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Predictors of recruited melanoma families into a behavioral intervention project ☆

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ABSTRACT

Background: Examination of families represents an important priority in health research. In this paper we report on individual and family-level factors associated with enrollment in a cancer prevention research project. We approached families affected by melanoma for possible participation in a randomized controlled trial of a web-based communication and support intervention.

Methods: We recruited three family members per family for assessment — the melanoma case, a first-degree relative (FDR), and a relative who is a parent of a child age 18 or younger. Recruitment involved three steps: requesting the physician's consent to approach the melanoma case, approaching the case to request their participation and family contact information, and they approaching the FDRs and parents.

Results: Of the 1380 families approached, 313 were enrolled, 263 were excluded because we could not find or contact a family member (FDR or parent), 331 did not have eligible family members, and 473 refused. The most frequently noted reason for refusal was being too busy or having no time. The primary predictors of participation for cases (OR = 1.6; CI = 1.01–2.51) and FDRs (OR = 2.15; CI = 1.11–4.13) included higher educational attainment. FDRs

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were more likely to enroll if they were female (OR = 1.77; CI = 1.1–.85) and parents were more likely to enroll if the case had been diagnosed more recently (OR = 3.3; CI = 1.9–5.93), if the parent was partnered (OR = 4.37; CI = 1.86–10.26), and if the parent lived in the same city as the case (OR = 2.88; CI = 1.08–7.68).
Conclusions: The results can provide information on potential directions for future family recruitment.

1. Introduction

The "family" is an important social and biological construct to study in health research. In the context of health and disease, families represent an important entity to study for at least three key reasons. First, because a family history of certain diseases – particularly cancer – has been consistently shown to be a risk factor for developing disease, a diagnosis of disease in one family member has implications for the health and potential disease risk for other family members [1,2–4]. Second, the family often serves as both the source of both information about disease risk and potential prevention, and a source of support if one person is diagnosed with an illness [5]. Third, the family is arguably the most important social and cultural context for the development and establishment of most health risk behaviors, such as smoking, dietary habits, and sun exposure patterns [6]. These extant connections within families are potential untapped avenues for disseminating information to the entire family, particularly for those who may be at risk for developing disease.

There has been little health research examining conceptualization of a family, beyond the conventional "family" as either two spouses, or as a parent and child [7]. However, in many health intervention studies there is great utility in recruiting beyond spouses or parent/child dyads. Approaches that conceptualize families as including multiple generations and multiple members within each generation will be useful as we move forward to intervene more effectively to promote health and reduce disease outcomes within families. This manuscript describes factors associated with recruitment into a study of melanoma risk reduction in families in which at least one member had melanoma.

2. Methods

2.1. Study sample

The data for these analyses are from the Suntalk Study, a randomized controlled trial of a web based communication and support intervention funded by the National Cancer Institute. The purpose of the Suntalk Study was to test the efficacy of a web-based communication tool to improve family communication about melanoma risk and prevention, and to improve melanoma prevention behaviors (i.e., sun exposure, self screening, and provider skin screening). Families with at least one case of melanoma were recruited and assessed via a telephone survey at baseline, and then randomized to either an immediate intervention or a delayed comparison group. Intervention families received access to the study website, which was an interactive communication-oriented system, for approximately one year. Enrolled family members completed a follow-up survey one year later, and then the comparison families received access to the study website.

We used two sources for recruitment of families: 1) the Northwest Cancer Genetics Network (NWCGN) a regional site of the Cancer Genetics Network and 2) The SEER registry (Cancer Surveillance System or CSS) at the Fred Hutchinson Cancer Research Center [8]. Melanoma cases diagnosed with a first primary melanoma between April 1st 1998 and October 1st 2004 were recruited from the NWCGN. The CSS is a population-based cancer registry, part of the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program. For both sources, cases included were those who were living, had a diagnosis of non-ocular melanoma, and had an address and telephone number available in the registry.

We recruited a family for this study as the combination of: the case of melanoma (case), a first degree relative (FDR) of the case, and a relative who was a parent of a child 18 years and under (parent). We focused on FDRs because of the increased risk for melanoma in FDRs once a case is diagnosed and we selected parents because of the importance of protecting children from intensive sun exposure before the age of 18. The eligibility criteria for the family members were:

1) The case was a family member diagnosed with melanoma, aged 18 years or older, with Internet access from a location where the participant would feel comfortable visiting the study website. 2) The FDR was defined as a parent, child or sibling of the case. This meant biological, adoptive, half or step relationships qualified; however, spouses of cases did *not* qualify. We included these half-related FDRs because in many ways they function similar to fully biologically related family members and it seemed disruptive to the family to only include fully biological relations. We explained the difference in the intervention materials. FDRs had to have Internet access from a location where they would feel comfortable visiting the study website. 3) The parent must have had primary responsibility for the child's health and the child must live with the parent at least 50% of the time. Both parent and child could have been biologically related to each other and to the case. Again, this means biological, adoptive, half or step relationships qualified; spouses of cases did *not* qualify. Parents could also be related via marriage to the case, but not on the spouse's side (for example, case's sister's husband qualifies as parent, case's spouse's sister does not qualify as parent). Parents had to have access to the Internet from a place that would be comfortable for accessing the study website.

2.2. Recruitment procedures

Recruitment and informed consent for each family consisted of three stages: physician, case, and relative. The IRB at the Fred Hutchinson Cancer Research Center reviewed and approved this study's procedures.

2.2.1. Physician stage

Prior to approaching the patient, his/her physician of record was contacted by mail with a letter explaining the study. The mailer included a response form for the patient listing the patient's address, date of birth, diagnosis, and diagnosis date for verification along with a request that FHCRC be informed of any reason that the patient should not be contacted (e.g. deceased, too ill). If there was no response from the physician after three weeks, the physician's permission to contact the patient was assumed.

2.2.2. Case stage

Each case with physician consent was mailed a letter and study brochure briefly describing the Suntalk Study and offering the opportunity to participate. The letter explained that a member of our research team would call in the next couple weeks to further describe the study, answer questions, and determine interest in participating and eligibility. The case passive consent letter, like the physician mailing, included the project's phone number for anyone wanting to decline or refuse participation. If no message was received after one week of mailing the case passive consent letter, study staff contacted cases by telephone to screen for eligibility and interest. The screening call included 1) a brief introduction of the staff member; 2) a query about the receipt of the approach letter; 3) a description of the project 4) a confirmation of consent to participate; 5) questions to confirm all eligibility criteria; and 6) specific questions about willingness to participate in various aspects of the study, including randomization into either immediate or delayed intervention group, and access of personal health information via a website. If the case was eligible and interested, project staff then collected the names, relationships, and contact information of all possible FDRs and parents. Cases were asked very specific questions to identify all relatives included in the Suntalk Study's definition of family. Permission to contact was documented for each relative. This report was the basis for recruiting FDRs and parents. Finally, participants were asked to complete a baseline survey over the telephone, either immediately following the screening survey or at a later time. The baseline survey took approximately 35 min to complete and asked questions about all of the study outcomes (sun exposure, self and provider screening), as well as perceived risk, normative beliefs about melanoma risk and preventive behaviors, personal knowledge and affect about melanoma and other study model variables.

2.2.3. Family member stage

All of the case's FDR and parent relatives provided by the case were then approached using the same methods used to approach cases for participation. The method for approaching family members was determined by the type of contact information available. More specifically, if a valid mailing address was available, we mailed an approach letter and study brochure. If we did not have a valid mailing address, but the case had given us the relative's email address, we emailed the approach letter without the study brochure. We randomly selected one FDR of the case to participate in the proposed study, from those FDRs with valid contact information. Following the one-week passive consent wait period, we contacted this person to complete the telephone screening survey. If the first FDR refused, was ineligible, or was unable to be reached, we selected, according to the random sample order, the next FDR. Concurrently, we approached parents using the same procedures.

If we did not have a valid mailing address or email address for the relative, but the case had given us the telephone number, we approached the relative directly by telephone. This scripted call asked for their mailing or email address in order to send the study information. If the FDR/parent agreed, we gave the FDR/parent details about the study over the phone and completed the screening survey. As with cases, all participants provided informed consent for themselves only, and not for others in the family.

Some participants completed the baseline survey, but were not enrolled into the study because we were not able to find an eligible and interested FDR and/or parent relative. These participants were not included in the randomization or further study activities; we sent a letter thanking them for their time and interest in the Suntalk Study.

2.3. Measures

We collected background information from cases using standard questions on age, gender, ethnic/racial background: (White/Caucasian, Black or African-American, Native American or Aleut or Eskimo, Asian, Pacific Islander, Hawaiian, Spanish, Hispanic or Latino, other), education level (8 years or less, some high school, high school graduate or GED, some college or technical school, graduated from college or beyond), marital status (never married, married or living as married, separated, divorced, widowed), income (less than $15 k, $15 k–$30 k, $31 k–$50 k, $51 k–$70 k, $71 k–$99 k, $100 k or above). These standard demographic questions came from BRFSS surveys (http://www.cdc.gov/brfss/). Categories were collapsed as needed when the sample size was too small for stable analysis. Information obtained from the SEER database for each case included diagnosis date and stage at diagnosis. We used zip code to identify whether family members lived in the same city as the case. Demographic information was obtained from the SEER database, the NWCGN core survey, and screening survey questions designed by the study team.

2.4. Analyses

Our analyses were designed to describe the enrollment level and examine the extent to which it was influenced by both individual- and family-level characteristics. We calculated overall response rates for each family type and for the family unit. We measured recruitment yields at each step, by family unit and by individual family member. We also characterized the reasons for refusing to participate provided by potential participants. Finally, we applied multivariate logistic regression to predict enrollment for each family member type. We used all available demographic information as predictors of enrollment. To accomplish this, we first estimated

the log odds of case enrollment (enrolled vs. not enrolled) using individual-level variables. Second, we estimated the log odds of FDR and parent enrollment (one model for each) using individual-level covariates.

3. Results

3.1. Enrollment yields

Recruitment was conducted from late 2005 to mid-2007. Table 1 presents recruitment yields for the 1380 families approached for possible participation in this study. As shown, 263 were excluded because we were not able to find or contact at least one of the family members required for family enrollment. A total of 331 families had at least one family type whose family member(s) did not meet the study eligibility criteria and 473 families had at least one relative type that refused participation. We enrolled a total of 313 families into the intervention study.

Table 2 presents the yields by recruitment stage for cases, FDRs, and parents. Relatively few potential participants were lost at initial contact, but larger numbers were lost because they refused to complete the screening survey or because they refused to continue after they completed the screening survey. Another reason for not being able to recruit families was determining ineligibility at the screening stage, indicating that the screening procedures were working as proposed. More baseline surveys were completed for cases than for the other family members, due to losses as interviewers worked through the interviews with relatives.

3.2. Reasons for refusal

Refusal reasons provided by each type of family member are listed in Table 3. Overall, being too busy was the main reason given for case refusal. Only 12% of the case refusals indicated that contact with family was the main reason. Other reasons were less frequently given, such as sickness and web access problems. Reasons given by relatives included general lack of interest, and refusal for no reason.

3.3. Enrollment process

Cases were recruited within a range of years since diagnosis (from 1 to 7 years). A total of 35% were recruited one year from diagnosis, with the rest evenly spread over the remaining years. The families were relatively small, with 46% of families reporting 6 or fewer relatives. Forty two percent of the cases lived in the same city as either the FDR or the parent. We obtained contact information and permission to have personal contact with a potential participant via multiple means: telephone, mail, email, and occasionally word of mouth were all used to obtain contact information and to ultimately have personal contact with a potential participant. The frequency of contact ranged from one attempt using one method, to multiple attempts using multiple methods over periods of 3–4 months. In one-third of the cases, study staff had to contact almost all or all of the FDRs and parents to obtain an interested and eligible relative for each relative type. In approximately 40% of the family entries, full contact information was not available from one family member, but required multiple contacts from multiple family members to complete.

Table 1
Suntalk Study recruitment yields of entire families.

Total initial sampling pool from all sources	1380
Families from NWCGN (genetics registry)	894
Families from CSS (cancer registry)	486
Families not included in the final study	1067
Ineligible	331
Refused	473
Unable to find or contact	263
Families enrolled into the study	313
Randomized to Intervention condition	157
Randomized to Delayed condition	156

Table 2
Suntalk Study recruitment yields by family member type.

Missing percent of totals in this table	Cases	FDRs	Parents	Total	Percent of total
Consent letter stage					
Total initial letters sent	1380	1248	766	3394	100
Bad address — returned	32	29	15	76	
Other	0	2	2	4	
Able to move to next stage	1348	1217	749	3314	
Total moved to screening stage	1348	683	534	2565	76
Screen not complete	446	190	116	752	22
No accurate contact info.	90	34	26	150	
Never contacted	44	37	9	90	
Deceased	30	0	0	30	
Moved	35	2	3	40	
Language barrier	4	3	1	8	
Contact lost	22	16	17	55	
Refused to complete screening	207	90	53	350	
Reported no skin cancer	6	0	0	6	
Too ill	8	0	0	8	
Other	0	8	7	15	
Screen complete	902	493	418	1813	53
Eligible, moved on to baseline	480	398	367	1245	
Ineligible	260	49	24	333	
Refused to participate in study	162	46	27	235	
Baseline survey					
Baseline not complete	42	38	34	114	
No phone/bad number	1	1	0	2	
15+ attempts	0	1	0	1	
Contact lost	8	18	12	38	
Refused at baseline	29	12	15	56	
Other	4	6	7	17	
Baseline survey complete	438	360	333	1131	33
Dropped post-baseline	125	47	20	192	
Randomized	313	313	313	939	28

3.4. Enrollment results

Table 4 presents descriptive statistics for sociodemographic variables for the potential participants. As seen in this table, there were mostly equal numbers of women and men participating in this study, and the age ranges were broad, in keeping with the eligibility criteria. The educational

Table 3
Reasons for refusal to participate in Suntalk, for each type of relative selected.

	Case		FDR		Parent		Total	
	N	%	N	%	N	%	N	%
Priorities other than work or family	1	(0.3)	0	(0.0)	0	(0.0)	1	(0.2)
Doesn't want comparison group assignment	2	(0.5)	0	(0.0)	0	(0.0)	2	(0.4)
Demands of work	3	(0.8)	5	(4.3)	3	(3.9)	11	(1.9)
Doesn't like phone calls	5	(1.3)	1	(0.9)	2	(2.6)	8	(1.4)
Doesn't want to access website	5	(1.3)	4	(3.4)	4	(5.3)	13	(2.3)
Other—doesn't like studies	7	(1.9)	2	(1.7)	3	(3.9)	12	(2.1)
Other—research requirements too long/cumbersome	9	(2.4)	3	(2.6)	2	(2.6)	14	(2.5)
Other—not in contact with parent relative	10	(2.7)	0	(0.0)	0	(0.0)	10	(1.8)
Family illness, death, emergency, other fam demand	11	(3.0)	3	(2.6)	2	(2.6)	16	(2.8)
Too sick, personal health reasons	15	(4.0)	5	(4.3)	2	(2.6)	22	(3.9)
Refuses to give reason	22	(5.9)	7	(6.0)	0	(0.0)	29	(5.1)
Other—family members wouldn't participate	42	(11.3)	NA		NA		42	(7.4)
Other—doesn't want us to contact family	47	(12.6)	NA		NA		47	(8.3)
Other—not interested	56	(15.1)	29	(24.8)	18	(23.7)	103	(18.2)
Other	63	(16.9)	33	(28.2)	15	(19.7)	111	(19.6)
Too busy/no time	74	(19.9)	25	(21.4)	25	(32.9)	124	(21.9)
Total	372	(100.0)	117	(100.0)	76	(100.0)	565	(100.0)

data proportions were comparable to Census data for the Pacific Northwest region. Most of the parents (and all of the FDR's) confirmed that they were first degree relatives of the case.

3.5. Factors predicting enrollment

Tables 5a and 5b present the results of logistic regression models predicting family enrollment using background data from the case (Table 5a) and the other two family member types (Table 5b). As shown in Table 5a, case income and case education were key predictors of enrollment into the study. Specifically, case participants from the two middle income categories ($51–70 k and $71–99 k per annum) were significantly more likely to enroll than those from the lowest income category. In fact, cases who made between 51 and 70 k had 2.24 times the odds of enrolling in the study compared to those who made 50 k or less (95% CI: 1.42, 3.54). Those cases from the highest income level (100 k or more) were not significantly more likely to enroll in the study than those from the lowest income group. Cases who had a college degree or more education had 1.60 times the odds of enrolling in the study (95% CI: 1.01, 2.51) compared to those who had a high school education or less.

As indicated in Table 5b, being female was the only significant predictor of FDR enrollment, although educational level and marital status were of borderline significance in predicting enrollment (overall p-value: 0.07 for both categories). Women had 1.77 times the odds of enrolling in this study than men (95% CI: 1.10, 2.85) For parents, years since the case was diagnosed, parent age, parent marital status, and living in the same city as the case all predicted enrollment into the study. Parents whose cases were diagnosed more (versus less) recently were more likely to enroll. More specifically, parents who had a relative diagnosed with melanoma 1 year ago had 3.38 times the odds of enrolling in the study when compared to parents whose relative had been diagnosed 6–8 years ago (95% CI: 1.68, 6.78). Age was positively correlated with enrollment, but this was only significant for individuals between the ages of 41 and 55. Parents aged 41–55 had 2.49 times the odds of enrolling in the study than those between the ages of 18 and 40 (95% CI: 1.52, 4.08). Similar to FDRs, parents who made 71 and 99 k had 2.53 times the odds of enrolling in the study than parents who made 50 k or less (95% CI: 1.16, 5.51). None of the other age groups were significantly associated with enrollment status. Those parents who were married had 4.37 times the odds of enrolling than those who were not married (95% CI: 1.86, 10.26). Finally, if a parent lived in the same city as the case they had 2.88 times the odds of enrolling in the study than those who lived in a different city (95% CI: 1.08, 7.68).

4. Discussion

This study sought to recruit a population-based sample of cancer families into a skin cancer prevention trial. Recruitment goals were met by contacting over 3 thousand potential participants to meet our sample size of families. Beginning with cases from rigorously maintained population registries and selecting potential participants at random from among the family members was intended to provide a sample that was representative of cancer families in the region. We were concerned that we would recruit a sample into the Suntalk Study that underrepresented families of lower income. The income levels of the recruited families, which were comparable to local census data in the Pacific Northwest, increases confidence that the sample recruited to the intervention study is one that can be generalized to the regional geographic area.

Recruiting 313 families into the project was labor-intensive; involving the contact of many cases and family members to obtain eligible, interested parents and FDRs. Although our operational definition of “family” was viewed as important to the study's quality, implementing the criteria occupied a large amount of investigator and staff time. For example, even obtaining accurate contact information for family members required multiple contacts with multiple ineligible members. More complex was the multiple communication methods used within a single family. Our interviewers told us that families had complex and often unique systems

Table 4
Descriptive statistics for individual-level variables at approach.

Variable	Case		FDR		Parent		Total	
	N	%	N	%	N	%	N	%
Sociodemographic characteristics for all family member types								
Sex								
Female	735	(53.3)	697	(56.1)	444	(57.8)	1876	(55.3)
Male	645	(46.7)	545	(43.9)	324	(42.2)	1514	(44.7)
Age								
18–30	43	(3.1)	135	(15.2)	29	(8.4)	207	(7.9)
31–40	139	(10.1)	98	(11.0)	115	(33.4)	352	(13.5)
41–50	293	(21.2)	147	(16.5)	163	(47.4)	603	(23.1)
51–60	371	(26.9)	198	(22.2)	32	(9.3)	601	(23.0)
61–70	290	(21.0)	158	(17.8)	5	(1.5)	453	(17.3)
71–80	205	(14.9)	103	(11.6)			309	(11.8)
>80	39	(2.8)	51	(5.7)			90	(3.4)
Missing/unavailable			352		424		776	
Household income[a]								
Less than $15 k	18	(2.1)	28	(2.5)	5	(1.2)	51	(2.8)
$15 k–$30 k	50	(5.7)	65	(12.9)	23	(5.5)	138	(7.7)
$31 k–$50 k	119	(13.6)	89	(17.6)	55	(13.2)	263	(14.6)
$51 k–$70 k	179	(20.4)	89	(17.6)	69	(16.5)	337	(18.7)
$71 k–$99 k	118	(13.5)	80	(15.8)	85	(20.4)	283	(15.7)
$100 k or above	251	(28.7)	106	(21.0)	168	(40.3)	525	(29.2)
Refused	141	(16.1)	48	(3.9)	12	(2.9)	201	(11.2)
Missing/unavailable	505		737		351		1592	
Education[b]								
8 years or less	3	(0.3)	2	(0.4)	2	(0.5)	7	(0.3)
Some high school	18	(1.5)	16	(3.2)	3	(0.7)	37	(1.8)
High school graduate or GED	177	(14.9)	71	(14.1)	33	(7.9)	281	(13.3)
Some college or technical school	400	(33.7)	170	(33.7)	119	(28.5)	689	(32.7)
Graduated from college or beyond	587	(49.5)	246	(48.7)	259	(62.1)	1092	(51.8)
Refused	2	(0.2)			1	(0.2)	3	(0.1)
Missing/unavailable			737		351		1281	
Marital status[b]								
Never married	104	(8.8)	70	(13.9)	11	(2.6)	185	(8.8)
Married or living as married	889	(74.9)	336	(66.5)	366	(87.8)	1591	(75.4)
Separated	13	(1.1)	5	(1.0)	5	(1.2)	23	(1.1)
Divorced	136	(11.5)	58	(11.5)	30	(7.2)	224	(10.6)
Widowed	45	(3.8)	36	(7.1)	3	(0.7)	84	(4.0)
Refused					2	(0.5)	2	(0.1)
Missing/unavailable			737		351		1281	
Relative relationship to case								
First degree			1242	(100)	491	(63.9)	1733	(86.2)
Second degree					165	(21.5)	165	(8.2)
Third degree					112	(14.6)	112	(5.6)
N	1380		1242		768		2010	

[a] Only available for complete screens.
[b] Only available for CSS cases with complete screens and for all NWCGN cases.

of contact that worked for their purposes and that we needed to follow if we wanted to find all eligible members. We did not systematically vary the methods of communication for family members, but simply used all communication methods until we found one that worked or we determined that the person did not want to participate. For example, some family members only used email to contact each other and did not actually have regular mailing addresses for all members. Other families avoided email but used the telephone extensively. However, there was not always symmetry within a family. For some family members, one communication system was preferred over others, and the rest of the family honored that request.

While labor intensive, our experience also provided important insights about the methods that are used by contemporary families in order to maintain contact with one another. No single mode of communication provide the sole means of maintaining contact and frequently, family members communicated with each other and through each other to other family members using multiple and diverse methods, including telephone, email, voice mail, face to face contact, and written contact. Researchers need to be prepared to use all of these methods to recruit a family group as sometimes those family members who relied on one method (such as telephone) did not have access to other methods (such as email).

Table 5a
Model predicting enrolled (n = 313) and not enrolled (n = 480) cases into the randomized trial.

Covariates	Enrolled (versus not enrolled)		
	Odds ratio	95% CI	Overall p
Years since diagnosis			0.49
Up to 3 years	0.78	(0.52, 1.17)	
4–5 years	0.95	(0.67, 1.35)	
6–8 years	REF	–	
Stage at diagnosis			0.66
In-situ	REF	–	
Localized	0.96	(0.57, 1.65)	
regional/distant	1.45	(0.67, 3.14)	
Unstaged	0.94	(0.33, 2.66)	
Gender			0.14
Male	REF	–	
Female	1.26	(0.93, 1.72)	
Age group at recruitment			0.44
18–40	REF	–	
41–50	1.00	(0.59, 1.69)	
51–60	0.92	(0.55, 1.53)	
61–93	1.24	(0.75, 2.04)	
Income			<0.0001
≤$50 k	REF	–	
$51 k–70 k	2.24	(1.42, 3.54)	
$71 k–$99 k	2.33	(1.39, 3.91)	
≥$100 k	1.39	(0.87, 2.21)	
Don't know/refused	0.60	(0.35, 1.03)	
Education			<0.0004
≤High school degree	REF	–	
Some college/technical school	0.82	(0.51, 1.32)	
≥College degree	1.60	(1.01, 2.51)	
Marital status			0.37
Not currently married	REF	–	
Married	1.19	(0.82, 1.73)	

Table 5b
Model predicting FDR enrolled (n = 313) versus not enrolled (n = 398) and parent (n = 313) enrolled versus not enrolled (n = 367) using respondent and case covariates.

Covariates	FDR			Parent		
	OR	95% CI	p	OR	95% CI	p
Years since case diagnosis			0.33			<0.0001
1 year	1.40	(0.75, 2.60)		3.38	(1.68, 6.78)	
4–5 years	1.42	(0.85, 2.37)		3.35	(1.90, 5.93)	
6–8 years	REF	–		REF	–	
Stage at case diagnosis			0.97			0.50
In-situ	REF	–		REF	–	
Localized	0.93	(0.37, 2.35)		1.94	(0.66, 5.67)	
Regional/distant	0.93	(0.26, 3.32)		2.04	(0.50, 8.35)	
Unstaged	1.37	(0.24, 7.89)		5.49	(0.47, 3.62)	
Respondent gender			0.02			0.53
Male	REF	–		REF	–	
Female	1.77	(1.10, 2.85)		1.19	(0.69, 2.08)	
Respondent age			0.79			0.003
18–40	REF	–		REF	–	
41–50	1.23	(0.65, 2.34)		2.49	(1.52, 4.08)	
51–60	1.34	(0.71, 2.54)		1.97	(0.70, 5.58)	
61–93	1.29	(0.71, 2.33)		1.03	(0.08, 12.74)	
Respondent income			0.65			0.10
≤$50 k	REF	–		REF	–	
$51 k–70 k	0.85	(0.44, 1.64)		1.16	(0.53, 2.52)	
$71 k–$99 k	1.54	(0.75, 3.05)		2.53	(1.16, 5.51)	
≥$100 k	0.99	(0.52, 1.89)		1.73	(0.93, 3.23)	
Don't know/refused	0.94	(0.41, 2.14)		1.42	(0.33, 6.05)	
Respondent education			0.07			0.60
≤High school degree	REF	–		REF	–	
Some college/technical school	1.54	(0.80, 2.97)		1.83	(0.56, 6.00)	
≥College degree	2.15	(1.11, 4.13)		1.68	(0.56, 5.03)	
Respondent marital status			0.07			0.0007
Not currently married	REF	–		REF	–	
Married	1.64	(0.97, 2.77)		4.37	(1.86, 10.26)	
Respondent lives in same city as case			0.90			0.03
Yes	0.97	(0.51, 1.82)		2.88	(1.08, 7.68)	
No	REF	–		REF	–	

Socioeconomic status was an important correlate of enrollment, as income and education were significant (or nearly significant) predictors for all three family types. This finding is true in other studies, as the burden of lower socioeconomic status makes participation in some of our other studies less likely [9,10]. One important caution here is the concern that family research in cancer prevention could end up being generalizable only to those with higher income and education levels, so specific interventions to increase research participation in underserved populations is needed to address this issue. How might we reach out to diverse families? Recruitment of families in underserved populations may require outreach efforts similar to those used for individually-focused research, but may also require novel recruitment strategies to maximize participation of multiple family members so that family-focused interventions in cancer prevention are ultimately relevant for diverse families. In addition, for Parents variables that could indicate the parent's closeness to the case (years since diagnosis and likelihood of living in the same city as the case) were significant predictors of increased enrollment for parents. This might mean that extra efforts must be made to include family members with children at home, in order to insure that participation occurs across a wide variety of family members. One of the important findings from this paper is that even though we approached a population-based sample of families, we did not end up recruiting a population based sample into the study. Accordingly, we must move with caution in drawing conclusions about family functioning and health behavior utilization if these findings are based on family research in highly educated, high income families only.

One of the study's limitations is the geographical limitation to the Pacific Northwest. This region, where the cases all were diagnosed, has specific demographic characteristics, including a relatively high education level, that limit the

sample's generalizability to other regions. Recruiting participants into an intervention study with an eligibility criterion of Internet access at home, work, or nearby also limited the sample's representativeness. One of the complications of this type of study is that we must rely on the family to communicate about each other, for contact information and case permission to contact. However, this procedure may have led to over-inclusion of families with more frequent or stronger intra-family communication patterns and under-inclusion of families with less frequent or weaker patterns. We want, however, to understand all types of communication patterns within families, including infrequent or nonexistent communication, but are limited by our inability to obtain contact information for relatives in some families. So a study like this one that both relies on communication for recruitment and wants to study communication will always be limited, by definition. From the data presented we think that this effect on sampling is small, yet it is present and we are unable to evaluate family functioning among multiple family members in families lacking discernible communication patterns. An additional limitation of this study is the small sample size for many of the cells in the models that limits the power to detect significant differences in responses.

The strengths of this study were its approach to family recruitment and the careful tracking of the recruitment process required to enroll three different types of potential participants. The approach was an attempt at population-based multi-generational recruitment process, rather than using a non-population based recruitment strategy to recruit conventional dyads. The tracking of participants enabled us to fully understand the number of contacts necessary per recruited family unit, information that will help in future research related to cancer prevention research and beyond.

The data collected and analyzed during this recruitment process point to several issues that can be emphasized during a population-based family recruitment process. First, multiple, diverse and repeated forms and modalities of communication must be used to capture an intact family if one is attempting to maximize contact with eligible family members. This will include most modern forms of electronic communication, as well as telephone and mail forms. Second, a large number of families must be identified in the beginning to provide a reasonably small number of enrolled intact families, due to both eligibility requirements and to ability to contact family members of specific types and enroll them into the study. Finally, even with vigorous efforts to contact all families, we were unable to recruit lower income families as frequently. This has led to some bias in the recruited families and subsequent lack of input into study findings from families with lower income or educational attainment.

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