

ORIGINAL RESEARCH

Cancer Screening of Long-Term Cancer Survivors

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Background: Although 64% of cancer survivors are expected to live at least 5 years beyond diagnosis, the receipt of cancer screening by this population is unclear. The objective of this study was to assess the relation between a cancer diagnosis and future cancer screening, exploring provider-, patient-, and cancer-specific factors that explain observed relationships.

Methods: The Wisconsin Longitudinal Study (WLS) and Wisconsin Tumor Registry were used to identify 2 participant groups: 415 patients diagnosed with nonmetastatic cancer between 1992 to 1993 (before cancer) and 2003 to 2004 (after cancer) and 4680 controls (no cancer). Adjusted average predicted probabilities of cancer screening were estimated with models that first did not include and then included, provider (provider relationship length), participant (depressive symptoms per the Center for Epidemiologic Studies Depression Scale), and cancer-specific (time since diagnosis) factors. Participants with a history of cancer associated with a given screening test were then excluded to assess whether relationships are explained by screening for recurrence versus second cancers.

Results: Female cancer survivors were more likely than no-cancer controls to undergo pelvic/Papanicolaou screening (survivors: 70%, 95% confidence interval [CI]: 63% to 76%; controls: 61%, 95% CI: 59% to 63%) and mammography screening (survivors: 86%, 95% CI: 78% to 90%; controls: 76%, 95% CI: 74% to 77%), though male cancer survivors were not more likely to receive prostate exams (survivors: 76%, 95% CI: 70% to 82%; controls: 69%, 95% CI: 67% to 71%). After excluding people with a history of the cancer being screened for, there were few significant differences in cancer screening between short- or long-term survivors (≥ 5 years) and no-cancer controls. Relationships were not sensitive to adjustment for provider or participant factors.

Conclusions: The significant positive differences in cancer screening between people with and without cancer can be explained by screening for recurrence. Long-term cancer survivors are not more likely to receive follow-up screening for second cancers. This information should be used by providers to ensure patients receive recommended follow-up preventive care. (J Am Board Fam Med 2012;25:460–469.)

Keywords: Cancer Screening, Longitudinal Studies, Preventive Health Services, Prevention, Primary Health Care, Registries, Survivorship

Cancer detection and treatment advances have produced declining cancer death rates,¹ with 64% of

cancer survivors expected to live ≥ 5 years from diagnosis.² Despite improvements, cancer survivors

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remain at risk of recurrence and second cancers.³ In recognition of these risks, the Institute of Medicine outlined a critical need to improve the long-term follow-up of cancer survivors, including cancer screening, to optimize health outcomes.⁴

Given long-term health risks, there is reason to believe cancer survivors would be likely to undergo recommended cancer screening,⁵ but evidence of whether this occurs is mixed. Several studies show cancer survivors to be more likely to receive mammograms,^{6–11} Papanicolaou smear/pelvic examinations,^{6–8} and prostate-specific antigen tests^{6,8} than adults without a personal history of cancer. Other studies found either no difference¹² or underutilization of certain services once people with a history of the cancer being screened for were excluded.^{10,12} These studies were largely analyses of administrative datasets (eg, Surveillance, Epidemiology and End Results Reporting [SEER]–Medicare) and focused on recently diagnosed breast and colorectal cancer survivors older than age 65. This limits the ability to control for a comprehensive set of patient-level factors or explore mechanisms through which a cancer diagnosis influences screening behavior.

The amount of time a person has lived with cancer may influence cancer screening behavior. Surviving 5 years is considered a “milestone”¹³ that represents a reduction in health risks,^{13,14} though many long-term survivors remain at risk of recurrence and second cancers. Studies using SEER–Medicare data suggest that mammography and cervical cancer screening decline after a diagnosis of breast and colorectal cancer.^{9,15} Cancer screening,

however, has not been described in individuals surviving longer than 5 years or compared with trends in people without cancer. Studies addressing this gap have important clinical implications. As the number of cancer survivors continues to increase, providers will need to remain vigilant in screening for recurrent and new cancers.

Research exploring factors that affect cancer screening has focused primarily on provider type and patient mental health. After 5 years from diagnosis, nearly two-thirds of cancer survivors visit their primary care physician (PCP) exclusively,¹⁵ making a shared care model for the systematic long-term care of cancer survivors less feasible. In primary care, continuity of care generally fosters patient adherence to physician recommendations for cancer-specific services,^{16,17} though this has not been explored for cancer survivors. Depressive symptoms are commonly reported by cancer survivors¹⁸ and could be a modifiable mechanism by which a diagnosis impacts screening, though to our knowledge this has not been explored. Cross-sectional studies have yielded mixed results, with some studies associating depressive symptoms with underutilization¹⁹ and others with more primary care visits^{20,21} or better guideline adherence.²²

We address prior limitations with a unique dataset that combines a longitudinal study with a state tumor registry database. This linkage allowed for an investigation of the relationship between a cancer diagnosis and cancer screening and provider and patient factors that explain screening behavior.

Methods

Population and Sampling

Participants were from the Wisconsin Longitudinal Study (WLS), a long-term cohort study of a one-third random sample of 1957 Wisconsin high school graduates ($n = 10,317$) and 8,778 of their randomly selected siblings. The WLS is representative of non-Hispanic white men and women with at least 12 years of education, an ethnic/educational subgroup that includes approximately two thirds of the U.S. population in the relevant age bracket.²³ Participants who responded to the 1992–1993 and 2003–2004 telephone and mail surveys were included ($n = 8054$). Among participants, 1992–1993 response rates for graduates and siblings were 93% and 87% for the telephone and 76% and 77% for mailed surveys, respectively. To capture incident

research uses data from the Wisconsin Longitudinal Study (WLS) of the University of Wisconsin–Madison. A public use file of data from the WLS is available at <http://www.ssc.wisc.edu/wlsresearch/data/>. Since 1991, the WLS has been supported principally by the National Institute on Aging (grant nos. R01 AG09775 and R01 AG033285), with additional support from the Vilas Estate Trust, the National Science Foundation, the Spencer Foundation, and the Graduate School of the University of Wisconsin–Madison.

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Conflict of interest: none declared.

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cancer cases, the sample was restricted to Wisconsin residents (66% of participants; $n = 5,317$).

The WLS was linked to the Wisconsin tumor registry,²⁴ allowing for a medical records–based assessment of cancer diagnosis year, site, and SEER summary stage, defined as in situ, localized, regional (direct extension and lymph nodes alone or in combination or not otherwise specified), and distant (metastatic).^{25,26} Participants diagnosed before 1992–1993 ($n = 174$) or at a “distant” stage ($n = 33$) were excluded. The sample was further restricted to respondents at the U.S. Preventive Services Task Force minimum recommended age for each of the cancer screening tests (age 40 years for mammogram and 50 years for prostate examination) in place at the time of survey administration,^{27–29} resulting in the exclusion of 15 men. The final sample included 415 participants diagnosed with cancer between 1992–1993 (before cancer) and 2003–2004 (after cancer) and 4680 participants without a cancer diagnosis in the state tumor registry during this time period.

Cancer Screening Variables

Our dependent variables included 3 cancer screening measures assessed in 2003–2004 (after cancer diagnosis for the cancer group). These questions asked whether participants received a pelvic examination/Papanicolaou smear, mammogram, or prostate examination within the previous 12 months (yes/no). The first 2 services are recommended by the US Preventive Services Task Force (A/B rating); prostate exams are not (“insufficient evidence” rating).³⁰ At the time of the survey, the American Cancer Society recommended annual mammograms,³¹ Papanicolaou/pelvic exams (unless 3 consecutive tests were negative),³² and prostate exams³³ for people in the age range of this cohort.

Explanatory Variables

The primary explanatory variable was a cancer diagnosis between 1992–1993 and 2003–2004 (yes/no). Provider-, participant-, and cancer-specific factors included (1) provider relationship length (no usual provider; <5 years, 5–9 years, 10–14 years, or ≥ 15 years); (2) depressive symptoms (measured in 1992–1993 and 2003–2004 using the Center for Epidemiologic Studies Depression survey³⁴); and (3) time since cancer diagnosis (no cancer diagnosis; diagnosed <5 years; diagnosed ≥ 5 years before 2003–2004).

Control Variables

Analyses were adjusted for factors (measured in 1992–1993) associated with the likelihood of a cancer diagnosis, cancer screening, or both. These factors were chosen on the basis of a cancer stress process model³⁵ that relates a cancer diagnosis to subsequent health behaviors and correspond to predisposing, enabling, and need factors included in the Andersen model of health services utilization.³⁶

Sociodemographic measures included age, sex, marital status, number of children, education, household income, and employment status. Health measures included self-reported diagnosed chronic conditions with a prevalence more than 10% in the sample—hypertension; heart disease (heart trouble, circulation problems); respiratory conditions (asthma/bronchitis/emphysema); and arthritis/rheumatism—with a summary indicator encompassing conditions with less than a 10% prevalence. Functional status was defined by a condition/illness/disability that limited activities now or was likely to in the future. Self-rated health was assessed as excellent, good, fair, poor, or very poor. A family history of cancer variable indicated whether a participant’s biological mother, father, or siblings had been diagnosed with cancer. Health behavior measures included body mass index (underweight/normal, $<24.9 \text{ kg/m}^2$; overweight, $25.0–29.9 \text{ kg/m}^2$; and obese, $\geq 30 \text{ kg/m}^2$)³⁷; physical activity (sedentary, light, moderate, and vigorous)³⁸; and cigarette smoking (never, former, current). Insurance status in 2003–2004 was categorized as public or private. Uninsured participants (2%) were included in the “public” category because of the small sample size and because both groups historically have had reduced health care access and screening rates relative to the privately insured.³⁹

Psychosocial measures included personality, stressful life events, social support, and participation. Personality (related to preferences for medical decision making⁴⁰ and provider choice⁴¹) was assessed with a modified version of the 5-factor model: extraversion, openness to experience, conscientiousness, neuroticism, and agreeableness.^{42,43} Stressful life events were measured with a scale^{44,45} that inventories 18 life events/problems (eg, spousal physical abuse). Social support is a reinforcing factor for preventive care use,⁴⁶ and along with life stress, influences health care use in older adults⁴⁷ and was measured as social participation (a count of participation in 16 social network types, eg, church-connected

groups)⁴⁸ and social relationships (a count of social get-togethers with friends/relatives in the prior month).

Statistical Analysis

Data were analyzed using STATA software version 10.0 (StataCorp, LP, College Station, TX). Though the item nonresponse rate averaged across items was low (2.4%), multiple imputation by chained equations was employed at the item level. Five imputed datasets were created. Parameter estimates (mean, proportion, regression) and standard errors were obtained using Rubin combination rules.^{49–53} Adjusted multivariable logistic regression models were fit to assess the relationship between a cancer diagnosis and cancer screening. Models were estimated separately for men and women and re-estimated including the “time since diagnosis” group, depressive symptoms after cancer, and provider relationship length variables to determine whether these factors accounted for between-cancer group screening differences. Participants with a history of the cancer being screened for then were excluded to assess whether the relationship between a cancer diagnosis and screening can be explained by screening for recurrence versus second cancers. We accounted for the clustering of sibling and graduate respondents by calculating 95% confidence intervals using the STATA “robust” command. Statistical significance was defined as $p < .05$.

To aid in interpretation, average predicted probabilities of cancer screening were estimated for the cancer and no cancer groups adjusted to the overall distribution of covariates. Covariate values for a given participant (eg, female, employed) were used to estimate the probability of receiving a given screening test, having or not having cancer under actual and counterfactual scenarios. This was accomplished by first setting all participants’ cancer status to 1 (indicating that they had cancer), while maintaining each participant’s unique set of other characteristics (eg, age, sex), and averaging individual probabilities across the sample. Next, cancer status was set to 0 for all participants (indicating that they did not have cancer), and the procedure was repeated. The difference in these 2 sets of mean predicted probabilities can be interpreted as the difference in the probability of the given screening between those with cancer and without for a population with the mix of other characteristics present in the sample. A similar approach was followed to calculate average predicted probabili-

ties for the 3 “time since diagnosis” groups. To obtain standard errors, individual predicted probability estimates were combined as previously described and averaged, with the process bootstrapped 200 times. The sample drawn during each replication represented a bootstrap sample of clusters.

Results

Survey participants in 1992–1993 (before cancer) were 53 years old, on average, with relatively high levels of income and education (Table 1). Eighty-nine percent reported good/excellent health. Participants who went on to receive a cancer diagnosis were significantly more likely than those who did not to be older, male, have a family history of cancer, and have a higher education level.

The most frequently diagnosed cancers were prostate, breast, and colorectal, which were commonly diagnosed at a local stage (Table 2). Fifty-six percent of cancers were diagnosed within 5 years of the 2003–2004 survey. There was moderate variation in the proportion of participants who received cancer screening (Table 3). Proportions ranged from 62% for Papanicolaou smears/pelvic exams to 76% for mammograms.

Controlling for factors before cancer and insurance factors, women with cancer were more likely than those without to receive cancer screening (Table 4). Female cancer survivors were more likely to receive Papanicolaou smears/pelvic exams (70%; 95% confidence interval [CI], 63% to 76%) and mammograms (86%; 95% CI, 78% to 90%) than were women without cancer (61%; 95% CI, 59% to 63%; and 76%; 95% CI, 74% to 77%, respectively). Once women with the cancer associated with a given screening test were excluded, the difference for pelvic examination/Papanicolaou smear remained (69%; 95% CI, 63% to 76%; and 61%; 95% CI, 59% to 63%, respectively), though the difference for mammograms was no longer statistically significant (80%; 95% CI, 69% to 86%; and 76%; 95% CI, 74% to 77%). Among men, cancer survivors were not significantly more likely than men without cancer to receive prostate exams (76%; 95% CI, 70% to 82%; and 69%; 95% CI, 67% to 71%, respectively), nor were they more likely to receive them after prostate cancer survivors were excluded (69%; 95% CI, 57% to 77%; and 69%; 95% CI, 67% to 71%, respectively).

Table 1. Key Characteristics of Cancer Cases and No-Cancer Controls at Baseline Assessment (N=5095)*†

Characteristics	Overall (N=5095)	No Cancer (n=4680)	Cancer (n=415)	Characteristics	Overall (N=5095)	No Cancer (n=4680)	Cancer (n=415)
Age				Cigarette smoking			
≤50	11	12	5	Former	36	35	41
51 to 54	10	10	7	Current	16	16	17
55 to 64	64	64	67	Physical activity			
≥65	15	15	20	Sedentary/light	43	43	43
Female	55	56	48	Moderate	43	43	42
Education				Vigorous	14	13	15
High school or less	63	63	56	Body mass index			
Some college	15	14	20	≤24.9	32	32	30
College degree	12	12	13	25–29	43	43	45
Postgraduate training	10	10	12	≥30	25	25	25
Insurance status*				Family history of cancer	57	56	64
Private	54	54	47	Marital status			
Public/uninsured†	46	46	53	Widowed/divorced/never married	15	15	13
Household income (\$)				Married	85	85	87
<20,000	15	15	15	Mean number of children	3 (2)	3 (2)	3 (2)
20,000–34,999	13	13	13	Mean stressful life event count	2 (2)	2 (2)	2 (2)
35,000–49,999	20	20	20	Mean social relationship count	8 (6)	8 (6)	8 (7)
50,000–64,999	19	19	19	Mean social participation count	4 (3)	4 (3)	4 (3)
≥65,000	34	33	33	Personality score (Mean)			
Percent employed	84	84	85	Openness to experience	21 (5)	21 (5)	22 (5)
Chronic conditions				Conscientiousness	29 (4)	29 (4)	29 (4)
Hypertension	23	23	26	Extraversion	23 (5)	23 (5)	23 (5)
Heart disease	10	10	12	Agreeableness	29 (4)	29 (4)	28 (4)
Respiratory conditions	10	10	9	Neuroticism	16 (5)	16 (5)	16 (5)
Arthritis	26	26	29				
Other diagnoses	22	22	21				
Functional limitation	17	17	16				
Self-rated health							
Very poor/poor/fair	11	11	12				
Good	63	63	64				
Excellent	26	26	25				

Values represent percent (ages) unless specified as mean (standard deviation). Bolded values indicate statistically significant difference between respondents with and without cancer ($p < .05$).

*Measured at the time of the 2003–2004 survey.

†Two percent of participants were uninsured at the time of the survey.

The association between a cancer diagnosis and cancer screening differed by the amount of time a person had cancer. Within 5 years of diagnosis, cancer survivors were more likely than controls to have had cancer screening tests other than for prostate cancer. However, the only difference in cancer screening among longer-term survivors compared to no-cancer controls was for mammograms (86%;

95% CI, 78% to 92%; and 76%; 95% CI, 74% to 77%, respectively) (Table 4). Once participants with a history of the cancer associated with the screening test were excluded, there were few significant differences for short-term survivors and no significant differences for longer-term cancer survivors compared with no-cancer controls. The magnitude of the differences described remained

Table 2. Cancer in the Wisconsin Longitudinal Study by Site, Stage, and Time Since Diagnosis (N = 415)

Cancer Characteristic	n (%)
Time between diagnosis and survey (years)	
0–4	231 (56)
≥5	184 (44)
Cancer site at diagnosis	
Prostate	133 (32)
Breast	113 (27)
Colorectal	39 (9)
Bladder	14 (3)
Lung	10 (2)
Other	106 (26)
Cancer stage at diagnosis	
In situ	38 (9)
Local	277 (67)
Regional	83 (20)
Missing	17 (4)

Participants with cancers diagnosed at a distant stage were excluded from the analysis.

when after-cancer provider and patient factors were included in the models.

Discussion

To our knowledge, this is the first study to prospectively assess the relationship between a cancer diagnosis and cancer screening in short- and longer-term survivors while exploring a comprehensive set of provider-, patient-, and cancer-specific factors that might explain observed relationships. Although the majority of cancer survivors received recommended cancer screening, there was important variation by screening type. Overall, cancer survivors were more likely than people without cancer to receive cancer screening, with propor-

tions that changed little with adjustment. However, once participants who had the cancer associated with a given screening test were excluded, the only statistically significant difference was higher Papanicolaou smears/pelvic exams for short-term cancer survivors. There were no differences in cancer screening among long-term survivors relative to no-cancer controls. The magnitude of these relationships did not change when depressive symptoms or provider–patient relationship length after cancer were included in the models.

It is encouraging and not surprising that cancer survivors were more likely than participants without cancer to receive the screening test associated with their cancer within 5 years of diagnosis because this likely represents screening for recurrence. Twenty percent to 30% of cancer survivors did not undergo screenings for other cancer types, however, despite evidence that many cancer survivors remain at risk of developing second primary cancers.^{5,54} This gap between recommended care and actual practice has been demonstrated in other studies.^{8,12} There were no significant differences from controls in the receipt of any of the cancer screening services ≥5 years from the time of diagnosis, again suggesting the influence on results of screening for recurrence within 5 years of diagnosis.

Given the health risks, one might expect cancer survivors to be more likely to follow screening guidelines than people without cancer. One explanation for lack of adherence may be access to care. However, our study cohort had few uninsured participants; even then, cancer screening rates were no better than national rates for breast cancer survivors.¹¹ This suggests that better access to care and higher socioeconomic status do not necessarily

Table 3. Descriptive Statistics for Dependent Variables

Characteristic	Overall, n (%) (n=5095)	No Cancer, n (%) (n=4680)	Cancer, n (%) (n=415)
Cancer screening			
Pelvic exam or Pap smear	2797 (62)	2599 (61)	198 (69)
Mammogram	2797 (76)	2599 (76)	198 (87)
Prostate exam	2298 (70)	2081 (69)	217 (79)
Cancer screening†			
Pelvic exam or Pap smear	—	—	195 (68)
Mammogram	—	—	88 (81)
Prostate exam	—	—	85 (72)

*Pelvic/Pap and mammogram for women only, prostate exam for men only.

†Excludes participants with cancer associated with screening.

Table 4. Adjusted Average Predicted Probabilities of Preventive Care Services for Respondents by Time Since Diagnosis, Controlling for Pre-cancer Characteristics and Insurance Status, With and Without Post-cancer Depressive Symptoms and Length of Participant–Provider Relationship (N = 5095)*

Variables	Controlling for Precancer Characteristics			Controlling for Precancer Characteristics, Depressive Symptoms, and Length of Time with Provider		
	No Cancer	Cancer Overall	<5 Years from Diagnosis	≥5 Years from Diagnosis	No Cancer	<5 Years from Diagnosis
						≥5 Years from Diagnosis
Cancer screening of all participants [†]						
Pelvic exam or Pap smear	61 (59–63)	70 (63–76)	71 (63–82)	68 (57–76)	61 (59–63)	68 (58–76)
Mammogram	76 (74–77)	86 (78–90)	87 (78–92)	86 (78–92)	76 (74–77)	86 (77–92)
Prostate exam	69 (67–71)	76 (70–82)	79 (69–85)	72 (62–81)	69 (67–71)	72 (60–81)
Cancer screening excluding participants associated with cancer						
Pelvic exam or Pap smear	61 (59–63)	69 (63–76)	71 (63–82)	67 (56–75)	61 (59–63)	66 (56–75)
Mammogram	76 (74–77)	80 (69–86)	76 (58–87)	83 (72–93)	76 (74–77)	82 (71–93)
Prostate exam	69 (67–71)	69 (57–77)	67 (53–80)	72 (58–84)	69 (67–71)	72 (57–84)

Values provided as percent (95% confidence interval).

Sample sizes for participants with and without cancer are indicated in Table 3.

*All models adjusted for variables as described in Table 1. Bold values indicate comparisons that were significant in the logistic regression model ($p < .05$) that compared screening behavior in participants with and without cancer.

[†]Pelvic/Pap and mammogram for women only, prostate exam for men only.

translate into preventive service guideline adherence. A second explanation may be related to provider type. Ninety-one percent of cancer survivors identified a PCP as their usual provider. Rates of non-cancer-related preventive care utilization have been shown to be higher for cancer survivors who see PCPs, whereas survivors who see oncologists receive more cancer screening,^{7,15,55} which may account for some of the observed effects.

It is noteworthy that adjusting for a comprehensive set of factors did little to affect cancer screening probabilities in the study cohort. Instead, probabilities were most impacted by cancer-related factors (site and time since diagnosis). Depressive symptoms may not impact cancer screening behavior in this cohort because of the relatively high levels of access to care coupled with long-standing provider relationships in the cancer and no cancer groups (10.4 and 10.7 years, respectively).

Some study limitations that should be noted. First, though US Preventive Services Task Force recommended age thresholds for cancer screening in place at the time of survey administration were used,^{27–29} thresholds for some of the screening services under investigation have changed. Prostate cancer screening is no longer recommended for men older than 75 years, nor is mammography for women after age 75 to 85 years or cervical cancer screening after age 65 years (unless patients is otherwise at risk or had adequate prior screening). However, given the higher risks of secondary cancers faced by many cancer survivors, one would expect cancer survivors to be more likely than people without cancer to receive cancer screening. This was not found to be the case for longer-term cancer survivors once participants were excluded who had a history of the cancer being screened for. Second, this study relied on self-reported cancer screening. Correlations between self-reported and medical-record-based assessments of cancer screening however are moderate to high.⁵⁶ Third, our study did not have information about recurrence or treatment. For participants undergoing cancer treatment, not undergoing screening for a cancer type other than their own may reflect energies rightly directed toward treatment. However, this is unlikely to explain all study findings because significant differences in screening between the cancer and no-cancer control groups were primarily seen within the first 5 years of diagnosis, when the

majority of survivors would likely be undergoing treatment and surveillance for cancer recurrence. Fourth, colon cancer screening was not available in the WLS. Therefore, the only follow-up cancer screening assessed in men was prostate cancer screening. Last, the sample size of cancer survivors precluded the examination of interaction effects and may have contributed to the lack of differences observed for analyses that excluded cervical cancer survivors.

Despite these limitations, the current study found that although the majority of cancer survivors receive recommended care, there remains room for improvement. Survivorship care plans that detail recommended follow-up care have been suggested as a mechanism to facilitate provider-patient communication.⁴ Given that 5 years from diagnosis nearly two thirds of cancer survivors visit their PCP exclusively,¹⁵ a plan such as this could provide additional opportunities for clear communication between health care providers (eg, oncologists and PCPs). Because only 28% of breast cancer survivors report good communication between their PCP and oncologist⁵⁷ and more than half of PCPs rate the transfer of care between oncologists and PCPs as poor,⁵⁸ a survivorship care plan has the potential to align provider and patient expectations and optimize care delivery and healthy outcomes for cancer survivors.

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