Colorectal Cancer and Return to Work: A Pilot Study of Recruiting Cancer Survivors and Their Employers

Inga Gruß, PhD; Cathy J. Bradley, PhD, MPA; Matthew P. Banegas, PhD, MPH

ABSTRACT

Introduction: In this study we assessed the feasibility of recruiting colorectal cancer survivors and their employers to participate in research on returning to work after a cancer diagnosis.

Methods: Semistructured qualitative interviews were conducted with 6 survivors and 4 employers to collect feedback on 2 recruitment approaches: 1) an employee/cancer survivor-focused approach whereby researchers obtained employer contact information directly from survivors and 2) an employer-focused approach whereby researchers interviewed employers to identify pathways to recruiting survivor-supervisor dyads. Recordings of all interviews were transcribed and analyzed.

Results: Of the 6 survivor participants, 3 (50%) consented to follow up with their supervisors. One of the 3 supervisors responded but declined participation in the study. The 4 participating employers included 2 compensation/benefits managers and 2 human resources managers. Employers identified specific avenues for potential recruitment of survivor-supervisor dyads, including first obtaining organizational support for participating in this type of research.

Discussion: While challenges and opportunities exist with both the employee- and the employer-focused recruitment approaches, our findings suggest that an employer-focused approach, whereby researchers obtain organizational support for the research first, may be more promising for recruiting survivor-supervisor dyads to studies on cancer and employment. Results from this study underscore the importance of gaining support from all stakeholders—from administrators to employees who are cancer survivors.

Conclusion: Our study informs recruitment strategies that bring together cancer survivors and employers to improve our understanding of the barriers and facilitators of returning to work after cancer, in effort to develop interventions that mitigate employment challenges for cancer survivors.

INTRODUCTION

The number of adults in the US living with a history of cancer is on the rise. In 2019, an estimated 16.9 million individuals with a history of cancer were alive, and this number is projected to increase to more than 22.1 million by 2030. Sixty-three percent of cancer survivors continue to work through treatment or return to work (RTW) after treatment. However, the short- and long-term effects of cancer and its treatment can affect a survivor’s ability to maintain employment. Limitations in physical and cognitive functioning, as well as emotional and psychosocial effects, may impair patients’ and survivors’ abilities to complete work-related tasks. Patients with colorectal cancer (CRC) may also have unique physiological symptoms that affect their ability to work, such as frequent or irregular bowel movements. Acknowledging and addressing these side effects is critical for supporting CRC survivors’ employment needs and goals. Maintaining employment is often critical for financial security and health insurance coverage, and offers cancer survivors a sense of normalcy.

A growing body of research has highlighted the need to obtain multiple stakeholder perspectives to illuminate the barriers and facilitators of continued employment for cancer survivors. These perspectives are critical for developing timely and well-managed RTW processes for individuals with cancer. Employers are a stakeholder group that have a key role in ensuring employment of cancer survivors, but their perspectives are largely absent from the literature. Cancer survivors have consistently identified organizational support as central barriers. While limited, existing research on the perspective of employers has identified open and ongoing communication and RTW policies as potential facilitators to RTW, and lack of knowledge about cancer and competing interests as central barriers.

These documented barriers and facilitators to successful RTW point to the importance of obtaining the perspectives of both cancer survivors and their employers to identify common areas of concern and priorities for improvement. Moreover, for future trials that will test interventions to improve RTW after cancer, participation of dyads will be required, and exploring ways to recruit them effectively is warranted. Only a few research projects, however, have recruited cancer survivor–employer dyads for research, using

Author Affiliations
1 Kaiser Permanente Center for Health Research, Portland, OR
2 Colorado School of Public Health, University of Colorado Denver, Aurora, CO

Corresponding Author
Matthew P. Banegas, MPH, PhD (Matthew.P.Banegas@kpchr.org)

Keywords: colorectal cancer survivors, employer perspective, employment, recruitment methods, return to work
snowball sampling as well as asking cancer survivors for consent to contact and enroll their supervisors.20,21 These studies documented certain challenges recruiting employers for research on cancer survivorship and employment, including the small number of survivors within a single employer, and confidentiality issues about health and work that make it challenging for employers to discuss individual cases of cancer survivors.10 As such, more research is needed to assess the feasibility of recruiting cancer survivor–employer dyads to enable a comprehensive stakeholder engagement program.

As part of a study assessing the challenges and needs of CRC survivors in maintaining employment and RTW from both the survivor and employer perspective,22 we assessed the feasibility of enrolling cancer survivor–employer dyads using 2 different approaches: 1) a survivor/employee–based approach that identifies the supervisors/employers through participating CRC survivors and 2) an employer-based approach that identifies supervisors through administrative-level access from the employer. We conducted qualitative interviews with survivors, human resource managers, and benefits managers to understand better the feasibility of these recruitment strategies, and to identify policies and context that could facilitate recruitment of survivor–employer dyads.

**METHODS**

**Study Population**

We recruited CRC survivors through the Patient Outcomes Research to Advance Learning (PORTAL) Network’s CRC cohort. This established cohort includes CRC survivors from 6 health-care systems who were diagnosed between 2010 and 2014.23 Survivors were eligible for recruitment if they were between 18 and 70 years of age, fluent in English, employed at the time of their cancer diagnosis, and enrolled at Kaiser Permanente Northwest (1 of the 6 PORTAL CRC sites). Forty survivors who met these criteria were selected randomly and sent recruitment letters. Eight of these 40 eligible participants reported to be either retired or not working at the time of the diagnosis, 10 declined participation, and 9 could not be reached. Of the 13 who agreed to participate, 10 survivors provided consent and completed a 30- to 45-minute telephone interview. Four of the 10 consenting survivor participants were employed in a position, at the time of diagnosis, that did not have a direct supervisor (self-employed [n = 3]) or no direct supervisor [n = 1] and were excluded from the analyses. The final analytic sample included 6 participants.

To assess the employer-based approach, from electronic health record data we generated a list of companies and organizations that employed PORTAL CRC cohort survivors, then submitted the list to Kaiser Permanente Northwest Workforce Health—a team that develops employee wellness engagement strategies and programs with organizations that offer health insurance plans through Kaiser Permanente. Eligibility for the employer participants included a willingness to discuss the challenges and needs of survivors in maintaining employment and RTW. Kaiser Permanente Northwest Workforce Health contacted and sent study information to 10 organizations. Five organizations responded to the initial recruitment inquiry. Study staff contacted these organizations by phone or email to describe the study in detail and to assess their interest in participating. Of the 5 organizations that responded, 1 declined to participate because of time constraints; 4 agreed to participate. All 4 participating organizations also consented to make a staff member available for a 30- to 45-minute phone interview. We enrolled 2 compensation and benefits managers and 2 human resource managers.

**Data Collection and Analysis**

We conducted all interviews by phone and recorded these conversations after obtaining participants’ permission. Recordings were transcribed and analyzed using NVivo 10 (QSR International). All participants were offered a $25 gift card for their participation. The Kaiser Permanente Northwest Institutional Review Board approved this study.

For survivors, part of the interviews focused on their willingness to contact about participating in the study the direct or immediate supervisors with whom they worked at the time of diagnosis and their willingness to share the contact details of these supervisors with researchers so that the employers could be recruited for study participation. The following questions were asked of all employee participants:

- We are exploring ways to hear from employee and supervisor/manager pairs about their experiences with colorectal cancer. If you were asked to provide your supervisor’s contact information so that study staff could invite him or her to participate in a confidential survey about cancer and the workplace, would you feel comfortable doing this? If not, what reservations do you have?
- Would you be willing to give us permission to contact your current/former supervisor to ask whether he or she would be willing to do an interview (just like the one we are doing now) about his or her experience supervising an employee with cancer? Follow-up note: Make sure we emphasize that the focus of the interview is not about the employee personally.

If the interviewee provided employer contact information, the study team attempted to contact the supervisor to request a 30- to 45-minute semistructured interview.

For employers, interviews focused on their willingness to help recruit both cancer survivors and their supervisors for a study on cancer and employment, and their suggestions for
how best to recruit supervisors for a study. The following questions were asked of all employer participants:

- We are especially interested in studying employee and supervisor/manager pairs. Do you have any thoughts about how we might reach out to employee and supervisor/manager pairs in a way that would allow both to feel comfortable? Follow-up prompts: What privacy or legal considerations do we have to be aware of? How can we respect the privacy of both parties?
- How comfortable would you feel with your employee giving us your contact information so that we could invite you to participate in a confidential survey about your experience managing employees experiencing cancer? Follow-up prompts: How comfortable do you think your employee might feel with regard to providing us with your contact information? Do you have any thoughts about how we could make employees who are cancer survivors feel more comfortable participating in research?

The transcripts for both survivor and employer interviews were analyzed by 2 researchers (Inga Gruß, PhD, and Matthew P Banegas, PhD, MPH), who combined inductive and inductive approaches to content analysis. First, the researchers developed an initial code list for the interviews, including predefined themes and additional codes identified during initial transcript review. Through an iterative process, each researcher coded 2 interview transcripts using the initial code list, after which we met to compare and discuss the coded transcripts, revise the codes and code definitions, and generate a final code list. The final code list was then used to analyze all interview transcripts.

RESULTS
Details of the study population have been reported in detail previously.22

Participant/CRC Survivor Approach
Of the 6 survivor participants included in the study, 5 had a direct supervisor at the time of diagnosis and returned to work; 1 participant had retired since receiving the cancer diagnosis. Of the 5 participants with a direct supervisor, 3 agreed to share their supervisor’s contact information, although 1 asked us to withhold their name when contacting their former employer. None of the 3 survivor participants who agreed to share their supervisor’s contact information was in the same job they held at the time of their diagnosis (2 had been laid off after RTW and 1 had retired from the position at the time of diagnosis, although all had moved to a new employer). Of the 2 survivor participants who reported they did not feel comfortable or willing to share their supervisor’s contact information, 1 declined to participate because of privacy issues and the other reported they did not think their supervisor from the time of diagnosis would be willing to participate.

Of the supervisors for whom survivor participants provided contact information, 1 was contacted by email whereas the other 2 supervisors were mailed letters to their place of work. The supervisor who was contacted by email responded, but declined participation in the study because of time constraints. Neither supervisor who was contacted by mail responded to our letters.

Employer Approach
Employer participants included 2 compensation and benefits managers who worked in public administration and 2 human resources managers who worked in the educational sector (secondary and tertiary education sector). Participants were primarily women (75%). All employer participants recognized the importance of the study and the interest in collecting data from both CRC survivors and their supervisors to understand better and to improve processes related to cancer survivorship and employment.

When asked about the approach they felt would be most appropriate for recruiting supervisors for a research study, they identified 2 potential pathways: 1) obtain consent from survivor participants to contact their employer, then initiate contact with the employer organization administrator (ie, human resources manager) to help identify and recruit supervisors; or 2) contact administrators at the employer organizations and then work with the organization to recruit supervisors within the organization who have experience with employees who are cancer survivors: “But I think you could do it both ways. You could do it through the . . . patient to the supervisor. And do they think that their supervisor would be interested in participating, because they could at least ask them. And then you go through the employer, through a contact person, and say, ‘This employee . . . needs to connect with us,’ so we know it’s okay. [Compensation and Benefits Manager]”

All the employer participants emphasized the critical role of organizational consent and support. Some felt that human resource departments could be helpful in identifying potential legal concerns (related to the Health Insurance Portability and Accountability Act) associated with representatives of the employer participating in research, and to ensure that any concerns are appropriately addressed: “But in terms of whether there would be a legal requirement for us as a public institution, for that kind of conversation . . . I’d probably go to my legal department and say, ‘You know . . . this question has come up. Do you see any problems?’ [Human Resources Manager]” Employer participants also noted that, if approval is sought at the organizational level, the research or compliance (legal) departments of these organizations should be integrated into the process to ensure all steps of the research process comply with organizational
policies and federal, state, and local laws: “We have our institutional research department. So, if I were to want to do a survey, I would work with them to make sure that it was a legitimate survey in terms of processes and . . . legal requirements and whatnot. So, I’m assuming that there are some kind of standards, you know, especially in the medical area with confidentiality issues, that there would be . . . things that may need to be signed or . . . you know, kind of disclaimers and whatnot. [Human Resources Manager]”

The employer participants described other advantages to contacting employers first, including: 1) the employer organization can encourage both employees who are cancer survivors and their supervisors to participate, 2) the employer organization can endorse organizational interest in improving RTW processes, and 3) the employer organization can convey to employee participants that information resulting from the research will or will not be shared with the organization: “So, I think it would be most appropriate if an email came from me or my office. And it said something like, You know, we have . . . a study related to cancer patients and . . . for those [employees] who have gone through a cancer diagnosis or are continuing to deal with or go through cancer treatment, if you feel comfortable . . . in wanting to participate in the survey with your supervisor, then you could contact us.’ [Compensation and Benefits Manager]”

The 2 employer participants who were human resource managers also identified practical considerations that could improve recruitment, such as conducting web-based surveys rather than qualitative interviews to improve feasibility, allow participants flexibility to complete the surveys on their own time, and protect the privacy of the participants. Employer participants also identified possible barriers to recruitment, including the inability of public service agencies to accept gift cards or incentives for participating in research, limited knowledge about privacy regulations among supervisors, and fear of violating these regulations: “[Protected Health Information is] a really big deal. And we are an employer, so we are completely connected to their [employees’] livelihood. And nobody [among supervisors] would even talk to me about [the employer] . . . . And I’m like, ‘Look, I’m not looking for [Protected Health Information], guys. You know, tell me about the people that you know that the supervisor knows there’s a [cancer] diagnosis. So that I can reach out to that supervisor and ask, Hey, here’s what’s going on. It’d be great to get your input.’ And they . . . just completely shut down. [Compensation and Benefits Manager]”

**DISCUSSION**

Through interviews with cancer survivors and employers of cancer survivors, we identified key challenges and opportunities of 2 approaches to recruiting survivor-supervisor dyads for research on RTW after cancer. Our findings suggest that an employer-focused approach, whereby researchers obtain organizational support for the research study first, may be a more promising approach for future studies on cancer and employment, rather than asking for help from cancer survivors to recruit their supervisors (the survivor/employee-focused approach). By collaborating with the organizational administration, the employer-focused approach may address potential barriers to research participation, including concerns about compliance with organizational policies. The survivor/employee-focused approach may not be practical or feasible because of changes in job roles/positions of both the survivor and the supervisor, policy concerns, reluctance to participate on the part of survivors, or lack of supervisor interest.

We found a benefit to including human resource managers or benefits administrators in conversations about study recruitment. These stakeholders can foster recruitment of supervisor participants by facilitating communication, connecting to specific staff, approving study participation across the employer organization, and ensuring organizational policies are upheld. This finding supports the results of previous work conducted by Tiedtke et al, 19 who found that human resources managers are likely to be knowledgeable about employer policies and legal restrictions, whereas departmental managers who maintain direct communication with their employees who are cancer survivors may lack this knowledge. Such organizational knowledge and support may improve the involvement of various administrative-level stakeholders during the recruitment process, and may empower supervisors to participate.

When recruiting employers to cancer studies, we found that 1 limiting factor to successful recruitment of sufficient numbers of employers may be the low number of cancer survivors in any given organization and, thus, few employer representatives who have experience with an employee/direct report who has been diagnosed with cancer. This may be particularly true among small organizations that have relatively few employees. Survivors employed in small organizations may need the most assistance with RTW because these organizations may not have established policies or legal protections, nor the experience with other employees with a cancer history, to develop procedures and accommodations that best support RTW after cancer.3

Prior studies on RTW after cancer have recruited employer participants using approaches such as recruiting through professional conferences and societies, insurance companies, LinkedIn, and disability management programs, and by using snowball techniques.14,17,19,21,25 Another approach may be for researchers to develop effective collaborations with large employer organizations, such as Chambers of Commerce or labor unions, that could provide
large sampling frames of employer organizations from which to engage and recruit participants for studies on cancer and employment.

Participants identified several challenges for recruiting cancer survivor–supervisor dyads. Fear of violating privacy regulations, as well as limitations on accepting study incentives, may discourage participation. Several participants had also changed jobs, which may further affect the interest in participating in a study, and poses challenges for recruiting dyads. Other challenging factors identified in previous research include confidentiality and legal issues surrounding employee health and workplace accommodations, as well as fear of job loss.10,22,25,26

Two previous studies that successfully enrolled cancer survivor–employer dyads relied on the snowballing method and participant-driven (ie, employee-focused) recruitment, respectively. Yagil et al21 recruited 12 dyads through Facebook and through human resource managers who contacted survivors and their supervisors by phone. The authors did not provide any information how they identified cancer survivors, or the number of dyads they contacted to enroll 12 successfully. Eskilsson et al20 recruited cancer survivors through an outpatient rehabilitation program and then contacted their supervisors; these researchers were able to enroll 16 of 22 dyads. Their success in pursuing a cancer survivor–employee-focused approach may be a result, in part, of the different social and cultural context within which their study was conducted. In Sweden, attitudes among cancer survivors and employers about participating in RTW research may be different.

**Limitations**

The focus of this work was to assess the feasibility of recruiting cancer survivor–supervisor dyads to research the impact of cancer on employment. Our findings are based on a small sample of survivors and employers. Study participants included a limited number of employer representatives, all of whom were either human resource managers or benefits managers, and may not reflect the views of supervisors or employer representatives. Furthermore, we did not collect information about the timing of their experience with a cancer survivor employee, which may have been several years ago (ie, recall bias) and may not reflect current policies or legislation. Self-employed cancer survivors and those without a direct supervisor, which we excluded from our analysis, may face different employment obstacles altogether. For example, self-employed cancer survivors have unique needs and, if they have employees, they may not want to share their diagnosis with them. Accordingly, developing research approaches that are inclusive of different types of employment and supervisory structures is essential for future research on cancer and employment.

Last, our sampling frame included employers who were recruited through their connection with Kaiser Permanente Northwest, which may lead to selection bias, as these organizations may be more likely to participate in research or differ in other characteristics.

**CONCLUSIONS**

Our study highlights the challenges and opportunities to both survivor-focused and employer-focused approaches to recruitment of survivor–supervisor dyads, and suggests that employer-focused approaches may be the most feasible for overcoming barriers to supervisor participation. Employer participants recognized the importance of participating in research of RTW after cancer and suggested different avenues of recruiting eligible survivor–supervisor dyads. Results from this study underscore the importance of gaining support from all levels of the employer organizations—from administrators to employees who are cancer survivors. Our findings help inform the development of recruitment strategies that bring together survivors and employers, improving our understanding of the barriers and facilitators of RTW after cancer, and leading to interventions that mitigate employment challenges for cancer survivors.


