Over half (55.3%) of providers reported having staff available to assist with financial issues. However, about a third (34.2%) reported their staff could benefit from additional training. The remaining 10.5% have no staff to assist them with financial issues.

To get more detail on the type of financial assistance provided, participants were asked to report whether or not they provide specific services. As indicated in Figure 36, the most common services provided include obtaining pre-authorization for diagnostic studies (84.8%) and coordinating insurance coverage (81.8%).

Figure 36. Type of Financial Assistance Provided



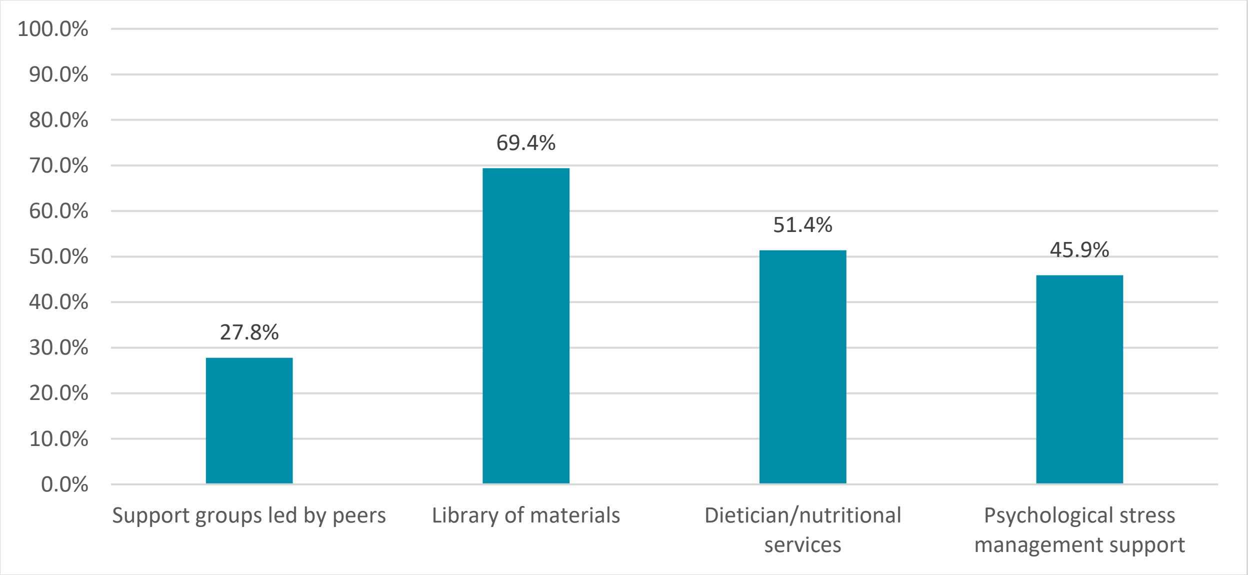
Note. *n* = 33.

Other responses for services were listed and included help with applying for financial assistance (*n* = 2), and one reference for each of the following: help with benefits (veteran, long-term care insurance), life insurance conversion options, coaching on setting up a GoFundMe account as a last option, and understanding the healthcare system/procedures.

Support Programs for Patients

Providers were also asked about the types of support programs they provide to patients. As illustrated in Figure 37, the most common support programs include having a library of materials for cancer patients (69.4%) and dietician/nutritional services (51.4%).

Figure 37. Type of Support Provided



Note: Support group (*n* = 36), library (*n* = 36), dietician/nutritional (*n* = 37), psychological/stress (*n* = 37).

A total of 12 participating providers stated that they do not offer supporting services within their organization, but that they refer them elsewhere. These referrals included Michelle's Place (*n* = 5), Loma Linda Medical Center (*n* = 4), American Cancer Society (*n* = 3), primary care physician (*n* = 2), and one reference for each of the following: inpatient services, local support groups, Orange County, Riverside County Office on Aging, Veterans Administration, Veterans A&A Assistance Providers, Life Insurance Conversion Providers, and Leukemia Lymphoma Society.

> *"We do have some services here but the majority we refer to Michelle's Place as well as the American Cancer Society, Leukemia Lymphoma Society"*

Participating providers were asked, "Does your office/practice offer any other supportive programs for cancer programs?" Results included a Children's Cancer Center, Coping with Cancer Support Group, pet placement, social services, hospice, alternative therapies, partnerships with other organizations, and whole person care.

Issues with Beginning Care

Providers were asked if they have any issues beginning care in locally the Southwest Riverside County area. As illustrated in Table 57, the majority of participating providers (65.7%) have problems beginning care locally.

Table 57. Issues with Beginning Care

Issues?	Percentage
No, we have no issues beginning local cancer care	34.3%
Yes, we have issues beginning local cancer care	65.7%

Note: *n* = 35.

These 23 providers were asked to check all issues that applied in regard to difficulty beginning local care. As illustrated in Table 58, over half of providers report that patients have difficulty with the distance to and from the treatment location.

Table 58. Specific Issues with Beginning Care

Specific Issue	Percentage
The patient has problems with the distance to and from the treatment location	56.5%
We lack enough cancer specialists	47.8%
We have problems with the amount of time it takes to get an appointment	34.7%
We have problems coordinating care between the primary care provider and the specialist	21.7%
Other problems	39.1%

Note: *n* = 23 who had issues with beginning care.

The "other" problems included issues with delays in authorizations for care (*n* = 4), financial issues for patients (*n* = 2), a lack of oncology specialists (*n* = 2), delays in pathology testing (*n* = 1), issues with in-home support (*n* = 1), difficulty hiring enough caregivers (*n* = 1), and a lack of diagnosis/biopsy/work-up prior to referrals being made (*n* = 1).

> *"Authorizations for care within HMOs as well as PPOs for regimens as well as patient financial cost shares stop many from immediate treatment until support/help can be acquired"*

Treatment Outside of SW Riverside County

A total of 86.5% of providers reported referring their patients with cancer for care outside of the area. When asked for the reason for this referral, most providers (68.8%) did so because of clinical trial availability, as illustrated in Table 59.

Table 59. Reason for Referral

Reasons	Percentage
Availability of clinical trials	68.8%
More therapeutic options available	46.9%
Rare cancer type	46.9%
Patient preference	40.6%
More diagnostic modalities available	34.3%
Lack of confidence in local oncology services	18.8%
Other	25.0%

Note: *n* = 32 providers who have referred their patients outside the area.

"Other" reasons for referring patients included for transplants (*n* = 5), and specialized services that were not available in the area such as gynecology oncology (*n* = 3), orthopedic oncology (*n* = 2), surgical oncology (*n* = 2), Whipple surgery for pancreatic patients (*n* = 2), and ophthalmology specialty (*n* = 1).

> *"There isn't many oncology specialist in the area have to send patients to other counties to see cancer specialist, or to get surgeries done and many patients struggle to get transportation outside of riverside county"*

Providers were asked, "For which type of cancer treatment service, if any, do cancer patients typically seek care outside of your area?" Most participating providers (53.1%) report that patients leave the area for their surgery services, as illustrated in Table 60.

Table 60. Outside Treatment

Type of Treatment	Percentage
Surgery	53.1%
Pediatric cancer services	40.6%
Targeted therapy	37.5%
Immunotherapy	28.1%
Chemotherapy	28.1%
Radiation therapy	21.9%
Other	21.9%

Note: *n* = 32.

"Other" types of responses included bone marrow transplants (*n* = 3), and one each for the following: alternative cancer treatments, gynecology oncology, clinical trials, and home infusions.

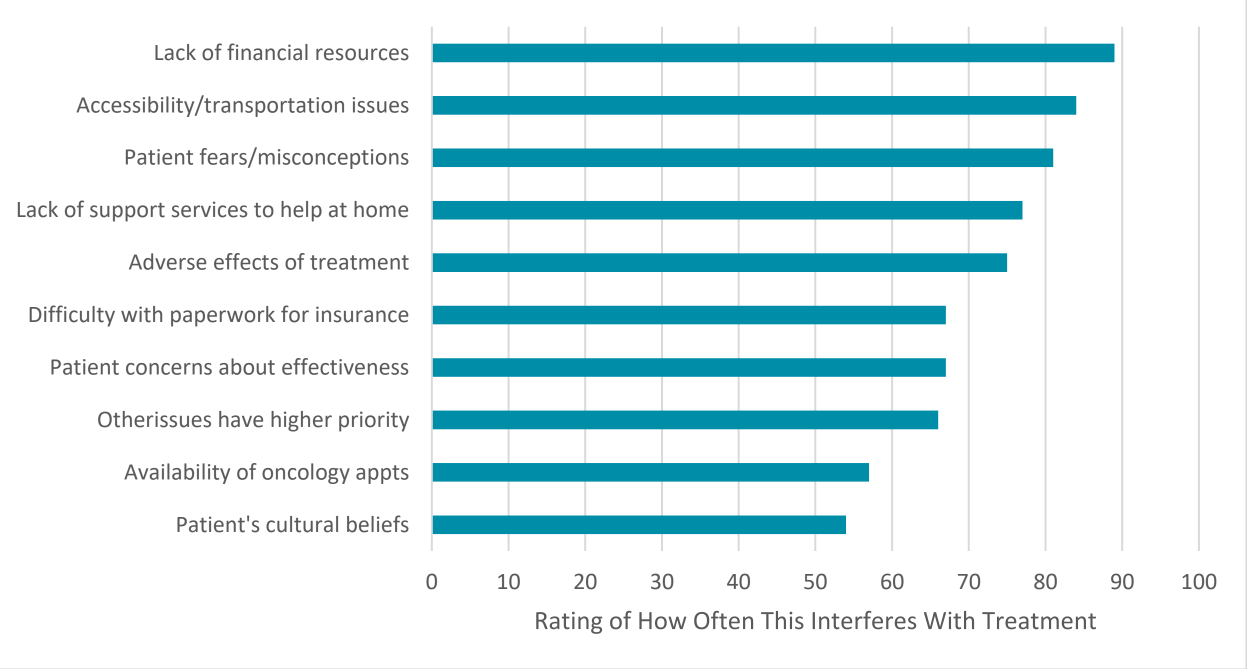
Issues with Treatment

Providers were asked to report how frequently certain issues interfere with patients' cancer treatment: frequently, sometimes, occasionally, or never.

These ratings were compiled into a single score to indicate how frequently these issues interfere with treatment, where 100 is the highest (all participating providers say that this issue "frequently" interferes with patients' treatment) and 0 is the lowest (all participating providers say that the issue "never" interferes with patients' treatment).

As illustrated in Figure 38, a lack of financial resources is the most common issue that interferes with treatment, followed by patient accessibility/transportation issues. Cultural beliefs are the least likely to interfere with treatment.

Figure 38. Ranked Issues with Treatment



Providers were also asked, “Are there any services your cancer patients require that you find difficult in arranging?” Seven participating providers had no issues arranging services. However, 16 providers did have issues arranging services.

As illustrated in Table 61, providers most commonly reported that setting up transportation for patients and setting up home healthcare and caregiving were difficult services to arrange.

Table 61. Difficult Services to Arrange

Service	Frequency
No issues	7
Setting up transportation	7
Setting up home healthcare and caregiving	5
Finding gynecology oncology specialists	3
Finding financial aid	3
Radiology centers are difficult to access	3
Getting pathology results is difficult	2
Providing PICC supplies for home maintenance	2
Conducting surgical consults	2
Nutritional counseling and support	2
Care coordination	1
Getting appointments	1
Outpatient medical services	1

> *“Transportation. Funding to pay for services. Lack of Caregiver Employees (we are always hiring!)”*

> *“Transportation and copay assistance”*

> *“Home healthcare, nutritional counseling and support, support for transportation to and from visits/treatment, PICC line supplies for home maintenance, PEG tube feeding formula”*

General Comments

To assess provider perceptions of local cancer care in their own words, providers were asked, “How can local cancer care facilities be improved?” and “Do you have any other comments you’d like to provide about cancer care in Southwest Riverside County?”

The majority of these comments were about getting more providers to the area, including specialized providers (“Need Gyn onc physician”), nurse navigators (“we should have nurse navigators for assisting patients one-on-one through the process”), or surgeons (“Need more onc surgeons”). For example,

> *“I wish there was more availability to the local Oncologists and their patients with more equipped hospitals. More trained nurses, doctors, PA, front office, maybe put more focus in the local colleges for these positions.”*

Transportation came up again as a theme, related sometimes to the lack of providers locally. For example,

> *“There needs to be more capable hospitals to help support the local Oncologists we already have. There also needs to be more Oncologists who can handle rare cancers in the area. Riverside County has a lot of older patients that can not drive and or there are young people or middle class that can't afford to be driving 50, 60 or 100 miles each way to get treatment done.”*

Several comments were also aimed at increasing clinical trial participation in the region (“Bring clinical trials to our area”). Others emphasized the need for financial support (“access to financial assistance and transportation for those pts without support” and “financial assistance from a local foundation will be very helpful”).

A few comments were aimed at health insurance: “ensure that the insurance market is fully contracted with local providers for cancer treatment” and “We need more providers who accept Blue Shield PPO”.

Two comments targeted home health care specifically, saying the industry is fragmented, difficult for families to understand, and should be accredited by the Joint Commission.

Finally, several comments emphasized that cancer care in Southwest Riverside County is very good, although patients may not realize it. For example,

> *"I would like our local valley residents that they can get the same or even better, more personal cancer care here in the valley without driving long distances and being away from their homes."*

> *"I believe that the majority of cancer patients can have excellent care within our community. However, I also believe that there is a miss conception by the public about the availability of that care and the level of care available to them. There are also providers linked to larger cancer care corporations that feed their own system by referring patients from our Valley to facilities in Orange County, or Greater LA County."*

> *"I would like patients to know that when they are diagnosed with cancer that they can see a local oncologist and receive the same if not better oncology treatment and care closer to home, that will provide the most up to date, targeted treatment available to them here in the area. Our facility alone strives to make each patient feel they are our only patient, providing them the best tx possible without leaving the area, from the phone which does not have a phone tree, an actual person always answers to the front office knows their name when they walk in to celebrating their milestones of their tx journey with us. Personal and caring tx from our knowledgeable experienced nursing staff. Knowing that our staff feels passionate about the fight against cancer and their individual cancer journey, sometimes as simple as being there to hold their hand when they need us."*

CONCLUSION

Overall, the results of this needs assessment describe the status of cancer care in Southwest Riverside County, as viewed by the patients, the caregivers, and the healthcare providers. There are some bright spots, and some weaker spots that the Task Force can focus on improving in order to improve the experience overall.

It is worth noting that many of the suggestions in this conclusion are large in scope, requiring serious consideration and investment of time, effort, and funding. Others are considerably easier. Overall, this is meant to be a multi-pronged effort to improve the lives of people with cancer in Southwest Riverside County.

Accreditation

Participating cancer patients/survivors felt that the #1 major issue in local cancer care was the lack of accredited cancer centers in the region, as did caregivers. About 33% of cancer patients/survivors said they chose their treatment facility because of its reputation as a high-quality facility, which is closely tied to accreditation.

To address the issue of accreditation, local hospitals should explore creating a formal cancer center, and beginning the process of becoming accredited, including any of the following:

- Commission on Cancer (CoC) accreditation, by the American College of Surgeons
- National Accreditation Program for Breast Centers, by the American College of Surgeons
- Members of the Association of American Cancer Institutes
- National Cancer Institute Designated Cancer Center

Accreditation is not easy nor is it simple; however, if the goal is to provide cancer patients with treatment within their own region, it is likely necessary. Any steps that can be made in this direction will have a positive impact. Task Force partners from local hospitals will need to educate the rest of the Task Force as to how we can support them on this journey.

Clinical Trials

Only 6% of participating cancer patients/survivors were a part of a clinical trial, and 18% of participating cancer patients/survivors say that lack of clinical trial opportunities in Southwest Riverside County is a major issue. Availability of clinical trials is the #1 reason why providers refer their patients out of the area; 69% of providers who refer out do so because of this reason. Thus, if we want to retain treatment here in SW Riverside County, we need to bring in more clinical trial opportunities.

Members of the Task Force who are engaged in direct care can help educate the rest of the Task Force as to what this will require, and how other Task Force members can support them.

Provider Supply

Patients and caregivers alike agree that the second most pressing issue in the region was the lack of specialized cancer care. This resulted in delays in care, and in the need to leave the region for treatment. For example, 31.6% of cancer patients/survivors had to wait more than 2 weeks between their diagnosis and their appointment with a cancer specialist. Subsequently, 54.4% had to wait more than 2 weeks between the appointment with the cancer specialist and the start of treatment. Reasons for the delay centered around the need for more providers, more specialists, more chemo chairs, etc.

Patients, caregivers, and providers alike noted that if a patient had a rare form of cancer, needed a transplant, wanted to participate in a clinical trial, had a very complex treatment plan, or other specialized issue, they were sent out of the area to major teaching hospitals and cancer centers.

To address the issue of a lack of providers, we must be able to attract and retain cancer care providers. The July Task Force meeting featured guest speaker Sonya Jackson, Physician Recruitment Development Director from the Riverside County Medical Association. Discussion with Ms. Jackson centered around how to market the region to potential providers, how to make new physicians feel welcome, and how to create networking opportunities. The Task Force members should continue to work with Ms. Jackson to attract and retain providers in the future.

Another way to bring in more physicians is to "grow your own". Recent research shows that 39% of family medicine residents stay within 25 miles of where they did their residency to practice.[4] Thus, it is likely that if a residency program could be started in Southwest Riverside County, many of its graduates would stay to practice medicine well beyond their years of residency. Like the accreditation issue, this is by no means a quick fix: getting a residency program is a lengthy and difficult process. However, it is a proven way to increase the number of physicians practicing in the area.

Once again, members of the Task Force who are engaged in direct care can help educate the rest of the Task Force as to what this recruitment, retention, and growth effort will require, and how other Task Force members can support them.

Communication About Resources

The #1 thing that cancer patients/survivors wanted help with was advice about community resources first and foremost; more than 32% would've liked assistance with this during their illness. Similarly, the #1 desired help for unpaid caregivers was information about additional resources (such as transportation programs, meal assistance, etc.); 54% would've liked help with this. It is clear that the need for information is strong for both cancer patients and their caregivers.

Thus, moving forward, it would be beneficial for the Task Force—or another entity, if more appropriate—to maintain a list or database of relevant resources. This resource

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[4] Fagan, E.B., et al. (2013). Migration after family medicine residency: 56% of graduates practice within 100 miles of training. *American Family Physician, 88,* 704.

should be made available in print and online, and will require regular updating to ensure that resources are accurate and up-to-date. The online version will need to be search engine optimized so that it will appear to those searching online for resources.

HARC has developed an initial list of resources. This list is ready for Task Force members to contribute their expertise and expand it, and then to be hosted online indefinitely. One member of the Task Force should take ownership of the resource list and be responsible for updating it, maintaining it, and ensuring that it is in the right people's hands (e.g., hospitals, provider offices, etc.).

Cancer patients/survivors say that the two best ways to reach them are via email (31%) and by printed materials sent to their home (20%), followed by messages from their healthcare provider (17%) and social media (14%). Any outreach that the Task Force does about cancer resources or treatment options should prioritize modes of communication accordingly.

Developing a Foundation

Financial support emerged as a definite issue in this needs assessment. Specifically, 33% of participating cancer patients/survivors find the high cost of treatment to be a major issue locally. More than 30% of participating cancer patients/survivors needed financial assistance. Some of this was provided by private organizations, pharmaceutical companies, charities, etc., but many were unable to receive help. About 24% of cancer patients/survivors say they need help paying for treatment, and nearly 21% said paying their bills was "very challenging". Providers say the #1 issue that interferes with patients' cancer treatment is a lack of financial resources.

To address this issue, the Task Force has previously discussed forming a nonprofit organization to help patients defray the costs of their treatment. Michelle's Place, a member of the Task Force and an organization supporting people with cancer, has already provided many patients with financial support. The Board and staff of Michelle's Place are willing to explore the possibility of expanding these activities to create a foundation arm to support locals with cancer financially.

Michelle's Place would be an ideal home for this resource; it was the most commonly accessed source of support for participating cancer patients/survivors (29% already utilize Michelle's Place for support in some way). Additionally, housing foundation activities within an existing nonprofit is far simpler than starting a nonprofit foundation from scratch.

However, this new service will require a revenue stream as well as oversight. The Task Force (or the Foundation Subcommittee of the Task Force) should consider ways in which to raise the necessary funds to support Michelle's Place staff in creating and administering the program, as well as raising funds to disperse to patients. HARC recommends that members of the Task Force would be ideal for an advisory board to guide this development of the foundation arm.

Additional Support

Family and friends are the primary source of support for household chores, home care, and transportation assistance. The majority of caregivers (75%) were part of an all-volunteer team; the patient had no paid caregivers. Most caregivers are providing emotional support and encouragement (93%), going to doctor appointments with the patient (84%), doing chores around the home (77%), and helping with transportation (75%). Thus, it is clear that friends and family are a crucial piece of a successful treatment and recovery.

But what of those cancer patients who are relatively isolated, and do not have many friends or family nearby to support them? It is likely that these individuals are seriously lacking in support, and could use assistance from outside agencies for things like household chores, home care, and transportation.

The Task Force should thoroughly investigate which agencies already provide these services, and where services could potentially be expanded to include these services for individuals who are relatively isolated. These resources should be carefully compiled and provided to all those who may come in contact with patients.

APPENDICES

Appendix A: Cancer Patient, Survivor, or Caregiver Survey

Are you a cancer patient, survivor, or a caregiver for someone with cancer?

If so, please take this confidential survey to help us better understand how cancer care in Southwest Riverside County can be improved, and what can be done to ease the burden of suffering on cancer patients and their loved ones.

By participating in the survey, you'll be entered to win a $100 Visa card.

HARC (Health Assessment and Research for Communities), a local nonprofit is conducting the survey in collaboration with the Southwest Riverside County Cancer Care Task Force.

If you have any questions or concerns about the survey, please contact the primary researcher at HARC, Jenna LeComte-Hinely, at jlecomte-hinely@HARCdata.org.

Eligibility

1. Do you live in Southwest Riverside County (Temecula, Murrieta, Wildomar, Lake Elsinore, Canyon Lake, Menifee, or surrounding areas)?
   - ☐ Yes *(please continue to question 2)*
   - ☐ No *(we're sorry, but at this time you are not eligible for this survey)*

2. Has a doctor, nurse, or other health professional EVER told you that you had cancer?
   - ☐ Yes *(please answer questions 4 through 37)*
   - ☐ No *(please continue to question 3)*

3. Have you been a caregiver for someone with cancer in Southwest Riverside County? Note: By "caregiver" we mean someone helping a family or friend, a home health aide, or other in-home caregiver. It does not refer to medical professionals such as nurses, PAs, or physicians
   - ☐ Yes *(please answer questions 38 through 51)*
   - ☐ No

Note: If you are both a cancer patient/survivor and have been a caregiver for someone with cancer, please complete the entire survey; we'd love to hear both sides of your experience.

Cancer Patient/Survivor Section

Cancer Diagnosis

4. How long ago were you told you had cancer? If you've had multiple cancers, please respond regarding your most recent diagnosis.
   - ☐ Less than six months ago
   - ☐ Six months to a year ago
   - ☐ One to five years ago
   - ☐ More than five years ago

5. What type(s) of cancer have you had? Please check all that apply.
   - ☐ Bladder
   - ☐ Breast
   - ☐ Colon and rectum
   - ☐ Kidney and renal pelvis
   - ☐ Leukemia
   - ☐ Lung
   - ☐ Bronchus
   - ☐ Lymphoma
   - ☐ Prostate
   - ☐ Skin
   - ☐ Uterus
   - ☐ Other (please specify): ____

6. What stage was your cancer when it was initially diagnosed?
   - ☐ Stage I
   - ☐ Stage II
   - ☐ Stage III
   - ☐ Stage IV
   - ☐ Don't know, can't recall

7. How long was it from the time you first thought something might be wrong with you until you saw a health care provider about it?
   - ☐ Less than a month
   - ☐ 1 to 3 months
   - ☐ 4 to 6 months
   - ☐ More than 6 months
   - ☐ Don't know/can't remember

8. If you delayed seeking care, why?
   - ☐ Financial reasons: lack of insurance/high deductible/couldn't afford
   - ☐ Didn't have a primary care provider
   - ☐ Lack of transportation to care
   - ☐ Childcare or other caregiver responsibilities
   - ☐ Work responsibilities
   - ☐ Afraid
   - ☐ Other life problems were more important
   - ☐ Didn't trust doctors
   - ☐ Other (please specify): ____

9. How long was it from the time you first thought something might be wrong with you until you were affirmatively diagnosed with cancer? ____________________________________

10. When you first went to the doctor for your issue, was it ever misdiagnosed as something other than cancer?
    - ☐ Yes
    - ☐ No

11. After you learned you had cancer, how long did it take for you to see a cancer care specialist to discuss treatment choices?
    - ☐ One to three days
    - ☐ Three to seven days
    - ☐ One to two weeks
    - ☐ Two to four weeks
    - ☐ More than a month

12. If it took longer than two weeks, why?

____

____

13. What type of specialist were you referred to?
    - ☐ A surgeon
    - ☐ Oncologist
    - ☐ Other (please specify): ____

Cancer Treatment

14. Are you currently receiving treatment for cancer? By treatment, we mean surgery, radiation therapy, chemotherapy, or chemotherapy pills.
    - ☐ Yes
    - ☐ No, I've completed treatment
    - ☐ No, I've refused treatment
    - ☐ No, I haven't started treatment

15. What is the name of the cancer care treatment office or facility where you received the majority of your treatment?

____

16. With your most recent diagnosis of cancer, did you have health insurance that paid for all or part of your cancer treatment? Health insurance includes Medicare, Medicaid, or other types of state programs.
    - ☐ Yes
    - ☐ No

17. Were you EVER denied health insurance or life insurance coverage because of your cancer?
   - ☐ Yes
   - ☐ No

18. Did you participate in a clinical trial as a part of your cancer treatment?
   - ☐ Yes, at ____ hospital/healthcare facility
   - ☐ No

19. What sources of information did you use to decide what cancer treatment to select?

	Very Important	Somewhat Important	Not very important	Not at all important	N/A
My oncologist's recommendations					
Alternative/complementary medical professional's recommendations					
Friends and family					
American Cancer Society					
Online resources					

20. What factors influenced your decision about which treatment to choose?

	Most important reason	Somewhat important	Not important	N/A
Financial/insurance coverage to pay for the costs				
Geographic proximity/transportation to and from the treatment				
Trust that the treatment would be successful				
Concern about side effects				
Advice from friends and family				
Ability to manage treatment while working				
Responsibilities at home				

21. After your first consultation visit with your cancer care specialist, how long did it take to begin your treatment?
   - ☐ One to three days
   - ☐ Three to seven days
   - ☐ One to two weeks
   - ☐ More than a month

22. If it took longer than two weeks, why?

____

____

23. During your cancer treatments, did you also consult alternative/complementary care providers?
    - ☐ Yes
    - ☐ No *(skip to question 26)*

24. If yes, what kind? Check all that apply.
    - ☐ Acupuncturist
    - ☐ Therapeutic massage
    - ☐ Counselors/stress management
    - ☐ Nutritional counselor
    - ☐ Naturopathic/homeopathic doctor
    - ☐ Other (please specify): ____

25. Where did you receive the most of your alternative/complementary cancer care?
    - ☐ In Southwest Riverside County at: ____
    - ☐ Elsewhere in Riverside County at: ____
    - ☐ Outside of Riverside County at: ____

Geographic Cancer Treatment

26. When you were seeking treatment for your cancer, where did you get the MAJORITY of your cancer treatment?
    - ☐ In Southwest Riverside County at: ____
    - ☐ Elsewhere in Riverside County at: ____
    - ☐ Outside of Riverside County at: ____

27. How far is it/was it from your home?
    - ☐ 0 – 10 miles
    - ☐ 10 – 25 miles
    - ☐ 25 – 50 miles
    - ☐ 50 – 100 miles
    - ☐ More than 100 miles

28. How do you/did you get there? ____

29. Why did you seek treatment at that particular facility? Please check all that apply.
    - ☐ It was convenient
    - ☐ It was well-known as a high-quality treatment center
    - ☐ My insurance would cover it
    - ☐ That’s where my doctor of choice practices
    - ☐ The type of treatment/specialty was not available closer to home
    - ☐ Other (please describe): ____

Issues/Problems/Areas for Improvement

30. During your cancer treatment and recovery, did you need assistance with any of the following? Were you able to receive that assistance? If you received assistance, who provided the assistance?

	I did not need this type of help	I needed help, but didn't receive help	I needed help, received it from… (specify)
Financial assistance			
Transportation assistance			
Utility assistance			
Lodging assistance			
Home care			
Household chores			

31. What do you think are the most critical cancer healthcare issues in Southwest Riverside County?
    - ☐ High cost of treatment
    - ☐ Lack of accredited cancer centers in the region
    - ☐ Lack of awareness of where to go to seek treatment
    - ☐ Lack of health insurance/difficulty finding providers that will take my specific health insurance
    - ☐ Lack of transportation
    - ☐ Lack of clinical study opportunities
    - ☐ Lack of specialized cancer care
    - ☐ Lack of cancer screening opportunities
    - ☐ Takes too long to make an appointment to see a doctor in this region
    - ☐ Other (please specify): ____

32. What areas, if any, would you have liked help with during your illness? Please check all that apply.
    - ☐ Advice about what community resources, social services and/or support groups are available
    - ☐ Help arranging care services at my home
    - ☐ Help arranging childcare or other care responsibilities
    - ☐ Help coordinating my care
    - ☐ Help in applying for any benefits I might be eligible for
    - ☐ Help paying co-pays/out-of-pocket costs for my treatment
    - ☐ Help scheduling and keeping track of my appointments
    - ☐ Help understanding my diagnosis and treatment options
    - ☐ Help with my insurance/billing paperwork
    - ☐ Help with transportation
    - ☐ Other (please specify): ____

33. What problems are you/did you experience during your cancer treatment?

	Very challenging	Somewhat challenging	Not an issue
Concerns about other people's learning of/reactions to my illness			
Paying my bills			
Keeping track of/organizing appointments			
Keeping track of/organizing my insurance and bills			
Keeping track of/organizing my medical records and test results			
Keeping track of/organizing my medications, refills, etc.			
My emotional state and my feelings about this experience			
My need to keep my job			
Other transportation			
Shopping and preparing meals			
Side effects of treatment			
Spiritual concerns			
Transportation to treatment/doctor's appointments			
Uncertainty about my future			
Worries about my family			

Support Systems

34. Did you/do you have help at home to assist you during your recovery?
   - ☐ Yes, my family/friends give all the help I need
   - ☐ Yes, family/friends give some help, but I could use more
   - ☐ I have help from a paid attendant(s)
   - ☐ I have no help at home, but would appreciate this
   - ☐ I don't require any assistance
   - ☐ I can't afford home assistance
   - ☐ Other (please specify): ____

35. Did you/do you now receive support from any of these organizations? Please check all that apply.
   - ☐ American Cancer Society
   - ☐ Cancer Care Co-Payment Assistance Foundation
   - ☐ Cancer Legal Resource Center (CLRC)
   - ☐ Cleaning for a Reason (donated maid service for women with cancer)
   - ☐ Michelle's Place (breast cancer resource center in Temecula)
   - ☐ Susan G. Komen
   - ☐ The Pink Ribbon Place (breast cancer resource center in Riverside)
   - ☐ Other (please specify): ____

36. Did you/do you now receive any of these types of support? Please check all that apply.
   - ☐ Counseling/individual therapy/stress management
   - ☐ Home health care
   - ☐ Hotlines or live chats (such as those provided by Susan G. Komen or the American Cancer Society)
   - ☐ Housekeeping/meal preparation help (e.g., Visiting Angels, etc.)
   - ☐ Occupational therapy
   - ☐ Patient navigators
   - ☐ "Road to Recovery" transportation service by American Cancer Society
   - ☐ Support groups/group therapy
   - ☐ Financial Assistance
   - ☐ Other (please specify): ____

Media/Distribution

37. We'd like to share cancer care resources with the community at large to make sure people know what resources exist to help them. What method of communication would be most likely to reach you?
   - ☐ TV
   - ☐ Radio
   - ☐ Newspaper
   - ☐ Printed materials mailed to my house
   - ☐ Emails
   - ☐ Phone calls
   - ☐ Community events
   - ☐ Messages from my healthcare provider
   - ☐ Social Media

If you are/have been a caregiver for someone with cancer, please continue to the next page.

If you are not/have not been a caregiver for someone with cancer, please skip to question 52 (the demographics section) to complete the survey.

Caregiver Section

Caregiving Relationship

38. Please specify the number of patients you cared for in Southwest Riverside County. Note: If you cared for more than one cancer patient, please complete the remainder of the survey referencing your most recent caregiving experience. # of patients: ____________

39. What was the patient's relationship to you?
    - ☐ My parent
    - ☐ My spouse/significant other/partner
    - ☐ My sibling
    - ☐ My child
    - ☐ My friend
    - ☐ My client
    - ☐ Other (please specify): ____

40. How would you characterize your role on this patient's caregiving team?
    - ☐ I was the only caregiver this patient had during their treatment/recovery
    - ☐ I was the main caregiver this patient had during their treatment/recovery
    - ☐ I was one of several caregivers this patient had during their treatment/recovery
    - ☐ I played a relatively minor role, mostly supporting other caregivers

41. Did this patient have any *paid* caregivers, e.g. home health aides, etc.? Note: This only applies to caregivers from outside the hospital, in the home environment—this does not include nurses, social workers, doctors, etc., that cared for the patient in the hospital or at the treatment facility.
    - ☐ Yes, I am a paid caregiver for this patient
    - ☐ Yes, the patient has a paid caregiver (but it's not me)
    - ☐ No, this patient has no paid caregivers

42. How long did you provide care for this patient? Note: If you are currently providing care, please select the category which is most appropriate for you currently.
    - ☐ Less than 6 months
    - ☐ 6 months to 1 year
    - ☐ 1 year to 2 years
    - ☐ 2 years to 3 years
    - ☐ 3 years or more

43. How recent was this caregiving?
    - ☐ I am currently caring for this patient
    - ☐ Within the past year
    - ☐ Between 1 and 2 years ago
    - ☐ Between 2 and 5 years ago
    - ☐ More than 5 years ago

About the Patient

44. What type of cancer did this patient have? Please check all that apply.
    - ☐ Bladder
    - ☐ Breast
    - ☐ Colon and rectum
    - ☐ Kidney and renal pelvis
    - ☐ Leukemia
    - ☐ Lung and bronchus
    - ☐ Lymphoma
    - ☐ Prostate
    - ☐ Skin
    - ☐ Uterus
    - ☐ Other (please specify): ____

45. What stage was the patient's cancer when it was initially diagnosed?
    - ☐ Stage I
    - ☐ Stage II
    - ☐ Stage III
    - ☐ Stage IV
    - ☐ Don't know, can't recall

Caregiver Responsibilities

46. What sort of support did you provide for the patient? Help with…Check all that apply.
    - ☐ Caring for the patient's children
    - ☐ Chores around the home (e.g., cooking, cleaning, laundry)
    - ☐ Coordinating medical appointments
    - ☐ Emotional support and encouragement
    - ☐ Financial support
    - ☐ Giving medications
    - ☐ Going to doctor's appointments with the patient
    - ☐ Handling insurance and/or billing issues
    - ☐ Managing symptoms and/or side effects
    - ☐ Transportation
    - ☐ Other (please specify): ____

47. How did you prepare for your role as a caregiver? Check all that apply.
    - ☐ I just jumped right in, no preparation
    - ☐ I researched cancer on the internet
    - ☐ I talked to other cancer patients/survivors/caregivers to get a better understanding of what it would take
    - ☐ I talked to healthcare providers to better understand cancer
    - ☐ I'm a professional caregiver
    - ☐ Other (please specify): ____

48. Did you ever access caregiver resources (such as the Cancer Hope Network's caregiver volunteer match system, or AARP's "Caregivers in the Community" connection program, etc.)?
    - ☐ Yes
    - ☐ No, but I'd be interested
    - ☐ No, I don't want caregiver resources

Needs/Barriers/Issues

49. What do you think are the most critical cancer healthcare issues in Southwest Riverside County?
    - ☐ High cost of treatment
    - ☐ Lack of accredited cancer centers in the region
    - ☐ Lack of awareness of where to go to seek treatment
    - ☐ Lack of health insurance/difficulty finding providers that will take a patient's specific health insurance
    - ☐ Lack of transportation
    - ☐ Lack of clinical study opportunities
    - ☐ Lack of specialized cancer care
    - ☐ Lack of cancer screening opportunities
    - ☐ Takes too long to make an appointment to see a doctor in this region
    - ☐ Other (please specify): ____

50. In your opinion, what service/support system would've been most beneficial for this patient in his/her treatment and recovery? Please check all that apply.
    - ☐ Help understanding diagnosis and treatment options
    - ☐ Help scheduling and keeping track of appointments
    - ☐ Help with transportation
    - ☐ Help arranging childcare or other care responsibilities
    - ☐ Help in applying for any benefits
    - ☐ Help arranging care services at home
    - ☐ Help with insurance/billing paperwork
    - ☐ Advice about what community resources and social services are available
    - ☐ Help paying co-pays/out-of-pocket costs for his/her treatment
    - ☐ Help coordinating care
    - ☐ Other (please specify): ____

51. If you were/are an unpaid caregiver, what areas, if any, would you like help with? Please check all that apply.
    - ☐ A support group for caregivers
    - ☐ Respite care/paid caregivers so I could get a break
    - ☐ Information about additional resources we may have been able to get (e.g., transportation programs, meal assistance, etc.)
    - ☐ Time off from work to be a caregiver
    - ☐ Other (please specify): ____

Demographics Section

52. What is your race? Please select all that apply.
    - ☐ White/Caucasian
    - ☐ Black/African American
    - ☐ American Indian/Alaska Native
    - ☐ Asian
    - ☐ Native Hawaiian/Pacific Islander
    - ☐ Other (please specify): ____

53. Are you of Hispanic, Latino, or Spanish origin?
    - ☐ No, not Hispanic, Latino, or Spanish
    - ☐ Yes, Mexican, Mexican-American, Chicano
    - ☐ Yes, Puerto Rican
    - ☐ Yes, Cuban
    - ☐ Yes, another Hispanic, Latino, or Spanish origin

54. What is your age? ____

55. What is the highest grade of education you have completed and received credit for?
    - ☐ No formal education
    - ☐ Elementary school
    - ☐ Some high school
    - ☐ High school degree or equivalent
    - ☐ Some college
    - ☐ Vocational school
    - ☐ AA/AS degree
    - ☐ BA/BS degree
    - ☐ Some graduate school
    - ☐ MA/MS degree
    - ☐ PhD or equivalent

56. How would you identify your gender?
    - ☐ Male
    - ☐ Female
    - ☐ Transgender
    - ☐ Other (please specify): __________________________________

57. What is your annual household income before taxes?

    ____

58. How many people live in your household IN ADDITION to yourself? _______________

59. What city do you live in? ____

Raffle

If you would like to be entered into a drawing to win a $100 Visa gift card, please provide your first name AND an email address or phone number.

Name: ____

Email or phone number: ____

Thank You!

Thank you for taking this survey. Your responses will be combined with others to inform us on the quality of cancer care in Southwest Riverside County.

If you have any questions or concerns about the study, please contact us:

Dr. Jenna LeComte-Hinely
Chief Executive Officer
Health Assessment and Research for Communities
760-404-1945
jlecomte-hinely@HARCdata.org

Appendix B: Healthcare Provider Survey

Thank for contributing to our survey. This survey is intended to help us better understand how cancer care in Southwest Riverside County can be improved, and what can be done to ease the burden of suffering on cancer patients and their loved ones.

This survey contains about 25 questions and will be completely confidential—no one will ever see your individual responses. A local nonprofit called HARC is conducting the survey in collaboration with the Southwest Riverside County Cancer Care Task Force.

At the end of the survey, you will have the opportunity to enter a drawing for a $100 Visa gift card.

If you have any questions or concerns about the survey, please contact the primary researcher at HARC, Jenna LeComte-Hinely, at jlecomte-hinely@HARCdata.org.

1. Are you a healthcare provider? If so, what type?

- ☐ Physician (MD, DO)
- ☐ Nurse (including NPs, LPNs, RNs, etc.)
- ☐ Physician assistant
- ☐ Pharmacist
- ☐ Patient Care Coordinator
- ☐ Social Worker (health/hospital/cancer related)
- ☐ I am not a healthcare provider
- ☐ Other type of healthcare provider (please specify): ______________________________

2. Do you treat patients in Southwest Riverside County, that is, in the cities of Temecula, Murrieta, Menifee, Wildomar, Lake Elsinore, Canyon Lake, or the surrounding unincorporated areas?

- ☐ Yes
- ☐ No *(we're sorry, but at this time you are not eligible for this survey)*

3. Name of your practice (Note: If you have multiple practices, please only reference those in Southwest Riverside County): ____

4. Your specialty: ____

5. Your title: ____

6. In terms of the cancer care continuum, where would you place yourself/your practice? Please check all that apply.

- ☐ Cancer screening
- ☐ Cancer diagnosis
- ☐ Cancer treatment
- ☐ Post-cancer treatment (including survivorship and end-of-life care)
- ☐ Other (please specify): ____

7. Where is your practice located? Please check all that apply.

- ☐ Lake Elsinore
- ☐ Menifee
- ☐ Murrieta
- ☐ Temecula
- ☐ Wildomar
- ☐ Canyon Lake
- ☐ Hemet
- ☐ San Jacinto
- ☐ Gilman Hot Springs
- ☐ Lake View
- ☐ Other (please specify): ____

8. Approximately what percentage of your patients have been diagnosed with cancer? _______

9. Approximately how many patients with cancer do you see each year? ___________________

10. How would you rate the quality of care for cancer patients available in Southwest Riverside County?

- ☐ Excellent, state of the art
- ☐ Very good, very good for most patients
- ☐ Average, standard or typical care
- ☐ Fair, but there are a few areas that need to be improved
- ☐ Poor quality such that I advise most of my patients to seek treatment options outside of the area
- ☐ Variable depending on factors such as type of cancer or patient's life circumstances
- ☐ Don't know/unsure

11. Please explain your reasoning for your response to item #10. _________________________

12. How would you rate the availability of cancer care in the Southwest Riverside County region as compared to other areas of Southern California (such as San Diego, Orange, or Los Angeles Counties)?

- ☐ Excellent
- ☐ Very good
- ☐ Average
- ☐ Below average
- ☐ Poor

13. Please explain your reasoning for your response to item #12. _________________________

14. What do you think is the most common problem that patients face when seeking… (please specify which problem you think is most common for each stage of care):

- Cancer screening: ____
- Cancer diagnosis: ____
- Cancer treatment: ____
- Post-cancer care: ____

15. Cancer patients often have financial concerns about their care costs, insurance coverage, loss of employment and income, applying for social security/disability, or paying for their housing and transportation. Do you have trained staff in your office to assist patients with financial issues?

- ☐ Yes
- ☐ Yes, but my staff could benefit from additional training
- ☐ No

16. What services does your office/practice staff provide?

	Yes	No	Not Sure
Help with coordinating insurance coverage			
Help with applying for public medical assistance programs			
Help applying for Social Security/Disability or other benefits			
Obtaining pre-authorization for diagnostic studies, chemotherapy, or other drugs/services			
Other (please specify):			

17. Does your office/practice offer any of the following supportive programs for cancer patients?

	Yes	No	Not Sure
Support groups led by peers			
A library of materials for cancer patients			
Dietician/nutritional services			
Psychological/stress management support			
None within our office and we do not refer them			
None within our office, but we do refer them here:			

18. Does your office/practice offer any other supportive programs for cancer patients?

19. If you and your patient decide to begin cancer treatment locally in Southwest Riverside County, do you typically have any issues beginning care? Please check all that apply.

- ☐ No, we have no issues beginning local cancer care
- ☐ Yes, we lack enough cancer specialists
- ☐ Yes, we have problems with the amount of time it takes to get an appointment
- ☐ Yes, we have problems coordinating care between the primary care provider and the specialist
- ☐ Yes, the patient has problems with the distance to and from the treatment location
- ☐ Other, please specify

20. Have you ever referred patients with cancer for care outside of your area?

- ☐ Yes
- ☐ No

21. If yes, why? Please check all that apply.

- ☐ Patient preference
- ☐ Availability of clinical trials
- ☐ More diagnostic modalities available
- ☐ More therapeutic options available
- ☐ Rare cancer type
- ☐ Lack of confidence in local oncology services
- ☐ Other (please specify): ____

22. For which type of cancer treatment service(s), if any, do cancer patients typically seek care outside of your area? Please check all that apply.

- ☐ Surgery
- ☐ Chemotherapy
- ☐ Radiation therapy
- ☐ Immunotherapy
- ☐ Targeted therapy
- ☐ Pediatric cancer services
- ☐ Other (please specify): ____

23. In your view, how can cancer care facilities in your region be improved to better meet the needs of cancer patients in Riverside County?

____

____

24. Please indicate how frequently the following issues interfere with your patients' cancer treatment—including cancer screening, diagnosis, treatment, and post-treatment care.

	Frequently	Sometimes	Occasionally	Never
Patient concerns about screening or treatment effectiveness				
Patient fears or misconceptions				
Adverse effects of the treatment				
Patient accessibility/transportation issues				
Availability of oncology appointments				
Patient's difficulty understanding/ completing paperwork for insurance				
Patient's lack of financial resources				
Lack of supportive services to help at home				
Other patient life issues have higher immediate priority				
Patient's cultural beliefs				

25. Are there any services that your patients require that you find difficulty in arranging?

____

____

26. Do you have any other comments you'd like to provide about cancer care in Southwest Riverside County?

____

Appendix C: Publicity Materials

Valley News Online Ad (clickable link), http://myvalleynews.com/, began 9/4/17:

Are You a Cancer Survivor?

Or a Caregiver for Someone with Cancer?

Then please share your story!

The Southwest Riverside County Regional Cancer Services Task Force is a group of cities and care providers that want to better understand cancer patients' experience so we can take steps to reduce the burden.

TAKE OUR SURVEY HERE

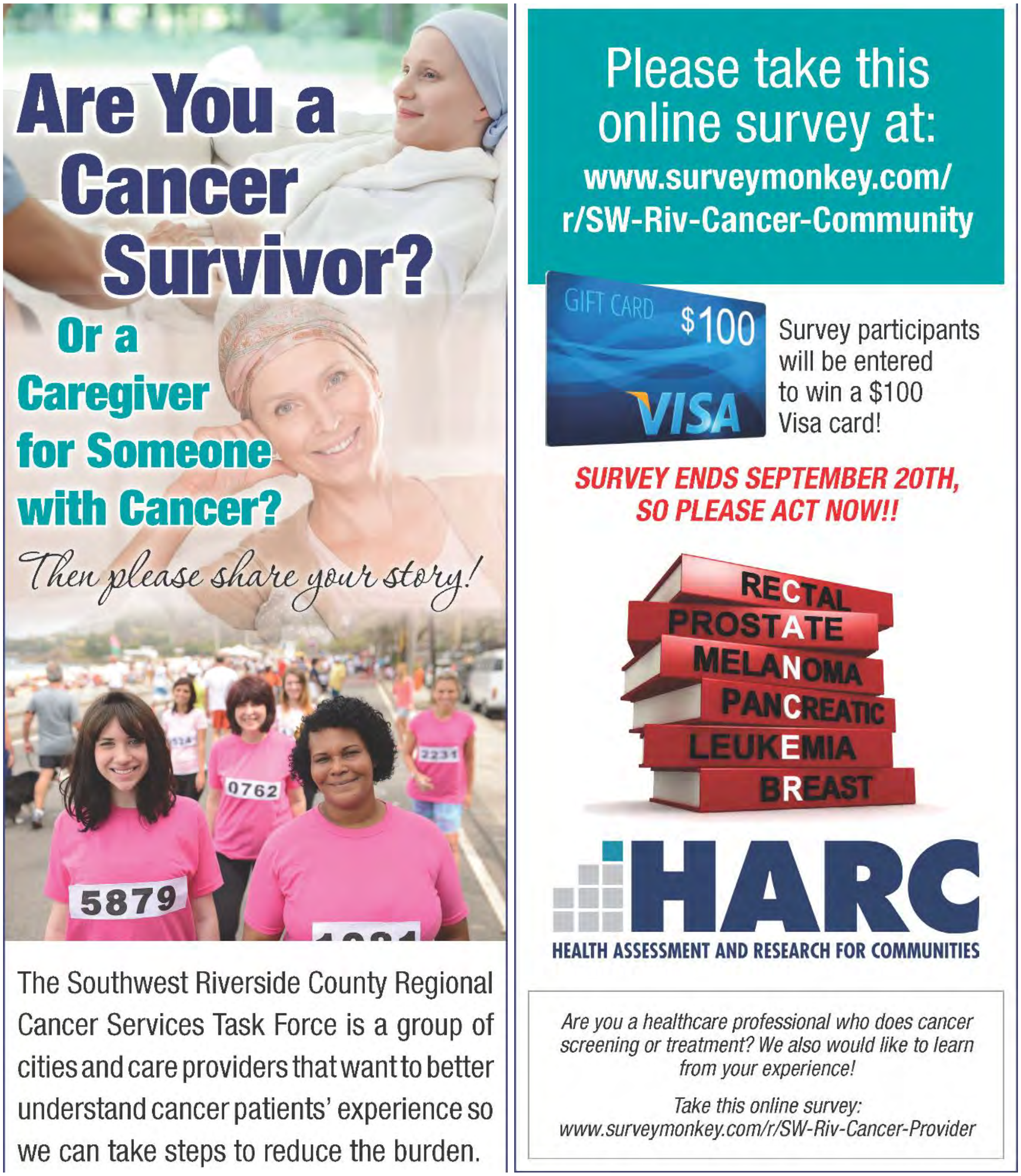
SURVEY ENDS SEPT 20TH, SO PLEASE ACT NOW!!

Survey participants will be entered to win a $100 Visa card!

HARC

HEALTH ASSESSMENT AND RESEARCH FOR COMMUNITIES

Valley News, Print Ad 9/8/17 and 9/15/17 (ad is one continuous image, presented here cut in half for easier viewing):



Are You a Cancer Survivor?

Or a Caregiver for Someone with Cancer?

Then please share your story!

The Southwest Riverside County Regional Cancer Services Task Force is a group of cities and care providers that want to better understand cancer patients' experience so we can take steps to reduce the burden.

Please take this online survey at:

www.surveymonkey.com/r/SW-Riv-Cancer-Community

Survey participants will be entered to win a $100 Visa card!

SURVEY ENDS SEPTEMBER 20TH, SO PLEASE ACT NOW!!

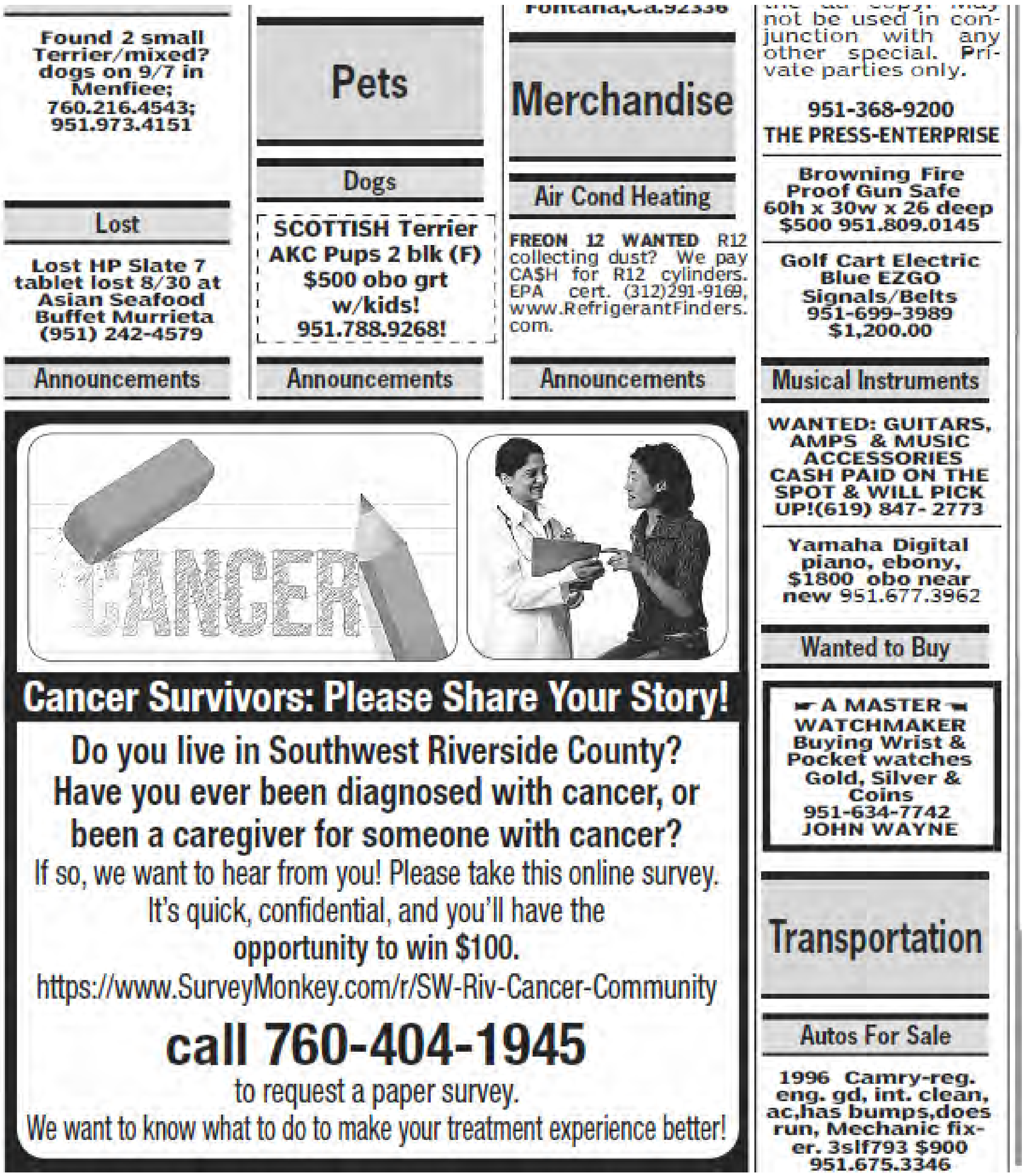
HARC

HEALTH ASSESSMENT AND RESEARCH FOR COMMUNITIES

Are you a healthcare professional who does cancer screening or treatment? We also would like to learn from your experience!

Take this online survey:
www.surveymonkey.com/r/SW-Riv-Cancer-Provider

The Press Enterprise, 9/10/17:



Found 2 small Terrier/mixed? dogs on 9/7 in Menfiee; 760.216.4543; 951.973.4151

Lost

Lost HP Slate 7 tablet lost 8/30 at Asian Seafood Buffet Murrieta (951) 242-4579

Announcements

Pets

Dogs

SCOTTISH Terrier AKC Pups 2 blk (F) $500 obo grt w/kids! 951.788.9268!

Announcements

Fontana,Ca.92336

Merchandise

Air Cond Heating

FREON 12 WANTED R12 collecting dust? We pay CA$H for R12 cylinders. EPA cert. (312)291-9169, www.RefrigerantFinders.com.

Announcements

Cancer Survivors: Please Share Your Story!

Do you live in Southwest Riverside County? Have you ever been diagnosed with cancer, or been a caregiver for someone with cancer?

If so, we want to hear from you! Please take this online survey. It's quick, confidential, and you'll have the **opportunity to win $100.**

https://www.SurveyMonkey.com/r/SW-Riv-Cancer-Community

call 760-404-1945

to request a paper survey.

We want to know what to do to make your treatment experience better!

not be used in conjunction with any other special. Private parties only.

951-368-9200
THE PRESS-ENTERPRISE

Browning Fire Proof Gun Safe 60h x 30w x 26 deep $500 951.809.0145

Golf Cart Electric Blue EZGO Signals/Belts 951-699-3989 $1,200.00

Musical Instruments

WANTED: GUITARS, AMPS & MUSIC ACCESSORIES CASH PAID ON THE SPOT & WILL PICK UP!(619) 847- 2773

Yamaha Digital piano, ebony, $1800 obo near new 951.677.3962

Wanted to Buy

☛ A MASTER ☚
WATCHMAKER
Buying Wrist & Pocket watches Gold, Silver & Coins
951-634-7742
JOHN WAYNE

Transportation

Autos For Sale

1996 Camry-reg. eng. gd, int. clean, ac,has bumps,does run, Mechanic fixer. 3slf793 $900 951.675.3346