



Needs assessment of cancer survivors in Alaska

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Abstract

Purpose Little is known about cancer survivors' needs in Alaska. To address this knowledge gap, the Alaska Cancer Partnership conducted a needs assessment survey; our objectives were to identify unmet needs of Alaska's cancer survivors; identify survivor sub-populations that might benefit from targeted interventions or programming; and develop recommendations for public health and community organizations and healthcare providers for addressing cancer survivors' unmet needs.

Methods Cancer survivors were identified using data from the Alaska Cancer Registry. A random sample of 2,600 individuals was selected to receive the survey, which assessed unmet needs across the following domains: information needs and medical care issues; quality of life; emotional and relationship issues related to cancer diagnoses; and support services. We calculated descriptive statistics for survey responses and assessed demographic predictors of unmet needs using Poisson regression.

Results We received 335 survey responses, for a response of 13.7%. Only 29.9% of cancer survivors expressed that all their needs were met. The most highly ranked unmet needs were as follows: help to reduce stress in life; to know doctors were coordinating care; and managing concerns about cancer coming back. After adjustment, men, adults younger than 65 at diagnosis, Alaska Native people, survivors still receiving or who had recently received care, and people who had to travel 50+ miles for most of their care had significantly greater unmet needs than their comparison groups.

Conclusion This assessment provided some of the first information regarding the needs of Alaska's cancer survivors. These results will be used by Alaska Cancer Partnership members across the state to inform healthcare delivery, programs, and public health messaging to support survivors.

Keywords Cancer survivorship · Needs assessment · Cancer survivors · Unmet needs

Abbreviations

AI/AN American Indian/Alaska Native
ACR Alaska Cancer Registry

Introduction

The lifetime risk of developing cancer in the U.S. is 39.5%, meaning that over a third of people will be diagnosed with cancer during their lifetime [1]. A cancer survivor is defined as a person diagnosed with cancer, from the time of diagnosis through the remaining years of their life [2]. Due to increased early detection through screening and improved effectiveness of treatment, the number of cancer survivors in the U.S.A has been steadily increasing: the National Cancer Institute estimates that as of January 2019, there were an estimated 16.9 million survivors in the U.S.A., a number that is projected to increase to 22.2 million by 2030 [1]. Cancer survivorship is associated with challenges, including long-term physical effects; late effects; psychological distress; information and support needs; continuing healthcare needs; increased risk of a second primary cancer diagnosis and/or recurrence of the first primary cancer; and resuming daily activities while simultaneously managing cancer as a chronic condition [3–7]. Understanding cancer survivors'

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needs across these domains is critical to providing appropriate programs, services, and resources that will support their ongoing health and well-being.

Just over 32,000 cancer patients whose cancers were diagnosed in Alaska may still live in the state as survivors (unpublished data, O'Brien, State of Alaska, Alaska Cancer Registry). Overall, Alaskans exhibit slightly lower all-cancer incidence, mortality, and survival compared to the U.S. population [8]. Alaska Native (AN) people specifically exhibit similar all-cancer incidence and mortality compared to U.S. non-Hispanic whites; however, they do have higher burden of several cancer sites, including colorectal, lung, and liver cancers [9]. Little is known about Alaska cancer survivors, or their needs, in part because this population has never been well described, and their needs have never been comprehensively assessed. In 2010 and 2014, surveys were conducted specifically among breast and prostate cancer survivors, respectively [10–12]; and in 2014, the Alaska Behavioral Risk Factor Surveillance System survey included the cancer survivorship module. These surveys broadly indicated the need for increased care coordination; increased awareness of and referral to support groups; increased attention to mental health; and for increased clinical and survivorship research. Yet, while these initiatives were informative, there was a need for a more comprehensive survey drawn from a population-based sample of cancer survivors to provide more generalizable and up-to-date data on survivor needs.

This study aimed to address gaps in knowledge regarding cancer survivors' needs in Alaska by conducting a needs assessment survey. The objectives of this study were to identify unmet needs of Alaska's cancer survivors; identify survivor sub-populations that might benefit from targeted interventions or programming; and develop recommendations for public health and community organizations and healthcare providers for addressing cancer survivors' unmet needs. We anticipate that these results will be of interest to public health agencies, community organizations, and clinicians who provide services to cancer survivors in Alaska.

Methods

Study partners

This study was conducted by the Alaska Cancer Partnership (Partnership), a coalition of organizations and individuals working to bring resources and expertise together to address the continuum of cancer prevention and control in Alaska. The Partnership comprises a range of organizational sectors, including Tribal and non-Tribal healthcare organizations, Tribal and non-Tribal non-profit organizations, state government; university; and individuals/volunteers. A full list of Partnership members is given on the State of Alaska's

website [13]. This study was led by the Alaska Comprehensive Cancer Control Program and conducted with collaboration of partners from across the Partnership, including the Alaska Cancer Registry (ACR), the Alaska Native Tribal Health Consortium, and the Alaska Chapter of the American Cancer Society. Data are available upon request; please contact the authors directly.

The Alaska Area and University of Alaska Anchorage Institutional Review Boards determined that this study was Not Research. Approval for publication of this manuscript was sought and received from the Alaska Native Tribal Health Consortium and the State of Alaska Division of Public Health.

Study eligibility, recruitment, and sampling

Cancer diagnoses in Alaska are recorded by the ACR, a population-based central registry of the National Program of Cancer Registries, funded by the Centers for Disease Control and Prevention to collect these data since 1996. A sample of 2,600 cancer survivors was selected from the ACR database. Eligibility criteria included diagnosed with a malignancy between 2004 and 2016; Alaska resident at the time of cancer diagnosis; aged 18 years or older at the time of cancer diagnosis; and not deceased at the time of survey mailing (September 2019). A stratified random sample of 200 eligible individuals per diagnosis year were selected for invitation to participate in the study and cross-referenced against death certificate data to remove those who were deceased. No other stratifying criteria (beyond year of diagnosis) were used to select the sample.

Invitations were mailed to the selected individuals during September–November 2019. During the first mailing, individuals received a study notification and opt-out postcard. In a second mailing, respondents who had not previously returned the opt-out postcard were mailed the survey and study information. Three weeks later, those who had not responded were mailed a reminder letter and a new copy of the survey. Participation in the survey was strictly voluntary; no incentive was offered. A pre-paid return mailing envelope was included with the survey.

Study instrument

The study instrument contained 41 questions, which were largely based on previously published and validated instruments, including the Cancer Survivors' Unmet Needs (CaSUN) survey [14] and the National Health Interview Survey [15]. In addition to demographic information, questions assessed unmet needs across the following domains: information needs and medical care issues; patient-perceived quality of life; and emotional and relationship issues related to cancer diagnoses. For these questions, survivors were asked to report

whether they had an unmet need in the last month, and if yes, the strength of that unmet need (weak/moderate/strong). Additional questions were asked about the financial burden of cancer, as well as use of and access to support services. Available responses to these questions were not at all/a little/some/a lot. Survivors were also asked to provide demographic information for quality control checking against the ACR records.

Statistical analysis

ACR variables included in the final dataset were age at diagnosis, sex, cancer primary site, laterality, histology, and behavior. For participants with more than one primary cancer, information on the first primary cancer only was included. Race categories were taken from the survey response data and defined as White, Alaska Native/American Indian (ANAI), other, and unknown in primary analyses, due to small numbers of responses from Black and Asian or Pacific Islander survivors.

We compared characteristics of survey respondents and non-respondents using chi-squared tests for categorical variables and t test for continuous variables. Time since diagnosis was calculated as self-reported age at survey response, less self-reported age at cancer diagnosis. For multivariable models assessing independent associations of unmet needs with demographic characteristics, we created summary scores for the four domains of need, as well as total needs. Summary scores were calculated as follows: each question per need category was assigned a score of 1 if any unmet need was indicated, regardless of strength of need. If a participant's answer indicated that there was no unmet need, the question was given a score of 0. Scores were then summed within in each of three domains of need. Individuals without information on any single need indicator were not included in the summary score for unmet needs in that domain; a total need score was not calculated if any indicators were missing. Poisson regression was used to determine associations of survivor demographic characteristics with summary scores. Multivariable-adjusted Poisson regression models were used to determine independent associations of survivor demographic characteristics with summary scores; variables included in the final models were chosen based on significance in unadjusted (bivariate) models. Statistical analyses were conducted with Stata 14.1. All statistical tests were two-sided, with a $\alpha=0.05$.

Results

Study participants

Of the 2,600 cancer survivors that were mailed study invitations and surveys, 240 individuals returned opt-out cards, 13 of which stated that they had not had cancer. Further investigation revealed that most of these individuals were those

with benign brain tumors that were included in the ACR but non-malignant. Subsequently, other cases that were benign or had unknown behavior were removed ($N=123$). A further 12 individuals were noted as deceased, leaving 2,452 eligible individuals. After excluding duplicate responses ($n=11$), the final sample included 335 surveys, for a response rate of 13.7%.

Demographic and clinical characteristics

Table 1 gives demographic and survivorship-related characteristics of survey participants. The mean age of participants at survey response was 65.7 years (SD 11.1; range 29–89); the mean reported age at diagnosis was 56.7 years (SD 11.4, range 21–82). The mean time since diagnosis was 8.7 years (SD 4.9, range 0–33). Over half of the survey respondents (59.4%) identified as female. The majority of respondents were White (81.5%), with 11.9% of respondents identifying as ANAI. Over half (54.7%) reported completing a college degree or higher. The majority of participants (52.9%) finished treatments over 5 years ago. The majority of survivors received treatment within one of Alaska's Metropolitan Statistical areas (i.e., in Anchorage or Fairbanks) and some (16.6%) received treatment outside of Alaska. Most survivors (50.8%) reported living < 25 miles from their cancer treatment location, whereas over a third (35.4%) were more than 100 miles from treatment.

Table 2 compares demographic and clinical characteristics between survey participants, and non-respondents. Participation was higher among breast and prostate cancer survivors relative to other cancer sites ($p<0.001$). Survivors of other cancers that responded in smaller numbers included colon and rectum ($n=32$); skin ($n=17$); uterus ($n=12$); and, respondents for all other cancer sites numbered < 10. Women were more likely to participate in the survey than men ($p=0.02$) and those of white race were more likely to respond to the survey than non-whites ($p=0.01$). We observed no difference between survey respondents and non-respondents in their diagnosis year or cancer behavior.

Cancer survivor needs

Table 3 gives participant responses from the 2019 Alaska Cancer Survivors Needs Survey covering three of the four domains: information needs and medical care issues; quality-of-life issues; and emotional and relationship issues. For every question in each domain, the majority of participants reported no unmet need. Yet, in each domain, there were a substantial number of respondents who did report unmet needs. Within the information needs and medical care issues domain, participants indicated the greatest level of unmet needs around needing to know their doctors talked to each other (26.5% of respondents expressed some

Table 1 Demographic characteristics of participants in the 2019 Alaska Survivor Needs Assessment Survey ($n=335$)

Total valid n , % missing	Mean (SD)
Age	
Current age (325; 3.0)	65.7 (11.1)
Age at first diagnosis (313, 6.6)	56.7 (11.4)
Years since first diagnosis (309, 7.8)	8.7 (4.9)
Total valid n , % missing	Number (%)
Gender (330, 1.5)	
Male	133 (40.3)
Female	196 (59.4)
Non-binary	<5 (0.3)
Race/ethnicity (329, 1.8)	
Hispanic or Latino/a	5 (1.5)
White	268 (81.5)
Black or African American	6 (1.8)
Alaska Native or American Indian	39 (11.9)
Asian or Pacific Islander	5 (1.5)
Other	6 (1.8)
Education (329, 1.8)	
High school or less, no diploma	10 (3.0)
High school graduate or GED completed	100 (30.4)
Completed a vocational or trade school/program	39 (11.9)
College degree (AA, AS, BA, BS, AB, etc.)	111 (33.7)
Graduate or Professional Degree (MA, MS, MBA, PhD, MD, DDS, etc.)	69 (21.0)
Stage of survivorship (316, 5.7)	
I am currently on treatment	32 (10.1)
I am living with cancer as a chronic illness	19 (6.0)
I finished treatment less than 1 year ago	12 (3.8)
I finished treatment between 1 and 5 years ago	75 (23.7)
I finished treatment 5 or more years ago	167 (52.9)
I am receiving hospice or palliative care	<5 (1.0)
I prefer not to answer or am unsure	8 (2.5)
Treatment location (332, 0.9)	
Within Metropolitan Statistical Area	207 (62.4)
Outside Metropolitan Statistical Area	70 (21.1)
Outside Alaska	55 (16.6)
Distance from treatment (331, 1.2)	
<25 miles	168 (50.8)
25–49 miles	33 (10.0)
50–99 miles	13 (3.9)
> 100 miles	117 (35.4)

level of unmet need); access to complementary and/or alternative therapy services (20.9%); and managing their health together with the medical team (19.1%). Within the quality-of-life domain, participants reported the greatest level of unmet needs around help to reduce stress (27.1%); help to find out about financial support or government benefits (21.0%); and help managing ongoing side effects or complications of treatment (19.2%). Within the emotional

and relationship domain, participants reported the greatest level of unmet needs around managing concerns of the cancer coming back (24.9%); help addressing problems with their sex life (20.3%); and having an ongoing case manager who is available to find out about services when needed (19.9%).

We also asked participants about the financial burden of cancer and use of support services (data not shown). When

Table 2 Demographic and clinical characteristics of participants and non-participants in the 2019 Alaska cancer survivors needs assessment survey (N=2,452)

	Eligible non-participants (N=2,117)		Participants (N= 335)		p value [†]
	%	n	%	n	
Diagnosis age, years					0.74
Mean (SD)	57.1 (12.9)		56.8 (11.0)		
Range (min–max)	18–94		21–82		
Gender					0.02
Male	46.4	982	39.7	133	
Female	53.6	1,134	60.3	202	
Race*					0.01
Alaska Native/American Indian	11.9	251	10.8	36	
White	78.7	1,665	84.2	282	
Other	8.5	179	3.3	11	
Unknown	1.0	22	1.8	6	
Diagnosis year					0.75
2004	7.8	166	7.8	26	
2005	8.1	171	6.3	21	
2006	7.8	165	6.9	23	
2007	7.9	168	7.5	25	
2008	8.1	171	6.0	20	
2009	7.8	165	7.5	25	
2010	7.8	164	7.2	24	
2011	7.4	156	9.0	30	
2012	7.1	151	9.0	30	
2013	7.7	162	7.2	24	
2014	7.7	162	8.1	27	
2015	7.3	154	9.9	33	
2016	7.7	162	8.1	27	
Laterality					0.02
Not a paired site	56.4	1,194	48.4	162	
Right	22.0	466	23.9	80	
Left	19.8	420	27.2	91	
One side, R/L unspecified	0.3	7	0.0	<5	
Bilateral	0.2	<5	0.0	<5	
Undefined	1.2	26	0.6	<5	
Site					< 0.001
Breast	24.0	507	34.6	116	
Prostate	18.3	388	18.2	61	
All other	57.7	1,222	47.2	158	
Behavior					0.37
In situ	11.5	244	9.9	33	
Malignant	88.5	1,873	90.2	302	

Source Alaska Cancer Registry (ACR) data

[†]For age p value is a t test; for other categories p value is from a chi-square

*Only one race is included in the ACR; ethnicity is not included

asked the degree to which cancer caused financial problems, a substantial proportion of participants (43.3%) responded not at all; 19.7% reported a little; 21.5% reported some; and 15.5% reported a lot. Only a small proportion of cancer survivors (17.8%) reported using professional counseling or

joining a support group after their diagnosis. Of the 82.2% that reported not using these services, 20.5% did not know they were available; 11.6% did not want it; 49.3% did not think they needed it; 1.8% could not afford it; and 15.8% gave another reason for not using these services. We also

Table 3 Alaska cancer survivors' unmet needs, 2019 Alaska cancer survivors needs assessment survey ($n=335$)

	Any level unmet need	No unmet need		Unmet need How strong is your need?		
		No need or not applicable (%)	Have need, but need is being met (%)	Weak (%)	Moderate (%)	Strong (%)
Information needs and medical care issues						
1. I need up-to-date information	59 (18.0%)	207 (63.1%)	62 (18.9%)	14 (4.3%)	28 (8.5%)	17 (5.2%)
2. My family and/or partner need information relevant to them	45 (13.9%)	244 (75.3%)	35 (10.8%)	18 (5.6%)	17 (5.3%)	10 (3.1%)
3. I need information provided in a way that I can understand	55 (16.8%)	217 (66.2%)	56 (17.1%)	16 (4.9%)	18 (5.5%)	21 (6.4%)
4. I need the very best medical care	53 (16.3%)	15 (47.1%)	119 (36.6%)	8 (2.5%)	21 (6.5%)	24 (7.4%)
5. I need local health care services that are available when I require them	54 (16.7%)	145 (44.8%)	125 (38.6%)	12 (3.7%)	17 (5.3%)	25 (7.7%)
6. I need to feel like I am managing my health together with the medical team	62 (19.1%)	141 (43.4%)	122 (37.5%)	15 (4.6%)	18 (5.5%)	29 (8.9%)
7. I need to know that all my doctors talk to each other to coordinate my care	86 (26.5%)	136 (42.0%)	102 (31.5%)	22 (6.8%)	32 (9.9%)	32 (9.9%)
8. I need any complaints regarding my care to be properly addressed	56 (17.3%)	197 (60.8%)	71 (21.9%)	16 (4.9%)	12 (3.7%)	28 (8.6%)
9. I need access to complementary and/or alternative therapy services	68 (20.9%)	219 (67.4%)	38 (11.7%)	25 (7.7%)	27 (8.3%)	16 (4.9%)
Quality-of-life issues						
10. I need help to reduce stress in my life	89 (27.1%)	186 (56.5%)	54 (16.4%)	26 (7.9%)	36 (10.9%)	27 (8.2%)
11. I need help to manage ongoing side effects and/or complications of treatment	63 (19.2%)	222 (67.5%)	44 (13.4%)	27 (8.2%)	20 (6.1%)	16 (4.9%)
12. I need help to adjust to changes in my quality of life as a result of my cancer	53 (16.4%)	229 (70.7%)	42 (13.0%)	24 (7.4%)	16 (4.9%)	13 (4.0%)
13. I need help with having a family due to fertility problems	15 (4.6%)	308 (94.2%)	4 (1.2%)	10 (3.1%)	4 (1.2%)	1 (0.3%)
14. I need assistance with getting and/or maintaining employment	22 (6.7%)	297 (90.8%)	8 (2.5%)	12 (3.7%)	6 (1.8%)	4 (1.2%)
15. I need help to find out about financial support and/or government benefits to which I am entitled	69 (21.0%)	243 (73.9%)	17 (5.2%)	23 (7.0%)	22 (6.7%)	24 (7.3%)
16. Due to my cancer, I need help getting life and/or travel insurance	42 (12.9%)	274 (84.1%)	10 (3.1%)	15 (4.6%)	14 (4.3%)	13 (4.0%)
17. Due to my cancer, I need help accessing legal services	34 (10.3%)	287 (87.2%)	8 (2.4%)	14 (4.3%)	8 (2.4%)	12 (3.7%)
18. I need more accessible hospital parking	27 (8.3%)	279 (85.3%)	21 (6.4%)	14 (4.3%)	8 (2.5%)	5 (1.5%)
Emotional and relationship issues						
19. I need help to manage concerns about the cancer coming back	82 (24.9%)	182 (55.2%)	66 (20.0%)	32 (9.7%)	26 (7.9%)	24 (7.3%)
20. I need emotional support to be provided for me	58 (17.7%)	220 (67.1%)	50 (15.2%)	25 (7.6%)	24 (7.3%)	9 (2.7%)
21. I need help to know how to support my partner and/or family	44 (13.4%)	252 (76.8%)	32 (9.8%)	22 (6.7%)	11 (3.4%)	11 (3.4%)
22. I need help to deal with the impact that cancer has had on my relationship with my partner	48 (14.7%)	253 (77.6%)	25 (7.7%)	19 (5.8%)	14 (4.3%)	15 (4.6%)
23. I need help with developing new relationships after my cancer	39 (11.9)	273 (83.5%)	15 (4.6%)	15 (4.6%)	13 (4.0%)	11 (3.4%)
24. I need to talk to others who have experienced cancer	53 (16.2%)	238 (72.6%)	37(11.3%)	21 (6.4%)	17 (5.2%)	15 (4.6%)

Table 3 (continued)

	Any level unmet need	No unmet need		Unmet need How strong is your need?		
		No need or not applicable (%)	Have need, but need is being met (%)	Weak (%)	Moderate (%)	Strong (%)
25. I need help to handle the topic of cancer in social and/or work situations	43 (13.2%)	266 (81.4%)	18 (5.5%)	21 (6.4%)	17 (5.2%)	5 (1.5%)
26. I need help to adjust to changes to the way I feel about my body	64 (19.5%)	240 (73.2%)	24 (7.3%)	22 (6.7%)	25 (7.6%)	17 (5.2%)
27. I need help to address problems with my/our sex life	66 (20.3%)	238(73.2%)	21 (6.5%)	30 (9.2%)	19 (5.9%)	17 (5.2%)
28. I need an ongoing case manager to whom I can go to find out about services whenever they are needed	66 (19.9%)	246 (74.3%)	19 (5.7%)	23 (7.0%)	16 (4.8%)	27 (8.2%)

asked participants if they received support from a patient navigator or caregiver. Almost a quarter (23.4%) reported that they did and it was helpful; 3.3% reported that they did and it was not helpful; 8.6% reported that they did, but it was not needed; and 8.3% did not know or remember. 56.5% of survivors did not receive support from a patient navigator or caregiver. Of those, 40.1% agreed that someone like that would have been helpful; 28.9% did not think they would have been helpful; and 31% didn't know.

Table 4 gives the summary scores for each domain of need. Among those with complete information on needs required to calculate a summary score, 29.9% had no unmet needs. The distribution of needs was right skewed, as most participants reported only a small number of needs. The highest level of unmet needs was observed within the emotional and relationship issues domain, followed by information and medical care issues.

Table 5 gives multivariable-adjusted associations of survivor demographic characteristics and need summary scores, both in each domain and total summary scores. We observed greater reported total unmet needs among males [Adjusted Incidence Rate Ratio (AIRR): 1.2 (95% CI 1.1, 1.4)]; those diagnosed before age 65 years [AIRR 18–44 years: 2.7 (95% CI 2.0, 3.5); AIRR 45–64 years: 1.6 (95% CI 1.3, 1.9)]; ANAI people (AIRR 2.0 (95% CI 1.7, 2.3)); those still in

treatment or who were in treatment < 1 year ago [AIRR 1.6 (95% CI 1.4, 1.8)]; and those who had to travel greater than 50 miles to receive their cancer treatment [(AIRR 2.01.2 (95% CI 1.1, 1.4)]. Similar patterns were observed across the individual domains.

Discussion

We administered a comprehensive needs assessment of Alaska cancer survivors' survey covering four domains of need: information and medical care; quality of life; emotional and relationship issues; and support services. Our results indicate that a large proportion of Alaska cancer survivors do not have unmet needs. Yet, many did report unmet needs across the four domains of inquiry and levels of unmet need varied by demographic factors. The leading unmet needs among Alaskan survivors were concerns around the cancer coming back, help to manage stress, and desire for care coordination. These findings show similarity and contrast to a recent review of survivor needs assessments from across the globe, which observed that the most frequently reported domains of unmet need were concerns about the cancer coming back, and information regarding what one can do to support staying well [16]. When

Table 4 Summary scores for unmet needs, by needs category among participants of the 2019 Alaska cancer survivors needs assessment survey ($n = 335$)

Needs category	Mean (SD)	Range	No unmet need (%)	Missing values
Information and medical care needs (Q1–9)	1.6 (2.7)	0–9	204 (65.4%)	23 (6.9%)
Quality-of-life needs (Q10–18)	1.2 (2.2)	0–9	201 (63.8%)	20 (6.0%)
Emotional and relationship issue needs (Q19–28)	1.6 (2.9)	0–10	201 (63.4%)	18 (5.4%)
Support service needs (Q 29/30, 31, 32/33)	1.0 (.9)	0–3	117 (36.0%)	10 (3.0%)
Total needs	5.0 (7.4)	0–31	86 (29.9%)	47 (14.0%)

Table 5 Multi-variable-adjusted associations of survivor demographic characteristics and need summary scores, 2019 Alaska cancer survivor need assessment survey ($n = 335$)

AIRR: Adjusted Incidence Rate Ratio	Information & medical care needs AIRR* (95% CI)	Quality-of-life needs AIRR* (95% CI)	Emotional and relationship needs AIRR* (95% CI)	Support services AIRR* (95% CI)	Total AIRR* (95% CI)
Gender					
Male	1.5 (1.2–1.9)	1.5 (1.2–1.9)	1.4 (1.1–1.7)	1.1 (0.9–1.5)	1.2 (1.1–1.4)
Female (ref)	–	–	–	–	–
Current age					
18–44	0.4 (0.2–0.8)	0.8 (0.4–1.5)	0.7 (0.5–1.1)	1.3 (0.7–2.5)	1.0 (0.7–1.3)
45–64	1.1 (.9–1.4)	1.1 (0.8–1.4)	1.0 (0.8–1.2)	1.0 (0.8–1.4)	1.2 (1.0–1.4)
65+ (ref)	–	–	–	–	–
Diagnosis age					
18–44	2.9 (1.9–4.6)	2.1 (1.2–3.5)	5.7 (3.6–8.9)	2.1 (1.1–3.7)	2.7 (2.0–3.5)
45–64	1.9 (1.4–2.7)	1.4 (1.0–2.0)	2.1 (1.5–3.0)	1.8 (1.2–2.7)	1.6 (1.3–1.9)
65+ (ref)	–	–	–	–	–
Race					
Alaska Native	2.1 (1.6–2.7)	2.2 (1.6–3.0)	2.1 (1.6–2.7)	1.0 (0.7–1.5)	2.0 (1.7–2.3)
Non-Native (ref)	–	–	–	–	–
Education					
HS or less	1.6 (1.3–1.9)	1.7 (1.4–2.2)	1.2 (1.0–1.5)	1.0 (0.7–1.3)	1.3 (1.2–1.5)
More than HS (ref)	–	–	–	–	–
Diagnosis year					
2011–2016	0.6 (0.5–0.9)	0.6 (0.4–0.8)	1.1 (0.8–1.4)	1.0 (0.7–1.4)	0.9 (0.7–1.0)
2004–2010 (ref)	–	–	–	–	–
Recent care					
Still in care now or < 1 year ago	1.9 (1.6–2.4)	1.7 (1.4–2.2)	1.8 (1.5–2.2)	1.3 (1.0–1.7)	1.6 (1.4–1.8)
Finished care 1+ years ago (ref)	–	–	–	–	–
Care in Alaska					
Received care in AK	1.3 (1.0–1.8)	1.2 (0.8–1.8)	1.3 (0.9–1.7)	1.1 (0.7–1.6)	1.2 (1.0–1.4)
Care from outside (ref)	–	–	–	–	–
Distance to care					
Travel 50+ miles to care	1.3 (1.1–1.7)	1.0 (0.7–1.3)	1.3 (1.0–1.7)	1.4 (1.0–1.8)	1.2 (1.1–1.4)
Care < 50 miles (ref)	–	–	–	–	–

*Bold indicates significance at $p < 0.05$. Multivariable-adjusted models included all variables shown in table

examining who experienced the greatest unmet needs, we observed that needs were higher among ANAI people, male respondents, and rural residents, highlighting particular population groups that might benefit from targeted interventions. Furthermore, many survey respondents were unaware of existing resources, including support services that were available to them. This suggests an opportunity to promote existing programs that could be useful to Alaska cancer survivors. Indeed, the most recent edition of the Partnership's Comprehensive Cancer Control Plan [17] highlights specific strategies across the domains of social and community context; healthcare access and quality; neighborhood and built environment; economic stability; and education access and quality that could be implemented by its members to address quality of life among Alaska's cancer survivors.

These results were shared with cancer care providers and the Survivorship Work Group of the Partnership; they have already informed several public health campaigns and also provide a baseline for future work in this area as the number of survivors continues to grow in Alaska.

Our sampling design enabled us to survey needs across survivors diagnosed 2004–2016, and many of our respondents were over 5 years out from their initial diagnosis. Nevertheless, we observed higher unmet needs among those diagnosed < 1 year prior to survey or who were in active treatment. This is in line with findings from a recent systematic review, which also noted that the prevalence of unmet needs was higher among those who had completed treatment more recently [16]. Additional work should be done to better understand the specific needs of Alaskans currently

undergoing or who have recently completed treatment. Others with higher unmet needs included ANAI people and those with greater travel distance to care. Approximately 33% of Alaska residents live in rural Alaska [18], many of Alaska's remote communities are off the road system, and while healthcare is accessible to many residents in local clinics or regional hospitals [19], tertiary care, including cancer care, is usually provided in one of Alaska's urban hubs (Anchorage, Fairbanks, Kenai, and Juneau). A minority of patients choose to receive their care out of state. Depending on one's community of residence and treatment location, travel to receive cancer care can be onerous for Alaska's rural residents. Furthermore, in small, rural communities, services to address survivors' needs may not directly be available in community. Opportunities using telehealth or other technology might prove useful in these contexts [20]; previous studies have indicated both feasibility and acceptability of telehealth among Alaska's rural and Indigenous populations [20, 21], including for delivery of cancer care [20]. Further, many of Alaska's remote and rural residents are Indigenous ANAI people, who may have unique cultural needs that should be considered, in addition to geographic isolation from cancer treatment providers. While further work will be necessary to identify how to best address the unmet needs of these population subgroups, the present results give us an indication of those who might benefit from focused resources.

Responses to individual questions within each domain also provide indications of specific needs expressed by Alaska cancer survivors that could be addressed by cancer care teams, public health programs, or other community support mechanisms. Within information needs and medical care issues, a quarter of respondents had concerns about care coordination. Care coordination is known to be important to cancer patients [22], and care coordination (or patient perception of coordination) has been linked to quality of life and other cancer outcomes [23, 24]. More than 20% of participants expressed an unmet need for access to complementary and/or alternative therapy services, while only 12% expressed this need that is being met. These results are in line with national figures that suggest that one-third of patients with a history of cancer use complementary and/or alternative medicines [25], which might include dietary change, nutritional supplements, lifestyle changes, and traditional medicines [26]. Such therapies may be particularly relevant for population subgroups, such as ANAI people, where they align with traditional cultural values [27]. Within the quality of life domain, the greatest need expressed was for help to reduce stress in life. In its Stress in America™ 2020 report, the American Psychological Association describes stress as a "national mental health crisis" that has only been exacerbated by the COVID-19 pandemic [28]. Stress has been linked to comorbidities such as heart disease

and stroke in non-survivors and survivors alike [29]. Additionally, more than 20% of Alaska cancer survivors surveyed expressed a need for help to find out about financial support or government benefits to which they were entitled, which may speak to financial hardships that are known to be associated with a cancer diagnosis [30]. Multi-level strategies to address financial toxicity associated with a cancer diagnosis [30], including financial navigation [31], should be considered by Alaska's cancer care providers. Finally, cancer recurrence is a very real fear for many cancer survivors [32, 33], although national statistics on the likelihood of recurrence are unavailable to indicate how common this is (these data are not collected by central cancer registries). Our survey indicated that a quarter of Alaska cancer survivors are concerned about their cancer coming back. Together, these findings indicate that Alaska cancer survivors have a range of unmet needs across domains, which will require a coordinated approach by multiple partners.

While there has been no previous population-based survey of Alaska cancer survivors' needs, there have been a small number of primarily cancer-specific assessments. In 2014 a survey was conducted specifically for prostate cancer survivors [12]. The findings from this survey were in line with some of those reported here and indicated both an under-awareness of available support services and a subsequent underutilization of these services. In the present survey, one-fifth of the respondents who did not utilize support services were unaware that these services were available. Yet, over half of respondents who did not receive support from a patient navigator or similar caregiver reported that they thought such a service would have been helpful. In the 2014 BRFSS module on cancer survivorship, over 70% of respondents indicated it had been over a year since their last medical check-up, while less than half of respondents were given a summary of their cancer treatment to share with their primary care provider in those check-ups. Together, these findings indicate a strong need for increased support services in Alaska, as well as for increased care coordination.

Our results can be compared to findings from similar studies conducted in other states, particularly since our questionnaire utilized questions taken from national surveys. Compared to respondents of the 2010 National Health Interview Survey [34, 35], Alaska cancer survivors were more likely to say they received professional counseling or joined a support group. Among those who did not seek these services, both U.S. and Alaska residents reported the reason was that they [survivors] did not think they needed it. However, while Alaska respondents' second most common reason was that they did not know this support was available, the U.S. sample indicated their second most common reason that they did not want it. This may reflect the lack of service availability in Alaska, particularly in remote rural Alaska, compared to the Lower 48 states. State-based

needs' assessments have been conducted in Vermont and Connecticut and showed generally similar findings to the present study [36]. For example, the most reported need (met or unmet) among survivors in both states was to feel they are managing their health together with the medical team (69% in Vermont, 57% in Alaska). Although the percentage of unmet needs among Alaska's survivors were greater than for Vermont's survivors on all available indicators (data not shown) [37]. A different survey was used in Connecticut but the greatest needs reported among survivors there included financial concerns, communication with their care teams, and not knowing what services were available [36]. Differences between the present and other surveys might, in part, be a result of differences in survey questions and methodology; however, it is possible that Alaskans may have unique (and greater) needs, relative to their Lower 48 counterparts.

This study has several strengths and limitations that warrant consideration in interpretation of its results. The primary strength of this study was that it was among the first surveys of Alaska cancer survivors and as such, provides new information to guide future policies and programs in a way that was not possible prior to this work. In addition, the use of the Alaska Cancer Registry for patient recruitment is a strength because it enabled us to recruit from a population-based sample, whereas prior assessments relied on self-selection for participation. The low response rate (13.4%) should be considered when interpreting these findings. A comparison of respondents and eligible non-respondents suggested that non-Hispanic White individuals, and females, were more likely to respond. Further, a large proportion of respondents reported having greater than a college-level education, which may indicate a more resource-heavy population. Future work might oversample under-represented population groups to understand their needs, since a lack of response may actually be indicative of greater need.

As the number of Alaska cancer survivors continues to grow, it will be important to ensure that programs and services tailored to their unique needs are available and that patients are aware of these services. Our results suggest that Alaska cancer survivors often have continuing need to address information and medical care issues; quality-of-life issues; emotional and relationship issues; and support services needs even several years after diagnosis. Future research could implement and evaluate pilot programming that addresses these needs, as well as determine if there are specific offerings that would be useful to population groups, such as ANAI people and rural residents, with greater unmet needs. Continued assessment of Alaska cancer survivors will be necessary to ensure that programming is responsive to changes in needs over time. These results provide a baseline for understanding cancer survivor needs in Alaska, and we anticipate will be of interest to public health agencies,

community organizations, and healthcare providers in our state and elsewhere.

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Data availability Enquiries about data availability should be directed to the authors.

Declarations

Conflict of interest The authors declare no financial or non-financial conflicts of interest.

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