UNIVERSITY OF CINCINNATI

Date: 27-May-2010

I, Ashley Parrott, hereby submit this original work as part of the requirements for the degree of:

Master of Science

in Genetic Counseling

It is entitled:

Media Coverage of Direct-to-Consumer Genetic Testing

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Media Coverage of Direct-to-Consumer Genetic Testing

A thesis submitted to the
Graduate School
of the University of Cincinnati
in partial fulfillment of the
requirements for the degree of

Master of Science

in the Genetic Counseling Program
of the College of Medicine
by

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May 2007

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Abstract

News media have played a major role in shaping public opinion of scientific developments. Direct-to-Consumer (DTC) genetic testing is a relatively new scientific development gaining attention. A better understanding of media coverage, especially the attitudes and ethical concerns found there, may allow for better understanding of public and consumer attitudes and behavior regarding DTC genetic testing. The purpose of this study was to determine the themes, attitudes, and ethical concerns that are presented by the U.S. news media regarding DTC genetic testing.

We identified a sample of 93 news stories published from 2006 to 2009 in print, broadcast and online media using a Lexis-Nexis search with the keywords “Direct-to-Consumer” and “genetic test”. The sample was coded for the attitudes about themes of genetic determinism, analytical and clinical validity, regulation, clinical utility, and cost as well as for the ethical concerns of privacy, discrimination, and the Genetic Information Nondiscrimination Act (GINA). Of news stories that addressed the theme, the majority displayed moderate genetic determinism and were neutral in their view of validity and clinical utility. Stories indicated that insurance and employers were the likely sources of potential discrimination, yet identified the medical record/physicians and DTC companies as the sources most likely to violate the privacy of individual medical information. Stories claimed that a lack of regulation would harm consumers, but the majority of post-GINA stories made no mention of the law or the protections it provided.

Attitudes on the cost of DTC genetic tests were rarely provided, although cost figures frequently were included. The results show a broad range of attitudes toward DTC genetic testing and its potential medical and social impacts. The way in which news media presents issues surrounding DTC genetic testing may influence opinion and utilization of those tests. The genetic community should be aware that the public has been exposed to multiple views of DTC genetic testing when discussing these tests with individuals.
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INTRODUCTION (Significance of Study and Literature Review)

The field of companies offering Direct-to-Consumer (DTC) genetic testing is growing. Three of the most popular companies, 23andMe, deCODEme, and Navigenics, have been launched within the past three years, and they allow individuals to order genetic tests without recourse to healthcare professionals. In traditional forms of genetic testing, health care professionals facilitate patient awareness and understanding of the evolving scientific and medical consensus on genetics and the clinical utility of test results. Yet, individuals ordering a DTC genetic test will not have access to the informational resources provided by clinicians and may also lack the social support necessary to cope with results indicating a medically undesirable condition. What information lay individuals will have to guide their interpretation of the test will come from the company offering the test and the news media. Previous research has shown that Direct-to-Consumer advertising of genetic tests increases awareness of, and interest in genetic testing (CDC, 2004; Lowery, Byers, et. al., 2008; Myers, Chang, et al., 2006), but DTC advertisements do not lead to an increase in the use of genetic tests (Goddard, Moore, et al., 2007; Mouchawar, et al., 2005). Goddard, Moore, et al. (2007) found that 73% of individuals who were aware of the tests “had heard or read about them through three media sources of information: television (46%), magazines (35%), or newspapers (29%)” (p.512).

Most individuals have been exposed to both advertisements and multiple news media. However, the potential exists for the news media to be viewed as the more “credible” or “objective” source of information, since the advertisements have an overt
goal of persuading individuals to use the service being presented. The goal of this study is to determine the themes, attitudes, and ethical concerns presented by the U.S. media regarding DTC genetic testing. Since news media are a key source of information and help shape the publics' attitudes about DTC genetic testing, a better understanding of how they present the DTC genetic testing may contribute to understanding public responses to, and uses of, such testing.

The news media's presentation of scientific concepts, especially genetics, has a significant impact on public understanding of science. Hargreaves, Lewis, and Speers (2003) argue that news media have a significant role in providing information and shaping the lay public's understanding of science: "Most people are aware of the main themes or frameworks of media coverage of science related stories...These themes or frameworks are then used as building blocks for people to make sense of an issue" (p.52). This is especially true for issues regarding genetics and health. Bowen, Battuello, and Raats (2005) note, "People are exposed to the mass media, both electronic and print, daily for information and opportunities regarding health. Therefore, it would be prudent to assess the current impact of media as a key source of information for genetics and genetic testing for providers and the general public" (p.679). The media are a conduit of information to the public, and they provide the themes and issues from which lay individuals construct their own understanding of an issue.

Mass media scholars have offered a number of theories to explain the interaction of the media and the public. A study of newspaper stories on genetics and race found that news coverage of the issue was multifactorial, with no theory of mass media effects fully supported (Lynch & Condit, 2006). Instead, articles portrayed a clear slant, or attitude,
toward one side of the scientific issues while presenting alternative viewpoints throughout the body of the article. Other scholars have argued that media presentations of science display a hype-space conflict: a story must hype, or exaggerate, the issues at hand in order to get attention: greater hype and controversy means that more space will be devoted to the issue, allowing for “balanced” presentation in the bulk of the article (Caulfield & Bubela, 2004; Wilcox, 2003). This hype-space conflict structures news stories so that the headline or opening sequence will “hype” the issue to create interest through controversy, while the bulk of the news story will present multiple viewpoints and attitudes on the topic.

Previous research has identified several areas of concern about genetic testing as a whole. Scholars have noted that the information produced by genetic tests can have deleterious effects on individuals and have identified three specific areas of concern: genetic determinism, discrimination, and privacy.

Genetic determinism is based on “the notion that our DNA is the location of our true selves, our true futures” (Silva 2005, p.106). In other words, genetic determinism is the belief that if a person has a gene that contributes to a specific condition, they will inevitably experience that condition. According to Clayton (2003), this attitude develops in part because “people tend to see genetic information as more definitive and predictive than other types of data... [it] includes an unwarranted sense of inevitability” (p.563).

The media have been identified by some as the primary means of fostering genetic determinism in the lay public (Djick, 1998; Hubbard & Wald, 1993; Nelkin & Lindee, 1995; Silva, 2005). Studies of the impact of news stories about genetics have not fully supported that concern: “A few studies have examined the impact of messages and
news headlines on genetic determinism, and... found that a single exposure to a message about genetics did not increase genetic determinism” (Lynch et al., 2008, p.43). Condit and Williams (1997) found indication that “those who had higher exposure to genetic messages also had less deterministic attitudes” (p.232). A study of multiple exposures to messages about genetics and race could not establish whether multiple exposures increased genetic determinism (Lynch et al., 2008). The inability to establish this relationship might result from people attributing different levels of genetic causation to different human characteristics (e.g. people attribute genetic causes to physical characteristics but are less likely to do so with mental qualities) and from the multiple and conflicting presentations of genetics and their causal power in the media (Parrott et al., 2003; Lynch & Condit, 2006). News media play a role in shaping attitudes and providing information on genetic testing generally and DTC genetic tests in particular, but the impact on audience attitudes has not been fully established, thus justifying the need to identify what information and attitudes appear in the news media.

When people believe that genes determine an individual’s fate, the possibility exists for discrimination based on genetics. A common concern with genetic testing is that “genetic information will be used in ways that could harm people...to deny them access to health insurance, employment, education, and even loans” (Clayton 2003, 562). Again, media have been identified as a contributor to this problem: Scholars have claimed the language used to describe genes helps justify discriminatory attitudes (Hubbard & Wald, 1993; Rothman, 1998).

The concern about discrimination is also shared by the public. Studies have found that individuals have identified discrimination from multiple sources as a major concern.
Sources identified have included health insurers and employers, as well as social
discrimination (Bevan et al., 2003; Hall & Rich, 2000; Penziner, E., Williams, J.K., et al.,
2008). A study on public reaction to advertisements of race-based pharmacogenomics
found that “possible discriminatory effects from pharmacogenomic research are a
substantial concern. A fear of discrimination, whether based on race, genetics, or
unspecified, is common” (Bates, Poirot, et al., 2004, p.550). Given the scholarly and
public concerns about discrimination, the existence of this theme in news media on DTC
genetic tests warrants further examination.

Concerns about discrimination become pressing if the privacy of genetic
information is not protected. Concern about privacy is driven “by the growing
recognition that health information is not entirely private... limiting access to the medical
record to the patient and the treating clinician is neither possible nor unequivocally
desirable” (Clayton 2003, p.562). While fears about privacy violations often focus on
insurance companies and employers (Clayton 2003), scholars and lay publics have voiced
concerns about other individuals with access to DNA samples and medical records,
including doctors, hospitals, and testing companies (Clayton, 2002, 2003; Bevan et al.,
2003).

While DTC genetic testing is a relatively new area, the three major concerns
identified above also apply to DTC genetic testing, and are extensively discussed in
literature on DTC testing (Gollust, Hull et al., 2002; Wade & Wilfond et al., 2006).
Additional concerns have been raised that pertain specifically to DTC genetic testing,
including amplified concerns about privacy, lack of regulation, limited information on
clinical validity and clinical utility, and cost of the tests.
Discussions of privacy in regards to DTC tests have an additional level of complexity. Since DTC genetic tests can be performed outside of a healthcare provider’s office, DTC genetic tests will not automatically become part of the medical record and thus may be unavailable to insurance companies: “Some DTC companies use privacy as a marketing tool, touting the benefits of obtaining genetic testing outside the health care system and thereby avoiding the risks of having genetic information contained in a medical record” (American Society of Human Genetics 2007, p.636). While some literature identify privacy as a positive quality of DTC genetic testing, others raise questions about how DTC companies will keep records secure and confidential (American College of Medical Genetics, 2008). While advertisements for DTC genetic tests create a positive view of privacy issues, it is not clear how news media discuss this issue.

Two main areas of concern with the validity behind DTC genetic testing have been identified. The first area of concern is that DTC companies are offering tests that are not clinically validated. In other words, the tests might not provide the accurate information on disease risk that the company claims DTC genetic tests provide. Kuehn (2008) has argued that DTC genomic profiling may use markers like single nucleotide polymorphisms (SNPs) that “have not been validated by other groups or by studies that explain the molecular mechanism by which these genes might lead to disease” (p.1503).

Consumers are unlikely to have access to information on the positive and negative predictive values of DTC genetic tests (McCabe & McCabe, 2004). The second area of concern focuses on analytical validity. Ries and Castle (2008) have raised concerns that “companies that sell DTC genetic tests may not be obliged to comply with regulatory
requirements to ensure the tests are analytically valid by demonstrating laboratory proficiency to carry out accurate genetic testing” (p.246). All companies offering DTC genetic tests are not required to prove the accuracy or reliability of tests they offer, although some do comply with the Clinical Laboratory Amendments Act (CLIA), which sets technical competency standards (Ries & Castle, 2008).

Currently, DTC genetic testing and the companies offering the tests are not regulated by a central authority (Gollust, Hall, et al. 2002). Furthermore, the advertising is not regulated, opening the possibility that unfounded claims are being made (Williams-Jones, 2006). Researchers have raised concern that the lack of regulation means consumers are not receiving adequate information both before and after purchasing a DTC genetic test and are not protected from predatory advertisements or shoddy products (Gollust, Wilfond, et al., 2003; U.S. GAO, 2006).

One major question is the clinical utility of these tests for medical practice. While genomic profiles generally are suggested as a means for identifying individual risk and offering patient-specific medical interventions (Haga et al., 2003), Kuehn (2008) has argued that “one of the biggest unanswered questions is whether scanning an individual’s genome has any clinical value” (p.1503). It is still unclear if genomic profiles are useful in improving individual health. The American College of Medical Genetics Statement on Direct-to-Consumer Genetic Testing (2008) states, “Many DTC genetic tests do not give a definitive answer as to whether an individual will develop a condition, but provide only a risk or probability of developing a disease.” The question remains if this risk figure is a meaningful tool in medical management, and if interventions are available to alter the risk figures provided by DTC genetic tests.
In the context of pharmacogenomics, lay people have identified cost as a concern (Bevan et al., 2003). Some researchers have raised concern that DTC genetic tests will not be affordable. For example, Hunter et al. (2008) insinuates that the cost of DTC genetic testing is unreasonable when considering the limited information the test will provide. Some researchers provide cost figures without providing their own attitude on the affordability of the tests (Gollust, Wilfond, et al., 2003; Kuehn, 2008; Wolfberg 2006). Given overall attention to the cost of genetic services, it is necessary to assess whether the news media present the issue of cost and whether it is presented as a positive or negative aspect of DTC genetic testing.

To assess the U.S. news media coverage of Direct-to-Consumer genetic testing, we sought to identify common themes, attitudes, and ethical concerns found in journalistic coverage of the topic. Findings from a sample of news stories are discussed in this article.

MATERIALS AND METHODS

Sample Collection

News stories included in the sample consisted of media publications from newspapers, wires, magazines, television and radio transcripts, blogs, and web publications. The sample was found using the Lexis-Nexis Academic Database. This is a search database which provides access to news, business, and legal publications. Keywords used to search for these articles were: “direct to consumer” and “genetic test.” The search included stories published between June 2006 and June 2009. This time period was chosen due to the increased availability of DTC genetic testing during this time. Three of the major companies in the business were launched during this time.
period: 23andMe and deCODEme, in 2007, and Navigenics was launched in 2008.

Lexis-Nexis allows for a variety of searches within the database; this sample was generated using three primary searches: (1) General Tab Easy Search (2) General Tab Power Search (3) News Tab Search. These multiple primary searches produced different, yet overlapping results. Sources chosen in the search included Major U.S. and World Publications, TV and Radio Broadcast Transcripts, Web Blogs, US Newspapers and Wires, Magazine Stories, Combined, and Web Publications.

Stories were included if they were published in the United States, or were published by a media outlet with wide distribution in the United States (e.g. The Economist). At least one-third of a story had to discuss DTC genetic testing in order for it to be included in the final sample. Stories that were republished by different media outlets in the sample were excluded. Using these criteria, the search generated a sample of 97 news stories.

Data Collection

A coding scheme was constructed in order to analyze media coverage of the following themes presented in the media sample: attitudes about genetic determinism, analytical and clinical validity, regulation, clinical utility, and cost, as well as ethical concerns surrounding privacy, discrimination, and the Genetic Information Nondiscrimination Act (GINA). These themes were selected by reviewing previous scientific literature and conducting a pre-reading of stories in the final sample. Codes under each theme were applied to the headline, lead paragraphs (defined as the opening paragraph plus additional paragraphs needed to include at least four sentences), and full article.
Two coders were trained on the coding scheme and independently analyzed 20% of the texts. This sample included stories from all media sources. A Cohen’s kappa was used to establish intercoder reliability, with a cut-off point of greater than 0.6, which Landis and Koch (1977) identified as “substantial” agreement. The remainder of the sample was then coded by one reader.

Data Analysis

Codes were inputted into the Statistical Package for the Social Sciences (SPSS). Frequencies for codes were produced for each theme, with differentiation between the headline, lead, and full article. Comparative statistics were generated using the chi square tests between the source/type of media for all themes, the year of publication for all themes, pre/post passage of GINA and its impact on the privacy and discrimination categories, and genetic determinism and its impact on clinical validity and clinical utility.

RESULTS

Story Characteristics

Of the 97 stories initially identified, four were eliminated because they did not discuss genetics or direct-to-consumer genetic tests, leaving 93 news stories in the final sample. 77 stories came from “old” media sources: 67 of them were from print media, which included magazines and newspapers, and 10 were from broadcast mass media (i.e. television and radio). 16 stories came from “new” media, specifically blogs and news websites, including the online versions of old media (i.e. the online version of U.S. News and World Report, which often includes more information about a story than found in the old media version). The length of stories ranged from 88 words to 7,974 words with a
mean of 1,109.5 words (Table I). 15 stories were published in 2006, 14 in 2007, 54 in 2008, and 10 in 2009.

<table>
<thead>
<tr>
<th>Year of Publication</th>
<th>Number of Stories Published</th>
<th>Range in Word Count</th>
<th>Mean Word Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>15</td>
<td>251 – 2248</td>
<td>834.9</td>
</tr>
<tr>
<td>2007</td>
<td>14</td>
<td>421 – 6257</td>
<td>1456.4</td>
</tr>
<tr>
<td>2008</td>
<td>54</td>
<td>88 – 3103</td>
<td>974.9</td>
</tr>
<tr>
<td>2009</td>
<td>10</td>
<td>160 – 7974</td>
<td>1762.8</td>
</tr>
<tr>
<td>All</td>
<td>93</td>
<td>88 – 7974</td>
<td>1109.5</td>
</tr>
</tbody>
</table>

Table I
Word Count Statistics by Year of Publication

Genetic Determinism

Genetic Determinism was coded according to the degree to which genes were discussed as primary factors in shaping health outcomes. Five categories were used. High Genetic Determinism was coded for stories that presented genes as the sole factor in determining human outcomes. High Genetic Determinism-Contested was coded for stories that primarily focused on genes as the sole factor in determining human outcomes but included discussion of opposing viewpoints. Moderate Genetic Determinism was coded for stories which presented genes and environment as equal influences and discussed both environment and genes equally. Low Genetic Determinism-Contested, coded stories that opposed the idea that genes are factors in determining human outcomes yet discussed opposing viewpoints, and Low Genetic Determinism was coded for stories which opposed the idea that genes are factors in determining human outcomes. A Cohen’s kappa (κ) of .85 indicated almost perfect intercoder reliability.
One headline was coded High Genetic Determinism, and one was coded Moderate Genetic Determinism. 18 leads (19.4%) were coded as a High Genetic Determinism. In the articles of which these 18 leads were a part, 3 articles overall were coded High Genetic Determinism, 3 were coded High Genetic Deterministic-Contested, and 12 were coded in the Moderate Genetic Determinism category. 7 leads (7.5%) were coded Moderate Genetic Determinism, and one lead was coded Low Genetic Determinism-Contested.

5 news articles (5.4%) were coded as having High Genetic Determinism. Another 5 also made claims were coded High Genetic Determinism-contested. 31 articles (33.3%) displayed Moderate Genetic Determinism. 2 articles (2.2%) were coded Low Genetic Determinism-contested. No headline, lead or article was coded Low Genetic Determinism. 50 articles (53.8%) did not address genetic determinism. Chi square ($\chi^2$) tests showed no significant differences in reporting of determinism based on media type or year published.

**Discrimination**

The theme of discrimination was used for stories that addressed whether DTC genetic tests would lead to discrimination and identified possible sources of that discrimination. 4 potential sources of discrimination were included: Insurance, Employment, Societal, and Other. For news stories that claimed DTC genetic testing would mitigate or eliminate the possibility for discrimination, a “Positive View” subcategory was also included. A Cohen’s kappa ($\kappa$) of .77 indicated substantial intercoder reliability.
Multiple sources of discrimination were discussed in news stories. News stories presented insurance as the most common source of discrimination, with 16 full news articles (17.2%) and 3 leads (3.2%) listing insurance as a possible source of discrimination. Employment was mentioned by 13 full news articles (14%) and 2 leads (2.2%), followed by Societal and Other each mentioned by 2 articles (2.2%). One news story was coded “Positive View.” Chi square (χ²) tests showed no significant differences in reporting of discrimination based on media type (value) or year published (value).

Privacy

The theme of privacy coded concerns about individuals or groups who might endanger or violate the privacy of individual medical information. Insurance was coded for news stories that mentioned concerns about keeping the results of a DTC genetic test away from an individual’s insurance company. Direct-to-Consumer Companies was coded for news stories that mentioned concerns about what DTC companies will do with an individual’s test result or DNA sample. Medical Record/Doctor was coded for stories mentioning concerns about keeping the results of a DTC genetic test out of an individual’s medical record, or private from their physicians. Employer was coded for news stories that mentioned privacy concerns about keeping the results of a DTC genetic test from an individual’s employer. Family Members was coded when stories mentioned that an individual’s family members may prefer the results of a DTC genetic test not be made public and when stories discussed finding previously unknown paternity information from a DTC genetic test. Other was coded for stories that mentioned other entities as a cause of concern for consumer privacy. Again, a Positive View category was coded for stories that mentioned viewed DTC genetic testing as a means of safeguarding
privacy since it keeps medical information out of the hands of doctors and insurance companies. A Cohen’s kappa (κ) of .79 indicated substantial intercoder reliability.

Medical Record/Doctor was the most commonly coded privacy concern, appearing in 9 full articles (9.7%) and one lead. The next most commonly coded concern was DTC Companies, mentioned in 8 articles (8.6%) and one lead. Concerns for Insurance was coded in 5 articles (5.4%) and 2 leads (2.2%). Family Members was coded in 4 articles (4.3%) and one lead. Employer was coded in 2 articles (2.2%). “Other” sources for privacy concern were coded in 13 news articles (14%), 4 leads (4.3%) and one headline. Finally, 10 news articles (10.8%) and 5 leads (5.4%) were coded for a Positive View on privacy. Chi square ($\chi^2$) tests showed no significant differences in reporting of publication based on media type or year published.

GINA

This sample contains news stories published before and after the passage of the Genetic Information Nondiscrimination Act. All stories were coded according to the manner in which GINA was addressed. A Cohen’s kappa (κ) of .92 indicated almost perfect intercoder reliability.

Of the 93 total stories, 49 were either published after GINA was passed or while GINA and its impact was being considered by Congress (i.e. within two months of its passage). Very few articles published during or after the time of GINA’s passage discussed the impact of the legislation. 10 full articles (10.8%), 2 leads (2.2%) and one headline were coded as claiming GINA would have an impact on the DTC genetic testing industry. 3 articles (3.2), one lead and 2 headlines were coded as mentioning GINA but not mentioning any potential impact of the law on DTC genetic testing. Chi square ($\chi^2$)
tests showed no significant differences in reporting of GINA’s passage based on media type or year published. Chi square ($\chi^2$) tests showed no significant differences between pre/post GINA publication times and reporting on discrimination or privacy.

**Regulation**

News stories were also coded for discussion of federal-level regulation of DTC companies, and whether the story reported that a lack of regulation may lead to consumer harm. Addressed-Supported was coded for news stories that raised the concern that there is no central authority regulating DTC companies, and that lack of regulation may lead to consumer harm. Addressed-Neutral was coded for stories that presented competing viewpoints on the need for regulation of DTC companies by federal authorities. Unaddressed was coded for stories that did not address concerns regarding regulation of DTC companies. A Cohen’s kappa ($\kappa$) of .84 indicated almost perfect intercoder reliability.

45 news articles (48.4%), 16 leads (17.2%) and 5 headlines (5.4%) were coded as addressed-supported. 10 news articles (10.8%), 2 leads (2.2%) and 4 headlines (4.3%) were coded addressed-neutral on the issue of regulation. 38 articles (40.9%) were coded as unaddressed. Chi square ($\chi^2$) tests showed no significant differences in reporting on regulation based on media type or year published.

**Analytical and Clinical Validity**

News stories were coded according to the manner in which they addressed analytical and clinical validity. Analytical and clinical validity was defined as any
reference to the accuracy of the DTC genetic test or proof that markers used in the test have the ability to predict the health conditions they with which they were associated.

Not Valid was coded for stories which raised the concern that DTC genetic tests have not been validated by scientific research. This includes all stories that raised the issue and offer no additional support or any refutation of this claim. Neutral was coded for stories which equally presented the arguments on both sides of the clinical validity issue, or made equivocal statements about the issue of validity. Valid was coded for stories which claim that DTC genetic tests are clinically valid. A Cohen’s kappa (κ) of .85 indicated almost perfect intercoder reliability.

30 news articles (32.3%) as well as 9 (9.7%) leads and 3 (3.2%) headlines made claims that DTC genetic tests are not valid. 39 articles (41.9%), 14 leads (15.1%) and 3 headlines (3.2%) were coded as neutral. 4 articles (4.3%) and 2 leads (2.2%) claimed that the tests are valid. Chi square ($\chi^2$) tests showed no significant differences in reporting of analytical and clinical validity based on genetic determinism, media type or year published.

**Clinical Utility**

News stories were coded according to the attitude presented on the clinical utility of DTC genetic testing. Clinically Useful was coded for stories which claimed that DTC genetic tests provide results which are useful in improving health or treatment, and offered no evidence that they may not provide useful results. Clinically Useful-Contested was coded for stories which claimed that DTC genetic tests provide useful results but also provides views of the disagreement, or raises questions about their usefulness. Neutral coded both for stories that made equivocal claims about DTC genetic tests (e.g. the tests
might some value for improving health or medical treatment) and for stories which claims for and against the medical usefulness of DTC genetic tests. Not Clinically Useful-Contested was coded for stories which claimed that DTC genetic tests provide results that are not useful but also provides views of the disagreement, or raises questions about their usefulness. Not Clinically Useful was coded for stories which claimed that DTC genetic tests provide results which have no use in improving health or treatment, and offered no evidence that they may provide useful results. A Cohen’s kappa (κ) of .75 indicated substantial intercoder reliability.

6 articles (6.5%) and 5 leads (5.4%) claimed DTC genetic tests were clinically useful. Another 3 articles (3.2%) also coded Clinically Useful-Contested. 25 articles (26.9%), 10 leads (10.8%) and one headline were coded Neutral. 12 articles (12.9%), one lead and one headline claimed tests were coded Not Clinically Useful-Contested. 6 articles (6.5%), 3 leads (3.2%) and 2 headlines (2.2%) were coded Not Clinically Useful. Chi square (χ²) tests showed no significant differences in reporting of clinical utility based on genetic determinism, media type or year published.

Cost

Finally, the sample was coded according to attitude on the cost of DTC genetic tests. A Likert Scale measuring from Very Affordable to Very Unaffordable was used. A Cohen’s kappa (κ) of .95 indicated almost perfect intercoder reliability.

The vast majority of articles, 87 in total (93.5%), provided no attitude on cost. 4 articles in the sample (4.3%) claimed the tests were Affordable. 1 story claimed the test was Unaffordable, and one story was Neutral on the issue of cost. Although specific attitudes were not found, 59 articles did provide a specific cost or range of costs for the
tests. The amounts reported ranged from $19.99 - $350,000 with $1000 being the most commonly presented cost of a DTC genetic test. The average cost was $31,000, and the median was $175,010. The average and median are inflated by 12 articles that reported costs over $100,000, which is the cost for more advanced, complete genome sequencing. When these 12 articles were excluded from the calculations, the average cost reported is $1,027 and the median is $997. Chi square ($\chi^2$) tests showed no significant differences in reporting on cost based on media type or year published.

**DISCUSSION**

These data showed a range of attitudes toward DTC genetic testing and its potential social and medical impacts. Our findings indicated that the same range of attitudes was presented between all years in the sample as well as between all media types, which may indicate that public concerns about DTC genetic testing have not changed. The consistency across different types of media is likely the result of several factors. Print and broadcast media have online versions that reproduce the content of "old" media in the format of "new" online media. Also, new media allow for hypertext, which is the linking of multiple sources to one website. The easy reproduction of news stories across multiple forums would allow variations of the same story to appear across multiple online venues, although variations on one story were excluded for the purposes of this study.

The proposed hype/space conflict, where the opening of a story will exaggerate or hype an issue in order to acquire space to present a more balanced account in the remainder, was mainly not supported, with the exception of some support when coding media sources for genetic determinism. Some leads reported High Genetic Determinism
while the article as a whole presented Moderate Genetic Determinism. A previous study designed to examine how newspaper stories cover genetics and race also found little support for hype-space accounts of news coverage (Lynch & Condit, 2006). There are at least two possibilities for the lack of hype/space conflict found in our study and that by Lynch & Condit. First, discussions of DTC genetics might be controversial enough without the need for journalistic “hype.” Certain topics might produce enough excitement and controversy that just mentioning them will generate interest from readers. Second, the studies initially describing the hype/space theory (reference) did not account for different types of news stories and assumed that all science journalism was “hard news” (i.e. stories aiming at the initial presentation of facts quickly after an event occurs). Many stories about DTC genetic testing fit the “soft news” or feature news categories where the goal is to provide a depth of understanding to facts already available or reported elsewhere. Often these stories focus on “human interest” and use the story of a lay person struggling with issues like the decision whether to take a DTC genetic test in order to aid the reader’s understanding of the issues. In these cases the presenting of the lay person and their situation becomes the lead that will draw the readers into the balanced presentation and eventual resolution of the issues.

The majority of news stories that addressed genetic determinism presented a Moderate level of determinism and presented both genes and environment as determinants of human health outcomes. Although the media attempted to display that a range of factors, such as genes and environments, shape human health, they did not establish the relationship between these factors, or how they interact.
Insurance and Employment were the most commonly identified sources of potential discrimination. This finding is congruent with other studies of media reporting on genetic testing in clinical settings (references). Journalists frequently identify discrimination in insurance and employment settings as fears the public is likely to have about genetic testing technologies. It is not clear whether the public expresses this concern thus leading to media coverage of it or the public expresses this concern as a result of media reports. This type of “chicken or the egg” problem cannot be addressed by textual analysis. The scientific community as well expresses concerns for discrimination, adding to the complexity of identifying where these concerns originate. Regardless of the cause, concerns about discrimination might be raised by lay people who have used DTC genetic testing and will need to be addressed by geneticists, genetic counselors, primary care providers and other medical professionals with interests in genetic technology.

News stories indicated that medical records and physicians were the most likely source for a violation of the privacy of medical information, followed by DTC Companies. Yet, multiple news stories presented DTC genetic testing in a positive light, as a means of keeping medical information from physicians and insurance companies and thus private. The existence of competing viewpoints on privacy might be the results of journalistic standards of objectivity that require allowing both sides to present their viewpoints. This would allow critics and the companies to make their opposing claims about whether DTC genetic testing companies protect or violate privacy. Regardless of the source of a violation of privacy, the continued concern about the violation of privacy in news stories about DTC genetic testing and other stories related to genetic
technologies indicates significant mistrust of the technology and those who control the technology and the information it produces by journalists and the public. Such mistrust will need to be consistently and coherently addressed by medical professionals as they deploy genetic testing technologies and respond to lay people who have used DTC genetic tests.

Discussion of regulation for DTC genetic testing generally was fairly robust. Close to half of the news stories indicated that regulations at the federal level were required and a smaller group of articles discussed competing viewpoints on regulation. Yet, discussion of GINA’s impact on DTC genetic testing specifically was relatively mute. The majority of new stories published after GINA’s passage made no reference to the law or its impact on DTC genetic testing. New stories identified the need for regulation yet did not discuss a law that will directly impact the DTC genetic testing industry. There are several possible explanations for this. First, journalists and their sources of information might not have identified the full ramifications of GINA for DTC genetic testing and therefore do not discuss it. Second, since DTC genetic testing is relatively new, journalists might focus on explaining what they view as a complicated and potentially contentious topic, and because they feel the need to provide substantial explanation of DTC genetic testing, they do not try to complicate the story by raising additional topics like GINA. Third, GINA might not be discussed because it is associated with medical professionals and the insurance industry, while DTC genetic testing is viewed as an individual choice by a consumer that does not directly involve medical professionals or insurance companies. If the issue of DTC genetic testing is framed as an individual choice, then the discussion will identify factors that shape a person’s choices
and regulation will be framed more as consumer protection from shoddy products rather than the protection of medical information.

The neutral or equivocal discussion of analytical and/or clinical validity is expected given journalistic standards for neutrality, but it is noteworthy that almost one-third of the news stories claimed DTC genetic tests were not analytically and/or clinically valid. Claims that the tests do not accurately identify SNP-disease linkages have been persuasive to journalists. Barring the creation of a list of commonly tested SNPs being created by DTC companies or a transformation in the technology used in DTC genetic tests, it is likely that the number of stories dismissing the analytical and clinical validity of these tests will increase.

The news coverage of clinical utility also had a slant toward claims that the tests were Not Useful, but when compared to the coverage of analytical and clinical validity, there was a wider array of viewpoints. Again, the majority of articles were Neutral, and the next most common category were stories that predominately claimed DTC genetic tests lack medical utility but presented opposing viewpoints. Unchallenged claims for the lack of utility appeared as frequently as unchallenged claims for the test’s utility. While greater adherence to journalistic standards of objectivity might explain this pattern in the news coverage, it might also reflect a view of medical decisions as unique, individual concerns. While analytical validity represents whether scientists can consistently perform a test and receive a reliable answer, clinical utility represents whether the evaluation of an individual’s unique genetic and environmental circumstances leads to improved health and or treatments. If the focus is again on an individual’s unique genetic and environmental circumstances, then generalized statements about the utility or lack of
utility that do not account for differences between individuals would appear
inappropriate.

Finally, judgments about the cost of DTC genetic tests were rarely made, but
specific prices for the tests were frequently given. By presenting only a price figure
without making a judgment about affordability, journalists remain in their socially
defined role as neutral information providers and allow individual readers to ultimately
make a judgment about the tests’ affordability.

This study has 3 limitations to mention. First, the media samples used in this
study were confined to those available through the Lexis-Nexis database and thus may
not be representative of all news stories in the time period. Second, the total N in this
study may have been too low to allow for relationships between the themes presented to
be drawn or differences in media presentation through the years in this time frame to be
seen. Finally, our study looks solely at the media’s coverage of DTC genetic testing, and
not its impact on public perception or understanding. Further studies will be needed to
determine the impact of media coverage on public perception.

The themes presented in this study reflect the journalistic coverage of DTC
genetic testing taking a stance of neutrality and objectivity. The wide range of coverage
under each theme represents the breadth of opinion and information circulated regarding
these tests. The lack of hype/space conflict in the coverage of DTC genetic testing may
support the notion that array of opinion on the subject is enough to draw interest and
excitement. This study is significant in that it is the first to our awareness that looks at
how the media presents Direct-to-Consumer genetic testing. An understanding of this
presentation may contribute to understanding public responses to, and uses of DTC
genetic tests. Geneticists, genetic counselors, and even primary care providers may face more questions and discussion from their patients regarding DTC genetic testing as this advancement gains further public attention. Members of the medical community who interact with the general public must be aware of the information being supplied to lay individuals if they hope to understand public opinion and perception and converse with individuals regarding the subject of DTC genetic testing. Further studies will be needed to determine how the themes generated in our study impact the public’s attitude and decision making regarding utilization of these tests.
BIBLIOGRAPHY


Their Physicians in a Managed Care Organization. *The American Journal of Managed Care, 11*, 601-608.


