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ORIGINAL RESEARCH

Transformative experience and the principle of informed consent in medicine

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Abstract

This paper explores how transformative experience generates decision-making problems of particular seriousness in medical settings. Potentially transformative experiences are especially likely to be encountered in medicine, and the associated decisions are confronted jointly by patients and clinicians in the context of an imbalance of power and expertise. However in such scenarios the principle of informed consent, which plays a central role in guiding clinicians, is unequal to the task. We detail how the principle's assumptions about autonomy, rationality and information handle transformative experiences poorly, appealing to several difficult cases for medical decision-making to illustrate the resulting problem, and we consider how the existing literature on complications with consent fails to offer a resolution. We argue that recognition of the problem has a role to play in achieving a more effective response to transformative decisions. In Sect. 1 we introduce several representative cases of challenging patient decision-making that clinicians might face. In Sect. 2 we detail how transformative experience has been analysed in the recent literature, before outlining in Sect. 3 the theoretical basis of the principle of informed consent, which plays a central role in how clinicians are expected to support decision-making. In Sect. 4, having laid the groundwork for a clear description, we return to the cases given in Sect. 1 to confirm how their transformative nature presents a problem: either clinicians treat the decisions faced by these patients as 'normal', encouraging them to focus on information provision that patients may be unable to act on, or they treat them as transformative, in which case they lack the resources to recognise whether they are helping patients make (subjectively) good decisions. In Sect. 5 we argue that the existing literature does not offer any escape from this problem. We close in Sect. 6 by noting the significant impact that appreciating the problem of transformative

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experience could have on supporting transformative decisions in medicine and briefly suggesting how we might aim to develop new approaches to dealing with these.

Keywords Transformative experience · Medical ethics · Autonomy · Rationality · Informed consent · Decision-making capacity

1 Challenging decisions

We will begin by introducing some challenging medical cases involving patient decision-making.[1]

Rhinoplasty

A is a 22-year-old who presents with longstanding asymmetry of the nose and a dorsal hump caused by unmanaged healing of a sporting injury, and requests an elective rhinoplasty to correct what they see as a significant cosmetic defect. They are informed that it is difficult to be assured of a result matching their expectations, that rhinoplasties are more likely than many other aesthetic procedures to lead to dissatisfaction with the outcome (77% rating procedure as 'worth it' vs. e.g. 93% for abdominoplasty and 83% for facelift according to Domanski and Cavale (2012); see also Khansa et al., 2016), and that features like asymmetry may well recur due to unpredictable healing. A nevertheless insists that they want to go through with the surgery as they 'want to look normal again'. During the consultation there are concerns about A's motivations as they present extensive research they have done on the 'look' they want, based on a range of celebrities; however it is decided to go ahead with the procedure. The operation is successful; on follow-up 6 months post-operation, A expresses regret about the procedure, saying that it 'wasn't what I expected it to be like'.

DIEP

B is a 38-year-old patient who has recently undergone treatment for breast cancer which included a mastectomy and radiotherapy. Having recovered from these treatments, B asks about reconstructive options as they feel 'ugly and scarred', and 'constantly reminded of their cancer'. They had previously been made aware of the surgical option of a 'Deep Inferior Epigastric artery Perforator' (DIEP) flap. This is a form of reconstruction following removal of breast tissue which recreates the appearance of a breast using fat and skin from the abdomen. An abdominoplasty ('tummy tuck') is performed and the fat and skin from this procedure is moved and given a new blood supply by plumbing the vessels into the chest to recreate the breast appearance. This is

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[1] A brief note on choices of example: our cases are based on real-life examples seen within plastic surgery departments due to the experience of one of the co-authors. We do not intend to restrict our claims to this setting but to use it as a useful starting point—this area is instructive because it stands out for involving drastic bodily changes where the patient is likely to be conscious and in a position for questions of consent to arise. All cases have been changed to avoid any risk of patient identifying information.

a long procedure (typically 8 h of surgery) and as well as the standard risks associated with undergoing surgery, there is a risk of the new vessels becoming blocked, affecting blood supply to the new breast and leading to it having to be removed. The procedure is entirely cosmetic, though it is frequently requested and seen as a significant part of breast cancer recovery. B's case is complicated by their having undergone radiotherapy, as this increases the risk of poor wound healing, but when informed of this B still wishes to go ahead. The operation is successful; on follow-up 6 months post-operation they express ambivalence about the procedure, saying that they feel more comfortable with their appearance than before, but that they don't feel like it's their body.

Amputated digit

C is a 50-year-old who presents having suffered an amputation of the middle finger of their dominant hand due to an accident with a circular saw. They are informed that they can be treated either (i) by attempted replantation of the amputated finger, which may allow them to recover better use of the hand but requires complex surgery and months of physiotherapy to improve function, with success rates subject to disagreement,[2] or (ii) by terminalising the digit, a more straightforward surgery that requires less time in hospital and minimal physiotherapy but may result in altered hand function. On being presented with the treatment options, including that option (ii) may result in an 'incompetent hand' (inability to securely hold small items when making a fist) C says they 'can't be bothered' with the rehabilitation process and want to get back to work quicker; they choose (ii). The operation is successful; on follow-up 3 months post-operation, C is of the opinion that their decision was a good one.

Facial flap

D is a 55-year-old who has been undergoing treatment for cancer of the tongue and floor of the mouth. They undergo removal of the cancer and reconstruction with a piece of skin and fat taken from the forearm. This is a lengthy operation, and its impact on the use of the mouth for eating, drinking and speaking is explained to them in-depth; their questions are answered, and they are satisfied with the consent procedure. Afterwards D wakes from the procedure with a tube in their neck to allow them to breathe, and a tube in their nose through which they are fed as they cannot eat or drink as normal. They cannot speak, instead communicating using a whiteboard. This is the case for 1 week until the new area of skin starts to heal. After a week, D is able to start eating small amounts of pureed food and to speak with considerable difficulty. 1 month into recovery, D is able to eat soft foods and to make themselves understood but at this point improvement slows down considerably. On follow-up 6 months post-operation, D reports very low mood and feelings of disappointment and resentment about the

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[2] According to one meta-analysis (Dec, 2006) the survival rate for a replanted digit after a clear cut is approximately 91%. However while some studies report significant improvements in function (Sebastin & Chung, 2011), others have found improvements to be limited (Morrison et al., 1977). The disagreement in the literature may be due to the many factors influencing functional results such as time and mechanism of injury, presence of co-morbidities and compliance with physiotherapy.

procedure; they do not dispute that they were informed of what to expect, but they feel unhappy in a way that they struggle to articulate.

Flame burn

E is a 57-year old who suffered a life-threatening flame burn to 65% of their total body surface area with inhalation injury, caused by a house fire that was started by a faulty appliance. Some of the burns are deep enough to require surgical intervention, while others require in-patient dressing management (where this includes frequent dressing changes that must take place under sedation due to pain levels). Flame burns are in general a significant 'insult to the body' and require very careful management; typical measurement of mortality risk for burns is done via the 'modified Baux score' (see Osler et al., 2010), which combines patient age, total body surface area of burn and presence of inhalation injury, and this score gives E's mortality risk at 84%. E initially undergoes emergency treatment in their best interests as at that point they lack decision-making capacity, but then gives consent for some early procedures. Some way into treatment, E starts to put off or refuse treatments, saying they are not ready to go through them. This escalates from refusing trips to theatre to also include basic management such as dressing changes and rolling to prevent pressure sores, despite E being informed that doing so is likely to lead to death. E is seen by a wide team including a consultant psychologist, psychiatrists and an ethicist, is never evaluated as suicidal, and does not express a wish to die. At a late stage E expresses regret about refusing treatment, but ultimately E dies as a result of infections from lack of treatment to their wounds.

2 Transformative experiences

It is clear that experiences affect us in many ways. Some can pass us by without our even noticing them much: the soothing colour of the walls in a room, the sound of traffic, or the mild discomfort of the saddle during a long cycle. Others can be described as disorienting, devastating, uplifting, inspiring, or a raft of other terms that aim to capture the fact that they are *life-changing*: having a child, joining the military, becoming homeless, etc. There is of course a spectrum of experience from the least to the most significant, but Paul (2014) argues for an important distinction between what we might call *normal* experiences and *transformative* experiences.

Paul identifies what she means by 'transformative experience' by outlining two features that experiences may have: they may be *epistemically transformative*, or they may be *personally transformative*. In brief:

- An **epistemically transformative experience** is an experience such that an agent cannot know what it will be like to go through the experience before actually going through it;
- A **personally transformative experience** is an experience such that having it changes the values an agent assigns to experiences in general;

- A **transformative experience** is an experience that is both epistemically transformative and personally transformative[3];
- A **normal experience** is an experience that is neither epistemically nor personally transformative.[4]

In order both to represent these experiences more clearly and to show the problem they generate, we will use the framework of *expected utility theory* (see Pettigrew, 2019).[5] According to basic expected utility theory, when making choices, agents can be modelled as assigning each outcome they are considering a utility (alternatively a 'subjective' or 'phenomenal' value) and a probability. The former represents how much they judge that they would favour that outcome, and the latter represents how likely they judge that outcome to be should they make that choice. In most cases it is important to also know the *non-favoured* outcomes of the choice, since it matters not just whether I win £10 on a coin-flip result of heads, but also whether a result of tails would mean nothing, or losing £10, or losing an arm! Thus we calculate the sum of the products of each outcome's utility and its probability, and the result is that choice's *expected utility*. We can then say that:

- A decision is **rational** iff no other available choice has higher expected utility;
- A decision is **irrational** iff some other available choice has higher expected utility;
- A decision is **non-rational** iff it is neither rational nor irrational.

By this categorisation, if presented with a decision between choosing to make a meal that is (a) delicious but likely to go wrong, (b) merely acceptable but reliable or (c) merely acceptable *and* likely to go wrong, either (a) or (b) will be rational depending on the exact utilities and probabilities, whereas (c) will clearly be irrational.

What of the *non-rational*, though? This captures those cases where it isn't possible to assign values at all. If for one or more live choice I have no way to assign utilities to outcomes, then I cannot calculate expected utility—in such a situation, I'm incapable of weighing the available choices against one another. One might reasonably expect borderline cases as well, where I have access to *some* information about the available choices but this is so minimal that my decision cannot comfortably be described as (ir)rational. For instance, suppose I'm told to choose between two 'mystery doors' in a situation that lacks information about what to expect from either one of them—while plausibly *some* information might be available (the person asking me to choose might display certain telling body language, or I might be able to discern a noise of merriment, or torment, that seems to come from behind one door), my assignments

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[3] It is somewhat confusing to use 'transformative experience' to refer only to those experiences with both elements, rather than using the term disjunctively and introducing a term like 'truly transformative experience' for the cases that have both features, but here we are following Paul's terminology (2014, p. 17).

[4] It should be noted that while the first three definitions are drawn directly from Paul's account, our definition of 'normal experience' is not found therein. This category is provided for convenience, and not to make a substantive claim about the significance of experiences that are non-transformative. Of course many 'normal' experiences will have a great impact on the life of the agent, but the appellation is intended to convey the idea that for these experiences, normal decision-making is adequate, where 'normal' is intended to convey both that the procedure is usual and that it is informed by rules or norms.

[5] Paul uses different terminology, speaking generally of 'normative decision theory' (2014, pp. 19–30). We do not anticipate that any serious matters will hinge on our choice of terminology here.

of utilities and probabilities would be so tentative and so broad that it may be just as appropriate to describe my decision as non-rational. This shouldn't raise eyebrows, since someone placed in such an awkward situation lacks the tools to choose well.[6] More worrying cases await, though.

The challenge begins when we consider the impact of epistemically transformative experiences. I cannot assign a utility to a choice whose outcome is that I have an epistemically transformative experience, since by definition I cannot know what that experience would be like. If so, then it seems to follow almost immediately that decisions involving epistemically transformative experiences are non-rational since for some choice(s) no expected utility can be generated. This would be alarming, since it is not difficult to come up with candidate epistemically transformative experiences: perhaps examples as straightforward as tasting something radically unfamiliar (say, one's first taste of durian fruit, to take an example from Paul) or taking part in completely novel activities (say, one's first skydive) would qualify. And perhaps it's correct that I can't reach a decision based on *what it will be like to skydive*, but there is a way to salvage rational decision-making in such cases: we instead re-describe the decision as one about the value of *finding out* what the experience will be like, as deciding whether to 'try new experiences for the sake of their newness' (2014, p. 39). While I don't have a value to assign to skydiving without having done it, I can assign a value to the experience of discovery, about which I have previous evidence and can form reasonable expectations. If each time I tried a new high-octane activity in the past I hated it, I have good reason to believe that I won't enjoy this either; if I am an adventurous individual who has enjoyed a range of new experiences, then despite the chance that skydiving could turn out to be unpleasant, or even just dull, for me, I can reasonably expect the finding out to be worth it.

This retreat to a higher-order judgement *may* resolve the problem for *merely* epistemically transformative experiences. However, an experience that is transformative in the strong sense as defined above will also be *personally transformative*, and the higher-order response certainly isn't effective in those cases. In such circumstances, there is a further level of uncertainty, because personally transformative experiences may change normally recalcitrant features of character and values that determine an agent's global assignments of value. For instance one might transform from the kind of person who values community to a fiercely independent person, or from a highly

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[6] A possible response here, suggested by an anonymous reviewer, is that the agent presented with the mystery doors *does* have relevant information, but the information is just very limited, meaning that they simply need to recognise that the range of possibilities is very wide in making their choice and either they should assign only a very slight preference for one option, or they should assign both options an expected utility that encompasses an extremely broad range of possibilities. We have two responses to such a point. First, while more plausible circumstances for such a choice, such as a gameshow, offer at least some basic information about possible outcomes such as that the agent shouldn't expect death to be one of them, we can imagine more extreme, perhaps fantastical, circumstances where the range of possibilities is too wide for the agent to fruitfully consider, such as if the choice between the doors is presented by a genie.
Second, our contention here is just that these are plausibly *borderline cases*, where it is unclear how appropriate it is to continue to evaluate such choices as rational or irrational. It is open to us to insist that agents can be described as rational or irrational in such cases, but it also seems plausible that those agents will not be epistemically praiseworthy or blameworthy regardless of which choice they make, and if we wish to associate rationality with these ideas, this may encourage us to describe cases where an agent is beyond praise or blame as non-rational.

cautious individual to a keen risk-taker. Rather than simply facing uncertainty about the particular value to assign, then, for a personally transformative experience the agent is uncertain about what the values assigned to *all* of their experiences will be.[7] Thus for a truly transformative experience such as, in Paul's view, having one's first child (2015), if one is trying to make a decision one remains in a tricky situation.

If I am deciding for the first time whether to have a child, when deliberating, I can identify two broad choices: to have a child, or not to have a child. For simplicity we can ignore the subtleties of different sub-options such as child-bearing versus adoption, and we can ignore the possibility of inability to achieve the chosen outcome (one might encounter all manner of barriers to having a child despite choosing to do so, and one might wind up having a child despite choosing not to, though of course even this is glossing over all manner of further decision points). The thought then is this: I know how I feel about children now, as well as responsibility, being well-rested, emotional attachment, etc., and for some of those things I can form an expectation of how having a child could promote or frustrate them, while for others I can't. But more seriously, whether I'm right or wrong in my expectations, it may turn out that the version of me that exists after I've chosen to have a child assigns radically different values to those features than the current version of me. This means that my uncertainty in transformative decisions is doubly extreme—both the appropriate values and the appropriate metric for assigning them are mysterious to me.

3 Autonomy, capacity and informed consent

Critical reflection on decision-making is clearly relevant to medicine for at least the minimal reason that some decisions are medical decisions. However several complicating factors demonstrate the importance of thinking specifically about decisions in medical settings. We can begin by briefly listing some such reasons.

First, medical decisions are often life-changing; whereas a large number of one's decisions are minor, such as what to eat for any particular meal, which way to walk to the shops, or whether to clean the house, those choices that are made in medical settings are more likely to be consequential. Second, medical outcomes are highly complex in ways that have been studied and mapped out—although *many* decisions have complex consequences, given the significance assigned to health and illness (and the impact of different treatments both at a personal level through individual interventions and at a societal level through different policies) we are more likely in medical settings to have a wealth of data on the impact a disease, procedure or lifestyle has on a person, often further separated by a range of demographics such as age, gender, ethnicity, etc. Third, medical decisions are mediated by a third party. This is necessary both because of the complexity of outcomes, understanding which requires extensive study and specialism, and because of the complexity of the kind of action taken, performing which requires the above as well as sophisticated practical skills. Fourth, medical decisions are often made in a context that creates an imbalance of both information

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[7] One might think that if there are experiences that are *merely* personally transformative, these can also be accommodated by expected utility theory. This is one way to interpret the cases of changing values explored at length in Pettigrew (2019).

and power. The information imbalance is clearly connected to the third point: a patient is unlikely to have the clinician's in-depth understanding of their condition and how it interacts with various other factors, nor of different options for treatment, what they involve, what benefits and risks they have, etc.[8]

These factors combine to produce a situation where an expert is required to support an agent with their decision-making, and where that expert has a significant influence on the agent, but where there are significant barriers and safeguards. First, a clinician cannot be forced to perform a procedure on a person if they do not wish to; second, a patient cannot be forced to undergo a procedure they do not wish to undergo except under very specific circumstances. The reason typically appealed to under the dominant approach to medical ethics in Western countries is autonomy.

Autonomy is one of the four constitutive principles of 'principlism', which is widely adopted as the standard guiding position within medical ethics (see Beauchamp & Childress, 2009, ch. 1, Sect. 9). Alongside beneficence, non-maleficence and justice, respect for autonomy is supposed to guide clinicians' treatment of patients. Some treat the principle as especially important: it has been called the 'first among equals' (Gillan, 2003, p. 311) and it has even been claimed that these principles, led by autonomy, can capture all ethical thinking both inside and outside the medical setting (ibid., p. 308)! Agents' autonomy arises from their capacity to establish and follow principles for action. In its strictest sense it is to be understood as the ability to *set laws for oneself*, and it plays this role in Kant's ethics—the moral (and free) agent must act autonomously, determining a rule as rationally required and acting in accordance with it because the

> moral law is founded on the autonomy of his will, as a free will which by its universal laws must necessarily be able to agree with that to which it is to submit itself. (1788, Bk. 2, ch. 2, Sect. 5)

In contrast the heteronomous agent acts in a way that is determined by external forces; they are pushed and pulled around by circumstance and lack genuine agency, much as a weathervane lacks agency when it points in the direction the wind is blowing. Within Kant's system the bar for autonomy can seem high indeed; however understood more permissibly, autonomy remains a right held by conscious agents in virtue of their acting for reasons.

To act for reasons is not necessarily to act rationally—after all, one's reasons for acting can be bad in all sorts of ways. But when we consider how to bring together the

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[8] We do not intend to claim here that the information imbalance is insurmountable (it's clearly possible for a patient to be as informed as the clinician treating them, though also clearly possible for a patient to wrongly believe this) and nor do we intend to claim that the information imbalance covers all relevant areas. While clinicians are well-placed to consider the *medical* implications of the relevant choices, patients have access to a wealth of first-personal information about how different outcomes will affect their lives. Such matters become especially significant for medical decisions that relate to deeply personal matters like those regarding gender-affirming care (on this subject, see the contributions to Shrage, 2009). Here there may be a serious mismatch between the clinician who is well-placed to evaluate medical implications but less well-placed to evaluate personal implications and the patient who is less well-placed to evaluate medical implications but as well-placed as anyone can be to evaluate personal implications. How to reconcile these is a serious challenge which we cannot fully address here, though we hope that our discussion of the inadequacy of information-based support may in fact increase clinicians' focus on engaging with the patient's perspective.

question whether someone acts for reasons and the previously discussed framework of expected utility theory, it appears that where someone acts for reasons and is therefore autonomous the question of rationality can at least be *raised*. Whether one is acting rationally or irrationally, one is acting for reasons, and only at the limit of this do they cease to be autonomous. In such cases, according to medical practice, they no longer have decision-making capacity (DMC).

Since it is of paramount importance for clinicians to respect patient autonomy, it is crucial for clinicians to have principles for determining when patients are acting autonomously, and this is done by assessing DMC. Looking at guidelines for assessing DMC illuminates this situation further. In the United Kingdom, practice is informed by General Medical Council (GMC) guidelines, which state that to have DMC with regard to a decision the patient must be able to:

1. Understand information relevant to the decision in question
2. Retain that information
3. Use the information to make their decision
4. Communicate a decision (GMC, 2020, p. 83, our emphasis)

This is specific to the UK medical setting, but similar principles are adhered to elsewhere, as shown by another representative statement of the constraints placed by DMC:

> [a patient with DMC] can clearly communicate her decisions, understands the information about her condition, appreciates the consequences of her choices…and can weigh the relative risks and benefits of the options. (Appelbaum, 2007, p. 1838)

Two points bear emphasising about the above. First, as already suggested, DMC is not regarded as a fixed property that one either has or lacks, but rather is treated as contextual and decision-specific. For instance, a patient with dementia may lack the capacity to reach decisions about their ongoing medication since they cannot understand or retain the information relating to their overall condition, but they may still have capacity to reach decisions relating to immediate pain relief. Indeed, a patient with dementia may lack the capacity to reach a wide range of decisions relating to their care when they are experiencing severe symptoms and are tired, malnourished and agitated, yet when their symptoms are milder and they are well-rested, well-fed and calm, there may be a very different range of decisions for which they have DMC.

Second, for important reasons of patient protection, there is a presumption of capacity. If a clinician wishes to claim that a patient lacks DMC for a particular decision, they must demonstrate that the patient has an impairment that interferes with DMC—dementia, as mentioned above, may be such an impairment, but others might be psychosis, traumatic brain injury, or other psychological and neurological conditions.

The principle of autonomy is seen as fundamental to ethical treatment of patients, however as the complexities displayed above make evident, *how* one can promote patient autonomy is difficult. For patients to be left with nothing but bare autonomy in the face of a decision for which the consequences, treatment options and even certain concepts were unfamiliar would be seriously problematic. When confronted with a vastly complex choice with absolutely no useful information, one may count as autonomous, but this is not much help since one is not in a strong position to make a good decision—think of the case (see Sect. 2) of the agent choosing between two 'mystery doors'. If that complex choice is one into which no one has insight, a lack of information may be regrettable but unavoidable; if that complex choice is well understood by someone in a position to provide support, a lack of information is a failure of duty. In circumstances of informal responsibility, such a failure of duty might be regarded as moral only, but in the clinician's case, that failure of duty also has an important legal element.

All of this is to stress the significance of the principle of informed consent. This principle is a key part of promoting autonomy, because consent to a choice offered is only seen as valid if it is appropriately informed. There are straightforward cases revealing its importance such as the example of a clinician simply lying to a patient—any consent given to a particular treatment will not be informed since the information relevant to their decision has been withheld and replaced with deceptive information. The question of what amounts to appropriately informing patients is a vexed one, but while previously there was some ambivalence about informed consent in the UK, with the 'Bolam test'—whether the clinician was acting in accordance with a respectable body of medical opinion—determining legal responsibility,[9] the significance of informing patients is now acknowledged in UK law, with clinicians 'under a duty to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments' (*Montgomery vs Lanarkshire Health Board* (2015) UKSC 11, paragraph 87, quoted in MDU, 2020).

At this point, we can summarise as follows: within medical ethics, the principle of autonomy is seen as of paramount importance. The establishment of DMC functions as a prerequisite for applying the principle of autonomy, and where that prerequisite has been met, the principle of informed consent functions to guide the clinician in judging what information to offer to facilitate the patient's autonomous decision.

4 Transformative medical decisions

As we have seen above, the weighing up of complex risks and benefits is important to questions that are of the most pressing nature for patients: about which treatment options to prefer, whether to accept certain complementary treatments, and when to refuse treatment entirely. Fitting such decisions into a framework like expected utility theory which facilitates comparative evaluation would, therefore, be highly beneficial if it could be done. At the same time the medical context has a clear tendency to require us to confront some of the most extreme circumstances we are likely to face in our lives—this much is obvious, and has already been discussed in Sect. 3. But are such extreme circumstances likely to place us in a position where we are faced with *transformative decisions*?

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[9] This test was initially established by *Bolam v Friern HMC* (1957) 1 WLR 583; see also (Beauchamp & Childress 2009, pp. 167–170).

This much has been argued in the literature—for instance it is claimed by Carel et al. (2016) that serious illness is in many cases a transformative experience:

> In what ways does illness transform people? We know that people experience a dramatic shift in their identity; for example, patients with cancer who recover view themselves as “survivors”…The values and desires of ill people can alter…Their world-view may change deeply. They may become depressed, or more religious, or happier. And, of course, they may not change at all. There is simply no telling how illness may change a person, which is precisely Paul’s point. (1153)

It is also, we take it, clear from the cases described in Sect. 1 that these are patients facing potentially transformative decisions. So there are good grounds for thinking that there are many instances of transformative experience to be found in the medical setting, and that there will be important upshots for patient treatment. Let us, however, revisit the cases from Sect. 1 to consider how transformative decisions present practical challenges for clinicians, before closing this section by articulating the clinician’s dilemma in general terms.

In A’s case, the relevant choices are to undergo a rhinoplasty or to remain as they are. Assuming that similar procedures aren’t part of A’s past, the experience of undergoing a possibly substantial change to the structure and appearance of their face could impact them in unforeseeable ways which might include a change in values; on the other hand they may worry about ongoing dissatisfaction if they do not choose to undergo the change. A clinician treating A would confront challenges in explaining the risks of surgery, including not only the risks of complications but also the risks of dissatisfaction with the outcome. They would also need to make judgements about A’s mental state in relation to the very specific expectations A has about ‘look’, trying to establish whether these merely reflect preferences or are indicative of problematic or even disordered fixation. These challenges are exacerbated by confronting the question of how A might be fundamentally changed by the procedure.

In B’s case, there are multiple potential transformations layered together. B has already undergone several experiences with a good claim to being transformative: a cancer diagnosis, double mastectomy and chemotherapy all could have radical impacts on B’s life. These changes are unlikely to be resolved and stable at least because B is still going through recovery—B may therefore be very uncertain about how they feel about themselves, bringing in further uncertainty about how they may react to a further radical change to their body. Judgements about patients’ reactions to such changes already influence clinicians’ actions, with the normal procedure being to offer patients both the option of a DIEP after healing from previous surgery and the option of completing the DIEP alongside the mastectomy as a single complex procedure, as well of course as the option of no reconstructive surgery. A clinician might wish to ensure that B carefully considers the option of declining reconstructive surgery given the aforementioned risk of problems with wound healing post-radiotherapy. Risks and benefits can be presented to B, but it is difficult to establish the range of information that B requires to make an informed decision, especially given the substantial uncertainty about how they will feel about their cancer diagnosis in future.

In C’s case, the relevant choices are to undergo replantation, attempting to bring about a situation where the hand is as close as possible to previous function, or to undergo terminalisation, simplifying the treatment process and avoiding risks of failure but ensuring that the appearance and structure of the hand will be very different. This case differs from the previous two in that the more likely transformative experience comes from the conservative treatment option—terminalisation is a safer and more comfortable alternative to doing nothing whatsoever, which would generally be seen as not a live option by clinicians due to factors like infection risk. Here it is worth noting that there may be significant influence from lay assumptions about hand function—one might assume that the loss of a finger would be significantly disabling, whereas replantation would offer the prospect of normal function. However the loss of the middle finger can be accommodated by the remaining fingers, in contrast with the loss of a thumb, which leads to a very significant loss of dexterity or counterintuitively the loss of a little finger, which leads to a very significant loss of strength in the hand; especially if the digit amputated was a thumb, the clinician might raise serious concerns at a patient expressing a preference for terminalisation. In C’s case, however, while there is a reasonable chance of the choice being a reasonable one for them, in line with their preferences, it should not be forgotten that they do not have experience of their anatomy being this way, being used as they are to having species-typical hand structure, and this could have led to a situation where they felt very differently about the choice after the fact. A clinician treating C would face difficult challenges deciding how far to press with the information they provide about the possible outcomes and how to consider the possible influence of features like non-compliance with physiotherapy.

In D’s case, barring a strong stance from the patient it is unlikely that there would appear to be a significant decision between options since the alternative to surgery would be non-treatment, which for cancer of the tongue and floor of the mouth would likely result in painful and debilitating illness leading to death. Nevertheless this is not a normal decision as the surgical treatment option involves very significant changes to D’s body that may fundamentally change the way they live their life. A clinician treating D would not face significant challenges in determining whether they wanted to go ahead with the surgery but would face significant difficulties communicating the potential impact of this surgery.

E’s case is the most drastic situation of all, and not just because of the outcome. This represents a situation where despite the immediate physical trigger of transformation—the burn—having happened, the patient cannot be said to have reached a state where they have had the opportunity to reconcile the events and so are in a position of stability. In such a situation, where the impact of the event and the place it has in their life is unresolved, every decision to be made seems to take on the significance of a transformative experience as what E does makes a difference to how their experience can be viewed within any narrative they give of their life. In this respect this case resembles what Ruth Chang calls ‘choice-based transformative choices’ (2015, p. 237), where the act of choosing plays the crucial role in the transformation rather than the outcome(s) of that choice. A clinician treating E is in the difficult position of trying to establish whether E’s inability to choose is the result of having no option that they see as acceptable, or of being in a position where they are struggling to understand their own preferences or visualise their own future.

In the cases we have described, and the many cases like them to be found across the medical spectrum, transformative experiences impact on patient decision-making. But the problem isn't simply one mirroring the general challenge we face when thinking about transformative experience—that we have a clear interest in being able to evaluate our choices about such things, but we seem forced to represent our choices as non-rational and resistant to evaluation. The challenge is more threatening in the medical setting.

As mentioned above a distinctive feature of the medical setting is that, barring a very small number of extraordinary cases, the decision-maker and the actor are not the same person. Clinicians have the expertise, access, and professional responsibility to conduct the procedures that may have a huge impact on patients' lives, but we do not typically judge that they should have the final say in what procedures (if any) are performed on the patient, thanks to the principle of autonomy. And the principle of informed consent aims to ensure that they are provided with the appropriate tools to prevent them from making this decision in the dark. This feature might be seen as an attempt to rectify the imbalance between the expert and the person to whom that expert's actions will make such a significant difference.

But recalling the GMC guidelines mentioned earlier, clinicians are required to establish whether a patient can 'understand information relevant to the decision [and] use the information to make their decision'. The alternative phrasing referring to ability to 'reason about the relative risks and benefits of the treatment options' is, if anything, a *more* difficult prospect, and both statements make clear that the assumption is that patients are to be informed because that information will help them to make a decision that is good from their perspective. Yet for patient decisions involving transformative experiences, it is far from clear that the information given will be used, since it is hard to see how the patient *could* use the information. Nor is it clear what counts as relevant information, since what would matter to the agent is up in the air when a transformation is on the cards. As for the ability to reason about risks and benefits, a phrasing which strongly suggests the weighting of preferences and probabilities, it would seem naive in light of Paul's arguments to suppose that this is available in the cases we're considering,[10]

We are now in a position to clearly state the clinician's dilemma. In all cases, there is overwhelming reason to believe that the individual has DMC—their situations do not provide evidence of impairments that would call DMC into question. The principle of autonomy is thus in play, so the clinician is obliged to support the individual as far as possible to make an autonomous decision, and to make a judgement regarding whether the patient has provided informed consent. However if the clinician treats the

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[10] There is a further complication here: one way to frame certain transformative experiences is as changing *who the person is* where this could be understood in an especially strong way, as involving a change in personal identity. This would introduce new issues relating to potential differences of identity in the individual at different points in their treatment. However we will not pursue this angle further in this paper, because (i) while changes in personal identity might be plausible in some cases, they won't apply in every case, and indeed most of our examples seem poor candidates for the kind of radical psychological change that tends to be seen as necessary for a change of personal identity, and (ii) even if a change of personal identity could be claimed in our cases it would nonetheless be unlikely to materially affect a clinician's treatment of the patient, and we are here interested in engaging with the practical problem confronting clinicians. Thanks to an anonymous reviewer for raising this class of potential responses to the issue.

experiences in question as transformative, then the assumptions behind the principle of informed consent (that someone with DMC is in a position to weigh up the options available) fail and they have no grounds on which to provide information. If on the other hand the clinician treats the experiences in question as normal, there ought to be an answer to the question "What information ought I to provide in order to reasonably judge the patient to be sufficiently informed?", but no amount of reflection will allow them to answer that question since they are not dealing with a decision about a normal experience.

In practice the first horn of the dilemma is unlikely to occur for clinicians because there is no guidance for how to deal with transformative experiences, meaning that clinicians will likely be stuck on the second horn. They will treat such experiences as though they were normal, leading to their making judgements about the appropriate information to provide which both they and the patient may lack the means to evaluate. The prominence of autonomy as a fundamental medical ethical principle, and the principle of informed consent as the central guiding force behind establishing how to ensure respect for autonomy, mean that clinicians are potentially placing themselves in a position where they are unable to make a reasonable attempt at supporting patients to make decisions that those patients regard as having been made well. This shows that a serious practical problem is produced by our lack of a way to incorporate transformative experiences into existing medical decision-making frameworks.

Before moving on, we should consider a potential reply. The critic might complain that the cases we have outlined are comparable to a class of cases that are not generally thought to present a deep problem for informed consent: experimental clinical trials. In certain situations patients might be offered, for instance, an experimental drug for cancer treatment where accurate information about the potential risks and benefits is not yet available. In such cases, the clinician can provide as much relevant information as possible, making clear the limitations of this information, and this looks intuitively like an autonomous decision that is as informed as it can be. However, the cases presented here are not like experimental clinical trials, because for such trials the relevant risks are identifiable (e.g., gastrointestinal distress, anaphylaxis, or death), yet their likelihood cannot be confidently stated, and perhaps their exact presentation in the patient will be unknown. This makes such cases comparable to either situations with very limited information or to epistemically transformative experiences—if the information about the salient risks were to become available, it would largely resolve the problem. However for at least some of the cases introduced in §1, the clinician doesn't merely lack information to supply the patient with on what the relevant experience will be like. Rather they lack a framework for supporting the patient with what it might mean for them to change as a person as a result of what has happened, or might happen, to them.[11]

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[11] Thanks to an anonymous reviewer for raising this comparison as a potential challenge.

5 Considering complications with consent

One might hope that some assistance can be found with transformative medical decisions by considering contributions to the debate on DMC. However there is no straightforward resolution, or so we will argue: two contributions are worth considering, as they will further clarify the clinician's dilemma.

Where else do we encounter concerns about inability to use relevant information? The debate about DMC has been dominated by situations where features of the patient make it unclear whether they meet the expected standard. In borderline cases a minor difference can have a major impact regarding the patient's role, and our choices about where we draw these lines are negotiable, so there are numerous arguments that we should depart from the typical standard. It is therefore potentially fruitful to consider whether examining this angle can provide insights.

One notable distinction made between possible capacity standards is threefold:

1. A *minimal* standard of decision-making capacity, which requires only that a patient express a choice;
2. An *outcome* standard, which requires that a patient select options that a reasonable person would select; and
3. A *process* standard, which requires that a patient have an appropriate process for making their decision, regardless of the content of what they choose. (Buchanan & Brock, 1989)

This distinction is coarse-grained, and at this level it's easy to see reasons for preferring the general stance that dominates in Western medicine. A minimal standard seems immediately too permissive, since it would permit even clear cases where an individual is not in a position to promote their conception of the good, such as coercion, radical delusion or complete confusion. On the other hand an outcome standard seems immediately too restrictive, since it amounts to a stringent rationality requirement to treat a patient's preferences as authoritative; aside from the clear failure to respect a right to self-determination in allowing only the 'right' choices, such a standard would be extraordinarily difficult to apply consistently, since one has limited insight into the preferences of others and it is challenging (to say the least) to suppress one's own preferences when evaluating others' choices.[12]

However, while process standards seem to provide an appropriate middle ground between two excesses, this doesn't mean that the discussion is settled. For instance Navin et al. (2021) argue that the kind of process standard that requires the ability to weigh up the options is excessively restrictive at least when it comes to the ability to refuse treatment. They argue that a patient might not meet the 'comparative judgement' (ibid., 2) standard because of an impairment, while nevertheless being able to articulate what they regard as *unacceptable burdens* or *non-negotiable goals*. For instance, despite being unable to understand the consequences of all treatment options when offered, a patient with dementia may be able to confidently assert that they don't wish to live in a state where they're confined to a wheelchair (i.e. they regard this as an

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[12] Such standards aren't *universally* seen as out of the question: for instance Savulescu and Momeyer (1997) argue for an outcome standard. However such claims are rare and are seen (correctly, in our view) as extreme.

unacceptable burden) or that they wish to die ‘naturally’ at home (i.e. they regard this as a non-negotiable goal). Navin et al. argue that refusals grounded in such processes should be seen as authoritative.

Does this provide any help with transformative medical decisions? While it might initially seem to offer a potential escape, since it would acknowledge that patient decisions can be authoritative even in cases where patients cannot weigh up the relative risks and benefits of their options, we claim that the escape is illusory even if the proposal is viable in the cases it aims to accommodate. First, Navin et al. acknowledge a limitation to their proposal: they explicitly argue for the validity of patient *refusals*, though rather than claiming that the view does not extend to consent more generally they remain agnostic on the matter (ibid., 10). However were the approach extended to cover consent to all options, it would sanction active interventions on the basis of patient preference despite inability to compare different options, leaving patients highly vulnerable to influence by suggestion—whether accidental, where a trivial feature of the presentation of options such as its order or the ease with which it could be retained was the deciding factor, or intentional, where a clinician might have an incentive to push a particular option in the knowledge that it could be made salient to the patient simply by presenting it clearly and simply against a background of confusing alternatives.[13] Second, this response has a more absolute limitation, which is that it doesn’t step outside the information-based approach but instead advises a revision that simply lowers the bar for what counts as sufficient information for autonomous decisions in certain circumstances. We think that the lesson of Paul’s exploration of transformative experience, though, is that when faced with potential transformations information is the wrong thing to look for—and if seeking more information is not plausibly going to help, it is also implausible that requiring less information would be appropriate.

It is perhaps unsurprising that the proposal discussed above is unhelpful—after all, it is firmly within the dominant strand of debate around DMC, where the main concern is whether features of the *patient* should influence judgements about how best to support decision-making. In our cases, though, it is features of the *experience* that may influence judgements about how best to support decision-making. However while this issue has received less attention, it is not entirely neglected, and we can consider a contribution to this debate to see whether insight can be found here.

One situation which clinicians are inclined to see as presenting challenges about consent is the administering of ‘mind-altering’ substances—the norm in medicine is typically that altered states of consciousness are, all else being equal, indications of disorder that are to be investigated and treated. However in recent years there has been renewed interest in *psychedelic psychiatry* due to the recognition of the potential of psychedelic substances for treatment of serious psychiatric disorders like treatment-resistant depression. However there is a challenge: as discussed by Smith and Sisti (2021),

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[13] Indeed this could be seen as a significant problem with the original proposal, since the refusal of treatment is often conceptually simpler, and adopting this approach may make it unacceptably easy to give the green light to refusals that are weak in the sense that they reflect goals or burdens that have an outsized role just because they allow a severely impaired patient to see themselves as articulating a clear desire despite more complex options that might have been compelling were they able to process those options.

> [t]he therapeutic potential of psychedelics appears to be related to the peculiar, so-called 'mind-manifesting', experiences they tend to induce…[such as] a sense of new, ineffable knowledge, feelings of unity and connection and encounters with 'deep' reality or God. (807)

These features are clearly extraordinary, and Smith and Sisti suggest that they are potentially transformative in Paul's sense (ibid., 812, n. 56). They therefore regard it as important to recognise the special circumstances, and their suggestion for ensuring appropriate patient support is to require 'enhanced consent' for such procedures. They propose a number of disclosures and questions that should be included in the consent procedure in these cases, aiming to acknowledge the impact the experience may have and the difficulty in articulating its nature except from a first-personal perspective. Some examples are:

- 'You may feel a sense that you have lost yourself, that everything is somehow connected, or that all is one.'
- 'You may become more spiritual—whether or not you currently consider yourself spiritual.'
- 'You may feel a greater sense of extroversion and openness to new experiences and ideas.'
- 'The benefits of this intervention may be related to or depend on these effects of the experience and these changes to your personality. We have found that encouraging participants to embrace the experience is important to achieving the benefits. In fact, trying to resist aspects of the experience can lead to more anxiety provoking and less beneficial outcomes.'
- 'Would any of these changes be difficult for you?' (ibid., 811, Table 2)

While it is promising that this discussion acknowledges how the nature of an experience may prompt a need for careful thought about how to ensure informed consent and therefore support autonomy, this contribution to the literature will not resolve our quandary for a complementary reason to the previously considered case. The majority of the features suggested for enhanced consent are aimed at trying to provide a description of the experience—while they are wide-ranging and also include some mention of the limitations of description from a third-person perspective, they remain attempts to plug a gap in information, and this makes the intervention in this case tantamount to *raising* the bar for what counts as sufficient information for autonomous decisions. This is not appropriate because it fails to appreciate the qualitatively different nature of the transformative experiences that are in the possibility spaces of all these decisions. Paul makes a similar point forcefully in response to the objection that for one of her central examples, having one's first child, the agent can do their research through reading, looking after others' children, etc., and thereby resolve the problem:

> You might think that having a description of what it's like to have a child will tell you what you need to know…But it doesn't, at least if you haven't experienced anything that closely resembles the experience, such as already having a child of your own…Without the relevant experience, no amount of information about resemblances will help. (Paul, 2015, p. 161)

The existing literature cannot help, then, because it remains within the dominant autonomy-based paradigm, within which the provision of information is assigned an excessively optimistic significance. This has at least two practical implications: patient preferences that are difficult to understand from the clinician's perspective may be mistakenly identified as being evidence of failing to understand the relevant information, and patients who have been informed but are struggling with an unacknowledged transformative decision may be mistakenly identified as having had their interests fully represented since by all appearances their autonomy has been respected.

6 Toward supporting transformative medical decisions

The goal of this paper has been to make a clear case for the claim that the general problem of transformative experience as introduced by Paul generates a deep and serious problem for the ethics of medical decision-making, and one that is tied to the way that the relevant medical ethical principles are formulated. Recognising this problem in itself has practical upshots: as suggested above, there may be cases confronted by clinicians where there is an illusory sense that supporting patient autonomy is straightforward and decisive in appropriately supporting their decision-making. By recognising the complexities behind these cases, clinicians can be in an improved position to provide support. The over-simplified approach that treats autonomy as the final word on ethical treatment of patients facing decisions should be called into question, even if the result is that we are left with problems which lack a clear solution.

However, is there any room to use this negative result to generate positive proposals? While the offering of principles to support transformative medical decisions goes beyond the scope of this paper, our arguments here place us in a position to close by saying something very brief about potential directions for development.

First, we have stressed the limitations of providing information to patients, which suggests that following the existing model of consent procedures (which are in practice highly variable in any case) but tweaking or adding further content is unlikely to be a fruitful avenue to explore. Nor is the exploration of the other components of principlism likely to help: beneficence and non-maleficence are concerned primarily with the prevention of harm, which does not help us to think about supporting patients *as decision-makers*, and reflecting on justice is more likely to provide answers to questions about what patients should have a right to than to questions about how to support them in deciding which of those things to which they have a right is appropriate for them. Generally, if autonomy as the 'first among equals' is found to fall short, this should lead us to pause before assuming that the dominant approach must contain the answer.

If one wishes to protect the place of autonomy in medical decision-making, a more promising route would be to consider relational accounts of autonomy (e.g. Westlund, 2009) to more fully recognise the role that patients and clinicians share in trying to establish a course of action with which the patient can feel satisfied. However this is far from straightforward, since Westlund's claim that 'our identities and commitments are not inflexibly determined by our social positioning, but are instead worked out on an ongoing basis in dialogue with real or imagined others' (42) does not give a clear indication of how that dialogue might function effectively in this specific real setting. Plausibly an important contributing factor is trust between clinician and patient, but how to effectively foster such a sense of trust without sliding into a paternalistic treatment relationship is deeply challenging. Another important factor is the patient's relation to their community, but this introduces its own serious challenges, for instance with identifying how to provide a role for patients' family members or support groups without potentially introducing another kind of paternalistic interference, or with determining how to accommodate cases where a patient's relationships might change or be in tension (e.g. where a patient feels significant ties to family that are at odds with the ties they feel with a cancer support group in ways that could impact their treatment).

One final route that may offer progress is consideration of authenticity. The route is suggested by Paul's work, albeit tentatively:

> authentic living partly involves the discovery of what it is like to choose and respond to events in one's life…[but] by preferring to discover the preferences we'd develop, then we must prefer to give up any current first-order preferences that conflict with the new preferences we'll end up with. Many of these first-order preferences may be preferences that we think of, in some way, as defining our true selves. (2014, pp. 120–121)

This is contested ground, with authenticity appearing to play the role for some of a deep ideal that is linked to one's substantive commitments (e.g. Taylor, 1991) while for others it captures a more minimal ability to treat values that have been taken on as one's own (e.g. MacKay, 2020); however the ability to recognise and take ownership of a choice would appear to be a promising common feature. There are two difficulties with pursuing authenticity as a response to the problems we have explored here, though. First, it is not entirely clear that it can be clearly distinguished from the 'higher-order' response to transformative decisions which appeared to be helpful for epistemically transformative experiences at best (see Sect. 2 above). Second, authenticity is often presented as *backward-facing*, that is, as reflecting how a choice relates to a pre-existing deep sense of self or one's attitude to values that have already been taken on. If authenticity is to be pursued here, though, it must be a *forward-facing* conception that allows one to take on a choice and its consequences as something that *will* be formative for the individual.

These brief comments have only served to indicate where we might look for a constructive response to the problem. Further work should acknowledge that if such a response can be found, it may require a *combination* of the above concepts or indeed something entirely new. Furthermore a crucial avenue which we hope to explore in future work is whether there are insights to be gleaned from the reports of patients and of clinicians on how they have experienced this sort of decision-making. Our core contention remains, however, that one cannot rest satisfied with a naive view that decision-making in the kinds of cases we have considered is the same as that applied to normal experiences. Supporting transformative medical decisions means at least recognising where the usual procedures break down.

Declarations

Conflict of interest The authors have no conflicts of interest to report.

References

Appelbaum, P. S. (2007). Assessment of patients' competence to consent to treatment. *New England Journal of Medicine, 357*(18), 1834–1840.

Beauchamp, T., & Childress, J. (2009). *Principles of biomedical ethics*. Oxford University Press.

Buchanan, A. E., & Brock, D. W. (1989). *Deciding for others: The ethics of surrogate decision making*. Cambridge University Press.

Carel, H., Kidd, I. J., & Pettigrew, R. (2016). Illness as transformative experience. *Lancet, 388*, 1152–1153.

Chang, R. (2015). Transformative choices. *Res Philosophica, 92*(2), 237–282.

Dec, W. (2006). A meta-analysis of success rates for digit replantation. *Techniques in Hand and Upper Extremity Surgery, 10*(3), 124–129.

Domanski, M., & Cavale, N. (2012). Self-reported 'worth it' rating of aesthetic surgery in social media. *Aesthetic Plastic Surgery, 36*, 1292–1295.

Gillan, R. (2003). Ethics needs principles-four can encompass the rest-and respect for autonomy should be 'first among equals. Journal of Medical Ethics, 29(5), 307–312.

GMC. (2020). *Decision making and consent*. General Medical Council.

Kant, I. (1788). *Critique of practical reason*. Hackett Publishing.

Khansa, I., Khansa, L., & Pearson, G. (2016). Patient satisfaction after rhinoplasty: A social media analysis. *Aesthetic Surgery Journal, 36*, NP1–NP5.

MacKay, K. (2020). Authenticity and normative authority: Addressing the agency dilemma with values of one's own. *Journal of Social Philosophy, 51*(3), 349–370.

MDU. (2022). Montgomery and informed consent. Retrieved December 29, 2022, from https://www.themdu.com/guidance-and-advice/guides/montgomery-and-informed-consent.

Morrison, W. A., O'Brien, B. M., & Macleod, A. M. (1977). Evaluation of digital replantation - A review of 100 cases. *The Orthopedic Clinics of North America, 8*(2), 295–308.

Navin, M. C., Brummett, A. L., & Wasserman, J. A. (2021). Three kinds of decision-making capacity for refusing medical interventions. *The American Journal of Bioethics, 22*(11), 73–83.

Osler, T., Glance, L., & Hosmer, D. (2010). Simplified estimates of the probability of death after burn injuries: Extending and updating the Baux score. *The Journal of Trauma: Injury, Infection, and Critical Care, 68*(3), 690–697.

Paul, L. A. (2014). *Transformative experience*. Oxford University Press.

Paul, L. A. (2015). What you can't expect when you're expecting. *Res Philosophica, 92*(2), 1–23.

Pettigrew, R. (2019). *Choosing for changing selves*. Oxford University Press.

Savulescu, J., & Momeyer, R. (1997). Should informed consent be based on rational beliefs? *Journal of Medical Ethics, 23*, 282–288.

Sebastin, S., & Chung, K. (2011). A systematic review of the outcomes of replantation of distal digital amputation. *Plastic and Reconstructive Surgery, 128*(3), 723–737.

Shrage, L. (2009). *'You've Changed': Sex reassignment and personal identity*. Oxford University Press.

Smith, W. R., & Sisti, D. (2021). Ethics and ego dissolution: The case of psilocybin. *Journal of Medical Ethics, 47*, 807–814.

Taylor, C. (1991). *The ethics of authenticity*. Harvard University Press.

Westlund, A. (2009). Rethinking relational autonomy. *Hypatia, 24*(4), 26–49.