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Article

Fit to Print? Media Accounts of Unproven Medical Treatments Across Time

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Background: Looking through the lens of the media reveals much about how new biotechnologies are portrayed and how these reports influence public policy and opinion. The roles of patients, scientists, and the government loom large in this equation. These stakeholders tell us what is important to them and why. But little research exists comparing representations of new clinical technologies in the mainstream media across time. What has changed in newspaper accounts of new biotechnologies since the 1970s? How are the stakeholders portrayed, and what do these individuals have to say? Here, we seek to answer these questions by examining media reporting of Laetrile and stem cell transplants during the time of their clinical advent. **Methods***:* Using a qualitative coding framework, we obtained frequencies of relevant excerpts and analyzed the data using the Mann–Whitney *U* test. **Results:** We saw significant differences in how stakeholders talk about their support and criticism of unproven treatments between the two time periods. During the Laetrile era, patients and advocacy groups more often invoked choice-based themes than during the stem cell period. Doctors and scientists expressed significantly more support of possible stem cell transplants, but equivocated on these views with caution and skepticism. We also discuss the role federal regulation plays in this discourse in each time period. **Conclusions:** In sum, we argue that in addition to representing current opinions, newspapers drive anticipation, enabling the production of possible futures that are lived and felt as inevitable in the present. These accounts render the hope of cures and the fear that science will fail us as important political vectors.

Keywords: bioethics, print media, Laetrile, stem cells, medical tourism, regulation, patient advocacy

News articles about biomedical advances attempt to inform, clarify, simplify, and sensationalize promising areas of science and their clinical applications. Media portrayals call the public's attention to both the scientific and the medical claims of emerging research (Iyengar and Kinder 1987). Over time, certain positions taken by newspapers can impact the direction of science and health policy (Wallack 2000), as well as change public discourse (Seale 2003).

Mass media can substantially affect the knowledge of health and the use of health services; a Kaiser Family Foundation poll found that 40% of the public uses media such as television, radio, and newspapers as their primary source of science information (Henry J. Kaiser Family Foundation 2005). Media and its deference to scientific authority can also cultivate trust in sources of information about emerging technologies (Anderson et al. 2011). Such trust is demonstrated in a study of print media and television features on influenza and its positive correlation to the elderly seeking the influenza vaccine (Yoo et al. 2010), and in an analysis of Canadian reports on genetic testing showing that media helped guide the policy agenda (Caulfield, Bubela, and Murdoch 2007). Overall, media informs and influences trust and decision making, both personal and public.

In recent years, coverage of cloning and stem cell research stand out as striking examples of mass media representation of the scientific and medical nuances of new research and the incendiary debate this research can ignite (e.g., the debate over embryonic stem cell research).

Combined with a shifting scientific lexicon and the ethics of our obligations to the sick and the unborn, the debate revealed deep political and moral divisions among Americans. Stem cell research brought public attention back to national controversies such as abortion, women's rights, and the advent of new technologies such as in vitro fertilization.

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THE MEDIA AND EMERGING TECHNOLOGIES

Recently, scholars have attempted to uncover the role of mainstream media as basic research is translated into clinical practice. If, as suggested in the preceding, mainstream media contributes significantly to trust and decision making, on the level of both the patients and the policymakers, the issues presented or not presented in mass media can impact mainstream clinical practice (Lambert, Masters, and Brent 2007). Balanced reporting also proves elusive, with subjective anecdotes about treatments being reported over objective policy. For example, there is a high prevalence of websites reporting on minors undergoing stem cell transplants and a paucity of discussions on stem cell policy (Zarzeczny et al. 2010).

Ethics scholars worry that reporting anecdotes in positive contexts can wrongly promote the legitimacy of unproven medical treatments. A study of 36 Canadian men and women examined readers' responses to a news article about stem cell treatments. Though the study group members read cautionary materials from the International Society for Stem Cell Research and had been instructed on the nascent state of stem cell therapies in focus groups, two-thirds of the respondents indicated that they were unaware of any risk. Given the same conditions as the patients in the media article, the majority of participants said they would travel for unproven treatments (Einsiedel and Adamson 2011).

Language, too, plays an important role. In the Netherlands, researchers found that in news articles about cancer treatments, articles oriented toward consumers and featuring positive "moral judgments" about palliative care became more frequent over time, especially in regional newspapers (Van den Berg, Eliel, and Meijam 2011). Proponents of unproven treatments justify their support with comments like "patient choice being the ultimate arbiter" and "evidence is not everything" (Ernst 2012). These arguments can be misunderstood, leading patients and policymakers astray. However, it is not always a simple case of misinterpretation, as researchers may themselves misinform. In prior work, we discovered that the titles and descriptions of early stem cell trials found on a key public national trial registry contained language that suggested a higher degree of therapeutic intent in those stem cell trials as compared to randomly selected Phase I or II heart disease drug trials. Furthermore, the language used to describe protocols was found to be unnecessarily complex (Scott, DeRouen, and Crawley 2010).

Media attention to stem cell research and emerging stem cell therapies coincides with the growth of medical tourism. This phenomenon involves patients leaving their established care arrangements in their country of residence with the intent of accessing medical care abroad. Medical tourists cross borders to access care, surgeries, drugs, or unproven treatments. Patients are motivated by regulatory delay, high costs, and lengthy wait times. In the cases of the desperately ill, traveling for a treatment is an option of last resort.

Emerging stem cell therapies are not the only instances of patients engaging in such tourism, nor are they the first putative medical advance reported by the popular media. Consider Laetrile, a purported anticancer drug of the 1970s. Sometimes called amygdalin, Laetrile was billed as an anticancer drug derived from apricot kernels and first tried in cancer treatment in Russia in 1845 (National Cancer Institute 2012). In the 1970s, Laetrile was available as an anticancer therapy in Mexico, specifically Tijuana and areas nearby.

Controversy surrounding its effectiveness raged throughout several decades. In 1976, murine studies using a broad range of dosages found amygdalin to be ineffective (Hill et al. 1976). A 1978 National Cancer Institute study found no conclusive proof that Laetrile had any effect on cancer (Ellison, Byar, and Newell 1978). The scientific evidence and the cross-border trafficking of desperate patients caused the Food and Drug Administration (FDA) to ban the substance in 1979. Indeed, one patient ingesting large amounts of raw almonds had transient symptoms of cyanide poisoning (Moertel et al. 1981). In a definitive trial reported in the *New England Journal of Medicine*, 178 cancer patients treated with Laetrile and a metabolic therapy experienced no discernible benefit in terms of cure, symptoms, or extension of life span (Moertel et al. 1982). Despite this contentious history, today several Internet sites advertise Laetrile as a viable treatment option (Milazzo 2007).

Thirty years later, the clinical translation of stem cells provides a compelling point of comparison to the Laetrile case. The basic biology and developmental potential of stem cells are studied widely and the mechanisms of actions and behaviors of stem cells have become increasingly well understood. Current research offers tantalizing glimpses of the therapeutic potential for a wide range of human diseases (Brunt 2012), and the clinical benefits of hematopoietic stem cells have been clearly demonstrated in some cancers and anemia (Trounson et al. 2011).

However, as in the case of Laetrile, it has been reported that unproven stem cell treatments, such as transplants for diseases like cerebral palsy (Pounds 2013), chronic kidney disease (Cyranoski 2010), and amyotrophic lateral sclerosis (Lynch 2005), are dangerous and risky without any evidence of efficacy or safety. Descriptive studies of newspaper articles and websites reveal the exorbitant costs for these unproven treatments paid by desperate patients (Regenberg et al. 2009). These practitioners of "stem cell procedures," which we define as unproven stem cell transplants, take advantage of vulnerable populations (Roehr 2010).

Laetrile and stem cell procedures share other historical similarities. As a result of intense social interest and the implications of treatments and cures, patient-centered media reporting was prevalent during both periods. Medical tourism, too, played a prominent role in stories about critically ill individuals, their families, and their communities. The two technologies share themes of the individual freedoms of persons to seek treatments for disease, regulatory gridlock, and the absence of a coherent system of federal oversight. Disreputable firms have also marketed these treatments without corroborating data from the FDA.

Despite the differences in the scope of treatment potential between these two technologies, we believe that similarities in the histories of the development and government regulations make it useful to compare Laetrile and stem cells to look at media representation of unproven therapies.

Little research exists in comparing representations of new clinical technologies in the mainstream media across time. What has changed in newspaper accounts of new biotechnologies since the 1970s? Are unproven treatments framed in a positive, neutral, or negative light? How are the protagonists (patients, doctors, regulators) portrayed, and what do these individuals have to say? How do the scientific, regulatory, and political environments of each period play a role in the discourse of emerging technologies? This article seeks to answer these questions by examining the portrayals of Laetrile and stem cell procedures across the times of their clinical advents, 1975–1979 and 2006–2011, respectively, in mainstream media.

METHODS

Search Strategy and Sampling

To examine how various stakeholder groups were represented in the news, our search strategy was designed to find stories about Laetrile and stem cell procedures in the U.S. print media. We used the search terms "Laetrile" and "stem cell," respectively. These terms were input into LexisNexis Academic, Proquest, and Newsbank databases across two time periods: for Laetrile articles, January 1, 1975, to December 31, 1979, and for stem cell articles, January 1, 2006, to December 31, 2011. Four widely circulated newspapers were selected from each time period to represent mainstream print media: the *New York Times*, *Los Angeles Times*, *Chicago Tribune*, and *Washington Post*. Our initial search yielded 1,144 articles featuring Laetrile and 2,699 articles written about stem cells.

The exclusion criteria used in our initial screening of our article searches and coding scheme were derived from methods described in Caulfield, Bubela, and Murdoch (2007). We screened for articles describing Laetrile and stem cell procedures in the context of an unproven technology. We also excluded editorials and advertisements from this search. Subjects of each article ranged from patient accounts of therapies to the government enacting regulations on the unproven therapies. Then we randomly selected 100 articles from each set and scanned the content for mentions of stakeholder groups and how the treatments were portrayed. We picked only those articles directly quoting or mentioning one or more of our designated stakeholder groups: patients, physicians/researchers, advocacy organizations, and government officials. This screening process yielded 84 Laetrile articles and 80 articles about stem cell research.

Coding Scheme

Two coders with backgrounds in the biosciences independently coded the articles using methods described by Krippendorff (1980), Carletta (1996), and Evans (1996). Intercoder reliability criteria based on Riffe, Lacy, and Fico (1998) and Ellis (1994) were established by the random sampling of 10 newspaper articles from each treatment type. To assess intercoder reliability, each coder independently scored the same random selection of 10 articles each from each time period, totaling 20 articles. The coders then held a consensus meeting to discuss their ratings and arrive at mutual agreement. Intercoder reliability was calculated using Cohen's κ on the support, criticism, and stakeholder subcodes in each data point. Our kappa scores ranged from 0.736 to 1.000, indicating good to excellent intercoder reliability. Consensus coding was used to bring agreement to 100%. A third researcher spot-checked coding as it progressed.

When a quote from or reference to a stakeholder group was found in an article, we excerpted the text and then categorized it using three criteria: (1) whether the excerpt was about a Laetrile or a stem cell treatment; (2) which stakeholder group was quoted or referenced in the excerpt; and (3) whether the excerpt was supportive or critical of the treatment in question. This categorization step yielded a total of 663 total excerpts: 314 in the Laetrile group and 349 in the stem cell group. An aggregate listing of excerpts by newspaper for each treatment type is found in Appendix 1.

We then subcoded the supportive and critical excerpts. For supportive categories, codes were assigned based on five themes corresponding to whether the intervention was described as (1) a last resort, (2) the treatment choice of patients, (3) effective, (4) less risky, or (5) advancing future research and treatments. Categories critical of the treatment were thematically organized by whether it (1) caused harm, (2) was ineffective, (3) needed more research, or (4) was costly. Thus, each excerpt has a unique identifier consisting of a treatment type, stakeholder type, and whether it contains content that is supportive and/or critical of the treatment in question. In certain cases, an excerpt can mention more than one stakeholder and theme. Therefore, excerpts can be assigned multiple final content codes. For example, an excerpt could contain codes that are both supportive and critical of a given treatment. For this reason, 822 total codes were used for the statistical analysis. A summary of our coding scheme is found in Table 1.

Table 1. Coding categories and themes for stem cell and Laetrile articles

Stakeholders	Support statement themes	Critical statement themes
Patients	Last resort	Causing harm
Physicians/ researchers	Treatment choice	Ineffective
	Effectiveness	Needs more research
Advocacy groups	Less risk	
Government	Advancing research	Cost

Table 2. Examples of supportive themes

Last resort	"It's the last chance. Nothing else helps her. I don't know what answer I'll get but I must try."
Treatment choice	"You've got to allow cancer patients to take what they want for their disease . . . what else is there to do but say, 'Sorry, fella—go home and die?"'
Effectiveness	"I have literally cured early Alzheimer's."
Less risk	"The results are promising and we don't see the complications that we see with other cell types."
Advancing research	"Optimists . . . believe that adult stem cells will be widely used in the next three to five years to heal burns, skin ulcers and bone fractures that don't mend on their own."

Tables 2 and 3 provide examples of coded excerpts taken from our dataset of news articles. Table 2 illustrates quotes and statements coded as supportive of the treatment type. Table 3 provides examples of quotes and statements coded as critical of the treatment type. Our full coding scheme can be found in Appendix 2.

Table 3. Examples of critical themes

Causing harm	"Unregulated therapy in the absence of any evidence that these cells are going to help patients is reckless. The potential to do harm is enormous."
Ineffective	"It's like the lack of data on its efficacy, we're faced only with testimonials of individuals receiving this material. We don't even know what's being given."
Needs more research	"Patients, please beware . . . Cells are not drugs. They can misbehave in so many different ways, it just is going to take a good deal of time to prove how best to pursue the potential therapy."
Cost	"But these new treatments . . . are considered experimental and can easily run into five figures each time a patient receives one. Costs quickly rise, and patients quickly become financially desperate."

Using an approach described by Henry (2010), we quantitatively compared the frequencies of our study variables. Particular codes appearing in an excerpt were counted. The Mann–Whitney U test was performed comparing the frequencies of each supportive and critical theme between the Laetrile and stem cell time periods, taking into account the distribution of those frequencies found in each article. Statistical analysis was done using IBM's SPSS Statistics 20.

RESULTS AND ANALYSIS

We found that certain themes are associated with particular groups of stakeholders. According to our examination of supportive quotes and statements overall, patients more frequently mention *last resort* as a theme. When considering *treatment choice* as a theme, government and patient stakeholders are most frequently represented. Physicians and researchers talk most about treatments *advancing research*, whether the treatment is *less harmful*, or whether it purports to be *effective*.

Among the categories critical of the treatment, physicians make up the majority of the stakeholders associated with every theme: *causing harm*, *ineffectiveness*, *needs more research*, and *cost*.

We note that the frequencies of some supportive themes in the media reports are quite different when comparing depictions of Laetrile in the 1970s and the present-day portrayals of stem cell procedures. For example, a patient's *treatment choice* is emphasized 12 times in Laetrile articles, while it appears only once in stem cell articles. The reverse holds when considering our supportive code *advancing research*. This code appears only three times in Laetrile articles, but rises exponentially to 93 instances in articles featuring stem cell procedures. With respect to critical themes over time, we see a similar pattern with *needs more research*. This theme appears only four times in the Laetrile period versus 73 during the stem cell years.

Using the Mann–Whitney U test analysis, we asked whether themes described by our stakeholder groups were significantly different between Laetrile and stem cell media articles. In our analysis, we found 12 stakeholder-specific themes to have statistically significant differences across the two time periods. We note that two stakeholder themes, though statistically significant, had low coding frequencies ($n < 10$), as did many non-statistically significant themes. Tables 4 and 5 list the statistical analysis of supportive and critical themes, respectively. We highlight the significant themes in each table.

Views of Patients and Advocates

Our data provide insight into how patients and their advocates view unproven medical treatments and the freedom to make health care decisions. When considering supportive themes, we found that discussions of a patient's ability to freely choose a treatment decrease significantly from the Laetrile (12) to the stem cell (1) time periods. Advocacy group mentions of patient choice similarly decreased from

Table 4. Statistical analysis of supportive themes between treatments by stakeholder group

	Supportive themes				
Stakeholder group	Last resort	Treatment choice	Effectiveness	Less risk	Advancing research
Patient					
Laetrile (*n*)*	7	12	31	3	0
Stem cell (*n*)	2	1	28	0	6
p value	.268	.035	.86	.089	.039
Physician/researcher					
Laetrile (*n*)	1	3	24	2	3
Stem cell (*n*)	1	0	85	16	73
p value	.972	.089	<.001	.001	<.001
Advocacy group					
Laetrile (*n*)	0	8	3	0	0
Stem cell (*n*)	0	0	4	0	2
p value	1	.009	.956	1	.146
Government					
Laetrile (*n*)	0	15	4	6	0
Stem cell (*n*)	0	1	1	1	2
p value	1	.011	.192	.109	.146

*n, Frequency of code.

the Laetrile (8) to the stem cell (0) time periods. We suspect that one reason that choice-based arguments—especially among patients—are mentioned less in the present day is because patients and caregivers have greater access to electronic information. Patients may feel that access to more information provides them with more autonomy about their health care decisions. They also may have increased ability to travel and seek these second opinions or undergo unproven treatments than they did in the 1970s. There are other possible explanations for this phenomenon, such as

Table 5. Statistical analysis of critical themes between treatments by stakeholder group

	Critical themes			
Stakeholder group	Causing harm	Ineffective	Needs more research	Cost
Patient				
Laetrile (*n*)*	1	0	0	0
Stem cell (*n*)	3	3	1	0
p value	.965	.306	.306	1
Physician/researcher				
Laetrile (*n*)	30	64	2	0
Stem cell (*n*)	42	44	64	5
p value	.135	.099	<.001	.02
Advocacy group				
Laetrile (*n*)	1	2	0	0
Stem cell (*n*)	3	6	1	1
p value	.29	.368	.306	.306
Government				
Laetrile (*n*)	29	76	2	0
Stem cell (*n*)	0	5	0	0
p value	<.001	<.001	.166	1

*n, Frequency of code.

the increased ability to directly express such views via blogs, social media, and other online resources.

Globalization and access to electronic media comprise a double-edged sword, however. Access to information does not necessarily translate to a truly informed medical choice. We add that patients never justified the access to Laetrile as necessary to advance research. Excerpts featuring stem cell patients, on the other hand, did mention this justification in six instances, perhaps a reflection of the changing attitudes toward altruistic human subjects research.

Another explanation of the differences is the regulatory regime of both periods. In 1979, the FDA declared the use of Laetrile illegal by invoking an interstate commerce ban, following the mid-1970s scientific literature demonstrating the compound's ineffectiveness. The FDA has yet to make such a definitive ruling on unproven stem cell transplants, though in recent months it has increased its regulative activity. Violations have been issued to clinics in Colorado and Texas, and U.S. attorneys for the agency recently indicted two men for conspiring to commit fraud on people suffering from neurological disorders (U.S. Attorney's Office 2012). The first major court decision on stem cells came in 2012, when the FDA won a federal court case enjoining a Colorado clinic to stop offering transplants. As in the Laetrile case, the court noted that the FDA was exerting its jurisdiction to prevent the interstate distribution of a misbranded and adulterated drug product (*United States of America v. Regenerative Sciences* 2012). It is ironic to note that until recently, most federal restrictions focused on the use of embryonic stem cells for research purposes, not on the protections of patients in transplant clinics.

Views of Physicians and Scientists

We observed significant differences between time periods when doctors and scientists talk about whether new therapies will advance research. We found that researchers and physicians talk much more about the promise of stem cell therapies (73) than they do about Laetrile's promise for treating cancer (3). We believe this is because Laetrile had few supporters in the scientific community during our period of study. As we discussed earlier, the compound was declared illegal in 1979, and cancer biologists had been skeptical of the drug's benefits for several years prior. This stands in contrast to the case of stem cell therapies, where basic research in the mid 2000s was still nascent and the therapeutic benefits were mostly imagined.

The national discourse and controversies surrounding human embryonic stem cells (hESC) certainly played a role in our results, as did presidential and congressional politics that restricted hESC research and attempted to criminalize its practice. This undoubtedly led to a greater diversity of individuals commenting on the research and its future. For example, some of our excerpts featuring scientific experts in media reports came from individuals who were not directly involved in stem cell research. Indiscriminant reportage and quotation may have contributed to the perception of unqualified support from the scientific community that might otherwise have been moderated by skeptics working in the field. Newspapers tend to report the initial findings more than follow-up or disputing studies (Gonon et al. 2012), furthering this perception. Therefore, optimism about stem cell treatments remained despite the fact that approved clinical trials using enriched populations of tissue-specific stem cells only began in 2004 and just two hESC trials received FDA clearance.

This optimism is shown in two other themes, *effectiveness* and *less risk.* Physicians and stem cell researchers overwhelmingly invoked support for reduced transplant risk and expected benefit, and the differences between the two time periods were highly statistically significant ($p \leq .001$). Unlike other unorthodox treatment approaches, which have been dismissed as quackery, there remains a sense within the biomedical community that stem cells may have clinically important uses in the future. This optimism may dilute the strength of critical statements made by the expert community that might otherwise be expected to include the staunchest critics of unproven treatment modalities.

We found that physicians and stem cell researchers are not always positive about stem cell therapies. When coding for statements and quotes that are critical of the treatments, we saw that doctors and scientists express caution about the effectiveness of both Laetrile (64) and stem cell procedures (44), a difference that is not statistically significant. When it comes to assertions that more research is needed, instances from stem cell experts (64) outnumbered those from Laetrile experts (2) by a wide margin ($p < .001$). This again may be due to studies that demonstrated Laetrile's ineffectiveness, leading to researchers having made up their minds about the drug. We add that some of our excerpts referenced those scientists who participated in studies disproving Laetrile's effectiveness. The picture for stem cell researchers is more complex: We see a tacking back and forth between imagining the benefits of future therapies, a defense of scientific freedom in the face of federal restrictions, and the realities of scientific progress. In this study, the phenomenon is represented by a thematic equivocation between support and criticism, and real uncertainty about the risks and benefits of stem cell procedures.

In sum, we saw that media representations demonstrate the complexity of the duties of scientists and physicians to properly inform the general public about the risks and benefits of emerging medical technologies. The expectation that "physicians are expected to have knowledge of . . . the *likely* development of this field to help evaluate preclinical evidence and potential treatment modalities" (Levine and Wolf 2012; emphasis added) depends on the maturity of the technology, the available evidence, and the enthusiasm with which they embrace the promise of a better future.

The Role of Government

We found that statements and references to government stakeholders reached statistical significance in two themes critical of treatments, *causing harm* and *ineffectiveness*. With respect to Laetrile, mentions of patient harm and the

intervention's lack of efficacy outnumber such references to stem cell procedures by large margins (29:0; 76:5, respectively). Many of our Laetrile excerpts quoted officials from the National Institutes of Health, the National Cancer Institute, and the Food and Drug Administration, speaking about the drug's ineffectiveness in treating cancer and its demonstrated harm. In contrast, until very recently, U.S. government representatives have largely been silent about the regulation of stem cell treatments. We believe this result is due to regulatory laxity, uncertainties in the field, and spillover effects from hESC controversies. If regulatory suggestions for unproven stem cell treatments from organizations such as the International Society for Stem Cell Research (ISSCR) had been incorporated into national and international policy and aggressively enforced, we might have seen more closely matching frequencies between the two periods (ISSCR 2008a; Sipp 2011). As we discussed earlier, though the FDA oversees approved stem cell and other tissue-based therapies, its regulatory framework must rapidly evolve to reflect the advances in stem cell research and to address the unethical practices of unregulated clinics (Halme 2006; Liras 2010). It is also possible that the litigation surrounding cases like *USA v. Regenerative Sciences* had a chilling effect on regulators' willingness to speak out on these issues. As the FDA is unable to comment on open cases, there may have been a reluctance to speak about issues of regulation.

Silent Spaces in Media Reporting

We were surprised to see so few mentions of *cost* in our study, though the difference in mentions between time periods was statistically significant. Ethics scholars and the International Society of Stem Cell Research specifically address treatment cost as a major warning sign for patients should they choose to pursue an unproven stem cell therapy (ISSCR 2008b; Lau et al. 2008; Regenberg et al. 2009). We note the lack of any mention of treatment cost in our sampling of Laetrile articles. At the time, medical groups stridently warned that the cost of Laetrile administration would have "increased the cost of care to patients without any assurance of benefit" (New York Academy of Medicine 1977). Given the concern of medical professionals, the expense needed to travel to places like Mexico to pursue Laetrile therapy, and the cost of the drug itself, we expected greater mention of concerns about the Laetrile treatment cost by patients or physicians in our sample of articles.

That we would see stakeholders describing both therapies as a *last resort* is not surprising. What was surprising was how few mentions of last resort were found in our sampling. It may also reflect patients' reluctance to acknowledge their situations as dire enough to seek a "last resort," or to refer to it as such.

References to or quotes from patients tend toward themes of autonomous choice and expected benefit. Tellingly, discussions of or reflections on risk, harm, altruism (unproven treatments as perceived benefits to society), ineffectiveness, or acknowledgment of the lack of scientific evidence are largely missing from our sample. This finding is consistent with our observations of the power of hope and the motivations of desperate patients with little or no medical options who seek unproven interventions (Scott and Murdoch 2010). In addition, the dearth of discussion of risk or clinical limitations of stem cell procedures is consistent with the unbalanced positive coverage of stem cells found in print media today (Zarzecny et al. 2010).

Limitations

There are three limitations of our study. First, Laetrile and stem cell procedures differ in their potential medical applications, the rigor of the basic research, and how long they were a part of public discourse. These factors may have influenced how stakeholders developed their opinions about them. It is true that Laetrile was subject to years of scientific scrutiny and criticism, which played a role in forming the opinions analyzed in our study. However, the many cures for various cancers promised by Laetrile are arguably as broad as the cures promised by stem cell procedures. We confined our analysis to the therapeutic promise of both technologies and note that both are unproven as therapies and were seen as treatments for incurable diseases in their respective time periods.

Second, our study uses reportage as a proxy for the true views and opinions of our stakeholders. Media accounts still hold great power over local and national policy agendas, but given that our comparison started with Laetrile in the 1970s, it does not take into account new media such as blogs or social media. Internet sources are increasing their share of the reporting about scientific advances, and the readership of print media is dropping with the competition from Internet news sources, possibly limiting our study (de Semir 2010). In addition, we examined only mainstream print media in the United States and did not look at local or global news environments (Henry et al. 2012).

Lastly, since this study only uses two treatments in their respective time periods as points of analysis, our findings may be less generally applicable to other unproven therapies that are being portrayed today. However, we believe our study does confirm what others have found about stem cells in general and that this study provides a baseline of the kind of reporting that is to be expected with unproven therapies.

CONCLUSIONS

Looking through the lens of the media reveals much about how new technologies are portrayed and how they influence public policy and opinion. These reports also reflect the discourse of the day. Through writers and reporters, the protagonists tell us what is important to them, and why. The role of scientists and researchers loom large in this equation. By asking experts to imagine how *likely* a discovery is to reach a therapeutic reality, newspapers drive anticipation, which enables the production of possible futures that

are lived and felt as inevitable in the present (Adams and Clarke 2009). These accounts render the hope of cures and the fear that science will fail us as important political vectors.

Laetrile had been first described in Russia in the mid-1800s. This fact gave experts in medicine, research, and policy time to form their opinions through years of anecdote and research. Stem cell research, by comparison, is in its infancy. Though some stem cell treatments are effective for certain kinds of cancers and blood disorders, many are unproven. Without clinical trials and time to understand these new technologies, experts cannot form an informed opinion and often equivocate. Excitement, skepticism, and political correctness are played out in the moral landscape of scientists as they try to engineer tomorrow, today.

Individualism, autonomy, resistance to regulation, and the hope for cures characterize patient portrayals in the media. Little has changed since the 1970s: The desperately sick choose to focus on the benefits of unproven treatments because to not do so would destroy their hope. It is true that the media reports predominantly on heart-rending accounts of suffering people; it is also true that it is precisely these people that biomedicine endeavors to help. In the case of Laetrile, the FDA rulings became the flashpoint for patients and advocates asserting an autonomous right to their own health care decisions. This serves as a warning to present-day policymakers. Since regulation of unethical stem cell clinics has been slow to develop in a climate of John Galt individualism and libertarianism, an uprising from patients who would be denied a choice of medical treatment on their home soil is a real possibility. Even though more FDA regulations are in place to ensure safety and efficacy of these treatments, we may see more examples of states like Texas following a policy of allowing unproven stem cell procedures with politically strategic motivations rather than one informed by good science (Cyranoski 2011). We believe that the underrepresentation of references to and quotes from government officials informs us about our recent history and our charged political environment. The relative lack of regulatory frameworks for unproven stem cell procedures in general can be attributed in part to the off-target effects of the national controversies over hESC research. Politics paints all stem cells with the same brush, with a regulatory vacuum as a result. ■

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APPENDIX 1: FREQUENCY OF NEWSPAPER ARTICLES AND EXCERPTS FOR EACH TREATMENT TYPE

	Laetrile	Stem cell	Total
Newspaper articles	84	80	164
Chicago Tribune	16	16	32
Los Angeles Times	20	19	39
New York Times	30	27	57
Washington Post	18	18	36
Excerpts	314	349	663
Chicago Tribune	74	84	158
Los Angeles Times	70	73	143
New York Times	98	101	199
Washington Post	72	91	163

APPENDIX 2: SUPPLEMENTAL METHODS

Coding Frame for Comparative Study of Print Media Regarding Laetrile and Stem Cell Procedures

Aside from sections (1) and (5), all codes should be phrased to adequately yield binary (Y/N) results.

1. Basic information
   a. Experimental procedures (S = Stem Cell, L = Laetrile)
   b. Source (New York Times, Washington Post, etc.)
   c. Coder ID
   d. Date written/published (YYYYMMDD)
   e. Title of article (First three words)

2. Quotes about or from person with mention of possible motivation for pursuit or study of therapy
   a. Last resort
      i. Has phrase indicating last resort or "nothing worked" but does not mention "hope"
      ii. Specifically mentions "Hope" in last resort context
      iii. Other
   b. Treatment choice
      i. Personal freedom
      ii. "Hope" that there is an effective treatment
      iii. Other
   c. Effectiveness
      i. Comparison of experimental treatment with treatment
      ii. Anecdotal story regarding positive results
      iii. Mentions research
      iv. Helps psychologically without mention of "hope"
      v. Offers "hope"
      vi. Palliative effects
      vii. Talks about mechanism
      viii. Other
   d. Less risk
      i. Less harm, compared to other therapies
      ii. Less harm, does not compare to other therapies
      iii. Other
   e. Advancing research
      i. Advancing treatment without previous positive results
      ii. Advancing treatment with previous positive results
      iii. Other

3. Quotes from or about a person citing problems with treatment
   a. Causing harm
      i. Personal experience
      ii. Anecdotal story about complications resulting from procedure
      iii. Mentions Evidence or Study about Harm
      iv. Possible risks of usage
      v. Prevents treatment from effective/legitimate sources
      vi. Preys on desperate populations
      vii. Other
   b. Ineffective
      i. Mentions research or evidence about efficacy
      ii. No evidence regarding effectiveness exists
      iii. Other
   c. Needs more research
      i. Not enough is known about the procedure to make any conclusions, no proposal on how to correct
      ii. Not enough is known to make conclusions, with proposal on how to correct
      iii. Other
   d. Cost
      i. Prevents access
      ii. Unreasonable due to experimental nature
      iii. Other

4. Who is cited (specifically named)
   a. Patients
      i. The patient
      ii. Relative/friend of patient
      iii. Other person describing named patient
   b. Physician/researcher
      i. Treating physician
      ii. Physician/researcher associated with cited non-governmental institution
      iii. Researcher with no specifically named affiliation
      iv. Research/physician organization with no cited person
      v. Other
   c. Advocacy group/person
      i. Patient issues with specific disease affiliation
      ii. Patient issues without specific disease affiliation

   iii. Group/Person that advocates for specific treatment
   iv. Other
d. Government
   i. Judicial branch
   ii. Legislator
   iii. Executive
   iv. Government agency
   v. Other
e. Other
   i. Business
   ii. Named person with other group affiliation than noted above
   iii. Named person with no affiliation

5. Who is cited (not specifically named)
   a. Patients/patient families
   b. Scientific/medical community
   c. Advocacy and lobby groups
   d. Government
   e. Other
      i. General public
      ii. Business
      iii. Any unnamed person/group that does not fit the above categories

6. Summary analysis
   a. Who is the main stakeholder of the quote?
   b. Is the excerpt a positive or critical quote about the unproven procedure?
   c. What subcategory does this quote mainly fall under?
7. Comments