

PRESIDENTIAL ADDRESS

2015 ISSLS Presidential Address

From Paternalism to Shared Decision Making: And Back?

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Spine 2016;41:827–831

Dear Fellow ISSLS members, ladies, and gentlemen. One day, a nearly 18-year-old Belgian girl walked into a tattoo parlor and came out with 56 stars tattooed on her face. When she came home, all hell broke loose and faced with the scorn of her parents she told them she had merely asked for “a few stars,” then had fallen asleep and woken up like that. It went to court, and during the proceedings, it became obvious that she had lied to her parents and had been awake throughout the procedure. This anecdote raises interesting considerations regarding consent and this is what I would like to talk to you about today.

I will take you from paternalism over consent to informed consent and finally to shared decision making and will tell you why I personally think this should be looked upon critically. Indeed, I have evolved from embracing shared decision making to looking at it with some reservation. Let us find out why.

Ideally, we would like to have a situation wherein a patient feels “Yes, yes, this is my doctor,” and at the same time, the doctor should feel “Yes, yes, this is my patient” and this would end in a harmonious decision on treatment. In order to get there, we will see how one makes decisions. In conversation, one always tries to read the mind of the other and this is extremely culture bound. When an Englishman says, for example, “I hear what you say,” what he actually means is “I do not agree at all with what you say.” So, how do we get there? Of course, I will refer to the literature, but will also use very scientific methods such as just asking

around and some of you may recall that I probed on the subject some months ago. Can there be a magic formula that would be universal and always applicable?

Consent is often implied within the usual subtleties of human communication, rather than explicitly negotiated verbally or in writing. How often does friendship not lead to sexual contact on a date with the parties not fully understanding the implications and consequences? What for the one signifies a casual affair may for the other mean a lifetime commitment. Like many human affairs, consenting is an evolving matter that may be inapplicable to or inappropriate for a particular individual. Take a Jehovah witness with critically low hemoglobin for instance. A doctor would like to do what she or he perceives to be best for the patient rather than what the patient would like. Now, to override a patient’s autonomy, we have to introduce the debate around the concept of medical paternalism. For such dilemmas, moral philosophy can contribute, but this is not my topic today.

In paternalism, good patients are like good children and their reward for obedience is that the good doctor brings them on a path toward healing. If we look critically, this was a charade where pervasive uncertainty and fallibility was hidden behind a mask of authority and competence.¹ But medical paternalism and the need for consent are not mutually exclusive. Take a doctor telling his patient: “This is what we will do, just sign here.” It was sort of consented, but certainly paternalistic. Over time, and driven mostly by litigation, there came a need for consent and later this became informed consent. As early as in 1914 with the Schloendorff² case, a surgeon who removed a fibroid tumor after the patient had consented to an abdominal examination under anesthesia, but had specifically requested that “no operation” would be performed, was condemned by the judge who ruled that “a surgeon who performs an operation without his patient’s consent commits battery.” Over the years, the concept of consent became described rather in terms of negligence rather than battery.³

The term “informed consent” as such first popped up in the late 1950s. In those days, it was not unusual to perform aortographies from posterior through the spine. In the Salgo⁴ case, a permanent paralysis resulted from a consented translumbar aortography, and the ruling focused on whether the consent had been “informed” when given. It

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The manuscript submitted does not contain information about medical device(s)/drug(s).

No funds were received in support of this work.

No benefits in any form have been or will be received from a commercial party related directly or indirectly to the subject of this manuscript.

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DOI: 10.1097/BRS.0000000000001122

Spine

www.spinejournal.com 827

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is indeed mandatory to mention potential complications, but where does this stop? Well, it is generally accepted that complications with an incidence of 1% or more have to be mentioned.⁵ But the reverse is also true. In the Truman⁶ case of 1980, where a woman who had refused a pap-smear died from cervical cancer, the doctor was condemned for not having informed his patient of the risks of *not* undertaking the test.

Whereas in clinical medicine, doctors have been merely encouraged to solicit consent, and in research, scientists have been compelled by regulation to obtain informed consent. This came about after what was perceived as abuses in the field of psychology. Remember the Milgram⁷ and Mock Prison⁸ studies on obedience where subjects saw no harm hurting their fellow human beings. Abuses on subjects for the sake of science are from all times yet culminating in extensiveness and extremity of harm with Nazi physicians engaging in so-called “biomedical experiments.” This not only led to the Nuremberg trial but also to the Declaration of Helsinki in 1964 where the moral, ethical, and legal aspects of research were described and where consent was coined as the central requirement of ethical research.

So, phrases like “this is a vitally important trial which will answer one of the most pressing questions in medicine and its results will benefit many, many people in the future” or “I did a lot for you, now it is your turn, and by the way, with participating in this trial at least you make a chance to get the wonder treatment” signify pressure that can lead to outright coercion or even threat and are unacceptable.

Earlier on, I mentioned autonomy. It comes from the Greek “autos” meaning self and “nomos” meaning the rule of law. This needs further definition. Indeed, the capacity to act autonomously is not equivalent to acting autonomously. A perfectly autonomous patient signing a consent form without reading it is qualified to give an informed consent but has actually not done so. And a perfectly autonomous patient may fail to give proper informed consent if very ill, overwhelmed, manipulated, and so on. A person acts autonomously if she or he acts intentionally, with understanding and without controlling influences.⁹ Whereas the first condition is a yes or no, the last two can be satisfied to a greater or lesser extent. People’s actions are therefore seldom really fully autonomous.

The influence of a doctor delivering the information needed to give an informed consent can go from completely controlling such as coercion, over manipulation to persuasion, which is completely uncontrolling. In type 1 diabetes, for example, the information given by a doctor should be such that informed consent to insulin therapy poses no problem. But in many medical situations, the answer is not that clear cut. Let us look close to home. In spinal stenosis, for instance, it is far from established what we should do. It can go from acceptance, over medication, and physical exercise to surgery. And for each of those options, there are again many variations. Surgery can mean simple decompression, which is what I would do, having been

trained by Rob Fraser in the rather conservative Adelaide school, but for others, it may mean fusion, total disc replacement, facet joint replacement, interspinous distraction, and so on. We need to meet in Seoul, San Francisco, and Singapore to try and sort it out! How can we expect our—even autonomous—patient to have a clear idea on what he or she wants? And this brings us back to the notion of shared decision making.

Because of the imbalance of relevant experience and power between the doctor and the patient, it is the doctor’s job to teach a culture of consent solicitation with words of encouragement and support. Nonverbal behavior is important such as body posture and seating position. The doctor has to appear unhurried and courteous and often more than just one contact is necessary. For shared decision making, the patient should be placed in a climate by the doctor that encourages him or her to ask questions. It requires a shared understanding. Now, according to his own belief, a spine surgeon may say to a low back pain sufferer: “I need to put screws in your back in order to fix the instability. A B and C are the risks.” What the patient hears is “without this surgery I risk breaking in two at any moment. Forget about A B and C.” There might have been some disclosure, but certainly no shared understanding leading to a proper shared decision making.

Intense pain may bring a patient to opt for quick pain relief by surgery, of which he downplays the risks, thus interfering with the efficient and effective processing of information. It makes no sense telling a patient that he has 0.5% chances to suffer a particular complication if the patient does not understand that this means that only five patients out of every thousand will suffer that very complication.

Shared decision making has been found to decrease overall medical expenses with 5.3%.¹⁰ In disk herniation, it was found to reduce the rate of surgery without diminishing patient outcomes. That decision aids improve decision making was shown in an analysis of 34 randomized trials,¹¹ and when there is a lack of evidence, explicit recognition thereof may make the patients more willing to agree to randomization. This was nicely shown in the surgical or conservative treatment for benign prostate hyperplasia wherein shared decision making was rated positively and indicated that the men ended up make appropriate choices.¹² So, let us say with Weinstein *et al*¹³ that shared decision making should address unwarranted variations in care, as it should produce the “right” rate of surgery, the rate at which patient’s values align with the surgery option.

At first glance, there appears to be a conflict between the wish to practice evidence-based medicine and the patients’ values and preferences. But this can be reconciled if patients are given access to the evidence as well as the doctor.

Often patients bring a relative or friend to a consultation, which increases the range and complexity of the interaction dynamics. Coalitions may form. Also, often patients are interacting with several physicians, each of whom may have a specific treatment preference.¹⁴ There is also a danger to

open discussion in shared decision making, as it may give more weight to the opinions of those who speak early and assertively, causing others to line up behind them. Then, there is the fact that doctors too can be conflicted. Take the oath of Hypocrates for instance, where we promised to do everything in order to help our patients. Well, the financial reality of the world in which we live makes this simply impossible. But here again we enter the field of moral philosophy.

With neo-liberalism came about a real “marketization” of society. Customers nowadays are keen for services to be tailored to their needs. There has been a subtle shift in the power relationship between doctors and patients and medicine became a commodity like another. This change in societal view coincided with the advent of the internet and subsequent globalization of medical knowledge. We are faced with the “increasingly clever patient.”¹⁵ In turn, this led to lay-peoples’s guides to health, “better health” magazines, an increasing array of nontraditional practices such as herbs, vitamins, acupuncture, copper bracelets, and, as mentioned, most dramatic of all, the internet. The prospect of a medical decision has become everyone’s worst nightmare.

Shared decision making implies that both the patient and the doctor decide. This in turn opens the question as to how one decides. I will shortly discuss five aspects of decision making. Intuitive heuristics¹⁶ and mood, fast and slow thinking, availability bias, option paralysis, and finally opportunity cost.

When discussing, we are used to say “pay attention,” which is apt: one disposes of a limited budget of attention, and if we go beyond, one will fail. Often a physician makes a complex diagnosis after a single glance at a patient. This expert intuition strikes us as magical, but it is not. What happens is that, faced with a difficult question, we often answer an easier one instead, because it was intuitive and came readily to mind, usually without us noticing the substitution. This is the essence of what is called “intuitive heuristics” and it applies to both doctors and patients. Yet, what both patient and doctor also share is one secure foundation: our almost unlimited ability to ignore our ignorance!

And of course, people make judgments and decisions by consulting their emotions. This is again true both for patient and doctor. As Haidt¹⁷ said, “the emotional tail wags the rational dog.” Mood influences decisions: when you feel stressed, you are more likely to be vigilant and suspicious, invest more effort in what you are doing, feel less comfortable, and make fewer errors, but you also are less intuitive and less creative than usual.

We are prisoners of our norms and influenced by unconscious baggage. I will give you an example to illustrate how decision making can be influenced—even twisted. Let me ask you a question: “how many animals of each kind did Moses take into the ark?” You are quick to think “two of course,” yet this is wrong as it was not Moses but Noah! You see, by creating the context I manipulated your answer

and this is because according to Kahneman, we have two ways of operating: a fast one and a slow one. We tend to jump to conclusions. However, this is not necessarily bad, if the conclusions are likely to be correct and the cost of an occasional mistake is acceptable and if the jump saved time and effort. But it may be risky if the situation is unfamiliar, the stakes are high, and there is no time to collect more information. Correcting one’s intuitive predictions is a task for the slow thinking system. The effort is justified only when the stakes are high and when one is particularly keen not to make mistakes.

Let us talk about availability bias. In disc herniation, for example, your statistics may not mean much to a patient who tells you he knows someone who did not fare well with a discectomy. This first-hand knowledge of a bad experience looms large in this patient’s decision making. This is called an availability bias. It is like taking the train to San Francisco because last month somewhere a plane crashed! Of course, this availability bias works both ways. After several good outcomes with a fusion for low back pain, a doctor may become overconfident as failure does not come easily to his mind.

Even compelling statistics will not change long-held beliefs or beliefs rooted in personal experience. Subjects’ unwillingness to deduce the particular from the general is matched only by their willingness to infer the general from the particular.¹⁸

According to Schwarz,¹⁹ too many options lead to option paralysis. We end up deciding not to decide. For him, the very wealth of options we are faced with turns us from choosers into pickers. A chooser is someone who thinks actively about the possibilities before making a decision. A picker does not do this. He grabs this or that and hopes for the best.

Of course, making a decision involves passing on opportunities. This is referred to as opportunity cost. It involves a certain trade-off to decisions. If we resist such a trade-off, we postpone or avoid the decision. But if we take a decision, we cannot put the rejected options out of our minds and we experience the disappointment of having our satisfaction with decisions diluted by all the options we considered but did not choose. This, in turn, leads to regret. Anticipated regret will make our decisions harder to make, and postdecision regret will make them harder to enjoy.

Hindsight has a pernicious effect on decision making. It is especially unkind to those who act as agents for others, such as doctors. Decision makers who expect to have their decisions scrutinized with hindsight are driven to bureaucratic solutions—and to an extreme reluctance to take risks. Increased accountability is indeed a mixed blessing. As malpractice litigation became more common, physicians changed their procedures in multiple ways, protecting them more than they benefited the patients. It is my belief that shared decision making as it is proposed to us may derive mostly from litigation and is perhaps a way to hide away from our responsibilities.

All this interferes with a doctor's way to present a situation. A doctor is the prisoner of his own beliefs and fears and this to my mind interferes with proper shared decision making. Also, a doctor is prisoner of his training and competence: a surgeon who never learned anterior approaches will not propose an anterior lumbar interbody fusion (ALIF). How can patient weigh the risks and benefits of ALIF and posterior lumbar interbody fusion (PLIF) when not presented with the option? A doctor will mostly advice operations he or she can handle. How many would say: "ideally you need to have such and such but I do not do that, go to my colleague down the road?"

According to Brody,²⁰ the philosophic basis of the radical change in health care decision making lies in the fundamental distinction between disease and illness. As diseases are observable and measurable, we have increasingly come to realize the profound shortcomings of treating exclusively diseases as patients live out their lives in bodies that may develop disease—but experience illness. Many patients' ordinary decision-making capacities are substantially diminished by serious illness. And even with this capacity intact, the enormous expansion of medical science, knowledge, technology, and treatment capacity would seem to leave the average patient ill-equipped to make decisions about his or her own health care.²¹ The patient is therefore also a prisoner of his beliefs and fears. And of course, not everyone has the same intellectual capacity to grasp what exactly is going on.

Over the years, I have tried to practice shared decision making, but I mostly failed, not only for all the reasons mentioned but also because of cultural reasons. It is my belief that cultural context is of paramount importance in the process of medical decision making and this affects both patients and doctors. My patients say: "Doctor what should I do?" So, I say "I am not you!" "Yes, but what would you do for yourself?"

By looking into the literature on my subject, I came face to face with the "streetlight effect." You all know the streetlight effect. It is night time and a man is looking for his lost keys under a lamppost. A passer-by helps and after a while wonders "are you sure you lost them here?" to which the man answers: "no, but it is here that there is light!" When searching PubMed for 'consent' and 'informed consent' I noticed that the terms started appearing in the late fifties with an incremental incidence ever since (Figure 1). A same trend can be noticed for "shared decision making," but with a much later start and much lower incidence. In PubMed, one also notices that authors from all corners of the world publish in English, irrespective of their mother tongue. Yet interestingly enough, on the topic of shared decision making, virtually all publications are originating from the Anglo-Saxon world and more specifically from the United States. So, do Medline searches on this topic reflect the situation on the ground, or are we faced with a streetlight effect? In other words, does the rest of the world care for shared decision making? In order to find that out I asked around to hear what people do. Whereas consent seems to be ubiquitous, shared decision making does not seem to be of great interest. It would be interesting to analyse if, say Italians or Brazilians, who now do not really care for shared decision making would be more approachable after migrating to the USA, for example. And I wonder if the research on shared decision making, as we read in the literature, were to be done elsewhere, what would the results be?

The observation of disparity in the practice of shared decision making leads to a series of questions. Is it possible to aim at introducing the concept to the four corners of the globe? And even if it were possible, would it be appropriate or even desirable? I was born in Antwerp, in the Flemish part of the country, was brought up speaking French and went to

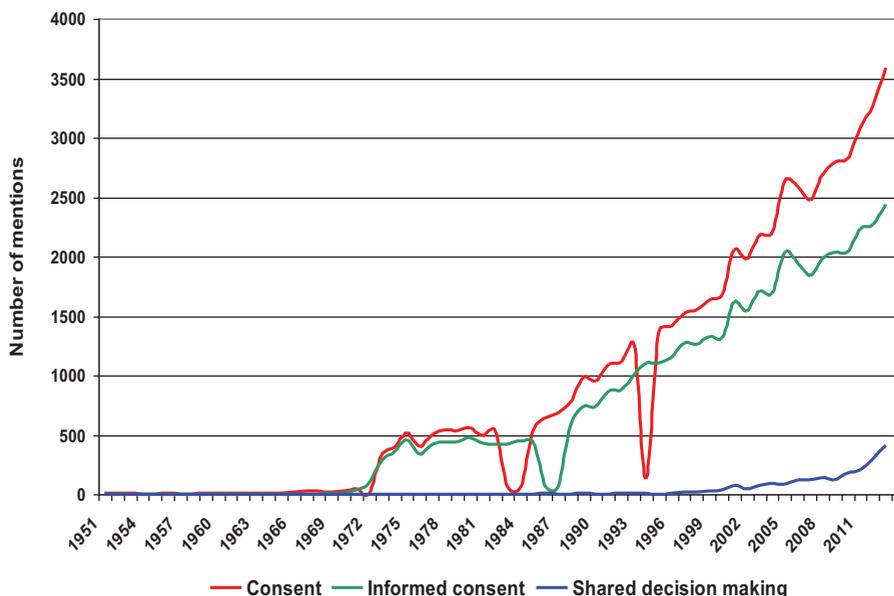


Figure 1. Incidence of mention over the years.

school in Dutch. Finally, I married an English-speaking person and ended up not only speaking several languages but also experiencing the cultural baggage each language carries. Intellectually, I am drawn to stand behind the concept of shared decision making wholeheartedly. I have tried it. I am still trying it but with surprisingly limited success. Not only for the reasons you will find in the literature: lack of time, “doctor if you don’t know how can I know” and so on, but I experience that patients where I live are not open for this approach. I purposefully do not say that they are not ready. It has nothing to do with readiness, more some kind of unwillingness to be drawn onto the middle ground of shared decision making.

Clearly, patients need help to make what is for them the right decision. Yet, it is my belief that the process is too much fraught with uncontrollable biases and cultural impact to be applicable as we would have hoped. So, I am brought to philosophically question whether it is opportune to pursue this avenue.

So, where does that leave us? There certainly is no blanket rule. I think that we should attempt to involve our patients in the decisions about their health, but where resistance to this approach is voiced, the doctor should use his common sense and professionalism to propose the best option for his patient. And not feel guilty about it.

In any case, one thing is certain: Life is but a choice: should I turn left or right? Eat an apple or an orange? Have a fusion or not? Let me finish with a quote of the French philosopher Albert Camus who posed the question: “Should I kill myself, or have a cup of coffee?” His point being that everything in life is about choice and decision making.

It was a pleasure to serve as ISSLS President. Thank you.

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