Consent in the face of death
Camilla Louise Scanlan, Cameron Stewart, Ian Kerridge

Abstract

While the traditional model of consent is supported by codes and theories of ethics, is enshrined in law, and provides the core of health policy and clinical governance, it is unclear how accurately it reflects clinical practice and in particular how accurately it accounts for decision-making in ‘high-risk’ situations where patients are critically ill and facing death.

Main text

In Western liberal democracies, the requirement for a patient’s informed consent prior to medical treatment is indisputable. The importance attached to consent reflects the cultural and philosophical privileging of autonomy, liberty, and human rights and the broad commitment to the recognition and maintenance of human dignity.

For a patient’s consent to be legally and ethically valid, it is generally assumed that a number of ‘criteria’ or ‘elements’ need to be satisfied, namely that the patient has the capacity to consent, has made the decision voluntarily, and has been provided with ‘material’ information about the proposed treatment, including its rationale, costs, risks and benefits. While differences remain between patient-centred and doctor-centred approaches to standards of information provision, it is clear that all common law countries demand that patients be told of the risks of having, or not having, treatment.

But while this traditional model of consent is supported by codes and theories of ethics, is enshrined in health law, and provides the core of health policy and clinical governance, it is unclear how accurately it reflects clinical practice, and in particular, how accurately it accounts for decision-making in ‘high-risk’ situations where patients are critically ill and facing death.
There are three principal reasons why we may feel uncomfortable about the alignment between ethics, law and clinical practice in regards to consent in high-risk settings. The first is that the way in which consent in constructed in law and ethics implies a sense of detachment that is simply impossible, particularly when patients are under the threat of incipient mortality. The second is that ‘risk’ is extraordinarily complex and may be understood both ‘objectively’ (as a probabilistic assessment of adverse outcomes) and ‘subjectively’, and also by reference to both the patient (as a function of their diagnosis and/or comorbidity – that is to say, a high-risk or low-risk patient) and the intervention (as a function of its necessity, efficacy, burdensomeness and complexity, and the uncertainty of its consequences). The third reason is that there is very limited empirical data regarding how consent is actualised in high-risk situations. In part, this is because such studies are enormously difficult to conduct because time is frequently of the essence and patients/participants are highly vulnerable and (perhaps ironically) because obtaining consent to participate in research of this kind is so ethically fraught. Consequently, the data that does exist often focuses on endpoints of questionable relevance, such as the documentation of consent, is derived from methodologies of dubious veracity such as retrospective interviews with ‘survivors’, and is drawn from highly selected patient populations most notably from patients undergoing major surgery, and so may have limited relevance to other ‘high-risk’ medical situations where therapeutic options are more limited and the clinical urgency more ‘pressing’.1

While it is tempting to suggest that the lack of clarity we feel about the application of consent in high-risk situations is simply a methodological problem, we suggest that high-risk situations reveal more fundamental problems with the way that consent has been conceptualized and the notion of autonomy that it presumes. More specifically, we suggest that attachment both to the notion of consent as ‘atomistic’ and to the idea that autonomy is best understood as an individual’s freedom to choose or to rationally and intentionally articulate one’s preferences and moral positions, is misplaced and misguided.2,3

While philosophical accounts of autonomy have traditionally focused on sovereignty and rationality, when faced with death patients are intensely vulnerable and they may become more concerned with their care and their future than their ‘power’ or independence. Patients, in particular those facing a high risk of death,
are often highly cognizant of both the degree to which they are reliant upon the expertise of the healthcare professionals and institutions upon which their survival depends, and of the ways in which their choices are determined by, and impact upon, their families and friends. This account of decision-making in high-risk situations is more consistent with feminist accounts of autonomy, which note the degree to which autonomy is ‘relational’ – located socially and not simply within the individual.

While relational autonomy does not ‘dull’ the immediacy or the starkness of the choices faced by patients in high-risk situations, locating autonomy socially, rather than individually, and describing it in terms of the specific medical context in which it is actualized, better accounts for the ways in which every element of consent is compromised or challenged by illness.

For patients are rarely, if ever, ‘free’ to make decisions about their healthcare in the sense that their decisions are independent from the impact of their condition and the concerns of others.

Patients often have compromised decision-making capacity, and may lack the information or understanding to fully comprehend the situation in which they find themselves. This may, of course, be a function of physical and mental debility, medications, pain, depression and anxiety but it may also be an inevitable consequence of illness and the limited options that patients have when faced with a threat to their life. Indeed, in many ways the greatest influences on decision-making, autonomy and agency may be disease itself, the existential threat of extinction and the social and moral worlds in which patients live. Consequently, in high-risk situations patients may not need more information about choices that they do not have, or even more detail about the interventions that represent their only therapeutic option other than palliation (which should be provided in any case). For in these situations, the notion of an ‘informed’ consent becomes a misnomer, as when the risk of death becomes closer to certainty, the materiality of the risks of treatment disappears. What is therefore needed is some shared understanding of the goals of treatment, the outcomes that are hoped for and the rationale for the choices being made, and a promise of care and ‘persistence’. In other words, a promise that the treating team will support the patient as they struggle to survive and, if this is not possible, as they die.
None of this denies the importance of respect for autonomy and of identifying and addressing the many ways in which healthcare institutions and healthcare professionals accentuate inequity and disability and diminish dignity and autonomy. Neither does it remove the obligation upon healthcare professionals to maximize patient’s agency and autonomy and provide them with the information they need to realize their treatment preferences consistent with their own values, needs and goals.

Instead, recognizing the medical and social context in which high-risk medical decisions are made reminds us that consent is far more limited and far more constrained that we may imagine it to be (at least in ethical and legal terms). It also illustrates the degree to which medicine is, as Ed Pellegrino has noted, frequently characterized by “a peculiar constellation of urgency, intimacy, unavoidability, unpredictably, and extraordinary vulnerability”. These insights, in turn, illustrate the manner in which medicine, law and ethics inform each other and the inadequacy of simply ‘applying’ abstracted ethical and legal constructs to the experience of illness and healthcare delivery.

The structural elements of informed consent perform important legal, ethical, institutional and educational functions. But when properly understood they are all, almost of necessity, complex, ill-defined, socially constructed and a matter of judgment. And, all, like every aspect of healthcare, rest upon foundations of care, trust and a realisation of the fragility of the human condition.

---

