The blogosphere and its enemies: the case of oophorectomy

Stephen Turner

Abstract: The blogosphere is loathed and feared by the press, expert-opinion makers, and representatives of authority generally. Part of this is based on a social theory: that there are implicit and explicit social controls governing professional journalists and experts that make them responsible to the facts. These controls don't exist for bloggers or the people who comment on blogs. But blog commentary is good at performing a kind of sociology of knowledge that situates speakers and motives, especially in cases of complex professional and administrative decision-making, as well as providing specific factual material that qualifies claims of experts and authorities. In many contexts the commentaries are examples of Habermasian demands for justification, to which there is a response. A major topic in women's health, and on the blogs, is the effects of hysterectomy, especially accompanied by oophorectomy, the removal of (normally healthy) ovaries. Physicians make extrême claims on web pages about the lack of consequences, or their manageability through hormone therapy, which they claim is supported by research. Blog posters, and a blog opposed to hysterectomy generally, claim that there are numerous damaging effects, and deconstruct the claims of experts. Blog posters fill in the claims with personal experiences and analysis of the conduct of physicians and nurses, as well as the motives of women who deny symptoms. Physicians provide their own critique and analysis of the blogs, to which they attribute great influence. A later meta-analysis and new longitudinal research affirms the bloggers, and explains why much of the research cited by experts is wrong.

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The blogosphere is loathed and feared by the press, expert-opinion makers, and representatives of authority generally. The reasoning is simple, and is part of a long tradition of anti-liberalism that stretches back to Comte, Karl Pearson, and Walter Lippman: uncontrolled public discussion is 'intellectual anarchy' and the ranting of the ignorant. Part of this is based on a social theory: that there are implicit and explicit social controls governing professional journalists and experts that make them responsible to the facts. These controls don't exist for bloggers or the people who comment on blogs. To the extent that their form of public discussion supplants the professional class of journalists and challenges

the authority of experts we trade 'a dictatorship of experts' for 'a dictatorship of idiots', according to Andrew Keen (2008: 35).

While it is true that the topics your mother told you to avoid at dinner – religion and politics (and especially core political ideologies) – remain as dividers in blog commentaries, the actual content of blogs contains much more. Especially in cases of complex professional and administrative decision-making, blog commentary is good at performing a kind of folk sociology of knowledge that analyses the interests and motives of participants in discussion, experts and lay observers alike. Blog comments on newspaper articles and columnists are especially effective detectors of bias. But commentary also provides specific factual material that qualifies the claims of experts and authorities, including testimony from actual personal experiences. Blog commenters often also have specialized knowledge and experience that bears on the issues, that is, technical knowledge or knowledge of normal procedures that journalists do not have and can access only with difficulty through the maze of spokespersons, official representatives, executives, and experts that present themselves professionally as explainers.

In many contexts, blog comments are examples of Habermasian challenges to provide justification. A rough sort of civility is enforced, and the course of the exchanges exposes the 'idiots' and ideologues, or they expose themselves. There is even an argot for this, identifying certain contributors as 'trolls', for example. Instead of a dictatorship of idiots, the discussion becomes a large schoolhouse in which opinion is tested, questioned and moderated. It has a special role in relation to expertise, particularly by supplying personal experience that conflicts with, specifies in detail, or balances the blanket assertions made by experts.

Discourse theory and the blogosphere

The emergence of the blogosphere, which I will define for this paper as the world of web pages, often linked, that allow for reader response and commentary, has produced a response by critics that has focused especially on the problem of expertise, and on the relation of traditional journalism to expertise. According to the critics, the rise of the blogosphere has produced a degradation of public discourse. The gold standard of public discourse is the professional work of journalists and commentators functioning as opinion leaders. Their work facilitates public discussion by providing ready-made correct or competent summary views for those who do not have the time and competence to construct opinions on their own, or to survey the range of competent opinion and fact on their own.

The blogosphere, according to this view, lacks the professional standards that make this work of facilitation possible, and tends, in a kind of Gresham's Law, to drive out competent discussion. The blogosphere distracts the unwary consumer of opinion and fact with false, scurrilous, inflammatory, and ideologically laden material. The economic problems of the media, together with the din of the blogosphere, threaten the quality of public discourse, and indeed have

actively degraded it, by diminishing the role of the professional channels of public opinion formation and creation.

The issues are especially serious in the case of expert knowledge, which, according to this model, is filtered by responsible professional journalists who explain it in terms accessible to the public and distinguish legitimate claims to expert authority from bogus ones. The blogosphere, which is open to anyone, has no filters, and allows false and misleading attacks on experts and assertions of fact that conflict with expert knowledge. Claims of this sort have been made, and countered, repeatedly in the popular press, and in other media, in relation to topics as diverse as wine-tasting and literary criticism (cf. Jacob, 2013; Jarvis, 2006; Kaiser, 2011; Killoran, 2013; Quinlan, 2011; Romano, 2012; Stan, 2011; Trueman, 2011). It is also clear that official announcements are being tailored to likely blogosphere responses. Among the fears cited by the critics of the blogosphere are several that are especially important in relation not merely to matters of taste, but to issues over expert claims with policy or medical consequences. The argument is that consumers are unable to sort through this collection of falsehoods and misleading commentary, and are prone to considering it as evidence against, or grounds for scepticism about, genuine expert knowledge. This undermines the kind of deference to fact that is essential to democratic discussion, and forces the discussion of questions that are properly subject to expert knowledge into the fact-free arena of ranting, speculation, and ignorant assertion characteristic of the blogosphere.

The blogosphere also raises questions about moderation: many immoderate opinions appear on the web, in the blogosphere. But the blogosphere also tends to undermine dominant voices. Could it be that the web produces moderation as a result of the same tumult of voices that Habermas and Keen find so disconcerting? And if so, can it be understood as a deepening of the genuine public sphere rather than its nemesis? These issues are brought out very sharply in the case of expert knowledge, and it would seem that here there is a strong case against the blogosphere and web democracy. In several instances, scientifically defective beliefs have been spread by these means. One example is close to the case considered here: the conviction by many mothers that their child developed autism as a result of mercury preservatives used in vaccination.

Habermas directly addresses these issues in a recent discussion. For him the web is a public sphere, but arguably it is a defective one, in which the pseudo-democracy of equal access to the means of disseminating one's opinions leads to a degenerate form of discourse, exemplified by the lack of respect for genuine expertise.

> Use of the Internet has both broadened and fragmented the contexts of communication. This is why the Internet can have a subversive effect on intellectual life in authoritarian regimes. But at the same time, the less formal, horizontal cross-linking of communication channels weakens the achievements of traditional media. This focuses the attention of an anonymous and dispersed public on select topics and information, allowing citizens to concentrate on the same critically filtered issues and journalistic pieces at any given time. The price we pay for the growth in egalitarianism

> offered by the Internet is the decentralised access to unedited stories. In this medium, contributions by intellectuals lose their power to create a focus (Habermas, 2006).

This line of argument is deeply rooted in Habermas's own thought: it is an extension of the arguments he made in *Structural Transformation of the Public Sphere* (1991 [1962]).

Structural Transformation was written against the backdrop of an important public event, the German elections of 1958. Habermas was attempting, in part, to explain the failure of the Left candidate. His explanation of this failure (Habermas, 1991 [1962]) derived from the famous study of *Personal Influence* by Paul Lazarsfeld and his collaborators (Katz and Lazarsfeld, 2006 [1955]; Lang and Lang, 2006). Lazarsfeld's basic insight was that people got their political opinions not from the media, as was commonly believed, but from their personal friends, especially certain local respectable people. Habermas regarded this kind of influence as a bad thing: 'those who engage in discussion more frequently . . . have a tendency to do no more than mutually confirm their ideas and at best to influence only the hesitant and less involved parties' (1991 [1962]: 213). This kind of private discussion undermined the possibility of a genuine public sphere and substituted the false public of misinformed opinion. Personal influence thus became a kind of filter, which curtailed the influence of the genuine public sphere and filtered its messages in a distorted manner.

The issue of the public has its own literature. So does the problem of expertise (Selinger, 2011; Selinger and Crease, 2006). The case for deference to expertise is strong: experts speak 'as' experts of a particular kind within the limitations of accepted knowledge in their group, and derive their authority from the fact that they are under the discipline of that group. In short, they are constrained. Journalists, for example, speak authoritatively in newspapers, which are concerned for their reputation. Their role is to translate the statements of experts into authoritative statements for the public. Walter Lippman then, Andrew Keen (2008) and Michael Schudson (2006) now, argue that deference to experts is not only healthy but necessary for democracy. Lippman put these issues clearly: It is an 'intolerable and unworkable fiction that each of us must acquire a competent opinion about public affairs' (1922: 18–19). He argued instead for 'intelligence bureaus', which can tell people that relevant issues have been considered. He accepted the implications of this for democracy. 'The common interests very largely elude public opinion entirely, and can be managed only by a specialized class' (Lippman, 1922: 310).

Recent discussions of climate change are even more explicit in their hostility to the reasoning capacities of the general public and even in asserting that curtailing or ignoring public opinion and democratic discussion – even eliminating liberal democracy – is necessary to save the planet: According to David Shearman in Australia *On Line Opinion*,

> The Chinese decision on shopping bags is authoritarian and contrasts with the voluntary non-effective solutions put forward in most Western democracies. We are going to have to look at how authoritarian decisions based on consensus science can

> be implemented to contain greenhouse emissions. If we do not act urgently we may find we have chosen total liberty rather than life. (Shearman, 2008)

Another commentator puts it as a proposal:

> Resolved: That liberal democracy, as a system, is incapable of dealing with the crisis of climate change and ought therefore to be abandoned in favor of an authoritarian regime guided by the consensus of scientists. (McHenry, 2008)

Issues over expertise rarely reach this level of extremism. The fact that they can, however, indicates something important about the relation between expertise and moderation: that expertise is not invariably associated with moderation, and that, indeed, political moderation as a practice or strategy may be in routine conflict with claims of expert authority.

A case: hysterectomy with oophorectomy

Many blogosphere discussions are short-lived and deal with immediate events. In this chapter I will deal with a far richer case, the subject of not only an extensive medical literature, a large body of web-based public education by health-care providers, and a well-developed web page critical of this information, but a large number of webpages that purport merely to provide forums for discussion. The case involves a particular problem of expert authority: medical authority in relation to hysterectomy, especially when combined with oophorectomy, the removal of the ovaries. The core issues with the blogosphere are brought out very sharply in the case of expert medical knowledge. It would seem that here there is a strong case against the blogosphere and web democracy. The case of hysterectomy and oophorectomy, however, points in a different direction: to the value of the blogosphere as a corrective to problematic expert opinion.

Hysterectomies are one of the most common operations for women – 22 million have been done in the US; 454,000 a year. It is the second most commonly performed non-obstetrical surgery in the US, after cataract surgery, and the economic mainstay of gynaecology as a specialty. The numbers are similar in the UK and Europe, with some variation, mostly in the direction of fewer operations. Up to 40,000 hysterectomy operations are carried out by the NHS on women in the UK every year and up to 75,000 in the UK as a whole. This figure means that one in five women in the US and Europe will have a hysterectomy at some point in their life. It is what is termed 'elective surgery'; this means that in most cases it is a choice rather than an emergency procedure. It is rarely performed for reasons of saving life, although there are a number of instances where it might be necessary for this reason.

Despite the ubiquity of the operation, there are major conflicts between 'experts' and the public over the effects of hysterectomy, especially on sexuality. The differences are stark. This is a statement from a website of a prominent British gynaecologist, John Studd: .

> It is often claimed that women have a loss of libido after hysterectomy but this should not occur even if the ovaries are removed if proper HRT is given. This is contrary to the message given in every women's journal in articles about hysterectomy which always indicate that the operation causes depression, loss of sexuality, marital disharmony and so on when the reality is that *every single randomised scientific trial has shown that hysterectomy with appropriate HRT is associated with less anxiety, less depression, better sexuality and better general health scores.* It is very odd that journalists continue to produce this fashionable but increasingly dishonest message about hysterectomy. (Studd, 2008a, emphasis added)

He admits that there are serious consequences of oophorectomy, the removal of ovaries, which is commonly done as a preventative measure to avoid ovarian cancer, a difficult to detect and much feared cancer. But he insists that these consequences can be compensated for by hormone replacement strategy:

> Ovarian deficiency following oophorectomy will, of course, produce the predictable menopausal symptoms and the loss of ovarian androgens will produce the Female Androgen Deficiency Syndrome (FADS) of loss of libido, loss of energy, depression, loss of concentration, and even headaches. This occurs frequently after hysterectomy without the adequate and appropriate hormone replacement therapy but it is unknown how often it occurs in normal, middle-aged women who have not had a hysterectomy or oophorectomy. It is probably quite common but is ignored by most doctors who prescribe HRT and virtually all psychologists and psychiatrists who are not familiar with the use of hormones. (Studd, 2005)

Studd goes on to claim that 'Many women say that when oestrogen therapy stops their depression, their loss of libido and their irritability, they become nicer people for their partners to live with. The depression, grumpiness and loss of energy can usually be improved considerably by the appropriate doses of the appropriate hormones. This may be testosterone as well as oestrogen' (Studd, 2009).

A standard information website seems to confirm Studd, but makes the concessions clearer:

> Oophorectomy very rarely impacts sexuality in women . . . it does not greatly reduce or eliminate the ability to have an orgasm, however occasionally there is a lowering of sexual desire. This reduction is greater than that seen in women undergoing natural menopause. Some of these problems can be addressed by taking hormone replacement. Increased testosterone levels in women are associated with a greater sense of sexual desire, and oophorectomy greatly reduces testosterone levels. Reduction in sexual well-being was reported in women who had been given a hysterectomy with both ovaries removed. (Psychology Wiki n.d.)

The phrases 'probably quite common', 'unknown how often it occurs', 'virtually all', are revealing. The statement also ignores the fact that HRT studies are strongly influenced by selection bias: the fact that a large proportion of the women who start the therapy drop it. The concession is this: oophorectomy, by greatly reducing the production of testosterone, reduces desire.[1]

Commentary on the blogs tells a different story, mixed, but with a vast preponderance of reports consistent with the concession. One informational

website, operated by the HERS Foundation (www.hersfoundation.com), is a source of anti-hysterectomy information and criticism of conventional expert sources, a data collection system, advocacy of informed consent (including presenting a video that explains the operation), and a forum for the reporting of individual experiences. The site has collected data since 1991, long before the topic was systematically researched in the medical literature. The data, all based on voluntary reporting and with no sampling, are far more extensive in terms of listing outcomes than any other research. The data show a 60–80 per cent major failure rate in every area of sexuality, personality, and so forth, with high rates of anxiety, suicidal feelings, and other psychological and cognitive symptoms. The foundation reports that 98 per cent of the women referred to them decide, once given appropriate counselling and information, that hysterectomy was not necessary. The site reports also that few women who have seen the informed consent video made available on the site go on to have the surgery.

A typical item on the webpage is a critique of the information on the website of a major medical centre, at the University of Pittsburgh. The critique takes the form of a paragraph by paragraph correction of the expert website:

> In the section 'Emotional effects' UPMC states, 'A woman's sexuality and femininity are not changed by a hysterectomy. During the recovery period from surgery, anxiety, fatigue, and fear of pain can cause a lack of sexual desire. Allowing time to heal and recover, sharing your feelings with your partner, and using a gentle approach can help you achieve sexual pleasure'.
>
> HERS comment: A sex organ can't be removed without altering sexuality and femininity. As we have said and is well-documented in medical literature, when the uterus is removed uterine orgasm can't occur. The vagina is shortened, sutured shut at the top, and women develop adhesions that are often very painful. This scarring, shortening, and loss of elasticity in the vagina often makes sex extremely painful during intercourse. Furthermore, the nerves that attach to the uterus branch out to the vagina and external genitalia. Those nerves must be severed to remove the uterus. When they're severed it causes not only a loss of physical sexual sensation, but it also often causes pain in the buttocks, groin, pelvis, and vagina. Severing of the ligaments affects skeletal structure, commonly causing pain in the lower back and hips. 'Sharing your feelings with your partner' and 'using a gentle approach' won't replace the functions of the nerves, ligaments, blood supply, or sex organs. Nor will they stop the painful aftermath of hysterectomy. Lack of sexual desire is to be expected when a sex organ is removed. (HERS, 2008a)

Much of the blog is devoted to individual comments.

Another site, called HysterSisters, produces similar testimony. Reports of lack of desire are overwhelmingly common:

> I am so saddened since my surgery I have had no sexual desire whatsoever. Where my husband and I used to be intimate more than 3–4 times a week. It has now been over a year. What has replaced it is depression, anxiety, arguments (not about sex) and my marriage is on the verge of divorce. I miss intimacy, I miss the wonderful sex I use to enjoy so very much ... Any ideas, supplements, anything????? (HysterSisters, LadyElaine, 9 March 2010)

> Hi, I sure know what you're talking about ... it's been years since I was even interested. My hubby is great but really misses me ... I miss having and feeling sexual feelings/thoughts. Sometimes I think having that hysterectomy was the worst thing I ever did. I almost wish I was still suffering that awful pain at least I was still myself ... (HysterSisters, Lrg Dog, 23 March 2010)
>
> I just started a new post about this as well! I too wish I had not had the surgery. What a shame it has been for my husband and myself to have lost the ability to communicate sexual. I have been keeping very active so as to keep depression from my door, but must admit, I feel like only a shell of what I had been. I guess the loss was more than body parts, and truly wish someone had advised of this before surgery. (HysterSisters, Newmember 2010, 30 August 2010)

These are the predominant messages on the blogs. But as with the physicians, there are mixed messages. One can also find testimony like this:

> For me, having a hysterectomy was one of the best things that could have happened. Before it happened, I was in so much pain, I couldn't have sex or do much of anything. Once the surgery was done and I was healed felt much better. I am taking hormone replacement. Now, I want sex all the time. My orgasms are more frequent. The overall pleasure of sex is remarkable. I actually feel sorry for the woman who have decided to not have any more sex or not have hormone replacement. This is one of the most wonderful times for me for sex. (Dragonteach, Experience Project 2012)

And this:

> Before I married my first husband and for a time after our sex life was fantastic until I was diagnosed with endometriosis and went into the hospital for a laparoscopy. I was still in pain a couple mos after the surgery so my physician put me on a drug that made me go through a temporary menopause while I was on it. We hardly ever had sex while i was on it, for about 5 mos. The pattern continued after i went off it. My physician kept telling me it was all in my head. I could not raise those emotions anymore even though I no longer had pain during sex. Little nitpicky things my husband would do would drive me up the wall, like something your brother would do. I felt sexually dead as a door nail inside towards him. This went on for years. I wanted my desire to return as bad as my husband did. ... I switched physicians but the stress from the sex problems eventually led to a divorce. This man had been the love of my life. After a lot of tears and feeling sorry for myself with thoughts that i would never have those feelings ever again because my sex life had been cruelly taken away from me I picked myself up and started dating. I'm happily married 11 years. We have an active and super satisfying sex life. I came to a sad realization. My loss of desire for my first husband is from the experiences i had with him while I had the endometriosis. Those experiences not only included painful intercourse but also included what I saw as insensitivity on my husband's part. He argued with me about it, was disrespectful and demanding (in my eyes). I lost my desire to share myself intimately with him. My stomach turned at the thought. I didn't feel the emotional connection with him i once felt. He became a friend not a lover where before he had been both. I know if I hadn't been so afraid of being told it's all in my head we could have worked through the problem. It seems so small now. I'm one of the lucky ones who found love again. (His & Her Health, Kkatherine, #1299)

The methodological issues here should be familiar to sociologists: the statistical problem of 'confounding' of multiple causes, which appears routinely in relation to causal models, is endemic to the personal experience of contributors to the blogs, as well as to the research literature. Other symptoms and medical issues invariably accompany the personal experience of oophorectomy or hysterectomy that could conceivably be the cause of the outcome, and the outcomes themselves are so diverse that each of them could have causes other than the procedure.

What is truth? Two collective heuristics

The case is a classic example of the conflict raised by Habermas between democratic knowledge distribution and expertise. But it contains a few more elements. The HERS Foundation, for example, is a case of what I have elsewhere called a commission from below: a counter-expertise organization, which in this case works to facilitate the blogosphere (Turner, 2003). But one of the most striking additional elements is the detail and complexity of the opponents' beliefs about one another, and the explanations they give about the errors of the other side. Beliefs about the interests of the other side are a basic part of political discussion in liberal democracy. But expert-public conflicts typically involve much more elaborate explanations of the reasons for the errors of opponents. In this case these considerations are mixed with a number of other kinds of issues, including methodological considerations, beliefs about the sources of the beliefs of the others, and beliefs about the experiences that motivate the others.

We can think of people, knowers and practitioners, such as physicians, or consumers, such as patients, as going through learning and decision-making processes utilizing heuristics, of which they are not conscious or only partly conscious. When these individuals work together, to make decisions, for example, about what normal practice requires, or simply to share information, they produce something like a collective result. If it involves a formal, explicit method, such as voting, we can see that the method itself is a kind of heuristic. And we can see that it has its own cognitive biases, deriving both from the cognitive biases of the participants and of the socially structured process they are part of. Experts are trained in ways that both involve what are essentially heuristics for assessing and processing information, and for decision-making. When they act collectively, formally or informally by such means as sharing information, the result is the product of this double heuristic: the individual ones and the collectively organized one that relies on the individuals employing their heuristics. To put this in somewhat more general terms, the issue is this: we all depend on others for what we know, other than for the most simple forms of knowledge. The relations we have with our sources of knowledge, the others on which we depend, are structured in various ways, some explicit but mostly hidden. We can become aware of the limitations of the sources of knowledge on which we depend, but this is not easy to do. We can, however, recognize that

particular ways we come to know have biases, or are prone to particular kinds of knowledge failure or knowledge risk.[2]

It makes sense to characterize groups, such as physicians, in terms of the individual and collective biases they have, and to contrast these with the cognitive biases of others, and the biases introduced by collective devices, such as the information sharing devices of the blogosphere. Science has its own much-discussed biases. Kuhn's *Structure of Scientific Revolutions* (1996) was a discussion of the way science was biased against new information, which was anomalous, and the way that scientists processed new information of this kind. Ulrich Beck, similarly, charged scientists with a reluctance to recognize risks (1992). These are examples of attempts to characterize the heuristics by which opinion is formed.

Although people do not explicitly theorize the problem in this way, there is a kind of folk sociology of knowledge that people think in terms of that makes similar distinctions. They think of professions, such as medicine, as having certain cognitive biases, and of the individuals in the profession as having biases as well. Medical science and clinical medical practice, for example, each have their own cognitive biases.

In the case of the conflict between oophorectomy and hysterectomy promoting medical practitioners and aggrieved patients, we have a large body of comment that involves images of the biases of the other side. These are especially well developed on the side of the experts, and for good reason: they need to explain away a vast body of reported experiences. The first problem for the experts is the fact that there are complaints at all. Explanations for the complaints routinely appear in the websites of proponents. The two most common explanations include these: that the patient simply failed to get adequate hormone treatment; that the effects of hysterectomy and the effects of ageing come at the same time, so that women confuse the two experientially.

Another frequent comment concerns sampling bias. Physicians comment that the reason someone is posting on a blog is that they experienced a negative outcome, and note that the patient with a successful outcome has no motivation to post on a blog. This implies that the silent patients are representative and the ones who speak out are not. The issue of sampling and self-reporting bias is critical for the HERS database: it is impossible to know whether this database is made up largely of women who have been persuaded to blame their medical problems on their hysterectomy. Questions of causality, in short, are not answered by self-reporting of causal beliefs based on personal experience, but require a more substantial kind of evidence. Here are two American physicians, Deborah Dotters and Audrey Garrett, addressing prospective patients on a website:

> No matter what you have read or found on the internet, or heard from your friends – what follows are the facts for the vast, vast majority of women. All the women who had a hysterectomy and are so happy with their results do not make websites, write books or talk about their surgery, so the internet and books are not a reliable source for most outcomes. (Dotters and Garrett, n.d.: 2)

Dotters and Garrett respond to the suspicion that the promotion of this surgery is rooted in self-interest or mindless deference to traditional medical practice by describing a fellow physician:

> Consider this: Kate O'Hanlan is a radical feminist, humanist, and question-authority type gal who would never do this procedure for women if it did not routinely cause benefit in their lives. She won't operate on you if you don't stand to benefit with a strong statistically significantly proven likelihood. (Dotters and Garrett, n.d.: 2)

Such statements are self-consciously concerned with the refutation of what was 'read or found on the internet, or heard from . . . friends'. And they have a clear picture of what needs to be refuted, both in terms of reported experiences, suspicions about conflicts of interest and about mindless medical traditionalism.

These perceptions are accurate. As HERS comments: 'hysterectomy is the goldmine of gynecology'. Moreover, the procedure is a major part of medical expense, and restricting it would substantially reduce physicians' incomes. As the HERS site explains:

> Approximately 29% of medical expenditures are surgery-related, and hysterectomy is the most commonly performed non-obstetric surgery performed in the U.S. Hysterectomy represents more than $17B a year to the medical industry. If hysterectomies that are not life saving cease to be performed, hospitals and gynecologists will no longer benefit from more than half a million medically unwarranted hysterectomies performed each year. (HERS, 2008b)

The contributors to the HERS website have other reasons to distrust physicians, rooted in experience. These reasons often relate specifically to assertions about the lack of consequences of the surgery for sexuality, which is the subject of a large proportion of the blog posts.

Physicians are well aware of these concerns, and of the web material in support of it, and respond to it. O'Hanlan exemplifies the practice of denying that problems were the result of the surgery. She denies any effect on sexuality:

> Many women complain of low libido. This can be for lots of reasons: too hectic a schedule, tension between partners, tiredness from child rearing or work, depression, poor physical fitness, low estrogen in the menopause, or because they are tired of having sex that was never really very rewarding to them before. The remedy for the first three causes is to fix your schedule and keep your relationship in good repair, perhaps with counseling for either or both of you. Hormones are addressed below and extensively in other sections of the website (O'Hanlan, n.d.)

Dotters and Garrett echo this:

> Hysterectomy does NOT ruin your sex life. Orgasms will be the same. Lubrication will be the same. Your libido will not change. But be aware that these things do change as you age, and particularly as a function of your hormone status. But a hysterectomy is 5 inches away from any of the nerves of orgasm, and will not ruin any sexual function. Neither will removal of the cervix with the uterus. If you know someone who claims her sexual function was worse after hysterectomy, suggest that she see another gynecologist to make sure that she is hormonally well tuned and medically well-tuned (thyroid and hormones and other things checked). (Dotters and Garrett, n.d.: 2)

They write about ageing in this way:

> B. Hysterectomy will NOT result in your aging faster.
>
> Neither will removal of the ovaries. If you are under or around age 50, you will probably want to take hormones for a short while to mimic your natural gradual transition into menopause. But remember that no matter what, you will continue to age! (That's a good thing.) And about 90% of women find they do not need hormones to feel like their normal selves after their early fifties, even though most take hormones for until then. The menopausal symptoms simply go away for most, so the hormones are no longer needed. The hormones would not and could not prevent aging, wrinkles or arthritis. (Dotters and Garrett, n.d.: 3)

The message is that the effects are benign, and mimic those of menopause; similarly for sexual effects.

Paul Indman presented a similar message, also responding to what he takes to be the widespread defamation of the surgery:

> What women tell me after hysterectomy: The most frequent response to the question of how sex and orgasm are a year after hysterectomy is a laugh and a big smile. Most women tell me that there is no change in the way they feel orgasm, and they are able to enjoy sex more since they don't have their original problem to interfere with sex. Many others report no change. Some women tell me orgasm is better and more intense after their hysterectomy (don't ask my why). A small number of women tell me they have less interest in sex, but rarely do they consider this a problem. I have heard once that orgasm was different than before. Not 'bad', just different. And some women who had sexual dysfunctions before hysterectomy had sexual dysfunctions after hysterectomy. (Indman, 2011)

It should be noted that other sources are more guarded. A standard information website makes similar claims, but with qualifications:

> Oophorectomy very rarely impacts sexuality in women, it does not greatly reduce or eliminate the ability to have an orgasm, however occasionally there is a lowering of sexual desire. This reduction is greater than that seen in women undergoing natural menopause. Some of these problems can be addressed by taking hormone replacement. Increased testosterone levels in women are associated with a greater sense of sexual desire, and oophorectomy greatly reduces testosterone levels. Reduction in sexual well-being was reported in women who had been given a hysterectomy with both ovaries removed. (AskDefine, n.d.)

Not only these claims, but the manner in which physicians acquire and treat the kind of evidence they use, such as Studd's references to his happy patients, is challenged by the blog writers. They have their own explanation of physicians' denials of the effects of the surgery, and report experiences with denial. But blog contributors also have a counter-theory, which explains why women do not complain more. The testimonies often refer to the way in which reporting of symptoms is repressed or ignored.

On 16 December 2010, 'UK lady' wrote:

> No-one warned me that I would totally lose my libido a few months after surgery and as it dawned on me I thought my heart would break. The doctors were so dismissive too. As far as they were concerned it didn't matter whether or not I had a sex drive – they had cured the cancer. (Forum.Idpub.com, 2010)

At 1.54 pm on 27 June 2010, 'Anonymous CT' said:

> My experience has been that many women are embarrassed to speak out about it. After all, a gynecologist has amputated their female sex organs and usually castrated them at the same time. Most women do not want the whole world to know they are less than whole and that their sexuality and health has been taken away from them. Why did it take the rape victims of priests or child abuse victims decades to speak out? (HERS, 2010)

At 2.08 pm on 27 June 2010, 'Anonymous Cindy' said:

> Kat, when I went back to my doctor after he hysterectomized and castrated me and told him about all the problems I was having, he told me I was just a big baby and none of my problems were caused from the surgery. If it wasn't for the HERS Foundation telling the truth about the damage this surgery does, all women would still be in the dark. (HERS, 2010)

There are also systematic issues noted by the patients in the way in which physicians perceive them and their sexuality.

Although there are measures of sexual function based on self-reported symptoms, the problems of interpreting female desire as an experience are such that these measures do not work well. The gap between experience and measures of sexual functioning is illustrated by a discussion that took place in the US over the drug Intrinsa, designed for women who have had their ovaries removed, which came in a patch. A panel of advisors for the Food and Drug Administration advisory panel concluded said preliminary research only suggested modest benefits.

> Procter & Gamble had submitted the results of two studies involving almost 1,100 women who had had their ovaries and uteri removed for medical reasons. One study found that, compared to women on placebo, women using Intrinsa experienced a 56 percent rise in sexual desire and a 74 percent rise in satisfying sexual encounters – working out to about one additional sexual episode per woman per month. (HealthDayNews, n.d.)

Members of the panel were quoted as saying 'So it's one event per month'. 'That's not insignificant, but to me it's outweighed by the worries I have about the dangers of long-term testosterone'. The blog response included this: 'I've read some of the comments the FDA reps made. What a bunch of insensitive jerks. I am anorgasmic. Even one a month would be nice' (HealthDayNews, n.d.).

Experts on experts: explaining expertise failure

Hysterectomy proponents on the web routinely assert that the practice is based on an overwhelming body of valid research, which should be treated as 'the facts' in contrast to 'the stories you may have heard or read':

> In medicine, we report patients' opinions and their experiences by analyzing hundreds of questionnaires and publishing the results so that you know what the probable results of your surgery will be and are not misinformed or biased by the individual stories that you have heard or read. In addition, the stories that you have heard or read may have had multiple other factors that were not accounted for, such as whether or not the ovaries were removed, and if so, was hormone therapy prescribed afterward? In the correct dose? Why was the hysterectomy done in the first place? Was it necessary? Was there a cancer? Was radiation given after the surgery? Were there adhesions? Was there an infection? Was there endometriosis? All of these factors can impact a woman's postoperative comfort and sexual function. (Advanced OBGYN Associates, n.d.: 4)

Studd, as noted, claims that '*every single randomised scientific trial has shown that hysterectomy with appropriate HRT is associated with less anxiety, less depression, better sexuality and better general health scores*' (2008a, emphasis added).

It should be noted that there are general issues over the validity of medical research that apply in this case: selective publication, conflicts of interest when the research is conducted by physicians whose income is derived from the surgery, small sample sizes and inadequate controls. Patients are likely to be aware in general of the existence of the issues, if not the details. The mere fact that conflicting research findings routinely appear would be sufficient grounds for scepticism (cf. Freedman, 2010, 2011; Ioannidis, 2005, 2010; Young *et al.*, 2008).

In the case of hysterectomy with oophorectomy, the research itself presents a mixed and confusing picture. Early research focused on immediate (within 24 month) outcomes. Typically this research reported improvements in sex lives, mostly as a result of less pain, and sometimes presented some odd findings suggesting increased libido. These studies are still quoted by advocates, as in this website:

> From so very many studies, including this 1999 study of 1,299 Maryland women undergoing hysterectomy [Rhodes *et al.*, 1999], the overwhelming evidence is that women thrive sexually and emotionally after hysterectomy when the hormones are tuned and cancer therapy is not needed. In the Baltimore study, most women had sex more often, and more regularly after their surgery. 71% had resolution of their previously lowish libido, while 4.3% reported a new problem with low libido after the surgery. 84% had resolution of pain during intercourse, while 2.3% developed a new pain during intercourse. 65% of women who had few or no orgasms before surgery noted improved orgasmic ease and frequency afterwards, while 2.6% developed a new

problem with orgasm frequency. After hysterectomy, more women had stronger orgasm, and fewer women were sexually inactive. (Advanced OBGYN Associates, n.d.: 4)

Long-term studies based on retrospective reporting were more consistent, and connected hysterectomy with loss of libido. Pro-hysterectomy experts typically dismissed these as a product of memory bias or confounding with effects of ageing. Blog commentary was consistent with the long-term research. There are many reports of enhanced sex drive after hysterectomy, within the first two years or so. Claims about long-term 'solutions' or satisfactory sex lives including orgasm, however, are very rare. The HERS data showed loss of sexual desire in 79.7 per cent of respondents (www.hersfoundation.org/effects.html) There are some strong testimonials to testosterone therapy. But there are many acknowledgments of medical issues that seem connected to the operation.

Nevertheless, the totality of the material in these sources is not entirely inconsistent, and it is possible to perform a rough meta-analysis that removes some of the conflicts, and is suggestive about the cognitive biases of practitioners who appeal to research to justify their practices. Here is an abstract of a recent meta-analysis:

> There is a growing body of evidence suggesting that the premature loss of ovarian function caused by bilateral oophorectomy performed before natural menopause is associated with several negative outcomes. In particular, studies have revealed an increased risk of premature death, cardiovascular disease, cognitive impairment or dementia, parkinsonism, osteoporosis and bone fractures, decline in psychological well-being, and decline in sexual function. The effects involve different organs (eg., heart, bone, or brain), and different functions within organs (eg., cognitive, motor, or emotional brain functions). Estrogen treatment may prevent some of these negative outcomes, but not all. (Shuster *et al.*, 2008)

This analysis was based on part on long-term retrospective studies with the same kind of material as the HERS data, but done by the Mayo Clinic. The basic result was that the surgery produced decreased risk of ovarian cancer, breast cancer, and increased risk of all-cause mortality, cardiovascular disease, stroke, lung cancer, cognitive impairment, parkinsonism, osteoporosis and fractures, psychiatric symptoms, impaired sexual function (Shuster *et al.*, 2008).

Balancing risks and benefits is not difficult. Premature death is a strong indicator of general health. Here the evidence is strong. 'Oophorectomy increased the risk of death from all causes (HR, 1.12; 95% CI, 1.03–1.21)' (Shuster *et al.*, 2010), and there was not a significant difference in risk by age at the time of oophorectomy. One of the major arguments for oophorectomy is that removing the ovaries eliminates the risk of ovarian cancer. But it is a relatively rare cancer, and the lifetime risk of dying of invasive ovarian cancer is about 1 in 95 in the US (Ovarian Cancer Alliance, 2012). The risk of premature death from oophorectomy, in contrast, is 1 in 24 (Parker *et al.*, 2009, quoted in Shuster *et al.*, 2010).

Hormone therapy, often taken to be the solution to the negative effects of oophorectomy, has been subject to a similar reversal based on long-term studies. A task force for the US National Institutes of Health analysed these, with the following results:

> A study released earlier this month suggested that hormone therapy started soon after menopause can ease depression, anxiety and hot flashes without raising risks for cardiovascular disease. But the study was seen as supporting short-term hormone use, not long-term use.
>
> In the new study, the task force, convened by the U.S. Agency for Healthcare Research and Quality, found that estrogen and progestin therapy is of 'moderate benefit' in reducing the risk of fractures and can create a 'small reduction' in risk of invasive breast cancer. But it found this plus was outweighed by 'moderate harms' such as an increase of risk for stroke, dementia, gall bladder disease and urinary incontinence, and a small increase in the risk for deep-vein blood clots.
>
> 'There are pluses and there are minuses to this therapy', said Michael LeFevre, vice chairman of the task force and a professor at University of Missouri School of Medicine. 'For an asymptomatic woman, the benefits do not outweigh the harms'. (Burton, 2012)

Both results are revealing with respect to expert bias. The experts were wrong in many ways, and their errors were errors of omission closely associated with these biases. They failed to deal with the long-term effects of oophorectomy because they did not observe it clinically, and perhaps as a consequence, and as a consequence of the difficulty of long-term prospective studies, did not research it. Randomized trials, because of their short duration, would not detect the long-term consequences of oophorectomy, which greatly exceed the levels of normal menopause. The reliance on these problematic studies is an example of confirmation bias. And the fact that the knowledge of these increased risks has had little impact on practice fits with other suspicions about the biases of practitioners: their conservatism and reliance on traditional means and biases resulting from their self-interest.

Conclusion

Habermas (2006), in the paragraph quoted earlier, takes a particular view of the problem of democratic speech, in which 'wild' or unorganized speech is to be distrusted. His means of 'improving' democratic discourse is returning it to the *status quo ante* the web, in which journalists and intellectuals lectured the public as acknowledged authorities. Experts acquire their information and aggregate it in their own ways, and then present the results to the public. The construction of expert opinion is itself not some sort of sanitized procedure which generates truth. It is simply a different procedure of aggregating information and selecting opinion, with its own cognitive biases. And this method can be corrected, and moderated, by free discussion in which the biases and

interests of the participants, including the experts, are open subjects. Open discussion has its own cognitive biases. But to reject the kinds of information that appear in the unsanitized discussion found in the blogosphere is to reject a potential corrective to expert error.

It is striking that so much of the blog commentary is reflexive, and concerned with the subject of cognitive bias. The experts complain about the biases of testimony (especially claiming that satisfied patients don't write on blogs) and of journalists. The patients and the counter-expert groups complain about conflicts of interest, refusals to discuss or consider the experiences of the patients, and the arrogance of physicians and the imperviousness of medical practice to evidence. The physicians complain that the complainers are not representative, or are not being given adequate therapy. But the very fact that the two sides respond to one another means that one cannot read these websites and blogs without recognizing that there are serious issues with the procedure.

The blogosphere, in this case, was not the empire of idiocy imagined by Keen and Habermas. It was, instead, a source of moderation. And one can see why this would normally be the case in the face of problematic expert knowledge. The biases of experts and process of expert opinion formation are directional: they tend toward the formation of consensus. In blogosphere there are fewer institutional pressures to conform. People comment in order to disagree or to add something, and very often the information they add is based on personal experience that is its own kind of evidence. The blogosphere is not always right. Like other means of aggregating information, it has its own biases. But it is a means of challenging and moderating expert opinion by getting different information, and using different collective heuristics to process it.

Notes

1 It should be noted that there are also many reports of women being told privately by physicians, contrary to these pubic statements, that loss of sexual desire and function is normal. One patient reports that 'Doctors say it is normal after this type of surgery (I had my cervix, ovaries and a hysterectomy performed) that I have no sexual desire' (HysterSisters, LadyElaine, 9 March 2010).

2 For a more detailed explanation of the ideas of double heuristics and knowledge risk, see Turner (2014).

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