



CANCER SURVIVOR FOCUS GROUP STUDY

Developing a better understanding of the needs and experiences of
cancer survivors in Nevada.

June 2017



NevadaCancerCoalition.org

Introduction

The 2016 – 2020 Nevada State Cancer Plan identified survivorship and quality of life as a priority focus, with an over-arching goal to:

Improve Nevada cancer survivors' quality of life through increased awareness, education, and access to survivorship resources and services.ⁱ

Cancer survivors are those who have been diagnosed with cancer, from the time of diagnosis throughout the remainder of his or her life. Survivorship and quality of life are critical issues for the health care and cancer community to address, as cancer affects not only the individual survivor, but their family, friends, and caregivers as well.

In Nevada there are an estimated 120,200 cancer survivorsⁱⁱ. People have begun to live longer after a cancer diagnosis due to early detection and treatment. In fact, today more than two-thirds of the people diagnosed with cancer are often told they have a life expectation of at least five years after diagnosis.ⁱⁱⁱ

The experiences of cancer survivors in Nevada are in many ways unique due to the state's geography which limits access to treatment and resources. Additional challenges within the state include known healthcare provider shortages and a high rate of uninsured residents, to name just two.

The Nevada Cancer Coalition (NCC), in partnership with the State of Nevada Division of Public and Behavioral Health's Comprehensive Cancer Control Program (CCCP), conducted a series of focus groups to gather information from cancer survivors in Nevada about their experiences and needs. This project was modeled on the successful Cancer Survivor Focus Groups completed in Vermont in 2006. Funding to support this project was provided by the Centers for Disease and Prevention Grant Number NU8DP003929-05.

The information gathered in the focus group series will be used by coalition partners to identify needs of cancer survivors and to develop strategies to meet those needs. This foundational knowledge may also contribute to future research opportunities.

Objectives:

- Identify the needs of cancer survivors in Nevada in the following domains: treatment; information and decision support; emotional, social, and spiritual; physical; activities and logistics of daily life; health and wellness; economic and legal; navigating service delivery systems.
- Identify to what extent cancer survivors feel their needs are being met.
- Determine if needs vary among cancer survivors by stage of survivorship, geographic location, or other variables.
- Identify any gaps in or barriers to receiving needed services and supports.

Due to the nature of the discussion, seeking feedback on lack of support or resources, much of this report focuses on challenges people faced throughout diagnosis and treatment, and after treatment. Many participants shared positive experiences as well, and some of those comments are shared at the end of this report.

This report describes the findings from four focus groups that were conducted January – March, 2017. As with all qualitative research, the findings are to be viewed as suggestive rather than definitive. The results are not statistically generalizable to the population of cancer survivors in Nevada as participants were not randomly selected and the sample sizes are small.

Design and Implementation

The project was originally designed as eight focus groups, with a maximum of 14 individuals each, in six communities throughout the state. We sought to include participants living in both rural and urban locations, including those with cancer treatment centers and those without. Additionally, two communities with larger Hispanic populations were targeted for two focus groups each, one in English and one in Spanish. Census data was used to determine communities with larger Hispanic populations, with Las Vegas (30%) and Elko (25%) selected due to their larger population of Hispanic residents and their urban and rural respective geography.

Table 1. Focus Group Locations and Regional Characteristics

Location	Type of Community and Level of Service in Region	
Reno/Sparks	Urban; two CoC accredited hospital-based cancer centers, oncology private practice, veterans hospital; offering surgery, chemotherapy, radiation, clinical trials	<i>January 2017</i>
Fallon	Rural; hospital with surgery and chemotherapy, no oncologist	<i>Cancelled – 0 enrollment</i>
Carson City	Larger rural; hospital-based CoC accredited cancer center with affiliation to larger cancer institute, community private practice, offering surgery, chemotherapy, radiation, clinical trials	<i>March 2017</i>
Las Vegas – English	Urban; multi-location comprehensive cancer center practice, multi-location oncology-hematology practice, multi-location radiation oncology practice, university-based CoC accredited hospital cancer center, one CoC accredited hospital cancer center, one hospital cancer center seeking CoC accreditation, at least 13 additional acute care or full-service hospitals, veterans hospital; offering surgery, chemotherapy, radiation, clinical trials	<i>February 2017</i>
Las Vegas – Spanish	<i>See Las Vegas – English</i>	<i>Cancelled – 0 enrollment</i>
Ely	Rural; critical access hospital with no cancer treatment	<i>Cancelled – 1 enrollment</i>
Elko – English	Larger rural; hospital with surgery and chemotherapy but no oncologist, private radiation center opened June 2015	<i>March 2017</i>
Elko – Spanish	Larger rural; hospital with surgery and chemotherapy but no oncologist, private radiation center opened June 2015	<i>Cancelled – 0 enrollment</i>

All cancer survivors were invited to participate and a diversity of participants was sought, including those: diagnosed at different stages of cancer; of different ages; with different types of cancers; who have had recurrence or secondary cancers; and, at any phase of treatment or time since last treatment. Participants were required to be 18 years of age or older.

In the case that more than 14 individuals enrolled in any one focus group location, the following selection criteria was applied:

- Those with pediatric-type cancers were excluded, as research in pediatric cancer survivorship and late-effects indicates the needs of pediatric cancer survivors are different from those of adult cancer survivors. The current research prioritizes survivors of non-pediatric cancers.
- No more than 50% of participants in a focus group are survivors of the same general type of cancer. Ex.: a group of 14 participants will have no more than seven breast cancer survivors. A representation of several different cancer types will better inform us as to the general needs of cancer survivors in Nevada.

- Researchers strived to achieve a minimum of 20% male participants within each focus group. It is important to understand the experiences of male survivors to identify if they are different than those of female survivors in order to best meet the needs of all Nevada survivors.

Enrollment was available online or via printed form and promoted with: flyers distributed throughout the community and by partners; news articles submitted to local newspapers; promoted posts on Facebook; newsletters from NCC and partners. Participants were offered \$20 and refreshments as incentive to participate.

Of 47 enrollees, a total of 30 participated in the four focus groups. Three were excluded from the Reno focus group due to size constraints, and the remaining enrollees did not show up at their respective groups. Twenty-five participants, about 83 percent, were female and five were male, nearly 17 percent. Ages ranged from 27 to 79. Time since initial cancer diagnosis ranged from two months to 38 years.

Table 2. Focus Group Composition

Location	Men	Women	Total no. of participants
Reno	3	11	14
Carson City	1	4	5
Las Vegas	0	3	3
Elko	1	7	8
Total	5	25	30

Participants reported a variety of cancer diagnoses and stage of survivorship. Additionally, one third (10) of participants reported a recurrence of the primary cancer, secondary diagnosis, metastasis, or even multiple additional diagnoses. Several participants also shared information about their spouse's or close relative's cancers.

Table 3. Cancer Diagnoses Represented

Cancer Diagnosis	Primary Diagnosis	Secondary/Additional Diagnosis or Metastasis
Breast	13	3
Colorectal	1	1
Prostate	2	
Ovarian	3	1
Cervical	2	
Bladder	2	
Thyroid	2	1
Brain	1	
Leiomyosarcoma, Uterine	1	
Hodgkins Lymphoma	1	
Head and Neck / Throat	2	
Acute Lymphocytic Leukemia		1
Duodenal		1
Lung		1
Melanoma		1
Liver		1

A discussion guide was adapted from the Vermont Cancer Survivor Focus Groups and members of NCC's Survivorship and Palliative Care Task Force provided feedback and guidance on modifications to better align with Nevada's demographics and project goals. The Vermont report noted an overly-ambitious scope of questioning for the two-hour timeline; NCC's discussion guide was shortened

accordingly and key questions prioritized. Despite this advance knowledge, several questions were skipped in several groups to fit the discussion within the time allotted.

Focus group discussions were recorded and transcribed verbatim to assist with analysis. Analysis and coding were completed with the assistance of DiscoverText cloud-based text analysis program.

*“My life is my family, my job, my happiness.
There is life after cancer, I have to believe that.”*



Findings

Twenty-six categories were identified in the initial review of discussion transcripts, and responses were sorted and coded accordingly. Based on those categories, six over-arching themes were identified. The six themes and associated findings are detailed here. Categories within each theme are called out with bold blue type.

Initial review of focus group transcripts suggested the experiences of breast cancer survivors and those living in Elko may differ from the overall participant population. As such, responses from breast cancer survivors and those in Elko were coded as part of the whole and then again separately to identify variations. These differences are noted at the end of the findings.

Theme One: Medical Care

“You’re just a case.”

Medical themes discussed within the focus groups covered anger, trust, respect, and support and education provided by both physicians and navigators.

Every focus group participant (100%) mentioned the medical community or medical support as having an impact on their survivorship. Discussion categories that fell within this theme dominated the conversation, covering eight categories and 37% of all focus group mentions.

Half of participants expressed **anger with healthcare**, spanning a variety of issues. Some grievances included:

“...so many doctors. They don’t know what they are talking about. Seriously. I had one doctor tell me ‘You see all these certificates on the wall? That tells you, I know what I’m talking about.’ I stood up and said ‘You see this body? That tells you I know what I’m talking about!’”

“I never wanted to see him or have him be my clinician again. I didn’t think he had my wellbeing... I don’t think he took it into consideration.”

However, nearly 60% of participants reported some degree of **trust and respect** for their medical providers. Nearly half of the comments expressed positive feelings of trust and respect, 10% expressed some trust or respect, and 40% expressed feelings of distrust and no respect.

Many participants indicated receiving treatment outside of the community where they reside. As such, **local healthcare** was identified as a separate category to differentiate sentiment regarding care received within one’s own community versus care received away from the community, such as across

the state or in another state. Many participants had negative experiences with local healthcare providers, or had limited or no access to quality local healthcare.

“...But you know, what I’d like to say about this town, or Nevada in general, is that if you go around the table, a lot of us have to go out of town to get those other opinions because we don’t have choices here, or people we can get those opinions from, it’s almost like a one stop shop. They all consult with each other.”

“When I went to the oncologist here it was like, you got 10 minutes with this person and then you are out the door, just running people through there. And I do believe part of it is because we don’t have enough physicians here. So you know, everybody suffers for it.”

Numerous participants felt healthcare providers could not or did not provide adequate **information to prepare** them for what treatment entailed, including sufficient discharge instructions or what side effects could be experienced. Additionally, they felt both **general information on their cancer and available resources** were not discussed by their providers.

“When I was at the doctor, they didn’t say ‘Ok here’s this information for you to understand or you can go to here for you know more resources’. I had none of that. I had to dig for everything myself.”

“Just getting the information out there. It needs to be provided without having to beg for it. It’s just got to be there.”

About one-third of participants discussed **complementary and alternative medicine**, with most indicating they had either used one or more types or were aware of but had not used. All participants who discussed these therapies indicated they were interested in more information, however some participants noted if they hadn’t asked about it specifically it would not have been discussed or offered to them. One participant went so far as to change treatment facilities to garner improved access to complementary therapies.

“So, my aunt [in northern California] had LIVESTRONG at the YMCA. She had acupuncture. She had a mental health provider. She had Riding Through Cancer. She had a very full and busy schedule. It was all coordinated through her [doctor’s] office. I think that is ideal, especially for where she was in life. I don’t know, I actually know, that that kind of network is not offered here in Southern Nevada.”

“I asked all my doctors at the VA ‘What do you think about medical marijuana?’ And every one of them answered it...So I was surprised that they would answer the questions, but if I had not specifically asked a certain set of questions, I would have never gotten that information.”



“I think we have already identified the biggest gap in program services is coordinated care and then actually having coordinated care across your life.”

Individuals with the **support of a nurse navigator** were grateful for the support. One participant was so impressed with the care delivered by a nurse navigator, she brought to the focus group a binder

provided by her navigator. The binder included information on common side effects and management, contact information for healthcare providers, a calendar to track appointments, and tabs to file treatment and prescription details. Those without access to a nurse navigator or some other support to navigate the treatment process wished they had.

“We need to be educated and laid out the path that we are going to go down. This is the journey, and these are the filling stations you can stop by on the way. You can get moral and spiritual support over here, you can get financial support over here. Kind of like a little map of where we are going and stuff.”

“There is no coordination... There is no...resource and guidance... There’s nothing to tell you how to navigate it or at least give you a heads up.”

Others also commented they believed nurse navigators were only available for breast cancer patients.

“The nurse navigator... I wasn’t quite as lucky.” [non-breast cancer survivor]

Participants had mixed responses regarding the **transition out of active treatment and back to regular primary care**, along with coordination of care across specialties during treatment. Responses in the enrollment questionnaire indicate five participants received survivorship care plans that also included a treatment summary, and an additional 15 received a treatment summary or medical records. Nine participants did not receive any documentation or care plans at the close of treatment.

Several participants noted the use of electronic health records eased their transition back to primary care because their treatment details could be easily accessed across the facility’s network. Others noted they had to be active in ensuring all their physicians received their records.

“And did the primary care doctor have good communication with the oncologist? No.”

“I think that I was very fortunate to be in the Renown system, for my oncologist and my primary care, and for a lot of other things. And they’re just really hooked up these days with the whole computer system, including myself because you know, I get a print out of all my records or MyChart, so I get to see what the results are of tests.”

“It seemed like when my medical treatments were over...it was just kind of like, ‘See you in six months.’ And you’ve spent two years at that point with surgeries, and treatments and radiation. And then all of a sudden it’s ‘Have a good life.’ There’s really no one to tell you what to do. All of a sudden you just move on, on your own.”

“If I were to give one suggestion to a cancer patient: take a breath and have a plan. Be comfortable with the plan. Trust your health provider, ask questions, and be a partner with your treatment.”



Theme Two: Social and Emotional Well-Being

*“It doesn’t go back to normal.
You have this new normal—which I hate that term.”*

The American Cancer Society suggests for cancer survivors, “feelings of depression, anxiety, and fear are very common and are normal responses to this life-changing experience.”^{iv} The National Coalition for Cancer Survivorship goes further, noting about one-third of cancer survivors experience anxiety or depression serious enough to require professional help.^v

All participants discussed issues related to social and emotional well-being. They spent 20% of the discussion time covering social and emotional topics such as negative emotions of **fear and uncertainty, generalized anger, stigma, and isolation**, as well as positive responses about **hope, spirituality, and empowerment through self-advocacy**.

The perception of cancer as a death sentence, while participants knew wasn’t the case, still loomed large and steered their emotions.

“Even kids know that the word cancer means you’re dead. It doesn’t. We all know that it doesn’t. But you know that that’s the first thing you think when somebody says cancer.”

For many, feelings of fear, resignation, frustration, and hope mingled together, demonstrating the complex nature of the emotional struggle survivors face.

“I can’t tell my daughter ‘It’s not worth fighting for me to live.’ So I never could say that. But...you have those moments. And I said ‘It’s a day by day struggle. Sometimes it’s hour by hour. Sometimes it’s minute by minute.’ But when you wake up and it’s like ‘Oh my god, I survived that, I got this.’”

“The materials are very happy...they were very kind of whimsical and happy...They try to paint this positive picture and in painting the broad stroke positive picture they leave out the reality of what can and did happen. So I didn’t find the materials very helpful.”

“But it is what it is. We just have to take this crap, and it’s all bestowed upon us for some reason, who knows why, because we are the ones that will rise to this and say that was a bad time of my life and it’s behind me and I beat it...There is life after cancer. I have to believe that.”

Feelings of guilt, blame, and shame also entered the equation. Some participants thought perhaps they caused their own cancer, and others experienced emotional distress caused by negativity from family, friends, and even strangers.

“There are plastic water bottles in the back of the car, when you were five years old you drank cows’ milk- you will never know! It makes me crazy.”

“And don’t look at me like I have leprosy! I hated that when I would go to Walmart and everybody would go around me like I had leprosy or something! Seriously!”

“I also felt really guilty. Like I had all of this internal guilt for making [my family] feel bad.”

“I just feel like I'm that grocery bag that gets caught in the wind, just kind blowing all over the place, not grounded.”

Some participants found solace in their faith, and turned to their spiritual community for support and emotional strength. Others expressed anger and had difficulty reconciling how their god could put them through the suffering of cancer. They questioned their faith or lost it altogether.

“In 2001 I was like yep, he did it, he brought me through it. And I would trudge on and tout religion from here till hell froze over. And then the second time...the radiation happened. And I became angry. Why did you keep me alive to turn around in 30 days and make me live out the rest of my life like this? You should have just pulled the plug.”

Many participants described becoming strong self-advocates out of frustration, overcoming or setting aside their negative emotions, or at times using self-advocacy to help combat fear and uncertainty. Several also noted self-advocacy was a requirement for experiencing cancer, because without this empowerment they would not have received the information or care they felt was vital to their survival. There was a strong feeling among participants that cancer survivors have to know what questions to ask of their health care providers in order to get the information they needed. Self-advocacy for many participants started with their own research and development of questions, then asking those questions and following up with more. Some participants wished there was a more easily-accessible resource where answers to all of these questions might be found.

“I advocated for myself a lot the second time. I sought out those kinds of help, doctors who were a little bit more on the integrative side...I literally had to fight for testing to find out I was right, something was very wrong. I'd be dead if I hadn't done that.”

“Getting a second opinion, or a third opinion... You have to be your own advocate. You can't just rely on your doctor being right all the time, telling you whatever he says is gospel, you've got to question everything they do, when they do it.”

Some of the things participants felt they had to self-advocate for included:

- Medical information, including details about their cancer diagnosis, statistics and data to aid in the decision process
- Treatment options, including access to additional testing, second opinions, and complementary and alternative medicine
- Physical and emotional support, including getting nutrition and exercise information from healthcare providers, and in getting appropriate emotional support from family and friends
- Financial assistance, including negotiating treatment costs and payment schedules

“You either rise to the occasion or you crumble. You can get through a lot if you have a positive mind.”



Theme Three: Social, Emotional, and ADL Support

“She was my lifesaver.”

While the previous section, “Social and Emotional Well-being,” dealt with the emotions cultivated throughout an individual’s cancer experience, this section deals more with the resources participants sought for social and emotional health and assistance with activities of daily living (ADL).

Most participants overwhelmingly identified **family and friends** as their key sources of support. Spouses and grown children were often relied upon. Types of support provided included:

- Attended and/or drove to doctor’s appointments, took notes, served as a second set of ears, managed paperwork, applied for assistance, researched for information
- Provided meals, personal assistance, and in-home care after treatment
- Provided company, watched movies, accompanied during chemo visits
- Hosted fundraisers to provide financial assistance
- In instances where a family member or close friend had cancer, they served as a sort of cancer peer

“My poor husband. When I would be on the bed curled in a ball and bawling my eyes out he was the rock.”

“The one thing I had was a supportive friend who was willing to go with me to all the appointments and listen to all the doctors and be my, be my memory because I had none.”

“There is this thing online, it kind of helps people sign up for times. And my husband had to do that and my friends just signed up to come sit with me during chemo. So my friends kind of took shifts.”

Several participants did state support for caregivers was a concern. Caregivers face extended periods of stress, anxiety, and frustration and can feel as isolated and alone in their experience as does the person for whom they’re caring. Participants noted caregivers tried to be the stronger person in the dynamic, carrying what burden they could. However, experts claim caregivers often forget to care for themselves through counseling, respite, or other forms of support.^{vi}

“I’ve been the cancer patient and the caregiver for a cancer patient. Because my husband had colon cancer and it was very interesting. It’s easier being the patient, believe it or not. Because the caregivers—everything is out of control.”

“One time [my husband] was in the garage and I couldn’t find him so I went in there and there he is bawling. Because he can’t be weak around me... And I’ll never forget that day. And he said, ‘I just need this... You can’t see me like this.’”

It’s important to note not all survivors are married or have family living nearby and cannot always rely upon others for support. Those without this type of support managed as best they could on their own, or at times had sporadic help from friends or adult children. Throughout the discussion, they acknowledged how lucky those with close family support were.

While the majority of people indicated the support received from family and friends was helpful and appreciated, some people did have negative experiences. Several noted friends and colleagues didn’t know how to interact with them once they revealed they had cancer. Most indicated they wanted friends, family, and colleagues to understand their lives were different, but they were also still the same people they were prior to diagnosis. Others found their experience served as a sort of barometer for the quality of their friends, finding solace in those who stepped up and losing contact with people who had been their closest friends.

“I lost friends. There were people that called themselves my friends, but when I got sick and all I wanted to do was sit on the couch and they didn’t want to do that [so] they left. And I don’t talk to them to this day.”

“I also asked those close to me and those that wanted to do something (like everybody wants to do something for you when you tell them), I gave them things they could do, and some of the homework was to do what you can to heal yourself about all the things you’ve heard about cancer or any particular disease. And to bring that in support to how you see me and how you see the situation. And so I did surround myself with those who felt that and were able to do that. And I was able to ask for that.”

About half of participants talked about **support groups**, with the majority identifying them as invaluable in providing guidance, encouragement, and a level of familiarity with the experience of cancer that friends and family couldn’t provide. Some even went so far as to say their support group was the most helpful thing they had during and after treatment.

Participants claimed support groups were of value in providing a forum to learn from others, but also to share input important to others in the group.

“I’m still tight with those women, they are awesome. And I feel like I’m at a point, that even though I’m still going through it, I have a lot to ask and a lot to learn, I can be there now for those women, those newly diagnosed women.”

“You might feel like you don’t need that support group, but someone in that support group might really, really need to know what you say.”

Additionally, several participants who had not attended a support group were motivated by their participation in the focus group to begin attending a local support group. They found the experience of talking about their cancer with others was therapeutic and more of a relief than they had imagined.

Some participants even noted the value of bringing a spouse or partner along to support groups:

“I went for a couple months before I got my husband to go and it’s also benefitted him. He realizes what other spouses are dealing with and how they deal with it, and seeing, not just hearing me moan and groan, but hearing it from everybody and knowing that I’m not bitching and it’s real!”

“[My husband] was going through a lot of the same things too. Because they do have to have that wall up. Because you gotta get that paycheck, and you gotta keep that insurance.”

However, access to support groups was a concern for some participants, who indicated either there was no support group organized within their community or at the facility where they were receiving treatment. This was noted in Elko, where many participants completed treatment outside the community and prior to the opening of the local radiation center, which helped to spearhead the Elko Cancer Network and its regular support group. Still, even though this support group now exists, many participants had not heard of it.

Some participants with later stage or recurrent cancers expressed concern about attending support groups also attended by earlier stage survivors. The concern was twofold: first, sharing details about recurrence or metastatic disease would frighten others and cause anxiety of recurrence; second, the emotional and physical issues faced by those with metastatic disease were vastly different from the issues of those at an earlier stage of disease.

Additionally, one patient noted of her doctor:

“He’s not in favor of support groups because he doesn’t like us comparing our fear and what you’ve got to what I’ve got.”

“Someone to talk to you, to know that you’re not crazy.”



Several participants noted **support from others who had cancer**, more specifically had a similar type of cancer or treatment experience, lived nearby, or were a part of their peer group, would have been beneficial. One participant noted family and friends work hard to provide positive support and encouragement, and she felt guilty not always sharing in that positivity. There was a great deal of guilt around making everyone worry or feel bad, and so feelings remained bottled up. She claimed a “cancer peer” whom one could turn to as needed would’ve been valuable.

“The only thing I wished through the whole thing was that I wished that I knew somebody that had the same type of cancer as me to ask, ‘Is this right, is this wrong?’”

“I felt like maybe it would have been helpful...if your physician could direct you to someone who has been there.”

“I wish I had another man to bounce stuff off of.”

Several participants identified **one-on-one counseling** with a psychologist, psychiatrist, or other trained counselor was of great value. This type of support was identified as in addition to support groups and peer support, not as a replacement for them. Participants who discussed counseling suggested seeing a professional for general emotional well-being, not specifically to discuss cancer, was a great help and should be suggested or offered to every person diagnosed with cancer, preferably soon after diagnosis. One participant went so far as to say it should be mandatory.

“I did six weeks of counseling with a non-hospital-related counselor. And it was the first time I’ve ever gone to counseling. I found it really wonderful to have a place where I could sit and say whatever it was that I needed to say.”

Additionally, participants suggested this counseling support be extended to families, including spouses and children. As was noted in some of the quotes above, spouses and caregivers bear a large emotional burden and often struggle to balance their role as a strong support person when in reality they may be scared and are under immense stress. Participants whose children were younger during their treatment also stated counseling for the kids would have been helpful. One participant struggled with how to tell their younger children about the cancer and how to help them emotionally process the information.

Theme Four: Physical Well-Being

“The physical changes are real. They’re forever.”

Discussions about physical well-being covered topics like fitness, nutrition, appearance and confidence, and fertility and sex. Many of the social and emotional issues overlap with discussions of physical well-being. For example, participants noted weight gain, hair loss, or weakened bones as resulting from treatment, which then led to depression, frustration, and isolation or stigma.

While mentions of physical well-being made up only 8% of total mentions across all focus groups, we broke this out as a theme because 80% of participants mentioned how the physical aspects of cancer impacted them during treatment, and at times, long after treatment was complete.

Of these physical themes, the topic of **fitness, nutrition, and overall wellness** has the largest number of comments. Participants discussed inability to perform regular daily tasks often due to fatigue or physical damage caused by treatment. They also discussed access to proper nutrition and fitness regimens, most often as a lack of guidance or recommendation for both. The lack of nutrition and fitness guidance was noted as leading to any of the following: lack of mobility, weight gain, or inability to care for oneself, all of which in turn led to depression and reduced confidence. Some of the frustration on this topic was due to the lack of integration or focus on the whole body/person; treatment focused on eliminating the cancer but not on the overall well-being of the patient. Survivors found after they completed treatment and began to revert to daily life they were unable to return to certain activities they had enjoyed before, which contributed to frustration and depression.

“I couldn’t do regular stuff. And meals—I had probably two meals a week because there was no one around to [help], and I couldn’t get up to cook after a while. I couldn’t get up to do anything.”

“I used to bike, I used to hike, I used to do all this stuff and I can’t do it anymore. And there are days when that really depresses me. Because I do not physically have the ability—I am not me, not the me I know in 2012.”

Some participants referenced simple regimens, such as walking, as beneficial. Others mentioned advantageous organized fitness activities tailored to survivors within their community, such as yoga and strength-training programs.

“When I was going through treatment I walked every single day...even the days I was puking my guts out, I would get up and walk my dogs close to a mile. If it was a really bad day I would give them a short loop close to half a mile. But I knew, if I got up and moved every day I would feel better.”

“I think walking, exercise, anything that gets those endorphins, the good stuff going, eliminates stress, elevates your mood.”

“I feel worse just laying on my couch. It’s worse for my head, my thoughts, and my body.”

Numerous participants expressed a desire to learn more about how they should or could modify their diet during and after treatment to ensure the best possible outcome, and how diet may improve outcomes. However, most indicated receiving nutritional guidance from their healthcare team was difficult.

“Not once did you hear the word diet change. Not once.”

“I went online and tried to look up things I should and shouldn’t be eating. I ate so many lima beans and then lemons. I added whatever nutritionally I could find on there.”

As mentioned previously, fatigue and inability to exercise as they had in the past led some participants to gain weight, which they felt was a negative impact to their appearance. Additionally, hair loss,

scarring, and other physical changes incurred from treatment led participants to have mixed feelings about how they looked. In addition to being unhappy with the **changes in their appearance**, some participants noted they were perceived differently by others because of their appearance, often negatively, which added to the previously discussed feelings of stigma and isolation.

“I have this thing on my head and when I would come in here to see the nurse I had people grabbing their babies, and putting them behind them because I looked like a monster.”

“I lost my hair. I hated that I didn’t have hair. It was almost worse than surgery. But I survived it. I wore a little hat... And I’d get up in the morning and do my makeup and put that stupid beanie on.”

“When I had hair and I was going through all of this no one knew. They said, she’s normal. But the second I wore that little beanie with no eyebrows and no eyelashes they knew I was sick.”

“I always say fake it until you make it. So to any of my chemo or doctor’s appointments I would always really dress up wear something really cute, really paint on the eyebrows. I went and got the fake eyelashes and everything... Even on my really, really crappy days I would try to get dressed if I could and that would make you feel just a little bit better, a little more normal.”

Very few participants discussed **fertility and sex** issues in during the focus groups. Using a follow-up questionnaire, several participants suggested that others may not feel comfortable discussing fertility and sex issues in mixed company; three of the four groups included both males and females. For those that did discuss the topic, concerns included:

- Stigmatism; suggestion from others that mastectomy or removal of organs, such as with a hysterectomy, made one ‘half a woman’
- Concerns about sensation, function, and potential pain during intercourse or other sexual activity
- Sadness and distress over inability to have children

Theme Five: Information and Resources

“The internet will scare the living daylights out of you!”

From the moment of diagnosis, patients wanted **information**. Participants sought:

- Facts and figures related to survival and outcomes
- Details on their specific diagnosis
- Information on potential treatments to assist with making decisions and anticipate what would be happening
- Services specific to cancer including: fitness programs, nutrition support, massage, yoga, daily living assistance, home care and hospice support
- Financial management and assistance, along with estimates on what treatment would cost
- Information on how to handle legal aspects, including workplace rights and advance directives
- Guidance on how to talk to people, especially children, about cancer

The primary sentiment from participants was a cancer diagnosis brought a high level of uncertainty to their lives almost immediately, and by securing as much information as possible they were able to feel more in control of their lives in that moment.

Most participants noted they initiated the search for information, but would have appreciated if more information had been provided by their oncologist or cancer care team. The most intensive time in the search for information and resources as noted by participants was between diagnosis and the start of treatment. Additionally, participants stated “the internet will make you crazy,” and it was difficult at times to determine the most reliable sites for information.

Others found **resources** through friends and connections made at support groups. The peer-to-peer sharing of information was so prevalent that in all of the focus groups, participants shared resources with each other.

“When I was at the doctor they didn’t say ‘Ok, here’s this information for you to understand or you can go to here for you know, more resources.’ I had none of that. I had to dig for everything myself.”

“Cancer doesn’t happen in a vacuum. Everything that goes along with it—there is nothing there to tell you. There’s not like a handbook, or at least I didn’t get a handbook, on how to manage all the things that go along with it.”

“I got most of my information, maybe not factual medical information but help, from other cancer patients.”

Those participants who identified having access to a nurse navigator early in the process reported greater access to information through the assistance of the navigator. They also affirmed the navigators themselves were a trusted resource they could turn to when questions arose.

During the discussion about seeking information, at least three participants specifically indicated they received binders/notebooks from their cancer care team which included resources and educational materials (two of these participants received care outside the area). Some indicated they had yet to read through all of the information provided, but the consensus was they felt assured that when they needed information, they had someplace to turn.

“They gave me this beautiful notebook, they went through it, explained everything and told me why and what did not apply to me. And since I was right there in the oncology unit there are tons of pamphlets...And they gave me lists of all these support groups, anything I could do. I’m just overwhelmed with information.”



“[Information] needs to be provided without having to beg for it... We all know about flu shot and the common cold and how not to get pregnant. But it’s not thrown in our faces every day on how to deal with cancer.”

Theme Six: Financial and Legal Concerns

“It’s a shame money should even play a consideration when someone comes in with cancer. It’s a hardship, it just causes more stress.”

The final theme participants touched on was financial and legal issues. This topic area had the fewest participants engage in discussion, yet it still generated mentions from 73% of the participants. This theme comprises the financial burden of cancer, insurance concerns, and advanced planning including advance directives.

Responses in this theme were far less decisive in one direction or another. That is to say, some participants had **insurance** and felt lucky to have little to no debt after treatment, while others had no insurance and either ceased treatment due to inability to pay or faced financial strain or ruin. Several participants noted everyone should be so lucky as to not get cancer until age 65 or older, as Medicare will cover the cost of treatment and often your home is paid for. Another noted the only way they were able to cover the cost of treatment was by negotiating bills with the doctor, but advised most people are unaware this tactic could be used.

In addition to the **financial burden** of treatment and related costs, participants who underwent treatment while they were still of working age noted the loss of income from not being able to work was a major impact. This financial strain impacted areas mentioned in previous themes. Spouses were unable to provide support or transportation for treatment because they had to maintain income. Participants were unable to use resources or support programs due to cost. Greater awareness of financial assistance resources was also suggested. Some participants who had insurance still struggled to cover daily living expenses.

“There was no place for me to go to help me to figure out how to financially manage it all and not end up homeless or destitute.”

“I am completely financially wiped and have no way of paying most of it. I’m paying off the hospitals what I can, I’m paying off my oncologist, I can’t pay off anyone else. Otherwise I don’t eat.”

“I have no insurance, I have no income. I have nothing...all of my follow up cancer treatments stopped the day they pulled the port out of my chest and canceled my insurance.”

Several participants suggested financial guidance and support on understanding insurance coverages would have been helpful from the start of treatment. Having some knowledge of what bills to expect and what costs might be would have relieved some anxiety. Additionally, several participants used money from 401Ks or other retirement plans to cover healthcare costs, but would have benefitted from financial guidance and a better understanding of the tax implications of doing so.

Additionally, many participants suggested turning over finances to a trusted family member relieved a lot of stress and allowed them to focus on recovery.

Some participants with insurance noted struggles with the insurance company in securing timely approvals for treatment, coverage for brand name drugs requested by physicians, or approvals for treatment. One participant felt that during the fight of their life the insurance company served as a non-medical gatekeeper, deciding which treatments were allowed and which were not.

*“I will still be in debt until the day I die.
There’s no way out of it.”*



Finally, many participants, both those facing financial struggles and those who were financially able to cover the costs of treatment, felt anger towards the lack of financial assistance resources.

“It’s just a real shame, that with all the millions of dollars that are out there being raised for cancer, particularly breast cancer...all that money isn’t going to the people who need it, it’s going somewhere else. Research is great, but if the people are dying because they can’t afford treatment... it’s a sin that that’s happening out there.”

“I’ve even tried filling out their little applications. They’re not little really, you know they want four months of bank statements, it takes about two and half hours. Three times I’ve been denied. And so one-by-one they are all going to collection.”

For those recovering from the financial blow of cancer treatment, some participants struggled even more due to inability to find employment.

“I kept looking for work. And as soon as people found out the reason I was out of work for over a year was because of cancer, that was it. I was just pushed out the door.”

The final topic covered was **advance planning**. About half of participants discussed advance directives and Physician Order for Life-Sustaining Treatment (POLST, not mentioned by name), and three-quarters of those were at a minimum aware of these tools, with some completing them. While the sentiment overall was, “yes, I need to complete that, it’s important,” many had yet to complete the documents.

For those who hadn’t completed their advance directive, the pressure to make decisions proved to be overwhelming. Others expressed fear and worry about what might happen to them during surgery, and the process of thinking “what if” that is involved in completing these forms proved too stressful. Others were worried they’d change their mind after they’d completed the document. Still others found the process too complicated, both completing the actual paperwork and making the decisions.

Many of those who did complete an advance directive or POLST often did so after receiving assistance and guidance from a professional. Furthermore, they often felt relieved upon successful completion the forms.

“We were fortunate again in that we are going to a class in a week or so...they offer it twice a month now. A class on advanced directives, and I think the power of attorney along with that. That’s really neat, that’s a free class.”

“I think it’s so wonderful that we can maybe spare our family from having to make those decisions and talk about that ahead of time.”

Elko – Key Differences

“...And we do live a long ways from real medical help...”

All of Elko’s participants received treatment for their cancer outside of the community, with most traveling to Salt Lake City. One participant received a portion of care in Elko, and a few others received treatment in Las Vegas, Reno, or Texas. When discussing the level of care and support received at out-of-home treatment facilities, all participants had positive opinions about the medical support and community in Salt Lake City.

“[A] woman said get to the Huntsman. Huntsman is people. Seattle is numbers. And you start watching it and it works that way. Or at least in our case, it worked that way.”

“Once I got to Huntsman, I was like Elko needs to get their crap together.”

Those who received treatment at Nevada facilities spoke kindly of specific physicians, but expressed frustration with the lack of consideration given for the distance traveled for an in-person visit, often simply to receive lab results.

“I went to a Reno doctor, I went to a Las Vegas doctor, and they do a test because they don’t know if you [have] cancer or not. They want you to drive back there two days later, three days later to get the results. And I drove five hours to Reno and saw a doctor for her to say, ‘Oh, this didn’t go well.’ And then you have to drive five hours back knowing in your mind that ‘you’re dead, you’re dead, you’re dead,’ even though you’re not and you’ve got to get past that. And it’s going to take you a few hours to get past that. And I said, ‘Why can’t you either give us those results over the phone and let us digest it before we have to drive those five hours, or give it to our primary care here?’... I’m not driving eight hours to get results.”

In Elko, anger with healthcare was identified by a larger portion of participants, 88% of Elko participants versus 53% for all participants combined. In fact, 44% of all participants who expressed anger with their healthcare were in Elko. Most participants also discussed bad experiences with local healthcare or times when they were unable to access the care they needed within the local area.

“I’m a huge Elko supporter. But, the medical part of Elko just sucks. It sucks. I learned it the hard way.”

“So for two years I ran around trying to get diagnosed ‘cause I knew something was wrong and nobody here would listen to me.”

“You can’t expect them to have the same amenities here. But can’t you expect them to have the same customer service and the same respect? Or treat you like you’re actually a human? That’s kind of what I expect.”

Complementary and alternative medicine was not discussed at all among participants in Elko, making it the only group of participants who did not touch on this topic.

When it came to social and emotional support, those in Elko were more likely to mention relying on family and friends for support. For some, spouses or close relatives were able to travel with them to treatment out of the area. However, others discussed the impact of distance; family members were unable to leave home for the extended time periods necessary to seeking care out of state due to responsibilities at home. Family members stayed home to work as their income was required to sustain

health insurance and pay bills, because work time off was depleted during earlier phases of treatment, or to care for young children.

“I was in Salt Lake for five weeks. And luckily my mom was able to go with me because someone has to stay here and pay our house payment. My husband couldn’t go up there with me. So I had my mom.”

Those in Elko also encountered difficulties in finding support outside of family and friends. Mental health counseling for children and adults, support group availability, caregiver support, and in-home and hospice care were all mentioned as lacking within the community. Of those in Elko who discussed support groups, two indicated that it was a “nice to have, if it was available here” and one indicated that an online support group was the only option.

“My husband and I tried to go to a couples’ counselor at one point. Because we noticed that the stress puts a lot of strain on your relationship. But it was hard. We had to call around to multiple people in the area. And there was one person that would take us and she was actually a student working with someone here.”

Breast Cancer – Key Differences

“This battle is pretty rough I’ll tell you. I’m over it.”

Breast cancer survivors were more likely to have and appreciate the support of a nurse navigator throughout treatment. Additionally, they identified much greater satisfaction with healthcare providers’ delivery of education and preparation for what to expect prior to and during treatment. This satisfaction is perhaps in part due to the support of the navigator.

“I know for me, my breast health nurse was a big help for me. Because I threw all my questions at her and she would talk to my doctors and explain something I didn’t understand.”

However, responses were still mixed.

“For me, there was no guidance or coordination from the medical profession...”

Additionally, participants in this group were more aware of complementary and alternative medicine and were more likely to have used one or more therapies during or after treatment. For the most part, breast cancer survivors discussed a wider range of complementary and alternative medicine therapies, including integrative oncology, fitness and nutrition, cancer massage, medical marijuana, reiki, yoga, and healing touch.

Breast cancer survivors were about equal to other focus group participants when it came to discussion of the value of support groups, however they were more likely to mention direct peer support from other women with the same or similar diagnosis as valuable. Half of all breast cancer survivors in the groups mentioned they either received direct peer support or wished it had been available to them.

“You spend all your time preparing for treatment or getting treatment, or getting prepared for the next one. And then it’s over. And if somebody could’ve told me that yeah, it feels horrible, but seven years down the road it will be a distant memory.”

Breast cancer survivors were more likely to discuss fitness, nutrition, and overall wellness than other participants, but had the same mixed responses on the topic. Some of the positive comments mentioned

greater access to or awareness of support programs for fitness and nutrition. They were more likely to be directed to programs by nurse navigators, and financial support programs were in place for some to be able to afford the services.

“It wasn’t explained to me that I was going to have no upper body strength after surgery... I voiced my frustration to [the nurse navigator] and she told me about the rehab center at St. Mary’s. Didn’t have the money for it, but Moms on the Run funded it.”

“There was a nurse navigator, and after that... you could get massage for lymphedema, and after that they said ‘Now go on over to the gym and join the cancer exercise rehab program,’ and along with that came the dietician. I thought that they were very thorough on the physical aspect side of things.”

When it came to appearance, breast cancer survivors often had more acute concerns over their appearance initially, often due to mastectomy and/or hair loss, but were also more likely to express empowerment about their current appearance.

“You know, if you can’t handle looking at my body like this it’s your problem.”

“It’s been over a year without having breasts so it doesn’t really phase me too much. Every once in a while I’ll look in the mirror and be like, ‘ugh.’ But you know what, you’re alive.”

“Well, if you are taking one, take two. Because I don’t want a flabby boob and a fake nice big cush hard boob!”

As mentioned, breast cancer survivors were more likely to have access to a nurse navigator. Participants who identified having access to a nurse navigator early in the process seemed to have greater access to information through the navigator. This access to information is seen in the greater awareness of resources noted above. In addition to what’s already been mentioned, breast cancer survivors had a greater awareness of advance directives and were far more likely to have completed an advance directive than survivors of other cancers.

Recommendations

Members of the Survivorship and Palliative Care Task Force reviewed focus group findings and provided actionable recommendations to reduce identified gaps and improve quality of life for cancer survivors.

Consistency and Coordination of Care

Survivors who had access to a nurse navigator and/or were part of a health system with an interconnected/comprehensive electronic health record system identified as having a more positive experience throughout their cancer treatment and survivorship than those who did not. In fact, those without access to a navigator wished access had been provided. Recommendations for this area include:

- Increase access to care coordination through either nurse or lay navigators, or a combination therein
- Promote use of GW Cancer Institute's Oncology Patient Navigator Training to increase the number of lay navigators available to assist survivors
- Promote the use of electronic health records (EHRs) and the health information exchange (HIE) to better support record sharing between providers, facilities, and patients, as well as nurses and registry professionals
- Increase access to medical/treatment records through a patient portal to empower survivors to share those records with other health care providers

Support Services for Patients/Survivors

Mental health support via counseling may not be readily available or accessible, especially for those with without insurance. Many participants did not access this resource early after diagnosis, or at all. Those who did seek one-on-one counseling, or sessions with a spouse or partner, were grateful for the relief it provided. Recommendations for this area include:

- Focus on palliative care from the time of diagnosis, as current practices within Nevada often incorporate this level of care too late in the treatment progression
- Provide referrals for mental health counseling soon after diagnosis, such as when a patient is seen to review or determine the treatment plan, to establish this level of support prior to the stress of treatment
- Promote policies maintaining health coverage for mental health counseling
- Identify and promote online or telephone counseling services that those without insurance or without access to in-person counseling are able to access

Peer support was identified as a “would have been nice” resource for a number of survivors. In one case, a participant identified a peer with the same cancer via an online forum and developed a strong bond of support. In fact, the findings of the Vermont Survivor Focus Groups, from which this project was based on, resulted in the creation of the Kindred Connections peer support/mentoring program within the state.

There are several organizations nationwide offering peer support and mentoring programs, often tailored for people with specific cancers or within a certain age group. These include: American Cancer Society's Reach To Recovery, face-to-face or phone support for breast cancer survivors; I Had Cancer, online forums and peer matching for survivors and caregivers; and 4th Angel, phone mentoring for patients and caregivers. However, in some instances survivors noted access to someone who lived nearby would be of greater benefit. Having a peer familiar with the health care environment or local resources can be of great value, especially for those living in rural communities.

Recommendations for this area include:

- Identify existing peer support or mentoring programs and opportunities to promote these to survivors at early diagnosis
- Seek funding and partners to pilot a year-long cancer peer mentoring program in a smaller community
- Based on outcomes from pilot program, develop a peer mentoring toolkit to be implemented in communities throughout the state

Caregiver Resources and Support

While the goal of the focus groups was to identify gaps survivors face, it also brought to light gaps their caregivers face. Emotional support and the need for respite care were both identified as lacking, while others mentioned useful tools their caregivers and family used but had to search for. There are a number of caregiver resources both in-state and nationally, however, as with survivor resources, they can be hard to find.

The execution of the Survivor Focus Groups coincided with an effort by Community Foundation of Western Nevada (CFWN) to address the needs of caregivers in northern Nevada with the Caregiver Support Initiative. The project's action items are scheduled to be largely completed by September 2017 and include: a caregiver guidebook; a comprehensive online resource database; and, an online forum where caregivers can share experiences and get advice. These tools will be tailored to Washoe County, the region where CFWN is based, however elements may be adaptable for statewide use.

Recommendations for this area include:

- Identify additional/new resources for caregiver support, such as respite care, community forums, and tools, to include in NCC resource directory or new Caregivers section on website
- Identify opportunities to better promote caregiver resources to both caregivers and survivors; this could be increased tools on online, support groups, or printed materials (such as the CFWN Caregiver Guidebook)
- Partner with other organizations focused on caregivers to increase capacity

Information

Many participants indicated they weren't provided adequate information or information at the right time. They felt they had more control and less anxiety by securing more information soon after diagnosis, preferably before initiating treatment. However, some participants acknowledged an overwhelming amount of information available at a time when stress is high and the ability to focus may be limited.

Some participants received binders with information on their diagnosis, treatment plan, and potential side effects, but of those who received this resource few had read them in their entirety. Some received full tours of infusion areas to prepare for chemotherapy treatments, while others weren't told how radiation works. While this information is often online, survivors may not know where/what to look for.

Recommendations for this area include:

- Identify existing or curate a "Cancer 101" education module to provide a menu of resources for newly diagnosed survivors and their family/caregivers. This could be video, online, or printed, or any combination therein
- Referring to the peer support recommendations above, identify opportunities for one-on-one mentoring prior to treatment with a cancer survivor
- Referring to the use of lay navigators recommendations above, identify opportunities for one-on-one "orientation" with survivors prior to treatment

Advance Directives

While many participants indicated they were aware of advance directives, those survivors who indicated they had completed them generally had done so either after receiving assistance or participating in a workshop. Some participants felt panicked and concerned about completion of the documents and felt having their cancer care team suggest completion of them to be somewhat fatalistic. Others felt the forms were too complicated. Recommendations for this area include:

- Educate primary care providers on the importance of patient counseling for advance care planning, such as advance directives and POLST, as part of annual wellness exams, including education on billing codes for providing this service
- Promote policies to require all insurers to reimburse providers for advance care planning services (currently covered by CMS for Medicare beneficiaries and by some commercial insurers for some plans)
- Work with community partners to increase opportunities for advance care planning workshops

Rural Support

While some resources are available to support rural survivors, many survivors are unaware of those resources. Additionally, those in rural communities were clear in declaring their cancer care team wasn't always cognizant of the barriers unique to rural patients. Recommendations for this area include:

- Develop continuing education opportunities, such as a session at the annual Nevada Cancer Control Summit, on working with rural cancer patients
- Promote the use of telemedicine in rural communities to better connect rural patients with urban providers
- Develop stronger partnerships between urban providers and rural services, such as community paramedicine, imaging and lab centers, and primary care, to better support patients through collaborative and coordinated care
- Better promote resources targeting rural patients, such as lodging, travel, and financial assistance programs
- Referring to the sections for peer support and caregiver support, identify and promote supportive programs for rural survivors

Additional Recommendations

Several participants identified very helpful resources that covered topics woven through many of the themes identified. However, not all participants were aware of those resources or had access to them. Or, they accessed them at a point in their survivorship not as useful as if they had learned of the resource sooner. Here are some of the resources mentioned, as well as the general feedback from participants:

- Cancer: Thriving and Surviving – the topics covered in this workshop span many of the themes survivors discussed, and participants who had completed the program had nothing but positive feedback. However, there was low awareness of the program among participants overall and the program is only available in two communities on a limited basis.
 - Recommendation: Increase the number of locations and/or times the program is available and identify opportunities to better promote the program to newly diagnosed survivors.
- Saint Mary's Fitness Center Cancer Rehabilitation Program – participants able to access this program were overwhelmingly positive in their feedback. Barriers to accessing this program were primarily due to cost. Scholarships are available through Moms on the Run, however they are limited to breast and gynecologic cancer survivors. The center is working with Reno Cancer Foundation to increase scholarships available to survivors of other cancers.

- Recommendation: Increase financial assistance opportunities for those with any cancer to participate in the program
- Carson Tahoe Cancer Resource Center – again, participants who had used the center had many positive comments about the center. Those not treated at Carson-Tahoe Cancer Center were largely unaware of the center and the resources available.
 - Recommendation: Identify opportunities to better promote the center to the Carson City region.
- The Caring Place – participants who used The Caring Place were very positive, however there is low awareness in the community.
 - Recommendation: Identify opportunities to better promote the center to the southern Nevada/Las Vegas area.
- Livestrong at the YMCA – participants who were aware of the program were very positive about the impact it had on survivorship. Task force members were so impressed with the program they suggested looking for ways to expand it into northern Nevada. Those survivors who were aware of the program found it difficult to schedule due to the time of day it was offered (for those still working or receiving treatment during the day). Additionally, there was low awareness of the program within the southern Nevada community.
 - Recommendation: Identify opportunities to better promote the program to the southern Nevada/Las Vegas area.

“My aunt did LIVESTRONG while she was going through her cancer treatment. My mom started post-cancer... and it was the first time she ever understood weights. And it was really funny because she also found Facebook at the same time. And she was like ‘I’ve lifted a ton!’... And it’s a great program but I don’t know that it’s made for someone who’s still in work life.”

Conclusion

Completion of this report is the first step in an ongoing process to improve the quality of life of cancer survivors in Nevada. Returning to where this report began, with the text of the Nevada State Cancer Plan, “There are great opportunities for collaboration on innovations for palliative care and survivorship programs across the state.” The process of completing the focus groups not only strengthened existing partnerships, but created new partnerships and connections.

There are a number of ways to become a partner or collaborator in making this report’s recommendations a reality.

Nevada Cancer Coalition and the Survivorship and Palliative Care Task Force will continue to collaborate with existing partners to bring this report’s recommendations to fruition. New partners are invited to join the task force, which meets every other month, or contact the coalition to determine other ways to participate. Details are available at www.NevadaCancerCoalition.org.

Positive Comments

"In all this cancer stuff in Elko, that radiation center. Thumbs up, five star. If you have people who want to go there, let them go because the people are amazing."

"I was fortunate, my oncologist got second opinions for me, just to help me make the decision..."

"Up in Truckee at the Cancer Center they have more of a holistic, not a business approach to treatment. I had the biofeedback, the acupuncture, the physical therapy, the massage. And that's all offered to you when you go up for treatment. So it's really nice. Treating the whole body..."

"St. Mary's...there was the diagnosis and then there was the surgery, and the radiation. After that, and there was a nurse navigator, and after that...you could get massage for lymphedema, and after that they said 'Now go on over to the gym and join the cancer exercise rehab program,' and along with that came the dietician. I thought that they were very thorough on the physical aspect side of things."

"I think the one thing in my experience was the PA. I preferred her. I said, 'You know what? You act like you have no other patients to see other than me!' That's great. She would ask me 'Do you have more questions?' She would explain my results and why we would put certain things off for a day because of certain results. These things totally made sense. But I was already in it. And I let her know that, how important it was that I felt like there was nobody else in the queue. I could ask anything, I could talk about anything, she would check what I wanted her to check. That was in place with her, the other one not so much. The initial diagnosis part should be more than just an appointment."

"I definitely think that the nurses are the backbone of our medical department as far as who we deal with. Because really, who do we deal with? We don't see the doctors much. We rely on the nurses."

"At St. Mary's there is an amazing cancer rehabilitation program, their gym, it is the best thing you will ever do for yourself."

"Another thing I found to be very helpful on a spiritual and an emotional level was the Sanford Center on Aging. And they did a cancer recovery program that was 6 weeks. And they just gave you tools to make decisions, tools to not just feel helpless. Tools that told you about diet, told you about pretty much the whole gamut."

"I signed up to go up to Northern California for a horseback ride...[at] a horse sanctuary and you could ride up and see all the wild horses and their babies. And yes, it was really helpful. It was like, 'I'm still alive and I can have fun again!'"

"I've gotten into a really old, old hobby, I guess I would call it. I'm back into cosplay, which I haven't done in years and years and years."

"You know what was awesome was that you didn't have leg hair for like a year."

"I'd have to say the nutrition part of it they were amazing. They always had stuff for me, ideas for me."

"Finally, someone pointed me to American Cancer Society and said they got a lot of information. You know, free stuff. I felt like that was a good connection. But I had to find out about them."

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A number of partners throughout the state also provided support to this project by offering locations to host the focus group discussions and distributing flyers to recruit participants. They include:

Access to Healthcare Network	PACE Coalition
American Cancer Society in Nevada	Partnership Carson City
Banner Churchill Community Hospital	Partnership of Community Resources
Carson City Health and Human Services	Renown Institute for Cancer
Carson Tahoe Health	Revivals Health & Wellness Council
East Fork Fire Protection District, Station 12	Saint Mary's Center for Cancer
Moms on the Run	Saint Mary's Center for Health
Nevada Cancer Research Foundation	Sanford Center for Aging
Nevada Community Health Clinics	St. Rose Dominican Hospitals
Nevada Health Centers	Summerlin Hospital Medical Center
Nevada Primary Care Association	University Medical Center
Northeastern Nevada Radiation Oncology	University of Nevada Cooperative Extension
Northeastern Nevada Regional Hospital	

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