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Social Networking Site Usage Among Childhood Cancer Survivors - A Potential Tool for Research Recruitment?

Erica D. Seltzer, DrPH, MPH^{1,3}, Melinda R. Stolley, PhD², Edward K. Mensah, PhD¹, and Lisa K. Sharp, PhD²

¹School of Public Health, University of Illinois at Chicago, Chicago, Illinois

²Department of Medicine, Section of Health Promotion Research, University of Illinois at Chicago, Chicago, Illinois

³Institute for Health Research and Policy, University of Illinois at Chicago, Chicago, Illinois

Abstract

Purpose—The recent and rapid growth of social networking site (SNS) use presents a unique public health opportunity to develop effective strategies for the recruitment of hard-to-reach participants for cancer research studies. This survey investigated childhood cancer survivors' reported use of SNS such as facebook or MySpace and their perceptions of using SNS, for recruitment into survivorship research.

Methods—Sixty White, Black and Hispanic, adult childhood cancer survivors (range 18 – 48 years of age) that were randomly selected from a larger childhood cancer study, the Chicago Healthy Living Study (CHLS), participated in this pilot survey. Telephone surveys were conducted to understand current SNS activity and attitudes towards using SNS as a cancer research recruitment tool.

Results—Seventy percent of participants reported SNS usage of which 80% were at least weekly users and 79 % reported positive attitudes towards the use of SNS as a recruitment tool for survivorship research.

Conclusions and implications for cancer survivors—The results of this pilot study revealed that SNS use was high and regular among the childhood cancer survivors sampled. Most had positive attitudes towards using SNS for recruitment of research. The results of this pilot survey suggest that SNS may offer an alternative approach for recruitment of childhood cancer survivors into research.

Keywords

Childhood cancer survivor; research study recruitment; social networking site; facebook

Corresponding author: Erica D. Seltzer, DrPH, MPH, Institute for Health Research and Policy, M/C 275, 558 WROB, University of Illinois, 1747 W. Roosevelt Road, Chicago, IL 60608, eseltzer@uic.edu.

CONFLICT OF INTEREST

The authors do not declare any conflict of interests.

INTRODUCTION

Childhood Cancer

Childhood cancer survivors represent a specific sub-population of cancer survivors that might uniquely benefit from recruitment efforts that embrace social networking. Approximately 12,000 children in the United States are diagnosed with childhood cancer each year and 84% will reach the 5-year survival point. [1] Although childhood cancer is rare, high survival rates have resulted in a large and growing number of adults who are survivors of childhood cancer. [2, 3] Estimates suggest that 1 in every 900 U.S. adults, age 15 – 45, is a childhood cancer survivor. [2] While cured of their original cancer, almost two-thirds of childhood cancer survivors will develop at least one chronic medical condition and one-third will develop a severe or life threatening health condition by early adulthood. [4] These conditions are the result of unintended effects of the chemotherapies and/or radiation therapy and may not become clinically evident for many years following treatment. [4, 5] On-going research efforts are targeting surveillance of and interventions with this vulnerable cohort to decrease the morbidity and mortality. Because of the relative rarity of childhood cancer, coupled with the need for large numbers of survivors to support statistical analyses, recruitment can be expensive.

Social networking sites

The recent and rapid growth of social networking site use presents a unique opportunity to develop more cost-effective strategies for recruiting hard-to-reach participants. Social networking sites (SNS) are “web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system“. [6] As such, social networking sites may offer a unique approach to overcoming some of the challenges inherent in recruiting adult childhood cancer survivors. For example, recruitment of survivors often relies upon cancer registry data such as the patient's name and contact information at the time of diagnosis. In many cases, survivors and family members have all relocated with no forwarding information which limits the utility of the information. [2] Internet searches on "people finder" sites can yield updated information. However, the mobility of young adults is such that often postal addresses, telephone numbers, and even email addresses that are located through these sites are not current. [2] The increasing reliance upon cellular telephones [7] has also complicated tracking of people due to frequent cellular telephone number changes, no national directory for cellular numbers, and inconsistent service with pay-as-you-go providers. Finally, surnames may change as female survivors marry making it more difficult to locate individuals.

Social networking sites may address one additional challenge to survivorship research which is inclusion of survivors from diverse ethnic minority backgrounds. In February 2013, Pew reported that 68% of online Blacks and 72% of online Hispanics use social networking sites, compared to 65% of Whites. [8] As ethnic minorities are often poorly represented in survivorship research, the high penetration of social networking site usage among these groups is appealing. In addition, social networking use has grown among all age groups. [9,

10] Thus, the use of social networking sites is an opportunity to reach the target population regardless of age and race/ethnicity.

At this time, social networking sites appear to be emerging as potential tools for research recruitment and retention. [11, 12, 13, 14, 15] To our knowledge, little is known about the use of social networking sites among childhood cancer survivors in general or for recruitment. Recruitment involves contacting a specific individual who is not personally known and who is not expecting to be contacted. More importantly, the content of the contact (i.e. childhood cancer survivorship research) makes it clear to the recipient that their personal health information has been disclosed. We felt it was important to understand survivors' perceptions about this type of contact before actually attempting to conduct recruitment to ensure that we were sensitive to their responses. With this in mind, the purpose of the current study was to explore the use of social networking sites among a diverse sample of adult childhood cancer survivors and assess their perceptions of using social networking sites for recruitment into future research.

METHODS

Participants and recruitment

Respondents to this survey were randomly selected and recruited from within a larger federally funded study, entitled the Chicago Healthy Living Study (CHLS). CHLS was an observational cross sectional study of adult survivors of childhood cancer. Recruitment was conducted using registry data from four cancer centers that treat approximately 90% of the children diagnosed with cancer in the immediate Chicago area. Details of the project have been previously published. [16] Briefly, the objectives of CHLS were to describe and compare the influence of ethnicity/race (African-American, Hispanic/Latino or White) and survivor status (cancer survivor or not) on individual health behaviors (diet, physical activity and smoking) and body mass index (BMI) and to identify differences in the mediators of each health behavior and BMI between these groups. Eligible survivors were diagnosed with childhood cancer before the age of 21 and at least 5 years before enrollment, self-identified as African-American/Black, Hispanic/Latino or non-Hispanic White/Caucasian, were at least 18 years of age at recruitment, not pregnant, and were currently cancer-free. Participants completed a one time, 1 ½ – 2 hour interview. [16] The final sample consisted of 150 of each Black, Hispanic, and White survivors for a total of 450 survivors. Recruitment was achieved with considerable expense and effort based upon contact information from cancer registries maintained by the four hospitals. For this survey, a sub-sample of 120 survivors stratified by race/ethnicity and sex were randomly selected from among approximately 250 survivors who had completed CHLS interviews at the time of sampling. This call list of 120 survivors consisted of demographic and basic study information, including name, age, sex, race/ethnicity, address, emergency contact information and CHLS interview date. Up to five telephone calls were placed to the first ten randomly selected survivors within each of the six groups (Black/Hispanic/White X male/female). If a telephone number was disconnected or the five attempts were unsuccessful in making contact, the next name on the list was contacted, until ten interviews were completed

for each group. Surveys were conducted between September 22, 2009 and November 03, 2009 with the goal of surveying ten survivors from each group (race/ethnicity X sex).

Data collection

Once survivors were contacted by telephone, verbal consent was obtained to conduct the eleven item survey assessing the use of social networking sites and the perceptions of using sites for research recruitment as shown in Table 1. All questions were open-ended unless otherwise specified.

This survey and the parent study had full Institutional Review Board approval. Written informed consent was obtained for the parent study and verbal consent was required prior to administering the telephone survey.

Statistical Analyses

Descriptive characteristics were used to summarize the demographics of the survey respondents and non-respondents. The responses to open-ended questions were coded by grouping into categories and the results were qualitatively described. A linear model with all predictors (age, sex and race/ethnicity) examined the relationship between the predictors and outcomes of interest (survey response, social networking site usage, OK to contact via SNS and Respond to SNS) in SAS PROC GENMOD and SAS PROC LOGISTIC. Comparisons were made between respondents (n=60) and non-respondents (n=43) and between SNS users (n=42) and non-SNS users (n=18). Chi-squared tests were performed to evaluate the dependence of the socio-demographic variables (age, sex and race/ethnicity) and the outcomes of interest (survey response and social networking site usage). T-tests were performed to evaluate the effect of the socio-demographic variable of age on the outcomes of interest (survey response, social networking site usage, OK to contact via SNS and Respond to SNS). All analyses were conducted using statistical software SAS version 9.2 for Windows (SAS, Inc, Cary, NC) with significance level of $p > 0.05$.

RESULTS

Of the 120 randomly selected eligible survivors, telephone calls were placed to 103 survivors before the goal of 60 surveys was completed, representing a 58% response rate, as shown in Table 2. Of the 43 survivors that were not reached, 20 had inactive phone numbers, 21 did not respond to messages, and two responded after survey completion. Notably, no survivors refused to participate once contact was made. There were no significant differences in age, sex and race/ ethnicity between respondents and non-respondents.

Below we present descriptive results for response rates to SNS survey and SNS usage. Results for the linear regression, chi-square and t-tests were all non-significant.

Fifty-five percent of the males and 63% of the females that were contacted went on to complete the SNS survey. Also, 59% of Blacks, 59% of Hispanics and 57% of Whites that were contacted went on to complete the SNS survey. Respondents ranged in age from 18 – 48 years of age and non-respondents ranged in age from 18 – 40.

Social Networking Site (SNS) usage

As shown in Table 3, 70% percent of all SNS respondents use Social Networking Sites.

White females, with 90%, reported the most use, whereas Hispanic males, at 50%, reported the least use. After controlling for race/ethnicity and sex, older respondents were less likely to report use of SNS ($p=0.0219$; 95% C.I. = 0.82 – 0.98).

Respondents reported using three social networking sites: facebook, MySpace and Twitter. Among the SNS users, 95% percent used facebook most often and 5% used MySpace most often. One respondent was not included in this website analysis due to her reported use of facebook and MySpace with equal frequency.

Purposes of SNS usage

Ninety-five percent of the participants used social networking sites for communication with friends. Other reported uses include work, academic, communicating with family, renting apartments, recreation/entertainment, meeting new people, religious activities, and monitoring their children's online and offline activities.

Frequency of SNS usage and time spent on SNS

Eighty eight percent of SNS users report at least weekly usage. Overall, on the days that they use SNS, users log-in an average of twice per day for a total of approximately one hour per day. Interestingly, although only 50% of Hispanic males reported SNS use, those who did had the most log-ins per day (average = 2.75) and the largest logged time per day averaging 2.0 hours. Three participants were excluded from the analysis of log-in activity. One Black male, one Hispanic male and one White female reported that they log-in to SNS once per day and remain logged in for 24 hours.

Perceptions of the use of SNS for research study recruitment

As shown in Table 4, 79% of respondents who use SNS reported positive feelings about being contacted for research via social networking sites and 71% reported that they would have responded if contacted initially through social networking sites instead of by phone or letter which was the approach utilized in the parent grant.

Differences were noted across several groups. Hispanic males reported the most positive feelings about being contacted for research via social networking sites (100%), while only 43% of White males reported positive feelings about being contacted. Eighty-three percent of all female SNS users and 72% of all male SNS users reported positive feelings about being contacted for research via social networking sites.

Interestingly, White participants had the largest discrepancy on reported feelings about SNS contact and likeliness to respond to SNS messages. Seventy-eight percent of White females reported positive feelings about being contacted via SNS, but only 44% indicated that they would have responded if contacted through SNS suggesting that they may be hesitant to respond to solicitations via SNS. Conversely, while only 43% of White males reported positive feelings about being contacted via SNS, 71% indicated that they would have

responded if contacted through SNS, suggesting that they might respond even though they felt negatively about being contacted. For preferred method of contact via SNS, 70% of all SNS users preferred contact via a private message. A private message is a message that is sent from one SNS user to the inbox of another SNS user and is only visible by the users. Not only does the user have the option of viewing the message or not, but the user can also block their page from receiving any private messages. A friend request is sent from one SNS user to another, requesting to be added to the recipient's "friend" list. Once the users are "friends", they are able to post public messages on each other's profiles in addition to being able to exchange private messages.

Suggestions on SNS recruitment

Twenty two (37%) offered additional ideas and suggestions on the use of SNS for recruitment:

1. Five (8%) participants suggested that the project post general research recruitment advertisements on SNS sites
2. Ten (17%) participants suggested that the project create a group or organizational SNS page to provide general and study-specific information for cancer survivors
3. Five (8%) participants suggested that the project develop an interactive discussion forum with survivorship education, information on additional research opportunities for survivors and updates on research projects.
4. Two (3%) participants expressed concerns about privacy as a barrier to recruitment via SNS. In addition, several respondents offered that recruitment materials needed to clearly indicate what institution and/or individuals were sending the SNS message.

DISCUSSION

The SNS Pilot Survey revealed that within this small sample of diverse childhood cancer survivors, social networking site use was common across sex and racial/ethnic groups. Furthermore, perceptions regarding recruitment through the sites were generally positive with only 21% feeling negative or neutral. It is important to note that feelings about being contacted did not necessarily line up with willingness to respond to the contact. For example, some survivors reported having negative feelings about being contacted on SNS, yet they reported that they would likely still respond to the contact and vice versa. Overall, the results suggest that survivors may be open to SNS recruitment approaches particularly if the contact made clear what organization was behind the contact. In addition to private messages directed at specific individuals, several additional approaches to SNS recruitment were offered by the survivors.

Limitations for this study must be considered. The sample was randomly selected from within a larger pool of survivors who had all completed a prior research study. This likely biases the sample towards survivors who are more favorable towards research and who may have reported more favorable attitudes towards SNS use for recruitment. Nonetheless, it includes more ethnically diverse sample than is typically seen in much cancer research. An

additional limitation of this study is that it asks for opinions about hypothetical research recruitment via SNS, and does not attempt to conduct actual recruitment. What survivors report and what survivors actually do may differ. Additional research is required to explore how effective SNS recruitment truly is in this population. Because recruitment of childhood cancer survivors is typically so challenging and costly, it is possible that significant financial savings could be realized if SNS recruitment worked for even that group of willing participants.

There are at least two advantages to the use of social networking sites for research studies. First, SNS usage is high across various ethnicities and socioeconomic levels. [17] In February 2013, Pew reported that 68% of online Blacks and 72% of online Hispanics use social networking sites, compared to 65% of Whites. [8] Second, SNS is inexpensive for both the recruiter and the user. There are fees for advertisements, but there are no user fees for facebook [18] or MySpace [19], so the user only incurs the costs associated with their device(s) used to access the internet.

Conversely, there are two significant challenges to the use of social networking sites for research studies - Institutional Review Boards (IRB) and social networking site user guidelines. In a recent webinar “Social Networking: Breakthrough in Patient Recruitment,” the Association of Clinical Research Professionals, revealed that many Institutional Review Boards had not yet developed guidelines and policies to address SNS usage for recruitment. Research studies require IRB approval, and thus advances in this area are critical to integrating SNS usage into study recruitment. In the present study, the IRBs at the various institutions had guidelines established for study recruitment via “internet postings”, but did not specifically address social networking sites. [20]

A second challenge to SNS based recruitment includes the guidelines set by the SNS sites themselves regarding safety, account registration and protection of rights. [18, 19] These guidelines may limit the ability to use SNS sites for research study recruitment. For example, site users must agree not to send or post unauthorized commercial, intimidating, harassing, discriminatory, misleading or unlawful communications. [18, 19] Research study recruitment may be misconstrued as any of the above. SNS site users must also agree not to provide any false personal profile information or post anyone's identification documents or sensitive information. Study recruitment could infringe upon these guidelines, if not carefully constructed. In order to comply with the user guidelines, researchers should disclose the institutional affiliation, the reason for contacting the participant and reveal the actual name of the researcher/principal investigator in the initial communication. In addition, the researcher should not disclose any personal or health information and should not continue to contact the participant after a reasonable number of attempts.

In conclusion, this pilot survey revealed that childhood cancer survivors regularly use social networking sites and 79% had positive perceptions of their use for recruitment of research study participants. Social networking sites appear to offer practical advantages for research recruitment including the potential to contact individuals worldwide. This could theoretically lend itself to recruitment and retention in research. Like much technology, harnessing the potential power of social networking sites and translating it into real

outcomes is likely to be challenging. Further research is necessary to develop and implement an SNS-based recruitment method to actually test the willingness of survivors to respond to SNS as a recruitment tool.

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Table 1

Social Networking Sites (SNS) Survey questions

1	Do you use any social network sites like facebook or MySpace? (Yes/No)
2	If yes, which ones?
3	What do you use these sites for?
4	Which one do you use the most?
5	On average, how often do you use this site?
6	On average, how many times a day do you log on to this site?
7	On average, how long do you use this site each time you log in?
8	How would you feel about being contacted through this site for recruitment to research studies?
9	What would be the best way to contact you via these sites? (Private message, Friend request, or Other --please specify)
10	If we had contacted you on (preferred site) instead of by letter or by phone, would you have responded? (Yes/No)
11	Do you have any ideas or suggestions about how to best recruit via these sites?

Table 2

Response Rates to SNS Survey by Race/Ethnicity, Sex, and Age.

Race/Ethnicity	Sex	Response Rate	Respondents (n=60) Mean Age (SD)	Non-respondents (n=43) Mean Age (SD)
Black		59%	30 (6.6)	27 (5.6)
	Male	56%	30 (6.3)	26 (6.6)
	Female	63%	29 (7.2)	27 (4.5)
Hispanic		59%	28 (7.3)	27 (5.0)
	Male	50%	28 (4.3)	25 (4.7)
	Female	71%	29 (9.7)	25 (5.9)
White		57%	33 (7.6)	31 (6.5)
	Male	59%	34 (6.9)	30 (6.9)
	Female	56%	31 (8.3)	33 (6.3)
Overall		58%	30 (7.3)	29 (6.0)

Table 3

SNS Use and Frequency of SNS Use by Race/Ethnicity and Sex

Race/ Ethnicity	Uses SNS? (N=60)*		Frequency of SNS use (n=42)			Log-in Total time logged-in (hours)
	Yes (n=42)	No (n=18)	Monthly	Weekly	Daily	
Black	65% (13)	35% (7)	0%	62% (8)	39% (5)	1.3
Male	60%	40%		67%	33%	1.1
Female	70%	30%		57%	43%	1.5
Hispanic	65% (13)	35% (7)	23% (3)	39% (5)	39% (5)	1.2
Male	50%	50%	20%	40%	40%	2.0
Female	80%	20%	25%	38%	38%	0.9
White	80% (16)	20% (2)	13% (2)	31% (5)	56% (6)	0.5
Male	70%	30%	14%	43%	43%	0.3
Female	90%	10%	11%	22%	67%	0.7
Overall (n)	70% (42)	30% (18)	12% (5)	43% (18)	45% (19)	1.0

Table 4

Perceptions regarding SNS for recruitment by Race/ethnicity and Sex

Race/ethnicity (n)	Feelings about being Contacted via SNS?			Likely to Respond to SNS contact message?	
	Positive (n)	Neutral (n)	Negative (n)	Yes (n)	No (n)
Black (13)	85% (11)	0%	15% (2)	77% (10)	23% (3)
Male	83%		17%	83%	17%
Female	86%		14%	71%	29%
Hispanic (13)	92% (12)	0%	8% (1)	85% (11)	15% (2)
Male	100%			80%	20%
Female	88%		13%	88%	12%
White (16)	63% (10)	19% (3)	19% (3)	56% (9)	44% (7)
Male	43%	43%	14%	71%	29%
Female	78%	0%	22%	44%	12%
Overall (42)	79% (33)	7% (3)	14% (6)	71% (30)	29%(12)