

From Two-Step Flow to the Internet: The Changing Array of Sources for Genetics Information Seeking

Donald O. Case, J. David Johnson, and James E. Andrews

College of Communications and Information Studies, 502 King Library South, University of Kentucky, Lexington, KY 40506. E-mail: dcase@uky.edu

Suzanne L. Allard

School of Information Sciences, 451 Communication Building, University of Tennessee, Knoxville, TN 37996.

Kimberly M. Kelly

College of Medicine, Department of Behavioral Science, College of Medicine Office Building, University of Kentucky, Lexington, KY 40536-0086.

The diffusion of the Internet has radically expanded the readily available sources for information of all types. Information that was once obtained second-hand from friends and acquaintances—the traditional “two-step flow”—is now found easily through the Internet. The authors make use of survey data to explore this thesis in regards to information sources about genetic testing and the influence of the Internet on the information seeking behaviors of the public. A telephone survey of a random sample of 882 adults asked them about their knowledge of, concerns about, and interest in genetic testing. Respondents were most likely to first turn to the Internet for information about cancer genetics, second to public libraries, and third to medical doctors. Overall, doctors were the most likely source to be consulted when second and third choices are considered. Age, income, and self-reported understanding of genetics are shown to be predictors of whether someone goes to medical professionals for advice, rather than to the Internet or public library. The results raise questions about the apparent tendency of the public to regard the Internet as the best source of information on complex topics like genetics, for which it may be ill-suited.

Background

Seeking and Sources

From its very beginnings (e.g., Lazarsfeld, Berelson, & Gaudet, 1948; Berelson, 1949; Dervin & Greenberg, 1972; Warner, Murray, & Palmour, 1973), research on informa-

tion seeking has focused on the choices that individuals make among sources of information. This line of investigation has continued over three decades (Case, Johnson, Andrews, & Allard, 2002; Johnson, 1996; Reagan, 1996) and has been of particular interest in the area of health information (Dervin, Nilan, & Jacobson, 1982; Haug, 1997; Johnson, 1997).

Large-scale investigations of where citizens acquire information include Warner, Murray, and Palmour (1973), Dervin (1973, 1976), Williams, Dordick, and Horstmann, 1977, Palmour, Rathbun, Brown, Dervin, and Dowd (1979), Chen and Hernon (1982), Dervin, Ellyson, Hawkes, Guagnano, and White (1984), and Durrance (1984). Most of these studies took a problem-oriented approach, asking, for example, “where would you go to find information on . . .?” The most widely cited of these is Chen and Hernon’s (1982) study of 2,400 New England residents. Fifty-two percent of the 3,548 “information-seeking situations” found by Chen and Hernon concerned the solution of day-to-day problems. The most common dilemmas had to do with work or specific tasks, and with consumer issues; health-related problems accounted for less than 5% of the situations.

In each case, interpersonal providers of information were ranked as much more important than institutions or the mass media. In relating who or what they considered consulting to address their problems, 74% of respondents cited their “own experience” as a source of information; this also was rated the “most helpful” source. The other popular sources were “friend, neighbor, or relative” (57%), “newspaper, magazine, or book” and “store, company, or business” (both 45%), “coworker” (43%), and “professional (e.g., doctor or lawyer)” at 41%. Other sources included government (27%), TV/radio (21%), library (17%), telephone book

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(16%), social service agency (13%), and religious leader (10%).

Dervin et al. (1984) interviewed 1,040 Californians, who reported an average of 8.5 problem situations within the last month. These situations most commonly concerned (in order): family/friends, managing money, shopping/buying, or learning; problems involving health were mentioned by 48% or more of those questioned. As in the Chen and Herson (1982) study, the most common strategy was to turn to one's "own experience" (89% said this), followed by "authorities/professionals" (58%), "family members" (52%), and "friends/neighbors" (48%). Other popular sources of help, ranging in order from 40% down to 30%, were coworkers (40%), mass media (37%), schools/colleges (32%), business persons (30%), libraries (30%), people in government (29%), and social service agencies (14%).

Observing human information seeking has demonstrated that people do not always choose actions that would lead them to the optimal result. For example, they may bypass the most knowledgeable information provider to ask questions of someone they know (e.g., Dervin et al., 1982). In fact, the typical findings of information seeking studies in various settings indicate that accessibility of information is the key factor involved in what sources people select, and that interpersonal sources are preferred over other channels (Johnson, 1997).

The tendency to consult certain friends and neighbors before print and electronic sources has been labeled "two-step flow" (Katz & Lazarsfeld, 1955, 1957) or the "dual-link model" (Bandura, 1986, p. 145). As related by Elihu Katz (1987, pp. 525–526):

Between 1940 and about 1960 . . . [Lazarsfeld was] . . . occupied with a series of panel studies on the role of mass communications in the making of decisions—to vote, to buy, to go to the movies, to change an opinion. . . . [T]he underlying theme of all this work has to do with choice.

Katz and Lazarsfeld, in their joint book, *Personal Influence* (1955), pointed out that many people acquire information and opinions from other people, rather than from the mass media or other, more authoritative sources. These influential friends, family members and acquaintances Katz and Lazarsfeld labeled "opinion leaders." Opinion leaders are regarded as authorities on, or as simply well-informed about, certain topics; they influence those around them by passing on information and opinions that may result in learning, decisions, choices, and opinion changes among those they are in contact with. As Katz later pointed out, the hypothesis was "[a]mended in a dozen ways to prefer influence over information, talk between equals over opinion leaders, multiple steps over two steps, etc." (Katz, 1987, p. S26). Katz and Lazarsfeld's work reinvigorated a long-standing interest of sociologists (e.g., Cooley, 1909) in studying "primary groups"—the face-to-face relationships (family, friends, and neighbors) that are such an important influence on human behavior.

In the years since the publication of *Personal Influence*, various other researchers have found support for the two-step hypothesis (Katz, 1987; McGuire, 1986; Okada, 1986). Case (2002) reviews dozens of studies in which colleagues, friends or relatives are regarded as the first choice among information sources in widely varying contexts. However, as Chaffee (1982) and Bandura (1986) point out, the extreme interpretation that "nonmedia influences are supreme" is not fully supported by empirical studies. In particular, Chaffee's review concludes that interpersonal sources of information are no more persuasive than mass media sources. A more recent study by Chatman (1990, 1991) found high mass media usage but low regard for interpersonal sources among the working poor. Of course, preference for sources is also influenced by culture as well as circumstance (see Johnson, 1997, and Sligo and Jameson, 2000, for a discussion of the role of these factors).

Considering the ways in which attributes of sources may vary, the psychologist Albert Bandura (1986, p. 145) concludes that:

Neither informativeness, credibility, nor persuasiveness are uniquely tied to interpersonal or to mediated sources. How extensively different sources are used depends, in large part, on their accessibility and the likelihood that they will provide the kinds of information sought.

We make use of the two-step flow hypothesis as a starting point in discussing the results of the present investigation, which examines the sources to which people might turn to obtain information about their genetic predisposition to cancer.

Seeking Health-Related Information

In the more specific area of health information sources there also has been a tradition of information seeking studies. Lenz (1984) found that the public obtained much of their health information from acquaintances and the mass media, in the course of their daily lives, a finding echoed by Reagan and Collins (1987) and typical of findings in the two-step flow tradition. Johnson and Meishcke (1992) found much information to be gathered passively from mass media sources. Manfredi, Czaja, Buis, and Derk (1993) found that a majority of callers to the Cancer Information Service (CIS) also consulted at least one other source, most commonly published literature (73%), or friends and relatives (40%). Cangelosi and Markham (1994) found a preference for personal sources like doctors and family members, with physicians being the most preferred source. Buller, Callister, and Reichert (1995) found that parents were most likely to receive health-related information from health care providers, but with a high reliance on family and friends. Gollop (1997) noted high use of doctors, mass media, friends and family for health information, and low use of public libraries, among older African-American women.

A study of 2,489 callers to the CIS, conducted by Muha, Smith, Baum, Ter Maat, and Ward (1998), reveals the beginning of a shift in information seeking habits. Muha et al. asked callers about the various sources of cancer information that they had used over the last 6 months, and their reasons for doing so. Fifty-nine percent had contacted only the CIS. The remaining 41% had contacted a wide variety of sources in addition to the CIS; of that group, 45% had consulted health care professionals or facilities (e.g., hospitals and cancer centers), 40% libraries or bookstores, 25% cancer associations, 14% online services, 12% patient support groups, 8% family members or friends, 7% print sources (mass media publications or medical journals), and 14% "other" sources (such as insurance or drug companies). While Muha et al.'s sample may be an especially motivated group—probably facing cancer in themselves or a loved one, as they have already contacted the CIS—their choices emphasize the importance of print and electronic sources.

The diffusion of the Internet has radically expanded the readily available sources for information of all types. Roughly 91% of Americans recognize the Internet as an "important" source of information (UCLA, 2003). Health care is a good example of this expansion of important sources, since it includes not only a wide array of documents (ranging from popular to scientific), yet is also the gateway to advice from a number of interpersonal sources (from laypersons to experts).

It has been estimated that there are over 62,000 health-related Web sites and lists currently online (DMOZ Open Directory Project, 2003). The Pew study of March 2002 found that 62% of Internet users had used that channel to seek health information—up from 55% in November of 2000. A Stanford University-based study conducted at the beginning of 2002 estimated, more conservatively, that 40% of adult with access had used the Internet for health-related purposes (Baker, Wagner, Singer, and Bundorf, 2003).

In November 2000, Pew (2000) found that 55% of such "health seekers" said that the Internet has improved their ability to get health information, and that 47% believed that it had affected the decisions they made regarding health care. The Stanford study found that up to 32% of users indicated that information on the Internet had affected their health-related decisions. Both studies make it clear that health information gathered from the Internet is not a *substitute* for medical care; in the earlier Pew study, only 2% of health information seekers used Internet information in place of a visit to a health care provider, similar to the 3% of the Stanford respondents who reported a decrease in physician visits due to the use of the Internet. Pew found that the Internet was most commonly used before (27%) or after (34%) a visit to the clinic, or for questions unrelated to a visit to a medical clinic (35%).

Recently concerns have been raised about the accuracy of information encountered over the Internet, just as similar concerns have been raised in the past about information from the mass media, friends, and family (Johnson, 1997). Culver, Gerr, and Frumkin (1997), for example, found that

89% of the messages they monitored on an online health discussion bulletin board were authored by persons without medical training, that one third of the advice was "unconventional," and that personal experience tended to be the source of the information provided. Even the few medical professionals in the discussion group rarely cited published sources for their advice. Other concerns about the quality of health information on the Internet have been raised by Silberg, Lundberg, and Musacchio (1997), Jadad and Gagliardi (1998), McClung, Murray, and Heitlinger (1998), Biermann, Golladay, and Baker (1999), Winkler et al. (2000), Rice and Katz (2001), and Pew (2002), among many others.

At the same time, the *Health Forum Journal* (1995), Widman and Tong (1997), and other commentators have pointed out the great potential for the Internet to be a positive source in helping patients. One important attribute of the Internet is its potential anonymity: It is possible to address sensitive issues without the threat of stigmatizing oneself (Goffman, 1959).

In summary, 20 years ago medical information was much more likely to be obtained (if at all) directly from health care professionals, or indirectly through friends or family members who were accessible and perceived to be opinion leaders. Now information about diseases, treatments, and prevention is readily available over the Internet; consumers may bypass entirely some of the more traditional sources of health-related information. We will illustrate these changes in source preference with the example of information on cancer genetics.

Genetics as a Topic of Information Seeking

Understanding more about the sources consumers choose is central to learning how to help people get the health information they need when they need it. To do this, we need to understand how people perceive their own level of skill in seeking particular information, and what resources they would consult for additional information. This is a particularly vital issue in regards to the complex field of information about cancer genetics.

Our genetic predisposition to disease is a topic ripe for information seeking as well as information seeking research. In many ways it is like "the perfect storm": The complexity and uncertainty of the information involved, the relatively primitive state of many patients' information seeking skills and health literacy regarding this context, the influence of habitual sources of information, and the high levels of anxiety involved make this an ideal situation for studying information seeking (Johnson, Andrews, Case, & Allard, 2003; Johnson, Andrews, & Allard, 2001).

In recent decades the general public has been encouraged to be more active participants in determining their options for health care. This consumer movement in health care raises serious issues, however, for cancer genetics; the genetic component of cancer is a complex topic and an area subject to rapid scientific discovery (Kreps, 1991); at the same time, individual circumstances vary widely in regards

to genetic susceptibility to various cancers. All of these factors make for difficult decision-making.

We believe that information about one's genetic makeup is due to become a major topic among a broad population. Past studies of general populations have found high levels of interest in genetic testing: from 82% (Andrykowski, Lightner, Studts, & Munn, 1997) to 87% for general predictive testing, and 97% for breast cancer in particular (Andrykowski, Munn, & Studts, 1996). Two other investigations (Bosompra, Ashikaga, Flynn, Worden, & Solomon, 2001, and Bunn, Bosompra, Ashikaga, Flynn, & Worden, 2002) examined intentions to obtain genetic tests during 1996 and 1998, respectively. The first of these studies found that 55% of the 622 respondents had heard about genetic testing for cancer and that 14% had "sought information about it from the mass media and other sources" (Bosompra et al.). Similarly, Bunn et al. say that 13.5% of 1,836 respondents had "looked for information in books, magazines, newspapers or other sources," 15.4% had discussed cancer-related genetic testing with family members, 15.8% had discussed it with friends, and 5.3% with their doctors. These studies predated widespread Internet use among the general population and did not specifically mention it as a potential source.

Articles in mainstream publications (e.g., Duncan, 2002; Kristof, 2003) have increasingly brought the issue of genetic testing to the attention of a broad audience. A recent editorial feature in *The New York Times* (Kristof, 2003) may typify the reactions and concerns of a future public:

I've just had my genome scanned, and unfortunately, I have common mutations that give me a mildly increased risk for dangerous blood clots, schizophrenia and type 2 diabetes. . . . On the other hand, I don't have plenty of common nasty mutations, like those associated with colon cancer and melanoma. . . . This kind of genetic screening may be the Next Big Thing. It offers a glimpse of how genetics will transform human life in this century.

To study this "Next Big Thing," we made use of a yearly telephone survey of a large population to ask several questions about the public's interest in, and sources of information for, genetic testing.

Methods

A computer-assisted, telephone survey collected responses from a random, equal probability of selection, sample of 882 adult residents of Kentucky. They were asked nine questions about their knowledge of, concerns about, and likelihood of uptake of genetic testing, along with details about their demographic background and a selection of other questions for different survey purposes. The calls were made by trained interviewers working for the University of Kentucky Survey Research Center during July and August 2002 as a part of a general social survey. (Due to the length and nature of the survey, we were limited to 10

questions regarding cancer genetics; however, there were other health-related and demographic questions included which inform our analysis here.)

To obtain the sample, Waksberg random-digit dialing procedures were used to contact a total of 2,454 potential respondents, of which 125 were determined to be ineligible (typically because they were not at least 18 years of age). Among the remaining households, 41% agreed to be polled. The sample consisted of 92% white respondents, 4% African American, and 3% "other" racial or ethnic background. Sixty percent of the respondents were female, and 63% were currently married. Twelve percent had less than a high school education, 32% percent had completed high school (or GED), and the rest (51%) had at least some college; over 11% of the sample had at least some graduate school coursework. Twenty-eight percent described themselves as living in rural areas, 36% in small towns, 13% in suburbs, and 23% in cities. The margin of error for the sample was approximately $\pm 3.3\%$ at the 95% confidence level. Compared to the actual population of the state, the sample underrepresents both African Americans (8.5% of the state population) and males, although it is otherwise a fair representation of Kentucky adults.

The initial three questions we were concerned with regarded the respondent's awareness of cancer "running in their family," their understanding of genetics, and their level of "worry" about inheriting cancer. Three follow-up questions concerned the sources they would look at if they were "trying to find information about inherited cancers"—their first, second, and third choice sources for such information. The final three questions concerned whether they would want or need help finding information on genetic testing, how much help they would need, and if they would choose to "have a genetic test to determine your risk for inherited cancer if it were readily available."

Findings About Sources Consulted

All analyses were performed using SPSS version 11.5. Below we present findings regarding sources consulted, followed by a discussion of the results of other study questions and associations among the variables.

Preference for Sources

Of central interest in this study was where people would turn for information on inherited cancer. Respondents were asked where they would turn first, second, and third; they were not prompted with examples. Almost 93% of the sample were willing and able to identify at least one source, 68% were able to name at least two sources, and 34% identified three. Altogether these respondents came up with 15 unique sources they would consult regarding genetics and health information.

The study found that respondents were most likely to first turn to the Internet (46.5%) for information about genetics, disease, and testing, second to a medical doctor

TABLE 1. Preferences for sources of information about inherited cancer.

Source	Percent choosing as			
	First choice (<i>n</i> = 817)	Second choice (<i>n</i> = 599)	Third choice (<i>n</i> = 303)	Overall percent choosing (<i>n</i> = 817)
The Internet or Web	46.5	19.0	6.6	62.9
Public library	14.1	33.7	29.7	49.8
Doctor	18.4	22.2	33.3	47.0
Family member	10.6	6.5	7.9	18.4
Cancer information service	3.3	6.7	6.3	10.5
Hospital program	4.2	4.8	5.6	9.8
County health official	1.2	2.0	2.3	3.5
Magazine	0.5	2.7	1.7	3.1
Family friend	0.4	0.7	3.3	2.1
National TV programming	0.4	0.2	1.7	1.1
Newspaper	0.1	0.5	1.3	1.0
Local TV programming	0.1	0.2	0.3	0.4
Friend at work	0.1	0.3	—	0.4
Child's school	0.1	0.2	—	0.2
Church or synagogue	—	0.3	—	0.2

(18.4%), third to a public library (14.1%), and fourth to a family member (10.6%). Other medical sources (hospital programs, the CIS, or county health officials) together counted for an additional 8.7% of responses.

Mass media sources (newspapers, magazines, and TV) other than the Internet together constituted only 1% of first-choice responses. This latter finding was unusual because mass media are often thought of as a good way to inform wide audiences about health matters (Atkin, 1981; Johnson & Meischke, 1992).

Surprisingly, friends of the family accounted for just 0.4% of the first choices and friends at work only 0.1%; this differs quite a bit from earlier studies (e.g., Manfredi et al., 1993; Buller et al., 1995) in which “personal sources” figured prominently. It is also an unusual departure from the “two-step flow” tradition, in which people first turn to those nearest and most accessible to them to learn about important topics.

Some potential information sources were mentioned rarely, or not at all. Only three respondents indicated their child's school as a possible source and just two mentioned “church.” Radio programming was not mentioned by any respondent as a potential source.

The details of the first, second, and third choices for information sources are found in Table 1. Each of the first three columns shows the percentages identifying the sources chosen for that choice—i.e., first, second, or third. The final column reflects all of the choices made by all respondents—i.e., the percentage of respondents who chose that source at any point, whether first, second, or third.

As one might expect, the length of time one has been using the Internet was positively associated with higher ranking of the Internet as a source of information ($n = 618$, $\rho = 1.67$, $p < .001$); it was not, however, statistically related to choices of other sources.

Overall, the dominant help-seeking strategy was to make use of either one's doctor, the Internet or both. As has been pointed out by Pescosolido (1992, p. 1112), people do not make a single decision nor do they plan a series of choices, but rather they continue to seek help from multiple sources until they resolve their problem or exhaust their options. So patients may turn to the Internet either before or after seeing a physician; as mentioned earlier, Pew (2000) reports that consulting the Internet after a doctor's appointment is a more common pattern among the general population—although it was apparently the less common sequence envisioned by these respondents.

Unfortunately, the Internet is not a good source for individuals seeking help with making decisions about genetic testing and treatments; the information to be found there regarding genetics is not typically geared toward laypersons (an exception is the National Library of Medicine's genetics Web site, which debuted in May 2003: <http://ghr.nlm.nih.gov>); more importantly, it does not address individual circumstances (e.g., family medical history). Even many physicians do not have the training to advise patients properly about genetic testing (Burke & Emery, 2002; Greendale & Pyeritz, 2001). It is encouraging, therefore, that a total of 10.5% of the respondents thought of calling the CIS—perhaps their best initial choice for information about the genetic component of cancer.

Other Findings

Understanding of Genetics

Almost 14% of the sample describe their understanding of genetics as “excellent,” 34.4% as “good,” 36.4% as “fair” and 10.8% as “poor”; so, nearly half (47%) of the sample judged their understanding of genetics to be inadequate.

This finding echoes those of Hietala, Hakonen, Aro, Niemela, Peltonen, and Aula (1995) and Lerman, Rimer, and Engstrom (1989), who found relatively low levels of knowledge about cancer genetics and the causes of cancer, respectively.

There was a statistically significant relationship between self-reported understanding of genetics and the number of sources of information named by respondents, along with some demographic variables. Those describing their understanding as “poor” or “fair” were much more likely to be unable to name any source to which they would go for information; in general the better their perceived understanding of genetics, the more sources the respondent was able to identify ($n = 842$, $\chi^2 = 55.905$, $df = 9$, $p < .001$).

It is possible that the latter finding could be explained by psychological theories about coping behavior, and in particular how people deal with threatening information. Information seeking styles have been characterized as either “monitoring” or “blunting” (Folkman, 1984; Lazarus & Folkman, 1984); “monitors” scan the environment for threats, while “blunters” tend to avoid threatening information or distract themselves from it (Miller, 1979, 1995). In this case, those who were aware of many sources might be monitors and those who could name few sources may tend toward the blunting end of the continuum. [The relationship of coping to information seeking is explored by Case, Johnson, Andrews, and Allard (2002a, 2002b).]

Better self-reported understanding of genetics was also positively-related to ranking the Internet highly as an information source; that is, respondents who claimed more knowledge of genetics also tended to rank the Internet higher as a source of information about the genetic basis for cancer ($n = 842$, $\rho = 1.43$, $p < .001$). Younger respondents also tended to identify more sources ($n = 873$, $r = 0.155$, $p < .001$) but be less likely to understand genetics ($n = 833$, $\rho = -0.081$, $p = .01$). Wealthier respondents (as measured on a 14-point household income scale) were also more likely to claim a better understanding of genetics ($n = 647$, $\rho = -0.087$, $p < .02$).

Needing Help

Regarding how much help they would want in making decisions about genetic testing, about two-thirds (67.6%) of the 846 who responded to this question said they *would* need such assistance. The number of sources respondents named were not related to their perceived need for advice about screening.

However, among the smaller number (569) of respondents who answered the next question about amount of help needed, a significant relationship was apparent: Those who were unable to name any sources were more likely to say they needed “a lot” of help ($\chi^2 = 20.771$, $df = 9$, $p < .02$). Interestingly, those respondents who identified the most sources tended to be those who said they needed “some” (in contrast to “none,” “a little,” or “a lot” of) help in making decisions. This may indicate an awareness among more

knowledgeable respondents of the complexity of issues surrounding the genetic basis of disease. It is also the case that needing more help is positively associated with higher income ($n = 650$, $\rho = 0.142$, $p < .001$) and education ($n = 796$, $\rho = 0.158$, $p < .001$); apparently the more affluent and educated respondents are more aware of their degree of ignorance on the topic—which raises the issue of a potential “digital divide” as regards cancer genetics (Rice & Katz, 2001).

There was somewhat of a tendency for those saying they needed more help to rank both the Internet, along with “other medical sources” (e.g., hospital programs and county health departments), higher as sources of genetics information ($n = 846$, $\rho = 0.67$, $p = .05$, for both); less informed respondents are apparently more likely to see those sources as having such information.

Logistic Regression

A logistic regression analysis was conducted to examine multivariate predictors of which types of sources respondents might consult to find information about cancer genetics. In this case, logistic regression analysis creates an equation that predicts whether respondents will fall in one of two groups: those who would first consult medical professionals versus those who would go elsewhere for information.

We found that the most noted statistical differences were between the 550 respondents who would first consult medical professionals (i.e., physicians, hospitals, county health officials, or the CIS) versus those who would first consult either the Internet or a public library (which may both indicate the same ultimate sources). The choice between these two types of sources was statistically associated with several potential predictor variables: age ($\rho = 0.179$, $p < .001$), total household income (fourteen categories, from “\$5,000 or less” to “\$120,000 or more”; $\rho = -0.164$, $p < .001$), education (a scale approximating number of years of education; $\rho = -.153$, $p < .001$), and self-reported understanding of genetics (on a four-point scale from “poor” to “excellent”; $\rho = -0.106$, $p < .01$).

The three most predictive variables—understanding of genetics, age, and household income—were used to classify respondents as to their likely choice of information sources (a binary variable representing medical professionals, versus the Internet and public library combined). Table 2 shows the results of the regression.

The set of predictor variables was significantly associated with the binary choices of information source type (model $\chi^2 = 36.27$, 3 df , $p < .01$). The regression was able to classify 74.7% of the information seekers correctly. By chance, 50% of the respondents would be classified correctly; thus, the functions are able to improve prediction of source type by nearly 25% above chance. In other words: If we know a person’s age, income range, and general understanding of genetics, we are able to provide a fair prediction

TABLE 2. Logistic regression analysis of preferences for cancer genetics information sources: Medical professionals versus the Internet or public library.

Variable	Odds ratio	95% confidence ratio interval (lower–upper)	Significance
Age (in years)	1.022	1.009–1.035	$p = 0.001$
Total household income (14 categories)	0.905	0.853–0.960	$p = 0.001$
Understanding of genetics (Poor–Fair–Good–Excellent)	0.768	0.613–0.963	$p = 0.022$
Model			$\chi^2(3, N = 550) = 36.27$ $p = 0.001$

of where they will first turn for information about the genetic basis of cancer.

The fact that household income discriminates among those who turn to medical professionals versus those who go to the Internet constitutes an interesting “digital divide” issue. According to Freimuth (1990), poorer patients tend to know less about cancer, disease prevention, and the health care system. Correlations in the present investigation show that the more education, income, and understanding one had, the more likely one is to turn to the Internet or a public library as a first choice of information. Increasing age was also positively associated with choosing medical professionals: the younger one was, the more likely to identify the Internet or library as the first-choice source of information about inherited cancers.

That variables such as income, education, and age can predict use of the Internet is, of course, not surprising in itself. The tendency for wealthier respondents to say that they would go to the Internet first is somewhat counterintuitive, as we would normally expect them to be more able to consult medical professionals than would the less affluent respondents.

Discussion

The popularity of the Internet among these respondents regarding information about cancer and genetics is cause for concern, given the potential for misinformation and misunderstanding (e.g., see Jadad & Gagliardi, 1998; Winkler et al., 2000). As with other studies (e.g., Culver et al., 1997; Pew, 2000, 2002; White, 2000), it appears that consumers are increasingly looking to the Internet for answers to important health questions—to both documentary sources and advice from other laypersons and professionals in discussion forums. Gone are the days when patients simply made the “obvious” (and indeed perhaps the only) choice of consulting with their doctor.

We see the new dominance of Internet sources as a further mutation of the famous “two-step flow hypothesis” that emerged from 20 years of research by Paul Lazarsfeld and others. The Internet—and particularly the World Wide Web—has changed the nature of information seeking. It is often a first choice for finding out about a host of topics, as

well as a conduit for discussing those topics with other Internet users; to some degree the Internet substitutes for older media (Kaye & Johnson, 2003). As a result, the emergence of the Internet as an omnibus source may also have changed the nature of opinion leadership; both more authoritative (e.g., medical journals) and more interpersonal (e.g., cancer support groups) are readily available and accessible online.

The frequent conclusion of past research—that most people first turn for advice to people (family members, friends, neighbors and also nearby experts, such as physicians)—is in doubt, at least for this particular problem. It could be that the issues surrounding genetics are so new that most members of the public do not know anyone with sufficient knowledge to appear as an opinion leader in this context. Alternatively, what we found in this survey could be an aspect of a broader trend that Shapiro and Shapiro (1999) refer to as “disintermediation”—the capability of the Internet to allow the general public to bypass experts in their quest for information, products, and services. Perhaps, faced with the wide array of information sources available to the public, the average person is more interested in facts, and less interested in being convinced or persuaded by local experts.

The Internet, in its accessibility, anonymity, and potential interpersonal authoritativeness, may now act as a substitute for the classic two-step paradigm, supplanting the social and physical proximity dynamics of interpersonal networks. Yet, we also recognize that the genetic basis of cancer is fraught with potentially emotional family-related issues; many people prefer to consult anonymous sources, such as telephone hot lines, when faced with stigma-associated health problems.

Are patients consulting the Internet to *substitute* for a doctor’s advice, or rather to *supplement* it? The Pew (2000) study results suggest that few (2–3%) access online information “instead of a visit,” and that it is more common to consult Internet sources *after* a visit to the doctor or clinic, rather than *before* (34% versus 27%). However, in the present investigation the opposite sequence is more common: Internet first, then health care providers.

As emphasized by Pescosolido (1992), Manfredi et al. (1993), and other researchers, patients do not rely on a

single source for health information but rather tend to seek help from multiple sources until they resolve their questions. Searches for health-related information take place within a network of documentary sources, health care providers, family, friends, and other people. Such sources can be thought of as a matrix, some combinations of which may be habitually chosen by some patients. The advent of the Internet is causing a shift in consumer preferences among sources, apparently based on the accessibility of Internet sources, and the perception that they contain authoritative information (see Wathen & Burkell, 2002); in contrast, one's own interpersonal network may not be perceived as containing information to answer the new questions that arise with advances in genetics.

In using the Internet, consumers may also bypass some of the traditional, first-choice sources, such as family members. On the surface this seems ironic, because family members may be the best source of information about susceptibility to cancer; a pattern of certain cancers occurring in one's family is an important sign of potential genetic risk, and it is just this sort of information that health care professionals would ask for to determine risk and to consider recommending genetic counseling to further determine if testing is needed. Yet, it is possible that the nature of cancer genetics—which may involve discussing sensitive, perhaps threatening, information with family members—has an information seeking dynamic that is unique. Learning about one's genetic predisposition to cancer (e.g., seeking genetic testing or counseling, which are highly individualized and authoritative forms of information) has implications for both individuals and their families. Obtaining such information may result in family tensions, such as ostracizing members *not* carrying a mutated gene, or can impact decisions on whether or not to have children. Receiving positive test results for diseases for which there are no known treatments may result in negative psychosocial reactions—such as extreme dismay or suicide (Geller, Bernhardt, Helzlsouer, Holtzman, Stefanek, & Wilcox, 1995). Even negative results can have undesirable effects; Lerman et al. (1999) found that about half of their interviewees indicated that negative test results would lead to unhealthy behavior due to either false reassurance or misunderstanding of risks. For these reasons, perhaps learning about genetic risks is distinct from other health-related information seeking.

Methodological Limitations of the Survey

It is important to recognize that these questions were prospective, rather than retrospective. That is, respondents were answering a series of "what if" questions rather than reporting on actual, past behavior. We do not know for sure what they would actually do if faced with a need for information about cancer genetics. In fact, we do know that many patients faced with cancer actually *decrease* their information seeking about the disease (Johnson, 1997).

It is also true that we do not know what other sources they may have already consulted at the time they answered the survey question; for example, if a respondent had already investigated what cancers had appeared among their relatives, they would *not* be inclined to say "I would ask family members" when they were surveyed. Relatedly, some earlier surveys (e.g., Chen & Hernon, 1982) prompted respondents with the alternative "I turned to my own experience," which was not a source considered in this survey.

In the present study it is likely that there was some unknown degree of bias due to demand characteristics of the situation and questions. As in other surveys, respondents may have been more likely to respond with socially desirable answers—what they thought they "should" say—rather than an accurate portrayal of their true opinions or likely actions. We are not able to assess the degree to which this affects our results, but given the hypothetical nature of the questions, we do not believe that any such bias would strongly affect our conclusions. Along with the previously stated need to tease out the various dimensions of "the Internet" as an information source, future research along these lines will need to consider the problem of socially desirable answers from respondents. There is also some potential overlap between several of the sources that respondents mentioned: Those who say that they would go to the public library might also search the Internet while there, as could also be the case for visiting the child's school. So answering "a library" or "school" might also reflect Internet usage.

Finally, there have been changes in American society that might account for some of these changes in source preferences. The decline of the nuclear family might result in less reliance on family members, for example.

Genetic Information Seeking as a Future Arena for Research

Genetics, and its connection with disease, present what in many ways is a perfect information seeking research problem. Three out of every four families will experience cancer first hand (Freimuth, Stein, & Kean, 1989). While only about 5–10% of cancer cases have a basis in our genes, a family history of cancer remains the strongest epidemiological risk factor that we know of (Stopfer, 2000). Given low public literacy on the topic and the possibilities for avoiding unnecessary suffering (and even death), genetic information seeking is an important arena for research.

Genetic counseling and testing centers are already experiencing high levels of demand, and the literature shows the general public to be very interested in predictive testing (Andrykowski et al., 1996, 1997; Elwood, 2000). As more cancer-causing genes are identified, testing methods become refined and available, and as genetic testing is more widely advertised directly to the public, more information related to genetics will be sought from a variety of sources. Unfortunately, there is a shortage of qualified cancer genetic counselors, and most primary care practitioners are not

prepared to satisfy either the informational or clinical needs of patients with genetic-related questions (Burke & Emery, 2002; Greendale & Pyeritz, 2001). There are also a host of ethical and legal issues surrounding the potential use of genetic data by HMOs, insurance companies, and the government (Rothstein, 1997; Collins & McKusick, 2001).

In terms of specific methods and questions, it will be crucial, in future investigations of this type, to tease out the distinct uses of the Internet. To what degree are information seekers about genetics (and other medical topics) using formal, authoritative sources versus interpersonal contacts? Some types of information which were previously obtained from family members and friends has now been supplemented, and to some extent replaced by, advice from Internet sources. Particularly in regard to cancer genetics, in which family members are key providers of information, we need to know more about the sources on which the public relies for health information.

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