

CLINICIAN INTEGRITY, PATIENT AUTONOMY AND THE PATIENT'S BEST INTERESTS

S Kling

Associate Professor, Department of Paediatrics and Child Health, Stellenbosch University and Tygerberg Children's Hospital

Email | sk@sun.ac.za

'I wish my life and decisions to depend on myself, not on external forces of whatever kind. I wish to be the instrument of my own, not of other men's acts or will. I wish to be a subject, not an object: to be moved by reasons, by conscious purposes, which are my own, not causes which affect me, as it were, from outside. I wish to be somebody, not nobody: a doer – deciding, not being decided for, self-directed and not acted upon by external nature or by other men as if I were a thing, or an animal, or a slave ... I wish, above all, to be conscious of myself as a thinking, willing, active being, bearing responsibility for my choices and able to explain them by references to my own ideas and purposes.' Isaiah Berlin, 1969¹

INTRODUCTION

Respect for autonomy as described by Berlin¹ has become the dominant ethical principle in guiding any decision-making involving competent adults in contemporary medicine. Respect for individual autonomy and the individual's rights supersede the other ethical principles. When I was a medical student, the doctors practised medical paternalism. They made a decision regarding the patient's treatment, truly believing that this was in the patient's best interests, and the patient had very little say in the treatment plan. Subsequently, the patient became a partner in the decision-making process: the doctor explained the treatment options and made a recommendation as to which option was the preferred one; the patient then made the final decision. Is there a limit to the patient's autonomy in modern medical practice? What ought the doctor do if s/he believes the patient has made the wrong decision?

In clinical practice two types of situation may arise that could lead to conflict for the clinician when having to respect the patient's autonomy. The first situation encompasses the patient's requesting treatment that the clinician believes is inappropriate or futile; the second arises where the patient refuses treatment that the clinician believes is in the patient's best interests.

Consider the following case scenarios.

1. *Keith Smith, aged 12 years, had a local reaction after being stung on his right arm by a bee. He was referred by the family's general practitioner, Dr Jones, to the allergy clinic at the academic hospital. The referral letter requested specific IgE testing to bee venom and a course of bee venom immunotherapy, as the Smith*

family live on a farm 20 km from the city, and Dr Jones is concerned about a potentially life-threatening systemic reaction should Keith be stung again. Dr Cooper, the allergologist at the referral hospital, explains to Keith and his mom that immunotherapy is not indicated for local reactions and that the immunotherapy is not without risk. Mrs Smith is extremely unhappy and insists on the immunotherapy.

2. *Mrs Denise Botha had a severe systemic reaction to a bee sting and was treated for anaphylaxis at the local hospital. She too consults Dr Cooper after being referred from the Emergency Department. She steadfastly refuses allergy testing and immunotherapy. She says she is prepared to carry antihistamine tablets and injectable adrenaline with her when walking outdoors. Despite extensive counselling by Dr Cooper, she will not accept immunotherapy, as she likens it to vaccination and she believes that vaccination is an assault on the immune system. Neither of her two children has been vaccinated, as Mrs Botha knows of a case of autism in a child who was vaccinated.*

A HISTORICAL PERSPECTIVE: FROM PATERNALISM TO AUTONOMY

During the 1970s doctors made decisions for their patients, 'usually made with beneficent intention but without open discussion, much less the full participation of the patient.'² The advantages of this approach were that the patient and family could be protected from difficult decision-making and the doctor could ensure that employing new technology in medicine did not cause harm to the patient. The disadvantages of paternalism are that it is difficult to be certain what is in an individual's best interests and that patients are not given the opportunity to truly be involved

in making decisions for themselves.

Towards the end of the last century the individual patient's autonomy became the most important consideration in medical decision-making. Quill and Brody believe that the swing of the pendulum from paternalism across to autonomy is potentially detrimental to patients in that a great deal of information is presented to the patient without any recommendation from the doctor. This means that the patient has to make decisions without any medical guidance. One of the reasons postulated for the doctor's remaining neutral is that it may prevent the doctor from being sued in the event that the decision proves to be incorrect.²

MODELS OF AUTONOMY IN MEDICAL DECISION-MAKING

Quill and Brody contrast the 'independent choice' and the 'enhanced autonomy' models in medical decision-making.² The former is 'patient centred' and requires the doctor only to provide the information, the options and the likely outcomes and for the patient to decide on the course of action. The idea is that the patient is able to make a decision without in any way being influenced by the doctor. Once the patient has authorised a course of action, the doctor has to carry it out, even if s/he disagrees with the proposed treatment plan.²

The 'enhanced autonomy' model promotes patient autonomy by providing not only the pertinent medical information but also the opinion and recommendation of the doctor, therefore enabling the patient to make a truly informed decision. It has been termed 'relationship centred' as it includes the medical team, the patient and the family. This model not only provides the medical information and treatment options with likely outcomes, but also takes into account the values of the doctor and the patient.²

The principle of autonomy has as its central tenet the concept of respect for the patient as a person. We have to be sensitive to the views of patients from different cultures. As an example, in the traditional African context, individual autonomy is less important than communitarian decision-making, and although it would seem that involving the family or community in medical decision-making violates the principle of autonomy, it in fact shows a higher level of respect because one is showing respect for the traditions and culture of the patient's community.³

Young children are not regarded as autonomous and so medical decisions are made for them by their parents or caregivers. Older children may well be able to participate in decision-making regarding their own healthcare, and South African legislation has made it possible for children older than 12 years to make healthcare decisions for themselves, provided that they have the capacity and maturity to do so.⁴

THE DUTY OF DOCTORS

Numerous codes of ethics and professional guidelines emphasise the doctor's responsibility in respecting the autonomy of the patient, and always to act in the patient's best interests. The Health Professions Council of South Africa's (HPCSA) 'Guidelines for Good Practice in the Health Professions'⁵ state the following:

The core ethical values and standards required of healthcare practitioners include the following:

- 1.1.1 Respect for persons: Healthcare practitioners should respect patients as persons, and acknowledge their intrinsic worth, dignity and sense of value.
- 1.1.2 Best interests or well-being: Beneficence: Healthcare practitioners should act in the best interests of patients even when the interests of the latter conflict with their own personal self-interest.
- 1.1.3 Autonomy: Healthcare practitioners should honour the right of patients to self-determination or to make their own informed choices, and to live their lives by their own beliefs, values and preferences.

The point is made that some of these values and standards may be in conflict, and that the doctor has to employ 'ethical reasoning' to resolve such conflicts.⁵

ARE THERE LIMITS TO A PATIENT'S AUTONOMY?

What happens if the patient's request for treatment conflicts with the doctor's opinion because the doctor believes it to be inappropriate? In such a case respect for the patient's autonomy may conflict with the doctor's professional integrity and values.⁶ Frequently, these conflicts arise in the context of end-of-life decision-making – for example, disagreements about do not resuscitate (DNR) orders or futile treatment. Clinicians are not obligated to provide treatment that they deem inappropriate and, therefore, they may place a limit on the patient's autonomy in such a situation. Lantos et al explain that 'patient autonomy has boundaries and limits' in that treatment choices are provided within a range of options. If this were not the case, then chaos could result, with resultant inefficiency and increased costs.⁶ They also make the point that

'[the] patient's right to forgo treatment is stronger than the right to receive a particular treatment. Competent patients can refuse most treatments, no matter how potentially beneficial they might be. Patients do not have the same authority to demand treatments, in part, because treatment usually requires the participation of a clinician. Thus, the clinician's own moral agency is engaged.'⁶

Clinicians may refuse patients' requests for treatment that the doctor does not feel qualified to provide or requests for treatment in an environment that is inappropriate to the patients' needs.

THE CONCEPT OF 'BEST INTERESTS'

The concept of 'best interests' is usually interpreted to mean the 'highest net benefit among the available options'

that apply to any situation in which a decision has to be made regarding the health of the patient.⁷

'The best interests standard protects another's well-being by assessing the risks and benefits of various treatments and alternatives to treatment, by considering pain and suffering, and by evaluating restoration or loss of functioning.'⁷

In cases where medical treatment carries low risk and offers substantial benefit to the patient, it is generally thought to be in that person's interests. The 'best interests' standard is the one employed in making healthcare decisions involving children. The difficulty with the best interests standard, however, is that it is not always obvious in any given situation what the best interests of the patient are. Some of the criticisms levelled at the 'best interests' standard are that it is unrealistic, too restrictive, and too focused on the interests of the incompetent or incapacitated person.^{8,9}

DO DOCTORS ALWAYS HAVE TO ACT IN A PATIENT'S BEST INTERESTS?

Although most guidelines and even legislation tend to emphasise the importance of the patient's best interests in medical decision-making, an individual patient's best interests cannot always be considered paramount. In truth, there are many circumstances under which the interests of other patients would outweigh those of the present patient.¹⁰ Wendler lists 27 exceptions to the traditional view of the obligations of the doctor in promoting the best interests of the individual patient.¹⁰ A few examples of these are:

- not transfusing a Jehovah's Witness patient who needs blood;
- leaving a patient's bedside to go and resuscitate another patient;
- vaccinating children to promote herd immunity;
- cost containment by prescribing cheaper, less-effective drugs;
- notification of infectious diseases, and
- incarceration of patients with multi-drug resistant tuberculosis.¹⁰

We are required to respond to the claims of other parties, but this does not imply that we do not care about the individual patient: 'Instead, this fact helps to define the nature of our relationships by clarifying the extent of our obligations to significant others.' However, Wendler also emphasises that good medical care depends on relationships with patients and that doctors cannot be required to further the interests of all individuals. The essence of a clinical relationship revolves around an individual patient. He suggests that the requirement to act in the individual's best interests while at the same time realising that others may also have a claim on the doctor can be addressed by seeing the present patient's best interests as a 'pro tanto' obligation¹⁰ (i.e. for so much or to a certain extent)¹¹ rather than as a

strict obligation that cannot be overridden. This permits the doctor to weigh up the present patient's interests against those of others.¹⁰

DISCUSSION OF CASE SCENARIOS

In the case of Keith Smith, his mother, Mrs Smith, insists on unnecessary and inappropriate therapy. Dr Cooper is not obligated to provide this therapy, but she should explore the reasons for Mrs Smith's insistence on the treatment. She should also take the time to explain the indications for specific IgE testing and bee-venom immunotherapy, as well as the fact that the immunotherapy is not without risk. Given Keith's age, he should also be involved in the counselling and decision-making process and be given full information regarding the indications for testing and immunotherapy.

The case of Mrs Botha is more difficult, as she is a competent adult refusing treatment, and her refusal should be respected if it constitutes a fully informed decision. However, given the scenario and the fact that she had a life-threatening bee sting, she should also receive extensive counselling regarding the risks of being stung. She must be given an anaphylaxis treatment plan and be carefully instructed on the use of the injectable adrenaline, as well as advice regarding precautions to be taken to avoid being stung. She should be counselled about anti-vaccine propaganda, the fact that vaccination is not 'an assault on the immune system', and the difference between vaccination and allergen immunotherapy. Many allergic reactions to vaccines originate in the additives, and the differences between these additives and the adjuvants present in allergen immunotherapy have to be explained.¹² To this end, Dr Cooper should have all the necessary knowledge to inform Mrs Botha fully about immunotherapy.

The issue of Mrs Botha's children not being vaccinated because of the fears of autism should also be addressed, but this is not the responsibility of Dr Cooper. Dr Cooper should suggest that Mrs Botha speak to her family doctor about this issue, and possibly suggest some resources for further reading.

CONCLUSION

Individual competent adult patients have the right to make choices regarding their healthcare in accordance with the principle of respect for autonomy. If disagreement arises about the course of action to be taken, careful discussion of the issues and options should take place, with attention to what is in the patient's best interests. However, if the disagreement cannot be resolved, the patient's final decision should be respected. Should the doctor feel that the decision is inappropriate or is against his/her values, s/he has the right to refuse to be involved. In that case the patient should be informed, and the offer made to refer the patient to another doctor, if possible.

DECLARATION OF CONFLICT OF INTEREST

The author declares no conflict of interests.

References available on page 189.