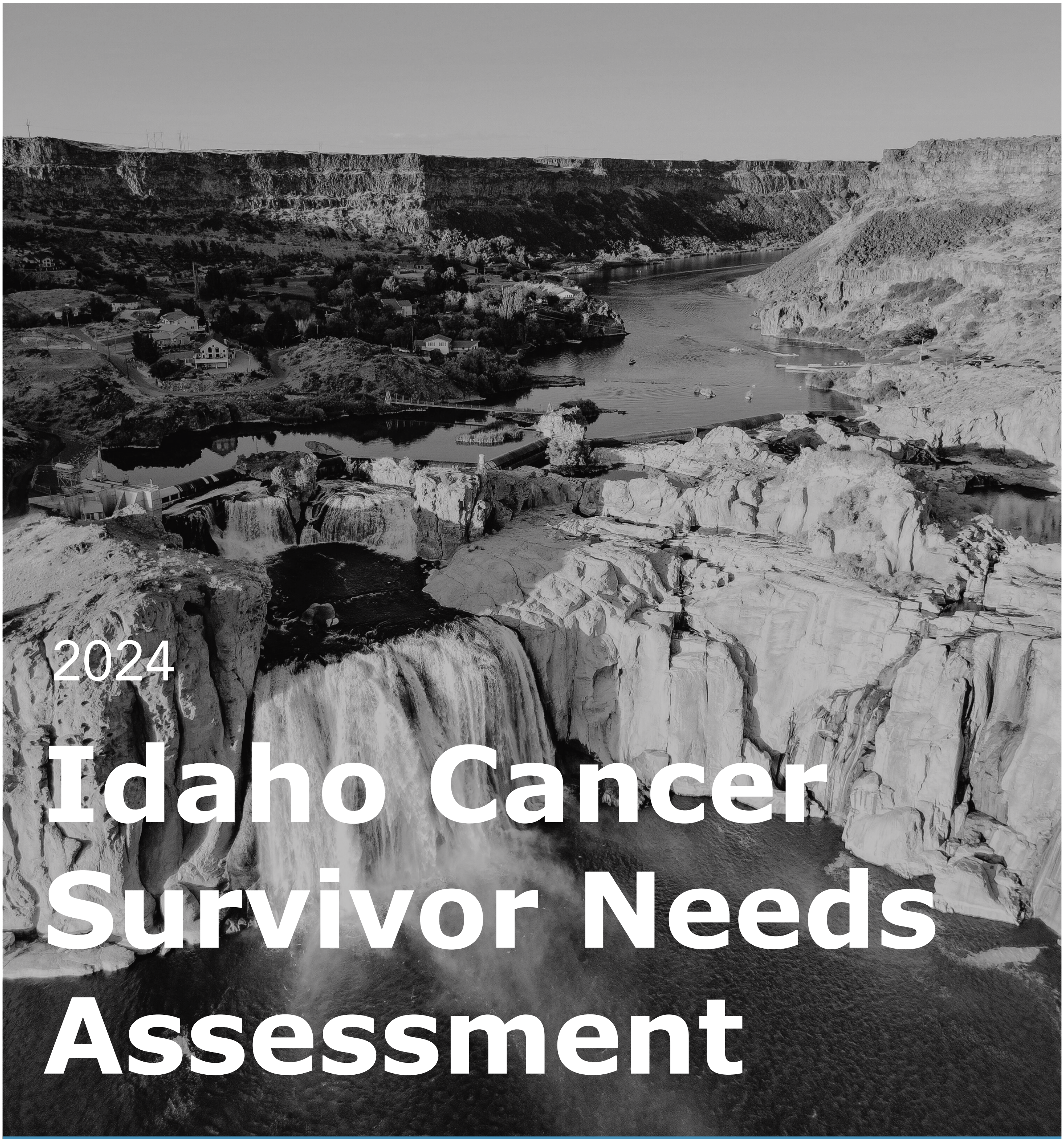


2024

Idaho Cancer Survivor Needs Assessment

Identifying survivor needs and resource gaps in Idaho.

ONE HEALTH
insights

Table of Contents

Executive Summary

Longer lifespans and advances in effective cancer treatments have led to an increase in the number of who have been diagnosed with cancer at some point in their lives. As the number of cancer survivors rises, it is increasingly important to understand how to best support them through diagnosis, treatment, and beyond.

This evaluation was designed to identify not only the top physical, mental/emotional, and practical concerns faced by survivors, but also ways to best support them as they navigate survivorship.
We surveyed both survivors and cancer care providers to better understand survivor's top concerns and the resources available to address those concerns. Additionally, we conducted key informant interviews with both medical and non-medical care providers to learn more about the specific organizations and opportunities currently available to survivors in Idaho. A gap analysis was performed to compare and contrast quantitative and qualitative results and identify key findings common across both the surveys and interviews.

Based on the results of the analysis, we identified five key findings relating to survivor needs and resource gaps:

- Mental health was a top concern for survivors.
- Survivors struggle with the financial burden of survivorship–and resources can be hard to find.
- A strong support network makes navigating survivorship easier.
- Not all providers share the same understanding of the resources available to cancer survivors.
- Each concern faced by survivors has the potential to impact other areas of well-being.

Based on our findings, we recommend the following to address gaps in survivor resources and approaches to survivorship care:

- Create and maintain a comprehensive, widely accessible resource hub for cancer survivors and cancer care providers in Idaho.
- Prepare survivors to navigate paying for medical and non-medical expenses by sharing details about the tools and resources available to assist with the financial burden of survivorship.
- Increase access to support groups for survivors to share experiences, get emotional support, and receive guidance from other survivors.
- Adopt a whole-person approach to survivorship care.

Every individual has a different and deeply personal experience of survivorship. This report is not meant to completely capture that nuance or to speak to every survivor's experience, but to serve as a jumping off point for organizations as they build programs and resources to help address the needs of Idaho's cancer survivors. Our hope is that this report offers some insight as to what those needs are, the current availability of resources that address them, and the ways we might continue to lift up and support cancer survivors across the state.

This publication has been funded in whole or in part with Federal funds from the National Cancer Institute (NCI) under Contract No. HHSN261201800006I and the Centers for Disease Control and Prevention (CDC) under the following Grants or Cooperative Agreement NU58DP006314. Its contents are solely the responsibility of the authors and do not necessarily represent the official position of CDC or NCI.

Background

An individual is considered a cancer survivor **from the time of diagnosis through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer.**

National Cancer Institute, adopted from the National Coalition for Cancer Survivorship.

A cancer diagnosis is almost always a life-changing event. From the time of diagnosis, survivors can experience a wide array of issues. These may include immediate impacts at the time of diagnosis - everything from anxiety and depression to physical changes from the cancer and treatments. New problems can occur during treatment or even after it ends, such as fear of recurrence and mounting financial burdens. A survivor's quality of life can be impacted for years after their initial diagnosis. Despite the potential for long-term problems, there is good news. New cancer treatment options are more effective than they once were, and survival time after a cancer diagnosis is improving. As of 2022, over two-thirds of people diagnosed with cancer in Idaho had survived at least 5 years after their diagnosis.[1] As the population lives longer and the number of cancer survivors continues to rise, it becomes increasingly important to understand the best ways to support them.

This needs assessment was conducted to answer the following questions:

1. **What are the needs of cancer survivors in Idaho?**
2. **Where do gaps exist in the availability and accessibility of resources to meet the needs of cancer survivors?**

In this report, we will summarize each step of the needs assessment and what was learned throughout the process. Based on what was learned about survivor needs, we will also identify strategic recommendations for the Idaho Comprehensive Cancer Control Program (ICCCP), the Comprehensive Cancer Alliance for Idaho (CCAI), and their partners.

ICCCP is funded by the Centers for Disease Control and Prevention's (CDC) Division of Cancer Prevention and Control to reduce the burden of cancer in Idaho. This assessment of cancer survivors' needs was supported by ICCCP. It is part of the broader strategy of the CCAI to reduce the burden of cancer on individuals, their loved ones, and their communities.

Cancer Survivors in Idaho

According to the Centers for Disease Control and Prevention (CDC), there are over 66k cancer survivors living in the state of Idaho that were diagnosed between January 1, 2001, and December 31, 2019.[2] This represents approximately 1 out of every 27 individuals (3.7% of the population) in the state. The number of male and female cancer survivors is very similar (50.1% male, 49.9% female), and the most common types of cancer diagnosed among survivors are prostate, breast, melanoma, colorectal, and thyroid cancers.

According to data from the 2022 Behavioral Risk Factor Surveillance System (BRFSS) survey, 8.0% of Idahoans are uninsured and nearly twice as many (15.8%) reported that they do not have a primary care provider (PCP). Since PCPs are often the first step toward screening for cancer and referring patients to oncology when needed, this indicates a sizable gap in the population's front-line access to cancer care. Furthermore, due to the rural nature of the state, Idaho cancer survivors are more likely to live in Health Professional Shortage Areas (HPSAs) where they have limited access to PCPs and cancer specialists. The Health Resources & Services Administration (HRSA) defines 37 of Idaho's 43 counties as Primary Care HPSAs and 40 of 43 counties are designated as Mental Health HPSAs.

66k

survivors living in Idaho that were diagnosed between 2001 to 2019

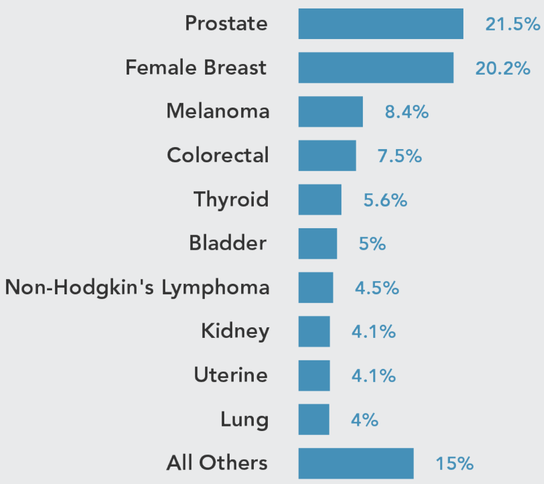
37

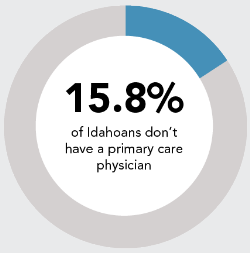
of Idaho's 43 counties are Primary Care HPSAs

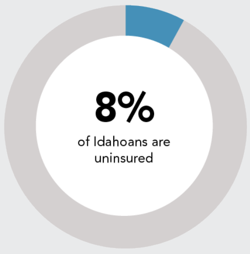
40

of Idaho's 43 counties are Mental Health HPSAs

Most Common Types of Cancer Diagnosed among Survivors in Idaho:



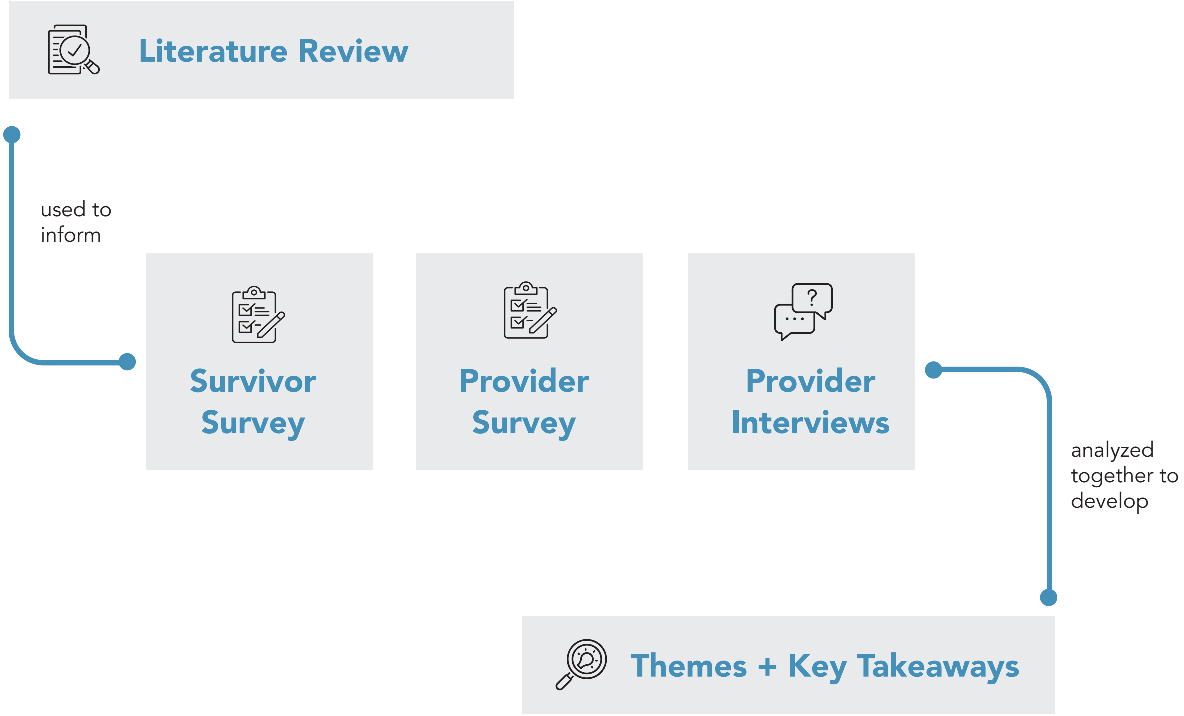




Approaches

To assess the needs of cancer survivors in Idaho, we used a mixed-methods approach for data collection and analysis:

- **Literature Review:** Research and themes regarding the needs of cancer survivors were compiled through a literature review.
- **Survivor & Cancer Care Provider Surveys:** Based on findings from the environmental scan and literature review, two surveys were designed; one for cancer survivors and one for cancer care providers.
- **Key Informant Interviews:** Cancer care providers (medical and non-medical) were interviewed.
- **Gap Analysis:** Using survey data and interview transcripts, a gap analysis was conducted to determine the top needs of cancer survivors and gaps in the resources available to support them.



The field of cancer survivorship focuses on the physical, mental/emotional, and practical effects of cancer from diagnosis through treatment and beyond. All of these aspects of a person's life contribute to their overall quality of life. Therefore, our analysis intentionally focused on components of each area to gain a better understanding of survivors' needs.

Literature Review

Question to be Answered

What are the needs of cancer survivors, in general?

What was Done

To better understand the important concepts and recent trends in survivorship care, we reviewed the websites of major cancer-related organizations such as the CDC, the National Cancer Institute, and the American Cancer Society. A PubMed search was also conducted using the search terms "cancer survivorship" and "cancer survivors." Finally, a recently published report on the needs of cancer survivors in Idaho was also reviewed.

What was Learned

The literature review revealed articles on transportation, technology and telehealth options, exercise, preventive care, and utilization of follow-up care services.[3-7] A meta-analysis of all articles published by the Journal of Cancer Survivorship (JCS) from 2007 to 2020 (Chan, 2021) was especially notable.[8] Through qualitative analysis, the study determined that the central theme of all of the JCS published cancer survivorship articles was 'quality of life.' Sub-themes included:

- Healthcare delivery and follow-up care
- Management of comorbidities and concurrent conditions
- Physical activity and exercise
- Healthy lifestyle/behaviors other than physical activity
- Disparity and social determinants of health
- Employment
- Management of symptoms/toxicity/late effects
- Psycho-oncology/psychosocial care
- Adolescent/young adult (AYA) cancer survivorship
- Health communications

This article illustrated the breadth of issues that can be affected by cancer- from topics as individual as managing disease to those as broad as healthcare delivery and communication. Alternatively, Assessing Quality of Life Among People Who Have Had Cancer (Brown, 2020) used interviews with sixteen Idaho cancer survivors to show the unique nature of each individual's cancer experience.[7] Taken together, these articles show that cancer concerns are both very broad and very specific, and that an assessment of survivor needs should reflect that as well.

Survivor Survey

Question to be Answered

What are the concerns of cancer survivors in Idaho? Did they seek help for those concerns, and were they able to easily find help?

Design and Dissemination

After reviewing over a dozen potential surveys used to assess quality of life (QoL) in cancer survivors, we decided to use a subset of a previously validated survey (the Experiences of Cancer Patients in Transitions Study survey) produced by the Canadian Partnership Against Cancer.[9] This survey touched on many of the concerns that were highlighted in the literature review. Cancer survivors were asked about specific concerns that pertained to their physical health, mental health, and the practical aspects of their lives. Based on the literature review, we added five topics to the list that were previously missing: Nutrition, physical activity, smoking, housing security, and food security. The survey was made up of three sections:

1. DEMOGRAPHICS

Background information was collected on survey participants including county of residence, sex, age, race, ethnicity, marital status, educational attainment, insurance status, and ratings of general physical and emotional health. Additionally, we asked survivors what type(s) of cancer they had been diagnosed with, what type(s) of treatment they received, which type of provider(s) and specialist(s) they saw regularly, where they found support for non-medical cancer-related needs, and how long they regularly traveled for cancer treatments.

2. CONCERNS

Survivors were asked about 25 different potential issues, categorized as either physical, mental/emotional, or practical. While this list of issues is meant to represent many of the concerns experienced by survivors, it is not an exhaustive list. Survivors were asked to classify each topic as either a big concern, moderate concern, small concern, or not a concern. If they were concerned about a topic, they were then asked if they'd sought help for that particular issue. If they sought help, they were asked to identify how easy it was to access help or resources to address the issue.

Physical Concerns

- Fatigue/tiredness
- Nerve problems/neuropathy
- Changes to concentration and/or memory
- Lymphedema
- Chronic pain/long-term pain
- Hormonal, menopause, or fertility issues
- Physical changes in sexual function
- Bladder and/or urinary problems
- Gastrointestinal problems
- Quitting smoking or tobacco use
- Physical activity/exercise
- Nutrition

Mental / Emotional Concerns

- Depression, sadness, or loss of interest in everyday things
- Anxiety, stress, or worry about cancer returning
- Changes in body image
- Changes in relationships with family members and/or partner
- Changes in sexual intimacy
- Changes in relationships with friends/ coworkers

Practical Concerns

- Taking care of children, parents, or other family members
- Return to work or school
- Housing security
- Food security
- Getting to and from appointments
- Paying for medical expenses
- Paying for non-medical expenses

3. ADDITIONAL COMMENTS

Three open-ended questions were also included to allow survivors to share positive and negative experiences that could benefit other survivors.

The survey was available online via computer, tablet, or smartphone, and was disseminated through social media and direct outreach to cancer care organizations including cancer centers, non-profits, and support groups. All survey questions were optional. Respondents were asked to confirm that they were over the age of 18 and had been diagnosed within the last 6 years.

Respondents

We received a total of 67 unique responses representing 17 counties across Idaho, with most respondents residing in the Boise area. Respondents were mainly white (85%), female (79%), age 51 and over (61%), college-educated (73%), and married (75%). Ninety percent indicated that they had health insurance coverage through Medicare and/or an employer-based health insurance company. Most were breast cancer survivors (57%) followed by prostate (12%) and blood cancer survivors (8%). Other cancer diagnoses included colorectal, gynecological (ovarian, cervical, etc.), kidney, lung, skin, stomach, and thyroid.

What was Learned

- Overall, anxiety and depression were the #1 and #3 concerns of survivors.
- Concerns about body image, sexual intimacy, and relationships with family and/or significant others were noted as concerns for at least half of survivors.
- Fatigue was the #2 survivor concern, with 76% of respondents noting it as at least a small concern. Cognition, sexual function, pain, and exercise were also top physical concerns for survivors, with more than 50% noting them as concerns.
- Paying for medical expenses was noted as a concern for at least 60% of survivors. Considering the fact that 90% of survey respondents were insured and almost three-quarters had a college degree, it can safely be assumed that paying for healthcare is an even larger problem in the general survivor population than this survey indicates.

- Survivors were less likely to seek help for emotional and practical concerns than they were for their physical concerns.
- In response to the open-ended survey questions, survivors wished for more attention to be paid to their emotional health, improved communication with care teams beginning at diagnosis, and additional resources to help pay for medical and non-medical expenses during and after cancer treatment.
- Survivors also shared details about the benefits of alternative therapies, including acupuncture, massage, nutrition, and exercise/mobility support, and the benefit of having an involved support network to help them meet their needs throughout treatment.

Care Provider Survey

Question to be Answered

What are cancer care providers' perspectives on the concerns of cancer survivors and the availability of resources to address those concerns?

Design and Dissemination

The same physical, mental/emotional, and practical concerns assessed in the survivor survey were also used for the provider survey. The survey contained two main sections:

1. DEMOGRAPHICS

Background information was collected on survey participants including name, email, type of organization worked for, job title, and which public health district in the state they served. Providers were also asked if they would be willing to participate in a key informant interview to further discuss the needs of cancer survivors in Idaho.

2. CONCERNS

Providers were asked to rank the same 25 concerns on a scale of 1 to 5, where 1 is not a concern, and 5 is a big concern for cancer survivors in Idaho. They were also asked to score the availability of resources to address each concern in Idaho, where 1 was considered to be a low availability of resources and 5 meant there were plenty of resources available for survivors.

The survey was available online via computer, tablet, or smartphone, and was disseminated through social media and direct outreach to cancer care organizations including cancer centers, non-profits, and support groups. All survey questions were optional.

Respondents

We received a total of 28 responses representing all seven public health districts (PHD) across Idaho, with 34% of respondents working with survivors in PHD 4 (Ada, Boise, Elmore, and Valley Counties). Respondents mainly worked for hospitals (46%) and nonprofits (28%).

What was Learned

- Providers ranked anxiety (4.6 out of 5), paying for medical expenses (4.6 out of 5), depression (4.5 out of 5), nutrition (4.5 out of 5), and paying for non-medical expenses (4.4 out of 5) as the top five concerns for survivors.
- Providers thought there were the fewest resources available to address concerns about changes in sexual function (2.0 out of 5), paying for non-medical expenses (2.1 out of 5), housing security (2.2 out of 5), sexual intimacy (2.2 out of 5), and paying for medical expenses (2.3 out of 5).
- Medical providers (physicians, nurses, pharmacists, surgeons, hospital patient navigators and social workers) and non-medical providers (non-profit staff and support group leaders) had different understandings of the top concerns of survivors and the availability of resources to address those concerns. Overall, medical providers gave all concerns a higher value and believed there were more resources available to address those concerts when compared to non-medical providers.

Care Provider Interviews

Question to be Answered

What are the most significant concerns that cancer survivors in Idaho face, what are the unmet needs related to those concerns, and what would help providers to best serve cancer survivors in Idaho?

Interview Guide

An interview guide was developed based on the framework used for the surveys to identify the top physical, mental/emotional, and practical concerns faced by survivors.

Care providers were asked to identify the most significant physical, mental/emotional, and practical concerns that the survivors they worked with faced. For each category of concern, providers were also asked:

- What does your organization do to address those concerns?
- What other resources do you know of in Idaho that address those concerns?
- What are the unmet needs related to those concerns?
- Across all categories, what do you think is the most significant concern faced by Idaho cancer survivors?
- Across all categories, what one thing would help you best serve Idaho cancer survivors?

Participants

Participants were recruited from the cancer care provider survey after expressing interest in being interviewed to further discuss the needs of cancer survivors. We conducted six 30-minute long, virtual interviews with three medical care providers and three non-medical care providers. Medical providers included a non-hospital provider, a patient navigator and an oncology nurse. Non-medical providers included two founders of non-profit survivorship organizations and a survivor support group leader.

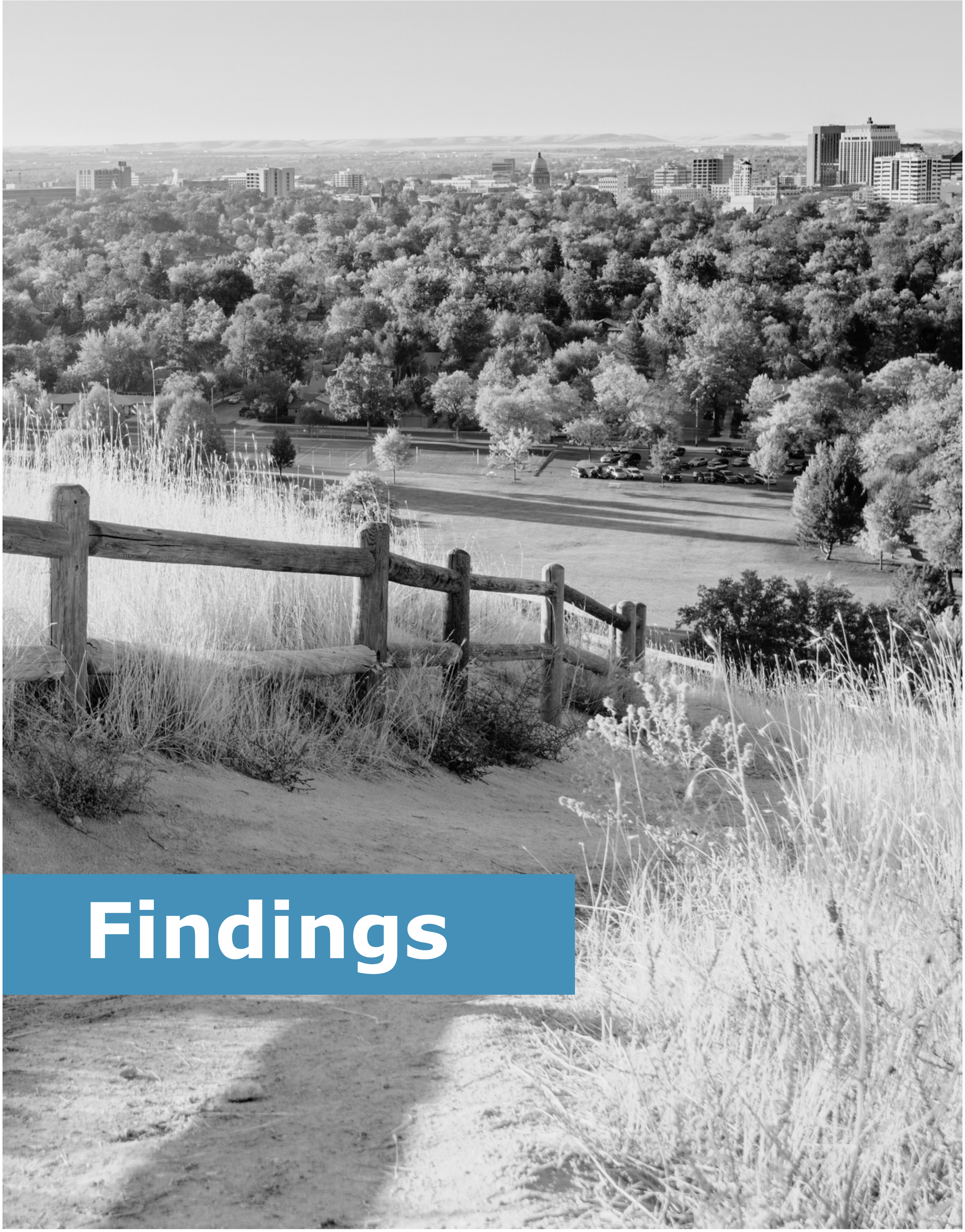
Thematic Analysis

After conducting the interviews, transcripts were cleaned and prepped for analysis. We developed a codebook of themes identified throughout the key informant interviews and applied the codebook to all transcripts using a qualitative analysis software.

The most commonly used codes (or code frequencies) were used to identify the top concerns in each category, while the intersections of multiple codes (or code relations) were used to help provide nuance and better understand themes across multiple codes. Code segments were additionally reviewed to provide further details and context to provider experiences and perceptions.

What was Learned

- Providers felt mental health concerns were the top issues faced by survivors, including anxiety, depression, stress, fear, and loneliness.
- Providers also described the impact physical changes can have on survivors, including issues like edema, scarring, weight gain, and hair loss, and how those changes may impact survivors' body image, and self-esteem.
- The need for and benefit of support networks was also a common theme noted by providers as benefiting survivors in all areas of their well-being.
- Financial concerns were noted as an area of high concern for survivors. Specifically, providers discussed how limited income can negatively impact survivors' ability to address their physical, mental/emotional, and practical concerns.
- Providers noted gaps in resources, specifically the lack of a comprehensive list of the resources available statewide to meet the needs of survivors and the lack of emotional and peer support services for survivors post-treatment.



Findings

MENTAL & EMOTIONAL HEALTH

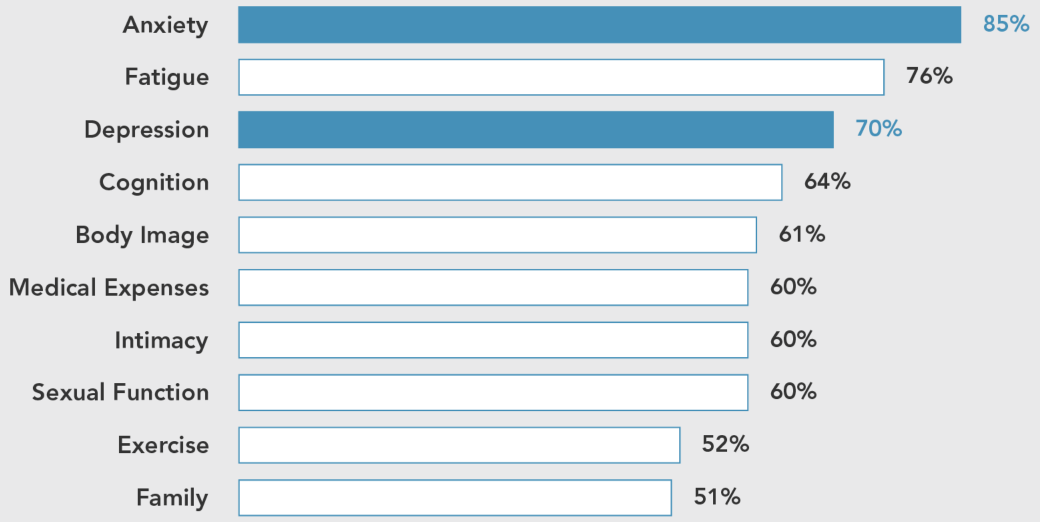
Mental health is a top concern for Survivors.

Anxiety and depression were the #1 and #3 concerns identified by survivors.

Anxiety and depression were the #1 and #3 concerns identified by survivors, with 85% and 70% noting them as a concern, respectively. Based on responses to the open-ended survivor survey questions, the largest gap in resources was access to mental health services. Survivors wanted more attention paid to their emotional wellness, with multiple respondents expressing their disappointment in the support offered and resources made available to address physical needs as opposed to emotional needs.

Many survivors wished that throughout their treatment, providers had asked more questions about mental health. Several respondents expressed a desire for referrals to mental health professionals, especially those who specialize in cancer support.

Top 10 Concerns for Cancer Survivors in Idaho:

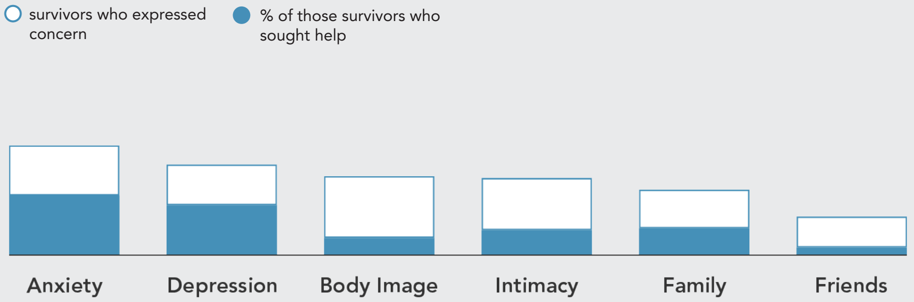


Survivors struggle to access support for certain emotional needs.

Survivors indicated that access to individual counseling for mental health concerns like stress, fear, and self-image–along with marriage, family, and addiction counseling–were gaps in survivorship care. Survivors were less likely to seek support for issues like body image, intimacy, and relationships with family and friends than they were to seek help for mental health concerns like anxiety and depression, with more than half seeking help for anxiety and depression and only 22% seeking help for body image issues, 33% seeking help for intimacy issues, 41% seeking help for issues with relationships with family members and/or partner, and 20% seeking help for issues with relationships with friends.

> **I don't remember anyone saying that even after all the surgeries, I'd feel terrible about myself. I think because it wasn't normalized, [the] more I felt alone... how it would negatively impact my marriage. I wish marriage counseling was a part of survivorship care.**
>
> CANCER SURVIVOR

Survivors seem less likely **to seek help for mental and emotional concerns.**



Providers believe mental health is a big concern for survivors.

Providers also indicated that mental health was a top concern for their patients, ranking anxiety and depression 4.6/5 and 4.5/5, respectively. Providers who participated in key informant interviews expressed how poor mental health can have an impact on overall health, including sleep, relationships with family and friends, one's ability to caregive and/or work, and one's ability to recover from treatment. The burden imposed by both medical and non-medical expenses, and the subsequent impact of that stress on a survivor's mental health, was also a common theme across provider interviews.

> **Finances also cause emotional concerns, because it's hard when you're already in a chronically ill state and having to worry about finances and things like that. A lot of things can cause [survivors] emotional trouble.**
>
> ONCOLOGY NURSE

FINANCIAL BURDEN

Survivors struggle with the financial burden of survivorship—and resources can be hard to find.

60% of survivors said paying for medical expenses was a concern.

Sixty percent of survivors said that paying for medical expenses was a concern. Of those who sought help paying for those expenses, 50% said help was hard or very hard to access, while another 14% were ultimately unable to find any help whatsoever.

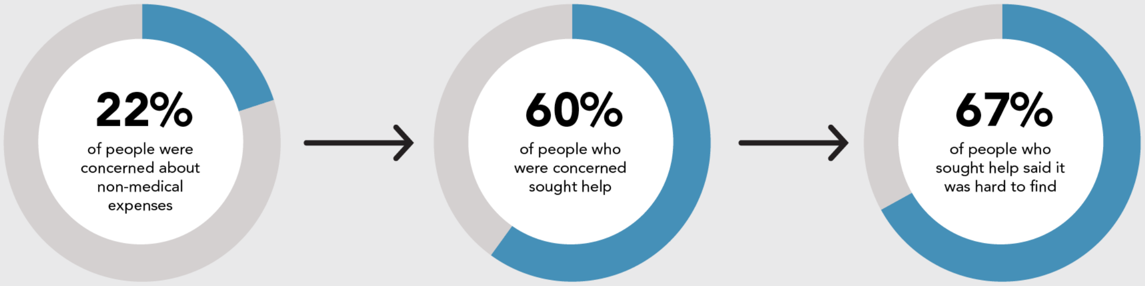
Despite having insurance, many survivors struggled to pay for all the expenses associated with cancer treatment. Survivors frequently mentioned that assistance addressing financial burden was a gap in survivorship care that affected the decisions they made during and after treatment. Many of those same survivors wanted more support with things like navigating disability services, communicating with insurance companies, and accessing earned social security benefits if a diagnosis was terminal. Some survivors and providers even noted instances of having to delay treatment because of a financial burden.

> **I reached out to a couple cancer facilities requesting help financially, asking for grants, etc. No one got back to me. So my surgery set for April was changed to August 2024 so that I could save money to live on while healing and off work for 3 months.**
>
> **SURVIVOR**

Medical expenses aren’t the only financial concern for survivors.

Some survivors also struggle to cover non-medical expenses. Of the 22% of survivors who indicated this was a concern, 60% attempted to get help. Of those survivors who sought help, 67% were either unable to find help or found it difficult to access help. Providers shared additional context about how paying for non-medical expenses can pose a major barrier to a survivor’s ability to maintain safe and adequate housing and access nutritious foods.

Not all survivors are concerned about non-medical expenses, but for those who are, resources can be difficult to find.



Providers also feel that medical and non-medical expenses are a big concern for their patients, but don’t feel there are adequate resources to help address them.

Providers recognized the impact financial burden can have on survivors, ranking paying for medical and non-medical expenses as the top two practical concerns for the survivors they work with. Financial concerns also made up two of the top three concerns for which providers felt there were inadequate resources available to survivors. Navigating insurance, Medicaid, and other assistance programs were all areas where providers felt that survivors needed more support. The cost of treatment, medications, travel to treatment, and lost wages were just a few of the barriers that providers felt impacted survivors financially.

> **I wish I had had help navigating medical bills. I was given emergency Medicaid at the time and then sent to Boise for surgery. After I had the surgery, Medicaid came back saying they would not pay for the surgery. Left me financially ruined while fighting for my life. Awful.**
>
> **SURVIVOR**

Financial concerns can quickly impact other areas of survivors' lives and well-being.

Providers and survivors both noted that financial concerns quickly take over other areas of survivor's lives. What begins as a financial barrier can quickly cause stress, fear, or anxiety, all of which impact a survivor's overall long-term health and well-being.

> **From what I've seen in the group, the majority of them are still working. That's a huge part of it. They're going through this reconstruction, they're going through surgeries, radiation fatigue, chemo side effects, and they still have to work for financial reasons. And I think that's part of where a lot of the fear that the ladies have comes from. Being able to physically do their job and provide for their families.**
>
> **NON-PROFIT FOUNDER**

SUPPORT NETWORKS

A strong support network makes navigating survivorship easier.

A strong support network was an important resource for survivors as they navigated different aspects of survivorship.

Survivors felt strongly about the need for and benefit of support networks as they navigate diagnosis, treatment, and life after treatment. Comments in the open-ended portion of the survey about the benefit of having a strong support network were the second most common theme from survivors. Many survivors shared the importance of having someone to help with daily needs like transportation, household errands, and caregiving. Reliable networks made up of family, friends, care teams, and other cancer survivors had an impact on all areas of an individual's well-being. Though caregiving was only a concern for 34% of survivor survey respondents, most did not seek support when it came to taking care of their children, parents, or other family members. However, those who did seek support found it difficult to find.

Strong support networks increase a survivor's ability to address their needs.

Active support networks also provide survivors with more opportunities to reach out and ask for help regarding issues where they're more reluctant to seek help. Concerns about cognition, relationships with friends, returning to work, and housing security–in addition to concerns about body image, sexual intimacy, and caregiving–were issues where survivors were much less likely to seek help to get their needs addressed. While survivorship looks different for every individual, understanding the concerns that some survivors may be less willing to seek help for can help inform the kinds of resources and support available to survivors.

> **I think it's just primarily talking to them to find out what their needs are and connecting them to the community. Validating with them that cancer is a very isolating event. And it's okay to continue to be scared. We get very, very focused on physically healing as opposed to emotionally recovering.**
>
> **NON-PROFIT FOUNDER**

Support networks–especially those made up of other cancer survivors–help survivors combat feelings of loneliness and isolation.

Providers and survivors expressed how support networks, especially those made up of other cancer survivors, can help survivors combat feelings of loneliness and isolation resulting from a cancer diagnosis. More traditional support groups, as well as Facebook groups and organizations that allow survivors to participate in shared activities together, are some of the resources for community and support utilized by survivors. Both providers and survivors felt that creating space for survivors to relax, reflect, or even spend time outdoors, were valuable ways to prioritize self-care and promote emotional healing.

> **Finding community and getting into nature. Adventure healing has been amazing. Also for young adult cancer patients finding others that will always live with the fear of remission.**
>
> **SURVIVOR**

> **The most impactful thing for me was to use social media to find another individual with the same diagnosis walking almost an identical journey to mine at nearly the same time as me. Having someone to talk through EVERYTHING (treatment plans, progress, self image challenges, sharing resources, etc.) was a game changer for me.**
>
> **SURVIVOR**

A supportive care team can have a big impact.

Survivors also felt it was important to have an engaged, interactive, and trusted care team. Many shared stories of how meaningful relationships with their physicians, surgeons, nurses, social workers, and other office and administrative staff had a big impact on their survivorship experience, especially while undergoing treatment.

> **Creating relationships with your care team is unbelievably important. One of my most cherished memories is of one of my chemo nurses handing me a card that she said made her think of me. It said, "We do the hard things."**
>
> **SURVIVOR**

UNDERSTANDING RESOURCES

Not all providers share the same understanding of the resources available to cancer survivors.

Medical and non-medical providers seem to have different understandings of the resources available to cancer survivors.

When ranking the availability of resources to address specific survivor needs, medical providers were more likely to say that resources to address physical, emotional, and practical concerns were available for survivors, whereas non-medical providers generally ranked the availability of resources as much lower, especially when it came to the resources available to address physical concerns.

Similar differences were found when discussing gaps in available resources with providers during interviews. Medical providers were generally less aware of resources available to address the needs of survivors outside of their own professional role, while non-medical providers were more likely to share names of other organizations that address the emotional and practical needs of survivors. Non-medical providers were also generally less aware of the resources available to address the physical needs of survivors.

> **I don’t know much outside of our organization. I do try to go to cancer events that could plug patients into external resources, but I myself as a nurse, I’m not super aware of outside resources, unfortunately.**
>
> ONCOLOGY NURSE

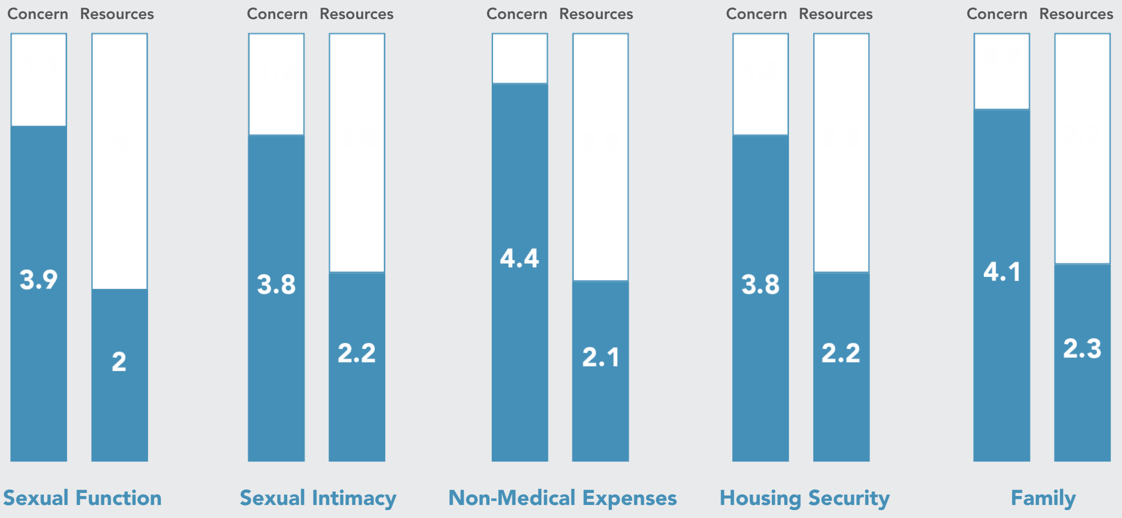
Providers agree that some resources are more limited than others.

All providers agreed that there were limited resources to address survivor concerns regarding changes in sexual function (2.0 out of 5) and sexual intimacy (2.2 out of 5).

Though the availability of resources to address issues regarding sexual function and intimacy were ranked the lowest by both types of providers, the availability of resources to support paying for non-medical expenses (2.1 out of 5), housing security (2.2 out of 5), and relationships with family members and significant other (2.3 out of 5) were also ranked very low by providers.

> **I think this is one of the areas we should talk about … all the side effects and everything that relates to sexual health. The ladies are very frustrated with the lack of options and communication that's being offered that they feel like they're on an island.**
>
> **NON-PROFIT FOUNDER**

Providers believe there are limited resources **for certain survivor concerns.**



> **[We need] more income-based housing. We have housing popping up all over our community, but $1,200 a month, when maybe all you get is $600 from Social Security… You know, income-based housing is needed, I would build a lot of those kinds of complexes. And then transportation, I mean, if you have someone [that can help] with transport, then they would have a particular place to go if a [survivor] has adequate housing.**
>
> **PATIENT NAVIGATOR**

WHOLE-PERSON APPROACH

Each concern faced by survivors has the potential to impact other areas of well-being.

Survivors and providers both made it known how a single concern quickly impacts other areas of survivors' lives, ultimately negatively impacting survivors' overall well-being.

Though we categorized concerns experienced by survivors as physical, mental/emotional, or practical, there is substantial overlap among all concerns. For example, issues that were labeled physical concerns like fatigue, pain, or nerve problems, may impact one's ability to go to work, making paying bills more difficult, and in turn increasing feelings of stress and anxiety.

> **What might be a fiscal concern turns into anxiety, stress, depression, loss of job, loss of work, loss of social connectivity. And then sleep. Sleep disorder is very high. So you might think of that as a physical issue, but lack of sleep also leads to depression, anxiety, fatigue.**
>
> **NON-HOSPITAL CLINICIAN**

Cancer survivors face needs far beyond immediate medical care and treatment.

While expressing immense gratitude to their care teams for being compassionate, understanding, and proactive, survivors also shared examples of instances where they felt that their providers were only focused on physical healing, resulting in their concerns about mental health or needed social services going unheard. A whole-person approach to survivorship requires a well-coordinated care team to address all aspects of well-being during and after treatment.

> **More attention to emotional well-being rather than just physical symptoms, no one ever asked me how I was doing emotionally or offered support or treatments to help me cope with natural fears.**
>
> **SURVIVOR**

Recommendations

Based on existing understanding of the needs of cancer survivors and findings from the gap analysis, we identified four major recommendations for where and how to best meet the needs of cancer survivors. Idaho cancer survivors represent all types of people, each with their own needs, circumstances, and experiences. This list of recommendations is meant to serve as a jumping-off point for survivorship organizations, healthcare providers, friends, and family of cancer survivors. By understanding where need is high and resources are low, we can locate opportunities for change to better serve survivors throughout survivorship—from diagnosis through treatment, and beyond.

Create and maintain a comprehensive, widely accessible resource hub for cancer survivors and cancer care providers in Idaho.

- Survivors need to know what resources are available in order to access them, and providers need to know what resources exist in order to make referrals and recommendations.
- A statewide cancer coalition with representatives from health care, non-profits, advocacy organizations, as well as survivors and caregivers, can provide a strong network that can be used to help disseminate information about these resources.

Prepare survivors to navigate paying for medical and non-medical expenses by sharing details about the tools and resources available to assist with the financial burden of survivorship.

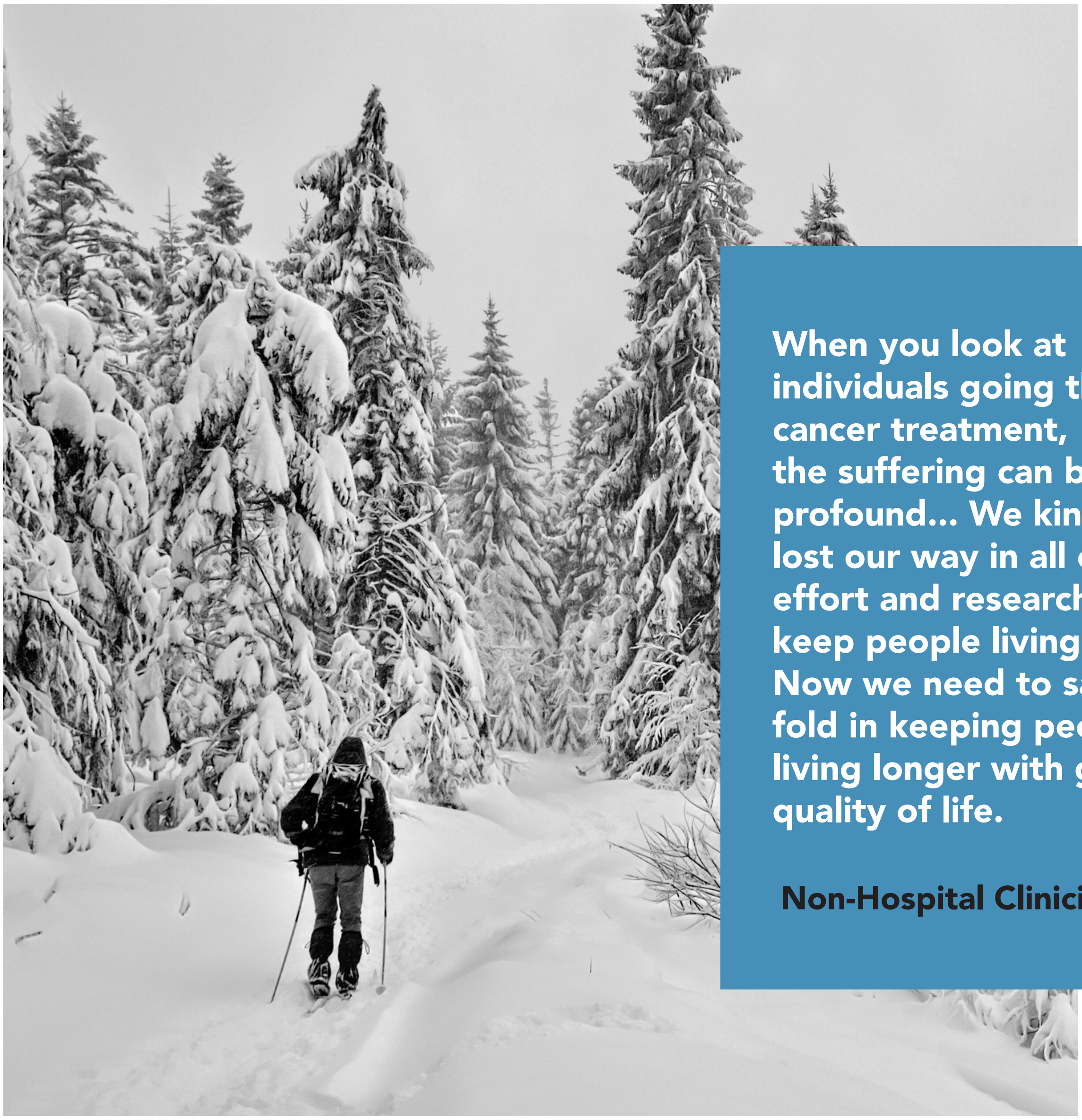
- Wherever possible, support survivors in navigating disability services, communicating with insurance companies, and accessing state or federal financial benefits or compensation that they might be eligible for.
- Give survivors the tools to have informed conversations about the cost of their treatments with billers and payers.

Increase access to support groups for survivors to share their experiences, get emotional support, and receive guidance from other survivors.

- Expand options for support groups that cater to the specific needs and challenges that survivors face, like site-specific support groups, support groups for parents, and support groups for the recently diagnosed.

Adopt a whole-person approach to survivorship care.

- For medical providers, emphasize emotional health and healing in addition to physical health and healing, and provide patients with referrals that support their mental health. Develop a multidisciplinary team of oncologists, primary care physicians, counselors, dieticians, physical and occupational therapists, social workers, and patient navigators to work collaboratively to provide whole-person care.
- Integrate a whole-person approach to survivorship programming, including access to resources that address social determinants of health like transportation, housing insecurity, and food insecurity, and emotional needs like individual, family, marriage, and financial counseling.



> **When you look at individuals going through cancer treatment, the suffering can be profound... We kind of lost our way in all of the effort and research to keep people living longer. Now we need to say let's fold in keeping people living longer with great quality of life.**
>
> **Non-Hospital Clinician**

References

1. Cancer Data Registry of Idaho. (2021). Annual Report: Cancer in Idaho - 2021. https://www.idcancer.org/ContentFiles/AnnualReports/Cancer_in_Idaho_2021.pdf

2. U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool, based on 2022 submission data (1999-2020): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; https://www.cdc.gov/cancer/dataviz, released in November 2023. Accessed June 2024.

3. Argenbright, K. & Berry, E. "Innovative Cancer Survivorship Services for Rural and Underserved Communities," JNCI Monographs 2021, no. 57 (2021): 31–34. https://doi.org/10.1093/jncimonographs/lgab001.

4. Smith-Turchyn, J. et al., "Characterizing the Exercise Behaviour, Preferences, Barriers, and Facilitators of Cancer Survivors in a Rural Canadian Community: A Cross-Sectional Survey," Current Oncology 28, no. 4 (2021): 3172–87. https://doi.org/10.3390/curroncol28040276.

5. Ginossar, T. et al., "'You're Going to Have to Think a Little Bit Different' Barriers and Facilitators to Using MHealth to Increase Physical Activity among Older, Rural Cancer Survivors," International Journal of Environmental Research and Public Health 18, no. 17 (2021): 8929. https://doi.org/10.3390/ijerph18178929.

6. Ou, J. et al., "An Investigation of Survivorship Clinic Attendance among Childhood Cancer Survivors Living in a Five-State Rural Region," Journal of Cancer Survivorship 12, no. 2 (2018): 196–205. https://doi.org/10.1007/s11764-017-0658-4.

7. Brown, H., Hall, L., Kaur, J. and Severson, L. (2020). Assessing Quality of Life Among People Who Have Had Cancer. University of Idaho, Moscow., ID. https://www.uidaho.edu/-/media/3C910CE87D174A6FB48930BC4CBDAA42.

8. Chan, R.J., Hollingdrake, O., Bui, U. et al. "Evolving Landscape of Cancer Survivorship Research: An Analysis of the Journal of Cancer Survivorship, 2007–2020." Journal of Cancer Survivorship 15 (2021): 651–658. https://doi.org/10.1007/s11764-021-01042-6

9. Shakeel, Saad et al. "Evaluation of Factors Associated With Unmet Needs in Adult Cancer Survivors in Canada." JAMA Network Open, vol. 3 (2020). doi:10.1001/jamanetworkopen.2020.0506