Maximizing patient autonomy to improve outcomes

The term autonomy is frequently used in ethical debates and taken for granted as a desirable value in medical practice. However, there is little consensus about what this term actually means, and it is also used differently within various disciplines. The previous article in this series (Stephenson et al, 2012) reviewed the concept of autonomy within philosophical tradition and historical context. This second article discusses the varieties of autonomy within clinical interaction and factors affecting the optimization of patient autonomy.

Introduction

As a doctor it is important to be knowledgeable about the philosophical concept of autonomy for the following reasons.

First, doctors frequently face complex ethical dilemmas which require careful navigation. Biomedical ethics and the law provide a protocol for dealing with these issues, but difficulties still arise as every situation has nuances, the management of which are unspecified. A fuller understanding of the values and concepts which law and ethics aim to uphold can help equip doctors to effectively resolve dilemmas they face.

Second, as discussed in the first article in this series, if doctors can help patients to feel autonomous even when managing an illness which curtails their freedom they are more likely to take their medications regularly and therefore have better outcomes (Williams et al, 1998; Stephenson et al, 2012). Instilling a sense of autonomy is no small feat, but the concept of autonomy has a rich philosophical tradition of exploring human experience and understanding and can offer important insights to aid this task.

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The previous article outlined the multiple meanings held by the term 'autonomy'. Following Bolton and Banner (2012) the authors suggested dividing the theoretical landscape of personal autonomy (in relation to clinical practice) into two broad groups. Accounts in the first group hinge on the idea that what makes an action autonomous is 'a particular kind of motivational pedigree within the agent's own internal psychology' (Bolton and Banner, 2012). Accounts of autonomy in the second group, however, refer to freedom of action understood as a political value, which requires that individuals are free of intervention by others.

This article moves on from this foundation to explore debate about the varieties of autonomy present within a clinical interaction and how they can be manipulated to improve a patient's experience of agency and so the patient's outcomes. However, it is important to hold in mind that pure autonomy remains an ideal which can only be travelled towards rather than accomplished.

External factors affecting autonomy

Autonomy curtailed by illness

It is important to recognize that autonomy is always limited in as much as we are faced with the physical constraints of human existence. We cannot always do what we want, for example, because doing so may harm another person or there may be insufficient resources to fulfil our desire. Within the medical context a person's choices are further curtailed as the very fact that the person is seeing a doctor may be because the patient's body has let the patient down in a way he/she would never choose. As a result the patient may be faced with a range of options which are all undesirable, e.g. between an inconvenient, lifelong drug regimen plus side effects or the progression of severely destructive rheumatoid arthritis. Bearing this in mind highlights the importance of enabling patients to grasp specifically those aspects of autonomy which are possible to achieve.

The ritual of informed consent

It is assumed that patient autonomy is explicitly respected by external parties when we ask patients for permission before we do something to them, or in other words, gain their consent. In most medical contexts there is a range of practice around gaining consent from assuming implied consent, e.g. when a patient holds out an arm to have a blood test done, to gaining written evidence of informed consent, e.g. when a complex and risky surgical procedure is planned.

The General Medical Council (2012) provides helpful guidance around when written proof of informed consent is required:

> **'[I]f: the investigation or treatment is complex or involves significant risks, there may be significant consequences for the patient's employment, or social or personal life, providing clinical care is not the primary purpose of the investigation or treatment, the treatment is part of a research programme or is an innovative treatment designed specifically for their benefit.'**

However, aside from organ donation or fertility treatment there is no legal requirement that informed consent must be formally documented. Therefore the patient must rely on the doctor to assess the level of risk at which more explicit explanation becomes necessary. From this perspective it is easier to sympathise with those who argue that documented informed consent is more for the doctor's benefit than the patient's. This is because if a treatment goes wrong the doctor can prove that the patient assented and accepted the risk involved.

O'Neill (2003) argues along similar lines that informed consent is less about respecting a patient's autonomy and more about protection from coercive medical interference. She supports Wolpe's (1998) understanding of informed consent as the 'modern clinical ritual of trust' (O'Neill, 2003). This idea is interesting because it is so accurate; when medical students do practical exams the vital rituals of hand washing, introduction, explanation and gaining consent are played out before any demonstration of practical ability. This argument suggests that the doctor's job is not done just because one has the patient's informed permission; this obligation merely protects patients from being treated because of a doctor's agenda. It is another step altogether to respect and foster autonomy in patients.

Lamenting the decline of paternalism

Some writers have expressed concern that with the decline of paternalism and the emphasis on patient autonomy within medicine we have lost something important – the element of the doctor–patient relationship which allows a patient to trust the practitioner. This may be partly a result of the rise in litigation. In a modern clinical consultation there is heavy emphasis on patient choice which could arguably put a responsibility to choose onto the patient which in fact he/she does not wish to have.

However, Kukla (2005) argues that patient autonomy is not necessarily to do with active self-determination as a patient can autonomously choose to defer a decision to a person he/she judges as trustworthy and who is better equipped to make a decision about the patient's health. If autonomy is understood in this way there is no need to recourse to paternalism in order to reclaim trust as an important factor in a clinical consultation. Beauchamp and Childress (2009) also emphasize that there need not be a conflict between authority and autonomy as long as a person can autonomously choose to submit to authority.

A knowledge gap

Knowledge is a vital factor in enabling a patient to act autonomously. First, there is an inherent inequality in a doctor–patient consultation; by virtue of the profession doctors have very specialized knowledge. Ensuring patients are equipped with the relevant information redresses this balance and helps protect patients from coercive influences thus promoting their freedom to choose and act accordingly. Second, one of the key factors in any decision is understanding the consequences of an action. Weighing up such consequences in accordance with the person's values enables the patient to prioritize his/her options thus promoting his/her ability to form an internally consistent decision.

Kukla (2007) argues that the sources of information which patients use have changed. She points out that many patients are no longer empty vessels but that before consultation they may have already accessed myriad sources of information (Kukla, 2007), particularly internet information sites and forums. On the one hand, these technological resources can promote a patient's ability to make autonomous decisions as the patient has unprecedented access to information and opinions which gives him/her the power to question an unorthodox piece of medical advice. On the other hand, being overwhelmed with information without the advantage of training in critical review can be disabling for the patient. There may be huge variation in the patients doctors see in clinics with regard to levels of verbal and statistical literacy and access to information sources outside the orthodox medical setting.

Collaboration aids personal autonomy

Until this point this article has focussed on the importance of the individual being able to decide to do what he/she wishes. However, Kukla (2007) highlights the importance of being able to form collaborative relationships in making autonomous choice. In practice this is a helpful consideration as it encourages a mindful awareness of the importance of interpersonal relationships between a doctor, the patient and the patient's family in helping the patient to determine his/her choice.

Internal factors affecting autonomy

Having explored ways in which a person's freedom to act may be affected within medical scenarios this article will now review ways in which internal and psychological factors can affect a person's ability to choose or, in others words, to lead him-/herself.

Personal autonomy in individual decisions

It is important to recognize the presence and impact of internal psychological inconsistency when a person is asked to make a decision, especially when the decision to be made concerns high stakes such as frequently occurs in medicine. Instantaneous emotional reactions such as anxiety and fear may affect one's ability to take in factual information and can sway and increase the intensity of various internal competing drives and desires, meaning that an internally consistent decision is difficult to come to.

Complications usually arise when a patient disagrees with what is thought to be in his/her best interests, especially in a situation where an intervention could be significantly life improving or life saving. A patient's right to make an unwise decision against medical advice is protected by law as long as he/she is judged to have the capacity to make that decision. Capacity is summarized as being a person's cognitive ability to engage in a particular decision-making process (Department of Constitutional Affairs, 2007). This is measured by the ability to understand given information, retain that information, weigh the pros and cons of taking a particular course of action, and communicate the decision via whatever means the person is able to use. In these difficult situations there are often lengthy discussions with the patient to (help him/her) uncover particular motivation or concerns which may be influencing the decision-making process.

Self-led long-term self-care

What is less often considered is a patient's ability to commit to and actively participate in a health improving regimen. A patient who agrees with the doctor in the clinic may not have a strong enough desire or will to continue a particular regimen. Several have argued that this longer term consideration of a patient's autonomy is of great importance and that 'the physician's task is, in part, to inculcate patients into the appropriate good health care regimes' (Kukla, 2005).

Kukla helpfully contrasts compliance with conscientiousness and points out that being a patient is more than agreeing with a doctor. She uses the example of diabetes to illustrate that patient autonomy is different to pure self-determination; a patient cannot independently generate the knowledge required to manage a particular condition. However, the patient does more than simply consent to take insulin. A proactive ongoing approach is required from the patient, with awareness about aspects such as self-monitoring, diet and the need to attend eye checks (Kukla, 2005).

Pearce and Pickard (2010) comment on the importance of encouraging a sense of agency in patients by viewing them as active managers of their behaviour rather than passive recipients of their illnesses which must be treated by doctors. In practise this might not seem easy for the clinician to achieve. However, increasingly techniques used in mental health services to treat addictions, such as motivational interviewing (Rollnick and Miller, 1995), are being used in the management of chronic medical conditions with impressive results (Rubak et al, 2005). Motivational interviewing takes a non-instructive approach to facilitating behaviour change. It aims to enhance the patient's conscious awareness of psychological contradictions. The interviewer and the patient work collaboratively towards resolving ambivalence to change by encouraging the patient to identify his/her most strongly held values and act in accordance with these.

Conclusions

The experience of illness can be particularly devastating because there is loss of autonomy, and the ability to control our body as we choose is lost. The role of a doctor is to treat illness and thus restore a sense of autonomy. The basic procedure of obtaining consent before proceeding with an intervention is a vital step as it respects a person's freedom to choose independently. However, a doctor has a greater role to play in promoting autonomy than simply avoiding coercion of his/her patients.

Skill and time is required to appreciate a patient's level of understanding about the condition which affects him/her and to provide accessible information. An appreciation of the importance of interpersonal factors in promoting patient autonomy can help clinicians develop relationships with their patients and their relatives which in turn support the patient in uncovering his/her own guiding values and helps the patient to choose and act accordingly.

Awareness of a person's competing desires and motivations, such as a particular treatment choice or committing to a long-term health regimen, can increase doctors' ability to communicate effectively with their patients. The overarching goal is to help patients in becoming informed decision makers with the ability to understand and manage their own disease, thus maximizing their experience of autonomy even in the midst of conflict and life-altering illness. **BJHM**

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KEY POINTS

- A wider appreciation of the concept of autonomy within philosophical tradition and medical ethics can inform practical ethical decision making, facilitate patient empowerment, improve outcomes and foster empathy.
- The term autonomy encompasses a variety of different meanings which can be divided into those which refer to autonomy as a person's freedom to act as he/she decides and those which refer to autonomy as a person's ability to make internally consistent decisions.
- Autonomy is curtailed by illness, as the body is less under the patient's control than before he/she became unwell. Doctors have a vital role in restoring autonomy by treating the illness and enabling patients to autonomously manage the condition.
- The ritual of gaining informed consent represents the most explicit respect for patient autonomy in everyday clinical practice.
- A patient can autonomously place his/her trust in a doctor without recourse to paternalism.
- The appropriate provision of accessible information and a patient's ability to use and respond appropriately to that information has a significant impact on a person's ability to act autonomously.
- A patient's ability to make an autonomous decision is impacted by his/her internal psychological state and ability to reconcile competing drives or desires.