Needs assessment of cancer survivors in Connecticut

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Abstract

Introduction There are knowledge gaps regarding the needs of cancer survivors in Connecticut and their utilization of supportive services.

Methods A convenience sample of cancer survivors residing in Connecticut were invited to complete a self-administered (print or online) needs assessment (English or Spanish). Participants identified commonly occurring problems and completed a modified version of the Supportive Care Needs Survey Short Form (SNCS-SF34) assessing needs across five domains (psychosocial, health systems/information, physical/daily living, patient care / support, and sexuality).

Results The majority of the 1,516 cancer survivors (76.4%) were women, 47.5% had completed high school or some college, 66.1% were diagnosed ≤5 years ago, and 87.7% were non-Hispanic white. The breast was the most common site (47.6%), followed by the prostate, colorectal, lung, and melanoma. With multivariate adjustment, need on the SCNS-SF34 was greatest among women, younger survivors, those diagnosed within the past year, those not free of cancer, and Hispanics/Latinos. We also observed some differences by insurance and education status. In addition, we assessed the prevalence of individual problems, with the most common being weight gain/loss, memory changes, paying for care, communication, and not being told about services.

Conclusions Overall and domain specific needs in this population of cancer survivors were relatively low, although participants reported a wide range of problems. Greater need was identified among cancer survivors who were female, younger, Hispanic/Latino, and recently diagnosed.

Implications for cancer survivors These findings can be utilized to target interventions and promote access to available resources for Connecticut cancer survivors.

Keywords Cancer survivors · Needs assessment · Psychosocial · Supportive care

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Introduction

A cancer survivor is defined as any person who has been diagnosed with cancer from point of diagnosis through the remaining years of life. Cancer survivorship is a distinct phase in the cancer control continuum [1]. The number of cancers survivors has been increasing over the past three decades due to improved early detection rates and thera-

peutic advances. As of 2007, there were approximately 11.7 million cancer survivors in the USA, representing 4% of the population [2]. The most prevalent cancer diagnoses among survivors are breast (23%), prostate (20%), colorectal (10%), and gynecologic (9%) cancers.

Cancer incidence varies in the USA, with the northeast having higher incidence rates for the most prevalent cancers (breast, prostate, colorectal, and lung) than other areas of the country [3]. Similar to national rankings, cancer is the second leading cause of death in Connecticut [4, 5]. High incidence rates combined with some of the lowest cancer-related mortality rates [6] gives Connecticut a burgeoning cancer survivor population.

The transition to survivorship following cancer treatment is often challenged by persistent or long-term physical effects, late effects, psychological and existential distress, informational needs, changes in social support, and practical concerns for managing everyday life [1, 7–12]. Persistent or long-term physical effects include symptoms, such as fatigue, that continue after cancer treatment and either resolve or become chronic. Late effects, such as cardiac toxicity, are those that occur months to years after cancer treatment. Both persistent and late effects are unique to the cancer type and specific cancer treatment therapy [1, 11, 13] Psychological needs are more universal and include fear of recurrence, uncertainty, decreased social support, changes in mood, existential concerns, as well as challenges to reintegration into family, social, and employment roles [1]. While physical, psychological, informational, and social support needs have been identified for cancer survivors, health care providers and agencies still lack the data necessary to help meet the needs of specific cancer survivor populations (e.g., by age and ethnic background). Thus, additional data are needed to develop and appropriately target interventions as well as facilitate access to resources for cancer survivors to promote overall health and optimal quality of life.

A recent review found wide variation in the prevalence of unmet supportive care-related needs, with differences based on active treatment or completion of treatment [12]. Prevalence of unmet need in cross-sectional studies of survivors has ranged from 30% to 50% [14–18]. However, the studies included in this review utilized many different instruments in heterogeneous cancer populations, making the results difficult to compare [12]. Importantly, research suggests that the presence of unmet needs can be detrimental to quality of life [19, 20].

To better understand the specific needs of cancers survivors in Connecticut, the Connecticut Cancer Partnership's (CCP) Survivorship Committee recommended a needs assessment of this population. The CCP is the voluntary comprehensive cancer control coalition in Connecticut, recognized by the US Centers for Disease Control and Prevention, to work in partnership with the state department of public health in supporting a coordinated approach to comprehensive cancer control. Working across the entire cancer continuum, the CCP has attempted to advocate for funding and support meaningful implementation programs to help reduce the burden of cancer on Connecticut's residents. Since many support services for cancer survivors exist in Connecticut, but are often unknown or underutilized by the populations for which they are designed, these findings can be utilized to target services and resources in the future.

Methods

Study population

Cancer survivors residing in Connecticut were invited to complete a self-administered (print or online) survivorship needs assessment survey (available in English or Spanish) between September 2008 and April 2009. Many strategies were employed to recruit the convenience sample of cancer survivors, including development of partnerships with organizations and institutions providing cancer-related care and information, outreach at one-time cancer-related events, collaboration with individual cancer care providers and professional agencies, and contact with organizations serving ethnic minority populations. Various marketing methods were also used, including advertising on radio stations, TV channels, newspapers, and in the public libraries of 15 cities and towns across Connecticut. Additionally, a one-time insert about the needs assessment was included in state employees' paycheck envelopes, reaching over 80,000 individuals.

Survey questionnaire

The self-administered survey instrument included questions on sociodemographics (e.g., gender, age, education, marital status, income, ethnicity), health behaviors (e.g., smoking, physical activity), and a one-item depression screener [21]. Insurance status at the time of completing the survey was also queried with the following options: private, Medicaid, Medicare, not covered, and other. These were collapsed into four groups: Medicaid only or Medicaid with private; Medicare only or Medicare with Medicaid; private or other; and Medicare with private. Participants also reported on several areas of their cancer history, including the year of their first cancer diagnosis, number and types of cancers experienced in their lifetime, the year of their most recent cancer diagnosis, and if they were cancer free at the time of the survey. In addition, participants were asked about where they obtained information regarding their cancer and which sources were most helpful.

A modified version of the validated Supportive Care Needs Survey 34 item short form (SCNS-SF34) [22] was included in the survey to assess participant needs. The SCNS-SF34 evaluates needs during the previous month across five domains: psychological, health system and information, physical and daily living, patient care and support, and sexuality. The SCNS-SF34 was ideal as it was built on preexisting needs assessments and has seventh to eighth grade literacy level with an easy to understand format using a 5-point Likert scale (1—not applicable/not a problem, 2—satisfied, 3—low need, 4—moderate need, 5—high need). Ten additional questions were added to the questionnaire to help capture the needs of the more diverse Connecticut population. Six of the additional items were taken from the SCNS-Long Form [23], and the remaining four items were recommended by the survivorship committee of the CCP.

Finally, based on a literature review, data generated by focus groups and community-based forums (full description below), and consultations with oncology experts in the CCP, 18 commonly occurring problems/barriers experienced by cancer survivors were identified. Participants were asked to report how much of a problem each item had been during the previous month (1—not a problem, 2—somewhat of a problem, 3—a severe problem).

Community forums

The purpose of the community forums was to target populations who might be less likely to complete surveys individually. A variety of outreach strategies were used in collaboration with community partners to target men, younger survivors, and minorities for these forums. Each forum was attended by at least two staff, one facilitator, and one note taker and focused on three topic areas: needs, barriers, and resources. All participants were asked to complete a hard copy of the survey at the meeting.

Statistical analysis

Descriptive statistics were used to characterize the distribution of sociodemographic characteristics, health behaviors, and cancer-related information of the population. Values were imputed for the enhanced SCNS-SF that had ≤50% of the information missing within each domain using the Markov Chain Monte Carlo method, with the imputed value determined by the average of five imputations. Raw scores were standardized, taking the number of items in each domain into account. If m is the number of questions in the domain and k is the maximum value for each item (in this study $k=5$), the standardized score for each domain is obtained by calculating (total raw score$-m$)$\times 100/[m\times(k-1)]$, so the score range for each domain will be from 0 to 100. Therefore, the higher the score on the domain, the higher the perceived need is for support in that domain.

We constructed a multivariate linear regression model to evaluate differences in overall and domain specific needs across selected characteristics. Problems identified by survivors were dichotomized as present or absent, and χ^2 tests were used to evaluate univariate associations with selected characteristics. All p values are two sided, and analyses were conducted using SPSS Version 10.

Results

A total of 6,235 print surveys were distributed and 1,164 were returned (19.0%). In addition, 429 surveys were completed online. Seventy-seven surveys were excluded for the following reasons: cancer diagnosis missing and 80% of survey incomplete ($n=54$), had not had cancer in lifetime ($n=4$), did not reside in Connecticut ($n=16$), and survey completed by proxy ($n=3$). After these exclusions, there were 1,516 evaluable surveys.

Participants were distributed throughout all eight Connecticut counties. Hartford (34.0%), New Haven (19.0%), and Fairfield (16.0%) counties had the largest proportion of participants. The majority (76.4%) of the 1,516 cancer survivors were female, and the average age was 61 years (range 18–96, Table 1). The vast majority of participants were white (87.7%), followed by African American/black (5.3%), and Hispanic/Latino (4.3%). Just over half of the participants had completed either a university/college or a professional/graduate degree (52.5%), and nearly two thirds (62.3%) of the participants were either married or living as married. At the time of the survey, 49.7% were employed and 30.2% of participants reported individual income at or above the state's median. Almost all of the participants had some health insurance coverage (98.6%), with 56% having private insurance.

The most prevalent lifetime cancer diagnosis was breast (47.6%), followed by prostate, colorectal, lung, and melanoma (all less than 10%, Table 1). The majority (77.4%) of the cancer survivors reported they were cancer free at the time of completing the survey. Approximately one third (30.3%) of the participants were diagnosed with their most recent cancer within the last year, 35.8% were diagnosed between 1 and 5 years ago, and 33.9% were diagnosed more than 5 years ago. The vast majority of participants reported receiving treatment for their most recent cancer diagnosis, with surgery being the most common form of treatment (75.4%).

More than half (52.8%) of the survivors reported that they had smoked in their lifetime (Table 1), with a mean of 19 years of smoking (data not shown). Physical activity more than 20 times per month, encompassing walking,

Table 1 Selected characteristics of cancer survivors in needs assessment (N=1,516)

Characteristic	Number[a]	Percent
Female	1,150	76.4
Age group		
18–49	264	17.5
50–64	662	44.0
≥65	579	38.5
Ethnicity		
White	1,322	87.7
African American	80	5.3
Hispanic/Latino	65	4.3
Other	40	2.7
Education		
Primary/secondary	366	24.3
Some university/college	349	23.2
University/college degree or higher	791	52.5
Marital status		
Married or marriage like	940	62.3
Divorced or separated	200	13.3
Widowed	192	12.7
Single or never married	177	11.7
Employed	735	49.7
≥Connecticut median income level (US $45,738)	412	30.2
Health insurance		
Not covered	21	1.4
Medicaid only or Medicaid with private	64	4.4
Medicare only or Medicare and Medicaid	208	14.1
Private or other	824	56.0
Medicare with private or other	354	24.1
Ever smoker	797	52.8
Physical activity status		
No physical activity	149	11.5
1–10 times/month	369	28.4
11–20 times/month	285	21.9
>20 times/month	496	38.2
Positive screening for depression	323	24.5
Lifetime self-report cancer type[b]		
Breast	710	47.6
Prostate	146	9.8
Colorectal	87	5.8
Lung	80	5.4
Melanoma	79	5.3
Time since diagnosis of most recent cancer		
≤1 year	445	30.3
>1 to ≤5 years	526	35.8
>5 years	498	33.9
Cancer free at the time taking the survey	1,139	77.4
Lifetime cancer treatment[c]		
Surgery	1,121	75.4
Chemotherapy	800	53.8

Table 1 (continued)

Characteristic	Number[a]	Percent
Radiation therapy	818	55.1
Hormonal therapy	423	28.5
Biological therapy	108	7.3
Bone marrow/peripheral blood cell transplant	25	1.7
No treatment	25	1.7

[a] May not sum to total due to missing data or selection of multiple choices

[b] Most common types. May fall in multiple categories if had more than one primary cancer

[c] Could select multiple answers

jogging, participation in sports, walking to work or to the store and household chores, was reported by 38.2% of survivors. One quarter (24.5%) of the participants answered yes to the one-item depression screener.

Needs as assessed with the modified SCNF-SF34 were greatest in the psychological domain followed by the physical and daily living domain and then sexuality (Table 2). With multivariate adjustment, overall need was statistically significantly greater among women (mean= 25.3) than men (mean=22.3), with women reporting higher levels of need in each domain with the exception of sexuality (Table 3). By ethnicity, Hispanic/Latino participants reported the highest level of need across the individual domains. With adjustment for other important characteristics, Hispanic/Latinos had statistically significant overall greater need than whites and African Americans. Age was another important predictor of need, as need was highest among those diagnosed under age 50. Participants diagnosed within the last year reported overall greater needs, compared to those who were diagnosed 1–5 years ago, as well as to those whose cancer diagnosis was more than 5 years ago. We also found that need was higher for those that were not cancer free at the time of taking the survey even after adjusting for other characteristics. Finally, we observed differences by insurance status, with the lowest overall need among those with private insurance, and highest need among those with Medicare or Medicare with private insurance.

For survivorship-related problems during the previous month, 42.3% of the survivors reported no problems. However, 3% of participants had experienced at least half of the 18 problems queried. Of the 57.7% of survivors who reported at least one problem, the five most prevalent problems identified were weight gain/loss (35.4%), difficulty with memory (32.4%), paying for care (15.3%), communication (14.3%), and not being told about available services (12.0%, Table 4).

Table 2 Overall standardized scores by domain for the modified SCNS-SF (44 items)

Domain	Number of items in survey	Mean	SD	Median
Psychological	11	31.13	27.19	25.00
Health information and system	13	23.88	23.13	23.08
Physical and daily living	5	27.61	28.35	20.00
Patient and care support	6	21.00	22.32	16.67
Sexuality	3	24.57	28.90	16.67
Additional items	6	22.38	22.54	20.83
Overall needs—44 items	44	25.32	21.47	22.16

We evaluated differences in prevalence of these problems by selected characteristics (gender, age, race/ethnicity) in the univariate setting only. Women were more likely than men to report problems in the following areas: child/elder care (5.5% versus 2.3%, $p=0.02$), lack of respect or equal treatment (5.5% versus 2.3%, $p=0.02$), weight gain/loss (38.4% versus

Table 3 Multivariate linear regression of mean scores of overall and domain specific needs on the modified SCNS-SF (44 items)

Characteristic	Psychological mean score	Health system and information mean score	Physical and daily living mean score	Patient care and support mean score	Sexuality mean score	Additional items mean score	Overall needs mean score
Gender							
Male	27.7	20.5	21.3	18.6	28.3[a]	19.6	22.3[a]
Female	31.4	23.9	28.4	20.9	23.1[a]	22.2	25.3[a]
Ethnicity							
White	30.1	22.6	26.3	19.7	24.6	20.8	24.1[b]
African American	27.1	24.8	26.2	22.9	16.1	24.1	24.2[b]
Hispanic/Latino	43.3	32.2	37.7	31.5	28.4	34.3	35.1[b]
Age (years)							
18–49	38.7	26.6	35.1	25.0	34.3	26.9	31.0[a]
50–64	35.0	25.3	30.4	22.2	29.2	25.0	27.8[a]
≥65	20.4	18.5	17.6	15.8	12.8	14.3	16.6[a]
Time since diagnosis (years)							
≤1	35.2	26.5	31.6	24.2	26.1	23.7	28.2[a]
1–5	30.2	23.1	26.9	19.7	25.4	22.4	24.5[a]
>5	26.4	19.9	22.0	17.7	21.4	18.6	21.2[a]
Education							
Primary/secondary	31.6	20.9	28.0	18.7	24.2	20.2	24.6[c]
Some college	32.4	25.8	28.7	22.3	26.4	24.8	26.8[c]
≥College degree	29.3	22.9	25.4	20.3	23.5	20.8	23.7[c]
Health insurance							
Medicaid only or Medicaid with private	45.1	36.9	40.5	32.8	37.2	35.4	37.3[d]
Medicare only or Medicare and Medicaid	34.8	27.4	32.6	22.7	28.9	27.9	29.7[d]
Private or other	26.4	20.1	22.9	17.7	21.0	17.7	20.9[d]
Medicare with private or other	36.7	26.3	31.5	24.1	28.6	26.0	29.8[d]
Cancer free at survey							
No	39.5	28.6	36.7	26.1	26.5	27.7	30.9[a]
Yes	28.2	21.7	24.1	18.9	23.8	20.0	23.0[a]

Each characteristics adjusted for all other characteristics in the table

[a] Mean is significantly different from all other groups within characteristic at $p<0.05$

[b] Means for group 1 and group 2 are significantly different from group 3, but not from each other at $p<0.05$

[c] Means for group 2 and group 3 are significantly different from each other at $p<0.05$

[d] Means are significantly different from all other groups except for group 2 versus group 4 within characteristic at $p<0.05$

Table 4 Percentage of cancer survivors who experienced 18 commonly occurring problems/barriers (could select multiple answers) during the past month

Problem	N (%)
Weight gain/loss	460 (35.4)
Memory/recall	422 (32.4)
Pay for care/treatment	200 (15.4)
Communication with provider (e.g., medical terminology)	186 (14.3)
Not told about available services	154 (12.0)
Transportation	138 (10.5)
Complete excessive paperwork to receive services	134 (10.3)
Follow-up care	129 (10.0)
Needs of caregivers/family not met	127 (9.9)
Obtaining medical records	124 (9.5)
Obtaining medications	107 (8.3)
Locating medical records	85 (6.5)
Services inaccessible (e.g., too far)	80 (6.2)
Child care/elder care	61 (4.7)
Lack of respect or equal treatment	61 (4.7)
Written materials in native language	31 (2.4)
Language translation	28 (2.2)
Compliance of treatment/other options with religious/personal belief	28 (2.2)

25.7%, $p=<0.001$), and changes in memory (34.8% versus 25.2%, $p=0.002$; data not shown). Hispanic/Latinos were more likely to report problems compared to both African Americans and whites (Fig. 1). We also observed some

differences in the percentage of cancer survivors experiencing certain problems by age, with prevalence much higher in those 18–40 years old as compared to older survivors (Table 5).

The vast majority of participants cited medical sources (96.9%) as the primary information source regarding their most recent cancer, followed by nonmedical sources (56.6%). Medical sources participants identified included primary care providers, oncologists, nurses, hospitals, and cancer centers, and nonmedical sources included other cancer survivors, cancer support groups, internet, family and friends, and cancer organizations. The five most helpful sources of information participants reported were doctors (38.4%), internet/books/media (18.7%), other healthcare providers/hospital staff (12.1%), family and friends (11.4%), and support groups (7.3%).

Qualitative data from community forums

There were eight community forums with a total of 133 participants. Three of the forums were specific to the following minority populations: Native Americans, Hispanics/Latinos, and Middle Easterns/Muslims. Themes which emerged from these discussions were similar to the overall survey results. Participants identified the need for information to manage treatment side effects and the need for improved communication with providers related to psychosocial issues. Barriers to survivorship care they identified were insurance coverage, transportation, and finances. Other cancer survivors, friends and family, and support groups were the most frequently reported resources for social support.

Fig. 1 Statistically significant differences in problems/barriers encountered within the last month by ethnicity (white, African American, Hispanic/Latino). Limited to those problems reported by ≥15% of each group
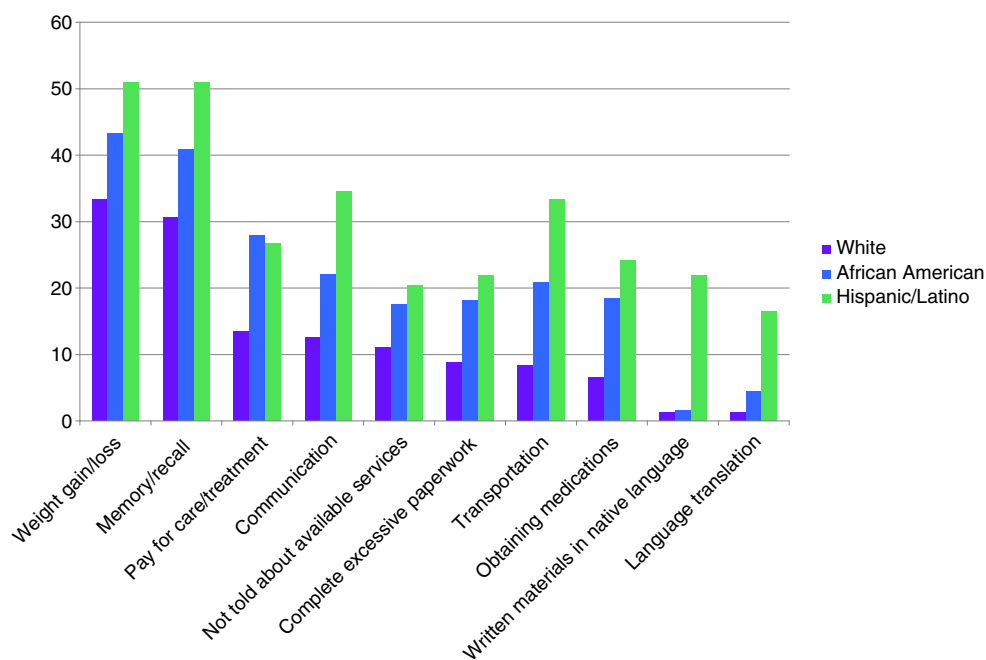
Table 5 Statistically significant differences in the percentage of cancer survivors experiencing problems/barriers by age group

Problem	Age groups (years)			
	% of those 18–49	% of those 50–64	% of those ≥65	p value[a]
Obtaining medications	13.6	7.3	7.0	0.005
Child care/elder care	14.5	3.0	2.0	<0.001
Pay for care/treatment	22.3	17.1	9.7	<0.001
Weight gain/loss	47.2	36.8	27.4	<0.001
Memory/recall	43.8	34.4	24.1	<0.001
Needs of caregivers/family not met	15.3	10.1	6.9	0.002
Follow-up care	15.0	9.3	8.0	0.011

[a] For χ^2 test

Discussion

In this population of cancer survivors in Connecticut, overall needs as measured by the SCNS-SF were higher among women, younger survivors, those diagnosed within the past year, those not free of cancer at survey completion, and Hispanic/Latino. We also observed some differences by insurance status, with those with private insurance reporting lowest needs, and education status. Needs were highest in the psychological domain, which includes anxiety, depressed mood, fear of recurrence, and uncertainty about the future, across all participants regardless of gender, ethnicity, age, or time since diagnosis. The most prevalent problems/barriers encountered by this population of cancer survivors in the previous month were weight gain/loss, memory/recall, paying for care, communication, and not being told about services. There was a higher prevalence of most of the survivorship-related problems/barriers among the minority cancer survivors compared to whites.

While this population of cancer survivors in Connecticut had greater level of need than those of cancer survivors in New South Wales, where the SCNS was first developed and used [16, 23, 24], there was a difference in time since diagnosis between the two populations. The majority of the New South Wales participants were more than 5 years postdiagnosis compared to the 64.8% of our sample who were less than 5 years since the time of their diagnosis. With 29.4% of our sample within 1 year since diagnosis, it is plausible that some were continuing in active treatment, which is known to be associated with greater needs [12]. However, a difference by time since diagnosis was present, even after adjusting for self-reported cancer-free status at the time of the completing the survey, our best proxy variable for active treatment. Therefore, proximity to cancer diagnosis may impact overall need through other factors than treatment, such as psychological/psychosocial well-being. In a more recent study in England, with a sample within 6 months from completion of course of treatment, the reported needs were very similar to our findings [8]. In that study, fear of recurrence predicted unmet needs in all but the physical and sexual domains; hormone therapy use and negative mood were also predictive of unmet needs [8].

The end of treatment is a vulnerable time as patients transition away from active treatment and have less contact and support from providers [25, 26]. While quality of life gradually improves by the 1-year mark, during the first year after treatment, many survivors experience persistent physical and psychological symptoms [19, 27]. The greatest areas of concern for survivors have been reported in the areas of psychological distress, specifically coping with fear of recurrence and need for psychological support [14–18], which is consistent with our findings. There is a recognized need for assessment, support, and interventions to reduce psychological consequences of cancer and cancer treatment [1, 19, 28].

In the current population, problems related to caregiving responsibility (child or elder), paying for care, weight and memory changes, obtaining medication, and unmet needs of family/caregiver were most prevalent among survivors less than 50 years of age. Based on the SCNF, younger survivors also had higher overall needs than their older counterparts. Poorer health-related quality of life and greater physical and psychosocial needs have been consistently reported for younger cancer survivors [9, 10, 29, 30]. This finding is also supported by other study findings in which younger age was predictive of unmet need [14–18]. Studies among female cancer survivors have also found that younger women are more vulnerable and experience greater psychosocial needs, decreased functional status, and lower quality of life compared to older women [14, 31, 32].

In our multivariate model, Hispanic/Latinos survivors reported significantly greater overall need than both whites and African Americans. Furthermore, there were statistically significant differences in the number of problems reported by African Americans and Hispanics/Latinos in the areas of transportation, obtaining medications, commu-

nication, paying for care, not being well informed, and barriers to access to services, with Hispanics/Latinos most likely to experience these problems. In Connecticut, African American and Hispanics/Latinos are less educated and have lower incomes compared to whites [33]. Although socioeconomic status is one factor that may influence access to care and services for these ethnic minority survivors [34], differences in need persisted for Hispanics/ Latinos even with adjustment for education and health insurance suggesting acculturation or language barriers may further contribute to unmet needs in this group.

There are nearly three decades of research published on weight change related to cancer diagnosis and treatment, specifically weight gain among women with breast cancer. Women gain weight during or after systemic adjuvant therapy and the pattern of gain often continues [35–37]. In the present study, 46.8% of participants were breast cancer survivors and when we evaluated weight gain/loss by gender, this problem was more commonly reported by women (38.4%) than men (25.7%). There are little or no data on weight change in male cancer survivors, but our findings may indicate this as an area for further exploration. Unfortunately, these data cannot discriminate the direction of the change in weight.

Changes in cognitive function, often termed "chemo brain" in the lay literature have been well documented. While some studies have included males in the samples [38], the overwhelming number of studies has focused on women with breast cancer who received chemotherapy [39, 40], with some additional recent studies addressing the effects of endocrine therapy on cognitive function [41, 42]. In our population, 34.0% of women and 25.2% of male cancer survivors reported memory problems. Most cognitive function changes among cancer survivors have been associated with chemotherapy. However, as only 52.8% of the participants reported having received chemotherapy, this suggests the possible involvement of other factors (e.g., depression, work, stress) in this condition. In addition, while overall cognitive changes are also often associated with aging, only 50% of our sample was 60 years or older and interestingly, memory problems were more prevalent among the younger survivors.

This study was strengthened by the use of a validated instrument for assessing needs among cancer survivors. While this study examined the survivorship needs in a convenience sample, there was representation of various cancer types as well as all counties in the state of Connecticut. The level of needs among survey participants may have been lower than cancer survivors that did not participate, as this group of survivors by virtue of being willing to complete a survey, may be more actively engaged in utilizing resources and services to address their needs. Although we observed statistically significant differences in both needs and problems by ethnicity, our sample had a relatively small proportion of ethnic minority cancer survivors. This lower percentage of cancer cases may partially be explained by the fact that ethnic minority populations in Connecticut tend to be younger than the white population. With this low participation, our sample may not be representative of all ethnic minority cancer survivors and these finding should be replicated in a larger population-based study. Since all information was self-reported and anonymous, we were unable to verify details provided by participants relating to cancer diagnosis and treatment, thus limiting our ability to examine cancer site and treatment-specific trends. In addition, our sample likely included individuals both in and out of active treatment, which is likely to impact one's level of need, and we did not specifically query if this was the case. Therefore, we had to rely on time since diagnosis and cancer-free status as proxies of treatment. Our sample was also relatively higher educated, so these results may not be generalizable to other populations in the USA. However, the composition of our sample by race/ethnicity was not that dissimilar to Connecticut's overall composition: 80% white, 9.4% black/African American, and 11.6% Hispanic [43]. Finally, the types of needs and problems assessed were limited to those included in the questionnaire, so we may have missed some areas of concern not included in the questionnaires. However, the SCNS-SF was developed in an oncology population and encompassed multiple need domains.

Overall, this needs assessment identified problem areas for targeting interventions across the Connecticut cancer survivor population. Since certain subgroups have reported higher levels of need and were more likely to experience problems/barriers related to their illness, the Connecticut Cancer Partnership can work with individual providers, agencies, and cancer care centers to promote access and use of supportive services to these individuals, with specific attention to ethnic minority cancer survivors.

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