How medical specialists appraise three controversial health innovations: scientific, clinical and social arguments

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Abstract  Medical specialists play a pivotal role in health innovation evaluation and policy making. Their influence derives not only from their expertise, but also from their social status and the power of their professional organisations. Little is known, however, about how medical specialists determine what makes a health innovation desirable and why. Our qualitative study investigated the views of 28 medical specialists and experts from Quebec and Ontario (Canada) on three controversial innovations: electroconvulsive therapy, prostate-specific antigen screening and prenatal screening for Down’s syndrome. Our findings indicate that the scientific, clinical and social arguments of medical specialists combine to create a relatively consistent narrative for each innovation. Our comparative analysis suggests that these narratives bring about a ‘soft’ resolution to controversies, which relies on a more or less tacit understanding of the social desirability of innovations and which sets the stage for their routinisation. Such an unpacking of medical specialists’ arguments both for and against new technologies is needed because such arguments may easily be considered authoritative and because there are few forums for debating the social desirability of innovations not generally deemed to be highly controversial.

Keywords: medical controversies, electroconvulsive therapy, prostate-specific antigen screening, prenatal screening for Down’s syndrome, medical specialists

Exploring the views of medical specialists regarding controversial health innovations

The emergence of health innovations often generates heated debate in scientific and medical communities as well as strong reactions from the patient and social groups involved in their adoption. While some analyses suggest that professional groups pursue their own vested interests, it is also important to examine epistemological issues and the way in which healthcare providers frame the social desirability of controversial practices (Cambrosio and Limoges 1991). More specifically, medical specialists occupy a unique position in the process of innova-
tion adoption (Moran and Alexander 1997). This is because they often contribute to the evidence base by conducting clinical research as well as interacting with the patients to whom the innovations are offered and with general practitioners who refer patients to them. Their appraisals of the value of innovations are thus a key element in the process through which the use of controversial innovations becomes established (Fuchs and Sox 2001, Vassy 2006).

Our study is a detailed comparative analysis of three cases: electroconvulsive therapy (ECT), prostate-specific antigen screening (PSA) and first-trimester screening for Down’s syndrome (DS). We scrutinise how medical specialists and experts practising in Quebec and Ontario (Canada) combine different kinds of arguments in their evaluations of these innovations. We also explore how their tacit understanding of an innovation’s social desirability sets the stage for its future routinisation.

The emergence of technological innovations: from medical aims to social uses

While conducting a literature search in preparation for a graduate course, our attention was drawn to a paper in the field of assisted reproduction and genetics that describes preimplantation genetic diagnosis (PGD), an innovation that has become the ‘gold standard’ for sex selection (Sills and Palermo 2002: 434). It explains the medical rationale behind the innovation, namely ‘the prevention of sex-linked genetic disease’, and then asserts that there are ‘compelling personal, social, cultural, or economic reasons’ (2002: 433) for couples to use PGD ‘simply as a way of choosing the sex of their offspring electively’ (2002: 434). Such use is even portrayed as a right:

Within the medical and scientific community, some have expressed the view that sex selection is intuitively acceptable to society and some patients may feel that if such an avenue is available to achieve this goal, then why not use it? From this perspective, elective embryo sex selection with PGD becomes but a simple extension of the individual right to control reproductive choice (2002: 434)

Even though this practice is not yet legal, this quote shows how a complex intervention that is initially aimed at solving a medical problem can be gradually re-framed as socially legitimate. We extend this idea in our study. In essence, we argue that the social desirability of a given innovation is shaped by the way in which medical specialists articulate knowledge – both scientific and clinical – with their vision of the social context in which innovations are used. Through their appraisal of an innovation, they thus seek to bring coherence to the existing controversy.

In his review of the theoretical frameworks used to conceptualise controversies in medicine, Martin (2004) notes that analyses may focus on knowledge, actors or social structures. For instance, innovation studies have often paid attention to the scientific basis of a controversy in an attempt to clarify, for example, whether or not the ‘social acceptance’ of a given innovation is appropriate (that is, consistent with knowledge about its efficacy and safety). Other studies have looked more broadly at how experts construct and challenge knowledge claims. Commenting on historical discoveries such as Lind’s use of vitamins to combat scurvy and Pasteur’s theory of micro-organisms, Jones (2004: 704) observes that the widespread acceptance of new theories and technologies depends on who wins the epistemological struggles:

The history of medicine has been a reflection of the struggle for the supremacy of one type of knowledge and one model of diagnosis over a number of others. Throughout the history of medicine, however, various forms of heterodoxy constantly arise to challenge the course of medical orthodoxy, these being either accommodated or opposed (2004: 74).
Because of medicine’s high status in Western societies and the centrality of knowledge in constituting its authority, some analyses have focused on the internal struggles that lead to the acceptance or rejection of a given innovation (Martin 2004). Wolpe (1994) notes three main challenges: (1) dissent, which questions current knowledge products that are considered to be facts (for example, disease prognoses) but operates within conventional assumptions about scientific method; (2) rebellion, which disputes the profession’s authority structure but does not challenge knowledge products or methods; and (3) heresy, which challenges the central values of the orthodoxy, including how claims should be evaluated. These three challenges arise only because there is a dominant group at which attacks can be directed. Dominant groups use a variety of different methods to force conformity, including ‘co-operation, isolation, subjugation, absorption and suppression’ (Jones 2004: 704). As Martin (2004) notes, however, examining professional struggles through a political lens that emphasises domination and marginalisation shifts attention away from epistemological issues to the role of socially embedded interests. In fact, the role of knowledge can hardly be divorced from the actors and social structures that generate and validate knowledge products in the first place. But how exactly can examining the social worldviews of those generating epistemological claims contribute to an analysis of controversies?

**Tacit knowledge and the social world of experts**

Science and technology studies (STS) provides a relevant theoretical framework for analysing not only how struggles unfold, but also, and perhaps more importantly, how actors and constituencies that do not contribute directly to debates, including the society at large, patients and healthcare systems, are framed (Moreira 2005). Controversy can, for instance, generate new identities and positions from which to engage in a debate around an innovation. By defining who benefits from an innovation and in what ways, medical specialists do not, therefore, simply appraise the clinical value of a medical innovation; they also construct its social value. Although this normative fashioning may sometimes be subtle, it nonetheless brings about significant social transformation. For instance, Vassy (2006: 2045) notes that some French researchers and elite clinicians adapted DS screening ‘to fit the French health system. … they played the role of ‘moral entrepreneurs’ for they promoted the new norms of healthy foetuses and legitimate abortions among front line health professionals and the general public’. She also points out that a report published in 1993 by France’s National Ethics Advisory Board, which argued in favour of expanding DS screening to all pregnant women, was drafted by two physicians, including a geneticist who was the first in France to karyotype a DS foetus.

This observation is not trivial given that experts reason and operate according to explicit and implicit social assumptions about what is desirable/undesirable in a given society (Mulkay and Gilbert 1988). As Cambrosio and Keating (1988) contend, all scientific disciplines rely on ‘unwritten knowledge’ that is incorporated into scientific practices and that is, for the most part, taken for granted. ‘Some things are left unsaid, not because of the impossibility of their being said, but for a variety of other reasons’: they may be seen as trivial, be common knowledge to everyone in the discipline, be difficult to express within a certain conceptual framework, or be deemed unthinkable (1998: 246). Examining how tacit dimensions may affect medical specialists’ appraisals of an innovation thus requires paying particular attention to their discursive repertoires (Moreira 2005). For instance, Martin (1988: 7) observed how scientists taking sides in the highly controversial water fluoridation debate mobilised a ‘contingent repertoire’ to underscore the underlying political and human factors in the production of scientific facts by their opponents. Because such narratives construct
certain relationships between knowledge and social action, they carve out a discernable path for the future routinisation of innovations, as will be discussed later.

Methodology

Our qualitative data were collected for a broader study aimed at understanding how medical groups, patient associations and the media perceive and shape debates around ECT, PSA testing and first-trimester DS screening. We chose these innovations because they were socially and scientifically controversial and because they were formally assessed in 2002 and 2003 by health technology assessment (HTA) agencies in Quebec and Ontario (Canada). Our goal was to provide an in-depth analysis of a broad range of views in order to explore how medical specialists envisage and make sense of the scientific, clinical and social promises and pitfalls of these innovations. We conducted a total of 28 semi-structured interviews, mostly face-to-face, in either French or English. They lasted between 45 and 90 minutes (the interview questionnaire is available upon request). Our recruitment strategy combined purposeful and snowball sampling techniques (Rubin and Rubin 1995). We first contacted medical specialists who had been invited to review the HTA reports and asked each of them to provide the names of colleagues known to have an opinion on the given innovation. This process yielded 10 respondents for ECT (9 psychiatrists and 1 medical doctor in a managerial position), 6 for PSA testing (4 urologic oncologists, 1 oncologist and 1 urologist), and 12 for DS screening (7 obstetrician-gynaecologists, 2 geneticists, 1 genetic counsellor and 2 medical doctors in managerial positions).

Our analysis of the transcripts relied on a mixed coding strategy using NUD*IST software. We began with three broad, pre-defined categories (scientific, clinical and social) and then tried to uncover empirical subtleties and nuances within each category. We first analysed material pertaining to each innovation independently (intra-case analysis), which enabled us to identify the overarching storyline. Comparative tables were then created in order to condense the empirical material and identify recurrent patterns across cases. This enabled us to explore the extent to which the respondents’ social assumptions were pivotal in determining an innovation’s desirability. Furthermore, as required by a symmetrical analysis1 of controversies (Martin 2004), we suspended a priori judgements regarding which arguments were right or wrong. We could thus explore in greater depth the claims that rendered innovations meaningful to the respondents. For this paper we selected verbatim extracts to illustrate the diversity of opinions gathered as well as the issues on which the respondents’ views converged. We translated from French to English when necessary.

Three narratives that combine scientific, clinical and social assumptions

ECT: Fighting against stigmas

In ECT, brief electrical pulses are applied to the patient’s brain. It is performed under general anaesthesia and requires the administration of a muscle relaxant, oxygenation and constant monitoring (Banken 2002). In the early 2000s, concerns were raised by healthcare authorities over the increased use of ECT in Quebec hospitals. The Quebec Ministry of Health therefore asked the provincial HTA agency to evaluate the technology. The report concluded that ECT was effective in the treatment of major depression and pernicious cata
tonia, and of limited use in the treatment of schizophrenia. It also recommended that its
use in clinical practice be monitored closely and that patient and advocacy groups be involved in clinical decision making.

From a scientific standpoint, most of the respondents were convinced that ECT was an effective therapy (see Table 1). Their views varied, however, with respect to the kinds of evidence on which psychiatric clinical practice should rely. Some felt that ECT was not being evaluated fairly, due to the weight given to Level 1 type evidence (i.e. randomised controlled trials). One respondent noted: ‘You can’t just discard all the studies that do not use the same standards as those applied for drugs. By rejecting these studies right at the outset, the argument [that there is a lack of strong evidence] becomes circular’ (Dr. E2). Several respondents pointed out the absence of long-term studies in the mental health field, and many were perplexed by the memory loss and neural damage potentially linked to ECT. One respondent underscored that ECT generates less severe side effects than drugs, especially for elderly patients who take multiple medications (Dr. E8). A recurrent epistemological concern for all respondents was the lack of a biological explanation for how ECT works (the term ‘black box’ was often used). In the face of such ongoing epistemological challenges, we discerned a general belief that psychiatry was being treated unfairly because it was being held up to unreachable standards.

A general sense of not having a firm scientific ground on which to base ECT use was discernible, but it was clinically counter-balanced by the technology’s visible and sometimes dramatic positive effects. The respondents gave various clinical arguments to justify their use of ECT, including intense suffering, a lack of response to other treatments and a prolonged duration of illness. It is striking that the majority of respondents were at a loss to explain ECT’s effectiveness and were influenced by the technology’s negative aura:

When I think about my first impression of ECT, the image that struck me the most was One Flew over a Cuckoo’s Nest, or Alys Robi [a popular Quebec singer in the 1940s who received ECT for severe depression] or what was said in the newspapers…. Even for me, it was something big and scary. You don’t know what it is, especially if you’re not in psychiatry and using it. A friend of mine, who is now a surgeon, said that when he did his internship in psychiatry, seeing ECT was devastating – the worst experience of his life. When I did my internship, it was the opposite, and it was then that I decided to go into psychiatry. I saw people having ECT and I finally understood what it was all about. But I remember being apprehensive and anxious, not knowing what to expect or what I’d see or how the patient would react to ECT – would he have convulsions or just sleep? Would he scream? You have all these ideas in your head. But then when you see it, all of the taboos rapidly disappear (Dr. E3).

So, using ECT did help to normalise the innovation for the psychiatrists. There was, however, some disagreement among the respondents on how the technology’s use should be governed. Some said that ECT was simple to learn and relatively straightforward to use because ‘recipes’ for anaesthetics are available and ‘psychiatrists do not need special training’ (Dr. E3). This perspective contrasts with that of Dr. E2, who was aware of how ECT was applied in other hospitals because he had been called to intervene in complex cases: ‘Not only are the machines different, but also the records, the rules, the involvement of anaesthetists, the team…. I am worried about the quality in other centres. So, standardisation of clinical practice is very important’. The underlying goal of these two seemingly contradictory views was the same: routinising ECT on irreproachable grounds.
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<td>While the therapeutic mechanisms underlying ECT are unknown, it is an effective but underused treatment. Since randomised clinical trials with ECT are unfeasible, the lack of Level 1 evidence should not be held against ECT. There is uncertainty about ECT’s impact on memory loss, the potential for neural damage and long-term effects.</td>
<td>Several patients, especially those who do not respond to other treatments, benefit from ECT. ECT is dramatic on a symbolic level: both physicians and patients who have no direct experience with ECT cannot know what it really is, while those who do cease to doubt its efficacy. Clinical indications are not always clear, practice variations are a problem and standardisation of practices is needed. Because it requires anaesthesia, ECT is a complex procedure; it requires experienced anaesthetists who use it on a regular basis. Patients must be told about the evidence as well as the uncertainty surrounding ECT.</td>
<td>Patients must be told about the evidence as well as the uncertainty surrounding ECT.</td>
<td>Genetic counselling is also necessary. Patients must be told about the range of available options, and physicians must remain neutral.</td>
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<td>The PSA test is not reliable enough (low specificity/sensitivity rates). Physicians and governments should wait because technologies should not be approved before conclusive evidence is available. There is no proof that early detection will result in improved survival and, as is the case with most screening tests, subsequent clinical management is unclear. The PSA test should not be used or interpreted in isolation. Although the PSA test may not be a good screening test for prostate cancer, it is a good for detecting benign prostatic hyperplasia. There is uncertainty and physicians need to search for and interpret evidence that can orient medical practice. Medical guidelines are helpful.</td>
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<td>The sensitivity and specificity of the new serum and other ultrasound markers have improved significantly. A problem is that parents may be forced to make a difficult decision when such a decision may not have been necessary (a significant number of DS foetuses are spontaneously aborted). Radiologists generate evidence that affects gynaecologist-obstetricians. DS is only one application of first trimester screening. Although some variation in clinical practice is inevitable, all obstetricians and sonographers need high-quality training. Multidisciplinary exchanges help to improve practice by widening the search for evidence. Mixed teams of, for example, paediatricians, geneticists and congenital malformation surgeons are useful for solving difficult cases. Appropriate patient counselling from referring obstetricians is pivotal; some patients show up for ultrasounds not knowing what the test involves.</td>
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<td>Social arguments</td>
<td>Past abuses by mental health practitioners/institutions, cinematic depictions and media reports have created a strong stigma around ECT and psychiatry in general. Patients for whom ECT has been beneficial do not wish to talk about it publicly, while the media overemphasises fears and cases that have ended badly. Ideological (anti-medicine) patient groups are generally a nuisance as they misinform patients.</td>
<td>No mention of how side effects of prostate cancer surgical treatment should be handled. Men are uncomfortable with talking about prostate cancer and patient groups misinterpret the available evidence. Despite the fact that the policy environment is impeding innovation, waiting for evidence remains the most reasonable approach.</td>
<td>Because there have been abuses in the field of genetics, extreme caution is required when drawing up policies. First trimester screening should be offered to all pregnant women and reimbursed by the government. Currently, it is available only at private clinics and must be paid for the patient, a situation that creates inequality. Abortion is controversial and disability advocates have concerns about screening for DS. From a cost perspective, large-scale screening would be beneficial as it could detect cases that might have been missed otherwise. Most women will terminate pregnancies if DS is diagnosed, thus avoiding institutionalisation and/or the heavy medical costs associated with these children. Women’s health issues have not been sufficiently supported by the government and increased lobbying efforts should be envisaged.</td>
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Within this perspective, public opinion seemed to be an important element: ‘There are a lot of statements made by the public, on TV or in newspapers that are really unfair and that do not take the clinical reality into consideration’ (Dr. E8). This view posits public discourse around ECT as a distortion of a clinical reality that is familiar to psychiatrists yet almost completely unknown to most of the public. Fighting effectively against ECT’s public stigma would, several respondents felt, require a more aggressive media presence, one that would portray what ECT does for mentally ill patients in a more positive light. In Dr. E3’s words:

> There are very few patients who have received ECT and now feel ready to be on TV and say, ‘I had ECT.’ Because of the taboo, people think, ‘You must be really crazy if you had ECT!’ It’s hard to find someone who will go on TV – someone who does not have a personality disorder, and who had severe depression and successfully recovered thanks to ECT.

One respondent also referred explicitly to the social stigma attached to psychiatry, which is seen as ‘hiding things from the public’ (Dr. E3). Similarly, one respondent felt that ECT’s history was inseparable from the history of psychiatry itself:

> I have no doubt that there have been abuses in the treatment of mental illnesses....

procedures that were performed to the best of doctors’ abilities at the time. Some procedures, like ECT, were probably seen as being state of the art at the time, and they did have some kind of benefit. But in mental health, and in psychiatry, it’s one of those practices that the public has never forgiven (Dr. E10).

In light of such comments, it is not surprising that several respondents reacted negatively to the HTA’s recommendation that ECT use be more closely monitored: ‘It’s a political move and it speaks to the stigma of mental health treatments and the symbols that are now associated with psychiatry. And certainly ECT is the symbol that is used the most for anything negative about psychiatry’ (Dr. E10). The idea that a community representative be included on committees prompted a number of different reactions from the respondents. Dr. E8 mentioned that he knew a couple of ‘good’ patient groups (i.e. one formed by the relatives of schizophrenics and one active in the area of Alzheimer disease), but several groups were ‘bizarre’, held outdated anti-medicine positions and were a ‘nuisance’. Furthermore, both patient and community groups were sometimes seen as not sufficiently informed (Dr. E2 was in favour of them playing a larger role but said funding would be required) or too preoccupied with emphasising the rights of patients (Dr. E3). A key challenge in treating mentally ill patients and in involving their representatives in clinical governance involves the issue of consent: ‘we always have to deal with the ill ‘organ’ giving its consent and the ill ‘organ’ being consulted’ (Dr. E8). Given the ideological tensions at play, the respondents were sceptical about the likely uptake of the HTA report’s policy recommendations.

> [At the Ministry of Health], mental health has always been in the hands of a bunch of weirdos who have never understood that mental illness is a physical illness and not simply a psychosocial thing. ... Community groups and primary care centres are not philosophically prepared to deal with what we call real mental illness as opposed to the blues [mal de vivre] (Dr. E8).

To summarise, we observed some dissent in the respondents with respect to the knowledge products in the field of mental health. In general, the psychiatrists highlighted issues related
to the strong social stigma attached to their profession, the regulation of therapeutic prac-
tices, clinical autonomy, and problems with how the efficacy and safety of ECT is evalu-
ated. They were afraid that a broader public debate about ECT would only lead to a
further weakening of their public image and to undue pressure on their socially stigmatised
patients.

**PSA testing: waiting for evidence**
The PSA test measures the blood level of prostate-specific antigen, a protein released by the
prostate. A high PSA level can be caused by inflammation, age-related enlargement or can-
cer (Slaughter et al. 2002). A positive PSA test must be followed up by a biopsy or other
procedures before cancer can be confirmed. PSA’s usefulness as a screening tool, that is its
systematic application to asymptomatic men, is hotly debated worldwide (Faulkner et al.
2000).

Of the three cases, this was the one in which scientific arguments formed the most signifi-
cant locus of controversy. The respondents were very articulate about the kinds of evidence
needed to resolve the controversy and about the processes and time required to generate
such conclusive evidence. In the words of one: ‘Because the event rate is so low and it is
mostly found in elderly patients, the primary issue is co-morbidity. The second issue is the
unreliability of the PSA test and the high false-positive/false-negative, or low-sensitivity/
low-specificity, rates’ (Dr. P4). Another respondent was worried about PSA levels being
treated as an arbitrary cut-off point, which ‘misses the whole point’ (Dr. P5). There is also
a lack of guidance about what treatments should follow screening and diagnosis. While
Dr. P1 admitted that ‘the whole field is full of uncertainty’, he pointed out that PSA was
not, in fact, controversial. Rather, there was simply not enough proof that the test improves
survival: ‘we’re confronted with multiple opinions, not scientific evidence’. At the same
time, some respondents were sceptical about the evidence-based approach, which draws
conclusions by summarising only one type of study:

The process tends to overemphasize data from randomised trials, which are quite
few and far between in this area, and underemphasize the data from many non-
randomised and phase 2 trials. That’s sort of a standard approach in epidemiology
but it’s a problem when you have so few randomised trials. It tends to bias the
outcome against the intervention (Dr. P1).

Despite such criticisms, all of the respondents agreed that the medical community and
patients should wait for solid evidence: ‘Until such time that we have done the trials and
have the data, I don’t think we should be approving a technology that really hasn’t been
conclusively proven’ (Dr. P5). Furthermore, in contrast to the case of ECT, the respondents
commenting on PSA testing did not provide strong clinical arguments in support of PSA
screening. Neither did they discuss whether patient-oriented clinical tools such as decision-
aids should be made available or whether mass media strategies should be used to better
inform the public. One oncologist said that his responsibility was to ‘search for the informa-
tion needed to make clinical decisions and extrapolate from the available information to
determine what should be done in the specific case at hand’ (Dr. P3). His view resonates
with the broader argument that posits PSA as just ‘one tool among many’ (Dr. P5), whose
complexity and subtlety require that its use remains under the authority of medical special-
ists.

Our respondents thus saw the PSA controversy as limited mainly to the domain of clini-
cal experts and shared fewer social arguments. Nevertheless, several psychosocial issues
have been raised in the literature, in particular the side effects of the surgery to treat prostate cancer (impotence and incontinence). The respondents’ quasi-silence on these issues is intriguing given that they are very significant to patients and their families. Only Dr. P2 alluded to the embarrassment of ordinary patients, who have a hard time coming out of the ‘closet’; he contrasted this with the ‘success stories’ of Canadian politicians, who talked publicly about being treated for prostate cancer and lobbied in favour of the PSA test. When probed about the expectations of patient groups, we observe a strong ambivalence. While these groups are sometimes seen as knowledgeable and a ‘positive force that has increased awareness’ (Dr. P1), they are sometimes perceived as being too ‘subjective’. Dr. P4 noted that they were ‘very well informed about the evidence, but … their conclusions are not necessarily objective and evidence based. … it’s the interpretation that may be suspect’. Another interviewee felt the views of patients were too volatile:

They are also easily swayed. If someone writes an article that says PSA screening is totally useless or PSA is harmful in terms of screening, you can guarantee I’ll get ten phone calls the next day, or people coming to my office with newspaper clippings or articles they have downloaded off the Internet. They ask me if what they’ve read or heard is true… So yes, they can be easily be misinformed and that’s the danger (Dr. P5).

One reason for such misinterpretation on the part of patients and patient groups could be related to their direct experience of illness: ‘There tends to be a lot of people in these groups who have very dogmatic views and defend them passionately. If you’ve been treated for cancer, you tend to have very strong views about that disease’ (Dr. P1). This comment is interesting given that the medical specialists also probably have ‘strong views’ about disease and treatments, yet they saw their interpretation of the evidence as inherently objective.

Overall, the medical specialists involved in PSA testing hoped that scientific studies would, in the near future, render a final verdict on this issue. Our respondents did not feel any great pressure from either their patients or the general public. They believe the truth will be uncovered by science and that there is no room for rebellion or heresy in the matter. In this wait-and-see context, in which social issues are downplayed, it is not only medical specialists who must wait, but also men and their families, who are told by other sources to worry about prostate cancer.

**Screening for DS: inequality of access**

We focused on a prenatal DS screening test that combines a foetal ultrasound scan and a biochemical analysis of maternal blood markers. This test is novel in that it is performed during the first trimester of pregnancy. The DS test measures nuchal translucency, or ‘the subcutaneous space between the foetal cervical spine and the overlying skin’ (Framarin 2003: 11). It determines the probability that a pregnant woman is carrying a DS foetus. Abnormal test results are usually followed by more invasive diagnostic procedures.

As in the case of PSA testing, a significant concern with DS screening is whether or not it should be offered systematically to all pregnant women. However, unlike the PSA test, because first-trimester screening is used in addition to several other screening and diagnostic modalities and because it can be used to detect other malformations or diseases, the respondents presented a broader range of scientific arguments. The majority believed that the DS test is sufficiently accurate and beneficial to justify reimbursement under the provincial healthcare plan. Both Dr. S7 and Dr. S11 felt that Quebec was ‘lagging behind’ when
compared to other Canadian provinces and European countries. The following quote summarises well the position of the respondents:

Nowadays, with serum markers and other ultrasound markers, the sensitivity and specificity has improved to such a significant degree that we should reconsider the test. And there’s so many other reasons to perform a first-trimester ultrasound that it should, I think, be offered routinely and covered by the government (Dr. S6).

Unlike the case of PSA testing, the medical specialists we interviewed were not waiting patiently for conclusive evidence to end the controversy. Such specialists share the scientific/clinical turf with radiologists, whose role in prenatal screening has grown substantially in recent decades. The accumulation of evidence renders the struggle between these groups particularly acute:

In my practice, I have to fight with radiologists, who perform a lot of obstetrical ultrasounds and who don’t believe in first-trimester screening like we do [integrated testing]. Radiologists come from another school of thought. They follow the ‘doctrine’ of Nicolaides [a British doctor and researcher who extensively studied the use of prenatal ultrasound] (Dr. S1).

While most respondents agreed that variations in prenatal screening practice were, to a certain extent, normal and even desirable, they all emphasised the importance of genetic counselling:

You can’t just implement a screening program without also having the appropriate counselling. It has to be part of a larger program. There are some screening programs in place that do everything from A to Z; the patient walks through the door, has the screening test and is counselled – everything is done before they walk out the door at the end of the day. And these are … clinics that we can use as role models (Dr. S6).

This perspective resonates with the clinical ethos of genetic medicine, which asserts that screening and diagnostic tools reveal information that can transform an individual’s understanding of family, kinship, reproductive options and future health states. Most gynaecologist-obstetricians tended to downplay the test’s potentially negative effects on patients; it was a genetic counsellor who emphasised that miscarriages often occur with DS foetuses and that positive test results generate anxiety and force a couple to make a decision that perhaps would have been ‘naturally’ avoided (S5). Several respondents were critical of their obstetrician peers who had no training in genetics and who refer patients without having properly educated them:

For me, the major area of uncertainty is whether or not patients are properly counselled before they come for nuchal translucency screening. Here we do a routine first trimester ultrasound for all patients but they come from a diverse group of referring obstetricians and they’re not all, I think, properly counselled. A lot of them show up on the ultrasound table and they don’t really know what procedures we are performing on them (Dr. S6).
While such situations are most likely to arise when DS screening has become a routine procedure, all respondents insisted on the importance of adopting a neutral position with pregnant women.

We’re very reluctant to go against the will of the patient…. from my perspective, particularly as a medical geneticist and because the field of genetics has been abused so badly... I am very careful to give good information and not be directive. So, basically our position is to give people all the information so they can make informed decisions. We like to have as much technology [as possible] at our disposal. People can use it if they want to (Dr. S9).

In reality, however, patients are not entirely free to choose the option that best fits their decision needs and reproductive preferences. As Dr. S6 notes, ‘the serum test, which has greater sensitivity and specificity, is not available to patients for free so they have to go to a private clinic and pay a lot of money’. The narrative around DS screening emphasises the need for the government to provide the test, free of charge, to all women in order to ensure equality of access. Moreover, respondents positioned their social arguments in the sphere of individual freedom. Perhaps more subtle was the tacit view, shared by all respondents, that having a child with DS is undesirable. Most physicians expressed this view in terms of the cost to society: ‘Most women will terminate these pregnancies so there’s a cost savings there because one sick child with Down’s who has to be institutionalised, or who has cardiac anomalies and has to be hospitalised for weeks or months, is very costly’ (Dr. S10). One may wonder what a non-directive approach to patient decision making actually looks like in practice because our respondents never questioned the likelihood that ‘most women will terminate these pregnancies’. 7

As in the case of ECT, some respondents noted that genetic medicine often carried negative social connotations. Dr. S4 felt that the province’s Ministry of Health was moving very slowly on this issue because of the ethical and religious dimensions involved: ‘we have to be clear … the direct consequence of DS screening is abortion. … These [influences] are not written anywhere but they must play a role’. Certain interest groups, like ‘disability advocates’ or ‘some religions’, were seen as potential opponents. Like the respondents in the other two cases, gynaecologist-obstetricians and geneticists believed that there are ‘good’ patient groups. These could become ‘allies’ in efforts to establish a first trimester screening programme as an effective way of ‘informing’ pregnant women and in ‘helping them make timely decisions over the likely issue of their pregnancy’ (Dr. S8). Several respondents therefore saw women’s health lobbyists as positive forces in the development of a DS screening program:

When we know there’s a possibility of moving forward at the ministry of health and that resources will be invested in it [screening for DS], we’ll try to get as much of it as possible. And then, yes, we’ll be able to raise women’s awareness, reach out to all the pro-choice groups so they will join with us and lobby for this women’s health issue (Dr. S1).

Overall, our findings for this procedure illustrate the presence of some dissent among medical specialists. Various issues related to scientific and clinical aspects, in addition to impeded access to the test, served as the backdrop to discussions of social equality and women’s health issues. The governing narrative, however, is informed by an understanding that it is socially desirable to abort DS foetuses.
Challenging medical specialists’ social assumptions about health innovations

Our comparative analysis suggests that the social desirability of an innovation is defined by an integrated set of claims; medical specialists’ scientific, clinical and social arguments all combine into a narrative that brings about a ‘soft’ sort of resolution to the controversy (see Figure 1). Despite some dissent regarding the current state of disciplinary knowledge, our respondents’ positions toward a given innovation translated into a largely shared understanding of that innovation’s social desirability. According to the respondents, ECT is desirable because it is effective and reduces patient suffering; it therefore should not be seen as just a treatment of ‘last resort’. PSA is not highly desirable because its reliability is problematic, its ultimate impact on mortality is unknown, and it generates uncertainty for clinicians and patients. Despite these recognised shortcomings, however, the respondents still felt that PSA was a useful clinical tool. Screening for DS is highly desirable because it is sufficiently reliable, and allows doctors to intervene earlier in pregnancy. Although some specific interest groups may oppose screening for DS, it is, overall, a socially desirable innovation.

As Figure 1 indicates, the process by which medical specialists bring coherence to the various scientific, clinical and social arguments about an innovation sets the stage for its routinisation. In all three cases, we observed a ‘technological imperative’ that went hand in hand with a ‘social imperative’ (although in the case of PSA screening this was less so as the respondents were not pushing for PSA to be covered under the provincial healthcare plan). In fact, we did not observe any rebellious or heretical views, perhaps because medical specialists occupy an already dominant position within medicine. Moreover, there are currently no impediments, in practice, to using the three innovations, which may explain why there are no open conflicts in the way the respondents envisaged the routinisation of these innovations. As a result, the three narratives that we uncovered in effect pave the way for the future of each innovation. For ECT, the key issue is to legitimise its practice by reducing the stigma attached to mentally ill patients and to psychiatry in general. For PSA, the reasonableness of waiting for more solid evidence seems to take precedence over the need to provide men with knowledge and tools that could help reduce their uncertainty. In the
case of screening for DS, responding swiftly to the existing inequality in access is of para-
mount importance and therefore active lobbying by clinicians and women’s groups should be envisaged.

Our findings have a number of policy implications. The three cases we examined, in which the social desirability of innovations crystallises before it can be democratically debated, show that there are different types of assumptions at work. Some are explicit, while others remain tacit. Some arguments are brought forward, while others are omitted. Such absences, nevertheless, contribute actively to the coherence of the narratives. In the case of ECT, although respondents see the need for a broad public communication strategy, they look for the ‘right’ patients or patient groups – those who would paint a positive image of ECT. This is compatible with what Stevens and Harper (2007: 1483) observed in interviews with clinicians who use ECT:

The knowledge and claims of ECT recipients who have experienced adverse effects are positioned as secondary to the knowledge and claims of the professionals who administer the procedure. These service users are positioned as poorly informed and forgetful. However, those who are critical of the procedure, but who have not been recipients, are implicitly positioned as even less authorised to criticise ECT (2007: 1483).

In the case of the PSA test, the respondents’ willingness to wait and see may have been a manifestation of passive marginalisation by neglect; that is, patient psychosocial issues were not considered significant enough to warrant concrete action (Martin 2004). Handling uncertainty can be achieved at the clinic, on a case-by-case basis. In the case of DS screening, the respondents recognised that one likely outcome of the test – abortion – is controversial. Nevertheless, none of them discussed whether or not the abortion of DS foetuses was socially acceptable. Rather, respondents emphasised patient autonomy and limited their comments to the test’s ability to detect DS.

Overall, our respondents’ appraisals were informed by mainstream scientific and clinical observations. However, they were also shaped by a set of fragile, untested social assumptions. In all three cases, medical specialists defined social needs and preferences in ways they thought were appropriate given their patients’ expectations. As medical specialists are members of society just like everyone else, their social assumptions may be the same as those of many other people (including patients). The problem is that these assumptions may remain undetected, while the socialisation of medical specialists reinforces the fairly unique position from which they determine which innovations are desirable or not (Moran and Alexander 1997). As Cambrosio and Keating (1988: 246) point out, although tacit dimensions often remain unspoken by the members of a given community of experts, they are part of their ‘conscious scientific practice and hence subject to negotiation, discussion and (re)construction’. Because medical specialists’ arguments are often considered authoritative by the general public, patients and policy-makers, and because there are very few forums for debating the alleged social desirability of innovations, we believe there is a need for processes that can challenge medical specialists’ assumptions.

One sensible policy avenue to address the assumptions of medical specialists would be to introduce, alongside current public and patient involvement initiatives (for example, in the fields of HTA or clinical practice guidelines), mechanisms that would enable social scientists and other groups to engage in discussions with medical specialists. As Stevens and Harper suggest, it may also be possible to draw on insights generated through discursive analyses ‘to develop training packages’ to help clinicians ‘become aware of the ways in which particular rhetorical resources may foreclose the offering of choices about interventions’ (2007: 1484).
Although our comparative analysis of three contentious innovations is solid, the transferability of our findings may be limited. While international networks undoubtedly play a major role in shaping medical specialists’ overarching views, it is also clear that local circumstances, professional regulatory frameworks, the division of labour among healthcare professionals, and national historical dimensions all shape physicians’ norms and social assumptions. Further research could examine whether and how the narratives of medical groups and their struggles with other professional groups actually influence policy-making.

Concluding remarks

Our study was designed to enrich the literature on medical controversies by providing an in-depth analysis of how medical specialists appraise the desirability of several different innovations. In a symmetrical analysis of controversial innovations, epistemological claims cannot be separated from those defining the social contexts in which innovations emerge and are used. While dissent and the quest for truth are germane to medical specialists’ struggles to come to grips with controversial innovations, our study shows that their visions of the social desirability of innovations provide a framework for achieving resolution. We argue that for the three cases we examined, the narratives are based on weak social assumptions about what kinds of technology are desirable in healthcare systems. We believe that dealing democratically with the implications of new technologies requires that we explicitly unpack medical specialists’ arguments either for or against these technologies.

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Notes

1 Asymmetrical analyses assume there are appropriate responses to ‘good’ science (that is, favourable reception) and to ‘bad’ science (that is, unfavourable reception). Symmetrical analyses tend to consider all beliefs and views equally, and they reject any dichotomy between scientific and social explanations (Bloor 1999).
‘Recipes’ are needed because certain anaesthetics interfere with ECT by increasing the convulsion threshold and therefore cannot be used in conjunction with ECT.

Dr. E4 expressed another concern: ‘In a team of 15 to 20 psychiatrists, where each of them performs ECT on an irregular basis, people will not be interested enough in the topic and it becomes like pushing a button.’

According to several respondents, there are various ideologies (anti-drug, spiritual, legal, etc.) that conflict with mainstream medicine. For instance, Dr. E1 was disappointed when his peers asked the administration to stop allowing representatives of a patient group to visit patients in his hospital. However, he recognized that this involved exposing patients to philosophical and ideological positions that do not dovetail with psychiatry.

According to Dr. S9, it is key that we rely on medical specialists who possess and cultivate certain intrinsic qualities that make them expert judges of scientific evidence as well as responsive to patients’ preferences and needs.

This specialist’s primary role was to provide easily understood scientific information to pregnant women in order to help them make an informed decision; perhaps this explains why she was familiar with, and reflected on, issues related to the broader implications of such testing.

The test may be presented in an ambiguous way. One physician said: ‘We don’t impose abortion on them. A woman who has a foetus with DS can decide to keep it. They’re very warm, friendly children … But we know that there are several complications and about 80% of couples divorce after having a child with Down syndrome’ (Dr. S8). Only Dr. S4 explicitly acknowledged the ethical argument that is raised by groups representing parents of DS children or the disabled.

Faulkner et al. (2000: 294) found that the judgments of UK-based urologists using the PSA test ‘may be informed by beliefs regarding the value of treatment in relation to patient age and life expectancy’. Similarly, our results show how specialists’ clinical judgments are embedded in a broader narrative that does not discard the PSA test, despite the current scientific uncertainty.

References


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