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Recruiting Young Adult Cancer Survivors for Behavioral Research

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Abstract

Young adults have been dramatically underrepresented in cancer survivorship research. One contributing factor is the difficulty recruiting this population. To identify effective recruitment strategies, the current study assessed the yield of strategies used to recruit young survivors for an exercise intervention including: clinic-based recruitment, recruitment at cancer-related events, mailings, telephone-based recruitment, advertising on the internet, radio, television and social networking media, distributing brochures and word-of-mouth referrals. When taking into account the strategies for which we could track the number of survivors approached, recruitment at an oncology clinic was the most productive: 38 % of those approached were screened and 8 % enrolled. When evaluating which strategy yielded the greatest percentage of the sample, however, mailings were the most productive. Given widespread use of the internet and social networking by young adults, investigators should also consider these low-cost recruitment strategies.

Keywords

Young adult; Cancer survivors; Recruitment; Internet

Until recently, young adult cancer survivors—those in their late teens, twenties and thirties—were largely overlooked in clinical settings and rarely the focus of biomedical or psychosocial research. This is unfortunate as approximately 70,000 individuals in their twenties and thirties are diagnosed with cancer each year and these young adults face significant medical and psychosocial challenges (Bleyer, 2006). Many face an increased risk for cardiovascular disease, second cancers, and emotional distress (Burgess et al., 2005; Hewitt & Rowland, 2002; Huddart et al., 2003; Hull, Morris, Pepine, & Mendenhall, 2003; Shapiro & Recht, 2001; Travis et al., 2005). Although they would clearly benefit from research to address their specific medical and psychosocial needs, young adult cancer survivors are dramatically underrepresented in clinical trials and other cancer-related research (Adolescent and Young Adult Oncology Progress Review Group, 2006).

A challenge to conducting research on young adult cancer survivors, however, is the difficulty recruiting this population. As cancer is still a relatively low frequency event among young adults, there are fewer young adult cancer survivors in any one geographic region. In addition, young adults are more mobile than middle-aged and older adults (US Census Bureau, 2006), making it difficult to reach young survivors using the contact information they previously provided to tumor registries or cancer-related organizations. Recruiting young adult cancer survivors through oncology clinics also may be challenging, as young adults are more vulnerable to loss of insurance and interruption in their medical care than older adults (Callahan & Cooper, 2005). Given these potential obstacles to the recruitment strategies often used with cancer survivors, it is unclear how best to access and recruit this population.

In this paper, we report on our efforts to recruit a sample of young adult cancer survivors for a web-based physical activity intervention. Due to the challenges inherent in recruiting this hard-to-reach population, we employed a wide range of strategies (see “Method” section). This exploratory investigation reports on the yield of each recruitment source, during the first year of recruitment.

Method

Participants

After receiving approval from the Miriam Hospital Institutional Review Board, participants were recruited for the Survivors Step into Motion study (May 2009–January 2011). To be eligible for this randomized, controlled pilot study, cancer survivors needed to be between the ages of 18 and 39, diagnosed in the past 10 years, in a cancer remission and sedentary (i.e., performing less than 30 min of moderate-intensity activity twice/week or 20 min of vigorous-intensity activity once/week). Survivors were excluded for any medical or psychiatric conditions that would make participation dangerous or very difficult (e.g., cardiovascular disease). Once a survivor expressed interest in the study, they were screened via telephone by research staff; those who appeared eligible were asked for the name of a physician who could verify that they were in a cancer remission and could safely participate in the study. The strategies used to identify and recruit cancer survivors are described below.

Recruitment Strategies

Mailings—Study brochures were mailed to 735 young adult cancer survivors using contact information obtained from a hospital-based tumor registry and 35 cancer survivors who had participated in prior research studies and indicated an interest in being notified about future studies.

Phone-Based Recruitment—Six young adult cancer survivors receiving care at a local oncology clinic were contacted by phone about the study. Thirteen young adult survivors who had participated in previous research and indicated a willingness to be contacted about future studies were also called.

In-Person Recruitment at Oncology Clinic—A researcher visited a local oncology clinic when potentially eligible patients were scheduled for a follow-up appointment. There were 13 such patients during the first year of recruitment. A treating physician approached each of these patients and asked whether the patient would like to know more about the study. Those who expressed interest were referred to the researcher for a face-to-face discussion.

Internet and Social Networking—A number of groups that serve the needs of cancer survivors (e.g., I'm Too Young for This!, Ulman Cancer Fund for Young Adults, Imerman Angels) advertised the study free of charge online, via email or through social media (e.g., Facebook, Twitter, Ning). Advertisements for the study were also placed on the Rhode Island and Massachusetts Craigslist websites and on the Providence Metro Classifieds website.

Word-of-Mouth and Incidental Referrals—Some participants were referred to the study from another study that was also recruiting young adult cancer survivors. In addition, some patients found out about the study through a friend or relative who saw recruitment materials or by searching the NIH database for clinical trials.

In-Person Recruitment at Cancer-Related Events/Groups—Members of the research team recruited at four cancer-related events (e.g., Leukemia and Lymphoma Society “Light the Night” walk). At each event, research staff was available to speak with survivors about the study. In addition, two researchers made a presentation about the study at a local support group for young women with cancer.

Media—An advertisement for the study was read on the *Stupid Cancer Show*, a radio show targeting young adult cancer survivors. A press release about the study was released by the hospital where the study is based. In addition, a local television station provided coverage of the study on the news in connection with Young Adult Cancer Awareness Week.

Brochures Available—Study brochures were made available at a number of locations likely to attract cancer survivors (e.g., oncology clinics), young adult cancer survivors specifically (e.g., Planet Cancer retreat) or young adults in the community (e.g., coffee shops). In addition, American Cancer Society staff members who regularly meet with newly diagnosed patients at local hospitals agreed to provide young adult patients with a study brochure.

Results

Table 1 indicates the number of young adult cancer survivors who were approached about the study (if known), in contact with the study, eligibility screened, and enrolled as a result of each recruitment strategy. A total of 770 young survivors were approached through mailings, resulting in 8 enrolled participants (i.e., 1 % of those approached). A total of 19 survivors were approached by phone about the study, but none were enrolled as a result. A total of 13 survivors were approached in person at an oncology clinic resulting in 1 enrolled participant (i.e., 8 % of those approached). Therefore, just taking into account the three strategies for which we have data on the total number of survivors approached, in-person recruitment at an oncology clinic appears to have yielded the greatest percentage of participants per survivor approached.

We also evaluated the yield of each strategy by considering the number of survivors in contact with, screened for, and enrolled in the study as a result of each recruitment method relative to the total number of survivors contacted, screened and enrolled. A survivor was considered to have had contact with the study if: the survivor emailed or called research staff to learn more about the study, research staff spoke to the survivor at an oncology clinic because the survivor expressed interest in the study, or research staff spoke to the survivor as part of a phone-based recruitment strategy. Although the “survivor contact” count, therefore, combines the survivors who initiated contact with the study and those who simply passively received it, it provides a rough estimate of interest in the study as a result of each strategy. A total of 73 young adult cancer survivor contacts occurred. As detailed in Table 1,

the majority of contacts resulted from mailings to survivors, phone-based recruitment, and internet and social media strategies. Word-of-mouth or incidental sources and recruitment at an oncology clinic also led to a number of contacts.

Of the 73 young adult cancer survivors who had contact with the study during the first year of recruitment, 42 (58 %) completed eligibility screening. Others were not formally screened for a variety of reasons (e.g., determined to be ineligible prior to screening).¹ As shown in Table 1, the recruitment strategies that yielded the greatest number of survivor contacts also generally yielded the greatest number of screened survivors. Among the 42 survivors screened, 12 were eligible and all 12 enrolled in the study. The survivors enrolled in the study were primarily recruited through mailings, though some were recruited through an oncology clinic or referrals.

Discussion

We have reported on the yield of the strategies used to recruit young adult cancer survivors for a behavioral intervention. When considering only the strategies for which we have information regarding the number of survivors approached, in-person recruitment at the oncology clinic yielded the greatest percentage of participants enrolled (per survivor approached); this may be due to the relationship between survivors and their physicians, who first approached them about the study. However, this strategy occupied a significant amount of staff time (i.e., approximately 28 %). When considering the relative yield of each strategy in terms of the *absolute number* of survivors enrolled, mailings appear to have been the most productive strategy. Over half of the sample was recruited through mailings. Prior research, including an exercise study with breast cancer survivors, has also found mailings to be an effective strategy (Harlan et al., 2011; Pinto et al., 2004). Further, this strategy imposes little burden on research staff and minimal cost to the study. Investigators interested in pursuing this strategy might consider collaborating with a state or hospital-based tumor registry that is willing to supply contact information for survivors.

Advertising the study online and through social media also yielded a number of survivor contacts. It is possible that, if our study could be expanded to include young adult cancer survivors living anywhere in the United States, this type of advertisement might have been our primary recruitment strategy. Indeed, young adults are now online more often than ever and use of social networking sites has become increasingly popular in this demographic (Lenhart, Purcell, Smith, & Zickuhr, 2010). Investigators who are able to partner with organizations that include a sizable number of young adult cancer survivors in their network may find these low-cost and no-cost options an ideal way to recruit this population.

Some limitations are important to note when interpreting the findings from this study. Seasonal effects may have influenced the success of certain recruitment strategies (e.g., mailings) which were only implemented sporadically. The ability to provide more study-related information with some recruitment strategies (e.g., phone calls) than others (e.g., online ads) may have impacted findings. The restrictive eligibility requirements for the study may have reduced the generalizability of findings, as only relatively healthy, sedentary survivors were eligible. Likewise, our findings may not extend to studies recruiting young adult cancer survivors for different types of behavioral interventions (e.g., smoking cessation). Even with these caveats, the findings from this investigation indicate that researchers studying young adult cancer survivors may need to employ a range of strategies in order to meet recruitment goals.

¹Note that another exercise intervention study with cancer survivors also screened 58 % of the survivors contacted (Matthews et al., 2007).

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Table 1

Young adult cancer survivors approached about, in contact with, screened for, and enrolled in the study the first year

	Survivors approached <i>n</i>	Survivor contacts ^a <i>n</i> = 73 <i>n</i>	Survivors screened <i>n</i> = 42 <i>n</i>	Survivors enrolled <i>n</i> = 12 <i>n</i>
Mailings	770	19	16	8
Phone-based	19	14	10	0
In-person oncology clinic	13	7	5	1
Internet/social media	-	11	3	0
Word-of-mouth referrals	-	8	6	3
In-person cancer event	-	2	2	0
Media	-	2	0	0
Brochures	-	0	0	0

^aInformation on recruitment strategy was not available for 10 survivor contacts. These survivors were among those who were not screened (e.g., determined to be ineligible before the screener) and the recruitment source was not determined during any brief communication with the survivor