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Survivorship care planning and its influence on long-term patient-reported outcomes among colorectal and lung cancer survivors: the CanCORS disease-free survivor follow-up study

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Abstract

Purpose This study aims to evaluate the relationship between survivorship care planning (SCP) and survivorship care and health outcomes reported by long-term lung and colorectal cancer survivors.

Methods Participants (n=832) were diagnosed and enrolled during 2003–2005. In 2012, patient-reported outcomes (survivorship care and health outcomes) and two patient-reported SCP measures (receipt of written summary of cancer treatment and receipt of instructions on who to see for routine cancer follow-up) were collected. Analyses controlled for SCP predictors collected from medical records and an interview 1 year after diagnosis.

Results One in four survivors reported receiving both SCP elements. Those receiving both were more certain which doctor was in charge (odds ratio (OR) 7.0; 95 % confidence intervals (95 % CI) 3.9–12.5), more likely to report follow-up checkup (OR 5.1; 95 % CI 3.3–8.0), and had an MRI/PET/CT scan in the past 2 years (OR 2.8; 95 % CI 1.7–4.7) compared to those receiving neither. Physician communication experiences were significantly more positive and having physical exams (OR 2.0; 95 % CI 1.2–3.4) and meeting exercise guidelines (OR 1.6; 95 % CI 1.004–2.4) more likely. Physical health (p=0.012) and good-to-excellent self-perceived health status (OR 2.2; 95 % CI 1.3–3.9) were better for those receiving both elements.

Conclusion SCP may lead to better cancer follow-up care, long-term physical health, and physician-patient communication experiences.

Implications for Cancer Survivors The positive association between outcomes and SCP suggests that efforts to implement SCP should be fruitful.

Keywords Cohort studies · Colorectal neoplasms · Lung neoplasms · Survivors · Quality of life

Introduction

In 2006, the Institute of Medicine (IOM) recommended that cancer patients receive a survivorship care plan (SCP) to help them make the transition from the period of active treatment to posttreatment survivorship [1]. Core elements of a SCP include a treatment summary and a plan for follow-up care. Population-based research has identified several deficiencies in care that could be addressed by SCPs [2], but randomized

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controlled trials have failed to show an effect for SCP use on such measures as psychological well-being, treatment satisfaction, health-related quality of life (HRQOL), or survival [3–5].

It is possible that results from existing randomized trials do not generalize to the kinds of patients who would benefit most from SCPs. For example, the three randomized controlled trials (RCTs) conducted so far have been conducted at either university-affiliated or tertiary care hospitals that may provide more comprehensive care in general. The effect of SCPs in the broad population remains to be assessed. It is also unclear how survivorship care planning affects care coordination, health behaviors, or usage of health-care services [6]. This is a critical area to explore, because these behaviors are likely to provide the mechanism through which SCPs could improve patient outcomes.

For this study, we analyzed data from long-term disease-free survivors of lung and colorectal cancer in the Cancer Care Outcomes Research and Surveillance Consortium [7] (CanCORS) study. We examined (1) patient characteristics associated with self-reported receipt of two core SCP elements (receipt of a written summary of cancer treatment and instructions on who to see for routine cancer follow-up) and (2) the relationship between receiving survivorship care planning and subsequent HRQOL, as well as patient-reported physician communication, use of cancer follow-up services, and meeting exercise and preventive service guidelines.

Materials and methods

Study population

Participants diagnosed with colorectal or lung cancer during 2003–2005 were prospectively enrolled approximately 4 months after diagnosis in the 7 year CanCORS cohort study. CanCORS sites recruited participants 21 years of age or older who were recruited though a number of population-based cancer registries, health maintenance organizations, and Veterans Health Administration hospitals from across the country.

We conducted baseline and 1 year follow-up telephone interviews with all study participants. A second follow-up interview was conducted in 2012, approximately 7 years after diagnosis for survivors considered to be disease free. Patient medical records were abstracted to cover a period from 3 months prior to diagnosis to 15 months after diagnosis.

We included only those participants who survived and completed the disease-free follow-up interview in these analyses ($N=832$; 210 lung and 622 colorectal cancer survivors). This cohort was comparable to the characteristics of the overall CanCORS participants [8] in terms of sex distribution (44 and 47 % female, respectively) and race. Survivors, however, had been diagnosed at an earlier stage and younger mean age than the overall cohort.

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

Measures

Analytical variables were obtained from surveys at all three time points and from medical record data at baseline (Fig. 1). Variables constructed using the baseline survey or medical records included age at diagnosis, sex, race/ethnicity, a summary comorbidity index (ACE-27) [9, 10], cancer site and stage, and cancer treatments.

In order to assess patient status at a time closer to their transition to follow-up care, we included the following variables from the 1 year follow-up survey (conducted approximately 15 months post-diagnosis): marital status, body mass index, alcohol use, smoking, and patients' overall ratings of quality of cancer care. Both the 1 and 7 year follow-up surveys queried patients on their general health and HRQOL. This included a single item self-rating of general health, the mental and physical summary scores from the SF-12 [11], and the preference-weighted health status index from the EQ-5D [12].

The SCP indicators of interest were assessed by two items in the 7 year follow-up survey: (1) "After completing your cancer treatment, did any doctor, nurse, or other health professional ever give you a written summary of the cancer treatments that you received" and (2) "After completing your cancer treatment, did you ever receive instructions from a doctor, nurse, or other health professional about where you should return or who you should see for routine cancer checkups after completing your cancer treatments?" Responses to the two questions were used to create a three-category summary measure of survivorship care planning: did not receive a written summary or follow-up instructions, received either a written summary or follow-up instructions, or received both a written summary and follow-up instructions.

Also from the 7 year follow-up survey, we obtained variables related to perceived care coordination (level of certainty about doctor in charge), physician communication in the preceding 12 months, cancer surveillance imaging in the past 2 years, preventive services, health-promoting behavior (four items queried whether respondents exercised regularly and for how long at two levels, moderate and vigorous), patient self-efficacy about taking care of their health, and health status and HRQOL measures.

Statistical analysis

Polytomous logistic regression methods were used to examine characteristics associated with the three-category SCP summary variable. Adjusted percentages (with their 95 % confidence

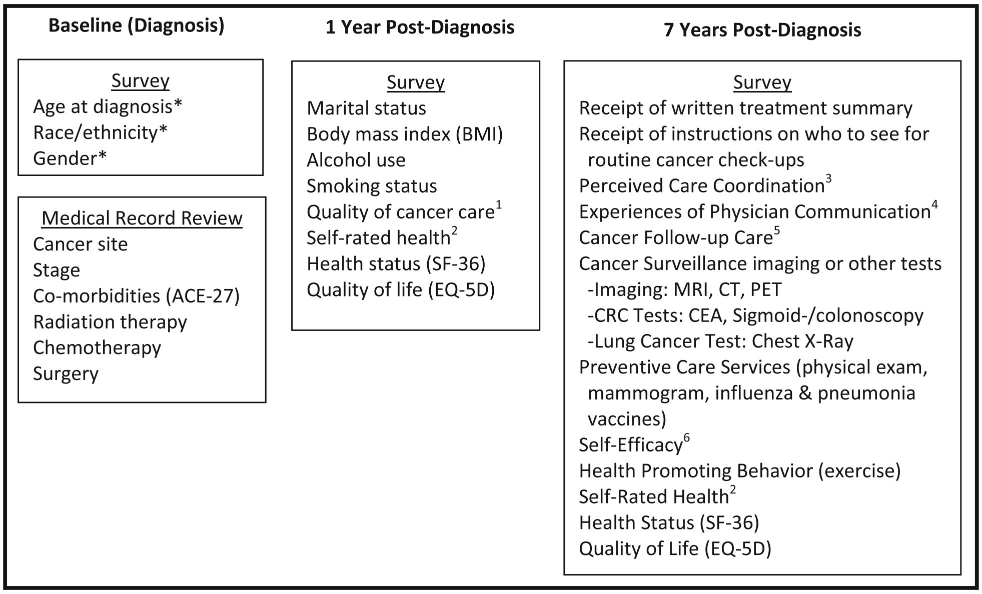

Fig. 1 Timing and source of data elements included in the analyses (exact wording of survey questions provided for selected elements)

*Age, race and gender were collected via baseline survey and medical record review; information from both sources were combined and reconciled to create the variables used in this analysis.

1. Overall, how would you rate the quality of your health care since we last spoke to you [at diagnosis]?
2. In general, would you say your health is… [Excellent/Very Good/Good/Fair/Poor/Don't Know]
3. After completing your treatment, how certain were you about which doctor was in charge of your cancer follow-up care?
4. In the last 12 months, did a doctor…
   - a. talk with you about specific things you could do to improve your health or prevent illness?
   - b. give you the help you wanted to make changes in your habits or lifestyle that would improve your health or prevent illness?
   - c. talk with you about how much or what kind of foods you eat?
   - d. talk with you about how much or what kind of exercise you get?
5. In the last 12 months, did you see any doctor for cancer follow-up care?
6. Overall, how confident are you about your ability to take good care of your health?

intervals) were generated to assess the magnitude of differences for categorical variables, using Graubard and Korn's extension to polytomous responses [13]. We assessed whether the SCP summary variable was associated with self-reported long-term outcomes in logistic regression models for each dichotomous outcome. Hypothesized potential mediating roles of self-efficacy and certainty about which doctor was in charge of follow-up care were examined by comparing the adjusted odds ratios (ORs) and 95 % confidence intervals in models with and without these variables. Continuous HRQOL scores were modeled with general linear model methods, and the magnitude of differences was assessed with least square means. Analyses were run in SAS 9.3 and statistical significance was defined as p values≤0.05.

Results

Table 1 displays the characteristics of patients according to whether or not they reported receiving one or both of the elements of a SCP. Of the 832 survivors, 210 (25 %) reported receiving a written summary of their treatment and instructions on who to see for routine care; 391 (47 %) indicated they received either a written summary of their treatment or instructions on who to see for routine care (but not both); and 231 (28 %) received neither SCP element. Of the same 832 patients, 247 (30 %) reported receiving a written summary of their treatment and 564 (68 %) reported instructions on who to see for routine care. Of the 391 survivors who received only one of the two SCP elements, 37 (9 %) received a written summary and 354 (91 %) received follow-up instructions.

Older people and lung cancer survivors were significantly less likely to report receiving survivorship care planning, while those who received chemotherapy were more likely. Survivorship care planning also varied by participating study site. None of the other baseline or 1 year measured characteristics were significantly associated with the SCP indicators in the multivariable model.

The adjusted associations between receiving survivorship care planning and perceived care coordination, experiences of physician communication, cancer follow-up care, receipt of preventive care services, self-efficacy, health-promoting behavior, and general health are illustrated in Table 2. Receipt of survivorship care planning was significantly associated with all four measures of physician communication about health promotion, with patients who received both SCP elements

Table 1 Description of baseline and 1 year characteristics associated with reported receipt of survivorship care planning by long-term (7 years) survivors

Characteristic	n (%)	Reported receipt of a written summary of cancer treatment and/or instructions on who to see for routine cancer follow-ups (N=832)							
		Unadjusted percent (95 % confidence interval)[a]				Adjusted percent (95 % confidence interval)[c]			
		Received neither (n=231)	Received only one (n=391)	Received both (n=210)	p value[b]	Received neither (n=231)	Received only one (n=391)	Received both (n=210)	p value[d]
Age in years					<0.0001				0.005
≤54	164 (19.7)	20 (14–26)	46 (39–54)	34 (26–41)		23 (17–30)	44 (36–52)	33 (25–40)	
55–64	252 (30.3)	22 (17–27)	50 (44–57)	28 (22–33)		22 (17–27)	50 (43–56)	28 (22–34)	
65–74	258 (31.0)	28 (22–33)	49 (43–55)	23 (18–28)		27 (21–32)	49 (43–55)	24 (19–29)	
≥75	158 (19.0)	45 (37–53)	39 (31–46)	16 (11–22)		41 (33–48)	41 (33–48)	19(13–25)	
Gender					0.833				0.775
Male	441 (53.0)	28 (24–32)	46 (41–51)	26 (22–30)		29 (25–33)	46 (41–50)	26 (22–30)	
Female	391 (47.0)	27 (23–32)	48 (43–53)	25 (20–29)		26 (22–31)	47 (42–52)	26 (22–31)	
Race/ethnicity					0.094				0.079
White	633 (76.2)	28 (25–32)	49 (45–53)	23 (20–26)		28 (24–31)	49 (45–53)	24 (20–27)	
Hispanic	22 (2.7)	36 (16–56)	36 (16–56)	27 (9–46)		33 (12–54)	34 (13–55)	33 (12–54)	
Black	105 (12.6)	26 (17–34)	38 (29–47)	36 (27–45)		30 (21–39)	34 (25–43)	37 (27–46)	
Other	71 (8.5)	24 (14–34)	46 (35–58)	30 (19–40)		22 (12–32)	49 (37–61)	29 (18–40)	
Marital status at 1 year					0.345				0.771
Married/living with partner	582 (70.0)	26 (23–30)	48 (44–52)	26 (22–29)		27 (23–31)	47 (43–51)	26 (22–29)	
Not married	250 (30.0)	31 (25–37)	44 (38–51)	24 (19–30)		29 (23–35)	45 (38–51)	26 (21–32)	
BMI at 1 year					0.090				0.249
Underweight/normal	210 (25.4)	34 (28–41)	43 (37–50)	22 (17–28)		33 (26–39)	42 (35–49)	26 (20–32)	
Pre-obese	316 (38.2)	28 (23–33)	47 (41–52)	25 (21–30)		28 (23–33)	46 (40–51)	26 (21–31)	
Obese	301 (36.4)	23 (18–28)	50 (44–55)	27 (22–32)		23 (18–28)	50 (45–56)	26 (21–31)	
Alcohol use (drinks per week)—1 year survey					0.632				0.512
None	367 (44.3)	29 (25–34)	46 (41–51)	25 (20–29)		31 (26–36)	45 (40–50)	24 (20–29)	
>0–<7	324 (39.1)	24 (20–29)	50 (45–55)	26 (21–30)		24 (19–29)	49 (44–55)	26 (22–31)	
7–10.5	109 (13.1)	31 (23–40)	43 (34–52)	26 (17–34)		27 (18–35)	43 (34–53)	30 (22–39)	
≥17.5	29 (3.5)	34 (17–52)	38 (20–56)	28 (11–44)		30 (13–47)	41 (23–60)	28 (11–45)	
Smoking status at 1 year					0.094				0.162
Never	281 (33.8)	23 (19–28)	51 (45–56)	26 (21–31)		24 (19–29)	50 (44–56)	26 (21–31)	
Former	410 (49.3)	28 (24–33)	47 (42–52)	25 (21–29)		28 (23–32)	45 (41–50)	27 (22–31)	
Current	55 (6.6)	25 (14–37)	44 (31–57)	31 (19–43)		27 (15–39)	47 (34–61)	26 (14–38)	
Unknown	86 (10.3)	41 (30–51)	38 (28–49)	21 (12–30)		40 (29–51)	36 (25–47)	24 (14–33)	
Comorbidity status at diagnosis					0.744				0.568
None	251 (30.2)	26 (21–32)	51 (45–57)	23 (18–28)		28 (23–34)	50 (44–56)	22 (16–27)	
Mild	351 (42.2)	28 (24–33)	44 (39–50)	27 (23–32)		28 (23–33)	44 (38–49)	29 (24–33)	
Moderate	148 (17.8)	28 (20–35)	46 (38–54)	26 (19–33)		26 (19–34)	45 (36–53)	29 (22–37)	
Severe	82 (9.9)	30 (21–40)	48 (37–58)	22 (13–31)		27 (17–37)	49 (39–60)	24 (14–33)	
Cancer type					0.138				0.039
Lung	210 (25.2)	28 (22–34)	52 (45–59)	20 (15–26)		24 (18–30)	56 (49–63)	20 (15–26)	
CRC	622 (74.8)	28 (24–31)	45 (41–49)	27 (23–30)		29 (25–33)	43 (39–47)	28 (24–32)	

Table 1 (continued)

Characteristic	*n* (%)	Reported receipt of a written summary of cancer treatment and/or instructions on who to see for routine cancer follow-ups (*N*=832)							
		Unadjusted percent (95 % confidence interval)[a]				Adjusted percent (95 % confidence interval)[c]			
		Received neither (*n*=231)	Received only one (*n*=391)	Received both (*n*=210)	*p* value[b]	Received neither (*n*=231)	Received only one (*n*=391)	Received both (*n*=210)	*p* value[d]
Cancer stage					0.554				0.162
Stage I	367 (44.8)	30 (26–35)	45 (40–50)	25 (21–30)		29 (24–34)	41 (36–46)	30 (26–35)	
Stage II	206 (25.2)	26 (20–32)	48 (41–54)	26 (20–32)		24 (18–30)	49 (42–56)	26 (20–33)	
Stage III	218 (26.6)	26 (20–31)	49 (42–55)	26 (20–31)		29 (23–35)	50 (44–57)	21 (15–26)	
Stage IV	28 (3.4)	14 (1–27)	61 (43–79)	25 (9–41)		17 (3–31)	64 (46–82)	19 (4–34)	
Had radiation treatment					0.645				0.501
Yes	118 (14.2)	29 (21–37)	43 (34–52)	28 (20–36)		33 (29–36)	43 (39–46)	24 (21–28)	
No	714 (85.8)	28 (24–31)	48 (44–51)	25 (22–28)		27 (19–35)	47 (38–56)	26 (18–34)	
Had chemotherapy					0.003				0.029
Yes	374 (45.0)	23 (18–27)	48 (43–53)	30 (25–34)		24 (20–28)	44 (39–49)	32 (28–37)	
No	458 (55.0)	32 (28–36)	47 (42–51)	22 (18–25)		30 (26–35)	49 (43–54)	21 (17–25)	
Had surgery					0.819				0.395
Yes	778 (93.5)	28 (24–31)	47 (44–51)	25 (22–28)		28 (15–41)	47 (32–61)	26 (13–38)	
No	54 (6.5)	31 (19–44)	44 (31–58)	24 (13–35)		25 (22–28)	39 (36–43)	35 (32–39)	
Quality of cancer care at 1 year					0.012				0.215
Excellent or very good	677 (82.1)	27 (24–30)	47 (43–51)	26 (23–30)		27 (24–30)	46 (42–50)	27 (24–30)	
Good	112 (13.6)	26 (18–34)	52 (43–61)	22 (15–30)		25 (17–34)	52 (43–62)	22 (14–30)	
Fair or poor	36 (4.4)	53 (36–69)	28 (13–42)	19 (7–32)		43 (26–60)	38 (22–54)	19 (6–33)	
Self-rated health at 1 year					0.023				0.170
Excellent/very good	419 (50.5)	25 (21–29)	50 (45–55)	25 (21–29)		26 (21–30)	49 (45–54)	25 (21–29)	
Good	278 (33.5)	26 (21–31)	49 (43–54)	25 (20–30)		27 (22–33)	47 (41–53)	26 (21–31)	
Fair/poor	132 (15.9)	38 (30–46)	35 (27–43)	27 (20–35)		34 (26–42)	35 (27–44)	31 (23–39)	

[a] Wald confidence intervals

[b] Unadjusted Pearson chi-square value

[c] Extension of Graubard and Korn [13]

[d] Wald chi-square *p* value. Adjusted for study site, age, gender, race, marital status at 1 year, BMI at 1 year, drinks per week at 1 year, history of smoking at 1 year, cancer type, cancer stage, surgery, radiation, chemotherapy, quality of care at 1 year, and self-rated health at 1 year

being the most likely to have talked with their physician about these issues. Patients who received survivorship care planning were much more likely to be very certain about which doctor was in charge of their cancer follow-up care and have more positive self-efficacy. They were also significantly more likely to have seen a physician for cancer follow-up care and to have an MRI, PET, or CT scan in the 2 years prior to the 7 year follow-up survey. However, they were no more likely to see a primary care provider in the past 12 months. Having a physical exam was the only preventive service associated with having received survivorship care planning. Survivorship care planning was significantly associated with achieving exercise guidelines. In general, associations between survivorship care planning and outcomes were stronger among those who received both elements compared to those who only received one, particularly in perceived care coordination and seeing a doctor for follow-up care.

HRQOL outcomes in relation to reporting receipt of survivorship care planning are presented in Table 2 (general self-perceived health) and Table 3 (SF-12 scales and EQ-5D index). After adjusting for variables shown to be significant in Table 1, patients who received survivorship care planning were significantly more likely to report good or better health status and had significantly higher SF-12 physical health

Table 2 Relationship of receiving survivorship care planning with perceived coordination of care, physician-patient communication, use of health-care services, self-efficacy, health (exercise) behavior, and self-rated health

Outcome variable	Received summary and/or instructions[a]	Adjusted[b] OR (95 % CI)
Perceived care coordination		
Very certain about which doctor was in charge of cancer follow-up care	Both	*7.0 (3.9–12.5)*
	One	*2.2 (1.5–3.3)*
Experiences of physician communication		
MD talked about things to improve health or prevent illness	Both	*2.6 (1.6–4.0)*
	One	*1.6 (1.1–2.4)*
MD gave help wanted to change lifestyle to improve health	Both	*2.8 (1.8–4.4)*
	One	1.2 (0.8–1.8)
MD talked about how much/what kind of foods to eat	Both	*3.6 (2.2–5.9)*
	One	*1.6 (1.02–2.5)*
MD talked about how much/what kind of exercise to get	Both	*3.3 (2.2–5.1)*
	One	*1.6 (1.1–2.4)*
Cancer follow-up care		
Saw any doctor for cancer follow-up care in the past 12 months	Both	*5.1 (3.3–8.0)*
	One	*2.8 (1.9–4.1)*
Saw any cancer specialists in the past 12 months	Both	*4.0 (2.5–6.3)*
	One	*2.1 (1.4–3.2)*
Saw a primary care provider in the past 12 months	Both	0.9 (0.3–2.6)
	One	0.5 (0.2–1.2)
Had an MRI, PET, or CT in the past 2 years	Both	*2.8 (1.7–4.7)*
	One	*2.0 (1.3–3.2)*
Receipt of preventive care services		
Had a physical exam in the past 12 months	Both	*2.0 (1.2–3.4)*
	One	1.3 (0.8–2.0)
Had a mammogram within past 2 years (females only)	Both	1.3 (0.6–3.0)
	One	1.6 (0.8–3.4)
Had a pap test within past 2 years (females only)	Both	1.7 (0.8–3.4)
	One	1.5 (0.8–2.8)
Had cholesterol checked in the past 12 months	Both	1.3 (0.8–2.4)
	One	1.2 (0.7–2.0)
Ever received a pneumonia vaccine	Both	1.5 (0.95–2.4)
	One	1.1 (0.7–1.7)
Had an influenza vaccine in the past 12 months	Both	1.0 (0.6–1.6)
	One	1.1 (0.7–1.7)
Self-efficacy		
Completely or very confident about ability to take good care of health	Both	*1.8 (1.04–3.1)*
	One	1.0 (0.6–1.6)
Health-promoting behavior		
Exercised regularly in last 4 weeks	Both	1.4 (0.8–2.5)
	One	1.0 (0.6–1.7)
Met or exceeded exercise guidelines (150 min moderate or 75 min vigorous activity per week)	Both	*1.6 (1.004–2.4)*
	One	1.3 (0.9–1.9)
General health		
Excellent/very good/good versus fair/poor	Both	*2.2 (1.3–3.9)*
	One	*1.8 (1.1–2.9)*

[a] Reference category refers to those who received neither a written treatment summary nor instructions about who to see for cancer follow-up care

[b] Adjusted for study site, age, gender, race, marital status at 1 year, BMI at 1 year, drinks per week at 1 year, history of smoking at 1 year, cancer type, cancer stage, surgery, radiation, chemotherapy, quality of care at 1 year, and self-rated health at 1 year. Significant values are indicated in italics

Table 3 Relationship of receiving survivorship care planning with health status and quality of life outcomes

Reported receipt of a written summary of cancer treatment and/or instructions on who to see for routine cancer checkup	Outcome measure Adjusted[a] mean score (standard error)		
	SF-12 mental health	SF-12 physical health	EQ-5D index
Received both	51.8 (1.4)	40.1 (1.4)	0.80 (0.02)
Received one	52.1 (1.4)	40.0 (1.4)	0.81 (0.02)
Received neither	53.3 (1.4)	37.8 (1.4)	0.78 (0.02)
p value	0.221	0.012	0.180

[a] Adjusted for participating site, age, gender, race, marital status at 1 year, BMI at 1 year, drinks per week at 1 year, history of smoking at 1 year, cancer type, cancer stage, surgery, radiation, chemotherapy, quality of care at 1 year, and score on the outcome measure at 1 year

component scores. There were no significant differences in mental health or EQ-5D health index rating.

A potential mediating role of self-efficacy and certainty about who was in charge of cancer follow-up care was evaluated by adding these variables to the other outcome models in Tables 2 and 3 (data not shown). The odds ratios for survivorship care planning did not change appreciably (i.e., the odds ratios decreased by only 11 % or less) for the physician communication and cancer follow-up care outcomes; however, there was evidence of a modest mediating role (odds ratio decreased by 25 %) for receiving a physical exam. The findings for the HRQOL outcomes were also unchanged.

Discussion

Recognizing that many cancer patients lack adequate support to successfully transition from being a patient to a survivor, the IOM recommended in 2006 that every cancer patient be provided a SCP that includes a treatment summary and a plan for future care. The IOM believed this was a “common sense” intervention that should be immediately implemented even though there was little evidence for its effectiveness at the time. Although a major US initiative has ensued to aggressively implement the IOM recommendation [1, 14, 15], randomized controlled trials have failed to show a consistent benefit of using SCPs [3–5].

We examined the survivorship care planning experience among 7 year disease-free survivors from the multicenter, population- and health system-based CanCORS cohort. This is the first large study to report on experiences of survivorship care planning in community practice among long-term lung and colorectal cancer survivors, and the associations reported here lend support for the major initiative underway to widely implement survivorship care plans. Although only one fourth of patients received both written treatment summary and instruction on who to see for routine cancer follow-ups, those who did had better outcomes. Specifically, those who reported receiving both of these core elements were more likely to report ongoing checkup with a doctor for follow-up cancer care and to have had cancer surveillance imaging. Health-promoting activities including having physical exams and meeting exercise guidelines were also more likely. Physical health scores were significantly better for those who reported survivorship care planning, though there was no difference in overall HRQOL or mental health. Patients who received both SCP components were more likely to be confident in their ability to take care of their own health. These community-based findings are more positive than the results of randomized trials of SCPs.

The first large randomized trial [3] compared breast cancer survivors who received a SCP to survivors who received a discharge evaluation along with a discharge letter sent to the follow-up PCP. Results showed no differences between the two groups in terms of distress, patient satisfaction, health status, or continuity of care. However, the relevance of the comparison group for US patients has been criticized [16]. Another randomized trial [4] involved a treatment group which met with a nurse practitioner to review a personalized SCP based on the template developed by ASCO [14] and also received a survivorship manual [17]; the control group received the manual alone. No differences were found among measures of treatment satisfaction, cancer impact, physical well-being, or quality of life except that the SCP intervention reduced health worry. A third study examined the experiences of gynecologic cancer survivors whose physicians were randomly assigned to SCP versus no SCP groups [5]. They found no differences on survivors’ perceived quality of care, satisfaction with health services, or rated helpfulness of written materials.

Whereas randomized trials have not found improvements in continuity of care or health status, we found improvements in both. One reason for this difference may be that randomized trials primarily include relatively high functioning people. For example, the cohort studied by Grunfeld et al. had low scores of distress at baseline [3, 18], and these people may be less likely to benefit from a SCP. Indeed, patients with lower mental well-being have reported the greatest need for health information. This effect is especially pronounced for those who had low confidence in their ability to obtain information

[19]. It is also possible that the settings of existing randomized trials, university-based or tertiary care hospitals, generally provide more comprehensive care to their patients. The follow-up periods for the trials were also much shorter than that in our study.

Comparatively, there is little research on the effect that SCPs have on potential mediating factors such as coordination of care, physician-patient communication, health behaviors, or usage of health-care services. This is a critical area to explore, because these behaviors are likely to provide the mechanism through which SCPs may potentially improve patient symptoms and HRQOL. Parry et al. developed a model that portrays care plans working within an infrastructure to affect the coordination of care among patients and all of their providers [6]. In this model, effective communication and coordination leads to better short-term outcomes (e.g., effective use of health-care resources) that, in turn, lead to better long-term outcomes (e.g., improved HRQOL). In support of the model, we found associations of SCPs with markers of care coordination, patient experiences of physician communication, and cancer follow-up care and health promotion. Others have shown that patients report high satisfaction with treatment plans, and they also believe it helps doctor/patient and doctor/doctor communication [20–23]. Another study has shown that treatment summaries are associated with more accurate survivor knowledge about breast and colorectal cancer diagnoses and the treatment they received [24]. Our results agree with other findings [25] that SCPs are associated with feelings of self-efficacy. We were unable to demonstrate compelling evidence of a mediating effect of self-efficacy on outcomes, however.

Similarly, primary care providers report that SCPs increase their confidence in their ability to care for cancer survivors' follow-up needs, and they also report that SCPs lead to better coordination of care and improved communication among physicians [26]. We found the effects of SCPs on cancer surveillance imaging and visits to cancer physicians, but little impact on preventive service use. One reason may be that the two SCP questions focused on cancer treatments and who to see for cancer follow-up care, and this may not correlate with providing advice with preventive services. One of the few studies to examine the effect of SCPs on the use of health resources evaluated a random sample of Hodgkin lymphoma patients who had not had a recommended screening mammogram or echocardiogram within the prior 2 years [27]. Six months after a short SCP with recommendations for surveillance was mailed to the survivors and their physicians, 41 % of the participants reported having a mammogram and 20 % reported having an echocardiogram. This suggests that SCPs can encourage appropriate follow-up care.

We found evidence of potential disparities in receipt of survivorship care planning. Patients were less likely to have received both elements of care planning if they were lung cancer survivors or over 65 at the time of diagnosis. These may reflect patient preferences for less information or lower perceived need for full survivorship care planning by physicians, either due to less aggressive initial treatment or lower expectations of longevity. It is possible that not all patients require the same degree of survivorship care planning. However, because of the number of patients affected (one fourth of long-term disease-free survivors were lung cancer patients and half were 65 years of age or older), these findings require future attention to ensure that survivorship care is delivered to all patients who need and want it.

Potential limitations

The CanCORS study enrolled a cohort of patients with lung and colorectal cancer diagnosed during 2003–2005 who would have been entering follow-up care about the time that the 2006 IOM report was published. Our focus, therefore, was not on any specific, contemporary SCP template. Rather, our focus has been on two specific elements that are core components of survivorship care planning: treatment summaries and instructions for follow-up. We found that 247 (30 %) patients reported being given a written treatment summary and 564 (68 %) patients reported receiving instructions on who to see for follow-up care.

In contrast, a recent nationally representative survey of oncologists found that less than 5 % reported providing written SCPs to their patients, and 32 % reported discussing who patients should see for follow-up care [28]. Although these metrics are conceptually different than our patient-reported measures, these data do suggest that patients experience survivorship care even if their oncologists do not often provide it formally. It is not clear what actually constituted a treatment summary as far as the patients were concerned. It could have been anything from a roughly sketched outline to a more complete summary. Also, we did not ask who provided the instructions about who to see and it could be that nurses or primary care providers are a frequent source of this information. Our findings essentially reflect patient perceptions of the two SCP components that were assessed by the surveys.

It is possible that other factors associated with SCP use are responsible for the improved outcomes we observed. Highly engaged patients, for example, may encourage physicians to provide documentation of their treatment plans, and these patients may also be more diligent about getting appropriate follow-up care, exercising, and communicating with their care team. Similarly, physicians who provide SCP elements may be more effective in encouraging patients in these same behaviors. Well-designed RCTs are generally not vulnerable to such limitations, and this illustrates the need for such prospective trials in community settings with diverse patient populations.

This study only included those who were disease-free survivors at 7 years post-diagnosis, and findings may not generalize to those who survived the initial treatment phase but then experienced recurrence and/or death prior to 7 years. If receipt of SCP and the outcomes of interest were both associated with surviving disease free to the 7 year assessment, then this could introduce bias in the estimated associations between SCPs and the outcomes of interest.

Indicators for receiving written treatment summary or instructions on who to see for routine cancer checkup were based on patient recall. Blinder et al. [20] reported high (>90 %) short-term recall of receiving a treatment plan or summary. However, our recall period was much longer. It is possible that the relationships we found are a result of better generalized recall of health-related issues. However, the specificity observed argues against this, such as the strong relationship with certainty about who to see for follow-up care, the smaller association with self-efficacy for taking care of health, and the much stronger relationships with cancer follow-up care than with preventive care and behavior. In addition, the greater frequency of care planning among patients who received chemotherapy (obtained from the medical record) could not be explained by recall bias. Patient recall of survivorship care planning also correlated with assessments of quality of cancer care that they made 6 years previously. This is a time when they were most likely to receive a SCP, although we do not have information on when patients actually received the SCP elements described here.

Conclusion

Since the IOM report was published in 2006 [1], studies have revealed specific areas of survivorship care that could be addressed through the use of SCPs. Arora et al., for example, found that over 60 % of posttreatment survivors in their study reported that they did not get the help they needed to improve their health once their treatment ended, and they also did not get support to make healthy lifestyle changes [2]. The same number of participants reported that their physician did not understand how their cancer had affected their quality of life.

Many organizations responded to this need and the IOM recommendation by developing SCP templates [14, 29, 30], and by 2015, cancer programs must employ SCPs in order to maintain accreditation from the American College of Surgeons Commission on Cancer [15]. Recent calls for better evaluation and attention to the processes involved in survivorship care planning are likely to result in improved models for delivering transitional and follow-up care. Our findings of positive relationships between survivorship care planning, health outcomes, and patients' ability to navigate their care and health needs suggest that these efforts will be fruitful.

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