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Recruiting Colorectal Cancer Survivors to a Surveillance Study: Barriers and Successful Strategies

Marvella E. Ford, PhD^{1,2,3}, Katherine R. Sterba, PhD^{3,4}, James Bearden, MD⁵, Lucy Gansauer, MSN⁵, Leslie A. Moore⁴, and Jane Zapka, ScD³

¹Medical University of South Carolina (MUSC) Cancer Disparities Program, Charleston, SC, USA

²MUSC Hollings Cancer Center, Charleston, SC, USA

³MUSC Department of Public Health Sciences, Charleston, SC, USA

⁴MUSC College of Medicine, Charleston, SC, USA

⁵Spartanburg Regional Healthcare System-Gibbs Cancer Center, Spartanburg, SC, USA

Abstract

Background—Colorectal cancer (CRC) survival rates are increasing. Effective strategies to recruit CRC survivors to surveillance studies are needed.

Objective—We analyzed the barriers encountered while recruiting CRC survivors to a study assessing their surveillance care experiences.

Methods—The study included three phases: (I) focus groups/key informant interviews; (II) cognitive interviews; and (III) a statewide population-based telephone survey.

Participants—In Phases I-II, clinic-based data and cancer center registries were used to identify CRC survivors who had received CRC resection within the past 18 months. In Phase III, survivors

Corresponding Author: Marvella E. Ford, PhD, Professor, Department of Public Health Sciences, Associate Director, Hollings Cancer Center, Cancer Disparities, 86 Jonathan Lucas Street, Hollings Cancer Center, Medical University of South Carolina, Charleston, SC 29425, fordmar@musc.edu, Telephone Number: 843-876-2433.

Authors

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CONFLICT OF INTEREST

Dr. Marvella E. Ford is a member of the Eli Lilly Minority Recruitment and Retention Advisory Board. Dr. Katherine R. Sterba has no potential conflicts of interest. Dr. James Bearden has no potential conflicts of interest. Lucy Gansauer has no potential conflicts of interest. Leslie Moore has no potential conflicts of interest. Dr. Jane Zapka has no potential conflicts of interest.

who had received CRC resection within the past two years were identified via a statewide, population-based cancer registry.

Results—In Phase I, 16 survivors participated in focus groups at two National Cancer Center-affiliated sites (response rate=29.6%). Eighteen additional survivors participated in individual interviews (response rate=50%). In Phase II, 11 survivors participated in cognitive interviews (response rate=81.8%). In Phase III, 150 survivors participated in the statewide survey (response rate=62.2%).

Conclusions—Group-based/ in-person recruitment efforts were unsuccessful due to scheduling barriers, lack of transportation, and remaining discomfort from previous resection surgery. Telephone-based data collection strategies produced higher response rates.

Practice Implications—To enhance CRC surveillance research, future studies could incorporate CRC survivor-centered recruitment strategies.

Keywords

cancer survivorship; colorectal cancer; cancer surveillance

INTRODUCTION

Colorectal cancer (CRC) is the third most commonly diagnosed cancer in the US, and in 2016, an estimated 134,490 new cases of colon and rectal cancer will be diagnosed.^{1,2} While the incidence of CRC is of concern, the number of CRC survivors is increasing, highlighting the need to enhance surveillance among survivors to adequately prevent or detect recurrence and address support and long-term care needs. There is growing concern about the variability in adherence to evidence-based surveillance guidelines which include office visits, carcinoembryonic antigen (CEA) tests, colonoscopy, and promotion of healthy lifestyle habits (*e.g.*, diet, physical activity).^{3,4} This adherence variability has prompted research on the multi-level mediating and moderating factors related to adherence and the identification of efficacious intervention strategies to promote receipt of appropriate long-term surveillance care and self-management habits. Given the need for research in CRC survivor surveillance adherence, it is vital to identify successful recruitment strategies that can bring representative sub-groups into epidemiologic and intervention trials related to improving the quality of surveillance care.

Many challenges to representative recruitment have been highlighted in the literature.^{5–9} The National Institutes of Health Revitalization Act of 1993 (P.L. 103-43) and its update in 2001¹⁰ state that women, and racially and ethnically diverse populations, must be included in federally funded research at rates proportional to their representation in the communities where the research takes place. Few studies have focused on ways to enhance participation rates of cancer survivors in research studies, and most of these studies have focused on young adults and breast cancer survivors.^{11,12}

The purpose of this article is to systematically describe the processes and outcomes in the recruitment of a representative sample of post-treatment CRC survivors to a surveillance research study that involved three phases: (1) focus groups/individual interviews to

characterize CRC survivors' experiences and preferences; (2) individual, telephone-based cognitive interviews to pretest a new survey instrument; and (3) a telephone-administered statewide survey to ascertain CRC survivors' surveillance experiences and preferences. Gaining a better understanding of recruitment processes and barriers in cancer survivorship research is important to the conduct of high-quality, multi-level intervention research in this growing field.

METHODS

Background

Study recruitment activities took place in the context of a parent study titled "Optimizing Survivorship and Surveillance after Treatment for Colorectal Cancer Study" (5R21CA152865-02). The overall objective of the study was to systematically investigate the role of multi-level factors affecting CRC survivors' adherence to guideline-based, post-treatment surveillance care. The study investigated the role of personal factors (*e.g.*, health status, knowledge, attitudes and demographics), provider factors (*e.g.*, physician-patient and specialist-primary care communication), and practice-level factors (*e.g.*, health care use, insurance) on survivor care experiences and outcomes.

Study Population, Setting and Data Sources

We aimed to recruit individuals who had completed treatment (*i.e.*, any combination of surgery, chemotherapy, and/or radiation therapy) for colon and/or rectal cancer 6 – 24 months prior to study enrollment. The data for the focus groups/individual interviews and telephone-based cognitive interviews was sourced from project management logs constructed of data from an academic, NCI-designated cancer center on the South Carolina (SC) coast and a community-based cancer center in the upstate region of SC. Racial/ethnic data was used to identify survivors at each cancer center site who were then invited to participate in racially/ethnically homogeneous focus groups. The data source for the statewide telephone-administered survey consisted of a Department of Health and Environmental Control (DHEC) SC central cancer registry. It is a population-based registry of cancer cases with a diagnosis date after December 21, 1995.¹³ The registry was designed to provide statistical information related to the incidence and prevalence of cancer and cancer mortality in SC.

Conceptual Framework

The recruitment strategies and identification of barriers to recruitment incorporated a conceptual framework developed by Swanson and Ward.¹⁴ This framework addresses barriers to recruiting minorities into clinical trials, and has relevance for general research recruitment as well. In the framework, Swanson and Ward¹⁴ categorize recruitment barriers in four different areas: 1) individual, 2) economic, 3) sociocultural and 4) barriers inherent to the study design (Figure 1). Sociocultural barriers refer to fear and mistrust of research and the cultural beliefs about certain illnesses. Economic barriers are the costs associated with taking part in a research study as well as the lack of access to care. It is thought that lack of access to care impedes access to clinical trials and opportunities to participate. Individual barriers include denial of disease, underestimation of one's vulnerability and competing

comorbidities. Barriers inherent in study design refer to elements of the research study that stand in the way of participation such as requiring participants to drive long distances, not offering study activities at convenient times, complex consent forms, and physician involvement that may engender fear or isolate potential participants.¹⁵ In the next section we will link the results of our recruitment efforts with the specific components of the conceptual framework.

RESULTS

Phase I Recruitment Activities

Survivor Focus Group/Individual Interviews Recruitment Activities—

Institutional Review Board approval was obtained at each cancer center to conduct the survivor focus groups/individual interviews. Following approval, individuals who for the survivor focus groups/individual interviews were recruited via the academic and community cancer centers' medical billing systems and clinic logs. The investigators then mailed an invitation letter (on institutional letterhead) and informational sheet in brightly colored envelopes to each potential participant. The content was written at an 8th-grade reading level and included a toll-free telephone number to call to opt-out of the study. If no opt-out was received within one week of the mailing, potential participants were called up to 10 times on various days/times.

Once contact was made, staff described the study and answered questions. The investigators used a standardized script to obtain verbal consent to administer the eligibility screen to confirm survivors' self-reported race, ethnicity, age, and clinical status (*i.e.*, time since treatment for Stage I-III CRC) and surveillance status. If they were determined to be eligible, participants were invited to participate in a focus group and were scheduled during the call. Focus groups took place at the clinical sites where participants received their CRC treatment, making it easier for them to find the location.

Focus groups took approximately two hours and refreshments were served. To accommodate the schedules and transportation concerns of participants who could not take part in the focus groups, individual interviews were offered and conducted with additional participants by telephone or in-person. These interviews took approximately 45 minutes to complete. At the start of each focus group or individual interview, each participant was administered the informed consent process and signed a consent form. At the end of each focus group/individual interview, each participant was given/mailed a \$20 gift card honorarium in recognition of their time.

Recruitment Results and Barriers for the Focus Groups/Individual Interviews

—Fifty-one potential participants were identified at the community-based breast cancer center and 42 potential participants were identified at the NCI-designated academic medical center. The iterative process undertaken to identify fruitful recruitment strategies for identification of CRC survivors reflected study design barriers. Several additional individual or economic level barriers were also identified. Of the 93 identified potential participants, three were found to be ineligible due to not meeting the study criteria (*i.e.*, were still receiving active treatment and some did not meet the racial/ethnic inclusion criteria), eight

had other non-cancer related illnesses (*e.g.*, hearing loss, problems with falling) that prevented them from participating. Two others contacted were ineligible to participate because they stated they had been diagnosed with a gastrointestinal cancer other than colorectal cancer (*e.g.*, appendix cancer), or only had a polypectomy.

Some participants were lost to follow-up and staff were unable to reach them using the contact information on the medical record ($n=6$). Other reasons for participant loss/decline included staff being unable to reach the patient after multiple attempts ($n=11$), finding that the participant was deceased ($n=1$), and ineligibility due to presence of metastasis and/or another synchronous cancer ($n=6$). Some participants' schedules would not allow them to participate in the focus groups ($n=4$). Others had transportation difficulties ($n=2$), and some agreed to participate but did not show up for their scheduled appointments ($n=5$). Also, the investigators canceled a focus group that 13 participants may have participated in, due to low turnout at previously scheduled focus groups. Subtracting from the denominator the ineligible, those unable to be contacted and those not pursued after study investigators decided to try a new data collection method ($n=39$ in total), the response rate for the focus groups was $16/54 = 29.6\%$. Six focus groups were conducted with 16 CRC survivors. As shown in Table 1, five of the participants were African American (31.3%; 4 females) and 11 (68.8%; 5 females) were European American. Four of the focus groups took place at a community-based cancer center (Designated as Site A in Table 1) and two took place at an NCI-designated academic medical center (Designated as Site B in Table 1). All participants in the focus groups and individual interviews were age 50 years and older.

Eighteen additional individuals identified at the NCI-designated academic medical center were later invited to participate in telephone-administered key informant interviews. Of this number, four were ineligible because they were still going through cancer treatment, had metastases, or did not meet the racial/ethnic criteria, one was deceased, one could not be contacted, and three were not interested due to the length of the interview or they did not want to use their telephone minutes for the interview. Six participated in the individual interviews, five by telephone and one in person. Subtracting the ineligible and those unable to be contacted from the denominator, the response rate for the interviews was $6/12 = 50\%$. Three participants were male and three were female. All of the individual interview participants were European Americans.

Phase II Recruitment Activities

Clinic-Based Survivor Survey Cognitive Interview Recruitment Activities—

Contact information for those unable to participate in focus groups or individual interviews was maintained and these potential participants were contacted to participate in the study's next phase, the cognitive interviews. Billing data were also used to identify additional survivors who were then invited and subsequently screened for study eligibility. If eligible, survivors were scheduled for a cognitive interview that took place either face-to-face or via teleconference at their convenience. The survey took approximately 45 minutes to administer, and this was described as a challenge by some potential participants when enrolling them in the study.

Recruitment Results and Barriers for the Cognitive Interviews—The majority of the 11 identified participants chose to take part in a telephone-administered interview (n=9). Two participants preferred in-person interviews instead of the telephone interviews. Of the 11 participants, nine were European American (81.8%), one was African American (9%), and one was Hispanic/Latino (9%). Eight were males (72.7%) and three were females (27%). Four of the 11 survivors were recruited from the community-based cancer center and the remaining seven were recruited from the NCI-designated academic medical center. Age was missing for most of the cognitive interview participants but among the four who reported their age, the mean was 58 years (range = 47-66 years). The cognitive interviews took three months to complete.

Phase III Statewide Survey with CRC Survivors

Recruitment Processes—Survey participants were identified through the South Carolina Central Cancer Registry (SCCCR). After receiving Institutional Review Board approval from the academic medical center where the study originated and from the IRB of the SCCCR, a series of steps were followed (Table 2) to identify CRC survivors who were 6 – 24 months post-treatment.

Recruitment Results—As shown in Figure 2, the final study sample for the statewide survey consisted of 150 CRC survivors, of whom 127 were European American and 21 were African American. Sixty-eight were males and 82 were females. The majority of survivors were colon cancer survivors (n=108); 28 were rectal cancer survivors; and 14 were colorectal cancer survivors. The survey took nine months to complete.

The Consolidated Standards of Reporting Trials (CONSORT) diagram (Figure 2) shows the denominator of 483 CRC survivors who were identified through the SC Central Cancer Registry. Of this number, nearly 100% had physicians who gave passive permission for their patients to be contacted by registry staff to learn about the study; 8.5% were deceased; 2.7% had incorrect contact information and could not be contacted; and 0.4% had poor mental status. As the registry staff proceeded to contact the remaining 422 identified CRC survivors, 57.6% (with two later found to be duplicate cases) opted into the study and were contacted by the study staff and invited to participate in the study, 30.8% chose to opt out of the study, and 11.6% gave passive refusal. Of the 243 participants, 9.5% were found to be ineligible; 6.5% declined participation; 5.4% passively refused to participate by not returning the call in response to repeated messages left by study staff and by not responding to the mailed invitations; and 150 completed the survey. Another 16.2% were in the recruitment pipeline but recruitment activities with them ceased after the goal of 150 participants was reached. These participants were sent a letter thanking them for their willingness to participate and informing them that their participation was no longer needed as the recruitment goal for the study had been met.

The initial survey sample (n=483) was predominantly European American (75.9%); African Americans comprised 22.8% of the initial sample. Of the 242 survivors who opted into the study, 79.3% were European American and 19.8% were African American, and of the 150

survivors who completed the survey, 86.0% were European American and 12.7% were African American.

The opt-out rate for the European Americans was 108/331 or 32.6% and 21/85 or 24.7% in the African American study population. The opt-in rate for the European Americans was 192/331 or 58.0% and 48/85 or 56.5% for the African American study population. However, the rate of passive refusals was threefold higher for African Americans compared to European Americans (6/48 or 12.5% versus 7/192 or 3.6%).

DISCUSSION AND CONCLUSION

Discussion

As post-treatment survival rates for cancer continue to grow, strategies to recruit cancer survivors will become increasingly important. The recruitment results of our study illuminate the factors influencing surveillance adherence among CRC survivors.. Response rates for the formative research components of this study were low. Here we summarize the barriers encountered with a focus on sociocultural, economic and individual barriers as well as barriers inherent to study design.¹⁴ Outlined below are the barriers identified within the Swanson and Ward¹⁴ recruitment model as they pertain to CRC survivor recruitment activities for in-person focus groups/telephone-administered individual interviews, cognitive interviews, and a statewide survey.

Recruitment Outcomes Related to Individual Barriers—Possible reasons for declining participation in survivorship research could be practical in nature. For example, although the age of some of the cognitive interviewees was not known, older adults appeared less willing to participate in the telephone-administered cognitive interviews. Vallance et al.¹⁶ report that older adults are willing to participate in telephone-based health surveys when randomly contacted, but the 45-minute length of the cognitive interview may have presented too great a challenge for the older adults asked to participate.

While recruitment rates in the formative research activities in Phases I-II were low, the majority of participants were highly adherent to their treatment. Altruism may have played a role in their willingness to participate, perhaps because they had wonderful care experiences or they wanted to give back to other cancer patients. Notably, some participants made similar statements during our focus groups/individual interviews and cognitive interviews, voicing enthusiasm and interest in helping other cancer survivors. Therefore, their CRC surveillance adherence rates may be higher than those who chose not to participate. Similar findings by Kunitake et al.¹⁷ on the long term effects experienced by CRC survivors who completed specific treatment regimens indicated that the participants tended to report receiving very high levels of surveillance care.

In the statewide survey, participants were within two years of an initial CRC diagnosis. With a bit more temporal distance from active treatment, survey participants may have become more reflective about their past experiences and expectations regarding future surveillance.

Recruitment Outcomes Related to Sociocultural Barriers—Sociocultural barriers may have been a more significant factor in the recruitment results of the state cancer registry compared to those conducted directly by the study sites. The registry staff had credibility with statewide study participants because the registry itself is under the purview of the South Carolina Department of Health and Environmental Control. Consequently, potential participants who received the state cancer registry's letter inviting them to learn more about the study by talking with a cancer center staff member likely viewed staff as credible. However, the cancer centers may have had less credibility with patients who did not receive their care there and who lived in distant regions of the state. This sociocultural barrier resulted in identified CRC survivors expressing a lack of interest in participating in the study. Other sociocultural barriers to participation included patients unwilling to be contacted by study staff because they were caring for a relative in poor health or were in poor health themselves.

The sociocultural barrier for African Americans, encountered in the studies cited earlier, where more call attempts were required to recruit African American participants,¹⁸ played a role in this study as well. Our prior research recruiting older African Americans with no cancer history¹⁹ and recruiting efforts for this research study confirm that compared to the general population, multiple call attempts to potential African American participants are needed for successful recruitment.

Recruitment Outcomes Related to Economic Barriers—Lack of transportation to the focus groups and interviews, and the cost to participate associated with this, presented economic barriers to recruitment and participation in this study. The two study sites serve CRC survivors across broad swathes of South Carolina's primarily rural areas. Even though the focus groups and interviews were offered on weekends and in the evenings, transportation to the sites was not provided for most of the participants, making it difficult for them to take part. Some agreed to participate but did not show up to their scheduled appointments, likely due to cost and travel barriers. For this reason, rural populations are a subset of populations that are least often included in clinical trials.¹⁴ Other reasons patients cited for not participating in the study were the cost to them of the 45-minute phone interview, especially if they had limited-minute phone plans. In light of the significant time and travel these patients had already devoted to completing their treatment, and the likelihood that they may have missed or fallen behind in work and household responsibilities due to treatment, participating in the surveillance study may have been seen as an expenditure they could not afford. It is apparently difficult for CRC survivors, due to competing life demands, to participate in scheduled group-based research activities.

Recruitment Outcomes Related to Barriers Inherent to Study Design—Barriers inherent in study design made it difficult to identify CRC survivors at either site willing to meet in a focus group or be interviewed regarding their CRC treatment and survivorship care experiences. Lack of real-time data on CRC survivors at the two study sites led to low identification rates of potential participants for recruitment into the study. Additionally, scheduling difficulties posed barriers to finding a time when multiple survivors could meet during a single focus group. Also, from a clinical perspective, many of the participants

reported experiencing bowel discomfort/flatulence/loose bowels associated with their previous resection surgery, and for these reasons, many stated that they would not feel comfortable participating in a focus group.

Most of the participants in the study's formative research components reported positive, favorable treatment experiences at the cancer care sites where the focus groups took place. It is possible that patients who had more unfavorable treatment experiences were less likely to consider returning to these sites of care to participate in the focus groups. The response rate may have been higher if the focus groups had been conducted in neutral, non-health care system settings. Holding the focus groups in community venues could have reduced sociocultural barriers, particularly for African Americans as this strategy has proven to enhance recruitment of diverse populations in previous studies.¹⁵

Conclusion

The results presented here confirm that specific and multiple recruitment efforts and strategies need to be tested and employed to ensure adequate representation of diverse populations in cancer survivorship research.²⁰ These efforts are especially critical to registry- and clinic-based research with CRC survivors. In our study, recruitment was challenging and each study activity took longer and required more effort than initially anticipated. Low participant numbers evident in the focus groups led to the need to conduct individual interviews.

While the Swanson and Ward¹⁴ conceptual framework for recruitment of minorities to clinical trials was applied to the study methods and results, significant potential changes to the model were noted in the present study. For example, altruism and happiness with health care experiences seemed to be an individual-level promoter of participation. However, our data showed that other barriers such as limited physician contact with patients after treatment and low rates of physician referral play major roles in inhibiting study participation regardless of race.

Practice Implications

It is possible that clinicians are more receptive to referring patients to treatment trials than to survivorship research studies. As Ott et al.²¹ note, further work is warranted to identify strategies that will increase the number of clinician referrals to studies conducted by non-clinician investigators. Another barrier is that CRC survivors may see their cancer care physicians infrequently, making these clinicians sub-optimal as a primary source for identifying and recruiting study participants. Kunitake et al.¹⁷ similarly described the challenges inherent to recruiting CRC survivors from clinical sites as difficulty locating CRC survivors, not having institutional commitment to support the study recruitment processes, and survivors' low interest.

More work needs to be conducted to refine recruitment strategies, making them more survivor-centered and effective. This work will be critical to improving rates of cancer research participation among CRC survivors and to the advancement of CRC surveillance studies.

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Figure 1.
Swanson and Ward's Conceptual Framework for Clinical Trial Recruitment

Figure 2.
CONSORT Recruitment Diagram for the Statewide Survey of CRC Survivors

Table 1

Focus Group (FG) Participant Characteristics

FG Location	FG Participants (#)	Males (#)	Females(#)	Ethnicity of Participants
Site A	4	2	2	European American
Site A	1	0	1	African American
Site A	5	3	2	European American
Site A	3	0	3	African American
Site B	2	1	1	European American
Site B	1	1	0	African American
Total	16	7	9	

Site A = 13

Site B = 3

Table 2**CRC Survivor Recruitment Process, Phase 2**

Step 1: The physician of record was contacted by mail by SCCC staff with a letter that described the study and asked permission to contact the survivor. If, after 2 weeks, no physician response was received, passive consent was assumed. In 99.8% of the cases, no physician response was received.

Step 2: For survivors identified through Step 1, a letter was sent from the SCCC Director to the survivor indicating that he or she was eligible for the study, and would be contacted within the next week by a SCCC staff member. A toll free number at the SCCC was listed in the letter; survivors were asked to call if they wanted more information about the study.

Step 3: An SCCC staff member contacted each identified survivor by telephone to describe the study and ask if he/she would like to take part or learn more about it. If the survivor agreed to participate, his or her contact information was then sent to the study staff at the academic medical center. If the survivor did not agree to participate, the reason was documented by the SCCC staff.

Step 4: The academic medical center study staff mailed the participant a study packet in a bright blue envelope. It included a cover letter, fact sheet about the study, and a survey answer guide.

Step 5: The academic medical center staff administered the survey over the telephone at the survivors' convenience. Upon completion of the 40-45 minutes survey, each participant was mailed a \$20 gift certificate.