

A Follow-Up Community Survey of Knowledge and Beliefs About Cancer and Genetics

Shannon M. Sweeney¹ · Janice L. Hastrup^{2,3} · Andrew Hyland³ · Cheryl Rivard³

Published online: 15 May 2015

© American Association for Cancer Education 2015

Abstract The purpose of this study is to assess changes since the launch of the US Surgeon General’s campaign in the public’s beliefs about the role of genetics in the etiology of cancer, as well as changes in recording family health history. We conducted a survey of 480 Western New York adults, assessing: (1) experiences with cancer, (2) beliefs about cancer and genetics, and (3) practices of recording family health history. Most respondents were aware of the importance of family history. The sample also showed increased knowledge about cancer and genetics compared with a previous survey. However, only 7 % kept written records that included medical conditions, which was not different from a previous survey. Time constraints, apathy, and reluctance to find out negative health information were the most reported barriers. Results suggest a need for continued education of the public, with increased emphasis on written family health records.

Keywords Cancer · Genetics · Family health history · Family history · Pedigree

Advances in genetics offer unparalleled opportunities for enhanced disease prevention and more personalized health care

The findings from this research were presented at the annual meeting of the American Association for Cancer Education, Buffalo, NY, September 2012.

✉ Shannon M. Sweeney
smsweene@syr.edu

¹ Syracuse University, 430 Huntington Hall,
Syracuse, NY 13244-2340, USA

² University at Buffalo, Amherst, NY, USA

³ Roswell Park Cancer Institute, Buffalo, NY, USA

[1, 2]. Since the completion of the Human Genome Project in 2003, the number of genetic tests used in clinical practice and clinical research has grown rapidly; more than 1800 genetic tests are currently available to clinicians and an additional 250 are presently under development [3]. Although genetic tests have traditionally been used for rare, single-gene disorders [4], an increasing number of genetic variants are currently being evaluated for their associations with common, complex diseases [5]. Family history of these common diseases is gaining importance in risk assessment and prevention because it reflects not only inherited genetic susceptibilities but also shared environments and behaviors, as well as complex interactive effects [6].

Although primary care physicians are trained to collect a detailed family health history from patients, they often neglect to do so because of the time and effort required, as well as perceived lack of knowledge and skill in interpreting such information and providing accurate management options [7–9]. The issue of time and effort is a daunting challenge, but one that may be alleviated with self-administered, electronic family history collection tools. In 2004, the US Surgeon General, in conjunction with other agencies within the US Department of Health and Human Services, launched a national public health campaign called the Surgeon General’s Family History Initiative [10]. This campaign includes an interactive online tool, called “My Family Health Portrait,” which assesses familial risk for six common diseases (coronary heart disease, stroke, diabetes, and colorectal, breast, and ovarian cancers) and then provides the individual with a personalized prevention plan, which includes recommendations for lifestyle changes and screening [11]. An impact trial found that primary care patients were able to use this risk assessment tool easily outside of the clinical setting [12].

Previous surveys administered before this campaign have shown that, although the majority of Americans consider family history important to their health, few actively collect and

document this information [13, 14]. In this study, we aim to: (1) assess changes in beliefs concerning cancer and genetics and (2) evaluate the impact of the US Surgeon General's campaign by monitoring changes in record-keeping of family health information.

Method

Consumer Telephone Surveys

In the spring of 2001, Roswell Park Cancer Institute co-sponsored a community-based education campaign entitled *Is Cancer in Your Family Tree?* (see [13] for a more detailed description). Two cross-sectional random-digit dialed telephone surveys of Western New York adults were conducted. Within a selected household, any adult willing to participate in the 10-min interview was eligible. The first survey involved 103 adults and was implemented 1 week before the campaign, while the second survey involved 151 adults and was conducted 2 weeks after the campaign. Only 30 of the 151 (20 %) participants reported exposure to the campaign, so the data were restricted to an aggregate of the ($N=103$) individuals who were interviewed prior and ($N=121$) individuals who were interviewed after, but who had not been exposed to the campaign.

In the spring of 2010, we conducted another cross-sectional random-digit dialed telephone survey of 480 Western New York adults. Within a selected household, the next-birthday method [15] was used to select an eligible adult for the 10-min interview. Survey questions were worded and administered as they had been in the 2001 surveys. Several additional questions were added to this follow-up survey in order to gain a better understanding of record-keeping practices. The majority of the results presented here compare the cross-sectional aggregate ($N=224$) of the 2001 surveys to the 480 respondents of the 2010 survey. The study was approved by the Roswell Park Cancer Institute Institutional Review Board and the University at Buffalo Institutional Review Board.

Data Collection

The follow-up survey consisted of a maximum of 52 items. Survey items included: (1) demographic characteristics; (2) experiences with cancer; (3) beliefs about cancer, genetics, and genetic testing; (4) beliefs about causes of cancer; and (5) practices of recording family health history. Interviews were anonymous; informed oral consent was obtained prior to beginning each interview. The cooperation rate for this survey, or the rate of cooperation after reaching an eligible respondent in a household, was 81 %.

Conducting telephone interviews resulted in a sample that overrepresents females and older individuals compared with

the general population. Over two thirds (71 %) of the total sample was female. Proportions of ethnic/racial categories for the respondents were comparable to the 2006–2010 American Community Survey (ACS) estimates of adults in the region [16]: White 90 %, African-American 7 %, Asian/Pacific Islander <1 %, American Indian/Alaska Native <1 %, and Other or more than one race 1 %; 1 % of the sample also reported that they were of Hispanic origin. Educational levels of the sample were higher than the 2006–2008 ACS estimates for this area: 40 % reported having graduated from college or attained a higher degree, 24 % indicated 1 to 3 years of college, and just under a third (30 %) had completed high school but no higher education. Only 6 % reported having less than a high school diploma. The gender, ethnic/racial, and educational attainment distributions were comparable to those from the previous 2001 survey, while the mean age of 56 was higher than in the 2001 survey ($M=49$).

Coding of Single-Response, Open-Ended Questions

Four single-response, open-ended questions were included in each interview. Interviewers were given five or six common responses to each question, based on previous research, to code these responses during the interviews. However, a large number of respondents mentioned unique, similar responses that merited additional coding during analyses.

For the question regarding facilitators of record-keeping of family health information, responses that directly cited the hereditary nature of certain health problems, or that indirectly cited heredity by speaking to prevention of health problems, were collapsed into one category. Another category was created for those who reported health/medical reasons, but did not specifically address the hereditary nature of these problems or prevention. For the question regarding barriers to record-keeping of family health information, a category that spoke to the affective barrier to record-keeping was created, including responses such as “fear of knowing” or “not wanting to worry.” The other categories for these two questions were maintained as they had been given to interviewers.

For the question regarding facilitators of genetic testing, responses that directly cited knowledge of hereditary problems or the respondent's own prevention were collapsed into one category. For the question regarding barriers to genetic testing, a category was created for those who stated they would want to know if they had a gene that put them at higher risk of getting a particular kind of cancer. The other categories for these two questions were maintained as they had been given to interviewers.

Results

Analytic Strategy

Cross-tabulations and Pearson's chi-square tests were used to explore the differences between experiences, beliefs, and practices from the 2001 survey and the follow-up 2010 survey. For belief items, where respondents were asked to agree or disagree with a variety of statements, "don't know/unsure" responses were collapsed into the incorrect answer. Several new questions were added to this follow-up survey, which were not part of the original 2001 survey.

Responses to belief questions about cancer and heredity, selected questions regarding record-keeping practices, and respondents' sources of information for learning information were examined for patterns associated with family history and sociodemographic variables, including gender, ethnicity, age, and educational attainment. Those with a personal experience with cancer, or who reported an immediate family member experiencing cancer, were classified as having a positive family health history; those without either were classified as having a negative family health history. For ethnicity, respondents were categorized as either "white" or "non-white." Age was split at the median into two categories, those "aged 18–57" and those "aged 58–94." Educational attainment was also split into two categories: those with a high school degree or less and those with a higher level of formal education. All of these analyses were carried out using PASW 18.0 [17].

Experiences with Cancer

A total of 92 (19 %) respondents reported that they had been diagnosed with cancer, which was higher than in the 2001 survey ($n=24$; 11 %; $P=.01$). The primary sites of skin ($n=25$; 27 %) and breast ($n=22$; 24 %) cancer accounted for about half of the reports. The mean and median age at diagnosis for those cancers was approximately 54 and 55 years, respectively. Additionally, there were 268 (56 %) respondents who indicated that someone in their immediate family had been diagnosed with cancer, as well as 286 (60 %) who reported that a more distant relative had been diagnosed with cancer. These were significantly higher cancer rates than in the 2001 survey, for both immediate family diagnoses ($n=86$; 38 %; $P<.01$) and distant relative diagnoses ($n=124$; 55 %; $P<.01$).

Experiences and Practices Regarding Family Record-Keeping

Responses to selected questions about family history and medical record-keeping are shown in Table 1. Just under a third of the sample ($n=144$; 30 %) had taken the time to draw a family tree, listing blood relatives, which was not different than the 2001 survey ($n=63$; 28 %). Only 7 % ($n=34$) of the

sample listed medical conditions such as cancer, which was not different than the previous survey ($n=18$; 8 %). There were also no differences by family health history or sociodemographic variables.

When asked what got the respondent's family to start keeping track of medical conditions among family members, 41 % ($n=14$) cited personal or family health issues. Other answers were varied: five respondents (15 %) indicated their own interest, four respondents cited the interest of a family member (12 %), another four (12 %) cited communication with family members (e.g., talking and family reunions), three (9 %) mentioned physicians, and two cited schooling (6 %). None mentioned the US Surgeon General's campaign or the media.

Responses to new, follow-up questions concerning written family health information are shown in Table 2. The majority of respondents ($n=339$; 71 %) indicated that they had not heard of any Internet websites that can help people keep track of their family health history. Of those who indicated they had heard of such websites ($n=134$; 28 %), the majority ($n=114$; 85 %) said they did not remember what group or organization sponsored it. Seven respondents (5 %) recalled [Ancestry.com](#) as the sponsoring organization. None of the respondents mentioned the US Surgeon General's website. Those with a positive family history were significantly more likely ($P=.03$) to recall hearing of an Internet website than those with a negative family history (31 vs. 22 %).

Of those who do not currently keep track of family health history ($n=446$), over half ($n=237$; 53 %) indicated that they would not know how to proceed if they decided to keep track of this information. Those with a higher degree of formal education were more likely ($P=.01$) to indicate that they would know how to proceed (49 vs. 35 %). A substantial number of these same respondents ($n=446$) also indicated that there was no one who could show them what to do ($n=103$; 23 %), and that they would not know how to look for help on the Internet ($n=91$; 20 %). Those with a higher degree of formal education were also more likely ($P<.01$) to indicate knowing how to look for help on the Internet (71 vs. 49 %), as well as younger individuals (81 vs. 42 %).

Barriers and Facilitators to Family Record-Keeping

When asked what is the most important reason why people keep track of family health information, 48 % of respondents ($n=229$) cited the hereditary nature of certain health problems; this included common responses such as "in case there's a genetic predisposition" and "to know what they're at risk for." An additional 13 % ($n=64$) reported the importance of such knowledge for offspring, while a smaller number ($n=33$; 7 %) cited protecting existing family members. Other answers varied: 6 % ($n=29$) responded "health/medical reasons," but did not mention heredity; 5 % ($n=25$) reported wanting such information for doctors' and/or hospital visits; and 5 % ($n=24$)

Table 1 Experiences and practices regarding family record-keeping

| | Agree | Disagree | Don't know | Change over time |
|--|------------|------------|------------|------------------|
| Have you ever taken the time to draw out your family tree, listing all blood relatives? | 144 (30 %) | 331 (69 %) | 4 (1 %) | – |
| Does your family tree list medical conditions such as cancer? | 34 (7 %) | 107 (22 %) | 3 (1 %) | – |
| If someone is developing cancer somewhere in the body, survival will be better if it's found early. | 470 (98 %) | 4 (1 %) | 6 (1 %) | – |
| A person's heredity plays a bigger role than smoking cigarettes in whether they will get lung cancer. | 141 (29 %) | 280 (58 %) | 59 (12 %) | – |
| If a person has a parent who had cancer, then that person is more likely than other people to develop the same kind of cancer. | 308 (64 %) | 112 (23 %) | 60 (13 %) | – |
| If a person has a family history of cancer, they should begin screening for that cancer at an earlier age than the average person. | 462 (96 %) | 6 (1 %) | 12 (3 %) | – |
| If someone has a family history of cancer, he or she can usually do something to reduce the risk of developing cancer. | 381 (79 %) | 55 (12 %) | 43 (9 %) | $p=.05$ |
| If someone has a gene that puts him or her at higher risk of cancer, there is almost nothing they can do to prevent cancer from developing. | 80 (17 %) | 345 (72 %) | 55 (12 %) | $p<.01^*$ |
| If someone has no family history of cancer, then there is little or no risk of developing cancer. | 23 (5 %) | 437 (91 %) | 20 (4 %) | $p=.01^*$ |
| If a blood test were available to identify an inherited gene that poses an increased risk for cancer, would respondent be willing to take this test? | 396 (83 %) | 44 (9 %) | 40 (8 %) | $p<.01^*$ |

* $p<0.05$

reported “just to know.” A small number ($n=31$; 7 %) could not think of any reasons or were unsure.

When asked what the biggest thing that deters people from keeping track of family health information, the answers were varied: 24 % ($n=116$) of respondents cited “too busy” or “too time-consuming,” 16 % ($n=78$) responded “fear of knowing” or “not wanting to worry,” and 16 % ($n=75$) cited “lack of concern” or “laziness.” An additional 15 % ($n=72$) could not think of any reasons or were unsure. Other answers included “lack of knowledge” ($n=22$; 5 %) and “ignorance” ($n=15$; 3 %). Only 5 % ($n=23$) mentioned privacy concerns, while an even smaller number ($n=21$; 4 %) of respondents cited infrequent contact with relatives.

Beliefs about Cancer, Genetics, and Genetic Testing

Responses to questions on opinions and beliefs about heredity and cancer are also shown in Table 1. Nearly all respondents ($n=462$; 96 %) were aware that someone who has a history of cancer in their family should begin screening for that cancer at

an earlier age, which was not different than the 2001 survey ($n=209$; 93 %). Additionally, 41 % of respondents ($n=198$) believed that an individual who is diagnosed with cancer early in life (<50 years) would have relatives who are at increased risk, which was also not different than the 2001 survey ($n=101$; 45 %). Younger individuals were more likely (46 vs. 36 %, $P=.03$) to subscribe to this belief, as well as those with a higher level of formal education (45 vs. 35 %, $P=.03$).

Almost all of those interviewed ($n=470$; 98 %) were aware that probability of survival is higher if cancer is detected early, which was not different from the 2001 survey ($n=217$; 97 %). Women were more likely ($P<.01$) to subscribe to this belief (99 vs. 94 %) than men. Almost three quarters ($n=345$; 72 %) of those interviewed believed that if a person has a gene that puts one at higher risk of cancer, the individual can do something to prevent cancer from developing; this was higher than in 2001 ($n=136$; 61 %; $P<.01$). A substantial minority of those interviewed ($n=80$; 17 %), however, believed there is almost nothing that can be done, and an additional group nearly as large ($n=55$; 12 %) reported they were unsure. Those

Table 2 Knowledge of tracking family record-keeping

| | Yes | No | Don't know/unsure |
|---|------------|------------|-------------------|
| Have you heard of any Internet websites that can help people keep track of their family health history? | 134 (28 %) | 339 (71 %) | 7 (2 %) |
| If you decided to keep track of your family health information, would you know how to proceed? * | 194 (44 %) | 237 (53 %) | 13 (3 %) |
| Is there someone who could show you what to do? * | 125 (28 %) | 103 (23 %) | 22 (5 %) |
| Would you know how to look for help on the Internet? ^a | 155 (35 %) | 91 (20 %) | 6 (1 %) |

^a These percentages are based on the sample who currently do not keep written track of family health information ($n=446$)

most likely to subscribe to deterministic beliefs were older individuals ($P<.01$), nonwhites ($P=.048$), and those with a high school degree or less ($P<.01$).

With respect to genetic testing, the majority of respondents ($n=396$; 83 %) said that they would be willing to take a genetic blood test for cancer, if it were available, which was higher than in the 2001 survey ($n=174$; 78 %; $P<.01$). Men (89 vs. 80 %, $P=.04$) and younger individuals (86 vs. 80 %, $P=.046$) were more likely to say they would undergo genetic testing.

Barriers and Facilitators to Genetic Testing

When asked why the respondent might want to find out if he/she had a gene that put him/her at higher risk for getting a particular kind of cancer, the majority ($n=377$; 79 %) of the single-response, open-ended answers focused on prevention, including common responses such as “to know what I’m at risk for,” “to get screened or treated earlier,” and “to live a longer, healthier life.” Few respondents, however, mentioned warning existing family members of genetic risk ($n=10$; 2 %) or preventing passing the gene to offspring ($n=15$; 3 %).

When asked why the respondent might *not* want to find out if he/she had a gene that put him/her at higher risk, the majority ($n=204$; 43 %) could not think of any reasons or were unsure. Other answers varied: 25 % ($n=119$) responded “fear of knowing” or “not wanting to worry,” 12 % ($n=55$) reported fear of being treated differently by friends and family members, and 7 % ($n=33$) maintained that they “would want to know.” Few respondents subscribed to the beliefs that “ignorance is bliss” ($n=20$; 4 %) and “nothing can be done anyway” ($n=17$; 4 %).

Beliefs about Major Causes of Cancer

When asked which factor was most responsible for cancer: 43 % of respondents ($n=204$) chose lifestyle factors like smoking and diet, 24 % of respondents ($n=117$) chose heredity, and 21 % ($n=99$) chose chemical pollution/environment. These beliefs were different than the original survey ($P<.01$), in which 36 % of respondents ($n=80$) chose lifestyle factors, 33 % of respondents ($n=73$) chose heredity, and 26 % ($n=58$) chose chemical pollution/environment. Generally, men were more likely ($P=.03$) to choose lifestyle factors (53 vs. 39 %), while women were more likely to choose heredity (26 vs. 22 %) and chemical pollution/environment (23 vs. 16 %).

Only a minority ($n=20$; 4 %) felt that there was little or no risk of developing cancer if there was no family history, which was lower than in 2001 ($n=24$; 11 %; $P=.01$). Those most likely to subscribe to this belief were older individuals ($P=.01$), nonwhites ($P=.02$), and those with a high school degree or less ($P<.01$). About a third ($n=141$; 29 %) of those interviewed believed that heredity plays a bigger role than

smoking cigarettes in causing lung cancer, which was not different than the 2001 survey. Those with a higher level of education were more likely (64 vs. 48 %, $P<.001$) to attribute lung cancer to smoking.

Sources of Information about Genetics and Cancer

Respondents identified from which source they learned the most about heredity and cancer. Multiple responses were not permitted. Their primary sources of information included family members ($n=103$; 22 %) and mass media outlets, including television ($n=73$; 15 %), magazines ($n=57$; 12 %), the Internet ($n=47$; 10 %), and newspapers ($n=44$; 9 %). Few cited physicians or health care professionals ($n=43$; 9 %), even though most reported having had a routine medical checkup within the past year ($n=422$; 88 %). An additional 8 % ($n=38$) mentioned their education or reading literature. The use of newspapers significantly decreased as a source of information since the 2001 survey ($P<.01$), while the reported use of family members increased ($P=.01$), as shown in Table 3. Other sources did not differ from the original survey.

Sources of information differed by gender, education, age, and family history, but not by ethnicity. Generally, men ($P<.01$) and those with a higher level of education ($P=.04$) were more likely to indicate that they learned the most from the Internet. Men and women had similar levels of education, suggesting these are independent effects. Respondents with a high school degree or less got more of their information from television ($P=.01$). Older individuals were more likely to obtain information from newspapers ($P<.01$), while younger individuals were more likely to obtain information from relatives ($P=.01$) and the Internet ($P=.01$). Finally, those with a positive family history were less likely to obtain their information from the television ($P=.02$).

Only a minority ($n=34$; 7 %) reported that their physicians or other health-care professionals recommended genetic risk assessments, which were not different than the 2001 survey. Of those who did get a recommendation, 11 of the 34 (32 %) completed it. Forty-two percent ($n=202$) of the respondents said they had spoken with a physician or health-care professional regarding concerns about inherited risks for cancer, which was higher than in the 2001 survey ($n=71$; 32 %; $P=.01$). Most of this group had spoken with their primary care physician ($n=173$; 86 %), a cancer specialist ($n=53$; 26 %), a physician–geneticist ($n=19$; 9 %), or a genetics counselor ($n=18$; 9 %).

The great majority of respondents ($n=394$; 82 %) reported that those in their immediate family usually shared information about medical conditions, including cancer, which was not different than in the 2001 survey ($n=184$; 82 %). However, almost a third of respondents ($n=147$; 31 %) reported that this information was not shared among more distant relatives, which was higher than in the 2001 survey ($n=44$; 20 %; $P<.01$).

Table 3 Sources of information about heredity and cancer

| | Previous survey | | Current survey | | Change over time |
|---------------------------------|-----------------|-------|----------------|-------|------------------|
| | <i>N</i> | % | <i>N</i> | % | |
| Your relatives | 30 | 13 | 103 | 22 | <i>p</i> =.01 |
| Television | 34 | 15 | 73 | 15 | – |
| Magazines | 33 | 15 | 57 | 12 | – |
| Internet | 15 | 7 | 47 | 10 | – |
| Newspapers | 48 | 21 | 44 | 9 | <i>p</i> <.01 |
| Physicians/health professionals | 16 | 7 | 43 | 9 | – |
| Education | 13 | 6 | 38 | 8 | – |
| Your friends | 22 | 10 | 33 | 7 | – |
| Other source | 6 | 3 | 15 | 3 | – |
| Don't know | 7 | 3 | 27 | 6 | – |
| Total | 224 | 100 % | 480 | 100 % | |

Respondents identified from which source they learned the most about heredity and cancer. For this question, multiple responses were not permitted. Individual 2×2 chi-square analyses were run testing the differences between survey years for each individual source

Discussion

This past decade has been marked with rapid advances in human genetics. However, a gap still exists between the swift pace of human genome discoveries and the slower rate of evidence-based applications for health care and prevention [18]. Family health history, which is used as a risk assessment tool and to guide preventive behaviors, can help close that gap [19, 20]. It is important to know how the public's record-keeping of family health information, as well as the public's beliefs about cancer and genetics, have changed over time; this allows us to evaluate the impact of the Surgeon General's campaign, as well as serving to improve design of future educational programs.

Absence of Written Family Health Information

Fewer than one in ten kept a written record of the family tree with medical information, including cancer, which was not different than in our previous survey. The lack of written records of family health problems is surprising, given that the great majority of respondents indicated that their immediate family members talk and share information about medical conditions. Very few cited infrequent contact with relatives or privacy concerns as hindering the collection of family health information. Instead, similar to other research [21], time constraints, apathy, and reluctance to find out potentially negative health information were the most commonly reported barriers to family health history collection.

Of those who indicated keeping records, none cited the Surgeon General's website. Since its launch in 2004, this national public health campaign has included both public awareness and provider education programs. In addition to

development and continual updating of the interactive online tool called "My Family Health Portrait," the initiative marked Thanksgiving as National Family History Day, to encourage families to discuss their health problems when they gather together [10]. Other efforts included distributing family history resource materials to chronic disease and genetic experts in state health departments and partnering with hospitals and health-care institutions to participate in the initiative. Despite these efforts, the results of our study suggest a greater need to increase public awareness about the campaign.

One of the most effective ways to further promote the campaign and help facilitate patient documentation of family health history may be through the engagement of medical professionals. One survey of primary care providers found that 73 % felt a patient-generated computer family health history would improve their ability to assess risk compared to the information they currently collect [22], suggesting that providers may be receptive to promoting and facilitating the use of web-based tools. However, despite this receptivity, providers report having little exposure to patient-generated family health histories, suggesting that additional efforts are needed to educate providers. Genetic counselors and nurses may be in a prime position to increase the knowledge and use of patient-generated family health history tools by primary care providers through practice sessions, didactics, and other educational strategies [22].

It may also be important to focus on patient characteristics in order to help facilitate patient documentation of family health history. The majority of our sample indicated that they would not know how to proceed if they decided to keep track of family health information. Substantial numbers also said there was no one to show them how to proceed, or that they would not know how to look for help on the Internet. These

results varied by education and age, with younger, more educated individuals being more likely to know how to proceed. This is consistent with commonly cited criticisms of online family history tools including accessibility for those without Internet access and complex medical terminology that may not be understood by the general public [23]. This suggests that there may be value in offering different subgroups a variety of options for tracking family health history. For example, one community-based project that offered a culturally appropriate toolkit, which involved oral traditions and family stories, to two minority populations was successful in increasing knowledge regarding family health history [21].

Improvements in Interpretations of Genetic Information Since the 2001 Survey

The majority of the sample showed increased knowledge regarding genetic factors in the etiology of cancer compared with the previous survey. Respondents were less likely to subscribe to deterministic beliefs: The number of respondents who believe nothing can be done to prevent expression of genetic inheritability decreased, as well as the number of respondents who believe absence of a family history indicates little or no risk. However, there is still a minority subscribing to deterministic beliefs. As also evidenced by our findings, the general public often uses mass media outlets to learn about genetics and cancer; these outlets frequently distort scientific findings, often by shifting clear shared gene–environment claims in one direction or another [24], which may contribute to these false beliefs.

Attitudes and Beliefs about Genetic Testing

Our results concur with surveys indicating that the public is eager to obtain their own personal genetic information [25]. The majority of respondents indicated willingness to take a genetic test for cancer, which was higher than the previous survey. The most common reasons cited for not wanting to take a genetic test were fear and anxiety. However, current research has shown that, while genetic counseling leads to increased knowledge of cancer and genetics, it does not have an adverse effect on cancer-specific worry, general anxiety, distress, and depression [26]. Few participants cited job or insurance discrimination; these fears may have been alleviated by the Genetic Information Nondiscrimination Act (GINA), which outlaws employers and health insurance companies from discriminating against individuals on the basis of genetic test results [27].

Limitations

Our results are based on a convenience sample of adults living in Western New York. Therefore, caution is warranted before

generalizing these findings to other adult populations within the USA. Indeed, our telephone-based survey was biased in favor of high-income and older individuals, who are more likely to have landlines. There was also an overrepresentation of individuals with a higher level of education, as well as those with a history of cancer. If anything, these biases would be expected to favor a group that would be more likely to record information about family health history, which makes the low level of record-keeping reported here all the more surprising. Future research should examine the generalizability of our findings by testing whether they replicate among other samples, including a wider range of sociodemographic backgrounds.

Conclusion

Our findings show increased knowledge concerning cancer and genetics, particularly in regards to reductions in deterministic interpretations of genetic information. However, despite the launch of the Surgeon General's campaign, the vast majority (93 %) still needs encouragement to record family health history information. Physicians and other health professionals, who have been shown to be receptive to computer-generated family health histories, may be instrumental in increasing awareness of this campaign and facilitating the use of such web-based tools. We also found an increased willingness to take a genetic test, reinforcing current research suggesting that the general public is interested in genetic testing. Overall, there is still a need for continued education about cancer and genetics, as well as encouragement to keep written records of family health information.

References

1. Feero WG, Guttmacher AE, Collins FS (2008) The genome gets personal—almost. *J Am Med Assoc* 299:1351–1352
2. Westfall JM, Mold J, Faqan L (2007) Practice-based research—blue highways on the NIH road map. *J Am Med Assoc* 297:403–406
3. The National Center for Biotechnology Information (2010) GeneTests. <http://www.ncbi.nlm.nih.gov/sites/GeneTests/>
4. Khoury MJ (1997) Genetic epidemiology and the future of disease prevention and public health. *Epidemiol Rev* 19:175–180
5. Christensen K, Murray JC (2007) What genome wide association studies can do for medicine. *N Engl J Med* 356:1094–1097
6. Valdez R, Yoon PW, Qureshi N, Green RF, Khoury MJ (2010) Family history in public health practice: a genomic tool for disease prevention and health promotion. *Annu Rev Public Health* 31:69–87
7. Rich EC, Burke W, Heaton CJ, Haga S, Pinsky L, Short MP, Acheson L (2004) Reconsidering the family history in primary care. *J Gen Intern Med* 19:273–280

8. Gramling R, Nash J, Siren K, Eaton C, Culpepper L (2004) Family physician self-efficacy with screening for inherited cancer risk. *Ann Fam Med* 2:130–132
9. Flynn BS, Wood ME, Ashikaga T, Dana GS, Naud S (2010) Primary care physicians' use of family history for cancer risk assessment. *BMC Fam Pract* 11:45, <http://www.biomedcentral.com/1471-2296/11/45>
10. U.S. Department of Health and Human Services (2010) Surgeon General's family health history initiative. <http://www.hhs.gov/familyhistory/>
11. Yoon PW, Scheuner MT, Jorgensen, CJ, Khoury MJ (2009) Developing family healthware, a family history screening tool to prevent common chronic diseases. *Prev Chron Dis* 6(1). http://www.cdc.gov/pcd/issues/2009/jan/07_0268.htm
12. O'Neill SM, Rubinstein WS, Wang C, Yoon PW, Acheson LS, Rothrock N, Starzyk EJ, Beaumont JL, Galliher JM, Ruffin MT (2009) Familial risk for common diseases in primary care: the family healthware impact trial. *Am J Prev Med* 36:506–514
13. Piniewski-Bond J, Celestino PB, Mahoney MC, Farrell CD, Bauer JE, Hastrup JL, Cummings KM (2003) A cancer genetics education campaign: delivering parallel messages to clinicians and the public. *J Cancer Educ* 18:95–99
14. Yoon PW, Scheuner MT, Gwinn M, Khoury MJ (2004) Awareness of family health history as a risk factor for disease—United States, 2004. *MMWR Morb Mortal Wkly Rep* 53:1044–1047
15. Salmon CT, Nichols JS (1983) The next-birthday method of respondent selection. *Public Opin Q* 47:270–276
16. U.S. Census Bureau (2010) 2006–2010 American community 5-year estimates. <http://www.census.gov/acs/www/index.html>. SPSS Inc. Released 2009
17. PASW Statistics for Windows, Version 18.0. Chicago: SPSS Inc
18. Khoury MJ, Gwinn M, Yoon PW, Dowling N, Moore CA, Bradley L (2007) The continuum of translation research in genomic medicine: how can we accelerate the appropriate integration of human genome discoveries into health care and disease prevention? *Genet Med* 9:665–674
19. Yoon PW, Scheuner MT, Peterson-Oehlke KL, Gwinn M, Faucett A, Khoury MJ (2002) Can family history be used as a tool for public health and preventive medicine? *Genet Med* 4:304–310
20. Yoon PW, Scheuner MT, Khoury MJ (2003) Research priorities for evaluating family history in the prevention of common chronic diseases. *Am J Prev Med* 24:128–135
21. Petruccio C, Mills Shaw KR, Boughman J, Fernandez C, Harlow I, Kruesi M, Kyler P, Lloyd-Puryear MA, O'Leary J, Skillman A, Terry S, McKain F (2008) Healthy choices through family history: a community approach to family history awareness. *Community Genet* 11:343–351
22. Fuller M, Myers M, Webb T, Tabangin M, Prows C (2010) Primary care providers' responses to patient-generated family history. *J Genet Couns* 19:84–96
23. Owens KM, Marvin ML, Gelehrter TD, Ruffin MT IV, Uhlmann WR (2011) Clinical use of the Surgeon General's "My Family Health Portrait" (MFHP) tool: opinions of future health care providers. *J Genet Couns* 20:510–525
24. Brechman J, Lee C, Cappella JN (2009) Lost in translation?: a comparison of cancer-genetics reporting in the press release and its subsequent coverage in the press. *Sci Commun* 30(4):453–474
25. Kaufman D, Murphy J, Scott J, Hudson K (2008) Subjects matter: a survey of public opinions about a large genetic cohort study. *Genet Med* 10(11):831–839
26. Braithwaite D, Emery J, Walter F, Prevost AT, Sutton S (2006) Psychological impact of genetic counseling for familial cancer: a systematic review and meta-analysis. *Fam Cancer* 5(1):61–75
27. Honey K (2008) GINA: making it safe to know what's in your genes. *J Clin Invest* 118(7):2369