
OUTLINES - CRITICAL PRACTICE STUDIES

• Vol. 15, No. 1 • 2014 • (49-62) •
<http://www.outlines.dk>

Is Evidence-based medicine about democratizing medical practice?

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Abstract

The authoritarian standpoint in medicine has been under challenge by various groups and researchers since the 1980s. The challenges have been ethical, political and medical, with patient movements at the forefront. Over the past decade, however, a deep challenge has been posed by evidence-based medicine (EBM), which has challenged the entire strategy of medical treatment from the point of view of a self-critical, anti-authoritarian and hereby also (it has been claimed) a more democratic medical practice. Previously, the challenges arose out of the patient rights perspective. EBM, by contrast, was taken to challenge the way doctors consider their medical practice as a whole. The present paper puts this claim of democratization into a historical context. Two dimensions of the democratization hypothesis are discussed and it is argued that they are insufficient to capture the substantial changes going on in the intersection between medical practice, biomedical science and citizens.

Introduction

Evidence-based medicine (EBM) has become a much lauded and influential model in decision-making in clinic practice (and, more generally, in health care policy). It is founded on the theory that we now have the research skills, communication tools and training to make sure that health care practitioners, in their clinical practice, can be optimally informed by state of the art research in therapies.

This development is not just of interest from the technical medical perspective, however, but registers as well as a social practice – in as much as it has been presented as a way of creating radical historical change in the status of the health care professions, with repercussions in the entire interface between society and its healers. Studied this way the texts written by the main figures in the EBM movement can be read as articulations of thoughts and ideas about not only how to elevate the level of treatment, but also of how to think about medicine as a social practice ought to develop. They argue that besides improving clinical practice the new EBM paradigm will change the power relation by

challenging the old practice of investing the doctor with an unchallengeable authority, based on the qualities of his experience, and that this will promote democratic ends.

In this article I will explore the historical development of EBM with a specific focus on the conceptualization of authority and democratization. In the final section of the paper the idea that science promotes democratic ends in medicine is discussed. I argue that in some cases in current biomedical science, non-scientists demand a democratization that goes deeper than access and use of the results from scientific research but even touches on the way those results are generated in the practice of science. This leaves us with a changing relation between biomedicine, science and citizens, making it difficult to answer when and where democratization is relevant in the intersection between scientific research and clinical practice. As the demand for democratization goes deeper, the idea that a more science-based medicine will promote democratic ends seems to be subverted by its own logic.

Introduction to evidence-based medicine

A landmark in the EBM movement is the group known as the Cochrane Collaboration, which first published a two volume study, “Effective Care in Pregnancy in Childbirth” in 1989. The contributors were asked to base their therapeutic choices on the latest information using randomized controlled tests. In a gesture to make this information even more transparent and available to the non-medical community, a guide was prepared from the book (Daly 2005, p.163). The Cochrane collaboration gathered significant figures such as Iain Chalmers and David Sackett, who had advocated developing best evidence principles as a standard protocol in improving decision-making in clinical practice. In spite of the expansion of scientific medicine – in fact precisely because that expansion is so vast – clinical knowledge often lags behind what is being discovered by state of the art research, which results in therapies that fail double blind test and are continued in use due to empirical or qualitative endorsements by doctors.

Great efforts have been put into developing clinical epidemiology and EBM through the creation and distribution of new and more sophisticated statistical tools; at the heart of the enterprise stands the randomized controlled trial (RCT), which should, according to EBM, decide the question of the effectiveness of therapies – or lack thereof. Equipped with these double blind tests, in which nobody doing the experiment or being experimented upon is supposed to know which is the control group and which the placebo, EBM claims to do away with the biases that constitute the conventional wisdom of doctors. Thus by continually improving our knowledge of therapies, in conjunction with our physiological knowledge, doctors or other trained health caregivers will have a scientific basis to prescribe this or that therapy. This of course does not mean certainty that the therapy will work. It means, instead, that the uncertainties inherent in the knowledge we have of any therapy will be acknowledged openly, and the probabilities associated with the results from tests and interventions will be presented in a clear and understandable manner. In this way, the justification of the choice of therapy will not just be based on personal opinion, experience or medical authority.

The EBM movement attempts to base public health issues and clinical decision-making on a more solid foundation. The evidence and knowledge on which decisions in clinical practice and health promotion are based must, from this point of view, be derived from scientific studies that use randomised controlled trials. The key point here is that the

improvement of the epistemological foundation of health care practices leads to the improvement of these practices.

The main proponents of the EBM movement, however, make even larger claims (sometimes explicitly, sometimes implicitly): they predict that making the knowledge foundation for different treatments, diagnostic tests etc. transparently referential to the current best research on therapies will bring about changes in the social context of medicine as well.

In 1983, one of the founding fathers of EBM, Iain Chalmers wrote the paper "Scientific Inquiry and Authoritarianism in Perinatal Care and Education" addressing the problem of authorities in childbirth education (Chalmers 1983), in which he suggested that EBM, with its openness to the uncertainty that governs scientific research projects and its demand for transparency, is inherently anti-authoritarian. More recently in 2002 David L. Sackett, another important figure in the EBM movement, wrote an article entitled "The arrogance of preventive medicine" (Sackett 2002), which accuses the medical 'experts' in preventive medicine of being aggressively assertive, presumptuous and overbearing when they "*go after the unsuspecting healthy*" often without basing their recommendations on "*the highest level of randomized evidence that our preventive manoeuvre will, in fact, do more good than harm*".

EBM thus harbours an ethical normative (Vos et al 2005) strategy that seeks to change the relationships between agents in health care practices. This agenda is not always clearly articulated, but must be extracted from the on-going denunciation of authority, arrogance, and the non-explicit and non-transparent character of (old) medical knowledge and medical practice. Those who are eager to present the ethical dimension argue that it will promote democratic ends because good science ultimately serves democratic ends (Chalmers 1983; Oakley 2000).

In order to understand this idea about medicine as too authoritarian and in need of reform it is useful to take a look at the era before EBM.

Golden age of medicine

From the middle of the nineteenth century on through the twentieth century, medical science, health care practices and the organisational and institutional structure of medicine underwent a transformation. New theories, treatments and technologies were developed. For example the search for specific microbiological disease entities ("germ theory") and the development of specific treatments to cure them. Paul Ehrlich's term 'the magic bullet' is characteristic of this kind of medicine (Brandt & Gardner 2000), with its confidence that finding the cause of disease can lead to the design of therapies that will palliate or cure the disease. Some of the important interventions in this kind of medicine are the array of antibiotics starting with streptomycin, which cured tuberculosis, then penicillin, new surgical techniques and new diagnostic technologies. It has become standard to speak of the period between the creation of the germ theory (or, for some, the invention of penicillin in the 1940s) up to the 1970s as the golden age of medicine (Brandt & Gardner 2000).

Hospitals became a central part of the health care structure during this period. The new kind of medicine required a different organisation for delivering treatment, one that could accommodate new technologies and treatments. This development seemed logical to

professionals, citizens and patients, who looked at the medical advances with awe, and resulted in an explosion of state and foundation funding for healthcare research and a new level of media attention to medical developments.

The status of the medical profession was legitimized by firstly, creating protocols for professional training and licensing, and secondly, by the profession's greatly increased power to cure, repair or palliate the suffering of the whole population. The trend of improvement was so constant that it seemed totally rational to think that even more effective and successful practices would come "on-line" in the future (Wartofsky 1985, Juul Jensen 2007). As a result of this success, both scientifically and in the forum of public opinion, paternalism and the granting of extensive authority to the doctor and to the medical profession became embedded in healthcare thinking as assumptions for any discussion of the medical system. It became an unstated premise that medicine concerned itself solely with the ideal of beneficence or 'doing good', thus validating the status, rights and routines of medical professionals. In turn, especially after Richard Doll used analytic epidemiologic methods to conclusively link smoking to lung cancer, professionals were turned to judge the habits of communities and community members, from sanitation to diet and recreation.

As this very brief sketch suggests, the development of medicine as a paternalistic or authoritarian practice is not simply based on the profession's use of its power over the patients and citizens, but is also intimately linked to the "progress" of medicine, i.e. that medicine is considered by medical professionals, governments and populations as being a practice that has successfully invented pharmaceuticals, treatments and procedures to cure disease and injury, palliate suffering and prevent death (Wartofsky 1985, Jensen 2007).

End of the golden age

The rough sketch of the golden age of medicine may be a bit of a historical caricature, but it serves the purpose of illustrating a widespread self-understanding of the medical profession (Le Fanu 1999).

However, beginning with the patient movements in the 1970s, this idea that medicine had found *the* road to progress and better health was challenged. Some have even questioned whether medical practice itself is self-evidentially beneficial. There are a number of reasons for this which, collectively have cast doubt on the professional self-image:

A. There has been a number of medical controversies and stories. For instance, it was revealed that inhuman experiments in medicine were not just the practice of the totalitarians like the Nazis, but were performed and countenanced as well by doctors in Western democracies. The Tuskegee-syphilis experiment stands out as an emblem of medical inhumanity. Over a period of decades a group of black people were purposely not treated for the disease in order to study its development, even though an effective, widespread treatment was available (Rothman 1991). Numerous other experiments could be mentioned.

B. A number of medical historians have raised doubts as to whether the improvement in overall life expectancy could be largely attributed to medical interventions and treatments, in comparison to the accumulation of improvements in nutrition and sanitation, among other well-known public health strategies (for example, Thomas McKeown 1976).

C. The ethnographic turn in cultural studies and qualitative social scientific research has turned up different meanings of health, illness, and disease, with the stress put on the existence of differences and even conflicts between doctors' and patients' understanding (for example by Eric Cassell 1991 and Arthur Kleinman 1988).

In the light of the complexity of healthcare issues, new theoretical disciplines like bioethics have emerged and found a foothold in standard operating practice in clinics as well as in universities. In bioethics, conflicting values and different ethical perspectives in relation to situations in health care problems are articulated, under the assumption that medical goods and beneficence are contestable artefacts and ideologies, and other ethical principles need to be taken into account as well - for example respect for autonomy (Beauchamp & Childress 2001).

D. The economic and political context within which the golden age occurred has irrevocably changed. The very success of medicine and the fascination with ever new technological fixes elevated the price of care considerably. New political and economic strategies then emerged in response to the rising expenses in medicine and health care practices. New methods are used to oversee health care institutions - for example the use of new public management (Hart 2006). In turn, all of these impinge on health care outcomes.

E. User groups, such as patient groups, were generated in the wake of civil rights movements, and employ a similar rhetoric and organizational strategy, with an emphasis on "making the voice of the patient heard" and "empowering the patient." This kind of pro-active stance was not seen in the era of the golden age (Epstein 1996).

None of this constellation of factors is mentioned in order to denigrate medicine or even to claim that it is not the central practice in the improvement of human health and in curing diseases; rather I am trying to illustrate how a completely different way of discussing and addressing medicine and other health care practices has emerged. The result is that medical methods, norms and purposes are now contested in a way that would be un-imaginable in an earlier era. It is this transformation in the social conditions of medical practice that makes possible the suggestion that democratisation should be understood in the context of medicine as a social practice.

EBM as anti-authoritarian and democratic medical practice

EBM is an attempt to make sure that health care practices are based on the best possible epistemological foundations, which implies that the clinician should be familiar with the latest research and also have the ability to analyze it with a high level of sophistication. However, EMB has a normative ethical/political dimension that seeks to redress some of the problems arising from the practices of the 'golden age'. Systematic use of randomized controlled trials and solid evidence generated outside of the clinic, and thus, less reliance on routinized clinical experience, will strip the doctor of his authoritarian persona, invigorating a more critical medical practice – or so say some advocates of EMB.

Among the pioneers of the EBM approach for example Archie Cochrane, have engaged in this anti-authoritarian polemic. So, importantly, has Thomas McKeown who we have previously referenced to for his remarks in *Effectiveness and Efficiency*. Cochrane argued in the early 1970's that several treatments, technologies and interventions used in the British National Health Care System (NHS) were based on unjustified optimism

concerning certain therapies and treatments. Iain Chalmers (the first leader of the Cochrane Collaboration) joined Cochrane in this critique.

In the work of Cochrane and Chalmers, the randomised controlled trial is elevated to a crucial role in generating more certain knowledge and evidence about diagnostic tests, treatments and other interventions. It is a tool that can be used to challenge those technologies and treatments of 'the golden age' that were grounded in optimism rather than in the clinician's understanding of statistically significant testing. EBM proposed that medical practice move away from golden age routines, dependent on authority based in qualitative experience, to a less dogmatic medical practice that would use a golden objective standard (the randomized controlled trial) for judging potential therapies.

Its proponents see this move as an epistemological progress. The normative foundation of medical practice is changed as well when "*The priority [is] given to the application of research based evidence over clinical knowledge in practice*" (Upshur 2002). Those supplanted practices consist of routines developed around unproven treatments, technologies and interventions that are prescribed with an alarming certainty. EBM argues that practitioners have been overconfident in the good they are doing. As Chalmers puts it: "*professionals sometimes do more harm than good when they intervene in the lives of other people, their policies and practices should be informed by rigorous, transparent, up-to-date evaluations*" (Chalmers 2003, p. 22)

In sum, proponents of EBM argue that we must make medical practice more transparent, promote modesty about the good intervention may do, educating the patient on probabilities, or what benefits it will bring. The clinician should use up to date evaluations and analyse them at a sophisticated level. And the clinician should not hide the uncertainty of practices. From an EBM perspective, these principles will pave the way to practices that will not (with the best intentions) recommend the wrong sleeping position for babies, for example, just because these positions have become the conventional wisdom. This will ensure that the ideal 'to do good for the patient' is not abused to implement obsolete therapies. Practices informed by rigorous, transparent and up-to-date evaluations are the best way to do more good than harm in policy and practice (Chalmers 2003).

Ann Oakley (even though she is not part of the movement, she has articulated some of its central ideas) argues that the EBM emphasis on aligning clinical practice with the most current epidemiological and therapeutic information must result in fundamental changes in the relation between the medical expert and the patient.

One very important value of well-designed experimental ways of knowing inheres in the democratic ends they serve: their capacity to interrupt the 'normal' power relations existing between dominant professional groups and their clients. The accumulation and wider accessibility of evidence produced by this means would bring about nothing short of a revolution in the traditional relationship between 'lay' public as targets of interventions, on the one hand, and professionals and others who practice these interventions on them, on the other (Oakley 2000, p. 312).

Since EBM is often criticized for giving a low priority to clinical experience and patient perspectives, this claim certainly should be examined closely. What kind of democratization is actually implied by EBM if it indeed makes medical practice more democratic? And to what extent will it help us understand and handle the changes going on in the relationship between lay public and medical experts?

Two dimensions of democratization

Oakley's (and Chalmers) argument (that EBM and more extensive use of the randomized controlled trial in decision-making in health care practices result in a more democratic medical practice) privilege the idea that a self-critical and more transparent medical practice is one that overturns the charismatic authority of the doctor. These are, I think, important elements, but at the same time, the merger of the impulse to democratise and the EBM movement is mediated through an abstract and formal understanding of democratization, which leave us without an answer to certain of the challenges we face in health care after 'the golden age' of medicine. Authority, here, is not given to the patient, who is not really involved in the EBM movement except at second hand. Folk medicine is condemned even more harshly by EBM than the misuse of uncertain therapeutics. The direction of the 'democratization' here seems all top down, the replacement of one set of experts by another.

1. Chalmers and Oakley's implicit appeals are organised around the idea that we must go beyond the situational interests, biases and authority of the healthcare professional. Doctors must liberate themselves from their particular experiences with a therapy, or with the patient, and judge a given phenomenon from the standpoint 'of nowhere'. If a medical routine survives its disproof due to the inertia that stems from memories of old textbooks, or anecdotal evidence, or the pronouncements of old authorities, it fails as medicine. It should be resolutely discarded if it fails randomized testing. Following the road towards detached knowledge and unbiased rationality will lead us towards democratization of the social relations between medical experts and patients.

This argument is not made explicit, but it does seem to be implied. The EBM movement democratizes the doctor-patient relationship to the extent that it liberates human rationality from the authority of tradition or the charisma of the healer and is detached from particular opinions, interests and attitudes.

The question is whether this abstract idea helps us handle the challenges we face in modern medicine when we try to negotiate different points of view concerning means and ends? Does it help us bridge the different perspectives that professionals and patients often cling to in relation to a health care prevention and therapy? Not all clinical decisions are complex, and it may be true that a pretty much universally agreed to protocol is easy to envision when we are talking of standard minor surgery. But it is easy to find other medically related activities and practices in which conflicting understandings of health and illness and what a desirable medical goal is might arise. Even what constitutes the best outcome, here, is contestable, especially when you throw in the fact that many therapies produce side effects which, to the patient, might create major quality of life problems. Of course doctors and patients have a common interest in saving lives and curing diseases. But medicine is now involved in the most intimate details of our lives, from our hormones to our diets and sexual habits. In Harry Marks words: "*medical advances determine not only whether we live or die, but, increasingly, how we live and die*" (Marks 1997, p. 246). Patients and citizens naturally want to have something to say about these issues. The way medicine is involved in our lives and deaths, and how it has expanded from an agency for the palliation of pain and the cure of diseases at the beginning of the golden age to the repository of wisdom about our total physical well-being, now, raises questions that necessarily touch on the interests of almost all citizens in developed economies. The abstract and detached conception of democratization of medical practice that defines it

solely in terms of universal rationality reproduces a relationship of asymmetrical information between the expert and the patient (who can't be presumed to (even though they sometimes do) understand sophisticated concepts in statistics, biochemistry and other medical areas) that does not provide us with democratic guidelines that really help patients and citizens to handle these problems. It merely provides us with transparency – a necessary but not sufficient condition for democratic practice.

2. Yet another line of thought about democratization of the social relations in medical practice is implied in the arguments. Even if the proponents don't use Habermas's vocabulary, their thinking includes at least one element often implied in deliberative conceptions of democratization.

EBM proponents prioritise, above all else, knowledge of the most current state of randomised controlled trials for all therapies. However, Chalmers, for instance, also argues that we need to be more explicit about the uncertainty surrounding our knowledge of any of our practices. Thus, the goal is to promote practices that, given our state of knowledge, promise the highest probability of success, but never its certainty. Thus, it is incumbent on the doctor to understand that all knowledge derived from randomised controlled trials is statistical knowledge, which means that it is never complete, always subject to revision, and possess that element of uncertainty which is inherent to all scientific knowledge. Following this line of thought and the methodology developed by R.A. Fisher and extended to medicine by (among others) Bradford Hill, it has to be recognised that a degree of uncertainty is always part of scientific knowledge (Chalmers 1983).

If healthcare practitioners make it part of their routine to communicate the statistical nature of their knowledge and the uncertainty that is part of their practice to patients and make the reasons for their judgments more transparent, we have, ideally, the conditions for deliberation. In this way, we get a more democratic medicine in the ordinary sense, one in which patients can make decisions for themselves given the probabilities they face, that is suggested by the enlightenment conception we examined above.

The notion that EBM is a more democratic medical practice finds, perhaps, firmer footing under the deliberative conception of democracy, as deliberation comes with an accountability dimension. Medical professionals and experts, it is argued, can be held accountable in a way they previously could not, as it makes medical knowledge more explicit and thus puts into perspective implicit beliefs and opinions of the experts and decision-makers. Accountability is no longer only invoked in cases of failed medical procedures. Rather, now the knowledge of the medical expert can be checked by patients with access to tools that didn't exist in the golden age when knowledge and skills were hard to access and medical advice was based on the authority of the doctor.

This argument implies the principle of Gutmann and Thompson's accessible reasons' (Gutmann and Thompson 2004). They argue that one of the basic principles upon which deliberative democracy is based is that decision-making is justified by reasons that are accessible to all. Thus, decision-makers are responsible for presenting reasons in a way that makes it possible for citizens to check them that is, to make their own judgment about the quality of these decisions. Decisions that are legitimated on the basis of an authority that references inaccessible reasons ('secret' records, for example, or keeping information deliberately couched in confusing language) do not respect this principle, making it impossible for other agents to judge the legitimacy of a decision-maker.

Following this line of thought, scientific reasons enter into deliberation legitimately when they are made transparent and legible to all concerned parties. A person might not understand the scientific reasoning completely, but it is possible (in principle) to access these reasons (Gutmann & Thompson 2004, p.144-145).

Democratization as the process of making reasons accessible, however, seems, practically, to leave untouched the asymmetries of medical communication. Patients and citizens can check the experts and the professionals in a way they could not when the data upon which the old medicine was based was not distributed or explained. But what happens if the patient prefers therapies that have not passed the randomized test? What if they have more confidence in the authority of the doctor they can see rather than the testers they can't see? Or if they rely to a greater extent on the second hand testimony and anecdotes of other people? Consider for instance the continuing popularity of homeopathy in spite of the condemnation of the medical establishment and the researchers alike in countries such as Denmark. After all, the decision makers create the tests and most often do not involve patients and citizens in these processes.

Thus, given the premises of deliberative democracy, we can't really conclude that the problem of the paternalistic, hegemonic, authoritarian nature of medicine present in the golden age of medicine is solved by referring patients to another line of experts, especially given the fact that analysing tests is a sophisticated procedure that we cannot reasonably expect most people to be expert at. This point, which should be evident, is oddly missing in the important discussions going on in modern health care today about the relation between experts, professionals and patients and other agents in judging medical knowledge, medical goods and the goals of medicine.

Participation, science, and medicine

I (of course) do agree that scientific evidence and the use of RCT is important in making decisions about interventions in modern medicine. However, the relationship between contemporary medical practice, biomedical science and citizens changes significantly in the light of EBM. The idea that EBM promotes democratic ends does not take into account all the aspects of the very legitimation crisis that it provokes. It does not help us handle 'the when and where' of citizen participation. Science promoting democratic ends is inadequate because in many situations – situations of controversy – citizens' and patients' demands challenge the structure of research activities. They do not just demand that authoritarian perspectives of medical professionals be challenged by scientific evidence; they demand recognition of their own stand points in scientific practice.

An interesting and highly controversial example illustrates how a medical dispute can touch on the methodology and legitimation of knowledge that governs which routines are preferred, which medical goods are chosen, to what patients they are recommended, and how innovations in therapy are assessed (the example has been extensively discussed by for example Epstein 1996 and Bohman 1999).

In the 1980's AIDS, a syndrome unknown to science before the late 70s, began spreading globally. It was, of course, a problem that was of vital importance to its sufferers and their communities as well as to medical researchers. In the Western part of the world considerable resources were invested in attempts to develop a treatment and a vaccine. However, there were several conflicting ends and means involved in this process. A strong

activist-movement emerged from the dissatisfactions with the way research was carried out.

Since a large number of people suffering from AIDS happened to be highly educated, they had considerable knowledge about different research strategies. In the US they went to Harvard where a lot of the most important research was carried out. They shouted slogans like: *"We're here to show defiance / for what Harvard calls 'good science'!"*, distributed a leaflet saying: *"Harvard-run clinical trials – Are subjects genuine volunteers, or are they coerced?"* and *"Medical elitism – Is the pursuit of elegant science leading to the destruction of our community?"* (Epstein 1996, p. 1)

This is just one example of the many activities performed by AIDS advocacy groups. And it is characteristic that the groups were not just fighting for more resources or political influence. They were not just fighting for recognition and the possibility of giving informed consent. They wanted to change the way research was done.

They claimed that their knowledge was not being recognised in the research communities and accused the researchers of being obsessed with running methodologically elegant trials and research than in finding out what would be therapeutically viable. They did not argue that tests were not necessary for developing new treatments and drugs, but they argued that other test methods than 'the golden standard' would produce a better, because quicker, outcome. To patients suffering from progressing symptoms time was of importance. Application to control groups could be fatal for a patient. More pragmatic tests were needed.

The activists gradually gained influence and became partners in the decision-making process by which the Food and Drug Administration conducted its overview of AIDS therapies; some of the activists were invited to join advisory boards at hospitals. This example has been widely discussed, with some claiming that it represents an unacceptable politicization of science, while others, on the contrary, view this activism as a model to be emulated, claiming that even at a basic epistemological level there are conflicts about which benefits, goods and ends to take into account and that patients should have a say in evaluating these conflicts. The EBM movement seems to base their argument that EBM will result in more democratic medicine on the premise that we all agree on what the medical good is. However, several dimensions of good are involved – for instance, in the AIDS case, the mortality of the disease may have demanded that less optimal but speedier remedies be given priority. Timeliness of an imperfect therapy, from this point of view, overrides the drawbacks of a higher rate of failure. Making a decision about which method to use in order to handle a certain problem is also making a decision about which means and ends to promote. If we wish to promote a more democratic medicine we must be aware of this complexity and develop means to handle it democratically.

I want to be clear that the AIDS example is not paradigmatic because it is frightening, but because there are other less frightening diseases and conditions in which the same question of means and ends is posed. Medicine is far too varied, and the difference between knee-surgery, the treatment of cancer, neurological diseases, cardiovascular diseases etc. and immune deficiency diseases makes it impossible to envision only one platform of doctor-patient collaboration. And endogenous standards in science (in the sense of using specific methodological strategies) are of course essential in modern medicine in understanding diseases and testing therapies. On another level, that of the aggregate of attention paid to and funding for medical research, there are complex political

questions about what the influence of a strong, articulate patient-group like the AIDS-activists implies for other less articulate and weaker groups.

However, I think the AIDS example is helpful because it illustrates how democratization and participatory decision-making is possible even in areas that we might not imagine could be affected by patient activism – creating effects that condition even the first level of expert research, which is accepted by so many EBM advocates without question. I will not attempt to give a one size fits all answer to the limits and the relevance of participatory decision-making in different medical practices. The variety of practices, activities and ends served makes every case different. The possibilities for democratization as participatory decision-making about the ends and means of medical practice all the way down, which played out in real life in the AIDS example, is often neglected because it is assumed that epistemology and knowledge on the research level is the domain of insulated experts and professionals. But once one dispenses with this idea, we get a picture of democratisation that may make EBM advocates uncomfortable. Our theories lag behind the new ways of participatory decision-making that have developed in recent years (or could be developed) because we have too readily assumed that the epistemological questions are best left up to experts. However, it seems like epistemological issues cannot be segregated from the ways medical practices emerge, develop, and are distributed in the health care space.

Conclusion

The problems I have underlined in this paper lead to the conclusion, I think, that EBM fails to extend democracy from the political sphere to medicine as a social practice in a substantial way, even if there are elements in the approach, namely transparency, that could be taken up as part of a truly democratic medical practice. The formal and abstract protocol advocated by EBM does not really determine (on a practical level) how we should handle the complexity of perspectives involved in decision-making in medical practice.

Medicine has achieved a uniquely powerful position in modern Western societies. It has legitimacy among citizens at all levels because it seems to be devoted to the physical wellbeing of human beings. Given the public's positive impression of healthcare providers in general, medical authority has become hegemonic in questions about health and disease. Due to the successes of the 'golden age' of medicine, this position went unchallenged from the development of the first antibiotics, in the twenties, all the way to the seventies. However, the situation began to change as certain movements (feminism, patient rights, advocacy for alternative therapies) started to challenge the methods and direction of medical policy-making, signalling biases in medical treatment and unconscious patterns of intolerance for the input of patients. A diffuse coalition of doctors, patient activists, health care managers and others challenged the legitimacy of this hegemony. This has led to the demand for transparency in conveying medical information and new inclusive clinical practices that addressed patient concerns. On another front, the old local knowledge and authority of the clinician is under attack by the EBM movement, which wants medical practices to be grounded in the most current research – a domain entirely under control of experts – and which refuses to consider those therapies that have not been subject to double blind randomized testing as fully scientific. According to Iain Chalmers these two movements are convergent - more systematic use of randomized controlled trials will actually result in a more democratic medicine, because it will

eliminate the arrogance and paternalism of doctors, expunging their illegitimate certainties and substituting them for probabilities and cautions. In this picture the patients are freed from being subjected to useless and maybe even harmful practices under the guise of being helped. However, we have shown that the two conceptions of democratization associated with EBM advocates are problematic, especially in so far as they merely displace the authoritarianism of the doctor decision-maker to that of the research experts.

My criticism is not intended to entirely negate the ethical gain of EBM. Rather, we have seen, through the AIDS example, that more deliberative practices can be developed throughout the medical domain, even in research, and we can imagine platforms in which it would be easier to come to consensus concerning questions about means and ends, and in particular the relevance of different kinds of knowledge in medical decision-making. The future of democratic and participatory practices will come about differently in different social domains, crystallizing around specific problems. One thing the EBM advocates get right: democratization will always evolve not only around ethics and economics, but around epistemology as well.

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