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## Informed Consent Under Ignorance

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### ABSTRACT

In recent years, an old challenge to informed consent has been rediscovered: the challenge of ignorance. Several authors argue that due to the presence of irreducible ignorance in certain treatments, giving informed consent to these treatments is not possible. The present paper examines in what ways ignorance is believed to prevent informed consent and which treatments are affected by that. At this, it becomes clear that if the challenge of ignorance truly holds, it poses a major problem to informed consent. The paper argues, however, that from both an empirical and a theoretical point of view, it is not convincing that ignorance prevents informed consent. Still, it seems important that the presence of irreducible ignorance is openly discussed during the informed consent process.

### KEYWORDS

Ignorance; informed consent; medical ethics; transformative experience; understanding

### INTRODUCTION

Informed consent is considered the core principle of bioethics (Eyal 2019). It has the power to transform an action that is morally unacceptable to a morally acceptable one (Manson and O'Neill 2007; Miller and Wertheimer 2010a; Bullock 2018). For instance, if a physician injects a patient with a drug or performs surgery on them, it is considered an assault unless the physician has the patient's valid consent. This is what some have called the moral magic of consent (Alexander 1996; Hurd 1996).

Historically, obtaining consent has not always been considered a moral obligation of physicians toward their patients. For example, while Plato (2000) says that a freeman doctor will not prescribe a treatment for a fellow freeman until he has first convinced him, the reason for doing so is not a moral one. Instead, it should bring "the patient more and more under his persuasive influences and set him on the road to health" (IV.720). In line with that, there is no indication in Plato's work that patients are granted a veto given that they are not convinced by their physician's treatment plan. This notion of the physician-patient relationship is echoed in the Hippocratic Corpus, which mentions beneficence and non-maleficence as guiding values, while remaining silent about consent (Faden and Beauchamp 1986; O'Shea 2018).

In the last century, the emergence of the principle of informed consent has led to the gradual replacement of a paternalistic understanding of medical choice, such as that defended by Plato, with a more autonomous one: capacitated patients should be empowered to make their own medical decisions, free from coercion and based on understandable, patient-relevant information. Today, the importance of informed consent is widely accepted, while the literature on informed consent continues to debate its precise requirements (see, e.g., Miller and Wertheimer 2010b; Müller and Schaber 2018; Eyal 2019). Discussions address questions such as what information physicians must disclose, to what extent patients must understand the information, what counts as coercion, and when patients are capacitated. Therefore, the typical question is *when* informed consent is possible for a treatment, but not *if*.

Contrary to this general position, some authors have argued already decades ago that for certain treatments, informed consent is never possible because these treatments come with too much irreducible ignorance for that (e.g., Dodds and Jones 1989).<sup>1</sup> While this argument, which I will call *the challenge of ignorance*, has long received little attention in the literature, this has changed in the last few years (e.g., Smith and Sisti 2021; Peterson et al. 2023; Hofmann 2023; Jacobs 2023). One reason for that is the rise of the topic of transformative experiences

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<sup>1</sup>A different constraint on consent is posed by morally intolerable cases, in which valid consent is sometimes seen as insufficient for morally transformative consent (cf. Bullock 2018).

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in analytic philosophy (Paul 2014; Lambert and Schwenkler 2020), which provides a suitable framework for the challenge of ignorance. This new literature makes clear that if irreducible ignorance truly prevents informed consent, then the core principle of bioethics is under broad attack. Therefore, clarification is urgently needed as to whether this is really the case. By examining the challenge of ignorance in detail, the present paper provides such clarification. It analyzes how exactly the challenge of ignorance is believed to undermine informed consent, how this connects to the concept of transformative experiences, and which treatments are affected by it. The paper then argues why the challenge of ignorance does not impede informed consent, making both an empirical and a theoretical case for this.

The remainder of the paper is structured as follows: Section 2 discusses the elements of disclosure and understanding within informed consent and what the current debates about these elements are in the literature, revealing a potential blind spot. Section 3 presents the challenge of ignorance. Section 4 examines in which treatments the challenge of ignorance is present. Section 5 analyzes whether the challenge of ignorance really holds.

## THE ELEMENTS OF DISCLOSURE AND UNDERSTANDING

Today's concept of informed consent is often described as being based on five elements (although it is debated whether all five must be present for consent to be valid): capacity, disclosure, understanding, voluntariness, and consent (Beauchamp 2010; Ach 2018). To set the stage for the rest of this paper, let us briefly examine two of these elements.

Disclosure means that patients must be provided with information that is material to their decision. But what information is considered material? There are three standards in the literature: The reasonable physician standard requires the physician community to determine what information must be disclosed (McKean, Trachsel, and Croarkin 2021). The reasonable patient standard requires physicians to disclose all information that would be material to a reasonable patient. Finally, in addition to these objective standards, there is a subjective standard that requires disclosure of all information that is material to the individual patient (Faden and Beauchamp 1986; Dranseika, Piasecki, and Waligora 2017). While this standard is rather seen as an ideal that might never be perfectly implemented, it requires physicians to try to find out what disclosure information is material for their patients. For example, a disclosure conversation, in which a patient is

encouraged to reflect on their beliefs, desires, and values and to ask questions, can be a helpful way to achieve this (Faden and Beauchamp 1986). There are still debates on what must be disclosed and which standard is preferable (e.g., Dranseika, Piasecki, and Waligora 2017; Millum and Bromwich 2021).

Understanding requires that the patient has not only been provided information but also has at least some understanding of the information. Accordingly, physicians must translate technical medical jargon into a language that is understandable to the layperson. In doing so, it is not necessary for the physician to give a medical lecture with the goal of having the patient understand every single detail. Having relevant beliefs about the nature and consequences of a medical intervention is usually seen as sufficient (cf. Beauchamp 2010). In addition, the patient must understand that by giving consent, they authorize the physician to perform the proposed treatment. Current debates involve to what extent disclosed information must be understood in order that giving consent is possible (e.g., Dougherty 2020; Millum and Bromwich 2021; Rogers and Johnson 2021).

More generally, the debates about the elements of informed consent sketched above address the question of what conditions are necessary for informed consent to be possible (and how feasible these conditions are). At this, it seems undisputed that informed consent is generally possible given that conditions are right. For example, a lack of understanding that prevents informed consent can be addressed by explaining the treatment in a more comprehensive and understandable way. Similarly, insufficient disclosure information preventing informed consent can be complemented with additional disclosure information until it is sufficient. As can be seen, the main question in the informed consent literature on these elements is therefore not *if* informed consent for a treatment is possible, but *when*. Could this be a blind spot?

## THE CHALLENGE OF IGNORANCE

We can find a line of argument in the literature on informed consent that says that for some interventions, informed consent is generally impossible. This is because some interventions are associated with too much irreducible ignorance to allow for informed consent.<sup>2</sup> For decades, this line of argument lived in

<sup>2</sup>I follow the standard view of ignorance in this paper (cf. Zimmermann 2008; Le Morvan and Peels 2016). In short, this view defines ignorance as the lack or absence of knowledge; being ignorant that  $p$  is a failure to know that  $p$ . Furthermore, in this paper, irreducible ignorance associated with an intervention implies that the lack of knowledge cannot be reduced (e.g., by gathering more information) except by undergoing the intervention.

the shadows of the medical ethics literature. But since Laurie Paul's (2014) highly influential book *Transformative Experience* and the many discussions it has sparked in analytic philosophy, the challenge of ignorance to informed consent has become a rediscovered topic (e.g., Smith and Sisti 2021; Peterson et al. 2023; Hofmann 2023; Jacobs 2023). What exactly does this challenge entail?

An early version of the challenge of ignorance can be found in Dodds and Jones (1989). The authors discuss the morality of surrogacy contracts, arguing that even if we assume voluntariness, such contracts are morally impermissible because they risk violating the surrogate's autonomy. The argument is as follows:

How a pregnancy will be experienced, in detail, is unpredictable, given the limitations of our knowledge of human psychology and physiology, so that even if a woman believes that she will have no emotional response to a child she had gestated, and she tries to ensure this, she may not be able to guarantee that she will not come to have a deep emotional attachment to the child. Thus, how can a woman give fully *informed* consent to part with a child that she will have felt growing and developing inside her, that she will have given form to through her body, before she knows the feelings these experiences will have produced? If bonding has occurred during a pregnancy, those feelings must be taken into account, but they can only be taken into account in retrospect. (9)

This line of argument touches on the two elements of informed consent discussed in the last section: disclosure and understanding. First, it could be argued that a woman misses information material to her decision, namely how she will emotionally respond to giving away the child after surrogacy. The element of disclosure is therefore not met, depriving her of the ability to give informed consent. Second, it could be argued that a woman lacks understanding of surrogacy because her beliefs about the nature and consequences of surrogacy, particularly its emotional impact on her, are insufficient. Consequently, she cannot give informed consent to surrogacy. Which of these arguments that challenge one of the elements of informed consent is/are convincing?

The claim that the element of disclosure cannot be met in the case of surrogacy is unconvincing. As the term "disclosure" indicates, physicians should not withhold information from their patients but disclose it. First and foremost, physicians are therefore failing their patients if they do not disclose the information that they know and that they assume (or should assume) to be material. Second, it could be argued that physicians also invalidate a patient's informed consent by failing to disclose information of which

they are negligently unaware (cf. Taylor 2009). Both of these conditions do not necessarily apply to the surrogacy case. We can think of a physician who discloses all available information to a woman interested in surrogacy, including the fact that she cannot foresee the feelings that surrogacy might evoke. Accordingly, the physician is neither withholding information nor negligently failing to disclose information, suggesting that the element of disclosure is met and does not prevent informed consent.

The challenge that surrogacy poses to informed consent must therefore lie in the element of understanding: women cannot give informed consent to surrogacy because they do not have adequate understanding of how undergoing surrogacy will affect them emotionally. This lack of understanding is fundamental, which means that it does not stem from a lack of capacity or insufficient disclosure.<sup>3</sup> Instead, it stems from a lack of personal experience. Only by undergoing surrogacy, a woman gets an understanding of what its emotional consequences are and how they feel like. In turn, being familiar with the emotional consequences of surrogacy is presumed to be necessary to have adequate understanding of it. Thus, in more general terms, the challenge of ignorance to informed consent is that we know too little about the potential outcomes of some interventions to have adequate understanding of them.

To get a better idea of how the challenge of ignorance undermines understanding, it is useful to look at a current hot topic in analytic philosophy: transformative experience. Paul (2014) has established the concept of transformative experience in her eponymous book. In very short, the book presents two main arguments. First, it emphasizes that experiences can lead to both epistemic and personal transformations. An epistemically transformative experience means that we gain knowledge through an experience that is otherwise unattainable (e.g., the sensory phenomenology of the experience). A personally transformative experience refers to an experience that radically changes our point of view, or, to use another term, our core

<sup>3</sup>There is also the argument that informed consent is often invalid due to a lack of capacity or insufficient disclosure. For example, patients frequently suffer from fallibilities of human reasoning (e.g., the impact bias), which cast doubt on whether patients are truly capacitated in their medical decisions even if they pass a decision-making capacity test (cf. Levy 2014). Or, in practice, it is simply not feasible to discuss all information about an intervention or research project, which sometimes would also include new information about new research studies, e.g., in biobank research (cf. Hofmann 2009; Boyd 2015). However, these challenges to informed consent differ from the challenge of ignorance as they are at least theoretically solvable (e.g., by becoming aware of one's fallacies or by strictly discussing all the information) and do not per se prevent informed consent.

preferences. Given that an experience is both epistemically and personally transformative, Paul calls it a transformative experience. Second, the book argues that decision theory faces a problem when one of the available options involves an experience that is or can be epistemically and/or personally transformative. The reason for this is that only by undergoing the experience, we learn the value of *living* it, which Paul calls the subjective value: agents derive the subjective value of an experience by performing a mental simulation of it, but this is not possible (at least not reliably) if we have not had the experience or a similar one before.<sup>4</sup> Next, without being able to anticipate the subjective value of the experience, it is not possible to evaluate the overall value of each option and determine the best choice. Finally, the situation is further complicated by the presence of personal transformation, as it can also affect the future values of known outcomes and requires individuals to choose which preferences they want to hold: their current preferences or transformed preferences (whose characteristics are likely unknown).

The most prominent example of a transformative experience in the literature is becoming a parent (e.g., Paul 2014; Barnes 2015; Paul 2015b; Pettigrew 2015; Reuter and Messerli 2018; Villiger 2023). On the one hand, only by becoming a parent you know how it is to be a parent. On the other hand, becoming a parent can radically change your point of view, making things irrelevant you valued before and vice versa. According to Paul, this makes it impossible to reach a rational decision to have a child, as you lack the necessary information to do so.

The step from the example of becoming a parent to the example of surrogacy is a short one. Dodds and Jones (1989) argue that women cannot foresee the feelings that surrogacy evoke but can only know about these feelings in retrospect. This is a perfect example of an epistemically transformative experience because the sensory phenomenology of surrogacy (including the feelings it evokes) can only be known by experiencing it. In line with that, pregnancy has already been described as being epistemically transformative (Woollard 2021). In addition, surrogacy may also be personally transformative. Let's think of a case where, in the beginning, a woman highly values the fact that she makes it possible for a couple to have a child and

start a family. The value of doing so compensates for the expected disvalue of relinquishing the baby she gives birth to. But during pregnancy, these values begin to change as she develops an emotional attachment to the baby, leading her to the point where she wants to keep the child. For example, we seem to find such a transformational process in the testimony of Terese McFadden (1988), who writes about her own surrogacy:

[B]y the time my pregnancy had reached near term, I had no way of coping with what I was about to do. I felt so confused about the couple to whom I was handing over my baby. I began to consider alternatives such as another [couple] or normal adoption. What I had realized at this point was that I really wanted to keep my baby myself. (75)

While this change of mind may have been solely due to an epistemic transformation, it is at least possible that it was (also) due to a personal transformation.

As can be seen, the concept of transformative experience provides a suitable framework for the challenge of ignorance to informed consent. Some medical interventions are or can be epistemically and/or personally transformative, which blocks us from assessing their value.<sup>5</sup> Therefore, we cannot gain adequate understanding of these interventions since their consequences are epistemically inaccessible.

## WHERE DO WE FIND THE CHALLENGE OF IGNORANCE?

Beside surrogacy, the medical ethics literature contains many other examples of interventions where the challenge of ignorance is explicitly or implicitly present.<sup>6</sup> At the moment, the most prominent one is psychedelic-assisted therapy. Several authors argue that a psychedelic experience can be both epistemically and personally transformative (e.g., Forstmann et al. 2020; Letheby 2021; Yudkin et al. 2022), and some already touched on what implications this might have for informed consent to psychedelic-assisted therapy (e.g.,

<sup>4</sup>This is why transformative decisions are different from decisions that simply involve a lot of uncertainty: It is not that we just do not know which future state of the world will occur, but that we do not know the very characteristics of one or more possible states of the world. Because of that, we are also ignorant of the value they provide.

<sup>5</sup>Note that if we follow Paul's argument, then even a non-negligible probability that an experience will be transformative impedes rational choice, because it already prevents you from evaluating all possible outcomes.

<sup>6</sup>There is also a discussion of the moral weight of advance directives for dementia patients (Walsh 2020). In short, the argument is that dementia is a transformative experience and, therefore, individuals at the onset of dementia setting up advance directives cannot foresee what their desires and preferences will be in the moderate-late stage of the disease. Consequently, we should reduce our confidence in the moral weight of advance directives for dementia patients. Although this argument also seems to be based on the challenge of ignorance, we will not discuss it further because the present paper is limited to cases where individuals retain their decision-making capacity.

Smith and Sisti 2021; Peterson et al. 2023). In a recent analysis of the issue, Jacobs (2023) concludes that the transformative nature of psychedelic-assisted therapy renders informed consent impossible due to inadequate understanding.

A recent article by Hofmann (2023) argues that disease itself can be transformative, which has several implications. First, interventions that result in disease, such as the amputation of a limb in cases of body integrity identity disorder (BIID), can be transformative and thereby prevent informed consent. This problem is also present in the case of treatments of which it is known that they *can* lead to another disease or make the present disease much worse. Second, the transformative nature of disease is relevant in the research context, for example regarding the question whether low-dose controlled infection is sometimes impermissible because unknown risks render informed consent impossible (see Chappell and Singer 2020 for such a discussion on COVID-19). This also raises the question whether patients can ever give informed consent to experimental interventions whose risks are not fully known (cf. Bernstein 2005).

In her book, Paul (2014) discusses the cases of a having a cochlear implant to treat deafness or undergoing retinal surgery to treat blindness. In the case of both treatments, it is impossible to anticipate how it will be to live with the new sensory ability, making the experience transformative. In turn, this complicates informed consent. Furthermore, Paul's primary example of a transformative experience, becoming a parent, can also pose a challenge to informed consent in the medical context, namely in the case of *in vitro* fertilization. If individuals cannot rationally choose to have a child, how can they have adequate understanding of a treatment that, if successful, will result in having a child?

While the challenge of ignorance has been explicitly emphasized in the examples mentioned above, it is sometimes more implicit, hidden behind another phenomenon: post-treatment regret. Post-treatment regret is a potential consequence of undergoing a treatment in the presence of ignorance, resulting in the wish: "If only I had known!" For instance, post-treatment regret plays an important role in the discussion of surrogacy: during the pregnancy, a surrogate may begin to deeply regret her decision, which some take as an indication that she did not have adequate understanding of surrogacy when choosing it (cf. Oakley 1992). The same line of argument can be found in the case of other treatments. To give two examples: (1) Several authors emphasize the major

ethical problems that regret cases pose to gender confirmation treatment and that it is imperative to try to prevent post-treatment regret (Landén et al. 1998; Smith et al. 2005; Olsson and Möller 2006). Some authors even treat the possibility of post-treatment regrets as a sufficient reason for gender confirmation treatment being impermissible (cf. McQueen 2017). One way to argue for this position is to say that individuals considering gender confirmation treatment do not have adequate understanding of its consequences, preventing informed consent. The fact that gender transition is generally seen as a transformative experience (e.g., McKinnon 2015; Villiger 2021) appears to be in line with this argument. (2) Concerns regarding potential post-treatment regret are also raised when it comes to sterilization requests, particularly for women under 30 who choose to remain childfree (Lawrence et al. 2011). The primary worry is that these women might change their minds in the future and desire to have children, leading to considerable regret. In other words, it is argued that young childfree women may not have adequate understanding of the potential consequences of their decision should their desire not to have children change one day. So here, it is not the treatment that is transformative. Rather, it is considered possible that a woman without a desire for children may at some point undergo a personal transformation that results in a reversal of that preference—something she may believe to be impossible at the moment of sterilization.<sup>7</sup>

While the list of examples given above is of course not exhaustive, it should become clear that the challenge of ignorance affects various medical interventions. Thus, if irreducible ignorance truly prevents informed consent, the core principle of bioethics is under broad attack.

## DOES IGNORANCE REALLY PREVENT INFORMED CONSENT?

I will provide two arguments why the challenge of ignorance does not prevent informed consent: an empirical one and a theoretical one. While the empirical argument will demonstrate that ignorance does not *per se* make informed consent impossible, the

<sup>7</sup>It could also be argued that interventions potentially leading to post-treatment regret are impermissible not because of inadequate understanding but because they may result in harm which a physician must prevent due to the principle of non-maleficence. There are two objections to this argument: (1) in the discussed cases, physicians prolong the suffering of patients if they refuse the intervention and thus, produce harm as well (cf. McQueen 2017); and (2) refusing the intervention disrespects the patient's autonomy.

theoretical argument will show that, in general, the challenge of ignorance does not make informed consent impossible. Let's begin with the empirical argument.

### ***Empirical Argument Against the Challenge of Ignorance***

The challenge of ignorance holds that the transformative nature of a treatment builds an epistemic blockade that prevents us from anticipating what it will be like to undergo the treatment. But is this blockade truly insurmountable? Several authors have argued that experiences can to some extent be imagined even if they are transformative (Sharadin 2015; Wilkenfeld 2016; Cath 2019; Ismael 2019; Kind 2020; Daoust 2021; Randell 2023). This is because we can make use of experiences' higher-order properties, which are properties that an experience shares with other experiences. If we have experiential acquaintance with the higher-order properties of a transformative experience due to our previous experiences, this allows us to partly imagine what undergoing the transformative experience will be like (cf. Villiger 2021). While the imagined outcome(s) will not perfectly match the actual outcome, it can still enable us to gain adequate understanding of the outcome(s). To take an illustrative example: The vast majority of people with BIID often or occasionally simulate their desired disability (Giummarra et al. 2011; Pennisi and Capodici 2021). This behavior called "pretending" helps them to come closer to their felt inner body image and to cope with their disease. For instance, those who desire to amputate a leg often tie that leg up and make it seem like it was amputated. In doing so, they learn how they will look like with an amputated leg, how it will be to be dependent on crutches or a wheelchair, how strangers will react to their disability, and so on. While such pretending cannot perfectly imitate what it is like to have a leg amputated, it does seem to give some understanding of it. In turn, this helps to surmount the epistemic blockade associated with the amputation of a leg (cf. Kasten 2009; White 2014).

But how do we know whether patients can truly have adequate understanding of a transformative treatment? One way is to examine the reasons why patients want to undergo a treatment and see if those reasons turn out to be valid after the treatment. To resume the example of BIID patients: most BIID patients claim that the primary reason they seek surgery is to correct what they perceive to be a discrepancy between their current body and their true self

(First 2005). Now, a study on 21 people with BIID who underwent successful amputation found that they were very happy with their bodies after the change, (closely) reached their ideal body image, and felt complete with their body (Kasten and Noll 2014). The fact that surgery obviously met their expectations supports the assumption that people with BIID can and often do have adequate understanding of amputation treatment.

Another (and somewhat easier) way to examine whether patients can truly have adequate understanding of a treatment may provide an analysis of post-treatment regret. For instance, although there are women who, like McFadden (1988), have second thoughts about their decision to become a surrogate, such cases are rare. Empirical studies on surrogate mothers show that a large majority does not regret surrogacy (Teman 2008; Busby and Vun 2010; Jadv, Imrie, and Golombok 2015). At this, Busby and Vun (2010) conclude that "the lack of regret and distress expressed by women who choose to be surrogates indicates that they make their decisions with informed consent, an understanding of what the surrogacy arrangement requires and a confidence that they can carry through with their initial decision to participate in surrogacy" (73).<sup>8</sup>

However, inferring from low post-treatment regret rates that patients had adequate understanding, as Busby and Vun do, comes with a major problem. A low regret rate primarily indicates that people are happy with their decision and not that they had adequate understanding when making the decision. In fact, it is possible that the only reason a person does not regret a treatment is because the treatment itself changed them personally in such a way that they now value its outcome. Put differently, if they had known the treatment's outcome in advance, they would not have chosen it, but in retrospect, after the personal transformation, they are glad they did. Ultimately, it is also unclear what a "high" regret rate tells us about understanding. For example, in the case of sterilization, we find a regret rate of about 20% for women 30 years of age or younger (Hillis et al. 1999; Curtis, Mohllajee, and Peterson 2006). Does that mean that these 20% had inadequate understanding before treatment or that this applies to women not older than 30 in general? In addition, regret may not always be indicative for inadequate understanding, as patients may

<sup>8</sup>As an aside, in the BIID study conducted by Kasten and Noll (2014) mentioned before, none of the participants regretted the surgery. Similarly, for gender confirmation treatment, a recent meta-analysis finds a regret rate of just below 1% (Bustos et al. 2021).

regret a treatment (or the rejection of a treatment) even though they had adequate understanding of it. This can be the case when a decision involved some risk which patients were aware of, but the risk taken did not pay off for them (cf. McQueen 2017). Taken together, it is difficult to draw conclusions about the adequacy of patients' understanding from post-treatment regret rates (in both directions).

An approach that seems to allow a more general analysis on whether patients can truly have adequate understanding of a transformative treatment is as follows: we compare our ability to anticipate the outcomes of transformative treatments with those of non-transformative treatments. While no such study has been conducted so far, there is a study that generally compares transformative and non-transformative experiences with respect to our ability of affective forecasting (Mathony and Messerli 2022). The authors find that our affective forecasting abilities are similarly poor for both types of experiences. This seems to indicate that, contrary to Paul's argument, ignorance caused by an outcome's transformative nature does not pose a special problem to ordinary reasoners. In turn, this suggests that the challenge of ignorance does not pose a special problem to informed consent for transformative treatments.

However, we must be cautious about this conclusion for three reasons: First, while the feelings that an experience evokes are certainly of great relevance for its subjective value, Paul (2015a) explicitly rejects reducing subjective value to the value of subjective feel. So, affective forecasting neglects aspects considered crucial to subjective value. Second, affective forecasting is blind to the challenges that the personally transformative aspects of experience can pose (i.e., who do I want to be/become?). Third, the findings of Mathony and Messerli show that people are rather poor reasoners in general. So, maybe we often lack adequate understanding of a treatment, regardless of whether the challenge of ignorance is present (cf. Levy 2014). However, this does not imply that the challenge of ignorance no longer poses a special problem: while inadequate understanding due to poor reasoning can be corrected, this is not possible when inadequate understanding is due to irreducible ignorance. Therefore, it is still important to distinguish between the two.

To summarize, assessing the adequacy of understanding by means of an empirical approach comes with problems. Still, there are empirical methods that seem to be able to demonstrate that ignorance does not per se impede understanding (cf. the BIID case). But ultimately, of course, the question of whether there

is adequate understanding depends on what adequate understanding actually entails. This brings us to the theoretical argument for why the challenge of ignorance does not make informed consent impossible.

### ***Theoretical Argument Against the Challenge of Ignorance***

So far, we said that adequate understanding of a medical intervention includes to have relevant beliefs about the nature and consequences of a medical intervention (cf. Beauchamp 2010). But what exactly does that mean? Beauchamp specifies that patients' "understanding need not be complete, because a grasp of the material facts is generally sufficient, but in some cases a person's lack of awareness of even a single risk or missing fact can deprive him or her of adequate understanding" (68).

If we compare Beauchamp's position with other positions in the literature, we find that it is roughly in the middle of the spectrum of how demanding the requirements for understanding should be. Millum and Bromwich (2021), for example, are at the less demanding end of the spectrum. They propose minimal requirements for understanding, including that patients giving consent must understand: (1) that they are being asked for consent; (2) how to exercise their right to give or withhold consent; and (3) to what they are being asked to consent. It is important to notice that this excludes the understanding of risks, purpose, and the like as necessary components of the understanding requirement. Instead, regarding the treatment, patients need only understand what normative boundaries are being redrawn by giving consent (i.e., what do I allow the physician to do with me).<sup>9</sup> Contrary to this, Jacobs (2023), for example, is at the more demanding end of the spectrum. He argues that a key aspect of understanding is to enable a value-aligned decision, which to him is roughly the same as a rational decision and thus requires extensive knowledge. It follows that if a rational decision is not possible, then understanding must be inadequate.

Obviously, ignorance becomes more of a challenge the more demanding the requirements for understanding are. For Millum and Bromwich (2021),

<sup>9</sup>The main argument of Millum and Bromwich (2021) is to separate disclosure and understanding requirements. While their proposed requirements for disclosure are quite demanding, their proposed requirements for understanding are minimal. Importantly, the challenge of ignorance also separates disclosure and understanding requirements, however, in a different way. While understanding the required disclosure information is not per se necessary for Millum and Bromwich, understanding the required disclosure information is not sufficient in the context of the challenge of ignorance.



ignorance does not pose a problem as long as patients understand to what kind of treatment they are giving consent to. So, if their requirements for understanding are correct, the challenge of ignorance is not valid (but many consider them too minimal). In contrast, for Jacobs (2023), ignorance caused by a treatment's transformative nature poses a big problem to understanding as it blocks rational decision-making (he follows Paul in this regard). How can patients make a value-aligned decision if they do not know the expected values of their options and how their preferences will change? So, if Jacobs is right, the challenge of ignorance is valid. Ultimately, for Beauchamp's (2010) account, it is *prima facie* unclear whether the challenge of ignorance prevents adequate understanding. This depends on how we interpret "a grasp of the material facts" and a "lack of awareness of a risk or missing fact." Taken together, a way to show that the challenge of ignorance is not valid is to find convincing arguments against Jacobs's (2023) position and for an interpretation of Beauchamp's (2010) position that allows informed consent despite the presence of irreducible ignorance.

Let's first analyze Jacobs's (2023) position that understanding requires the possibility of a value-aligned decision, which is not given for transformative treatments (he uses the example of psychedelic-assisted therapy). We can object this position in two ways: in the presence of ignorance, a value-aligned decision in Jacobs's sense is (1) still possible or (2) not necessary for adequate understanding. Regarding the former, there are various accounts in the transformative experience literature that show that rational transformative decision-making is possible even if we cannot infer future values under transformed preferences through mental simulation (e.g., Pettigrew 2015; Pettigrew 2019; Schulz 2020; Villiger 2021; Villiger 2023). Moreover, McQueen (2017) argues that if a treatment leads to a personal transformation, future values under transformed preferences are irrelevant for the decision at hand. Instead, "one should be sure that the treatment is consistent with who one is *now*" (1060). This is in line with Isaacs (2020) interpretation of decision theory and critique on the discussion of transformative experience. Therefore, it is much contested whether ignorance prevents value-aligned decisions.

But even if we assume that ignorance prevents value-aligned decisions in Jacobs's sense, it is doubtful that this renders understanding inadequate. If we look at the history of informed consent, we see its function in the gradual overcoming of a paternalistic

understanding of medical choice (cf. O'Shea 2018). At the center of this development was the right to self-determination and autonomous choice, which requires patients to be adequately informed about treatment options (this has come to be known as the self-determination theory of informed consent; see, e.g., Faden and Beauchamp 1986; Beauchamp and Childress 2013; Ach 2018). So, the role of understanding in informed consent is to reduce the understanding asymmetry of treatment options between physician and patient: it should enable patients to (at least partially) understand the physician's arguments for and against certain treatment options, so that they can make an informed autonomous decision. First and foremost, understanding is therefore an obligation of physicians toward patients which includes that they do not only disclose but also explain and discuss information, and make sure that patients understood it. Specifically, physicians must ensure that patients have a grasp of the general risks and benefits of a treatment and explore whether there are individualized risks and benefits that need to be understood.<sup>10</sup>

Admittedly, understanding should then support patients in making a good decision, which suggests that a function of informed consent is to promote good decision-making (cf. Bromwich and Millum 2017; Dickert et al. 2017). Thus, physicians also seem to have some obligation to support patients' decision-making (Millum and Bromwich 2021).<sup>11</sup> But the (recommended) decision does not need to be value-aligned in Jacobs's sense, which requires knowledge about the transformative outcome(s), including one's transformed self. Even Savulescu (1994), who proposed one of the most demanding concepts of autonomous medical choice, acknowledges that patients can autonomously choose to explore the unknown as long as they have gathered as many facts as possible about the unknown. This implies that there is nothing inherently irrational about choosing an option one unavoidably lacks information about (cf. Savulescu and Momeyer 1997). Thus, even if one were to adopt Savulescu's highly demanding position, giving informed consent under ignorance would still be possible, provided that the presence of irreducible

<sup>10</sup>Note that Bromwich and Millum (2017) would argue here that these understanding requirements are already too demanding.

<sup>11</sup>Since it is good for patients to make better decisions, we can also derive this duty from the duty of beneficence which physicians have towards patients (Burt 1979; Emanuel and Emanuel 1992; Katz 2002). It is important to note, however, that physicians do not have an obligation to ensure that patients *do* make good decisions, but only to promote good decision-making.

ignorance is openly discussed. Overall, then, we can reject Jacobs's (2023) account of understanding.

The arguments outlined above also guide us in how to interpret Beauchamp's (2010) position on understanding in the context of ignorance. Ignorance does not per se prevent "a grasp of the material facts," since while patients may not have imaginative acquaintance with certain outcomes, they can still grasp that such outcomes are possible (cf. Brock 2007). In addition, there is no "lack of awareness of a risk or missing fact," since such awareness can and should be promoted by the physician when discussing the presence of ignorance with the patient. Therefore, even in the context of transformative treatments, physicians can fulfill their obligation toward patients to establish adequate understanding. Once they have done so, the patient is in a position to give informed consent, and it is then up to the patient to make the final decision and take the risk, or what Jacobs (2023) calls the "leap of faith," that comes with a transformative treatment. But what about a patient for whom it is important to know how a transformative outcome feels like and/or in what precise way it may change their preferences? Obviously, the physician cannot provide this information to the patient. Yet, it is generally accepted that "ought" implies "can". Thus, the inability of the physician to disclose certain information due to irreducible ignorance cannot in itself result in a breach of duty. Because of that, the patient can still give informed consent to the transformative treatment.<sup>12</sup>

Finally, we can also approach the discussion from the opposite direction: What are the implications of assuming that patients cannot give informed consent to transformative treatments due to a general lack of adequate understanding? Presumably, this would create an obligation for physicians not to perform transformative treatments because of the irreducible ignorance they are associated with. Consequently, informed consent, which is supposed to promote patient autonomy, would ultimately promote a form

of "rational paternalism" by prohibiting patients from choosing transformative treatments.

If we leave the self-determination theory of informed consent and look at other theories on the ethical importance of informed consent, we see that the challenge of ignorance is not a problem either. The social benefit theory basically understands informed consent as a safeguard for social benefits such as trust, which is essential for a functioning health care system (O'Neill 2002). Because of that, physicians are required to refrain from exerting controlling influence over patients. As the challenge of ignorance has nothing to do with exerting controlling influence over patients, it does not pose a problem to this account. The patient benefit theory of informed consent includes that informed consent is a suitable instrument for promoting patient's well-being and preventing harm (Wear 1998). This is because individuals usually know best what is good for themselves (cf. Mill 1993), and patients' active participation in the medical decision-making process has beneficial effects on the therapeutic process (Ach 2018). The challenge of ignorance does not undermine either of these two reasons for informed consent: by disclosing irreducible ignorance, physicians emphasize that they are not in principle in a better position to decide what is in the patient's best interest, and by discussing such ignorance they let the patient participate in the decision-making process.<sup>13</sup> Finally, while there is not enough space to discuss second-order accounts of the ethical importance of informed consent (e.g., Wertheimer 2014; Eyal 2015; Eyal 2018), here too, there seems to be no reason why the challenge of ignorance should prevent informed consent.

## CONCLUSION

The present paper analyzed the challenge of ignorance which gained momentum in the last few years, partly due to the upcoming concept of transformative experiences. The challenge of ignorance holds that for certain treatments it is per se impossible to give informed consent to, as one does not have the required knowledge to do so. The underlying problem is a lack of understanding of the treatments'

<sup>12</sup>It might be objected that the paper misses an element of informed consent that is also relevant for the challenge of ignorance: authenticity. There is a long-standing debate about whether informed consent requires decisions to be made consistent with one's authentic values and desires, meaning values and desires that are truly one's own. Interestingly, Paul (2014) also emphasizes the importance of authentic decision-making, which, according to her, is only possible if we can mentally simulate the outcomes. If we follow Paul, authentic transformative decisions are therefore not possible. Consequently, if authenticity is a requirement for informed consent, informed consent for transformative treatment seems not possible either. However, authenticity has been largely rejected as an element of informed consent (cf. Faden and Beauchamp 1986; Gunderson 1990; Nelson et al. 2011; Ahlin 2018). This is why the present paper has set it aside.

<sup>13</sup>It could be argued that within the patient benefit theory, informed consent under ignorance is not possible because it is unclear which option maximizes expected value. However, this misunderstands the function of informed consent under this theory, which is to promote patient benefit. Even if we assume that it is fundamentally unclear which option maximizes expected value, the informed consent process certainly enables the patient to make a more reflected and likely better decision. Accordingly, the function of informed consent is still preserved.

consequences. As the paper has shown, the challenge of ignorance applies to a vast range of medical interventions. So, given that it truly holds, it poses a major problem to medical ethics. However, the analysis of its validity revealed that the challenge of ignorance is neither convincing from an empirical perspective nor from a theoretical perspective: there are transformative treatments where most patients get what they expected, suggesting that they can have adequate understanding of them; and theories on the ethical importance of informed consent are compatible with irreducible ignorance. Therefore, given that the presence of ignorance is openly discussed, it does not prevent informed consent.

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