

# Respect for autonomy: Consent doesn't cut it

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Clinical Ethics

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As we all know, respect for a patient's ability and freedom to make decisions about healthcare matters that concern them (i.e. 'respect for autonomy') is necessary for the ethical conduct of clinical practice. In contemporary liberal societies, the slogan 'the doctor knows best' is no longer afforded much currency. Indeed, even when the spectre of paternalism rears its head in specific, unusual situations, for example, during the COVID-19 pandemic,<sup>1</sup> it tends to be accompanied by a sense of unease among ethicists, legal scholars, patients, and healthcare practitioners.

In most jurisdictions worldwide, informed consent is seen as the application of the principle of 'respect for autonomy', a perception that has been supported by now classic discussions of patient autonomy in medical ethics and law.

The roots of the alignment of informed consent and respect for autonomy can be found in late-1950s US case law, which employed the language of autonomy to introduce the concept of informed consent to clinical medicine.<sup>2</sup> These developments in law permeated medical law, ethics, education, and Western clinical practice in the 1970s.<sup>2,3</sup>

Today, the initial legally motivated links between the concept of autonomy and informed consent have become conceptually entrenched in the domains of healthcare and biomedical research, and the conflation of these two concepts is now a widespread assumption in law and clinical and research ethics frameworks.<sup>3–6</sup> In short, the courts, regulators, clinical ethics teams, and biomedical researchers have assumed that when an individual gives valid consent, it is autonomous.

This assumption is deeply problematic with wide-ranging ethical, legal, and well-being implications. From a theoretical point of view, informed consent is the standard mechanism through which a patient exercises their *liberty* at law, giving permission for, and setting the limits of, bodily interference.<sup>3–8</sup> By contrast, according to Feinberg, the concept of autonomy can refer to the *capacity* to govern oneself, the authentic exercise or achievement of self-government, a value that one instantiates such that one should be afforded equal standing, or the value that paternalism, coercion, and other malign influences fail to respect.<sup>9</sup>

The concept of informed consent fails to adequately capture any of these interpretations of autonomy. The practice of informed consent does not take into account whether an individual has rationally responded to their values, desires, or motives or whether these values are *truly* theirs.<sup>4,6</sup> In addition, standard requirements for informed consent are such that some individuals who should arguably be afforded the opportunity to make claims to autonomy are denied.<sup>5,6,10</sup> Further, the giving of valid consent does not imply that the decision has not arisen from normatively significant external influence.<sup>11</sup> Finally, because the *capacity* conditions for valid consent are framed in purely *cognitive* terms, consent does not account for important relational or embodied (i.e. *non-cognitive*) factors that have been shown to affect or constitute one's capacity for autonomy.<sup>12–15</sup>

The main upshot of this conceptual confusion is that a patient can give valid consent and thereby be perceived to have had their autonomy respected, yet still fail to make an autonomous treatment decision (i.e. because, for instance, they've failed to satisfy certain autonomy conditions beyond those required by informed consent).

At this point, defenders of consent as the mechanism for respecting autonomy may argue that these problems are purely theoretical and to be expected if we rely on *ideal* theory, and that, when it comes down to non-ideal, concrete situations, informed consent is our best bet for living up to the spirit – albeit not the letter – of the principle of respect for autonomy.

I am hugely sympathetic to the idea that although medical ethicists can develop clear, principled analyses of what ought to happen in clinical contexts, the demands of clinical reality are such that it can be of little use to patients and practitioners to point to the ideal. If the issue were purely a theoretical one, then I'd be content to accept consent as a proxy for respect for autonomy in the interest

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of meeting the needs of patients and practitioners. What self-respecting, compassionate medical ethicist wouldn't?

The problem is that this isn't just a purely academic issue of principle. Firstly, a series of recent studies conducted by Joanna Demaree-Cotton and Roseanna Sommers has shown that ordinary people (i.e. those we would expect to be patients or potential research participants) infer a clear distinction between the concept of autonomy and the concept of consent.<sup>16</sup> This means that if we are genuinely committed to the principle of respect for autonomy, then the employment of informed consent is unlikely to be a suitable way of demonstrating that commitment.

Secondly, the conflation of consent and autonomy can yield substantive ethical, social, and well-being implications for those who are often the most vulnerable in society. Joel Anderson and Axel Honneth observe that one of the hallmarks of liberalism is its commitment to safeguarding individuals' autonomy and one of the standout features of liberal social justice is its commitment to protecting the vulnerable.<sup>17</sup> On that basis, they argue that 'liberal societies should be especially concerned to address vulnerabilities of individuals regarding the development and maintenance of their autonomy' (p. 127). However, rather than supporting the autonomy of vulnerable individuals, we currently have a situation where patients perceived by healthcare practitioners and/or the law to be vulnerable are likely to be denied liberty to consent because any consent they would provide is considered to be problematic.<sup>5,6</sup> The issue is that an individual's vulnerability is deemed to be sufficient reason for denying them the opportunity to consent even if they fulfil the requirements for autonomous choice.<sup>6</sup> This can render a vulnerable patient even more vulnerable, provide support for discriminatory and paternalistic healthcare policies/interventions, and – *contra* the commitment of liberal social justice – preclude obligations to support a patient's autonomy.<sup>6,18</sup>

Similarly, the conflation of consent and autonomy raises practical and ethical questions in the context of biomedical research. Evidence suggests that there is an association between ethnic minority status, mistrust in biomedical research, and a reluctance to donate samples.<sup>19,20</sup> Of course, one of the key factors behind this association is the historical experiences of certain ethnic and cultural minority groups with exploitation, both in general and as research participants. At the same time, and, in part, linked to such historical experiences, individuals within minority groups perceive consent processes to be a barrier to their participation; not only do they consider acknowledgement of, and respect for, their moral, religious, and/or cultural values to be essential for overcoming their mistrust of biomedical research, but they also acknowledge that most consent processes do not engage with their underlying values and, thus, allow them to make genuinely autonomous decisions concerning the scope of, and limits to, the use of their donated biomaterials.<sup>21,22</sup> Thus, potential

research participants from minority groups tend to not perceive consent as an adequate substitute for autonomous decision-making.<sup>22</sup>

Given that the conflation of consent and respect for autonomy is not solely a theoretical issue, several questions present themselves: should the central concern of clinical or research ethics be respect for an individual's liberty rather than their autonomy? If consent does not respect autonomy either in principle or practice, how should we operationalise the principle of respect for autonomy? Do alternative models of medical decision-making (e.g. shared decision-making) respect a patient's autonomy? What theory of autonomy should underpin respect for autonomy in medical decision-making? Indeed, is a 'one-size-fits-all' approach appropriate and should we afford so much currency to philosophical theories of autonomy when investigating what respect for autonomy might mean in clinical or research contexts?

Of course, in relation to at least some of these questions, medical ethicists and legal scholars have developed many different approaches to patient autonomy in light of different conceptions in the philosophical literature. But the issue remains: which (if any) of these abstract approaches best meet the needs of patients and practitioners, who make actual, important judgments about patient autonomy on a routine basis, often in morally charged situations that have real-life stakes and consequences? The demands and pressures of non-ideal clinical reality suggest that we should perhaps be paying more attention to what those working on the frontline think about the nature and function of respect for autonomy.

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