

YOHANNA YANSHIYI DANGATA,

MBBS MSC LLM PHD FRSPH, Director of the Holistic Global Limited, United Kingdom

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THE IMPACT OF PATIENTS' AUTONOMY IN MEDICAL PRACTICE IN THE UNITED KINGDOM: RESPONSIBILITIES OF STAKEHOLDERS

1. Introduction

In most civilised parts of the world, the paternalistic approach to medical practice, whereby the patient was only a recipient of healthcare is defunct. The patient wants to be involved, by knowing what the care is, who gives it, why it is given, their potential choices and entitlements, the possible complications of such care, and the role of the state and other stakeholders in its provision¹. Today's patients seek autonomy in their healthcare delivery; i.e. they want the right to decide how they live and how they die², and to maintain their privacy; being own masters³. Essentially, patients seek to be allowed to express their personal autonomy, i.e. to exercise their right to make decisions about their medical care without their healthcare providers influencing their choices unduly.

Personal autonomy is, at a minimum, self-rule that is free from both controlling influence by others and from limitations, such as inadequate understanding, that prevent meaningful choice⁴. Lord Scarman describes autonomy in *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* as 'what is no more and no less than the right of a patient to determine for himself whether he will or will not accept the doctor's advice... the patient's right to make his own decision... may be seen as a basic human right protected

by the common law⁵. Autonomy is in contrast to heteronomy, i.e. being ruled by others. It is the counterweight to traditional medical paternalism, wherein the practitioner acted on what he or she considered «good» for the patient, whether or not the patient agreed. The core idea of personal autonomy is freedom from the controlling interference of others.

The present work sets out to look at the impact of such patient autonomy on the practice of medicine in the United Kingdom. The background to patients' autonomy, part of this research, has already been reported elsewhere. The first of three of reports here deals with the role of the stakeholders in appropriating autonomy. The second deals with infringement of autonomy and the remedies. While the third deals with how to fine-tuning autonomy.

2. The role of government in facilitating autonomy

In the UK, in addition to a majority of medical services being free for British and EU citizens, patients can choose their primary care practitioner⁶. This is currently undergoing an expansion by which, for example, patients referred to see a specialist can choose where they are treated from any NHS hospital. Patients are also entitled to treatment in other countries of the EU if conditions demand it⁷. However, in some cases, such as accidents and other emergencies, the power of patients to

choose may be restricted and the choice may have to be done by, say the ambulance crew.

In addition, the Department of Health (DH), as a means of empowering patients to exercise their autonomy for their healthcare, has continually sought to engage patients in the design and delivery of services. They are routinely asked for their views about their experience on the services they received. By so doing decision making in the design, implementation and monitoring of healthcare services becomes more tailored towards the needs of patients. The DH has reiterated that it is committed in this regard⁸.

Again, the DH has a Patient and Public Empowerment division that provide NHS institutions with the knowledge and expertise required to enable them to achieve their task of PATIENT empowerment. *Inter alia*, the Division is to provide information to people about their care to facilitate them to make better choices consequently better health. The Division is also to enhance people to achieve a stronger voice so they could be involved in their healthcare delivery⁹. The DH also has an Equality and Human Rights Group whose remit is «to work in a respectful and inclusive manner with partners and stakeholders...and to develop partnerships with stakeholders, regulators and patients»¹⁰.

With regards to consent, the General Medical Council (GMC) has issued guidance to doctors to work together with patients to ensure consent is well informed¹¹. It is clear from the foregoing government has shown commitment to facilitate the patient to maximise his or her autonomy in the uptake of healthcare services.

3. The doctor's role in autonomy

The scope of the doctor's responsibilities to his patient is very wide and cannot be dealt with in full in the present work. However, some aspects that frequently come into play in the context of patients' autonomy deserve some attention.

3.1. Duty of care

By accepting a patient into his list, a GP owes the patient a duty of care¹², so does the

NHS for all patients registered under it by virtue of its vicarious liability¹³. To ensure high standards in discharging such duty of care, there are guidelines from the various professional bodies involved in delivering healthcare, including the GMC, Dental Council, Nursing and Midwifery Council, Royal Pharmaceutical Society of Great Britain and the Pharmaceutical Society of Northern Ireland, as well as the Medical Royal Colleges. These periodically draw up protocols for treatment and to provide authoritative guidelines on good practice to enhance the discharge of the practitioner's duty of care.

The care relationship that exists between the doctor and his patient is that of trust. Within such a fiduciary relationship, the doctor has a duty, *inter alia* and most obviously, to diagnose and treat the patient's medical condition¹⁴. It is, therefore, not surprising this has become a frequent area of patient's dissatisfaction with the doctor's standard of care.

3.2. Duty to facilitate the patient's autonomy

It is also the doctor's duty to provide his patient with information that it seems likely he would need to make an informed decision with regards to his treatment thus endorsing the patient's rights¹⁵, as well as enhancing the quality of his care¹⁶. To enhance the exercise of the patient's autonomy, it is arguable that it is essential for him or her to be able to make an

Intelligent decision whether or not to undergo the proposed treatment¹⁷. On this, the importance of effective communication between doctor and patient in their care relationship scarcely needs mention, for it goes to the heart of the doctor-patient relationship, and is central to the «lack of informed consent» claims¹⁸. As a result, there is a growing emphasis on enabling patients to make informed choices or consent by providing them with adequate relevant information. For example, the GMC has stressed this in its guideline on consent: «Consent: Patients and Doctors Making Decisions Together»¹⁹.

In an Australian case, *Chappell v Hart*²⁰, the patient had surgery for a pharyngeal pouch.

She sustained an oesophageal perforation, and as a result, developed an infection which, in turn, led to paralysis of her right vocal cord. The patient's proceedings against the surgeon were on grounds that, had she been informed of the risk of sustaining the injury, she would have deferred the operation to ensure she engaged the most experienced surgeon she could find. The surgeon's breach of his duty to warn her of a material risk of injury to her laryngeal nerve, consequently the loss of her voice.

This makes the case for autonomy in that although it was chance, not negligence that caused the injury, the patient is entitled to know the risks and to choose whether or not to have the operation. In other words, failure to inform is in breach of the patient's autonomy.

3.3. Duty of confidentiality

The issue of confidentiality to private information and private life is not only relevant to the medical profession but in virtually all spheres of life, for example the media as in *AG v Guardian Newspapers (No 2)*²¹ and *Campbell v Mirror Group Newspapers Ltd*²². However, in other spheres of life this is in context of common torts, whereas when this concerns healthcare, it is in the context of the patient's autonomy.

The doctor/patient relationship rests on the platform of confidentiality. The right of patient to respect for his private and family life, his home and his correspondence, has been well defined in the Data Protection Act 1998²³ and Article 8 of the ECHR, which have strengthened the principles of confidentiality long established in common law. In *Z v Finland*²⁴ the court said: «Respecting the confidentiality of health data is a vital principle... It is crucial not only to respect the sense of privacy of a patient but also to preserve his or her confidence in the medical profession and in health services in general». The doctor is not to divulge any information he holds on his patient to a third party without the patient's consent. To do otherwise could invoke litigation by the patient if he so wishes.

This notwithstanding, there are circumstances, as for example, where the public in-

terest overrides that of the patient, when the doctor can disclose a patient's information after obtaining declaration from the court to do so. At times, in spite of the medical profession itself seeking to address the issue by providing guidelines, drawing the boundaries as to what information of a patient could be released, when to do so and for whose interest could be difficult²⁵. As part of its self-regulatory measures²⁶, the GMC, in its documents «Confidentiality: Protecting and Providing Information»²⁷ and «Good Medical Practice»²⁸, warns doctors to be vigilant in maintaining their duty of confidentiality with regards to patients' information.

Other key areas in which patient's confidentiality could be breached include medical research, particularly involving retrieval of information from patients' personal data and the release of information to third parties other than for the public interest, for example, to family members and the judiciary. This is an important area from the point of whether invasion of privacy is an invasion of autonomy. In other words it raises the major point that autonomy is not just a matter of consent – but is essentially a matter of the integrity of the individual.

4. The patient's responsibilities in autonomy

4.1. Commitment to the uptake of services

While patient autonomy lies at the heart of the doctor/patient relationship, it is also widely recognised as having a correlative imperative in the uptake of ideal healthcare services. One reason for this is that, by taking personal responsibilities for their health, patients can make significant contributions to ensuring that resources are responsibly used for their own, and the community's, well-being. While both the NHS Constitution for England²⁹ and a Consultation Paper on Patients' Rights Bill for Scotland outline the NHS responsibilities to patients, the documents also define the latter's responsibilities for their own and their community healthcare. This is in order for patients to acknowledge the fact that they are in

partnership with other stakeholders involved in their healthcare, and this calls for mutual recognition. Defined patients' responsibilities include:

- Ensuring they register with a GP, the main point of access to healthcare services.
- Ensuring they keep their appointments, and if they must cancel them, to do so with a reasonable notice so that other patients could use the appointments.
- Providing relevant and accurate information about their health, condition and status.
- Ensuring they comply with the treatment mutually agreed with their doctors.
- Informing their healthcare providers of any change in their condition.
- Respect for NHS staff and all those who are involved in delivering their care.
- Respect for other patients.
- Avoiding nuisance or disturbance on NHS premises.
- Where possible, seeking, understanding and using health information appropriately.
- Participating in important public health programmes such as vaccination.

Summing up these responsibilities, in her foreword to the Scottish Consultation Paper on Patients' Rights Bill, Nicola Sturgeon, Cabinet Secretary for Health and Wellbeing, said; «as tax payers and as citizens, we all have a stake in how the NHS operates, and are part-owners of the NHS. That gives us rights, but also responsibilities...I want you to see yourselves not as passive recipients of NHS services, but as active partners in decisions about your health and healthcare...I want you to know how your NHS will help you to access your rights and, where appropriate, support you in accepting your responsibilities»³⁰.

This call for responsibility serves to emphasise the paramount position now accorded to patient autonomy in what is seen as shared decision making³¹.

4.2. Consent

This alliance between patient and their doctors is primarily designed to enhance the quality of care the former anticipates³². To reciprocate this, it is expected that the patient will take well-considered decisions on the issue of consent to the treatment. This notwithstanding, there are times when, by exercising their autonomy, mentally competent patients decide against the treatment proposed for them by their doctor. The important thing here is not the rationale of the decision but the patient's autonomy which has to be respected.

There are occasions where patients believe they are rational in their decisions for their treatment as in *Re C (Adult: refusal of medical treatment)*³³. The patient, diagnosed with chronic paranoid schizophrenia, suffered from ulcerated gangrenous foot for which he needed amputation otherwise had small chance of survival. He refused to consent to amputation, but allowed conservative treatment. He got better on conservative treatment, but the hospital refused to give undertaking that the leg would not be amputated in the future. The patient applied for an injunction against amputation without his consent. His application was held on ground that it had not been established that his general capacity was impaired.

This case sets the three stage test for capacity namely: comprehending and retaining information for treatment, believing it and weighing it in the balance to arrive at a choice. A patient passes the test by s3(1) of the Act, and thus has absolute right to refuse treatment. However, if the patient fails the test the doctor should treat him in accordance to his best interest as provided by s1(7) of the Act³⁴. However, of some implication is how to assess the stages of the test in practice.

4.3. Consideration for others

Autonomy would be lopsided if it is seen only to make the patient's rights count for everything while the doctor counts for nothing³⁵ other than being reduced to a mere technician delivering the consumer-patient demands³⁶. This would be a mistaken interpretation of au-

tonomy³⁷; for, much as autonomy empowers the patient for self rule, it calls for acceptance of personal responsibility for the exercise of such rights³⁸.

Therefore, a more rational appropriation of autonomy by patients would be the communitarian approach whereby patients, rather than being egocentric in the exercise of their autonomy, should consider also the impact of their decisions on others, thus recognising

They are integral parts of their community³⁹.

Arguing for this, Margaret Brazier first highlights the fact that, for most of the 20th century, judges were too ready to endorse doctors' decisions as to what was considered best for the patient⁴⁰. She points out that, since the rise of autonomy, there has been an over correction of the balance, so that patients tend to forget they have responsibilities towards others. They demand their doctor to «do no harm» to them and to behave ethically towards them, but the question is: «Does the patient have a reciprocal duty towards the doctor – respect for the doctor's autonomy?» She argues that people have ethical responsibilities towards others which do not disappear simply because they are patients⁴¹.

A sense of ethical and moral responsibilities of the patient to others would be a true weaning from the paternalistic era that gave him or her little or no responsibilities. As David Hume puts it: «All our obligations to society seem to imply something reciprocal. I receive the benefits of society and therefore ought to promote its interests»⁴². This is even more so where healthcare is publicly funded as this calls for collaboration between doctors and patients, between the sick and the well and between the sick and the sick. Even if health were not publicly funded, it is not purely a personal issue; one's good or ill health has a great potential to impact directly or indirectly on others in the community in which he lives.

While patients' responsibilities call for their personal accountability in the appropriation of their autonomy as a means of their active participation in attaining ownership

of their healthcare for their direct personal benefits, this should be balanced with their commitment not to infringe on others' autonomy, but to pave the way for members of their communities to exercise their own autonomy. This balance would be made feasible by a continuous conscious awareness of the fact that it is the members of their community that make the realisation of their autonomy possible. Therefore, the patient, applying the adage, «do to others what you would want done to you», should discharge his responsibility in exercising his or her autonomy, not from an egocentric perspective, but in a manner that enhances other stakeholders involved in his or her healthcare delivery to also realise theirs. Being a stakeholder means having proportionate acquisition of the stake, and not overbearing on other stakeholders, a fact the patient ought to constantly be aware of so as to maintain a symbiotic role in the strive for autonomy, if he or she must allow other stakeholders their fair and proportionate share of the stake – healthcare.

4.4. Patients' appropriation of autonomy

It is not surprising that patients, who are well aware and conscious of their legal rights, sometimes see themselves empowered by these rights to demand rather than request their medical care. However, such a demand involved resolution of issues such as the limits of a patient's rights, when they crystallise, whether they are absolute for all types of treatment, and how they compete with the rights of other patients. For example, Article 2 of the ECHR addresses legal issues such as an individual's right to die, or the legality of allowing patients in persistent vegetative state (PVS) to die by withholding or withdrawing treatment. More recently, however, in *NHS Trust A v M, NHS Trust B v H*⁴³, it was held that Article 2 does not impose an obligation to prolong life in the PVS. Also contentious issues under Article 2 are abortion rights, the legal rights of foetuses for personality and when a right of life accrues. Associated with this list are patients' efforts to exercise their

autonomy in deciding when and how they die, consequently opening up the big subject of euthanasia. Such patients' pleas by the invocation of Articles 2, 3, 8, 12, and 14 of the ECHR have seldom succeeded either at the national or Community level⁴⁴.

At the back of this is the fact that doctors cannot be forced to give treatment they believe to be clinically unnecessary, futile or inappropriate. All these issues beg for an in-depth discussion as to their growing significance in society today.

Thus at the outset it looks glaringly as though, while autonomy assertively promotes the rights of the patient, the doctor has no rights within the context of the Hippocratic principles when choosing his treatment for his or her patients. The increasing emphasis on the patient's autonomy at the expense of the doctor's has contrived to widen the gap in the ideal doctor/patient relationship. This needs not be so. The way to satisfy this relationship is not through confrontational profession of rights but, rather, through the realisation of both parties of a mutual obligation to work towards the ideal in healthcare delivery. Furthermore, personal autonomy should be measured against the needs of society as a whole – for society itself demands a just distribution of resources. All the foregoing point to some restraints as to the level of patient empowerment that results from the exercise of autonomy by patients.

5. Doctor and patient working together to enhance autonomy (Shared decision making)

In the UK the principal stakeholders in healthcare delivery are the government, the medical profession and the patient. To achieve effective healthcare delivery, there has to be working collaboration among the stakeholders based on patients' rights, public responsibilities, accountability, resources, support and stewardship. This is particularly more so in the current time of rapid social change⁴⁵.

Although the foundations for a shared decision-making model seem to have been laid by Lord Bridge in *Sidaway*⁴⁶ and by Lord

Woolf MR in *Pearce v United Bristol NHS Trust*⁴⁷, patients and doctors appear not yet actually to be fully engaged in the model⁴⁸. It is suggested that for effectiveness in SDM the doctor should go beyond information giving to information seeking, thus reciprocating the process. Thus the doctor should give the patient room and encouragement to ask questions⁴⁹.

This is because for a patient to make a truly informed decision on his management, for example, he or she must understand the options, the consequences of acting on them, and their cost and benefit consequences in terms of the patient's personal values and priorities⁵⁰. Effective interaction between the doctor and his patients has been shown to be central to patients' willingness to adhere to treatment regimes and to follow the doctor's recommendations and, consequently their, satisfaction with their treatment⁵¹.

In its guideline document to doctors on consent for example, the GMC says, *inter alia*:

- «You must work in partnership with your patients.
- You should discuss with them their conditions and treatment options in a way they can understand, and respect their right to make decisions about their care.
- You should see getting their consent as an important part of the process of discussion and decision-making, rather than as something that happens in isolation.
- Whatever the context in which medical decisions are made, you must work in partnership with your patients to ensure good care.
- In so doing you must listen to patients and respect their views about their health...maximise patients' opportunities, and their ability, to make decision.
- You must not make assumptions about the information patients want or need.
- You must give patients the information they want...»⁵². The SDM model

requires the patient, having got all the information from his or her doctor, to make a rational decision on her or his treatment.

Although the line between control and share-decision making is fine⁵³, it is important that healthcare professionals do not seek to over-control consultations. A key safeguard for control of consultation is avoiding interrupting patients when they are speaking⁵⁴.

As a means of patient and doctor working together, Quil TE and Brody H recommend what they call the «enhanced autonomy model»⁵⁵. In this model, while they believe an autonomous decision is best made without external influence, they hold that such decisions should be enhanced rather than undermined, and this should be governed by input and support from a well-informed physician. The fulcrum of the model is dialogue in which the physician and patient aim to inform each other as this is crucial in the patient being able to fully appreciate the medical possibilities he has⁵⁶. Although final choices belong to the patient.

6. Conclusion

The present report has outlined the engagement of the principal stakeholders in the appropriation of autonomy through their respective and collective roles. By its responsi-

bility in providing healthcare, the government is committed to avail, facilitate and regulate delivery of care through its agencies; most important of which is the doctor and other healthcare professionals. The doctor, who is in direct delivery of care to the patient, is in a relationship of trust with the patient. He is required to be engaged with the patient for an informed delivery and uptake of care, under the auspice of duty of care, confidentiality and informed consent. The patient, having been liberated from medical paternalism, is required to exercise his autonomy responsibly by personal commitment to the design and uptake of services, as well as mutual engagement with his doctor for decision making with regards to his healthcare. While autonomy facilitates the patient for his healthcare, he has to exercise this in the context of the symbiotic relationship that exists between him and his community. Where individual's autonomy interests conflict with his community's, the latter supersedes. While the patient's autonomy is distinctive, the doctor's is ill defined in the context of his profession. Although, central to the appropriation of autonomy is for it to be hitch free, conflicts may still arise. This leads us to the subject of the next part of this report – infringement of autonomy and its remedies.

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РЕЗЮМЕ

Починаючи з середини ХХ століття, принцип автономії пацієнта набуває особливого значення у медичній практиці. Центральним інститутом, пов'язаним з автономією пацієнта, є інформована згода. Сьогодні отримання інформованої згоди на медичне втручання чи участь у дослідженнях є обов'язковою вимогою. Однак внаслідок цього відносини «лікар-пацієнт» у значній мірі опинилися під загрозою. У той час, як пацієнт позбувся лікарського патерналізму і отримав право на автономію, обсяг професійної автономії лікаря залишається невизначеним. Подолання проблем у відносинах лікаря і пацієнта можливе завдяки спільному прийняттю рішень, коли доктор і пацієнт взаємодіють в інтересах пацієнта. У разі, якщо конфлікти все ж таки виникають, доктор і пацієнт повинні намагатися вирішити їх шляхом переговорів. У випадку неможливості мирного урегулювання спору починають діяти правові механізми. При цьому необхідно врахувати, що інтереси пацієнта є першочерговими. Однак коли вони суперечать інтересам суспільства, перевага має бути віддана інтересам суспільства. Загалом, хоча концепт автономії пацієнта здійснив революцію у медичній практиці Сполученого Королівства, як і більшості інших розвинених країн сучасного світу, для того аби не відставати від розвитку медичної професії та суспільства в цілому, необхідна подальша розробка питання застосування принципу автономії пацієнта.

РЕЗЮМЕ

Начиная с середины ХХ столетия, принцип автономии пациента приобретает особое значение в медицинской практике. Центральным институтом, связанным с автономией пациента, является информированное согласие. Сегодня получение информированного согласия на медицинское вмешательство или участие в исследованиях является обязательным принципом. Однако вследствие этого отношения «врач – пациент» в значительной степени оказались под угрозой. В то время, как пациент избавился от врачебного патернализма и получил право на автономию, объем профессиональной автономии врача остается неопределенным. Преодоление проблем в отношениях врача и пациента возможно благодаря совместному принятию решений, в ходе которого врач и пациент взаимодействуют в интересах пациента. В случае, если конфликты все же возникают, доктор и

пациент должны пытаться разрешить их путем переговоров. Если же мирное урегулирование спора оказывается невозможным, начинают действовать правовые механизмы. При этом необходимо учитывать, что первоочередными являются интересы пациента. Однако когда они вступают в конфликт с интересами общества, приоритет должен отдаваться интересам общества. Хотя концепт автономии пациента совершил революцию в медицинской практике Соединенного Королевства, как и большинства других развитых стран современного мира, для того, чтобы идти в ногу с развитием медицинской профессии и общества в целом, необходима дальнейшая разработка вопроса применения принципа автономии.

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