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Business and Breakthrough: Framing (Expanded) Genetic Carrier Screening for the Public

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Abstract

A growing body of research has given attention to issues surrounding genetic testing, including expanded carrier screening (ECS), an elective medical test that allows planning or expecting parents to consider the potential occurrence of genetic diseases and disorders in their children. These studies have noted the role of the mass media in driving public perceptions about such testing, giving particular attention to ways in which coverage of genetics and genetic testing broadly may drive public attitudes and choices concerning the morality, legality, ethics, and parental well-being involved in genetic technologies. However, few studies have explored how mass media are covering the newer test, ECS. Drawing on health-related framing studies that have shown in varying degrees the impact particular frames such as gain/loss and thematic/episodic can have on the public, this study examines the frame selection employed by online media in its coverage of ECS. This analysis—combined with an analysis of the sources and topics used in such coverage and how they relate to selected frames—helps to clarify how mass media are covering an increasingly important medical test and offers considerations of how such coverage may inform mass media scholarship as well as health-related practices.

Mass media, including a blend of news and information sources published or presented across a multitude of platforms, play a critical role in the dissemination of information to the public (McCombs, 2004). In particular, mass media are pivotal in the explanation of complex issues such as health information, which remains one of the most popular topics of interest among the public (Slooten, Friedman, & Tanner, 2013). In their efforts to meet public demands for such information, mass media have frequently come under fire for leaning too heavily on biased sources and frames—storytelling devices that help guide understanding of a topic or issue—that place more emphasis on health innovations and breakthroughs and how they may affect individuals rather than offering balanced coverage that relates such effects on a more societal scale (Coleman, Thorson, & Wilkins, 2011). Such challenges have been answered, at least in part, by various factions of the mass media, including news and health information organizations, that have shown evidence of presenting more balanced coverage of salient health issues such as diabetes, obesity, cancer reduction, and prenatal health (Holton, Lee, & Coleman, 2014).

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The majority of these studies have also challenged mass media and health communication scholars to more deeply explore the effects of framing on the public and the ways in which mass media employ certain topics, sources, and frames in coverage of novel, and potentially more complex, health issues (Coleman et al., 2011; O'Keefe & Jensen, 2007). This study takes up the latter call, drawing on mass media coverage of a relatively novel elective medical test that provides planning or expecting parents with probabilities for genetic diseases and disorders in their children. Expanded carrier screening (ECS), which allows for the screening of more than 100 genetic diseases and disorders (Edwards et al., 2015), has received a growing amount of attention in the mass media since its commercial laboratory release in 2009 and the publication of a foundational research article in 2010 (see Srinivasan et al., 2010). Such a rise in coverage, coupled with topics, terminology, sources, and frames used in coverage of issues related to genetics and genetic testing, may play key roles in shaping public perceptions about these emerging areas of science and health (Bunnik, Schermer, & Janssens, 2014; Lillie, Tarini, Janz, & Zikmund-Fisher, 2015). Accordingly, a close examination of mass media portrayals of ECS is warranted.

Recent studies have shown that health perceptions and behaviors may be driven by attributes of narratives, including the attainment of goals (gain-related frames) or the abandonment (loss-related frames) of such goals (Lee & Shapiro, 2016). In other words, the framing of health issues, even those such as ECS that are not interventions or driven by particular outcomes, may influence health perceptions and planned behaviors. This study thus uses a content analysis of the frames of online media coverage of ECS and the sources and topics related to such coverage to provide a foundational examination of ECS coverage. Results could provide insights into coverage of similarly novel health topics that are gaining, or will gain, more attention. With no existing studies available to determine the possible effects that current coverage of ECS has on public perceptions or behaviors, this study provides an initial associative perspective that will guide future explorations. This information is important for health care providers such as obstetricians, gynecologists, and genetic counselors as they interact with patients who are considering screening. The results also have implications for mass media, particularly those actors and organizations covering complex health issues such as ECS.

Literature Review

Expanded carrier screening for genetic diseases and disorders, which employs genotyping or DNA sequencing to help people identify risks for passing on such conditions to their future children, is a critical component of prepregnancy and prenatal decisions and care for millions of families (Edwards et al., 2015; Lizarin & Haque, 2016; Yarnall et al., 2015). Recent advancements in technology enable screening of more than 100 diseases and disorders, allowing individuals and couples to determine their risk of passing on genes while planning possible alternatives, such as in vitro fertilization or adoption, to reduce risks (Srinivasan et al., 2010; Wienke, Brown, Farmer, & Strange, 2014). Despite these advancements, little is known about how knowledge and perceptions about ECS are developed. Prior research about professional and personal perceptions of ECS has yet to explore key drivers of those perceptions, including mass media coverage of ECS.

Professional and Personal Perceptions of ECS

Research has shown that when considering ECS, medical professionals tend to focus on issues concerning (a) guidelines for determining what conditions should be included in test panels; (b) knowledge that health care providers have about the tests, conditions, and results; (c) adequate counseling or education for patients, both before and after test administration; and (d) the benefits and drawbacks of ECS. Medical professionals have urged the development of widely recognized, formal guidelines for what to include in ECS panels (Benn et al., 2014; Edwards et al., 2015; Grody et al., 2013; Langlois, Benn, & Wilkins-Haug, 2015). Edwards et al. (2015) authored a joint statement of the American College of Medical Genetics and Genomics, American College of Obstetricians and Gynecologists, National Society of Genetic Counselors, Perinatal Quality Foundation, and Society for Maternal–Fetal Medicine concerning ECS. They noted a number of uncertainties involved with many of the conditions screened in ECS panels, including the variable age of onset for some conditions, phenotypes that are not clearly defined, conditions that are not recommended for general population screening in current screening guidelines, and rare conditions for which risk after negative screening results are not known. Rose (2015, p. 2) further added, “Independently derived guidelines and oversight from professional organizations are needed. The development of smaller, focused screening panels, removing the very rare and the very common disorders, as well as those that are not clinically significant should be reevaluated.”

Many medical professionals have expressed concerns about the general lack of ECS knowledge among health care providers who are most likely to interact with patients before and after tests, including gynecologists, obstetricians, and other nonspecialist health care providers (Benn et al., 2014; Lindheim, Stammier, & Jaeger, 2015). For example, Benn et al. (2014) conducted a survey of obstetricians and gynecologists and found that only 33% were comfortable counseling patients before testing and even fewer, 24.9%, were comfortable explaining results. Clearly, these professionals, to whom planning or expectant parents are likely to turn for expert knowledge about ECS, do not view themselves as equipped with the knowledge they need to pass on necessary information to their patients. Genetic counselors and other genetic professionals echo that concern. Cho, McGowan, Metcalfe, and Sharp (2013) found that genetic professionals did not view reproductive health care providers as having the knowledge needed to interpret results of panels that include so many genetic conditions. Most professionals agree that genetic counseling is critical for patients to understand what testing will include, what results will and will not indicate, and what results mean (Cho et al., 2013; Edwards et al., 2015). The concern for genetic counseling for patients is particularly problematic, given evidence that very few reproductive health care providers consider themselves knowledgeable enough to provide the necessary information (Benn et al., 2014; Lindheim et al., 2015).

Scholars have recently noted that more research is needed to understand the individual, professional, legal, and societal implications of ECS (e.g., McGowan, Cho, & Sharp, 2013; Rose, 2015). In addition, scholars note that more research should address factors influencing attitudes toward and participation in ECS, such as cost and complexity of understanding how the test works and what the results may indicate (Langlois et al., 2015; Rose, 2015). Two

prior survey studies investigated the type of information people want to know before deciding whether they will have ECS conducted. Ormond et al. (2009) included pregnant women who had high literacy levels. Results of that study indicated that 83.8% of participants preferred to make decisions with as much information as possible, including information from news sources. Indeed, this sample of highly literate women prioritized details such as options for carriers, the value and purpose of testing, and prognosis if their child has a disease over information about turnaround time for results, insurance coverage, or costs of the test. However, 80% of participants wanted their physicians to recommend whether or not they should opt into screening. Reeves and Trepanier (2015) extended the Ormond et al. study by including a more diverse sample of students and staff at a large university, including both males and females. Results were similar to the earlier study, however, in that a majority of participants (74.5%) preferred more detailed information about genetic diseases and the test procedures over less detailed information (25.5% preferred).

When searching out such detail-rich information, people frequently turn to the Internet, where a host of mass media sources provide content that can help interpret complexities related to health issues such as ECS (Bunnik et al., 2014). The attributes of that information (i.e., topics of coverage, sources used, frames employed) may play a significant role in shaping attitudes, opinions, and behaviors toward health issues such as ECS (Lillie et al., 2015).

Constructing Health Information

When examining how the mass media present health topics, scholars have frequently relied on the theoretical construct of framing, which refers to the channels and content used to describe or explain issues or events (Entman, 1993; Reese, 2007). Most notably, journalists and other actors providing news and information to the public rely on specific frames to analyze complex issues, discuss problems and solutions, and convey important issues and topics to the public in meaningful and understandable ways (Boykoff, 2007; Reese, 2007). Mass media tell the public what to think about and how to think about it through topic selection and by presenting which topics relate to others, sources, and pertinent information (McCombs & Ghanem, 2001).

The selection of topics and sources is particularly critical in conveying health information, which, given its complex nature, often requires expert insights to explain such intricate information (Len-Rios, Hinnant, Park, Cameron, Frisby, & Lee, 2009). Sources who provide a blend of authoritative fact and opinion may help the public to better understand health risks, assume more proactive approaches to health, and assign blame for particular health concerns (Holton, Weberling, Clarke, & Smith, 2012). Sources may also help media professionals to develop story ideas, guiding them either through suggestions for coverage or by offering nuanced details about a number of topics (Tanner & Friedman, 2010). Health journalists tend to favor sources who are readily available, can easily contextualize information, and can offer insider perspectives (Myrick, Major, & Jankowski, 2014). As Myrick and her colleagues (2014) noted, when faced with new or complex information, the public may rely on sources within mass media coverage to guide their thinking. They may

also be met with a combination of topics and subtopics within a story. Suran and her colleagues (2014) argued that the mass media as well as media scholars sometimes combine a multitude of topics and subtopics in order to create a more meaningful narrative. The public responds to the inclusion (or exclusion) of topics in varying ways. Major (2009) found that individuals assign blame for obesity and cancer much differently, while Taggart and her colleagues (2012) found that the success rate for interventions for negative health behaviors varied based on a variety of health issues, or topics. Similarly, Suran et al. (2014) found that topics in online health content, along with particular frames, could be significantly affecting the way readers respond to those topics. For example, stories that focused on obesity and personal health produced more episodic and gain-framed responses from readers while mental health topics were idiosyncratic with thematic responses.

Findings from prior studies suggest that the interplay between sources, topics, and frames in health-related news and information may play a role in the development of attitudes, beliefs, and behaviors toward health issues. Health scholars have given a more notable amount of attention to how the mass media frame stories, focusing primarily on thematic/episodic frames and gain/loss frames (Foster, Tanner, Kim, & Kim, 2014; Myrick et al., 2014). Thematic frames—those that emphasize issues more broadly and connect them to society—may cue the public how to think about and act on issues at a societal level, moving away from assigning individual blame for societal problems (Iyengar & Simon, 1993). The news media have been encouraged by health professionals to include more thematic frames in their coverage of health topics with the hopes of creating a more collectively proactive public, though the exact benefits of such inclusion remain subject for debate (O’Keefe & Jensen, 2006, 2007). Episodic frames—those that emphasize the role of the individual—may “put human faces on stories” and help the public relate with information (Suran et al., 2014), though they often assign responsibility to an individual in a potentially disengaged manner. In an effort to objectively balance coverage of issues, news organizations may attempt to engage both frames equally, though health scholars continue to urge more thematic approaches in order to enhance public understanding of societal causes and solutions (see Hawkins & Linvill, 2010).

Public perceptions and reactions to health issues may also be affected by gain and loss frames (Quick & Bates, 2010). Gain frames emphasize positive outcomes of actions such as healthy dieting or childhood vaccinations, while loss frames primarily focus on negative outcomes. Gain frames have been successful in interventions for low-risk behaviors such as annual exams and consumption of vitamins, while loss frames are most frequently used in collaboration with higher risk health issues such as lifetime diseases and intensive medical procedures (O’Keefe & Jensen, 2007).

The combined effect of sources, topics, and frames in coverage of health issues remains murky at best. Scholars have urged for more thorough examinations of how these issues are being presented, particularly through a more holistic lens. Noting the relative novelty of ECS, along with its complexities and growing news media coverage, this study addresses that call by asking:

RQ1: What sources are being represented in online news articles about ECS?

RQ2: What association, if any, is there between these sources of information and frames (episodic/thematic, gain/loss) in online news articles about ECS?

RQ3: What topics are being represented in online news articles about ECS?

RQ4: What association, if any, is there between these topics and frames (episodic/thematic, gain/loss) in online news articles about ECS?

Method

Sample

Though ECS became available to the public in 2009, the test did not receive much media attention until a foundational research article detailing the test was published in 2010 (Srinivasan et al., 2010). Thus, a Google News search for the term “expanded carrier screening” for the period of January 2010 to February 2015 was used to develop the sample. Inclusion criteria for articles to remain in the study were (a) publicly available website; (b) main issues covered in article were ECS or related issues; (c) article was a “news”-type article reporting on some issue relating to carrier screening, rather than a policy document or position statement that was not disseminated with the intent to report information to the general public; and (d) article was not a book review or advertisement. After removing articles that did not meet the inclusion criteria, 227 articles were included in the study.

Measures

Drawing on multiple relevant studies (e.g., Coleman et al., 2011; Manganello & Blake, 2010; Suran et al., 2014), the study team developed a codebook for topics within stories, quoted sources within stories, and frames used within stories.

Topics coded included genetic carrier screening, expanded genetic carrier screening (ECS), breakthrough or research, treatment, business issues, innovation, specific lab or tests, prepregnancy issues, pregnancy issues, legal/ethical issues, religion issues, political issues, cost, and other. Topics were not coded as mutually exclusive; therefore, stories could have one or several topics. Table 1 provides topic codes and data exemplars from the sample.

Coding for sources quoted within the articles included pharmaceutical company/representative, medical research company/representative, individual physician, individual researcher, genetic counselor, screening advocacy organization/representative, religious organization/representative, government organization/representative, business organization/representative, expecting or planning parents, current parents, educational/academic resources, and other.

Coders recorded the number of paragraphs within each story that contained thematic, episodic, and gain and/or loss frames. Thematic instances underscored broad issues or topics such as AIDS, cancer, long-term illness, policy issues, and so on, and how they relate to society or the public more broadly. Episodic instances were more narrative in nature and often used people or other anecdotes to tell stories. Gain frames emphasized the benefits or rewards of certain health actions such as quitting smoking or getting a vaccination. Loss

frames focused on the risks or disadvantages for avoiding health actions. Frames were not mutually exclusive, and some stories (and some paragraphs) could have one or more frames.

Coding Reliability and Analysis

Two research assistants were trained on the coding procedure, each going through multiple rounds of pretesting. All 227 articles included in the main sample were then divided and coded by the research assistants. Inter-coder reliability (ICR)—based on 44 dual-coded articles—established acceptable Krippendorff's alpha scores (.80 or higher; Hayes & Krippendorff, 2007) for all individual variables. All data were analyzed using the Statistical Package for Social Sciences (SPSS), which allows for multiple analysis approaches. Paired samples *t*-tests were used to compare thematic versus episodic frame counts and gain versus loss frame counts within an article. Kendall's tau was used to report the nonparametric correlation coefficients between sources and frames, and between topics and frames. We adjusted our alpha level to $<.001$ to signify statistically significant relationships due to the large amount of correlations we are reporting.

Results

In terms of how ECS stories were framed, there were significantly more thematic frames ($M = 1.92$, $SD = 2.02$) than episodic frames ($M = .94$, $SD = 2.76$; $t(226) = 4.64$, $p < .001$) and significantly more gain frames ($M = 2.02$, $SD = 1.77$) than loss frames ($M = .67$, $SD = 1.11$; $t(226) = 11.68$, $p < .001$).

To answer RQ1, which asked what sources are being represented in online news articles about ECS, Figure 1 shows that more than half included a business organization representative ($n = 124$, 54.6%), and approximately half used medical research company representatives ($n = 110$, 48.5%). Notably, approximately 1 in 20 quoted a genetic counselor ($n = 12$, 5.3%), and even fewer included expecting parents as quoted sources ($n = 4$, 1.85%).

To answer RQ2, which asked what association, if any, there is between these sources of information and frames (episodic/thematic, gain/loss) in online news articles about ECS, analyses show the largest correlation exists between current parents and episodic frames ($\tau_b = 0.711$, $p < .001$). Results indicate articles that utilized current parents as a source were highly likely to use more episodic frames in reporting. Articles that used current parents as a source were also likely to use more gain and loss frames ($\tau_b = 0.273$ and $\tau_b = 0.220$, $p < .001$, respectively). The next two highest correlations showed a relationship between screening advocacy sources and the number of episodic and loss frames ($\tau_b = 0.336$ and $\tau_b = 0.331$, $p < .001$, respectively). This gives evidence that articles using screening advocacies as sources are more likely to use episodic and loss framing. When articles used religious organizations as sources they were nearly identical in correlation with thematic, episodic, gain, and loss framing ($\tau_b = 0.230$, $\tau_b = 0.218$, $\tau_b = 0.202$, and $\tau_b = 0.266$, $p < .001$, respectively).

To answer RQ3, which asked what topics are being represented in online news articles about ECS, Figure 2 shows that the majority of articles included topics directly related to genetic

carrier screening broadly ($n = 197$, 86.8%), followed by ECS ($n = 167$, 73.6%), lab tests ($n = 176$, 77.5%), and breakthroughs or research ($n = 123$, 54.2%).

To answer RQ4, which asked what association, if any, there is between these topics and frames (episodic/thematic, gain/loss) in online news articles about ECS, analyses showed four of the five largest correlations exist between the topic of cost/economics and thematic, episodic, gain, and loss frames ($\tau_b = 0.376$, $\tau_b = 0.286$, $\tau_b = 0.360$, and $\tau_b = 0.300$, $p < .001$, respectively). These results indicate articles covering the topic of cost/economics were likely to use more of each of four of the frames. The third highest overall correlation coefficient was between legal/ethical issues and loss frames ($\tau_b = 0.329$, $p < .001$). This suggests that articles covering topics of legal/ethical issues generally used loss framing. Articles covering the topic of medical treatment were likely to use more episodic, gain, and loss frames ($\tau_b = 0.259$, $\tau_b = 0.217$, and $\tau_b = 0.258$, $p < .001$ respectively). Articles about prepregnancy health tended to use more episodic, and gain frames ($\tau_b = 0.260$, and $\tau_b = 0.220$, $p < .001$ respectively).

Discussion

The purpose of this study was to examine how ECS is being represented to the public online in news-related articles. Medical professionals have conveyed cautious support for expanding the scope of prenatal genetic testing, yet until now little was known about whether that caution is mirrored in mass media coverage of the issue. Prior research on public perceptions of ECS also indicates patient support for the tests, but that research indicates a high degree of confidence that providers will have the requisite knowledge to help patients understand procedures and implications of tests that reveal information on more than 100 genetic conditions (Ormond et al., 2009; Reeves & Trepanier, 2015). Results of the analysis here indicate important trends in the information about ECS being presented to the general public in online news articles. We first discuss the implications of the sources being used for online news and then interpret findings regarding topics covered in articles. We conclude with suggestions for how findings of this study may be used in future research concerning ECS attitudes, communication, and behavior.

It is clear from the analysis here that far more information about ECS is coming from businesses, including medical research companies, than from medical practitioners such as physicians and genetic counselors. This is important to note because previous research regarding professional and public perceptions of ECS places a high premium on information shared between providers and patients (e.g., Cho et al., 2013; Edwards et al., 2015). The heavy reliance on business representatives, particularly of those companies engaged in the business of medical research, could be constructing a public discussion about ECS that focuses much more on research-based perspectives than it does on health practice-based perspectives. Interestingly, prior research on practitioner perceptions has often sought genetic counselors' opinions (e.g., Cho et al., 2013; McGowan et al., 2013). However, news reporters are clearly not seeking such opinions. Genetic counselors were only cited in 12 of the 227 articles.

When considering frames used within news articles, it is important to note that citations of individual researchers as sources of information were positively correlated with both gain and loss framing. This indicates that when researchers are cited in news articles, they may not be associated with more thematic or episodic frames but rather may be employed to help negotiate the benefits and drawbacks to ECS in more balanced ways.

Notably fewer articles cited current or expecting parents as sources of information or included topics related to them (i.e., pregnancy health, prepregnancy issues). Not surprisingly, both types of parent sources significantly correlated with episodic frames, which focus on individual experiences. This does indicate that the “personal side” of ECS is being presented, although clearly less than the “business side” of ECS. Screening advocacy organizations also correlated with the use of episodic frames. However, it is important to note that there was a significant correlation between using screening advocacy organizations as information sources and employing loss frames within the articles. This finding could point to a general tendency for screening advocacy organizations to emphasize the negative aspects of living with genetic disorders that can quite severely impact quality of life for children and parents alike.

Consistent with the reliance on representatives from business and medical research companies as sources of information, articles were more likely to cover topics about business-related aspects of ECS than other topics. The business-related issues presented in Figure 2 combine for 521 references to these topics in the 227 articles. In comparison, only 130 references were made to medical topics, such as treatment and health issues. Topics receiving the least attention in online news articles about ECS were ethical and social issues, such as ethics, religion, and politics, with only 76 references. This finding, in combination with the results regarding sources of information, is a strong indicator of the public conversation being hosted on the Internet about expanded carrier screening. Clearly, business is driving the conversation. Yet prior research on medical professionals’ perceptions indicates that careful and extended attention should be paid to the legal, ethical, and social implications of ECS (e.g., Edwards et al., 2015; Rose, 2015).

When considering how topics associate with frames used within articles, only the specific topic of cost/economics was significantly correlated with particular frames. However, it is interesting that this topic, appearing 70 times in our sample, significantly correlates with both episodic and thematic as well as with both gain and loss frames. This finding could indicate that when costs of ECS are discussed, there is a somewhat balanced presentation of the issue. A similar result emerged for the topic of medical treatment, which was significantly correlated with both gain and loss frame use. However, the medical treatment topic was only correlated with episodic framing, possibly suggesting that when articles discuss medical treatments, they focus more on individual-level consequences than on societal-level concerns. Such presentations of health-related issues, especially those that involve interventions or elective procedures, have come under fire for failing to convey health issues in ways that connect society rather than focusing solely on individuals (Dorfman, Wallack, & Woodruff, 2005; Suran et al., 2014).

Theoretical Implications

Two novel theoretical implications emerge from findings of this study. First, results comport with recent health communication research using institutional theory as a framework for understanding how people engage with health issues and behaviors (e.g., Currie & Suhomlinova, 2006; Lammers & Lambert, 2016; Rauscher, Young, Durham, & Barbour, in press). Briefly, institutional theory holds that “institutional structures influence what counts as knowledge, who is recognized as sources of such knowledge, and what procedures are accepted for creating and disseminating requisite knowledge” (Canary, 2016, p. 262). Results from our analysis of online news coverage over a 5-year period could be indicating institutional norms of several industries, including journalism, medical research, and health care, that are structuring how knowledge of ECS is constructed among those involved in the development and use of the tests. Representatives from medical research and other business companies are used as sources much more than professionals who interpret results for people who are screened (Figure 1), highlighting the technological, innovative, and economic aspects of ECS over other social, personal, or ethical aspects of the screening tests. The norm of focusing on innovation and economics is also seen in the most frequent topics of articles (Figure 2), with ethical, legal, religious, and other social issues representing far less news coverage than business and innovation issues.

A second theoretical implication concerns our framing results. Although more thematic and gain frames emerged in the news coverage than episodic and loss frames, correlational analyses indicate that all frames associate with certain sources and topics. Such findings are consistent with prior framing research demonstrating the importance of more nuanced understandings of framing when dealing with health topics (e.g., Coleman et al., 2011; Shugart, 2011). As mass media professionals cover increasingly complex health topics, such as genetics, for an increasingly diverse audience, such as found online, framing analyses may need to become more nuanced and less dualistic. Future research, suggested in the following, may further address both of these theoretical implications.

Limitations and Future Directions

While previous studies have shed light on professional and public perceptions of ECS, this study is the first to examine how mass media are presenting the issue. As such, this study focused on a primary source of mass media coverage of ECS: online news articles. Prospective parents or health professionals might gain their knowledge about ECS from non-news websites and texts, such as through professional associations or in organization-specific documents. Furthermore, the sample did not include social media conversations or posts, such as those found on Facebook or similar websites. Focusing on public responsiveness to particular attributes of news coverage such as topics, sources, and frames can reveal much about public perceptions, attitudes, and (intended) behaviors and should be considered as a next step in this thread of research. Future studies can also build on the methodology of this study and include social media exchanges or posts to develop a broader idea of the online public exchange of information about ECS and similar tests or procedures. The sample was also limited to a particular period of time (i.e., approximately 5 years), which was necessary for managing the analysis. It would be productive to maintain an effort to collect articles on an ongoing effort to scan the media environment concerning ECS to

identify changes in informational trends over time, especially noting a recent uptick in coverage of ECS and ECS-related issues.

Despite these limitations, the analyses of sources, topics, and frames in this study relate to several research directions identified by Edwards et al. (2015) as important for developing requisite knowledge about the implications of ECS. Specifically, results of this study indicate what types of information patients may be exposed to before they interact with their health care provider about having ECS done, which may influence their attitudes toward ECS. Importantly, physicians are exposed to general online news sources as well, and news coverage of ECS could also impact their attitudes toward ECS. Results here can be used to design future experimental studies that compare how different combinations of sources, topics, and frames influence ECS attitudes of patients and providers.

This study provides a foundation for more in-depth analyses of mass media and public discourses about expanded carrier screening, suggesting that the former may be framing ECS in ways that focus much more on the business side of ECS than on its implications for medical practitioners, genetic counselors, and expecting, planning, or current parents. Notably, mass media appear to be answering previous critiques of health-related media coverage that have called for more thematic framing. Indeed, coverage of ECS examined in this study showed more thematic-framed and more gain-framed coverage, suggesting the mass media may be attempting to connect ECS on more societal, and potentially positive, levels. Still, the lack of particular voices in media coverage—particularly those of planning, expecting, or current parents and genetic counselors—suggests room for improved coverage that emphasizes the effect ECS may have on individuals and families and who is available to appropriately explain such impacts.

To conclude, findings of this study contribute to the growing body of research concerning how mass media impact attitudes toward a variety of health topics, not only those involving changes in health behaviors (e.g., Major, 2009; Suran et al., 2014). As medical technology continues to develop, increasingly sophisticated tests will be available to the public generating an array of complex information. Future research will build on results of this study to further investigate the role of online news information in how health care practitioners and their patients develop knowledge about genetic testing, make screening decisions, and consider their medical options.

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References

- Benn P, Chapman AR, Erickson K, DeFrancesco MS, Wilkins-Haug L, Egan JF, Schulkun J. Obstetricians and gynecologists' practice and opinions of expanded carrier testing and noninvasive prenatal testing. *Prenatal Diagnosis*. 2014; 34:145–152. DOI: 10.1002/pd.4272 [PubMed: 24222397]

- Boykoff MT. From convergence to contention: United States mass media representations of anthropogenic climate change science. *Transactions of the Institute for British Geographers*. 2007; 32:477–489. DOI: 10.1111/j.1475-5661.2007.00270.x
- Bunnik EM, Schermer MHN, Janssens ACJW. Naming and framing in genomic testing. *Trends in Molecular Medicine*. 2014; 20:63–65. DOI: 10.1016/j.molmed.2013.11.001 [PubMed: 24485561]
- Canary, HE. Constructing organizational knowledge: Theorizing processes and practices conducive to health. In: Harrison, TR., Williams, EA., editors. *Organizations, communication, and health*. New York, NY: Routledge; 2016. p. 258-274.
- Cho D, McGowan ML, Metcalfe J, Sharp RR. Expanded carrier screening in reproductive healthcare: Perspectives from genetics professionals. *Human Reproduction*. 2013; 28:1725–1730. DOI: 10.1093/humrep/det091 [PubMed: 23589535]
- Coleman R, Thorson E, Wilkins L. Testing the impact of public health framing and rich sourcing in health news stories. *Journal of Health Communication*. 2011; 16:941–954. DOI: 10.1080/10810730.2011.561918 [PubMed: 21660828]
- Currie G, Suhomlinova O. The impact of institutional forces upon knowledge sharing in the UK NHS: The triumph of professional power and the inconsistency of policy. *Public Administration*. 2006; 84:1–30. DOI: 10.1111/padm.2006.84.issue-1
- Dorfman L, Wallack L, Woodruff K. More than a message: Framing public health advocacy to change corporate practices. *Health Education & Behavior*. 2005; 32:320–336. DOI: 10.1177/1090198105275046 [PubMed: 15851542]
- Edwards JG, Feldman G, Goldberg J, Gregg AR, Norton ME, Rose NC, Watson MS. Expanded carrier screening in reproductive medicine—Points to consider: A joint statement of the American College of Medical Genetics and Genomics, American College of Obstetricians and Gynecologists, National Society of genetic Counselors, Perinatal Quality Foundation, and Society for Maternal–Fetal Medicine. *Obstetrics & Gynecology*. 2015; 125(3):653–662. DOI: 10.1097/AOG.0000000000000666 [PubMed: 25730230]
- Entman R. Framing: Toward clarification of a fractured paradigm. *Journal of Communication*. 1993; 34:51–58. DOI: 10.1111/j.1460-2466.1993.tb01304.x
- Foster C, Tanner AH, Kim S-H, Kim SY. National conversations about the costs of U.S. health care: A content analysis of media coverage, 1993–2010. *Science Communication*. 2014; 36:519–543. DOI: 10.1177/1075547014536882
- Grody WW, Thompson BH, Gregg AR, Bean LH, Monaghan KG, Schneider A, Lebo RV. ACMG position statement on prenatal/preconception expanded carrier screening. *Genetics in Medicine*. 2013; 15:482–483. DOI: 10.1038/gim.2013.47 [PubMed: 23619275]
- Hawkins KW, Linvill DL. Public health framing of news regarding childhood obesity in the United States. *Health Communication*. 2010; 25:709–717. DOI: 10.1080/10410236.2010.521913 [PubMed: 21153987]
- Hayes AF, Krippendorff K. Answering the call for a standard reliability measure for coding data. *Communication Methods and Measures*. 2007; 1:77–89. DOI: 10.1080/19312450709336664
- Holton AE, Lee N, Coleman R. Commenting on health: A framing analysis of user comments in response to health articles online. *Journal of Health Communication*. 2014; 19:825–837. DOI: 10.1080/10810730.2013.837554 [PubMed: 24446785]
- Holton AE, Weberling B, Clarke CE, Smith MJ. The blame frame: Media attribution of culpability about the MMR–autism vaccination scare. *Health Communication*. 2012; 27:690–701. DOI: 10.1080/10410236.2011.633158 [PubMed: 22236220]
- Iyengar S, Simon A. News coverage of the Gulf crisis and public opinion: A study of agenda-setting, priming, and framing. *Communication Research*. 1993; 20:365–383. DOI: 10.1177/009365093020003002
- Lammers, JC., Lambert, NJ. Institutional theory and the communication of health care organization. In: Harrison, TR., Williams, EA., editors. *Organizations, communication, and health*. New York, NY: Routledge; 2016. p. 275-294.
- Langlois S, Benn P, Wilkins-Haug L. Current controversies in prenatal diagnosis 4: Pre-conception expanded carrier screening should replace all current prenatal screening for specific single gene disorders. *Prenatal Diagnosis*. 2015; 35:23–28. DOI: 10.1002/pd.v35.1 [PubMed: 25395388]

- Lazarin GA, Haque IS. Expanded carrier screening: A review of early implementation and literature. *Seminars in Perinatology*. 2016; 40(1):29–34. DOI: 10.1053/j.semperi.2015.11.005 [PubMed: 26718446]
- Lee TK, Shapiro MA. Effects of a story character's goal achievement: Modeling a story character's diet behaviors and activating/deactivating a character's diet goal. *Communication Research*. 2016; 43(6):863–891. DOI: 10.1177/0093650215608236
- Len-Ríos ME, Hinnant A, Park S-A, Cameron GT, Frisby CM, Lee Y. Health news agenda building: Journalists' perceptions of the role of public relations. *Journalism & Mass Communication Quarterly*. 2009; 86:315–331. DOI: 10.1177/107769900908600204
- Lillie SE, Tarini BA, Janz NK, Zikmund-Fisher BJ. Framing optional genetic testing in the context of mandatory newborn screening tests. *BMC Medical Informatics and Decision Making*. 2015; 15(50):1–7. DOI: 10.1186/s12911-015-0173-3 [PubMed: 25889846]
- Lindheim SR, Stammeler S, Jaeger AS. Expanded preconception carrier screening (GPCS) in clinical practice: Opening Pandora's box. *Andrology & Gynecology: Current Research*. 2015; 3:1–2.
- Major LH. Break it to me harshly: The effects of intersecting news frames in lung cancer and obesity coverage. *Journal of Health Communication*. 2009; 14:174–188. DOI: 10.1080/10810730802659939 [PubMed: 19283540]
- Manganello J, Blake N. A study of quantitative content analysis of health messages in US media from 1985 to 2005. *Health Communication*. 2010; 25:387–396. DOI: 10.1080/10410236.2010.483333 [PubMed: 20677043]
- McCombs, M. *Setting the agenda: The mass media and public opinion*. Malden, MA: Blackwell; 2004.
- McCombs, ME., Ghanem, SI. The convergence of agenda-setting and framing. In: Reese, SD, Gandy, OH., Grant, AE., editors. *Framing public life: Perspectives on media and our understanding of the social world*. Mahwah, NJ: Lawrence Erlbaum Associates; 2001. p. 67–81.
- McGowan ML, Cho D, Sharp RR. The changing landscape of carrier screening: Expanding technology and options? *Health Matrix Cleveland*. 2013; 23:15–33.
- Myrick JG, Major LH, Jankowski SM. The sources and frames used to tell stories about depression and anxiety: A content analysis of 18 years of national television news coverage. *Electronic News*. 2014; 8:49–63.
- O'Keefe D, Jensen JD. The advantages of compliance or the disadvantages of noncompliance? A meta-analytic review of the relative persuasive effectiveness of gain-framed and loss-framed messages. *Communication Yearbook*. 2006; 30:1–43. DOI: 10.1207/s15567419cy3001_1
- O'Keefe D, Jensen JD. The relative persuasiveness of gain-framed and loss-framed messages for encouraging disease detection behaviors: A meta-analytic review. *Journal of Communication*. 2007; 59:296–316. DOI: 10.1111/j.1460-2466.2009.01417.x
- Ormond KE, Banuvar S, Daly A, Iris M, Minogue J, Elias S. Information preferences of high literacy pregnant women regarding informed consent models for genetic carrier screening. *Patient Education and Counseling*. 2009; 75:244–250. DOI: 10.1016/j.pec.2008.09.020 [PubMed: 19013744]
- Quick BL, Bates BR. The use of gain- or loss-frame messages and efficacy appeals to dissuade excessive alcohol consumption among college students: A test of psychological reactance theory. *Journal of Health Communication*. 2010; 15(6):603–628. DOI: 10.1080/10810730.2010.499593 [PubMed: 20812123]
- Rauscher EA, Young S, Durham W, Barbour JB. "I'd know that *my* child was out there": Egg donation, the institutionalized "ideal" family, and health care decision making. *Health Communication*. (in press).
- Reese S. The framing project: A bridging model for media research revisited. *Journal of Communication*. 2007; 57:148–154. DOI: 10.1111/jcom.2007.57.issue-1
- Reeves, A., Trepanier, A. Comparison of informed consent preferences for multiplex genetic carrier screening among a diverse population. *Journal of Genetic Counseling*. 2015. Online First. Retrieved from <http://link.springer.com.ezproxy.lib.utah.edu/article/10.1007/s10897-015-9854-4/fulltext.html>
- Rose NC. Expanded carrier screening: Too much of a good thing? *Prenatal Diagnosis*. 2015; 35:1–2. DOI: 10.1002/pd.4638

- Shugart HA. Heavy viewing: Emergent frames in contemporary news coverage of obesity. *Health Communication*. 2011; 26:635–648. DOI: 10.1080/10410236.2011.561833 [PubMed: 21541866]
- Slooten EV, Friedman DB, Tanner A. Are we getting the health information we need from the mass media? An assessment of consumers' perceptions of health and medical news. *Journal of Consumer Health on the Internet*. 2013; 17:35–53. DOI: 10.1080/15398285.2013.756338
- Srinivasan BS, Evans EA, Flannick J, Patterson AS, Chang CC, Pham T, Patrizio P. A universal carrier test for the long tail of Mendelian disease. *Reproductive BioMedicine Online*. 2010; 21:537–551. DOI: 10.1016/j.rbmo.2010.05.012 [PubMed: 20729146]
- Suran M, Holton AE, Coleman R. Topical punch: Health topics as drivers of idiosyncratic reader responses to online news articles. *Journalism & Mass Communication Quarterly*. 2014; 91:725–739. DOI: 10.1177/1077699014550093
- Taggart J, Williams A, Dennis S, Newall A, Shortus T, Zwar N, Harris MF. A systematic review of interventions in primary care to improve health literacy for chronic disease behavioral risk factors. *BMC Family Practice*. 2012; 13:13–49. DOI: 10.1186/1471-2296-13-49 [PubMed: 22405186]
- Tanner AH, Friedman DB. Authorship and information sourcing for health news on local TV web sites: An exploratory analysis. *Science Communication*. 2010; 33:3–27. DOI: 10.1177/1075547010364926
- Wienke S, Brown K, Farmer M, Strange C. Expanded carrier screening panels: Does bigger mean better? *Journal of Community Genetics*. 2014; 5:191–198. DOI: 10.1007/s12687-013-0169-6 [PubMed: 24062228]
- Yarnall S, Bristow SL, Kellogg GR, Kumar N, Rodriguez S, Shraga R, Keefe DL. How many carriers are you missing?: The value of expanded carrier screening. *Fertility and Sterility*. 2015; 104(3):65–66. DOI: 10.1016/j.fertnstert.2015.07.199

Figure 1.
Frequency of sources.

Figure 2.
Frequency of topics.

Table 1

Data codes and data exemplars.

Code	Example
Genetic carrier screening	Counsyl, a San Francisco-based organization dedicated to affordable genetic carrier screening for disease-causing mutations.
Expanded genetic carrier screening	JP Morgan Labcorp CEO discusses plans for expanded genomic testing.
Breakthrough or research	Jacob's Cure has raised \$10 million to fund medical research in the hope of finding a cure for the progressive neurodegenerative disease.
Treatment	Giving parents the option to have IVF [in vitro fertilization] to select and implant embryos without the genetic changes.
Business issues	Natera is a leading genetic testing company that has developed a proprietary bioinformatics-based technology (NATUS).
Innovation	Cell-free fetal DNA testing is a significant advance in prenatal screening.
Specific lab/test name	The division is developing the Pervenio™ Lung RS assay, a 14-gene expression profile.
Prepregnancy issues	Panorama is a non-invasive screening test that provides early information for assessing pregnancy risks for women.
Pregnancy health	A woman may consider, in consultation with her physician and results of other medical assessments, whether to pursue or forgo invasive diagnostic testing, which carries a slight risk of miscarriage.
Legal/ethical issues	Life Tech's will develop a simpler assay platform, with FDA [Food and Drug Administration] approval.
Religious issues	Should interfaith and same-sex couples also get screened? Yes. The risk frequency might be lowered by marrying someone who isn't Jewish, but it still exists.
Political issues	Congress passed the Genetic Information Nondiscrimination Act of 2008 to protect Americans against discrimination based on their genetic makeup.