

How confident are young adult cancer survivors in managing their survivorship care? A report from the LIVESTRONG™ Survivorship Center of Excellence Network

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Abstract

Introduction This study examined the association between sociodemographic, cancer treatment, and care delivery factors on young adult cancer survivors' confidence in managing their survivorship care.

Methods Survivors aged 18–39 years ($n=376$) recruited from the LIVESTRONG™ Survivorship Center of Excellence Network sites completed a survey assessing self-reported receipt of survivorship care planning, expectations of their providers, and confidence in managing their

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survivorship care. Multivariate logistic regression identified characteristics of those reporting low confidence in managing their survivorship care.

Results Mean age was 28 years; mean interval from diagnosis was 9 ± 8 years. Seventy-one percent reported currently attending an oncology survivorship clinic. Regarding survivorship care planning, 33% did not have copies of their cancer-related medical records, 48% did not have a treatment summary, and 55% had not received a survivorship care plan. Seventy percent identified the oncologist as the most important health care provider for decisions regarding test and treatment decisions while 10% reported using a “shared-care model” involving both primary care providers and oncologists. Forty-one percent were classified as having low confidence in managing survivorship care. In multivariate analysis, low confidence was associated with non-white ethnicity and lack of a survivorship care plan (both $p<0.05$).

Discussion/conclusions Findings suggest that provision of survivorship care plans for young adult cancer survivors can be used to improve confidence in managing survivorship care, particularly for ethnic minorities.

Implications for cancer survivors Survivors should consider advocating for receipt of a survivorship care plan as it may facilitate confidence as a consumer of survivorship care.

Keywords Neoplasm · Young adult · Cancer survivors · Delivery of health care · Survivorship care plan

Introduction

There are nearly 12 million cancer survivors in the USA including 500,000 young adult survivors of both pediatric and adult malignancies [1, 2]. Cancer survivors have unique health care needs as they transition from active therapy to the survivorship period. A seminal Institute of Medicine (IOM) Report, “From Cancer Patient to Cancer Survivor: Lost in Transition” highlights the need to establish survivorship as a distinct phase of care, as well as to develop and use a written treatment summary and survivorship care plan to guide a survivor’s follow-up care [3,

4]. The “shared-care model” has been proposed as an optimal framework for delivering survivorship care within the USA in which the cancer survivor receives care coordinated between the treating oncologist and the primary care provider (PCP) [5–8]. Yet, the health care setting in which survivorship care is delivered varies significantly from survivor to survivor [6, 9]. Furthermore, recent research indicates that survivors and physicians have different expectations when providing survivorship care which can contribute to deficiencies in care [10].

Young adult cancer survivors face several challenges during their transition from cancer patient to cancer survivor. They are at high-risk for medical and psychosocial sequelae from cancer and its treatment [11–16]. Young adult survivors can also experience anxiety due to uncertainty when transitioning from active treatment into the survivorship phase [14, 17]. It is important to understand the health care setting where young adults survivors are receiving their survivorship care given that most are receiving minimal surveillance for these late effects that impact their risk for morbidity and mortality after cancer [18–20]. In addition, given that both oncology and primary care providers can have unique roles when caring for cancer patients with complex medical needs, such as the young adult population, further research aimed at understanding the primary care-subspecialty care interface is an important area of research [21, 22].

The IOM recommends that cancer survivors have a treatment summary and survivorship care plan to serve as a roadmap and a communication tool to optimize coordination of care [3, 23–25]. Having a treatment summary and survivorship care plan can serve to increase survivors’ confidence in their ability (i.e., self-efficacy) to manage, coordinate, and advocacy for their survivorship care as this document can summarize the cancer treatment received and succinctly outline recommendations of optimal care needed [26]. Interventions to promote self-efficacy have been specifically recommended in the young adult survivor population given the often complex cancer treatment history and need for post-treatment symptom management [27]. Using the survivorship care plan as a tool that can promote self-efficacy and promote patient-centered care is an important area of research as survivors face many difficulties communicating their concerns with their providers [23, 28–30]. Although empirical research on the outcomes and benefits of survivorship care planning is lacking [22, 31], until research confirms or proves the contrary, the IOM assertion that survivorship care plans will improve care for cancer survivors has strong face validity [3, 23, 32].

We used the LIVESTRONG™ Survivorship Center of Excellence (COE) Network to conduct a survey of young adult cancer survivors who received treatment at one of the

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Network affiliated National Cancer Institute (NCI)-designated Comprehensive Cancer Centers. The study objectives were to: (1) describe the health care settings utilized during the survivorship phase of care, (2) describe the self-reported receipt of survivorship care planning, (3) define survivors' expectations of their providers, and (4) explore characteristics of survivors who report low confidence in managing their survivorship care.

Methods

Participant recruitment and survey

The LIVESTRONG™ Survivorship COE Network was created by the Lance Armstrong Foundation among eight cancer centers to increase the effectiveness of survivorship care through research, development of new interventions, and sharing of best practices, as reported previously [33]. The coordinating center for the study was the Fred Hutchison Cancer Research Center. The Institutional Review Boards of each participating site approved the study. Informed consent was obtained from each participant.

Participants were identified from the survivorship databases at each participating institution. Study eligibility included: current age between 18 and 39 years of age (using the NCI's definition of a young adult) [34]; diagnosed during the pediatric (0–14 years) or adolescent or young adult years (15–39 years), treated for any type of cancer; completed active phase of treatment (i.e., chemotherapy, radiation therapy, and/or surgical resection). Survivors who did not have a recent survivorship visit (i.e., ≤ 1 year) at the participating institution were eligible to participate. Survivors on hormonal therapy, monoclonal antibody therapy (e.g., Rituximab) or imatinib were eligible to participate. Non-English speaking survivors were excluded.

The survey consisted of 57 items organized in six conceptual domains: (1) sociodemographic information which included education completed, race/ethnicity, marital status, health insurance coverage, and household income; (2) cancer diagnosis and treatment which included age at diagnosis, years off cancer therapy, type of cancer, and treatments received (chemotherapy, radiation therapy, surgery, and/or bone marrow transplant); (3) experiences with doctors which included questions regarding doctors most important in follow-up care related to symptoms, testing, and types of doctors seen for general health care and cancer care; (4) survivor's knowledge and recall of late effects education which included questions regarding late effects topics discussed, doctors who have these discussions, receipt of cancer treatment records, receipt of a treatment summary defined as a doctor has summarized your cancer medical records, receipt of a written plan or list of

recommendations that discusses health care needed after completion of cancer treatment (i.e., survivorship care plan); (5) current health status which included questions regarding overall health status, emotional/psychological health and daily cancer-related stress; and (6) opinions regarding resources for cancer survivors. The survey was developed through an iterative process with investigators at each of the eight COE sites using interobserver reliability methods [35]. Authors constructed survey items were based on key domains previously published in the survivorship literature on a survivor's knowledge regarding previous cancer treatment and treatment summaries, assessment of health status and health care transitioning of adolescent and young adult survivors [36–39]. Additionally, questions were constructed based on the Health Belief Model to assess the confidence level (i.e., self-efficacy) of survivors to manage their survivorship care. Using the theoretical constructs of the Health Belief Model, survivors perceive themselves to be confident in their ability to manage their survivorship care when they perceive themselves susceptible to the sequelae of an illness (i.e., late effects), understand the seriousness of the illness, and believe the benefits outweigh the barriers or costs [40, 41]. Cues to action (i.e., having medical records, treatment summary and survivorship care plan) are modifying variables that were asked as they influence self-efficacy to manage survivorship care.

We used a convenience sample of survivors who were invited to participate either at their clinic visit or by a mailed invitation letter. Data collection procedures for survey administration included completion of the written survey administered in person if the survivor was in clinic, by returning the written survey in the mail, or via telephone utilizing a trained research assistant. Instructions were included at the beginning of the survey. The survey took approximately 20 min to complete.

Statistical analyses

Self-reported demographic, health care setting characteristics, receipt of survivorship care planning documents, and expectations of health care providers were summarized using descriptive statistics. We classified participants' level of confidence in managing their survivorship care based on their responses to five items scored on a 4-point Likert scale (not at all confident/somewhat confident/confident/very confident): (1) knowledge about cancer treatments received, (2) knowledge about late effects, (3) steps to take for long-term physical effects, (4) steps to take for psychosocial effects, and (5) how long to continue screening for recurrence. Agglomerative hierarchical clustering analyses of these five items using multiple different linkage methods including average linkage, complete linkage and Ward's

method consistently identified two clusters of individuals characterized by high and low overall scores. Hence, scores on the five items were averaged and participants below and above the midpoint of the scale of 2.5 were classified as low or high confidence, respectively. Bivariate and multivariate logistic regression with low confidence group membership as the dependent variable was used to characterize the association with demographic, medical, receipt of survivorship care planning documents, and health care setting characteristics. Survivorship care planning documents included: (1) copies of cancer treatment records, (2) a treatment summary, and (3) a survivorship care plan during the survivorship period. Health care setting variables were defined as having an oncologist only, PCP only, other specialist, or using the “shared-care model” (oncology and PCP). Data were analyzed with SAS Statistical software (SAS Version 9, SAS Institute Inc., Cary, NC).

Results

Participant characteristics

As shown in Table 1, 376 young adult cancer survivors completed the survey. The mean age at time of survey was 28 years (SD=5) with 12% of the sample being in the 18–19 year age group, 51% in the 20–29 age group, and 37% in the 30–39 age group. One fourth of the participants were from ethnically diverse backgrounds. One third had a bachelor’s degree and 20% had graduate degrees; the remainder (46%) reported high school graduation or some college. Fifty-four percent of participants had total family incomes at \$60,000 per year or above, and 93% had health insurance.

Diagnostic/treatment variables As shown in Table 2, the largest groups of participants were survivors of leukemia/lymphoma (38%), bone and soft tissue sarcomas (14%) and female and male genital system, excluding breast (13%). Six percent reported multiple cancer diagnoses. The mean age at cancer diagnosis was 18 years (SD=10), ranging from 1 to 39 years. The mean interval from diagnosis was 9 years (SD=8) and ranged from less than 2 years (10%), 2–4 years (28%), to 5 or more years (62%) from diagnosis. Fifty-seven percent of respondents were diagnosed under the age of 20. Sixty-one percent received multi-modal cancer therapies, and 11% received a bone marrow transplant. Nine percent rated their current overall health status as fair or poor.

Self-reported survivorship clinic utilization and receipt of survivorship care As shown in Table 3, 71% of participants reported that they currently visit an oncology or survivor-

Table 1 Participant characteristics (N=376)

Characteristic	No.	Percent
Gender		
Male	173	46
Female	203	54
Race/ethnicity		
Non-Hispanic/Latino white	278	74
Hispanic/Latino	30	8
Asian	23	6
Black	12	3
Mixed race/ethnicity	32	9
Not reported	1	0.3
Age at survey [years] (28±5) ^a		
18–19	44	12
20–29	192	51
30–39	139	37
Not reported	1	0.3
Annual household income		
<\$20,000	48	13
\$20,000–\$39,999	35	9
\$40,000–\$59,999	46	12
\$60,000 and higher	205	54
Not reported	44	12
Education		
High school or some college	173	46
Bachelor’s degree	123	33
Graduate or professional degree	77	20
Not reported	3	1
Marital status		
Single	234	62
Divorced/widowed	11	3
Married	120	32
Not reported	11	3
Health insurance		
Private insurance	313	83
Public insurance	39	10
None	14	4
Not reported	12	3

^a Mean±SD

ship clinic. Forty-five percent reported traveling greater than 30 miles to their oncology/survivorship clinic. Twenty percent of the participants reported no discussion of late effects with their doctors. One third did not have copies of their medical records, and 48% did not have a written treatment summary. More than half (55%) did not have a written survivorship care plan. Nineteen percent reported having none of these three survivorship documents, and 26% possessed all three. Participants’ report of the roles played by different health care providers in survivorship

Table 2 Clinical characteristics of the participants and their self-reported health status

Characteristic	No.	Percent
Cancer diagnosis		
Leukemia	77	20
Lymphoma (Hodgkin and non-Hodgkin)	69	18
Bone/soft tissue sarcoma	53	14
Testicular	44	12
Brain/central nervous system	22	6
Breast	17	5
Thyroid	16	4
Kidney	14	4
Neuroblastoma	8	2
Melanoma	8	2
Colon	5	1
Cervical/ovarian/germ cell	5	1
Head and neck	3	1
Other diagnosis	12	3
Multiple diagnoses indicated by respondent	23	6
Cancer treatments received		
Chemotherapy only	50	13
Surgery only	48	13
Radiation only	3	1
Chemotherapy and surgery	86	23
Chemotherapy and radiation	38	10
Surgery and radiation	27	7
Chemotherapy, surgery, and radiation	80	21
Bone marrow transplant (with or without other therapies)	42	11
Not reported	2	0.5
Age at cancer diagnosis [years] (18±10) ^a		
5 and younger	54	14
6–10	27	7
11–14	48	13
15–19	87	23
20–29	102	27
30–39	56	15
Not reported	2	0.5
Interval from diagnosis [years] (9±8) ^a		
Less than 2	37	10
2–4	106	28
5–9	100	27
10 or more	130	35
Not reported	3	1
Current overall health status		
Excellent	74	20
Very good	172	45
Good	99	26
Fair or poor	34	9
Not reported	2	0.5

^a Mean±SD

Table 3 Self-reported survivorship clinic utilization, receipt of late effects counseling, and receipt of survivorship care planning documents

	No.	Percent
Currently go to oncology/survivorship clinic	265	71
Frequency of visits to oncology/survivorship clinic (among the 265 participants currently attending)		
More than once a year	128	48
Every 1–2 years	125	47
Less frequently	12	5
Doctor has discussed late or chronic effects of cancer treatment		
Yes	288	77
No	74	20
Not reported	14	4
Have copies of medical records		
Yes	248	66
No	125	33
Not reported	3	1
Have written treatment summary		
Yes	191	51
No	179	48
Not reported	6	2
Have written cancer survivorship follow-up care plan		
Yes	163	43
No	208	55
Not reported	5	1
Number of these above 3 items in possession		
0	71	19
1	104	28
2	105	28
3	96	26

care can be found in Table 4. Most participants indicated that their oncologist played the dominant role in tests and treatment decisions (70%), providing cancer care in the next 6 months (69%), and was most likely to know about or treat symptoms (56%). PCPs scored much lower in these three areas of survivorship care (4%, 10%, and 18%, respectively), as did the “shared-care model” (10%, 5%, and 6%, respectively). No association was found between interval since cancer diagnosis and the predominant care model ($P=0.40$, Chi-square test).

Table 5 presents results of bivariate and multivariate logistic regression analyses predicting low confidence in survivors managing their cancer survivorship care. Forty-one percent (155/376) were classified as low confidence using the five-item composite index. Significant bivariate findings were: racial/ethnic minority survivors having higher odds of belonging to the low confidence group, compared with non-Hispanic whites (OR=1.66, CI=1.04–2.64), fair or poor self-reported health status respondents having higher odds of being

Table 4 Participants' reports of health care provider roles in survivorship care

	Doctor most important for test/ treatment decisions (<i>N</i> (%))	Doctor in charge of cancer care for next 6 months (<i>N</i> (%))	Doctor most likely to know about or treat symptoms (<i>N</i> (%))
Shared-care (both PCP and oncologist)	38 (10)	18 (5)	23 (6)
Oncologist only	265 (70)	258 (69)	211 (56)
PCP only	16 (4)	38 (10)	69 (18)
Other subspecialty	56 (15)	56 (15)	56 (15)
Not reported	1 (0.3)	6 (2)	17 (5)

in the low confidence group (OR=2.20, CI 1.07–4.50), and respondents reporting lack of copies of medical records, a written treatment summary or survivorship care plan having higher odds of low confidence (OR=1.57, CI=1.02–2.41; OR=1.76, CI=1.16–2.66; and OR=2.80, CI=1.81–4.33, respectively). In the multivariate analysis, being an ethnic minority survivor and lacking a survivorship care plan all remained significantly associated with higher odds of being in the low confidence group. The odds ratio for fair/poor health status was essentially unchanged in the multivariate model; however, it was imprecisely estimated due to small sample size.

Discussion

There is a growing population of young adult cancer survivors who require long-term follow-up care to assess for both medical and psychosocial late effects of cancer treatment [4]. This national survey of young adult cancer survivors of both pediatric and adult malignancies describes patterns of post-treatment health care utilization, frequency of receipt of survivorship care planning documents, role expectations of providers, and the relationship between sociodemographic, self-rated health status, and post-treatment care patterns with self-reported confidence in cancer survivorship care planning. Through the LIVE-STRONG™ Survivorship COE Network, we obtained a diverse sample of young adult cancer survivors cared for within a wide variety of tertiary health care settings with different models for delivering survivorship care [33].

There were several notable findings. This sample of young adult cancer survivors had high levels of education, income, and health insurance, along with access to care at an NCI-designated Comprehensive Cancer Center. Nonetheless, a significant proportion of survivors were lacking important documents that could facilitate post-treatment care, specifically, not having copies of cancer treatment medical records, a treatment summary, and a survivorship care plan. Only 26% of survey respondents reported possessing all three survivor-

ship care planning documents which are considered indicative of good quality survivorship care [3]. These findings, however, likely over-represent the proportion of young adult survivors having these survivorship care planning documents, since the majority of young adult survivors do not utilize cancer centers for follow-up and infrequently receive recommended late effects screening based on their previous cancer treatment [42, 43].

The high percentage of survivors not reporting receipt of a survivorship care plan (55%) is particularly concerning. The factors that may account for the lack of receipt of a survivorship care plan include outpatient infrastructure barriers and a focus on screening for cancer recurrence in the outpatient oncology setting rather than on health promotion and disease prevention for survivors [44]. The outpatient infrastructure barriers may include having insufficient time within clinics to prepare for survivorship care discussions. There also may not be an incentive in the outpatient oncology setting to invest the time in developing a survivorship care plan due to lack of adequate insurance reimbursement. Additionally, survivors may not recall receiving a survivorship care plan as this study is using self-reported data, which highlights the complex nature of delivering cancer-related follow-up between the survivor and providers of survivorship care. Deficits in any one area, for example having a survivor who is neither well-informed nor participatory in their survivorship care planning, can ultimately impact on their long-term health outcomes [45]. Research evaluating the most effective communication strategies for delivery of survivorship care plans is an important area of future investigation.

Even though post-treatment survivorship care is a recognized distinct phase of oncology care, providing survivorship care plans appears to be a work-in-progress in the oncology setting based on our findings. In addition to considering provider roles, efforts to increase cancer survivorship care planning should also examine patient-related barriers. These barriers may include cancer stigma, avoidance and lack of awareness of the need for late effects discussions and survivorship visits [6, 36, 37, 46–49]. Young adults may not want to have survivorship discus-

Table 5 Odds ratios for membership in low confidence group by participant characteristics

Characteristics	Percentage in low confidence group (% (n/N))	Bivariate logistic regression (OR (95% CI))	<i>P</i>	Multivariate logistic regression (OR (95% CI))	<i>P</i>
Sociodemographic factors					
Gender					
Male	38 (67/176)	0.83 (0.55–1.25)	0.36	0.83 (0.51–1.35)	0.44
Female	43 (88/203)	1.00		1.00	
Race/ethnicity					
Minority	51 (49/97)	1.66 (1.04–2.64)	0.03	2.29 (1.30–4.02)	0.004
Non-Hispanic white	38 (106/278)	1.00		1.00	
Education					
Bachelor's or higher	42 (83/200)	1.02 (0.67–1.54)	0.93	0.94 (0.54–1.66)	0.84
Some college or less	41 (71/173)	1.00		1.00	
Age at survey					
18–29	42 (58/139)	1.03 (0.67–1.57)	0.91	0.88 (0.47–1.66)	0.70
30–39	41 (97/236)	1.00		1.00	
Health insurance status					
Private	40 (124/311)	0.88 (0.30–2.61)	0.38	2.80 (0.65–12.1)	0.50
Public	51 (20/39)	1.40 (0.41–4.81)	0.34	4.29 (0.87–21.2)	0.08
None (reference)	43 (6/14)	1.00		1.00	
Cancer treatment variables					
Age at cancer diagnosis					
20–39	44 (69/158)	1.21 (0.80–1.85)	0.35	0.99 (0.43–2.30)	0.99
19 years or less	39 (84/216)	1.00		1.00	
Interval since diagnosis					
10 years or more	39 (51/130)	0.92 (0.57–1.49)	0.73	1.03 (0.48–2.22)	0.93
5–9 years	43 (43/100)	1.07 (0.64–1.80)	0.79	1.10 (0.60–2.04)	0.75
0–4 years	41 (59/143)	1.00		1.00	
Diagnosis					
Leukemia/lymphoma	39 (57/146)	0.86 (0.57–1.32)	0.49	0.80 (0.46–1.38)	0.42
Solid tumors	43 (98/230)	1.00		1.00	
Treatment received					
Multiple treatments (chemotherapy, radiation, and surgery)	40 (93/231)	0.87 (0.54–1.40)	0.75	0.91 (0.51–1.63)	0.79
Bone marrow transplant (w/ or w/o other tx)	40 (14/42)	0.88 (0.42–1.83)	0.86	0.98 (0.40–2.40)	0.96
Single treatment	44 (44/101)	1.00		1.00	
Current health status					
Overall health status					
Fair/poor	59 (20/34)	2.20 (1.07–4.50)	0.03	2.23 (0.92–5.40)	0.08
Excellent/very good/good	36 (134/340)	1.00		1.00	
Receipt of survivorship care planning documents					
Have copies of medical records					
No	48 (62/128)	1.57 (1.02–2.41)	0.04	1.31 (0.78–2.19)	0.31
Yes	38 (93/248)	1.00		1.00	
Have written treatment summary					
No	48 (89/185)	1.76 (1.16–2.66)	0.008	1.41 (0.82–2.44)	0.22
Yes	35 (66/191)	1.00		1.00	
Have follow-up survivorship care plan					
No	52 (110/213)	2.80 (1.81–4.33)	<0.001	2.65 (1.52–4.61)	0.001
Yes	28 (45/163)	1.00		1.00	

Table 5 (continued)

Characteristics	Percentage in low confidence group (% (n/N))	Bivariate logistic regression (OR (95% CI))	<i>P</i>	Multivariate logistic regression (OR (95% CI))	<i>P</i>
Currently go to oncology/survivorship clinic					
No	45 (49/110)	1.22 (0.78–1.92)	0.38	0.91 (0.53–1.58)	0.75
Yes	40 (105/265)	1.00		1.00	
Care model ^a					
Oncologist only	40 (106/264)	0.92 (0.48–1.74)	0.25	0.99 (0.48–2.05)	0.98
Primary care provider only	54 (13/24)	1.62 (0.60–4.38)	0.23	2.21 (0.68–7.15)	0.19
Other subspecialty	27 (7/26)	0.50 (0.18–1.44)	0.20	0.40 (0.11–1.43)	0.16
Shared-care (both oncologist and PCP)	42 (19/45)	1.00		1.00	

^a Care model variable is based on which doctor is reported as most important for test/treatment decisions

sions with their oncologists or other providers of care as they seek to return to “a normal life” and integrate with their peers [24, 50]. Future research should explore the impact psychosocial issues may have on the discussions and receipt of survivorship care planning in young adult survivors.

This is the first study to our knowledge to identify the positive effect that survivorship care plans can have on young adults in preparing them to be confident consumers of survivorship care. The finding that the lack of a survivorship care plan is associated with higher odds of being in a low confidence group of survivors adds to the growing body of literature within medical oncology discussing how survivorship care plans can promote optimal care by functioning as an efficient communication method among providers [25, 51]. Survivorship care plans seem to prepare survivors to be more self-assured in being their own health advocates. There have been several national efforts to improve the dissemination of survivorship care plans in the medical oncology setting, including the development of survivorship care plan templates for use by providers or survivors [52–55]. Future research should explore the use of different strategies for delivering survivorship care plans and whether they improve confidence and health promotion actions in young adult survivors.

There is an evolving area of research seeking to understand how survivorship care plans are used by survivors and health care providers to coordinate and improve survivorship care. While survivors in this study report that oncologists have the primary role for cancer-related care and symptom management, prior research has demonstrated that the majority of survivors are seen in the community medical setting during the young adult years [42]. Given the multiple settings in which young adult survivors can receive care, survivorship care plans should delineate and clarify providers’ responsibilities in survivor-

ship care management [10]. It is difficult, however, to implement effective communication technologies when providers are practicing within different health care settings, including the primary care office, community-based oncology office, academic center, and/or cancer center [56]. As a result of this fragmentation of care and poorly coordinated health care system, young adult survivors are often left responsible for coordinating their own care, from active cancer treatment to off-therapy, between their different providers of care. Our findings suggest that these survivors do not endorse the “shared-care model” with involvement of both the oncologist and primary care physicians in managing their health care needs. Instead they rely on their oncologist for symptom management and testing and treatment decisions [6]. The lack of transition by young adult survivors in this study from the oncology to the primary care setting may originate from the lack of awareness that survivors have non-cancer-related health needs [57] and/or a strong therapeutic relationship with the oncology team.

Also noteworthy are the health care factors that did not predict low confidence in managing survivorship care, including whether the survivor is currently visiting an oncology or survivorship clinic or other models of care delivery including the “shared-care model” or PCP only. Age at diagnosis and current age were also not statistically significant predictors in either the bivariate or multivariate models. Given these findings, there is no single model of care that conveys advantages in promoting cancer survivor self-confidence, as long as survivorship care plans are prepared and shared with survivors.

Lastly, an important significant finding is that ethnic minorities were a high-risk group for low confidence in managing their survivorship care. This result reinforces previous research demonstrating significant disparities by race/ethnicity and language in cancer survivors’ views of quality of care [58]. In colon cancer survivors, problems

with coordination of care and access to care have been found to be significantly more common for African-Americans, Asian/Pacific Islanders, and non-English speaking whites. Other exploratory studies have found limited understanding and misperceptions of cancer risks in minority populations. In African-American men, participants recommended community-based health education or word-of-mouth education from their peers to improve their cancer risk knowledge [59]. Qualitative research in minority breast cancer survivors has found that survivorship care plans have the potential to serve as a health-enhancing tool by decreasing anxiety following the completion of treatment, increasing the use of late effects screenings, and increasing confidence in discussing health concerns with their PCP [60]. Given our findings, future research exploring interventions to improve the awareness of the need for survivorship care planning within diverse populations of young adults is an important area of investigation.

There are study limitations that should be considered in the interpretation of these results. A convenience sample was obtained from NCI-designated Comprehensive Cancer Centers across the USA, and we cannot be certain of the generalizability of our findings. Sampling bias, as a result of the challenges of tracing lost-to follow-up young adult cancer survivors, is a recognized challenge in young adult survivorship research as this population is very mobile due to their life transitions [61, 62]. The sample also included a significant percentage of survivors with higher socioeconomic resources. This may lead to overestimation of the rates of reported survivorship confidence as these participants had access to cancer centers, which specialize in survivorship care. Taken together, these study limitations could restrict the generalizability of the findings, which may yield overestimates of survivor self-confidence in managing their survivorship care. Conversely, there is also the limitation of using self-reported data for the measurement of receiving late effects counseling. The oncology literature has shown disagreement between self-reported information and medical record information concerning knowledge of cancer diagnosis with a significant proportion not adequately recalling even their cancer diagnosis [63, 64]. However, given that the young adult survivor is the center of the patient–clinician relationship, it is important to have a clear understanding of what they report knowing about their cancer diagnosis and treatment. If discrepancies are identified, targeted educational interventions can be developed to improve the survivorship care that young adult survivors receive.

In conclusion, lacking survivorship care plans was associated with greater likelihood of reporting low self-confidence in managing cancer survivorship care. Non-white race/ethnicity is an independent factor for reporting

low confidence in managing survivorship care. These findings suggest that interventions to increase provision of survivorship care plans for young adult cancer survivors should be tested to potentially improve confidence in managing survivorship care, particularly for ethnic minorities.

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