Rethinking informed consent in the age of behavioral sciences and relational autonomy

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Acknowledgements: The authors wish to thank Tamara Perez for her contribution to language editing and proofreading.

Funding: This work by N.O. Gaucher and O. Drouin was supported by a Chercheurs-Boursiers Cliniciens Award, from the Fonds de recherche du Québec – Santé.

Declaration of interest: The authors declare that they have no competing interest.
Introduction

Informed consent is one of the cornerstones of modern medicine, clinical ethics, and biomedical research. Its current operational model chiefly values patients’ autonomy, advocating for effective conversations in which patients are given enough information to decide which treatment option best matches their personal preferences and best interests[1]. Traditionally, four cognitive abilities have been considered fundamental to this decision-making process: (i) understanding, the ability to comprehend information specific to disease or treatment; (ii) appreciation, the aptitude to recognize how these facts are relevant to oneself, in the present and future; (iii) reasoning, the ability to compare options and infer consequences of different choices; and (iv) expressing a choice, the ability to clearly communicate a decision[2]. As such, the quality of decision-making processes in medicine is judged on the integrity of each of these four abilities. Notably, the underlying assumption of this model is that patients make decisions rationally and independently, free from contextual and relational influences.

However, growing evidence in behavioral sciences challenges the classic rational view of the human mind[3]. Indeed, the processes of understanding, appreciation and reasoning may be swayed by important cognitive biases — oftentimes subconsciously. In turn, these biases influence our ability to weigh risks and benefits and compare options. In particular, low numeracy, difficulties with forecasting, and altered risk perception dispute the current model of informed decision making and informed consent. In this essay, we examine emerging empirical evidence of these biases, in line with the most recent research in behavioral sciences. We then present how these findings resonate with many criticisms advanced by ethicists and conclude by exploring possible ways forward.
Low numeracy limits understanding

A good understanding of numbers, statistics, and probabilities is crucial when comparing options and making decisions in a medical context. Unfortunately, growing evidence shows that ratios and probabilities are not intuitive and very difficult to grasp for a majority of the population, including physicians[4-6]. In one demonstration, people judged “a disease that kills 1,286 people out of every 10,000” as riskier than those who were told about “a disease that kills 24.14% of the population” even if the first risk is about half the second[7]. Indeed, absolute numbers evoke vivid images, more so than do percentages[8, 9]. These widespread difficulties in interpreting probabilities undermine the true understanding one has of both disease- and treatment-related information that are frequently presented in such a way. Such failings in turn weaken the processes of appreciation and reasoning.

Probability of rare outcomes

Interpreting probabilities of rare events is particularly challenging. For example, authorities state that the lifetime attributable risk of developing a cancer after exposure to a single computed tomography scan is one in one thousand[10]. Such small risks are often overweighed when making a decision, and may be blown out of proportion if they trigger a strong emotion or if they are presented in a more salient way[4, 11, 12]. Overestimation of small probabilities also occurs when alternative outcomes are not fully specified. For example, when considering the likelihood of a single event (e.g. that a patient may die during a particular admission for a myocardial infarction), expert physicians deem its likelihood as greater if it is the only outcome mentioned, and smaller if alternatives are explicitly specified (e.g. that the same patient may survive the admission but die within one year, that they may live more than one year but less than ten years,
etc.)[13]. Furthermore, when making a decision based on personal experience (instead of
deciding based on a description, such as evidence from research), small probabilities may be
either over- or underweighted[14]. For example, recently experienced outcomes may skew
decision making based on overestimation of their likelihood, whereas the likelihood of outcomes
not previously experienced may be underestimated[14, 15]. While the conditions leading to over-
or underweighting of probabilities are still incompletely understood[14, 16], these insights raise
important questions regarding the way to discuss small but serious risks involved in many
clinical decisions requiring consent.

**Framing**

Different ways of presenting the same information can lead to different decisions, a phenomenon
known as the framing effect. For example, McNeil et al asked patients and physicians which of
two therapies they would prefer as a treatment of lung cancer: surgery or radiation. When
describing the outcomes of surgery over the first month, half of the participants were told that the
survival rate was 90%; while the other half were told that there was a 10% mortality rate. To
note, radiation therapy had virtually no treatment mortality, but approximately two thirds of the
five-year survival rate of surgery. Overall, surgery was considerably more attractive in the
survival frame (75%) than in the mortality frame (58%) — and consistently so amongst both
patients and physicians[17]. Some have tried to solve this problem by presenting both survival
and mortality rates. Interestingly, this approach yields results more similar to a survival frame
than a mortality frame[18]. Without a reliable reference point however, it is hard to conclude
which approach, if any, really achieves the goal of eliminating bias and empowering patients to
make decisions consistent with their preferences and goals of care.
**Number of risks**

Beyond the probability of a given risk, the mere *number* of risks presented to patients may also matter, even when it should not. In one study, participants were presented two hypothetical surgery scenarios for colon cancer. In scenario A, surgery had a 20% mortality rate. In scenario B, surgery had a 16% mortality rate, as well as additional 1% risks of four other complications (permanent colostomy, chronic diarrhea, intermittent bowel obstruction, wound infection) all deemed less severe than dying by the participants. Despite both surgeries having the same 20% complication rate, and mortality being higher in scenario A, participants preferred the 20% mortality scenario presumably because it had a lower number of different complications[19].

**Limits in forecasting affect appreciation**

In the process of informed consent, patients have to imagine at least two hypothetical futures, which sometimes may be distant and very different from their current situation. This exercise in *appreciation* is difficult and can also be influenced by various cognitive biases. In turn, such difficulties in *appreciation* hinder the process of *reasoning*. Nevertheless, when establishing patients’ personal preferences, current methods of informed consent rely heavily on such forecasts.

**Affective forecasting**

Many of our decisions are based on the consequences we expect from our choices. This includes predictions about our future emotions: whether certain choices will make us more or less happy, for example. *Affective forecasting* is our capacity to predict and envision the affect or emotion we will have at a given time, or after a certain event[20]. However, like any prediction, affective forecasting can turn out to be wrong: the type of emotion, its intensity, its duration, and the effect
of certain events have all been shown to be prone to cognitive errors[20-22]. For example, people greatly underestimate the overall quality of life of people with disabilities and people who become handicapped after an injury, not accounting for response shift and changes in values and expectations[23].

**Miswanting**

Errors in affective forecasting may lead to what Gilbert and Wilson have dubbed *miswanting*[24]. As they put it: “much unhappiness has less to do with not getting what we want, and more to do with not wanting what we like”. Miswanting highlights issues regarding the objectives of medical decision making and informed consent. For example, when faced with the possibility of having a colostomy, most people are willing to trade away many years of life for a shorter life without a colostomy — whereas those actually living with a colostomy have a much less negative view of their quality of life[25]. Even more surprisingly, patients whose colostomy has been since removed share a similar view with those who have never had the intervention, suggesting that the former have somehow “forgotten” how not-so-bad it had been to live with a colostomy[25]. Indeed, much evidence supports how unreliable our memories may be and how this may also contribute to miswanting: when we recollect a past experience, we tend to focus on certain elements (e.g., worst pain, physical limitation) while overlooking its overall impact on well-being[26-28]. Current models of informed consent tend to ignore issues of miswanting, as it seemingly undermines the core principle of auto-determination. Yet, by acknowledging the associated costs on well-being, these insights indicate how valuable it may be to integrate considerations of miswanting in consent discussions with patients.

**Optimistic bias**
Other difficulties in appreciation stem from the optimistic bias whereby people underestimate their risk of a negative event (such as developing a disease), both in absolute terms, and when asked to compare with other members of a group[29, 30]. Of interest, this bias appears to be greatest when risks are perceived as controllable (e.g., risk of excessive weight gain) and less when they are considered random (e.g., risk of developing a cancer)[31, 32]. Although some optimism may have some health benefits[33], it may also unduly influence decisions in ways that undermine provision of healthcare that is consistent with patients’ own goals of care.

**Emotions and altered risk perception influence reasoning**

When evaluating risks and benefits of alternative options, informed-consent discussions seek to elicit long-standing personal values and foster rational decision making[1]. However, incoherent risk perception, transient mood, and other emotional influences may undermine optimal reasoning in informed decision making.

**Loss aversion**

In risk-benefit calculations, losses loom larger than gains of the same magnitude[34]. Loss aversion can however lead to decisions which may not be in one’s best interest. In medicine, risk aversion explains why some may refuse prophylactic interventions involving possible side-effects, even when the estimated benefits of these interventions considerably outweigh the risks of these possible side-effects. For example, this may contribute to some of the anti-vaccine rhetoric[35] and explain the reluctance of many patients at increased risk of breast cancer to take tamoxifen. Indeed, although tamoxifen is known to reduce the incidence of new breast cancers by almost half in high-risk patients, one study found that almost all women opted against its use for fear of its marginally higher risks of endometrial cancer and thrombotic events[36].
Interestingly, loss aversion varies depending on what is perceived as the status quo or reference point. This influences decisions including advance end-of-life directives, where patients have been shown to favor either comfort-oriented or life-extending care more frequently based on which is presented as the default choice[37]. In this way, loss aversion also contributes to explaining some other biases, including framing effects (see Framing).

**Transient mood and emotions**

Transient mood states may sway decisions by decreasing responsiveness to evidence or altering one’s preferences[38]. For example, transient happiness and anger are associated with greater optimism and risk-seeking decisions, whereas fear leads to risk-averse decisions[39]. Being in a negative mood heightens one’s vigilance and consideration for details[40] and makes people more likely to change their mind than those in a positive mood[41]. As such, transient moods and emotions directly impact healthcare decisions, including those regarding end-of-life treatment options (e.g., whether or not one would want CPR or tube-feeding if one suffered from a stroke or colon cancer)[41]. Of note, healthcare professionals also experience emotions that significantly affect their clinical decisions and their interactions with patients[42].

**Responsibility and regret**

With choices and responsibility comes a potential for regret, which in itself may sway decisions. Regret is felt most when one has acted contrary to the norm or can easily imagine having acted in an alternative way[43]. In healthcare, anticipated regret may explain why some patients may prefer brand-name medications instead of generics, as brand-name products may appear as safer options[44, 45]. Anticipated regret may also contribute to the pursuit of futile interventions at the end of life, where the escalation of commitment may be motivated by the fear of not having
“tried everything”[46]. Being overwhelmed by anticipated regret may also lead patients to delegate decision-making responsibilities to others, as this may decrease one’s sentiment of personal responsibility and the likelihood or intensity of regret[47]. However, delegating treatment decisions to someone else, such as health professionals, may conflict with currently-advocated informed-consent practices[19]. Of note, physicians may also be influenced by anticipated regret, favouring protocols and risk-averse choices, even when alternatives may be better adapted to specific patients[48]. Finally, anticipated regret is often greater than the regret we actually experience, in part due to an underestimation of our psychological defences and resilience[49].

In all, growing evidence in behavioral sciences challenges the classic rational view of the human mind, highlighting the influence of contextual factors and cognitive biases in clinical decision making. As we will see next, these findings clearly resonate with relational ethics and its critique of the underlying in-control account of patient autonomy in current practices of informed consent.

**Relational Autonomy**

Traditional accounts of autonomy have considered patients as independent and in-control moral agents, able to transcend emotions and prioritise rational thought in decision-making[50]. Informed consent is understood as a legal minimal standard that upholds this individualistic view of patient autonomy (i.e., having the opportunity to decide whether or not oneself will undergo a medical intervention is both necessary and sufficient for patient autonomy)[51]. Here, healthcare professionals are encouraged to avoid influencing their patients within the professional-patient relationship[50].
In contrast, relational approaches understand autonomy as self-determination (not independence or self-sufficiency), the defining quality of free moral agents who are rational, emotional, creative and socially embedded[52]. Relational ethicists suggest that power relationships are intrinsic to the professional-patient relationship and that clinicians do not (cannot) present value-neutral information to their patients[53]. Moreover, relational autonomy is not considered a static state (i.e., patients are either autonomous or not) but a capacity that can be developed, empowered by the web of relationships in which patients exist[54]. Here, the inherent influence of relations and context in decision making clearly resonate with the previously discussed findings in behavioral sciences[55].

In line with the evidence from behavioral sciences, a relational understanding of autonomy also leads one to conclude that the current minimum standard of informed consent (i.e., having the opportunity to decide whether or not to undergo a medical intervention, voluntarily, after medical disclosure) doesn’t do enough to ensure that patients truly exercise their autonomy[51]. To promote patient autonomy, clinicians must recognize the social conditions that may undermine their patients’ capacity for autonomous reasoning and take positive steps to counteract these effects[51]. Clinicians are called to discuss more than objective facts with their patients, but also to consider patients’ emotional and lived experiences, internalized social and cultural norms, etc., as these are all crucial in decision-making processes[50]. As such, relational ethicists advocate for an enhanced informed consent process, where clinicians play an active role in fostering environments and relationships that empower patients’ autonomous decision-making.

Ways Forward
Cognitive debiasing

Albeit scarce, some evidence can inform the way forward within the clinician-patient relationship. Firstly, low numeracy can be partly overcome with visual aids. For example, icon arrays — graphic displays of stick figures or circles used to symbolize a particular risk in a population — have been shown to increase accuracy of medical risk evaluations in both low- and high-numeracy populations[56, 57]. Secondly, forecasting challenges may be addressed by integrating narratives of other persons’ experiences. By having access to stories they can relate to, patients may better appreciate how different health outcomes may be relevant to themselves[58]. Large initiatives of the sort include the Database of Individual Patients' Experience of illness (DIPEX)[59]. Thirdly, when time permits, a simple way to improve reasoning is allowing for some more time to make a decision. This extra time encourages careful consideration of all risks and benefits and mitigates the impact of transient emotions. In particular, spending more quality time with their physician has shown to help patients feel more confident with the quality of their decisions[60]. People also make better decisions after allowing some time for unconscious deliberation (i.e. after taking a short break or “sleeping on it’”)[61, 62]. Furthermore, some initiatives have sought to combine many of these methods by providing detailed decision aids designed to empower patients’ thoughtful decision making[63, 64]. In turn, by reducing decision uncertainty these methods of decision support also reduce the potential for regret[65] Nonetheless, many biases in informed decision making remain challenging to address and, although appealing, the success of various forms of cognitive debiasing remains limited[66].

Choice architecture to mitigate bias

While continuing to ignore these biases is not acceptable, and eliminating them entirely may not be feasible, it is imperative that an alternative be identified — one that acknowledges the
influence of structural and cognitive biases in decision making and that suggests new strategies to help patients decide what’s best for them given their context and personal preferences. At the clinician-patient relationship level, taking into account the choice architecture [67] in which medical decisions are made, clinicians may better help patients consider and navigate the inevitable influences of context, relationships and emotions in informed decision making[55]. This requires thinking beyond which information is communicated to patients and further attending to how the relevant information should be conveyed.

**Integrating the ethical perspective of relational autonomy**

Relational autonomy calls on healthcare professionals to recognize the role and influence they exert in patient decision making, given the inherent power imbalances that exist in the physician-patient relationship and clinicians’ own biases[68, 69]. Both behavioral sciences and relational autonomy call for a more comprehensive understanding of patient decision making and for the development of meaningful, autonomy-enhancing partnerships between patients and clinicians. They do not warrant a return to previous forms of medical paternalism[70, 71]. Within these partnerships, healthcare professionals need to recognize the subtle influences they exert — even unintentionally — and the many opportunities they have to enhance patient autonomy through their relationships with their patients[72]. Finally, through these autonomy-enhancing partnerships, patients and clinicians can become advocates for shaping the sociopolitical factors influencing healthcare delivery and patient autonomy[73, 74].

**Conclusion**

Behavioral sciences and relational ethics have highlighted limitations of current models of informed consent, further supporting a shift towards an ethics of relational autonomy. At the
patient-clinician level, limitations in understanding probabilities, mistaken projections, and altered risk perception undermine the processes of understanding, appreciation and reasoning that are fundamental to informed decision making. Yet, these influences in healthcare are often ignored and have so far been left largely unaddressed. Healthcare professionals have a duty to ensure that patients’ decisions are well-informed and coherent with their preferences. It is therefore imperative to develop a practical and ethical framework that takes into account these contextual and relational influences, while mitigating their negative consequences. Integrating insights from behavioral sciences and relational autonomy into improved informed-consent practices will no doubt require important discussions amongst healthcare professionals, ethicists and patients themselves.
References


