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Marginal voices in the media coverage of controversial health interventions: how do they contribute to the public understanding of science?

M. Hivon, P. Lehoux, J.-L. Denis and M. Rock

While the media are a significant source of information for the public on science and technology, journalists are often accused of providing only a partial picture by neglecting the points of view of vulnerable stakeholders. This paper analyzes the press coverage of four controversial health interventions in order to uncover what voices are treated marginally in the media and what the relative contributions of these voices are to the stories being told. Our empirical study shows that: 1) patterns of source utilization vary depending on the health intervention and less dominant stakeholders are in fact represented; and 2) the use of marginal voices fills certain information gaps but the overall contribution of such voices to the controversies remains limited. In order to strengthen the media coverage of science and technology issues, we suggest that further research on journalistic practices: 1) move beyond the dichotomy between journalists and scientists, and 2) explore how different categories of readers appraise the meaning and relevance of media content.

Keywords: media sources, media and sciences, marginal voices, knowledge transfer

1. Introduction

Health technologies affect our lives in many ways. “We pay for their implementation and bear their social costs. Public understanding of their social implications, their technical justifications and their political and economic foundations is in the interest of an informed and involved citizenry” (Nelkin, 1987: 172). Yet, to participate in social and political debate on technologies and to think critically about decisions affecting their lives, citizens need to be informed. In this respect, the media represent a significant source of information for lay audiences. Hence it is important that they provide their audiences with comprehensive and accurate information on issues related to science and technology.

It is often argued that media culture and organizational constraints prevent journalists from providing comprehensive coverage (Nelkin, 1987; Friedman et al., 1999; Seale, 2003). At times, journalists are accused of confusing the audience by giving too much weight to maverick ideas (Friedman et al., 1999; Weigold, 2001; May, 2005). At other times, they are accused

of neglecting the voices of people who could potentially bring much-needed nuance to the debate (Conrad, 1999; Williams et al., 2003; Bubela and Caufield, 2004). Such conflicting interpretations may stem from the fact that most empirical studies of media coverage have focused on a single case, preventing scholars from understanding how certain scientific, social and political dimensions may affect the scope of voices being mobilized by journalists. By contrast, this paper addresses a gap in the literature by emphasizing the spectrum of voices—including those seen as marginal—represented in the media coverage of four controversial health innovations, and by examining the respective contributions of these voices to the stories being presented to readers. Using a mixed method analysis (quantitative and qualitative), we examined a corpus of articles published in Canadian newspapers between 2000 and 2006 on two controversial therapeutic interventions—electroconvulsive therapy (ECT) and cyclooxygenase-2 drugs (COX-2s)—and two contentious screening tests—first-trimester prenatal screening (PST) for Down syndrome and prostate-specific antigen (PSA) screening.

We first define the concept of “marginal voice” and summarize the issues raised by how such voices are treated in the media. We then present the marginal voices that were included in our four empirical cases. The last section discusses the extent to which marginal voices contribute to the understanding of the controversies. In order to strengthen the media coverage of science and technology issues, we suggest that further research on journalistic practices: 1) move beyond what we call the journalism/science dichotomy, and 2) explore how different media coverage strategies may modify the understanding of, and judgments about science and technology issues of various categories of readers.

About marginal voices

The fact that often only a partial picture of a controversy is presented in the media has been explained in terms of media culture and organizational constraints. Journalists are faced with organizational constraints such as the limited time and availability of experts on whom they rely for background information and clarification (Nelkin, 1987; Einsiedel, 1992; Conrad, 1999; Stocking, 1999; Weigold, 2001; Waddell et al., 2005). Furthermore, following the principle of objectivity dear to their culture, they try to avoid taking a position when controversies arise (Dunwoody, 1999). Consequently, journalists often strive to provide readers with a *balanced* story, one in which extreme and often opposite points of view are presented and given equal weight, without providing any hint as to how representative of the larger community these viewpoints really are (Nelkin, 1987; Conrad, 1999; Dunwoody, 1999; Rowan, 1999; Stocking, 1999; Weigold, 2001; Anderson, 2002; Seale, 2003; May, 2005). By emphasizing the “pros” and “cons” of technological innovations or scientific findings, this dyadic framing ultimately “contributes to the exclusion of more nuanced debate” (Williams et al., 2003: 810). The points of view of certain stakeholders are ignored or marginalized. Such apparently balanced treatments may also leave readers with the impression that there exists considerable difference of opinion on a topic, while in fact there may be broad consensus. As a result, readers may be misinformed, misled or confused.

Scientific journals and scientific experts constitute, by in large, the main source of information for health and science journalists (Nelkin, 1987; Einsiedel, 1992; Conrad, 1999; Weigold, 2001; Nisbet et al., 2003). In general, these are followed by government and industry (Einsiedel, 1992; Nisbet et al., 2003). By contrast, patients and their advocates are often cited as being underrepresented. Conrad (1999) underlines their quasi-absence in the media coverage of genetics and behavior, concluding:

Since news presentations influence how people conceptualize and evaluate new findings ... and as the media play a significant role in agenda setting, it is politically important to bring these voices to the fore. Their articulation, even as quotes, adds important balance

to the reporting and introduces neglected viewpoints into the public discourse. Until these voices are routinely consulted and quoted, journalists will not have gotten the whole story. (Conrad, 1999: 301)

Williams et al. likewise point out the absence of feminist perspectives and women's voices in the media reporting of stem cell research despite the role of women "in producing eggs that might be used in stem cell research" (2003: 807). They argue that a greater diversity of viewpoints needs to be included to ensure that an "inclusive democratic debate" takes place (2003: 810). Similarly, Collins et al. (2006) highlight the minimal representation of associations of health care professionals in their study of the media coverage of Canadian health care reform debate.

For the purposes of this paper, we define marginal voices as *categories of sources that are given limited or no space and voice in media coverage and that therefore remain marginal or peripheral to the stories being told*. Sources are individuals whom journalists contact for background information, clarification or comments. We should note that for the purpose of our analysis, the views expressed by these marginal voices are not necessarily marginal in society. It is the *limited treatment* they receive in media coverage that makes them marginal. Through our empirical analysis, we wish to examine the extent to which certain viewpoints have been brought to the readers' attention as being relevant to understanding and forming a judgment about four different controversial technologies that have generated scientific controversy, public controversy, or both.

2. Multiple case study design

Selection of controversies

In our previous work, we examined the way six Canadian Health Technology Assessment (HTA) agencies interacted with professional and lay stakeholders (Lehoux et al., 2005). This work highlighted the need to better understand how medical innovations that generate a significant level of scientific and social controversy attract (or do not attract) the attention of the media. Did journalists actually use the scientific literature reviews produced by HTA agencies? Did they examine the ethical, social, economic and political issues related to the medical interventions that HTA agencies addressed in their reports? This led us to focus on two Canadian agencies (in Ontario and Quebec) and, as a starting point, we selected four reports that were moderately or significantly controversial from among their recent publications: 1) *The Use of Electroconvulsive Therapy in Québec* (Banken, 2002); 2) *First-trimester Prenatal Screening for Down Syndrome and Other Aneuploidies* (Framarin, 2003); 3) *Prostate-specific Antigen (PSA) Screening in Asymptomatic Men* (Slaughter et al., 2002); and 4) *What Effects do Provincial Drug Plan Coverage Policies for New Drugs Have on Patterns of Use and Cost?* (Paterson et al., 2003). The drugs concerned in the last report are cyclo-oxygenase-2 drugs (COX-2s), which are anti-inflammatories used in the treatment of arthritis and chronic pain.¹

Selection of newspaper articles

We used four Canadian electronic databases of newspaper and magazine articles (Biblio branché, Repère, CPI and CBCA) to build our sample. We selected articles related to the intervention discussed in each HTA report, using keywords such as electroshock (used solely as a therapy), prenatal screening tests, Down syndrome, PSA, prostate cancer, arthritis and COX-2. The intervention had to be mentioned either in the title or in the text. We looked at articles from

2000 to 2006, the period during which the four HTA reports were published. We selected articles from both English- and French-language Canadian newspapers and magazines aimed at the lay audience. We excluded all newspapers and magazines targeting professional audiences, such as the *Canadian Medical Association Journal*, *Médecin du Québec* and *Medical Post*. Since we wanted to examine the media space our chosen topics occupied, we included duplicates (that is, identical articles published concurrently). This method yielded a large spectrum of newspaper articles, including a few articles in which the main focus was not necessarily the health intervention per se.² Overall, our sample comprised 23 articles on prenatal screening tests for Down syndrome, 24 on electroshock, 139 on PSA screening, and 224 on COX-2s.

Indexing and analysis

The analysis was performed by the first author (MH) and discussed by the whole team on several occasions. We created one Excel document for each intervention. We developed and pre-tested an analytical extraction form based on a literature review and discussions with colleagues who had done similar work (Davidson et al., 2003; Kroll-Smith, 2003; Prior, 2003). Articles were read in full two or three times and their content indexed according to several pre-defined codes. We first compiled basic information about the sources (e.g., name, title). We then categorized the sources as: 1) scientific expertise (researchers, scientists, studies and reports, scientific journals); 2) clinical expertise (associations of health care professionals and professionals); 3) lay expertise (associations of patients, patients and their families); 4) management expertise (health care administrations, governmental institutions); 5) industry expertise (industry representatives and scientists); or 6) other (analysts, lawyers, etc.). These categories were defined empirically as they appeared to encompass all of the cited sources and permitted comparisons across the four technologies. They are also very similar to those used in other studies on media sources (Einsiedel, 1992; Conrad, 1999). Finally, we transcribed comments made by the sources into our Excel file in order to substantiate our findings.

By performing simple descriptive statistics on the source categories used in the articles, we were able to identify which voices were treated marginally by the media for each controversial intervention (Table 1). Then, we created comparative tables to assist with a qualitative analysis of the sources' position toward the interventions, across source categories and across the four medical interventions.

We present our results separately for each health intervention. First, we summarize the main storyline of the media coverage for the period 2000–6. Then, we identify which sources were treated marginally and examine their views.

3. The media coverage of electroconvulsive therapy (ECT)

Electroconvulsive therapy involves applying brief electrical pulses to the patient's brain. It is performed under general anesthesia and requires the administration of a muscle relaxant, oxygenation of the patient and constant monitoring (Banken, 2002). Our corpus included 9 articles on the subject of lawsuits dating back to use of ECT in the 1950s. The remaining 15 articles covered new studies on ECT or discussed the pros and cons of this intervention.

The main storyline

In general, these articles presented ECT as an effective technology, but one that must be used with caution (6 articles). ECT was reported to be effective in treating certain mental illnesses,

Table 1. Breakdown of source categories cited in the newspaper articles by intervention

Source category	Treatment interventions				Screening interventions				Total	
	COX-2s		ECT		PSA		DS			
	N	%	N	%	N	%	N	%	N	%
Scientific expertise	531	39	45	31	275	49	31	46	882	42
Clinical expertise	52	4	27	19	74	13	9	13	162	8
Lay expertise	94	7	38	26	112	20	19	28	263	12
Management expertise	279	21	19	13	41	7	0	0	339	16
Industry expertise	234	17	2	1	24	4	0	0	260	12
Other	155	12	14	10	35	6	9	13	213	10
Total	1345	100	145	100	561	100	68	100	2119	100

in certain individuals, and in cases where medication has failed (4).³ However, it was associated with serious side effects, including various cognitive troubles and memory loss (8). Seven articles reported that a great deal of uncertainty surrounding ECT remains because no one is able to explain exactly how or why it works on some patients and not on others. It was also emphasized that the administration of ECT has improved significantly in the past thirty years and that its side effects are now limited (7). Some articles mentioned the need for better training of future psychiatrists and the implementation of quality control programs (4). Finally, 9 articles mentioned one woman's lifelong battle for compensation for having undergone ECT in the 1950s at a Montreal hospital.

Marginal voices

Scientific expertise constitutes the most often cited source in the coverage of ECT (31 percent). Interestingly, this is closely followed by lay expertise (26 percent) and clinical expertise (19 percent). Administrators and industry are almost absent from the coverage, representing only 13 percent and 1 percent, respectively, of all sources cited in the articles.

With respect to industry, we learn from a scholar that the increase of ECT in the province of Quebec may be linked to the pharmaceutical lobby. This assertion, however, is not further developed (*Capital Santé*, 10 September 2003). With respect to administrators, we learn that the Quebec government requested an HTA report on ECT following an increase in its use in the province, suggesting there was cause for concern, but nowhere was it explained why (2).

Health care professionals (19 percent) were mainly cited by journalists to convey *the positive and clinical aspects of ECT*. According to the remaining clinicians cited, ECT is the best technology currently available for treating depression, "eliminating the symptoms in 50% to 90% of the cases" (*The Globe and Mail*, 1 March 2003). They also recognized the uncertainties surrounding ECT, but argued there is not enough evidence to conclude that the intervention causes brain damage or is responsible for memory loss (1). Some minimized the importance of side effects, arguing there are consequences to every treatment (5). Others minimized the perceived violence surrounding this treatment (2) and accused opponents of preventing them from treating more patients who would benefit from the technology (4). For example, one article noted: "Dr. Vanier claims that if it were not for 'the big fuss made by human-rights groups' and the taboo surrounding ECT, he would be able to save many more depressed people" (our translation from the French (TFF), *Nouvelliste*, 10 December 2001).

Patients and their advocates were well-represented in ECT coverage (26 percent). Journalists cited them mainly to emphasize *the negative side effects of ECT*. Their main arguments were that ECT is inhuman, dangerous and degrading (2). They emphasized the fact that no one is able to explain why ECT works and why only for some people, and insisted that the side effects outweigh the benefits. They suggested that patients are not always in a position to give their informed consent; in effect, some are being forced to accept and undergo the treatment (4). "Little information is given to people and we wonder whether the patient really has a choice," denounces Doris Provencher, the coordinator of a Quebec advocacy group for the mentally ill (*Le Soleil*, 5 March 2003). These sources called for more research on the side effects of ECT (1) and on alternatives to ECT (1). Only four patients of the 38 lay sources cited had positive stories to tell (3). For instance, Curtis Hartmann, age 47, a Massachusetts lawyer who has received about 100 electroshocks since 1976 to help control his bipolar illness claims: "Electroshock has been the only thing that has ever let me feel 100% ... Depression is like being a corpse with a pulse. I tried everything else. I had a loving family, thousands of hours of good psychotherapy, and none of it ever helped" (*Time Canada*, 26 February 2001). However, the coverage of such success stories definitely took second place to the horror stories and the opposition of patient associations.

4. The media coverage of prenatal screening tests (PSTs) for Down syndrome (DS)

In this analysis we focus our attention on a prenatal screening test that combines a fetal ultrasound scan and a biochemical analysis of maternal blood markers. The novelty about this test is that it is performed during the first trimester of pregnancy. It measures nuchal translucency, which is "the subcutaneous space between the fetal cervical spine and the overlying skin" (Framarin, 2003: 11). The test gives the probability that a pregnant woman will be at a higher-than-average risk of having a DS fetus (Vassy, 2006: 2042). Our sample of the press coverage of prenatal screening tests for DS includes 18 articles covering the pros and cons of prenatal tests, and 5 articles covering lawsuits launched by parents claiming their physicians failed to inform them about PSTs.

The main storyline

The advantages of prenatal screening, and more generally of earlier screening and earlier diagnosis, were discussed at length based on information provided by scientific experts and clinicians. We read that PSTs make it possible to: a) terminate a pregnancy at a moment when it is clinically safer and psychologically easier (11); b) avoid intrusive and more risky prenatal tests (6) or better orient women in the choice of diagnosis methods (5); c) reduce the period of anxiety for mothers at high risk of having a DS child (1); and d) provide parents with more time to prepare for the forthcoming birth of a DS child should they decide to continue with the pregnancy (1). This position in favor of PSTs was also echoed in articles covering lawsuits launched by parents against their physicians.

Marginal voices

Most cited sources represented scientific expertise (46 percent). This was followed by parents of DS children or patient associations (28 percent) and clinical experts (13 percent). Management and industry expertise were totally absent (0 percent) from the coverage.

Here again, the positions of health care professionals emphasize *the positive aspects of PSTs* (4). Most of them welcomed a PST that could be administered earlier in pregnancy, explaining that earlier screening enables physicians to orient patients toward the best screening and diagnosis tests, thereby avoiding more invasive ones (1). Thus, PSTs are not there to encourage pregnancy termination, but rather to help decide which women should go through invasive tests. The cited experts believe the test should be offered to all women at high risk for having a DS child (1). “‘Prenatal counseling and diagnosis are not a search-and-destroy mission,’ insisted Dr. Malone, who has seen many of his patients choose to continue a Down pregnancy. ‘Most of us would not answer the question, Doctor, do you think I should terminate? It’s not for us to decide’” (*Time Canada*, 21 November 2005).

Five articles gave testimonials from parents of DS children, the source that most clearly and *directly addressed the ethical and social issues* around prenatal screening. It was clear to many that early PST and diagnosis was aimed at terminating pregnancies (1). The parents did not oppose a woman’s right to reproductive choice, but expressed serious concerns about the way information is being provided to future parents and what they do with it (1): “... most Canadians, including many physicians who will be giving the results of tests, have an unduly pessimistic view of Down syndrome, and fail to recognize that the vast majority of children born with the condition live full and fulfilling lives” (*The Globe and Mail*, 21 November 2005). Thus, they emphasized the fact that DS fetuses were persons-to-be who are entitled to full quality of life. “Will people open their eyes to the possibilities of these kinds of kids? ... Most of the people who make these decisions don’t know an individual who has Down syndrome. They don’t know about the advances in recent years” (*Time Canada*, 21 November 2005). Finally, some of these sources said they would prefer to see the money used on PSTs reallocated to services for DS children and to educating society “toward acceptance of difference” (*Voices across Boundaries*, Winter 2004: 27). This position, however, was not held by the parents who filed lawsuits against their physicians for having failed to inform them about PSTs. All of these women said they would have chosen to terminate their pregnancy had they known they were pregnant with a DS child (5).

5. The media coverage of PSA

The PSA test measures the blood level of a protein released by the prostate, the prostate-specific antigen. A high PSA level can be caused by inflammation, aging-related enlargement or cancer. A positive PSA test has to be followed up with a biopsy or other procedures before cancer can be confirmed. The media coverage of PSA in newspaper articles included 47 articles on potential screening tests for prostate cancer that could replace or complement PSA, 89 articles on PSA and population-based screening for prostate cancer, and 3 articles on a lawsuit by the family of a deceased man.

The main storyline

The majority of scholars, health care provider associations and major patient associations cited were against population-based PSA screening. We read about the low accuracy of PSA testing (51) or its failure to provide any information about the aggressiveness of a tumor detected (5). We learn about the consequences of high levels of false-positive and false-negative results (46), as well as the consequences of radical treatment (e.g., impotence and incontinence) (16). The absence of evidence demonstrating a direct link between PSA and a

reduction in mortality was often stressed (31). On the other hand, we also read about the importance of early detection of cancer in order to maximize the chances of being cured (48). Thus, readers are confronted with articles that emphasize early detection by means of a PSA test: "Early PSA Screening May Reduce Risk of Prostate Cancer Death: Study" (*Canadian Press*, 8 July 2005). Or they are alarmed by the consequences of this early detection: "Men May Be Over Diagnosed with Prostate Cancer: Study" (*Toronto Star*, 5 July 2002). More than one-third of newspaper articles (36 percent) ended with recommendations similar to those made by the Canadian Cancer Society, which emphasize individual choice:

Men over the age of 50 years [should] discuss with their doctor the potential benefits and risks of early detection of prostate cancer using the Prostate Specific Antigen (PSA) test and digital rectal examinations (DRE) so that they can make informed decisions about the use of these tests. Men at higher risk because of family history or those of African ancestry should discuss the need for testing at an earlier age. (Canada NewsWire, 16 September 2004)

Marginal voices

Here again, the main source cited was scientific expertise (49 percent). This was followed by lay expertise (20 percent) and clinical expertise (13 percent). Administrators and industry sources were marginal voices, representing 7 percent and 4 percent, respectively.

Industry was mainly quoted for its research and development activities in prostate cancer detection. These articles discussed new tests being developed that could, in combination with PSA, improve screening for prostate cancer, help avoid invasive interventions and treatments, and reduce the costs of health care services (12).

Administrators did not really depart from the main storyline; they were usually cited as being against population-based PSA screening (20). In Canada, most provincial governments reject the idea of population-based screening for prostate cancer since there is no clear evidence supporting a link between PSA and reduced mortality rate (10). "PSA detects cases earlier, but this doesn't mean that lives will be saved. ... the test may sometimes even lead to unnecessary interventions, and this is why no jurisdiction will put forward a population-based screening program, as has been done for breast cancer" (consultant in a public health division of the Quebec government, TFF, *Le Droit*, 23 September 2003).

Interestingly, there was a discrepancy between the government's official position on PSA and the testimonials of individual politicians. Two cases of prominent Canadian politicians being diagnosed with prostate cancer were covered. After successful treatment, both men departed from the official line, maintaining that PSA screening had saved their lives and recommending that all men be tested. One article cited the long-time adviser of Reform Party founder, Preston Manning, who was diagnosed and successfully treated for prostate cancer: "He's taking a lesson from that, that other men should also be tested" (*Canadian Press*, 13 December 2000).

We observed a similar difference of opinion among health care providers. While major provincial associations of urologists and the College of Physicians have positioned themselves against mass screening (21), some individual physicians are in favor of making the PSA test available to all men. Talking about his patient, the former health minister Alan Rock, Dr. Jim Paust states: "Mr. Rock's situation is an excellent example of how early detection and early treatment can lead to a total cure. ... it is a good reminder to all men over the age of 40 to be tested regularly and to keep track of their yearly PSA levels" (*Canadian Press*, 13 February 2001). A study of Ontario urologists conducted by a pro-PSA support group "found

that 85 per cent of Ontario urologists surveyed said that screening tests for prostate cancer help reduce deaths and should be covered by OHIP [Ontario Health Insurance Plan]" (*Canadian Press*, 3 November 2005). In fact, most physicians quoted recognize the limitations of the PSA test but believe it is the best tool available for early detection of this illness (16): "The logical approach is to carry on with PSA until better means are developed" (TFF, *Nouvelliste*, 13 September 2004). Some asserted that excessive treatment resulting from the PSA's lack of accuracy could be prevented by the active surveillance of patients at risk (6). They also seemed to support findings according to which PSA velocity—the fluctuation of PSA level within a certain period of time—is a good indicator of the presence of cancer and its aggressiveness: "Awareness of PSA levels allows men to know their prostate health status, essential in determining a logical strategy and best therapy in the event of cancer" (*The Globe and Mail*, 21 September 2005). This, however, means regular screening tests.

Finally, we find a similar discrepancy between the recommendations of patient representatives and the individual testimonials of cancer survivors. Major patient associations such as the Canadian Cancer Society and the American Cancer Society have come out against universal prostate cancer screening, but they encourage men over 50 to discuss the potential benefits and drawbacks of PSA screening with their doctors before making their own decision (12). They believe, however, that men who decide to undergo a PSA test should have access to it. However, when the testimonials of smaller groups such as the Early Prostate Cancer Diagnosis Ontario (EPCDO) or individual patients were used in the newspaper articles, it was always to illustrate a clear position in favor of widespread PSA screening (13). Drayton McLane, owner of the Houston Astros stated: "I feel very fortunate that the doctors caught this so early. It is proof that early detection is the right path for everyone" (*Canadian Press*, 8 October 2002). Thus, the media are conveying two messages: get information about the test in order to make an informed choice, and by all means go and get tested.

6. The media coverage of COX-2s

Cyclo-oxygenase-2 or COX-2 drugs are prescribed for the treatment of inflammation and pain associated with arthritis and other musculoskeletal conditions. Mostly known under the brand names Vioxx™, Celebrex™ and Bextra™, they were introduced in Canada at the end of 1999 on the strength of studies showing they cause fewer upper gastrointestinal side effects than traditional non-steroidal anti-inflammatory drugs (NSAIDs) such as Advil™ or Motrin™. There were 224 articles published on COX-2s between 2000 and 2006. Of these, 177 were published after September 2004 when one of the COX-2s, Vioxx™, was withdrawn from the market after studies showed it was associated with an increased cardiovascular risk.

The main storyline

At the beginning of 2000, COX-2s were presented in the media as an alternative to NSAIDs, which are associated with serious gastrointestinal side effects (44). However, controversy arose soon after they hit the market. There were studies that challenged their superiority in terms of efficacy and reducing gastrointestinal effects (8). Moreover, new studies aimed at examining the efficacy of COX-2s in the treatment of certain types of cancer and Alzheimer's suggested that they were associated with an increased cardiovascular risk (20).

In September 2004, Merck Frosst decided to withdraw Vioxx™ from the market after its own study showed it doubled the risk of heart attack or stroke if taken for 18 months or longer (90). Following this spectacular withdrawal, debate raged in the scientific and health

professional communities about whether or not the risks associated with Vioxx™ were common to all COX-2s (32). Health administrations in Canada and the United States were accused of failing to protect the public (13). Merck Frosst was accused of putting profit ahead of public safety (33). Expert review committees were formed by the FDA (US Food and Drug Administration) and Health Canada to examine the evidence, assess the benefits and risks of COX-2s, and provide recommendations (9). They concluded that the benefits of COX-2s outweigh the risks, and Vioxx™ was allowed back on the shelf provided specific conditions were met (3). Celebrex™, which remained on the market throughout the uproar, also came under more severe restrictions (6). Bextra™ was the only medication that was pulled off the shelves indefinitely because it was shown to cause a rare but fatal skin problem (19). Although the reputation of the COX-2s had been restored, thousands of lawsuits were launched, mostly against Merck Frosst, Health Canada and the FDA (33). And the public controversy is not over for the media continue to cover these lawsuits.

Marginal voices

The most striking observation here is the relative absence of clinical and lay points of view. While clinical expertise represented 13 percent to 19 percent of all the sources quoted in the three other cases, it represented only 4 percent in the case of COX-2s. The same is true of lay expertise, which represented 20 percent to 28 percent of the cited sources in the three other cases, compared to only 7 percent in the case of COX-2s. A different pattern emerged for administrator and industry expertise: while almost absent from the coverage of the other three health technologies, they represented 21 percent and 17 percent, respectively, of all the sources cited in this present case. Scientific expertise is also dominant, representing 39 percent of the sources cited.

Before 2004, there were very few references to clinical expertise in the media. The media refer to this expertise in general terms such as “doctors.” We read that “doctors” continue to prescribe Vioxx™ and other COX-2s despite warnings against cardiovascular risks because of the medication’s effectiveness at controlling gastrointestinal problems (1). After 2004, their position toward Vioxx™ and COX-2s as presented in the media was more variable. Some positioned themselves as completely against COX-2s and called for a ban (5). Others argued that COX-2s constitute an important alternative to traditional medications and that, when used with caution, they can benefit many people suffering from excruciating chronic pain (1). A few stated that the withdrawal of Vioxx™ from the market was not a “big deal” since other alternatives exist and the medication is expensive for the little additional benefit it provides (1). Representatives of rheumatologist associations argued that studies showing increased cardiovascular risks were incomplete. Those cited contended that COX-2s are valuable as they significantly reduce gastrointestinal problems and show promise as a cure for certain types of cancer. Besides, they say, any treatment entails both benefits and risks. Dr. François Couture, president of the Quebec association of rheumatologists stated:

We condemn a class of medication that is very promising for preventing cancer and that has important benefits in the treatment of arthritis on the basis of far less rigorous studies than those necessary for the approval of new drugs. I don’t want data to be hidden, but medicine must be based on evidence, not speculation. (TFF, *La Presse*, 23 December 2004)

They disagreed with the stance that all COX-2s present similar risks (3), but advised their members to be careful in prescribing the drug until additional studies have clarified the situation. According to some, the Vioxx™ controversy led physicians to re-examine their prescription habits (2). They underlined that these medications have often been prescribed to people for whom they were not designed, and they called for greater caution in the future (2).

How the media used lay expertise was very similar to how it used the expertise of health care providers. The media presented the testimonials of people for whom COX-2s had not been very beneficial: "It had no reaction whatsoever on me except on my pocketbook" (*National Post*, 27 August 2001). It also presented patients that felt that the risks associated with these medications did not outweigh the benefits: "I appreciate Health Canada's concern for my health, but in the final analysis, I should, as an adult, be able to weigh all the risks and decide my own course of action. As adults, we have choices to make. My choices are living with risks and a quality of life or living in a long-term facility with no quality of life" (*Canadian Press*, 9 June 2005). Throughout the controversy, the position of the Arthritis Society of Canada favored the cautious use of COX-2s.

Each patient is unique. There are over 100 types of arthritis. The severity of the disease varies from patient to patient as does the stage of their disease, and the presence of other diseases. Physicians are in the best position to assess the relative risks and benefits of each medication prescribed to a patient. ... We need to make sure that we strike a balance between giving people access to the best available drugs and ensuring that both doctors and patients know about all the risk factors when they are making treatment decisions. (*Canadian NewsWire*, 22 December 2004)

The Society recognized that COX-2s are effective and that the associated risks are generally minimal (2). However, as in the case of prenatal tests for DS, this cautious position was not shared by the thousands of patients who launched lawsuits against Merck Frosst for having put their safety at risk (33).

Throughout the controversy, contrary to the relatively nuanced position of most stakeholders in the coverage of COX-2s, the industry was always presented as being thoroughly in favor of these drugs. Before 2004, both Merck Frosst and Pfizer maintained their products were safe and that studies suggesting the contrary were incomplete (13). Commenting on the VIGOR study that showed Vioxx™ users were twice as likely to suffer serious cardiac problems as those taking naproxen, Merck's Senior Director of Cardiovascular Clinical Research stated: "The Vioxx™ study involved patients with rheumatoid arthritis, a disease that raises the risk of heart trouble. The results may reflect naproxen's potential heart-friendly benefits rather than any negative effects from Vioxx™" (*Canadian Press*, 21 August 2001). Merck denied the risks associated with Vioxx™ up until its own study confirmed it. Once the risk became obvious, the company reacted immediately by withdrawing the product from the shelves. Merck Frosst's competitor, Pfizer, also denied similar risks for its own products, Celebrex™ and Bextra™. Pfizer's President of Worldwide Development stated: "the results revealed in that study [increased cardiovascular risks] are not consistent with a 'large body of data' that the company had collected" (*Canadian Press*, 1 February 2005).

Finally, the media mainly referred to the government in three specific contexts: a) when it announced the decision to refund a specific drug (2); b) when it approved the commercialization of a new drug (6); and c) when new risks associated with a drug required taking action (10). The controversy surrounding the Vioxx™ withdrawal put this last function of the government to the test. Both Health Canada and the FDA managed the risks by asking the companies for additional data on the drugs (11), by compelling them to modify their product monographs (14) and by warning the public about the new risks (9). The official position of both administrations in the controversy around Vioxx™ and COX-2s was one of caution. They suggested that until more complete data on the safety of COX-2s became available, patients should discuss with their physicians their particular risks for cardiovascular or gastrointestinal problems before using the drugs (14). Thus, they emphasized the need for additional studies (6) and underlined the need to balance the risks and benefits of the drugs (8).

They assembled a review panel of experts to examine the evidence, assess the benefits and risks of COX-2s, and provide recommendations (9). Following these recommendations, they allowed Vioxx™ back on the market subject to specific conditions, maintained the sale of Celebrex™ subject to severe restrictions, and withdrew Bextra™ from the market (28). The controversy also highlighted the limited power of government to compel the industry to provide additional data once a medication has been approved for sale (2). In response, the government re-examined the review process leading to the approval of new medications for sale (11). Thus, in the media coverage of COX-2s, health care administration was an important actor in the controversy.

7. Discussion

Several studies on the media coverage of health technology, when examining a single case, often end up criticizing the fact that specific groups are silenced by journalists (Conrad, 1999; Williams et al., 2003; Collins et al., 2006). They also argue that a more inclusive treatment of stakeholders in the media would make the debate around science and technology issues more democratic. Our study contributes to current knowledge by suggesting that the above criticism is perhaps not fully justified, and that the above suggestion, while valid, needs qualification. Our results show that: 1) the pattern of source utilization varies between health interventions and does indeed include stakeholders typically seen as vulnerable; and 2) the views expressed by the marginal sources fill information gaps and bring nuance to the stories being told, mostly by emphasizing aspects not addressed by the dominant voices (Box 1).

However, as we argue below, journalistic practices tend to reproduce social assumptions about whose views matter and why, and about what kinds of technologies are desirable or threatening. As a result, if the goal of scholars in the area of the public understanding of science is to strengthen the democratic foundations of the perspectives brought forward by journalists, two assumptions need to be revisited. Further research should: 1) move beyond the journalism/science dichotomy; and 2) explore more systematically how different journalistic strategies may modify the understanding of, and judgments about, science and technology issues on the part of different categories of readers.

Moving beyond the journalism/science dichotomy

The current body of research on the media coverage of science and technology issues addresses journalists' use and misuse of scientific expertise and highlights the distortion of scientific facts that may ensue (Conrad, 1999; Dunwoody, 1999; Nelkin, 1987; Waddell et al., 2005). Several critics have suggested cross-fertilizing the worldviews of scientists and journalists by improving the scientific training of journalists and the communication skills of scientists (Dunwoody, 1999; Nelkin, 1987; Ransohoff and Ransohoff, 2001; Waddell et al., 2005; Weigold, 2001). The assumption is that these "two worlds" need to be bridged. Nevertheless, not much research has tried to understand how non-scientific sources are identified, selected and mobilized by journalists and what contribution they can make to the public understanding of science and technology. Conrad (1999) and Williams et al. (2003) suggest including the voices of socially marginal stakeholders in order to ensure a more nuanced and democratic debate. But, what sources are most likely to provide thorough information on the scientific, political, social and ethical issues raised by science and technology matters? And how can journalists ascertain whether the views they gather are meaningful to the story being told?

**MARGINAL VOICES IN THE MEDIA COVERAGE OF CONTROVERSIAL
HEALTH INTERVENTIONS:**

ECT

Industry may be linked to increased ECT use.
Administrators are concerned by the increase in ECT use.
Health care professionals are mainly in favor of ECT.
Lay experts are mainly against ECT, although a few success stories are given.

DS prenatal screening

Industry and administrators are completely absent from the debate.
For health care professionals, PST helps orient patients toward more adequate interventions.
For lay experts, PST leads to the desirable/undesirable termination of pregnancies.

PSA

Industry is involved in R&D activities to find tests that can be used in combination with PSA.
All major institutions in all source categories are generally against populationbased PSA screening.
Individual testimonials in all source categories are in favor of population-based PSA screening.

COX-2s

Administrative, clinical and lay experts are divided on the risks associated with COX-2s.
Industry is clearly in favor of COX-2s and minimizes their risks.

Box 1. Summary of the views expressed by marginal voices.

Our analysis of the coverage of four health technologies that are controversial for different reasons has highlighted various patterns of source utilization. Contrary to what has been suggested by several authors (Conrad, 1999; Nisbet et al., 2003; Williams et al., 2003), our analysis shows that sources treated marginally in the media are not necessarily socially marginal stakeholders. While affected groups—the vulnerable or voiceless and their advocates—have

often been pinpointed as the key “silences” in media coverage, our study draws a significantly different picture. Patient associations, patients and their families were, in fact, significantly represented in the media coverage of three of the four health interventions studied. In the case of ECT, they came close to scientific experts in terms of representation (26 percent versus 31 percent). While other studies have suggested that the main cited sources are usually scientific experts, industry and government (Einsiedel, 1992; Nisbet et al., 2003), we found that the latter two sources were almost absent in the coverage of three of the four interventions. These voices were thus treated marginally when in fact they are significant stakeholders whose views matter from a public health policy perspective. Our point is not that all the categories of sources we examined should be equally represented in the media. But understanding why journalists deem certain groups to be relevant stakeholders for the purposes of their stories calls for further research in order to build on the current conflicting and inconsistent findings.

For instance, in his study of the press coverage of “behaviors” associated, either rightly or wrongly, with genetics (alcoholism, mental illness and homosexuality), Conrad (1999) suggests that the level of politicization of the socially marginalized group may favor its inclusion by journalists. When he asked journalists why they sought the points of views of homosexuals, but not those of mentally ill people or alcoholics, the response was that “it simply had not occurred to them” (1999: 300). Conrad concludes: “... the rise of the gay liberation movement and the struggle for gay rights has produced organizations that have acquired a seat at the press’s table. Whenever a new genetic finding is reported, science writers seek out views of gay spokespersons and some of the ‘affected’” (1999: 300). This interpretation partly converges with our own findings. Most patient associations concerned with ECT or Down syndrome are politicized since they militate for human rights (Heitman, 1996). This may compel journalists to seek their views when reporting new scientific findings in these areas. This is less obvious, however, for patient associations dealing with prostate cancer or arthritis, where the main mission is to obtain better diagnosis and treatment as opposed to defending patient rights. This apparent lack of any stake to be defended may explain why the voice of laypeople is less represented in the press coverage of PSA and COX-2s. But it does not explain why the government or industry is largely absent from debates around ECT, PST and PSA. The responsibility and accountability of these groups are, in principle, key to the stories being told. These groups are, by definition, highly politicized and usually occupy an important place in the media. Moreover, in all the cases we examined, their formal authority and responsibility in the development and use of health technologies could have been used by the media to invigorate and democratize the debate. In the case of COX-2s, where journalists clearly addressed the failure to protect the public, the larger presence of government and industry is noticeable but happens somewhat late in the unfolding of the controversy. This treatment may simply reflect journalists’ (sometimes) uncritical social assumptions about whose views matter. However, it may weaken the democratic process by which members of the public form judgments about new technologies.

The contribution of marginal voices to the debate around health interventions

Our study shows that marginal voices do fill certain information gaps and bring some interesting nuances. For example, in the case of ECT and prenatal screening tests, patient associations put forward ethical issues around informed consent and the consequences of these technologies on patients and society—issues that were not necessarily developed by the scientific experts cited by the media. Are severely depressed people truly informed about the risks and benefits of ECT? Will pregnant women be adequately informed about the pros and

cons of living with a DS child? Does this lead to an informed choice about whether or not to terminate their pregnancy? In the case of ECT and COX-2s, health care professionals also brought new perspectives. They emphasized the side effects of these technologies, reminding readers that any treatment bears consequences, and that these consequences vary between individuals. Reflecting on their own prescription practices, they pointed out that the problem with a medication like Vioxx™ might not be with the drug itself, but rather in the way in which it is used or overused.

While these perspectives bring important insights to the debates, the problem is *they remain marginal* in the media coverage that purports to be balanced. Thus, the extent to which they catch the attention of readers and inform their judgment about the various issues at stake remains unclear. Indeed, despite health care professionals' efforts to make ECT look less alarming, the media coverage of this technology remains fairly negative and dramatized. Despite patient associations' concerns over the consequences of prenatal screening and the positive aspects of raising children with DS, the coverage of PSTs is overwhelmingly positive.⁴

Our study suggests that the use of marginal voices to create a balanced story may also increase confusion. For instance, the current dominant, scientific view is that there is no solid evidence that the PSA test saves lives and that the benefits of the test outweigh the risks and inconveniences. However, the marginal voices brought in—those of a few health care professionals and cancer survivors—encourage men to get tested. These voices thus convey a radically different message. Contrary to the nuance brought by marginal voices in the other stories, here the position of the various types of marginally treated stakeholders converge and make a compelling case in favor of the test. Readers are told two opposing stories that are nonetheless portrayed as equally valid: the test is worthwhile *and* cancer over-detection due to the test is a serious issue. How does such a dual message affect the reader's judgment about PSA testing?

As noted above, researchers who have found that journalists tend to misrepresent scientific facts have more or less implicitly suggested that if journalists were scientifically more literate, their news stories would be more valid. Nevertheless, while scientific experts could help journalists understand “the processes of research, dead ends, and wrong turns” (Nelkin, 1987: 173), or the benefits, risks and costs of new medications (Cassels et al., 2003; Moynihan et al., 2000), they are not necessarily in the best position to clarify the “ideologies or social priorities that guide science policy decisions” (Nelkin, 1987: 173). This would require, on the part of journalists, telling news stories through the lenses of an explicit socio-political framework and seeking sources that can offer a solid scaffolding for public understanding of science to take place.

8. Conclusion

The broad objectives of our research program were to understand how the media shape the socio-political environment within which health technology assessments are disseminated and used. As suggested by one reviewer, the opposite exercise would have been to examine how the socio-political environment shapes journalistic practices. Such an analysis may indeed help explain why “industry remains hidden from view” in several news stories and “appreciate the rise of social movements, including their links with the industry, many of which are also hidden.”

Despite its limitations, one of the values of our study lies in the fact that it shows the respective contribution of marginal voices at the same time as it shows their limited role in the unfolding of science and technology-related controversies. Different groups of stakeholders

tend to shed light on different issues, which can in principle contribute to readers' understanding of science and technology. The key question for journalists thus becomes: how can they identify, select and organize a meaningful set of views and develop more than a seemingly neutral, balanced treatment of advantages and disadvantages?

We therefore believe that the call by some researchers to bridge the two worlds of journalism and science and to include other categories of sources, while important in that it helps ensure a more democratic debate, is not sufficient. How do different categories of readers form a judgment around scientific controversies? Do they assess the credibility of non-scientific and scientific sources in the same way? Do they give the same weight to the various voices being presented by the press? How do they assess the validity of the knowledge claims presented in the media? How do these processes differ between newspaper articles and other sources of information? Interestingly, while studies of Internet users have proliferated in recent years, very few scholars have examined how various publics form a judgment about what they read in the newspapers (Rogers, 1999). Further research could examine how publics appraise the cited sources and how these sources influence their views on scientific news and controversial health technologies.

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Notes

- 1 The report on COX-2s is slightly different from the other three in that it emphasizes policies rather than technologies. However, the HTA agency was about to follow up on this report by publishing several papers on these antiinflammatory drugs, and extensive media coverage of these reports was expected. We therefore selected this report as a starting point for examining the media coverage of COX-2s.
- 2 For instance, many were about lawsuits in which certain aspects of the technologies were contested. This had an impact on our results since it contributed to an overall feeling of negative coverage for ECT, PST and COX-2s.
- 3 Owing to space limitations, for the remainder of the paper, we give the number of articles mentioning the given issue in parentheses.
- 4 The positive or negative character of the coverage of each technology was measured in two ways. We examined whether the intervention was presented in the title mainly as a problem or as a solution (Smith, 1987), and whether advantages and disadvantages were mentioned (Einsiedel, 1992; Cassels et al., 2003). The detailed results of this analysis are available upon request.

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