

Patients' autonomy: does doctor know best?

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Respect for patients' autonomy is now firmly entrenched in medical ethics but some doctors are reluctant to relinquish paternalism. This article discusses some of the perceptions of doctors who do not think autonomy is in their patients' best interests.

What is autonomy?

Autonomy is a Greek word meaning self-rule. Historically the term related to political self-rule, but in medical ethics it is widely used to cover personal autonomy: an individual's moral right to make and act on personal choices without interference. The writings of Immanuel Kant and John Stuart Mill have strongly influenced contemporary thinking about autonomy as an ethical principle. In medicine, respect for autonomy 'obliges doctors to disclose information, to probe for and ensure understanding and voluntariness, and to foster adequate decision making'.¹

Respecting patients' autonomy is more than a platitude; it is an ethic for doctors to effect. This means not only providing patients with information, but also helping them to understand it, without undue influence or coercion; hence, allowing them to make informed decisions. This includes assisting patients to comprehend the pros and cons of treatment options (including anticipated side effects) and of treatment refusal.

In a post-*Rogers v. Whitaker*² era, most doctors are aware of their legal obligation to disclose sufficient information to enable patients to make informed decisions about proposed treatments. Although the concept of 'informed consent' was born out of case law, respect for autonomy is about practising ethically not about obeying the law. Some doctors are reluctant to show respect for their patients' autonomy; this may be, in part, because they see it as a legal requirement rather than an essential part of good clinical practice.

A paternal past

Paternalism is on the way out but some of the practices associated with it remain. Many doctors still believe in concealing information or overriding patient wishes because 'in the end it



will be for the best'. This has long been the case. In a 1927 article published in the *Harper's Monthly Magazine*, a US physician, Joseph Collins, wrote that the longer he practised medicine, the more he was convinced that every physician should cultivate the art of lying.³ He was not referring to lies that would benefit the doctor but to lies that 'contribute enormously to the success of the physician's mission of mercy and salvation'.³

Dr Collins was not a deceitful man but believed that his patients were better off not knowing all the details about their condition, thereby avoiding potential anxiety, depression or loss of hope. He was not alone. Doctors then did not routinely disclose information to patients let alone express clinical uncertainty to them.

In 1999, Dr Atul Gawande described in *The New Yorker* the shift in medicine away from paternalism and towards information sharing with patients, so that they could make informed decisions.⁴ Dr Gawande and Dr Collins lived in different times and described vastly different approaches to information sharing with patients. Despite their differences, they both agreed that clinical practice is not straightforward, and, sometimes, following a patient's wishes will be against the patient's best interests.

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What are doctors to do?

There is no prevaricating about whether patients have a right to self-determination. Since the civil rights movement in the 1960s, respect for patients' autonomy has grown and now occupies centre stage in medical ethics. Under patients' autonomy sit truth telling, confidentiality, privacy, disclosure of information and consent.

If the ethical position is clear, why are doctors ambivalent about sharing information and providing treatment only with the express permission of the patient? The problem is that although the ethical position is clear, interactions between patients and doctors contain many variables. Over the last 18 years, I have heard doctors raise the following issues and concerns about patients' autonomy.

Many doctors...argue that their authority is undermined when patients question their knowledge or seek additional information...even though it is impossible for doctors to know everything.

'Doctors have years of training and are the experts'

Neil McIntyre and Karl Popper pointed out in the *British Medical Journal* that professional ethics for most of the 20th century were mistakenly based on the view that scientific knowledge was certain, and could be accumulated, acquired and stored in a person's mind.⁵ This perception, they believed, permitted a culture of authority to rise and dominate medicine.

Many doctors still subscribe to this view and argue that their authority is undermined when patients question their knowledge or seek additional information. They maintain this view, even though it is impossible for doctors to know everything about medicine. There are more than 40,000 biomedical journals, and the number doubles every 20 years.⁶ To keep up to date, a GP would have to read 19 articles each day, 365 days a year.⁷

Doctors who espouse the authority model deny patients their autonomy. Not only do they deny their patients information, but also their patients are more likely to follow doctors' orders than other patients. Some studies have shown that patients willingly accept their doctor's recommendations without carefully weighing the risks and benefits.⁸

Many doctors of the authority school may provide complete information to their patients but still not meet autonomy requirements. This is because the way the information is provided and

framed influences a patient's response. Patients can be subtly coerced. This is more common when clinicians are convinced of the rightness of the treatment for the patient. Clinical opinions are often expressed at the same time as information is being provided about risks and benefits. As far as possible, factual information should be provided within a value-free environment. Maintaining patients' autonomy requires that their values and desires (rather than clinicians') guide treatment choices.

A stark example is when patients refuse blood transfusions for religious reasons. In this situation, treating doctors may focus on the risks to the patient of not having the transfusion because they believe that the patient's life is in jeopardy. For physicians, a strong ethical obligation is 'do no harm'. If they are concerned about a patient's decision, then making the patient aware of the implications of the decision is appropriate, especially if it means the patient could die.

A doctor is morally obliged to attempt to persuade patients to accept life-saving treatments. Explaining the necessity and rationale for such treatments is important if patients are to understand the consequences of their refusal. If there is no understanding, there can be no autonomy. A full sharing and explaining of information gives expression to patients' autonomy; it anticipates a refusal as well as consent.

Another reason to pursue detailed discussion is to determine whether a patient's refusal on religious grounds is an autonomous decision. People may fear shaming, ridicule or expulsion from their religious group if they act contrary to the group's belief system or teachings. Therefore, ascertaining if their choice is consistent with their character is important, but discussions beyond those necessary for clarification and understanding breach autonomy.

'It is impossible to know how much information should be provided to patients'

What, when and how much information should be disclosed? These considerations may have legal clout, but in the context of autonomy it is more fruitful to view information exchanges as processes to enable patients to make informed choices. Disclosing information is about informing patients, not about protecting doctors from complaints.

There are general rules, but no one rule fits all. The best guide for doctors is to focus on the individual patient's informational needs. We all differ in how much information we want and can take in. For me, the amount of additional information I want will often depend on the person treating me, and whether I trust that person to disclose everything that I need to know. The key is for my doctor to focus on my needs by providing the important information and responding to my situation and my questions and silences.

The standard applied here is the subjective standard, from

the perspective of the patient. The adequacy of information is judged by reference to my particular informational needs, not those of a hypothetical 'reasonable patient' or a 'professional person'. I have a family history of breast cancer so my doctor will spend time talking to me about risk and address any anxieties that I may have. If I am anxious, a doctor withholding information about risk may be undermining my autonomy. However, the next patient having a routine breast examination may not need as much time spent talking about risk, and then there would be no undermining of autonomy if detailed discussions about risk were not held. We are being treated differently. But how am I to know what information is important and how is a doctor to know which patient requires what?

At a minimum, patients should be given information about treatment when there is the potential for significant harm, even if the risk is tiny, and when side effects, even if minor, occur frequently.

At a minimum, patients should be given information about treatment when there is the potential for significant harm, even if the risk is tiny, and when side effects, even if minor, occur frequently. Applying these rules in the context of the individual patient works best. This approach also enhances communication by providing opportunities for interaction through dialogue.

Some doctors think that providing all the information will fulfill their obligations for respecting a patient's autonomy. Information overload is well recognised, and most doctors realise that patients will not retain important information given at a time of high anxiety, particularly if a difficult (for the patient) diagnosis is made. Hence, too much information as well as too little will prevent patients from making autonomous decisions. Using jargon and failing to clearly describe treatments and their consequences will also diminish patients' understanding, which is essential for their autonomy.

'Many patients do not want to make decisions about their treatment'

It is true that many patients do not want to make decisions about their treatment. Patients are as varied as humanity. They differ in their education, comprehension and age. In addition, and not least, many are sick, vulnerable and not capable of operating on full throttle. The fact that patients do not wish to

exercise their autonomy does not negate the principle. Patients can only relinquish autonomy if they have it in the first place. Moreover, when patients ask their doctors to make decisions for them it does not mean they wish to forever withdraw from interactive communication. Some doctors interpret such requests as a sign that patients wish to opt out of further discussion. However, discussion, explanation and answering questions are still necessary to maintain respect for patients' autonomy.

Consider a parent having to make a decision about whether his or her child should be intubated and put on a ventilator or observed, adopting a wait and see approach. Neither option is without risk. The parent would still be acting autonomously if after hearing and considering all the information, he or she decided to hand back the treatment decision to the doctors, as long as the information had been provided separately from the doctors' opinions and preference. Continuing to engage the parent by explaining the selected management plan and expectations will maintain the parent's autonomy.

Conclusion

Discussions about autonomy in healthcare mainly focus on information sharing and decision making. The obsession with individual rights in the community has given patients' autonomy a helping hand but a 'rights' context is not necessarily in the best interests of all patients. The way doctors can respect autonomy is to relate to their patients as individuals with distinct needs, and to communicate with them on their terms and not just as another patient in a busy day. **MT**

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