



ANALYSIS

“Informed choice” in a time of too much medicine—no panacea for ethical difficulties

Providing information to enable informed choices about healthcare sounds immediately appealing to most of us. But **Minna Johansson and colleagues** argue that preventive medicine and expanding disease definitions have changed the ethical premises of informed choice and our good intentions may inadvertently advance overmedicalisation

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The idea of informed patients who make reasoned decisions about their treatment based on personal preferences is appealing in a Western cultural context, with its focus on the autonomous individual. Rightly, many doctors now reject paternalism if the patient does not specifically ask for it. They prefer to elicit the patient's preferences and embrace an open discussion of risks and benefits of different options within a shared decision making approach.¹ However, the rise of preventive medicine, the transformation of risk factors and common life experiences into diseases, and the lowering of diagnostic thresholds have changed the ethical premises of informed choice by pushing responsibility on to often ill prepared citizens.²⁻⁵ We call for careful reflection on the potential downsides of trusting informed choice to resolve ethical problems and complex value judgments in an era of “too much medicine.”⁶

New pathways to informed choices

When the clear cut needs of a patient to solve a health problem set the framework for the medical consultation, the ethics of informed choice can be fairly unambiguous. A patient with osteoarthritis consulting a doctor because of serious, long lasting knee pain that inhibits daily function may exemplify this. Most of us would appreciate being informed about the pros and cons of knee replacement surgery and other options, including doing nothing, and thereby being enabled to make an informed choice based on personal preferences. In such situations, informed choice is clearly better than previous paternalistic approaches. However, in medicine today, the path towards an informed choice is often far more tortuous.

Dangers of diagnostic cascade

Consider a middle aged man who consults his general practitioner because of a mild headache, dizziness, and a feeling of strong heartbeats. Among other things, the doctor measures his blood pressure, which is moderately raised. Although the man's blood pressure is unlikely to cause the observed symptoms, and a reasonable response might be to set aside this finding after exploring the personal history further, many doctors will feel pressure from guidelines⁷ or quality measures to proceed to medical action. After the diagnosis is confirmed through monitoring ambulatory blood pressure, the patient's risk of cardiovascular disease is assessed in accordance with current guidelines.⁷ He is given individualised information on the potential benefits and harms of treatment for hypertension and hyperlipidaemia and encouraged to make an informed choice about whether to start potentially lifelong preventive drugs.

In the process of medical work-up, the doctor explores the patient's symptoms further. These are obviously stress related. Based on a short questionnaire and the conversation that took place at the consultation, the doctor diagnoses moderate depression and provides the patient with information on the pros and cons of selective serotonin reuptake inhibitors, perhaps combined with cognitive therapy. After exploring the patient's preferences the doctor facilitates a decision on whether to start treatment. As doctors, we are taught to feel proud of ourselves in this situation; we took the time to make sure that the person was informed and to explore personal preferences. We thus respected our vulnerable patient's autonomy.

However, we see major ethical problems arising from this approach, which in this case might smoothly transform a person

in temporary distress into a lifelong patient, or at least someone who for the rest of their lives has “previous, medically treated depression.” A common consultation for symptoms such as those discussed above, with strong ties to stressful life circumstances, can evoke a diagnostic cascade that to some extent is legitimised by offering choices about medical treatment, choices demarcated by an unquestioned framework of medical interpretation and classification.

Screening asymptomatic citizens

Mass screening programmes further complicate informed choice. Here, the initiative arises from within the healthcare system. Asymptomatic citizens are offered an examination they have not asked for. In a best case scenario, potential participants receive balanced information on both the pros and cons of the intervention and can then make a choice. But who considers the ethics of presenting such a complex choice in the first place? An analysis of informed choice in healthcare must reflect on the locus of initiative.⁸ In a population screening programme, the healthcare system is explicitly mandated to place citizens in a situation with no possibility to avoid making a choice. And in medical reality, the choice is often undermined by biased information giving weight to the potential benefits and downplaying the risk of harm from false positive results and overdiagnosis.^{9 10}

Expanding disease definitions

Expanding disease definitions present another major challenge for informed choice. Conventionally, people are informed about the pros and cons of different treatment options—but who is charged with discussing the validity of the underlying diagnostic label? There are now important controversies about whether thresholds for diagnoses and risk factors have become too low across a range of conditions, including pulmonary embolism,¹¹ osteoporosis,¹² chronic kidney disease,¹³ and hypertension.¹⁴ For gestational diabetes, a new diagnostic threshold that almost triples the prevalence is being heavily promoted globally, despite being rejected by a National Institutes of Health consensus conference in the United States.¹⁵ Should doctors be diagnosing according to the old or new threshold, and for women with newly defined diabetes, should informed consent include information about the controversy around the expanded definition?

Similarly, more and more of life’s challenging experiences are turned into diagnoses through the inexorable expansion of the number of and criteria for mental disorders.¹⁶ This is exemplified by DSM-IV including the controversial “hypoactive sexual desire disorder” in women.¹⁷ Our biomedical framework for understanding disease makes us sort our patient’s illnesses and suffering into diagnoses that are technically correct but not necessarily existentially meaningful in the sense of enhancing the patient’s ability to engage in life.⁴

Informed choice—a fake fix?

We argue that general reliance on informed choice to resolve ethical problems and closely balanced value judgments in contemporary medicine might be a fake fix. There are five main reasons for this, as discussed below.

Doubts about personal preferences—In a cultural context permeated by the belief that “more is better,”^{18 19} it is doubtful whether we can expect people to make truly informed choices when considerable uncertainty exists about the benefits and harms of interventions and diagnostic labels. Information

speaking to our intellect is likely to have a small role in decision making compared with emotions and cultural influences.^{20 21} This questions the conventionally perceived relevance of being informed when making a choice. In a US study, two thirds of laypeople stated they would want to be screened for cancer even if there was no treatment available.¹⁸ Should this be considered a “personal preference” worthy of medical pursuit? Or should we also take into account that the long term misperception of the benefits of screening—fuelled by professional presumptions, advocacy groups, and financial and political interests—pushes people’s preferences in the direction of more medicine and more screening?

Transfer of responsibility—There are downsides to being forced to make informed choices. For example, if patients choose not to have their risk factors treated, they may feel guilty if they are later affected by the condition.²² Such feelings of guilt are amplified by the “prevention is better than cure” dogma but are ethically objectionable and uncalled for, given that a preventive intervention makes no difference for the majority. Additionally, there is a risk that informed choice transfers responsibility for treatment harms from the health professional to the patient. This presents a great ethical difficulty, particularly when not all facts have been provided or understood or when facts have been presented in a skewed paternalistic manner to promote a certain choice.

Information can cause trouble—Informed choice implicitly suggests that information is inherently good, a view reinforced by a reluctance in our societies to accept uncertainty. But information is not the same as insight. Information can be harmful if it leads to unjustified distress or interventions that eventually inflict harm. Additionally, information about our risk of getting a symptomatic disease based on asymptomatic risk factors can negatively influence the perception of our health and quality of life.⁴⁻²⁴ How is our ability to trust our own bodies affected by receiving multiple diagnoses and treatments while being free of symptoms?

No neutral territory—Inherent to the idea of informed choice is an ideal of the doctor as a professional conveyor of neutral information. However, the practice of medicine inevitably includes many value judgments, both implicit and explicit. Furthermore, the idea of a neutral doctor contrasts with the fundamental importance of the interaction and relationship between the doctor and the patient. The strong focus on individual autonomy and informed choice may divert attention from some of the underlying, unspoken premises and assumptions that are fundamentally important to clinical decisions.⁴ For example, the wish of a relative to do everything possible to prolong the life of a patient at death’s door, no longer able to speak for herself, might spring from a fear of being the one to decide when a loved one should die. Informed choice does not solve such questions behind the question, and a lot can be at stake.

Opportunity costs—Facilitating genuinely informed choices in the context of preventive medicine will consume much time and money. This risks redistributing ever more scarce resources to healthy individuals when these resources could instead be spent on people with the greatest need: those who are already ill.⁵

Call for reflection

What we do in medicine is inevitably value laden; it reflects the values of the surrounding society all the way from the choice of research questions to the choice of information to provide in the individual consultation.²⁵ If we fail to analyse and critically

reflect on the values leading to the call for an informed choice, the whole process risks serving as a conveyor belt for more medicalisation and “too much medicine.” When there is any risk of overmedicalisation, we believe a more questioning approach is warranted. Before feeling satisfied for navigating someone through an “informed choice,” perhaps doctors should start with some more humble reflections. Did we, the patient, or some other force, initiate the process leading to an informed choice being necessary? Is it likely the person will benefit from having to make an informed choice? Can she or he be harmed? In the time of too much medicine, shared decision making may need to be more sensitive to the downsides of the many decisions necessary. We also need to think more critically about which new disease criteria and interventions with a close benefit-harm balance we should offer.

A relevant response to the man with increased blood pressure in the example above might be to sit back and really listen. Among the myriad reasons for his symptoms might be a poor relationship with a family member or imminent downsizing at the workplace. Such problems are not resolved by use of antidepressants or assessing cardiovascular risk. A more laidback and listening approach from the doctor might favour salutary choices with great importance to health and might represent greater respect for individual autonomy then offering medical choices the patient did not ask for.

We are not opposed to providing information or involving patients in decisions. But we want to raise a note of warning; there is increasing complexity in making choices about the many disease labels and interventions that bring only marginal benefit and considerable harms. Most importantly, providing information to make “informed choices” does not address the many deeper drivers of medical excess, be they technical, professional, commercial, or cultural. Moreover, it imposes new ethical questions that healthcare providers and policy makers are yet to consider.

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Key messages

Informed choice is increasingly considered as the best way to determine appropriate care
Providing information does not tackle the deeper drivers of overdiagnosis and overtreatment
Requiring an informed choice can cause harm when controversy exists about treatment or diagnostic thresholds
Without critical reflection our good intentions may enhance medicalisation and too much medicine