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Follow-up Care Education and Information: Identifying Cancer Survivors in Need of More Guidance

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Abstract

Background—Cancer survivors engage in cancer screenings and protective health behaviors at suboptimal rates despite their increased risk for future illness. Survivorship care plans and other educational strategies to prepare cancer survivors to adopt engaged roles in managing long-term follow-up care and health risks are needed. In a sample of cancer survivors, we identified patient characteristics and psychosocial predictors associated with increased follow-up care informational needs.

Methods—Cross-sectional surveys were administered to early stage breast and prostate survivors (N=278; 68% breast) at least two years post-treatment from four community hospital programs in New Jersey between May 2012-July 2013. Patient demographics, medical history, psychosocial characteristics (i.e., worries about the future, fear of disease recurrence, and patient activation) and perceptions of oncology and primary care were assessed.

Results—African American survivors (AOR =2.69, 95% confidence interval [CI] 1.27–5.68) and survivors with higher comorbidity (AOR=1.16, CI 1.01–1.33) were more likely to want additional information to guide follow-up care. Adjusting for race and comorbidities, survivors who wanted more information to guide their follow-up care reported greater worries about the future ($p<0.05$) and fears about disease recurrence ($p<0.05$) compared to those who did not want additional information.

Conclusions—Results emphasize the need to develop cancer survivorship educational strategies that are both responsive to the needs of specific populations (e.g., African American survivors and

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patients with multiple comorbidities) and the psychosocial profiles that motivate requests for more extensive follow-up guidance.

INTRODUCTION

There are 14.5 million cancer survivors living in the United States, with the most commonly diagnosed cancers of breast (41%) in women and prostate (43%) in men [1]. It is anticipated that by 2022 cancer survivors numbers will surge to exceed 18 million, and projections suggest that this group will include 12 million people who will be “longer-term” cancer survivors living at or beyond the 5 years post diagnosis mark [2]. Many cancer survivors do not optimally receive necessary cancer screenings or adopt protective health behaviors (e.g., smoking cessation, physical activity) known to prevent and detect new or recurrent disease despite their increased risks for future illnesses [3]. Further, cancer survivorship concerns appear to distract patients’ attention away from focusing on their other chronic illnesses care needs [4]. This is an important consideration given that 70% of cancer survivors have at least one additional comorbid illness [5]. Developing educational strategies to inform patients and to encourage their active participation during this phase of care is a potential lever to improve surveillance for cancer recurrence and secondary cancers, as well as and to enhance the management of long term, late effects and comorbid conditions. To date, evidence-based strategies to address this need have been lacking.

Long-term survivorship care requires three components: (1) comprehensive coordination; (2) follow-up and transitional care; and (3) ongoing discussions about care planning, coping skills and health behavior to mitigate the long term risks of having a cancer history and being treated for cancer [6]. However, even the early phases of post treatment (<5 year post diagnosis) are a point in care where less guidance and support is available to patients [6]. Recommendations to address this gap in care include: using educational tools such as survivorship care plans (SCPs) [7], redesigning existing care models [8], and educating and preparing the healthcare workforce [6] to enhance awareness and clinical skills to guide and support patients. Many of these strategies rely heavily on patient skills to broker care transitions despite limited preparation for patients about what they should be doing to optimize their health [9].

Currently, the most widely promoted patient education tool to facilitate the cancer survivorship transition is the Survivorship Care Plan (SCP), which is a comprehensive summary of cancer care and recommendations for follow-up care [6, 7]. The goals of SCPs are to enhance patient-provider and provider-provider communications in hopes that this will lead to better survivorship outcomes, including increased adherence to preventive screening and management of late and long term effects of cancer and its treatment, including psychosocial sequelae and diagnosis [10]. Qualitative studies describe patients as wanting SCPs [11, 12], but there is a need for additional data that supports the educational benefits of SCPs [10]. In practice, the adoption of SCPs has been slow for many reasons, including: (1) resource intensity required for their development; (2) lack of provider buy-in about their utility; and (3) reimbursement issues [7, 10]. Despite the lack of an evidence base demonstrating the efficacy of SCPs in either preparing patients or facilitating communication transfer between providers [7, 10], leading oncology professional

organizations (including the American Society of Clinical Oncology and the American College of Surgeons Commission on Cancer) are in support of their adoption. Indeed, it is anticipated that SCPs will become the standard of care in the near future [10].

Different information seeking styles among cancer patients after an initial diagnosis are well characterized in the literature, and these styles are associated with differential adherence to medical recommendations [13]. Specifically, two coping styles— monitoring and blunting— have been shown to influence information seeking, self-management behaviors, and the psychological experience surrounding cancer information seeking post diagnosis[13]. Monitors are more active information seekers, are more likely to comply with medical advice, have more knowledge about their health conditions, and are more likely to experience psychological distress; whereas, blunters who distract from information that is threatening, experience less psychological distress and are less likely to adhere to medical recommendations [13]. It is likely that these information-seeking styles persist after treatment has ended. Therefore, it is important to understand how patient preferences influence information seeking after the treatment phase is completed.

Informational preferences are not well characterized in the literature for post-treatment cancer patients. In this study, we aim to identify patient level characteristics (i.e. socio-demographics and medical history) that motivate patients' requests for additional information to guide follow-up care. Further, we aim to delineate which psychosocial characteristics (i.e., worries about the future, fear of disease recurrence and patient activation) and process of care factors (i.e. coordination of care, satisfaction with cancer related information provided by oncology and primary care providers) are associated with patient desire for information to guide follow-up care. Finally, we describe the informational modalities preferred for the delivery of follow-up care guidance among the cancer survivor information seekers.

MATERIALS AND METHODS

Study Participants

A total of 325 early stage (I or II) breast and prostate cancer survivors were recruited from May 2012-June 2013 from four community oncology hospitals that are a part of the Rutgers Cancer Institute of New Jersey's network of affiliated hospitals (CentraState Medical Center, Cooper Cancer Institute, Somerset Medical Center, The University Hospital). These institutions were chosen to reflect the diversity of this area's American College of Surgeon's accredited community oncology ambulatory care settings (e.g., community and academic). English speaking patients, at least two years post-active treatment (excluding hormonal maintenance therapies) for cancer at the point of recruitment were eligible for the study. Participants completed a written survey that took approximately 15 minutes to complete.

Prior to initiation, the Institutional Review Board of the Rutgers Robert Wood Johnson Medical School approved this study and written informed consent was received from all participants. Patients were approached about the study at the time of their follow-up visit or through identification from an onsite patient registry. Patients received a survey and consent form in the mail with a cover letter from the facility where they were treated and a letter

from the study principal investigator that introduced and described the study. After two weeks, if patients did not respond a reminder post-card was sent. After one month, a final survey was sent to the participant and if the participant did not return a completed survey this was considered refusal. Site response rates averaged 60%.

Measures

The survey instrument included items that assessed whether patients wanted additional information to guide follow-up care, socio-demographic characteristics, medical history, psychosocial characteristics and patient perceptions of care processes. For patients who endorsed wanting additional information to guide follow-up care, preferred modalities of this information was also assessed.

Outcome Variable—The main variable of interest, desire for additional information to guide follow-up care, was measured using a single, self-report measure to the question, “Would you like to receive information to help manage your follow-up care?” (yes/no).

Patient Characteristics and Psychosocial Factors

Socio-demographics: Socio-demographic items included in the analysis were age, gender, race/ethnicity, educational attainment, employment status, and marital status. Race was dichotomized as White/Caucasian vs. Black/African American. Educational attainment was condensed from an initial eight item response category into high school, some college, 4-year college, or Masters/graduate school. Employment status was categorized as full-time, part-time, not employed and retired. Marital status was collapsed into married or living with partner vs. not married. The latter category comprised those responding as single, never married, divorced, widowed, or other.

Medical history: Gender was used as a proxy variable for cancer diagnosis (male=prostate and female=breast). Co-morbidity was measured using the Charlson Comorbidity Index [14]. Length of time since treatment was assessed in the following phases post-treatment: 2–5 years, 6–10 years, or 10+ years. Type of treatment site (academic vs. community) was coded at the time of recruitment. To assess receipt of a written care summary, patients were asked if they had ever been given a written summary with the response options: yes, no, or not sure. Responses were pooled into dichotomous groups (yes vs. no/not sure) for analysis.

Psychosocial Characteristics: *Patient Activation* is a term used to describe patient's knowledge, skills and confidence for self-management. To assess patient activation we used the validated, 13-item, Patient Activation Measure which has a scoring range of (0–100) [15]. Patient activation levels were calculated using established cut points [15]. Evidence supports the characterization of four levels of patient activation with progressively more engagement seen among those whose score higher on the range of activation. Levels of patient activation are characterized as follows: at level one patients are passive care recipients; at level two patients may lack information but express some motivation to engage in their care processes; at level three patients understand the basic facts but lack confidence to take action; and at level four patients have made changes to their health but may waver in times of stress [15].

Worries about the Future and Fear of Cancer Recurrence: Two single item questions were used to assess worries about the future and fear of disease recurrence, respectively. Both were measured on a 5-point Likert (0=almost never to 5=almost always).

Patient Perception of Care Processes: *Satisfaction with cancer related information* was assessed using two, single-item frequency question about how often cancer related clinicians and PCPs, provided as much cancer-related information as patients wanted. Possible responses available were: never, sometimes, usually and always.

Coordination of care assessed patient's perceptions of how PCPs and Cancer Related Clinicians received and incorporated information from other doctors into visits and patient care processes related to their follow-up. This was measured by calculating the mean for the five items on the coordination of care subscale in the Components of Primary Care Instrument [16].

Informational Modality Preference was assessed only for cancer survivors who endorsed wanting to receive information to help manage follow-up care. This was measured using a multiple-response, forced-choice item asking how patients would want follow-up information provided, with the possible responses: website, pamphlet, smartphone application, navigator or care manager, and lecture/lunch and learn.

Statistical Analysis

Means and standard deviations (SDs) or frequencies were used to summarize survivor demographics and psychosocial factors. Logistic regression analyses assessed the association of socio-demographics and medical history with desire for more information to guide follow-up care. Backward stepwise selection identified control variables (i.e., race and comorbidity burden) that had statistically significant effects on the outcome variable (desire for follow-up information). Confirmatory analyses estimated the association of each of the other demographics, separately, with the outcome, controlling for race and comorbidity burden. Additional logistic regression models examined the psychosocial factors as predictors of desire for follow-up information. For these factors, the means (SDs) were calculated for those who do and do not desire additional information. Statistical significance was assessed at an alpha of 0.05. The analysis was carried out in SAS® Version 9.3. Percentages summarized the format by which cancer survivors preferred to get additional information, among those who desired it. Responses from 325 participants were available for this analysis. Of the 325 participants, 47 in total were excluded from the sample. Reasons for exclusion included having received treatment less than two years ago (n=20), not racially identifying as either African American/Black or Caucasian/White because sample sizes were too small to meaningfully compare other racial/ethnic groups in the models (n=24); and cases missing data on the dependent variable (n=3). Thus, the final sample included 278 cancer survivors.

RESULTS

Table 1 presents the demographic characteristics of the participants. This study included more (68%) female breast cancer survivors, than male (32%) survivors of prostate cancer.

Most participants were married (71%) and the average age of our sample was 64 years old (SD=10.8). All participants reported achieving at minimum of a high school education or GED (26%); almost one-third (30%) some college, one-fifth (21%) a four year degree and nearly a quarter (23%) having a masters or graduate degree. A majority of the sample was White/Caucasian (86%), the remainder self-identified as African American/Black race (14%). Most of the sample was either retired (47%) or not currently employed (14%). Almost one-third of participants reported working full time (30%) with a smaller group (9%) who reported working only part-time. Most of our sample was recruited from academic cancer centers (64%) with the remainder recruited from community cancer centers (38%). Most of the survivors (57%) were in the earlier phases of survivorship (2–5 years post treatment), with a third in the interim phase (6–10 years out), and a smaller group (12%) among the longer-term (10+ years post treatment) trajectory. The average Charlson Comorbidity Index score was 2.46 (SD=1.9). The mean self-reports for fear of cancer recurrence and for worries about the future were 2.89 (SD=1.1) and 2.44 (SD=1.1), respectively. Most survivors self-reported the highest levels of activation (54%) or a moderately-high level (41%). Fewer survivors reported low-moderate activation (41%) or the lowest level (13%) of patient activation. Overall, 51% of survivors reported that they desired additional information about follow-up care.

Table 2, displays the results for the logistic regression models, adjusted for race and comorbidity. African American/Black respondents were more likely (adjusted odds ratio [AOR]=2.69, P=0.01) than Caucasians/Whites to want additional follow-up information. Respondents reporting more comorbid health conditions were more likely (AOR=1.16, p=0.03) to endorse wanting additional follow-up care than those reporting less comorbidities. No other demographic or physical health factors were associated with desire for additional information to guide follow-up care.

Table 3, displays the means (M) of the psychosocial and perceptions of care variables for those who wanted and did not want additional follow-up information, along with p-values from the corresponding logistic regression models, adjusting for race and co-morbidities. Reporting worries about the future was predictive of wanting additional information (P=0.005), with a higher mean (M=2.64, SD=1.10) among those who wanted follow-up information than among those who did not (M=2.24, SD=1.07). Fear of cancer recurrence was also predictive (P=0.04) with a higher mean among those who wanted additional follow-up information (M=3.03, SD=0.97) than among those who did not (M=2.75, SD=1.96). Neither patient ratings of care for PCP and oncologist, nor satisfaction with cancer information provided by the PCPs or oncologists were significant predictors of wanting more information when controlling for race and comorbidities. Further, patient activation level was not a significant predictor for desiring additional information when entered into the logistical regression models as a categorical variable by level of activation or in the general linear model as a continuous variable, when controlling for race and comorbidities.

Among the 141 participants who reported that they wanted to receive information to manage follow-up care, the preferred information formats were website (30%) and informational

pamphlets (30%). Fewer survivors preferred lectures or “lunch and learn” formats (18%), patient navigators (12%) or phone applications (4%).

DISCUSSION

This study aimed to delineate the patient level factors that motivate requests for information to guide follow-up care with the ultimate goal of informing the assessment and tailoring of cancer educational programs for cancer survivors. The results suggest that two specific populations of survivors—African Americans and patients with more comorbidity, were more likely to request additional information to guide follow-up.

To date, the emphasis on tailoring educational messages for African American cancer survivors has focused largely on female breast cancer patients to the exclusion of men and those with other cancer sites. Additionally, much of that breast cancer literature has focuses on the acceptability of SCPs among patients. In general, these studies report that African American breast cancer survivors are receptive to receiving SCPs. However, it remains unclear whether these tools would be helpful in overcoming the challenges described by African American breast cancer survivors. [11, 17, 18]. For example, in one qualitative study African American breast cancer survivors expressed concerns about the use of difficult to understand technical jargon in SCPs and expressed that cautionary messages in SCPs, about limiting specific imaging tests were viewed as a form of medical rationing [11]. Further, in another study, African American breast cancer survivors described complex concerns that could not be solved by the delivery of a SCP, including: (1) worries about access to care (e.g. loss of insurance benefits) and care quality due to race; (2) mistrust in research protections for African Americans that act as a barrier to clinical trial participation; and (3) cultural taboos around disclosing cancer history to members in their community [19]. One study described the tailoring of health information for African American breast survivors based on population health risks; and recommended that SCPs need to be adapted to more extensively cover health history and comorbidity management due to their known contribution to increased morbidity and mortality [17].

No studies were found in the literature about prostate cancer patients' perspectives on survivorship care plans or post treatment preparation. This absence in the literature is consistent with the underrepresentation of African American men in research, including clinical trials [20]. There is a need to explore informational needs and preferences generally in this population, and identify the concerns specific to African American prostate survivors to inform the development of targeted survivor educational materials. Further, inadequately tailored informational and educational resources for African American men have the potential to become a point of disparity if future work does not identify methods to tailor these materials [17, 21].

Consistent with the existing literature, cancer survivors with a history of breast and prostate cancer and comorbid illnesses are more likely to want information to guide follow care. An earlier study focused on patients with a history of leukemia, colorectal or Non-Hodgkin's lymphoma, similarly identified increased informational needs among both African Americans and those with more comorbid health issues [21]. In the present study, we found

that African American race and patients with more comorbid illness were predictive of wanting information to guide follow-up care. Survivors with comorbid illness have complex care needs. Not surprisingly they have a greater need to understand how to mitigate their long-term medical risks. Although there are no clear guidelines about adjusting standard cancer therapies due to the presence of comorbid conditions, it is clear that this happens at the practice level for both breast and prostate cancer patients [22, 23]. However, it has been difficult to amass the evidence to formulate guidelines given the complex and overlapping factors (e.g. aging, sex, different clusters of comorbidities) [24], which also makes the task of educating patients about their role in self managing their health more challenging. Further research is needed to identify best practices in tailoring information to guide follow-up care among patients with higher comorbidity burdens.

After controlling for race and comorbidities, we found significant differences in preference for additional follow-up information among those who had more worries about the future and fears about disease recurrence. Therefore, those patients who were more concerned and fearful about their future and cancer recurrence were more likely to seek or request more information to help them navigate this phase of care.

Further research to understand how these recurrence worries about the future are related to coping styles and informational preferences in the post treatment cancer survivor are needed. Our findings are consistent with this body of work, which suggests patients who are more worried and fearful about their illness are also more active seekers of information that can help them to manage this threat [13]. Based on this work, recommendations to tailor information based on coping style in cancer patients during the treatment phase has been shown to benefit patients psychologically, behaviorally and physiologically [13]. Research to understand how this extends in the post-treatment phase may have important clinical implications. There is currently an emphasis in practice on the implementation of distress screening and SCPs, and future research would illuminate if these efforts could be strengthened by more sensitive assessments that also consider the relationships between information seeking, coping style and distress management.

This study has several limitations that should be considered in interpreting the findings. First, this is a cross-sectional design using a sample of cancer survivors with wide ranges in length of survivorship, and it is likely that the informational needs of survivors may change over time. The sample was not large enough to compare these groups for this analysis. Second, due to small sample sizes of minority groups, this study was limited to comparisons between white/Caucasian and African American/Black cancer survivors. Therefore, the findings may not generalize to other minority populations. However, these limitations notwithstanding, future studies should utilize measures that are more sensitive about the different types of information that might be appropriate to guide follow-up care information to provide a broader understanding of different strategies that support patients during this phase of care

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Table 1

Cancer Survivors Demographics and Patient-level Characteristics

Variable	Categories	Mean (SD) or Percentage
Age		64 (10.8)
Married		71%
Education	High School	26%
	Some College	30%
	4 Year Degree	21%
	Masters/Graduate School	23%
Race	White	86%
	African American/Black	14%
Employment Status	Full time	30%
	Part time	9%
	Not employed	14%
	Retired	47%
Cancer Diagnosis	Breast	68%
	Prostate	32%
Treatment Site	Academic	64%
	Community	36%
Years Since Cancer Treatment	Early (2–5 years)	57%
	Mid (6–10 years)	31%
	Long (10+ years)	12%
Patient Activation	Level One	4.68%
	Level Two	8.63%
	Level Three	41.37%
	Level Four	45.32%
Fear of Recurrence		2.89 (1.1)
Worries about the Future		2.44 (1.1)
Charlson Comorbidity		2.46 (1.9)
Received a treatment summary		38%

Table 2

Patient Characteristics Associated with Desire for Additional Follow-up Information

		Adjusted Odds Ratios	CI 95%	Type III p-value
Race	AA/Black v. White (ref)	2.69**	1.27, 5.68	0.01
Charlson Comorbidity		1.16**	1.01, 1.33	0.03
Cancer Site	Breast v. Prostate (ref)	1.36	0.80, 2.29	0.26
Marital Status	Married vs. Not Married	1.28	0.74, 2.20	0.38
Age (10 years)		0.85	0.68, 1.07	0.17
Education	Some college vs. H.S.	0.94	0.49, 1.80	0.52
	4 year college vs. H.S.	1.20	0.59, 2.46	
	Graduate vs. H.S.	0.69	0.34, 1.39	
Employment	Part-time vs. Full-time	1.99	0.78, 5.05	0.08
	Not Employed vs. Full-time	1.09	0.48, 2.48	
	Retired vs. Full-time	0.67	0.38, 1.18	
Treatment site	Academic vs. community	1.08	0.65, 1.7	0.78
Years since treatment	Mid (6–10) vs. Early (2–5)	0.96	0.56, 1.66	0.54
	Long (>10) vs. Early (2–5)	0.64	0.29, 1.42	
Received treatment summary	No vs. Yes	0.91	0.55, 1.50	0.70

**
p<0.05

Controlling for race and comorbidity burden.

Table 3

Association between Psychosocial Factors and Desire for Additional Follow-up Care Information

	Yes	No	P-values for logistic regression models
	Mean (SD)	Mean (SD)	
Worries about the future	2.64 (1.10)**	2.24 (1.07)**	0.005
Cancer recurrence fear	3.03 (0.97)**	2.75 (1.96)**	0.04
Patient Activation***	67.15 (16.03)	67.75 (14.39)	0.97
PCP coordination	4.00 (0.89)	3.88 (0.82)	0.36
ONC coordination	3.86 (0.92)	3.76 (0.93)	0.45
Satisfaction with PCP cancer related info	3.08 (1.12)	3.25 (1.06)	0.26
Satisfaction with ONC cancer related info	3.74 (0.58)	3.88 (0.40)	0.08

**
p<0.05

Modeled as a continuous predictor

Controlling for race and comorbidity burden.