




# Misapplying autonomy: why patient wishes cannot settle treatment decisions

Colin Goodman<sup>1</sup> · Timothy Houk<sup>2</sup> 

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## Abstract

The principle of autonomy is widely recognized to be of utmost importance in bioethics; however, we argue that this principle is often misapplied when one fails to distinguish two different contexts in medicine. When a particular patient is offered treatment options, she has the ultimate say in whether to proceed with any of those treatments. However, when deciding whether a particular intervention should be regarded as a form of medical treatment in the first place, it is the medical community who has the ultimate say. Some argue that particular interventions should be allowed by virtue of the fact that they are autonomously requested. But making such an argument fails to distinguish between these two contexts and misapplies the principle of autonomy, ultimately having the potential to instigate problematic changes in the practice of medicine.

**Keywords** Autonomy · Aid-in-dying · Assisted suicide · Elective amputations · Philosophy of medicine · Goal of medicine

## Introduction

The question of whether a medical intervention is appropriate for a given condition is difficult to answer. What should physicians consider when making this kind of judgment? The answer is not immediately clear because the term “appropriate” triggers two separate analyses. First, whether an intervention is *medically* appropriate (i.e.,

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✉ Timothy Houk  
timothyho@cos.edu

Colin Goodman  
colin.goodman@utsouthwestern.edu

<sup>1</sup> McGovern Medical School, University of Texas Health Science Center at Houston, Houston, TX, USA

<sup>2</sup> Philosophy Department, College of the Sequoias, Visalia, CA, USA

whether it contributes to the patient's health and whether it fits within the scope of medicine). Second, whether it is *ethically* appropriate.

There is further complication as there are also two different contexts in which a medical intervention can be deemed appropriate. First, the medical community can determine whether, in general, an intervention is appropriate as a form of medical treatment (the administrative context). This occurs apart from any particular patient's healthcare decisions. Second, particular medical professionals and particular patients can make actual decisions about which medical treatments they will pursue (the clinical context). We argue that the distinction between these two contexts is often neglected in the medical ethics literature and, as a result, the relevant ethical principles are not applied properly—specifically the principle of autonomy. And although we are not the first to suggest that patients are not entitled to receive any medical intervention upon demand, we identify a specific kind of misuse of the principle of autonomy by identifying the differences between these two contexts and demonstrating where others have conflated them.

There has been extensive discussion about limits on autonomy and when medical practitioners are justified in refusing patient requests, but we argue that being sensitive to the distinction between the two aforementioned contexts helps to further explain this limit. Past discussions have focused on whether clinicians are allowed to refuse or remove treatment from patients who are no longer autonomous [1], whether fully autonomous patients have a right to refuse treatment,<sup>1</sup> whether clinicians are allowed to override such autonomous requests when it is believed that the patient incorrectly estimates what their quality of life will be [3], whether clinicians are allowed to refuse treatment due to judgments of medical futility [4], and whether clinicians can refuse to administer treatments that go against their conscience [5]. All these discussions fail to address the fact that novel medical interventions go through a process of approval before becoming a part of standard medical care. Not only do such interventions get tested for safety and efficacy, but they must also be regarded as fitting within the goals and scope of medicine. And we argue that this latter process has little to do with patient autonomy. This explains *why* patient autonomy cannot be used to justify offering novel interventions before they have been determined to be a proper form of medical treatment.

The plan for this paper is as follows. In the next section we describe these two contexts in more detail. Subsequently, we discuss the relevant guiding principles of bioethics, describe some accepted limits on autonomy, and explain how the two contexts relate to the limits on these principles. Then, in the following section, we offer examples of where others have conflated the two contexts and misapplied autonomy. More specifically, we consider two different medical interventions—healthy limb amputation and physician aid-in-dying—and we cite several authors who argue in favor of offering these interventions. We argue that such arguments inappropriately employ the principle of autonomy by conflating the clinical context with the context of the development of medical standards. In the final section, we discuss why keeping these contexts distinct matters for the practice of medicine.

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<sup>1</sup> For a review of appellate court cases on the matter, see [2].

## The administrative context versus the clinical context

Determining whether an intervention is ethically appropriate is a complicated matter, but one common approach involves looking to the four principles of biomedical ethics that have become the standard for evaluating ethical dilemmas in medicine: autonomy, non-maleficence, beneficence, and justice. Although the ethical landscape of medicine is complex and goes beyond these principles, they still serve as pillars in debates about medical ethics. These principles are intended to work *prima facie*, meaning each principle is presumed to be authoritative unless they conflict, in which case one principle may outweigh another depending on the case [6]. However, in what context should these principles be considered? We argue that there are two distinct contexts to consider. First, there is the context in which the medical community decides whether an intervention is appropriate based on the goals and scope of medicine. Call this the *administrative context*. Second, there is the context in which patients make decisions about whether treatments fit within their own goals of care. Call this the *clinical context*.

When it comes to the question of whether treatment is appropriate, there are two parties who have a primary stake in the answer: the patient and the medical community.<sup>2</sup> In the clinical context, the patient is given the final say. The patient has a vested interest in their own health and should be as free as possible to make decisions based on their health goals. Thus, patient autonomy is the driving principle within the clinical setting. But in the administrative context, the medical community has final say. Medicine is largely a self-regulating profession in which it is primarily members of the medical community—not patients and not even the state—that create guidelines and codes that govern the standards of medical practice and care.<sup>3</sup> Of course, there is some external regulation by the state. But it is the medical community that is concerned with the practice of medicine *per se* and judges the appropriateness of care based on the goals and scope of medicine [8].<sup>4</sup>

One might object here by noting that the clinical and administrative contexts are not mutually exclusive. The desires, values, and experiences of patients can play a role in the administrative context and the standards of care are often informed by such matters. We agree. However, the fact remains that these are two distinct contexts, and the standards of medical practice are developed before they are implemented in the clinical setting, such that the question of whether a treatment is medically appropriate is first answered in developing the medical standards of practice, and then answered by individual patients. To put it another way, we should not be asking, “is the patient autonomously requesting the intervention?” (a question asked in the clinical context) *before* we have answered, “Is this intervention a form of treatment that fits within the goals and scope of medicine?” (a question asked in the administrative context). The

<sup>2</sup> We will use the ‘medical community’ throughout this paper to mean any person or body that plays a role in developing the standards of medical practice (i.e. physicians, the FDA, hospital administrations, etc.).

<sup>3</sup> This is often referred to as “soft law.” For a detailed discussion see [7].

<sup>4</sup> One might raise the dilemma: what if the medical community is divided in its opinion over newly proposed treatments? This problem will inevitably arise in medicine, but it does not negate the fact that the medical community is the most natural arbiter in matters of appropriating medical treatments.

former question is important but is subsequent to the latter. So, although the clinical and administrative contexts are not wholly separate, they are distinct and have different norms that govern them.<sup>5</sup>

It is important to note that we are not taking a position here about the precise nature of the goals and scope of medicine. For example, we do not make any assumptions about whether the goals of medicine are determined by medicine's natural *telos* and are something to be "discovered" or whether they are socially constructed [9]. Our account is compatible with a wide range of views about how the goals and scope of medicine are determined.<sup>6</sup> Furthermore, we are not saying that medical professionals are solely responsible for creating or determining the nature of medicine. Rather, we are arguing that—regardless of how medicine came to have its specific goals—it is the proper role of those in the medical community to judge whether a proposed intervention contributes to patient health and whether it fits within the scope of medicine.

Why does this distinction of contexts matter? In recent debates over controversial topics in medicine, there has been an emphasis on using patient autonomy as a primary justification for why certain medical treatments should be deemed appropriate [10, 11]. While we applaud the effort to put medical decisions in the hands of patients, we think this effort is out-of-order. To understand why, we must be clear on the two previously mentioned contexts in which bioethical principles are considered. While the principle of autonomy should play a major role in the clinical context, it should play little to no role in the administrative context. However, in modern debates, the administrative and clinical contexts have been conflated, and thus, autonomy has been misapplied in determining the appropriateness of medical treatment.

## The principles of bioethics

Before examining cases where the principle of autonomy has been misapplied, let us first lay out three (of the four) principles of biomedical ethics—autonomy, beneficence, and non-maleficence—and discuss how they interact in different contexts.<sup>7</sup>

### Autonomy

'Autonomy' has many different definitions and uses. For our purposes, we need not adopt any particular account of autonomy. Broadly put, autonomy involves self-

<sup>5</sup> Another issue that might seem to blur the lines between these contexts is that clinical research often occurs in the clinical context (where a patient is offered an experimental intervention), so determining whether an intervention should be a form of treatment appears to partially occur in the clinical context. However, this actually serves to reinforce our claims that the administrative and clinical contexts are distinct because patients participating in research are explicitly informed that the purpose is to generate knowledge and that what they are receiving is not considered a form of treatment.

<sup>6</sup> Though our account is compatible with the goals of medicine being socially constructed, it is incompatible with any account of medicine (socially constructed or not) that defines the goals and scope as purely meeting consumer demands since that would collapse the distinction between the administrative and clinical contexts.

<sup>7</sup> We omit a discussion of the principle of justice because, in the cases we are concerned with, it is not one of the principles in conflict.

determination such that a person has sufficient rational capacity to understand their options, possesses enough relevant information (especially about risks) to make an informed decision, and can consent without undue influence or coercion. This framework closely resembles the account provided in Beauchamp and Childress [6, p. 104]. And, as Jennifer Blumenthal-Barby notes, although there are more robust notions of autonomy that are operative in moral and political philosophy, this is the notion of autonomy that is typically operative in medicine where the concern is primarily about whether a patient meets the minimal conditions of providing informed consent [12].<sup>8</sup>

Importantly, any account of what autonomy is will not include the scope of autonomy. If a patient meets the standards of autonomy, does that mean she gets to elect any treatment she wants? The short answer to this question is ‘no.’ To understand why, we must distinguish between two types of autonomy—positive and negative. Negative autonomy is the right to refuse medical treatment, while positive autonomy is the right to demand medical treatment. As Dr. Robert D. Orr states: “it is a common misconception that patients have an autonomous right to demand, as well as refuse, treatment” [15]. While negative autonomy is well-protected in medicine, positive autonomy is not. Furthermore, we must determine the contexts in which these two types of autonomy operate.

Negative autonomy takes the form of refusing medical care in the clinical context and is protected even if refusals will result in death. One of the only ways to justify overriding patient refusals is to prove that the patient does not meet the requirements of autonomy. So long as a patient is acting autonomously, healthcare professionals cannot force treatment on him out of respect for his free choice.<sup>9</sup> This principle is what justifies refusing life-sustaining treatment. Negative autonomy, then, has ultimate authority in the clinical context. Furthermore, negative autonomy has no role in the administrative context because the context involves hypothetical scenarios and there is no actual patient to refuse anything. The case for positive autonomy is quite different.

Refusals differ from demands in that demands require action on the one being demanded upon. The freedom to refuse treatment is not the freedom to demand treatment. This is in part because of right of conscience laws that protect physicians from providing treatment that contradicts their moral conscience.<sup>10</sup> There is also the issue of medical futility, which concerns cases in which patients (or their surrogates) pursue interventions that are deemed futile by the medical community [18]. Classically,

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<sup>8</sup> For example, Harry Frankfurt’s account of autonomy [13] requires that a person have higher order approval of their first order desires and Jon Crisman’s account [14] requires that an agent approve of how they came to have the desires that they have.

<sup>9</sup> The one caveat being disease that poses serious threat to the public, such as legally-enforced treatment of patients with tuberculosis (see CDC’s guidance on tuberculosis management: <https://www.cdc.gov/tb/programs/laws/default.htm>). These are rare cases in which the principle of justice overrides autonomy, but they do not represent the standard for the vast majority of cases.

<sup>10</sup> The Health Services, Medicare and Medicaid include protections for physicians unwilling to perform sterilizations and abortions. Forty-five states have right of conscience statutes. See also Article 9 of the European Convention of Human Rights [16]. Of note, there are authors who argue against physician right of conscience [17].

these cases involve terminally ill patients or patients in vegetative states who remain on life-support despite medical advice against these interventions.<sup>11</sup>

Beyond the right of conscience and medical futility, however, are the standards of medical practice [7, 15]. As Beauchamp and Childress note, “physicians do not have a moral obligation to carry out their patients’ wishes when they are incompatible with acceptable standards of medical practice [6, p. 226].” These standards, we argue, are developed in the administrative context. Understood within this limitation, positive autonomy means that *of the options available for treatment*, a patient who has capacity, understands the options, and is free from coercion can freely choose what treatment plan she wants to follow in the clinical context. Positive autonomy is limited in the clinical context by the standards of medical care developed in the administrative context.

This distinction between positive and negative autonomy is not new and others have noted that patients do not necessarily have the right to request any medical intervention that they want. However, what we add to this discussion is the distinction between the administrative and clinical context and how it helps patients and medical professionals understand why positive autonomy has this limit. It is limited because there is no particular patient involved in the context of determining the broader standards of care and what counts as medical treatment.

### Non-maleficence and beneficence

Beyond autonomy, there are also the principles of beneficence and non-maleficence, which are two sides of the same coin. They obligate physicians to abstain from harming patients and to promote patients’ well-being [6, p. 152]. However, there are two complications involved with these principles. First, whether something counts as a ‘harm’ or a ‘good’ is a difficult matter, which plausibly depends (at least in part) on what a patient wants and what the patient views as good [21]. Second, even if we can settle what is good or harmful for a patient, the principles of beneficence and non-maleficence can conflict with the principle of autonomy since it is possible for a patient to autonomously choose something that brings him harm or fails to promote his good.

The ideal situation occurs when both physician and patient have the same goal, such that the non-maleficent and beneficent aim of the physician works in concert with the autonomous choice of the patient. But not every situation is ideal, and at times conflict occurs between the physician’s and the patient’s goal of care. It is possible for non-maleficence and beneficence to conflict with patient autonomy, in which case the question becomes what is meant by ‘harm’ and ‘good’ of the patient.

It may be tempting to suggest that the patient’s conception of her own good is what ultimately matters in such situations. This seems especially true when reflecting on how much weight we give patient autonomy and preference in the clinical context. Physicians work with patients to promote their autonomy so long as it does not con-

<sup>11</sup> Two notable cases are the Helga Wanglie case [19] and the Baby L case [20]. Of note, while we omit a direct discussion of medical futility, arguments in favor of upholding the concept of medical futility strengthen the central claim of this paper.

tradict physician conscience or acceptable medical standards of practice. Thus, the principles of non-maleficence and beneficence are generally dictated by the patient's understanding of 'harm' and 'good'. However, it is important to note that this is only when considering specific medical decision-making within the clinical context. When considering the administrative context and determining the standards of care, we are not concerned with any particular patient, so we cannot consider any particular patient's conception of his own good when developing such standards. Instead, the medical community must view 'harm' and 'good' more broadly and in relation to human health and the goals and scope of medicine. The function of non-maleficence and beneficence in the administrative context is not to serve a single patient, but to guide the medical community in developing the standards of medical practice. The medical community's conception of health and well-being informs the principles of beneficence and non-maleficence in such contexts. Patient autonomy, then, is, in a sense, outweighed by the principles of non-maleficence and beneficence in the administrative context because patients cannot make decisions about the standards of medical practice.

To be clear, patient autonomy and individual conceptions of 'good' are not entirely irrelevant in the administrative context. The medical community can, and should, listen to patient requests when deciding whether certain interventions are appropriate as medical treatments. And what the populace regards as 'good' should serve to help inform the medical community when developing general standards of care. After all, medicine is a service profession and patients are the beneficiaries of care. But it is in the power of the medical community, not particular patients, to decide whether interventions coincide with the goals and scope of medicine and to determine whether they fit within a reasonable account of health and well-being. This structure protects physicians from becoming 'scalpels for hire' and allows medicine to maintain its integrity as a profession focused on health and well-being.<sup>12</sup>

## Examples of misapplying autonomy

With these distinctions in mind, we are now able to review specific examples where the differences between the administrative and clinical context have been neglected and the principle of autonomy has been misapplied.

### Misapplication #1: healthy-limb amputation

Would you intentionally blind a healthy patient if she requested it? For many people this request sounds absurd.<sup>13</sup> Why would a physician intentionally disable a healthy patient, even if the patient wanted it? But for Jewel Shuping's psychologist, this request was deemed reasonable. In 2006, Shuping was blinded by her psychologist

<sup>12</sup> This phrase was coined by Leon Kass and refers to the loss of a well-defined purpose to medicine, such that medicine becomes more of a business dictated by consumer requests [22]. We will discuss the import of 'scalpels for hire' in the section of this paper entitled "Consequences of misapplying autonomy."

<sup>13</sup> See Arthur Caplan's [23] and Robin Henig's [24] comments.

at her request, which was the fulfilment of a lifelong dream [25].<sup>14</sup> Shuping suffered from a disorder known as Body Integrity Identity Disorder (BIID), which is a rare condition in which a person does not identify with a certain body part (often limbs) and wishes to maim or amputate it.<sup>15</sup> Much of the debate over healthy-limb amputation involves the question of whether this disorder inhibits the patient's autonomy [27].<sup>16</sup> If BIID is shown to be a type of delusional disorder, then requests for healthy-limb amputation can be overridden by medical judgment because the request fails to meet the conditions of autonomy.<sup>17</sup> But many authors, including famous author and surgeon, Robert Smith, argue that patients with BIID are fully capable of autonomous choice.<sup>18</sup> If this is the case and someone like Jewel Shuping met the requirements of patient autonomy, then was her request to be blinded responded to appropriately?

In order to answer this question, we must understand the primary stakeholders in this debate: the patient and the medical community. Numerous arguments over the justification of BIID overlook these principal stakeholders. For example, Floris Tomasini argues for the moral permissibility of healthy-limb amputation and suggests that refusing to offer such intervention involves “forcing [the doctor’s] own view of the world on the [patient]” [29]. However, this line of reasoning ignores the decisive role of the medical community in determining the appropriateness of this intervention. Aimee Bryant also makes a case that “public perception should not be allowed to take precedence over this right [to surgery for BIID sufferers]” [30]. These arguments heighten the tension between public and patient interest, pitting public distaste for self-inflicted disability against patient autonomy, but in doing so, they ignore the interests of the medical community and considerations about the goals and scope of medicine.

One of the more explicit autonomy-based arguments for this kind of intervention comes from Tim Bayne and Neil Levy. They argue that granting requests for healthy-limb amputation can be justified based on the principle of autonomy. They state, “it is [sic.] well-entrenched maxim of medical ethics that informed, autonomous desires ought to be given serious weight” [11, p. 79]. And on this basis, Bayne and Levy argue that we should grant requests for healthy-limb amputation *because* they can be autonomously requested. They make their argument by drawing a parallel between requests for amputation and the refusal of life-saving treatment by a Jehovah’s witness based on religious grounds [11, p. 80]. Both cases are supposed to highlight the weight of autonomy in medical decisions. If autonomy justifies the latter, then it justifies the former. Bayne and Levy acknowledge that the cases differ insofar as the former requires *action* while the latter is an *omission* of action from the physician.

<sup>14</sup> There is some uncertainty about whether Shuping was actually blinded by her psychologist or whether it was done by someone else. The account is based only on her testimony and the psychologist in question was not identified.

<sup>15</sup> Many other cases of BIID have been reported, the most famous being the two men who received elective amputation of healthy limbs by the Scottish surgeon, Robert Smith [26].

<sup>16</sup> We will collectively refer to maiming healthy body parts as ‘healthy-limb amputation.’

<sup>17</sup> This is Muller’s conclusion [27, pp. 41–42].

<sup>18</sup> Robert Smith brought this topic into public view in the late 1990s when he amputated the healthy limbs of Kevin Wright and Hans Schaub [28].



But since the moral relevance of the act-omission distinction is unclear, they argue it is irrelevant, and thus the autonomous request for healthy-limb amputation is comparable to the widely accepted ethic of refusing life-saving treatment. Requesting the amputation of healthy limbs is, therefore, within the scope of patient autonomy.

This analogy breaks down from the lack of two critical distinctions: positive versus negative autonomy, and the clinical versus administrative contexts. While the act-omission distinction may be irrelevant in Bayne and Levy's analogy, the positive-negative autonomy distinction *is* relevant. Their analogy fails to distinguish positive and negative autonomy and thus equates the two. While refusing life-saving treatment is protected under negative autonomy, as we discussed earlier, requesting healthy-limb amputation is not protected under positive autonomy. Negative autonomy allows a competent, informed patient to refuse care, even if it causes death, but electing for interventions is limited by the judgment of the medical community. As Annemarie Bridy notes, "even if apotemnophiles are regarded as competent to consent to elective amputation...the question remains whether the medical profession will accept (and hospital administrators permit) so unorthodox a therapy" [31]. So, the Jehovah's witness is free to refuse life-sustaining treatment since negative autonomy is weighed heavily in the clinical context, but the patient with BIID cannot be granted healthy-limb amputation on the basis of his autonomy, since his positive autonomy in the administrative context holds very little weight. Healthy-limb amputation would first have to be approved by the medical community as a viable treatment for BIID, and only then can the patient elect for it.

If this response is correct, one might ask why it is that a patient's positive autonomy is limited in this way. We argue that the distinction between the clinical context and the administrative context answers this. Autonomy allows patients to choose among options for their medical treatment in the clinical context, but it holds minimal weight in the decisions made in the administrative context regarding the standards of medical practice. Those decisions are made by the medical community, and rely primarily on non-maleficence, beneficence, and justice. Thus, Bayne and Levy are correct to identify the significant weight of autonomy in medical ethics, but to argue for the appropriateness of an intervention on the basis of autonomy before it is deemed an appropriate form of treatment is to mistakenly take the weight of autonomy in the clinical context and apply it in the administrative context. The question, then, of whether healthy-limb amputation (or other elective treatments related to BIID) is medically appropriate, is not a matter of whether patients are autonomous enough to choose it. Rather, the question we should be asking is whether the *medical community* thinks healthy-limb amputation is an appropriate treatment and whether it is within the goals and scope of medicine.

Bayne and Levy are not alone in making this kind of argument. A very similar argument was recently made by Amy White. She uses the principle of autonomy to argue for allowing those with BIID to receive surgical interventions. She says:

Respect for autonomy is a fundamental principle in medical ethics... Given this value placed on autonomy... to justly ban BIID patients from seeking a surgical solution, a strong reason is needed to override the importance placed on self-determination. This reason has to be justified by more than mere paternalism as

we regularly accept the competent decisions of others even when they appear to be unwise. A decision-maker's autonomy is often respected even in cases where the decision may seem irrational to an outsider (i.e., a Jehovah's Witness refusing a blood transfusion) [32].

Note that the emphasis is on autonomy and self-determination. The suggestion is that if an intervention is autonomously requested, then it should be given unless there is a "strong reason" to override such a choice. But again, not only does the comparison with a Jehovah's Witness refusal of a blood transfusion conflate positive and negative autonomy, but the assumption also that an intervention should be given simply because it has been autonomously requested and before it has been deemed a suitable form of treatment, is to conflate the administrative and clinical contexts. We agree that one must have a strong reason to prohibit a patient from receiving treatment, but there is a difference between determining whether an intervention counts as treatment and preventing a patient from receiving something that has already been deemed a form of treatment. To say that "a strong reason is needed to override the importance placed on self-determination" is to neglect the administrative context and to inappropriately use autonomy to justify offering an intervention before it has been determined to be treatment.

To their credit, Bayne, Levy, and White do not rely solely on patient autonomy to justify offering these interventions. After arguing for the healthy-limb amputation on the basis of autonomy, Bane and Levy go on to argue for it on the basis of its therapeutic effects. They argue that such interventions can relieve suffering, which cannot be secured by less dramatic means, and that such relief is worth the cost. Similarly, drawing on comparisons of BIID and Gender Dysphoria (GD), White goes on to argue that healthy-limb amputation could alleviate suffering and that since "the medical profession has already accepted that some patients can request that their healthy bodies be operated on for a broader conception of health"—such as sex-reassignment surgery—healthy-limb amputation should be carefully considered [32, p. 232]. Here White focuses on the therapeutic value of such interventions and acknowledges that the *medical community's* adoption of sex-reassignment surgery into the arsenal of possible treatments for GD *legitimizes* its practice in medicine and argues for healthy-limb amputation on that basis. These kinds of arguments do not depend on misapplying autonomy. On the contrary, this is precisely the kind of reasoning that ought to be reflected in the administrative context—reasoning about therapeutic value and what constitutes an appropriate therapy given the goals and scope of medicine. Although we will not evaluate these specific arguments here, we support this kind of reasoning about therapeutic value and suggest that it should have a more prominent place in these debates.

One might object here and suggest that, since these authors appeal to both therapeutic value *and* to autonomy, they must not be misapplying autonomy. However, it is important to note the way in which they are using the principle of autonomy and how this relates to the distinction between the administrative and clinical contexts. These authors are not merely arguing that patients with BIID are capable of autonomously requesting healthy-limb amputations; they are appealing to the fact that an autonomously requested intervention is justification for providing it as a form of treatment.

We are arguing that doing so conflates the administrative and clinical contexts. It is good that they go on to argue that such interventions can also have therapeutic value, but that does not change the fact that they have misapplied the principle of autonomy.

## Misapplication #2: physician aid-in-dying

It is reasonable to think there is little connection between healthy-limb amputation and physician aid-in-dying (PAD).<sup>19</sup> Most of us will never request healthy-limb amputation, or even experience BIID, but all of us will face death. Furthermore, there seems to be a reasonable desire for death, especially among patients who are terminally ill or suffering greatly, but it is harder to make the case for a reasonable desire for healthy-limb amputation. But these cases are similar in that they both raise questions regarding the weight of patient autonomy in medical decisions, and proponents of both make the same errors in misapplying autonomy. On the one hand, the medical community may want to prohibit PAD, since it welcomes deliberate killing into medicine which seems inappropriate [33]. But on the other hand, patients have a vested interest in their quality of life and opinions vary greatly in why they think life is worth living. As Dan Brock points out, “the great variability among people on this question makes it especially important that individuals control the manner, circumstances, and timing of their dying and death” [34]. Even if patient autonomy does not extend to healthy-limb amputation, it might still be used to justify assisting patients in their voluntary death.

Marcia Angell thinks these decisions should be in the hands of patients as an extension of their autonomy. Similar to Bayne and Levy, she notes the weight of patient autonomy in medical ethics: “I begin with the generally accepted premise that one of the most important ethical principles in medicine is respect for each patient’s autonomy, and that when this principle conflicts with others, it should almost always take precedence” [10, p. 50]. As we noted with Bayne and Levy, she is describing the weight of autonomy in the *clinical* setting without making this distinction explicit. She also overweighs autonomy against the other three bioethical principles by failing to distinguish positive and negative autonomy. She is correct in saying autonomy always takes precedence if she is referring to negative autonomy in the clinical context, but the same does not hold true for positive autonomy or for negative autonomy in the administrative context.

Angell proceeds to argue that PAD is justified on the basis of patient autonomy. She first points out that PAD, along with euthanasia and withdrawing life-sustaining treatment, is a form of hastening death. And she notes that the debates about these practices have typically hinged on the physician’s role. For example, in PAD and euthanasia, the physician’s role in the patient’s death is considered “active,” whereas in withdrawing treatment the physician’s role is considered “passive.” And this active versus passive distinction is sometimes cited as a reason for thinking that withdrawal of life-sustaining treatment is justified, but PAD and euthanasia are not. However,

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<sup>19</sup> This is sometimes referred to as “physician-assisted suicide,” “physician-assisted dying,” or “medical aid-in-dying.” Additionally, we are not discussing euthanasia explicitly as it is a more extreme case. However, all our arguments in relation to PAD also apply to euthanasia.

Angell goes on to say, “we should ask ourselves not so much whether the doctor’s role is passive or active but whether the *patient’s* role is passive or active” [10, p. 21]. With this new perspective in mind, Angell suggests that a hastening of death is best justified when the patient is “active” in the process, for it ensures that it only occurs at the voluntary request of the patient, and that it is impossible to perform PAD without consent because the patient is autonomously and voluntarily active in the process. Considered from this perspective, PAD, like withdrawing life-sustaining treatment, is an active process engaged by the patient, and thus, should be permitted as an extension of patient autonomy.

Angell’s reframing of the question to be patient-centered is an interesting approach, but it appeals to the power of patient autonomy in the clinical context in order to justify the appropriateness of a controversial intervention. Patients already have an active role in the clinical context by refusing unwanted care and electing for care that is available to them, but patients do not have the ability to elect for care that is yet to be made available. Although not explicitly stated, Angell can only be using patient autonomy in its positive function. Angell’s argumentation for PAD based on patient autonomy follows the same structure as Bayne and Levy’s argument for healthy-limb amputation, and both make the same mistake in conflating the clinical and administrative contexts, and thus in misapplying patient autonomy.

Another discussion about the justification of PAD comes from Thomas Beauchamp. In his article “The autonomy turn in physician assisted suicide,” he offers a response to a common argument against PAD [35]. It is sometimes argued that PAD is unjustified because it makes the physician causally involved in the patient’s death in a way that removal of life-sustaining treatment does not. This line of reasoning typically hinges on the debate about the differences between “killing” and “letting die.” When removing life-sustaining treatment, it is the illness that causes the patient’s death, so the physician lets the patient die, but does not kill the patient. Whereas, when engaging in PAD, it is the treatment itself (which is typically provided by the physician but administered by the patient) that causes the patient’s death, so the physician is involved in killing the patient. This is supposedly why PAD is unjustified while the withdrawal of life-sustaining treatment can be justified.<sup>20</sup>

In response to this argument, Beauchamp argues that even in some refusals, it is obvious that the *removal of unwanted treatment* is a relevant causal event in the patient’s death (e.g., removing a nasogastric feeding tube). Suppose, however, that a physician removed life-sustaining treatment against the patient’s wishes. In such a case, the physician would have killed the patient. So, Beauchamp argues, the relevant moral issue is not causation, but *authorization*. He says, “if [the removal of life-sustaining treatment is] validly authorized, the act is a letting die; if unauthorized, the same act is a killing. The justification of forgoing the medical technology, not the physical condition of death, is therefore the key condition both in conceptually distinguishing killing and letting die and in the moral and legal justification of letting die.” So, whether PAD is justified, argues Beauchamp, hinges not on the cause of

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<sup>20</sup> Another popular response can be found in Bonnie Steinbock’s widely anthologized article “The intentional termination of life” where she argues that the relevant issue is that withdrawing life-sustaining treatment does not necessarily involve an intention to end the patient’s life whereas PAD does [36].

death, but rather on whether the death is autonomously requested. Therefore, PAD, if autonomously authorized, is justified and should be regarded as a way of “showing respect for the person’s autonomous choices [35, p. 120].

Perhaps Beauchamp is correct in his analysis about causation in arguing that there is not an essential moral difference between “killing” and “letting die.” We grant that there is a legitimate distinction between causation and authorization, and that authorization is important in this case. Causation is not just difficult to assess, but as Beauchamp points out, we already allow instances in which patients can authorize something that knowingly results in their own death. However, it does not follow that physicians are justified in participating in any form of killing patients when such killing is autonomously authorized. The key point is that this authorization of killing, when justified, still occurs in the form of a patient *refusal*, meaning a patient exercises his negative autonomy in the clinical context. As discussed previously, negative autonomy has ultimate weight in the clinical context. In this scenario, either we can obstruct the patient’s right to refuse care, which violates autonomy via paternalism, or we honor the patient’s negative autonomy in the clinical setting and, as a result, kill him. Negative autonomy wins out in the clinical context, and so killing the patient is inevitable. But this is not the same as developing a standard of medical care that allows patients to elect for intentionally ending their own lives, because although negative autonomy has ultimate weight in the clinical context, positive autonomy has minimal weight in the administrative context. If the medical community determines that PAD is an appropriate form of treatment, then it would be within the purview of a patient’s positive autonomy to authorize such treatment. But until then, the autonomous authorization of a patient is not sufficient to justify it.

## Consequence of misapplying patient autonomy

We have argued that the principle of autonomy has been misapplied and used to justify decisions about the standards of medicine. And this occurs because there is a failure to recognize the difference between the administrative and clinical contexts. But we might ask, what are the risks of pushing the limits of autonomy?

A full exploration of this issue is beyond the scope of this paper, but one of the potentially undesirable consequences of misapplying patient autonomy is the disintegration of the goals and scope of medicine. Modern medicine in its current structure retains some goals and scope, and, at least for now, they do not involve merely meeting consumer demand for any intervention that a person autonomously requests. Regardless of the origination of medicine and its goals and scope, the medical community (taking into consideration the values and ideas of the public at large), by nature of its expertise in medicine, has become the natural steward of those goals and its scope. The issue with pushing the limits of autonomy too far is it collapses the distinction between the clinical and administrative contexts, pushing medicine towards a consumer demand model. If the medical community loses its ability to guide and preserve the goals and scope of medicine, then physicians quickly become what Leon Kass describes as “scalpels for hire” [22, p. 12].

Patients, by nature of being individuals with no obligations to the profession of medicine, have little incentive to preserve the goals and scope of medicine, and may in fact, push the limits well beyond their current state. And certainly, at times the boundaries need to be challenged, but consider where this might lead. Say a patient comes to his physician with the persistent desire for flagellation. We might construct an argument in favor of this treatment along the lines of his autonomy. The patient would be evaluated for his capacity to make decisions and the risks, benefits, and alternatives would be discussed. Similar regulatory processes could be implemented as is proposed for BIID and healthy-limb amputation, such as, failure with alternative therapies and a persistent desire for torture [37]. One could even argue that physicians are best equipped to administer such a treatment given their expertise in human physiology, pain, bleeding risk, and so on. Of course, we have never heard such a case, but we are beginning to hear stories like the one of Jewel Shuping, in which a psychologist supposedly blinded his patient at her request. So, it raises the question of who should be keeping the goals and scope of medicine in check, and we believe it should be the medical community, lest medicine becomes a practice in which physicians are mere “scalpels for hire,” where patient requests need only willing physicians to meet them.<sup>21</sup> We think that this kind of result would be detrimental to the practice of medicine.

Even if this analogy is unconvincing, the fact remains that the principle of autonomy is insufficient as a justification for legitimizing medical interventions. As we discussed earlier, the limited scope to patient autonomy is rarely explained and autonomy is typically defined in terms of what conditions a patient must meet when in the clinical context. Patient autonomy only functions in a positive sense in regard to predetermined options set by the medical community and the practice of medicine. Arguments that endorse patient autonomy as having power beyond this function are really arguing for a change in the structure of modern medicine. It is possible this could have its benefits, but given medicine’s current framework, it makes little sense to cite autonomy as a primary justification for any new medical treatment, because patient autonomy plays almost no role in those kinds of decisions.

In reality, medicine is a dialogue between patients and the medical community. If our discussion thus far seems to strictly divide patient choice and medical judgment, it is only to emphasize the structure that undergirds decisions about the nature of medical treatment, not the lack of dialogue that does and should exist between patients and physicians. Even authors like Howard Brody and Franklin Miller, who make arguments for an internal morality to medicine, recognize that the normative ethics of democratic society will shape medical practice and that certain medical practices are best understood as “peripheral” to medicine [38]. This is why we emphasized earlier that positive autonomy is not useless in the administrative context, but rather, it informs the medical community of patient perspectives and how we might respond to them.

We should also mention that this paper is not an argument against all justifications for healthy-limb amputation or PAD, but only a critique of arguments that specifi-

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<sup>21</sup> It is worth noting that other professions (e.g. law, academia, etc.) function similarly with their own goals and scope, so medicine is not unique in this regard.

cally rely on autonomy as the primary justification for any medical practice. There are numerous arguments made in support of these interventions which require their own attention. We have used healthy-limb amputation and PAD as examples of how people conflate the clinical and administrative contexts and misapply the principle of autonomy when determining the appropriateness of medical treatments.

## Conclusion

We have argued against the misapplication of autonomy in decisions regarding the appropriateness of medical treatments. This misapplication occurs when one conflates the administrative and clinical contexts and prioritizes the question, “is the patient autonomously requesting the intervention,” over the question “is this intervention a form of treatment that fits within the goals and scope of medicine?” It primarily falls on the medical community to answer the latter.

Our hope is that this paper clarifies the importance of distinguishing the contexts in which autonomy functions. This distinction restructures the debates over the appropriateness of new medical interventions because it shows how little patient autonomy affects these decisions. Patient autonomy is simply not equipped to accommodate this type of role. This is one of the more difficult points to accept regarding autonomy because it seems to restrict patient choice. But there are benefits to this design, including the preservation of medicine’s integrity. So long as medicine retains enough of its goals and scope to avoid falling into a consumer-demand “scalpels for hire” model, patient autonomy should be promoted and respected, but also primarily limited to the clinical context where questions of acceptable treatments and standards of care have already been settled beforehand. At the very least, the takeaway is that debates over the appropriateness of medical treatments should focus on the goals and scope of medicine instead of being reduced to matters of autonomy.

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## References

1. Dresser, Rebecca S., and John A. Robertson. 1989. Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach. *The Journal of Law Medicine & Ethics* 17 (3): 234–244. <https://doi.org/10.1111/j.1748-720x.1989.tb01101.x>.
2. Annas, George J., and H. Leonard, and Glantz. 1986. The Right of Elderly Patients to Refuse Life-Sustaining Treatment. *The Milbank Quarterly* 64 (2): 95–162. <https://doi.org/10.2307/3349961>.
3. Savulescu, Julian. 1994. Rational Desires and the Limitation of Life-Sustaining Treatment. *Bioethics* 8 (3): 214–216. <https://doi.org/10.1111/biot.1994.8.issue-3>.
4. Jecker, Nancy S., and Lawrence J. Schneiderman. 1993. Medical Futility: The Duty Not to Treat. *Cambridge Quarterly of Healthcare Ethics* 2 (2): 151–159. <https://doi.org/10.1017/S0963180100000852>.
5. McLeod, Carolyn and Jocelyn Downie. 2014. Let Conscience Be Their Guide? Conscientious Refusals in Health Care [Special Issue]. *Bioethics* 28(1).
6. Beauchamp, Thomas, and James Childress. 2013. *Principles of Biomedical Ethics*. New York: Oxford University Press.
7. Campbell, Angela and Kathleen Glass. 2001. The Legal Status of Clinical and Ethics Policies, Codes, and Guidelines in Medical Practice and Research. *McGill Law Journal* 46 (2): 473–489. <http://search.proquest.com/docview/71402986/>.

8. Brody, Howard, and Franklin G. Miller. 1998. The Internal Morality of Medicine: Explication and Application to Managed Care. *The Journal of Medicine and Philosophy* 23 (4): 384–410. <https://doi.org/10.1076/jmep.23.4.384.2572>.
9. Pellegrino, Edmund D. 2001. Philosophy of Medicine: Should It Be Teleologically or Socially Constructed? *Kennedy Institute of Ethics Journal* 11 (2): 169–180. <https://doi.org/10.1353/ken.2001.0015>.
10. Angell, Marcia. 1997. The Supreme Court and Physician-Assisted Suicide — The Ultimate Right. *The New England Journal of Medicine* 336 (1): 50–53. <https://doi.org/10.1056/nejm199701023360108>.
11. Bayne, Tim, and Neil Levy. 2005. Amputees By Choice: Body Integrity Identity Disorder and the Ethics of Amputation. *Journal of Applied Philosophy* 22 (1): 75–86. <https://doi.org/10.1111/j.1468-5930.2005.00293>.
12. Swindell, J. S. 2009. Two Types of Autonomy. *The American Journal of Bioethics* 9 (1): 52–53. <https://doi.org/10.1080/15265160802635680>.
13. Lemmens, Willem. 1998. Discussion with Harry Frankfurt - Frankfurt on Care, Autonomy and Self. *Ethical Perspectives* 5 (1): 36–43. <https://doi.org/10.2143/EP.5.1.563106>.
14. Taylor, James S. 2005. *Personal Autonomy: New Essays on Personal Autonomy and Its Role in Contemporary Moral Philosophy*. Cambridge: Cambridge University Press.
15. Orr, Robert D. 2013. Autonomy, Conscience, and Professional Obligation. *AMA Journal of Ethics* 15 (3): 244–248. <https://doi.org/10.1001/virtualmentor.2013.15.3.msoc1-1303>.
16. Article 9. European Convention of Human Rights. European Court of Human Rights. [http://www.echr.coe.int/NR/rdonlyres/D5CC2A47-DC13-4318-B457-5C9014916D7A/0/Convention\\_ENG.pdf](http://www.echr.coe.int/NR/rdonlyres/D5CC2A47-DC13-4318-B457-5C9014916D7A/0/Convention_ENG.pdf). Accessed August 10, 2020.
17. Emmanuel, Ezekial J., and Ronit Y. Stahl. 2017. Physicians, Not Conscripts — Conscientious Objection in Health Care. *The New England Journal of Medicine* 376 (14): 1380–1385. <https://doi.org/10.1056/NEJMs1612472>.
18. Council on Ethical and Judicial Affairs, American Medical Association. 1999. Medical Futility in End-of-Life Care: Report of the Council on Ethical and Judicial Affairs. *Journal of the American Medical Association* 281 (10): 937–941. <https://doi.org/10.1001/jama.281.10.937>.
19. Angell, Marcia. 1991. The Case of Helga Wanglie: A New Kind of Right to Die Case. *The New England Journal of Medicine* 325 (7): 511–512. <https://doi.org/10.1056/NEJM199108153250712>.
20. Paris, Crone. 1990. Physicians' Refusal of Requested Treatment: The Case of Baby L. *The New England Journal of Medicine* 322 (14): 1012–1015. <https://doi.org/10.1056/NEJM199004053221420>.
21. Bester, Johan Christiaan. 2020. Beneficence, Interests, and Wellbeing in Medicine: What It Means to Provide Benefit to Patients. *The American Journal of Bioethics* 20 (3): 53–62. <https://doi.org/10.1080/15265161.2020.1714793>.
22. Kass, Leon. 1975. Regarding the End of Medicine and the Pursuit of Health. *Public Interest* 40: 11–42. <https://www.nationalaffairs.com/storage/app/uploads/public/58e1a4bee18cf463065065.pdf>.
23. Dotinga, Randy. 2011. Out on a Limb. Last modified September 25, 2011. <https://www.salon.com/2000/08/29/amputation/>.
24. Henig, Robin Marantz. 2005. At War with Their Bodies, They Seek to Sever Limbs. *New York Times*, March 22, 2005. <https://www.nytimes.com/2005/03/22/health/psychology/at-war-with-their-bodies-they-seek-to-sever-limbs.html>.
25. Midlane, Tom. 2015. Psychologist Blinds Woman with Drain Cleaner - Because She Wanted to be Disabled. Last modified October 1, 2015. <https://www.mirror.co.uk/news/real-life-stories/psychologist-blinds-woman-drain-cleaner-6552282>.
26. Dyer, C. 2000. Surgeon Amputated Healthy Legs. *The BMJ* 320 (7231): 332. <https://doi.org/10.1136/bmj.320.7231.332>.
27. Müller, Sabine. 2009. Body Integrity Identity Disorder (BIID)—Is the Amputation of Healthy Limbs Ethically Justified? *The American Journal of Bioethics* 9 (1): 36–43. <https://doi.org/10.1080/15265160802588194>.
28. Gillet, Aden. Complete Obsession: Body Dysmorphia. BBC, 17 Feb. 2000, [www.bbc.co.uk/science/horizon/1999/obsession\\_script.shtml](http://www.bbc.co.uk/science/horizon/1999/obsession_script.shtml). Accessed 31 Aug. 2020. TV broadcast transcript.
29. Tomasini, Floris. 2006. Exploring Ethical Justification for Self-Demand Amputation. *Ethics & Medicine* 22(2): 99–115. <https://tmc.illiad.oclc.org/illiad/illiad.dll?Action=10&Form=75&Value=411535>.
30. Bryant, Aimee Louise. Consent, Autonomy, and the Benefits of Healthy Limb Amputation: Examining the Legality of Surgically Managing Body Integrity Identity Disorder in New Zealand. *Journal of Bioethical Inquiry* 8(3): 281–88. <https://doi.org/10.1007/s11673-011-9310-6>.



31. Bridy, Annemarie. 2004. Confounding Extremities: Surgery at the Medico-Ethical Limits of Self-Modification. *The Journal of Law Medicine & Ethics* 32 (1): 148–158. <https://doi.org/10.1111/j.1748-720x.2004.tb00460>.
32. White, Amy. 2014. Body Integrity Identity Disorder Beyond Amputation: Consent and Liberty. *Hec Forum* 26 (3): 225–236. <https://doi.org/10.1007/s10730-014-9246-4>.
33. Gaylin, Willard, Leon R. Kass, and Edmund D. Pellegrino, and Mark Siegler. 1988. ‘Doctors Must Not Kill’. *Journal of the American Medical Association* 259 (14): 2139–2140. <https://doi.org/10.1001/jama.259.14.2139>.
34. Brock, Dan W. 1992. Voluntary Active Euthanasia. *The Hastings Center Report* 22 (2): 10–22. <https://doi.org/10.2307/3562560>.
35. Beauchamp, Thomas. 2006. The Autonomy Turn in Physician-Assisted Suicide. *Annals of the New York Academy of Sciences* 913 (1): 111–126. <https://doi.org/10.1111/j.1749-6632.2000.tb05166>.
36. Steinbock, Bonnie. 1979. The Intentional Termination of Life. *Ethics in Science & Medicine* 6 (1): 59–64.
37. Ryan, Christopher. 2009. Out on a Limb: The Ethical Management of Body Integrity Identity Disorder. *Neuroethics* 2 (1): 21–33. <https://doi.org/10.1007/s12152-008-9026-4>.
38. Brody, Howard, Kevin C. Chung, and G. Franklin, and Miller. 2000. Cosmetic Surgery and the Internal Morality of Medicine. *Cambridge Quarterly of Healthcare Ethics* 9 (3): 353–364. <https://doi.org/10.1017/s0963180100903074>.

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