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# Temporising and respect for patient self-determination

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## ABSTRACT

The principle of self-determination plays a crucial role in contemporary clinical ethics. Somewhat simplified, it states that it is ultimately the patient who should decide whether or not to accept suggested treatment or care. Although the principle is much discussed in the academic literature, one important aspect has been neglected, namely the fact that real-world decision making is temporally extended, in the sense that it generally takes some time from the point at which the physician (or other health care professional) determines that there is a decision to be made and that the patient is capable of making it, to the point at which the patient is actually asked for his or her view. This article asks under what circumstances, if any, temporising—waiting to pose a certain treatment question to a patient judged to have decision-making capacity—is compatible with the principle of self-determination.

## INTRODUCTION

The principle of self-determination is widely regarded as a cornerstone of clinical ethics.<sup>1</sup> It is codified in legal frameworks and guidelines all over the world, and it has had a significant impact on our understanding of how to address various medico-ethical issues. Various accounts of the content and implications of the principle have been put forward, but they have at least one common denominator: the idea that if the issue arises of whether or not to introduce or continue giving certain medical treatment to a patient, it is that patient who ultimately, after receiving relevant information, must decide whether to agree to it.

The principle of self-determination raises many issues. One is: to whom does the principle apply? Since a right to self-determination has traditionally been ascribed only to individuals with sufficient decision-making capacity, a key question is what it takes for a patient to be above the crucial threshold. Important as this issue is, we shall leave it entirely open. Instead, the focus will be on the question: *when*—at what point in the clinical encounter—should a patient deemed to have sufficient capacity be ‘offered’, or presented with, information about his or her condition and asked to make a decision about treatment? Real-world decision making is temporally extended in the sense that it generally takes some time from the point at which the physician (or some other healthcare professional) determines that there is a decision to be made and that the patient is capable of making it, to the point where the patient is asked about his or her view. This temporal aspect of decision making raises normative issues. One of those, the one we shall address in this article, is under what circumstances, if any, *waiting* to pose a treatment question (hereafter: temporising) to a patient judged to

have decision-making capacity is compatible with the principle of self-determination. This, in other words, would be a choice on the part of the physician, in whose power it typically is to decide when to introduce the issues that should ultimately be for the patient to settle.

Temporising has received limited attention as an ethical problem in the clinical context.<sup>1</sup> One can only speculate on why this is the case, but regardless of the explanation, exploration of this important aspect of self-determination is long overdue. The extent to which patients are in reality granted a right to self-determination depends not only on whether their decisions are constrained or overturned by others, but also, and crucially, on whether they learn that there are decisions to be made at all. Power is exercised by physicians and other healthcare professionals through coercion, or through decision-making procedures that pre-empt patients’ choices, but also in the framing of issues and, not the least, in decisions about when to introduce them to the patients. Unless this is recognised certain practices which, in effect, involve the exercise of power, and which deserve to be discussed, may fly under the radar.

Temporising becomes an option from the moment a physician concludes that a patient will have to make a decision of some kind regarding his or her own care. It might concern minor routine issues, but also rare, invasive and high-risk procedures. It may consist in postponing discussing with the patient whether to try out a new drug for a condition from which the patient suffers, in deferring dialogues about the option of not trying to resuscitate the patient in case of heart arrest, in waiting a few weeks to suggest to the psychiatric patient that he or she tries a treatment programme one is convinced might help, or in waiting to introduce the possibility to the patient with obesity of having a gastric bypass. Sometimes the decision may also involve proxy decision makers, as when one waits to suggest withdrawal of life-sustaining treatment from a severely ill and unconscious patient, whether an adult or a child. (Since this article focuses on problems of temporising in relation to the right of self-determination, we shall not however address the role of proxies, although we do believe that that issue adds to the complexity of temporising and needs to be addressed in its own right.)

The issue of temporising is a general one, and our reasoning will reflect this, as it mostly abstracts away from the particulars of the clinical

<sup>1</sup>One interesting exception is a brief comment on the challenges raised by decisions to withdraw life-supporting treatment after spinal cord injury.<sup>10</sup>



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situations in which the issue might arise. When illustrating the problems of temporising in the light of the principle of self-determination, we will, however, frequently take as an example decisions about life-supporting medical treatment in patients with chronic diseases, specifically in the context of dialysis in the care of patients with chronic kidney disease. These decisions are real, high-stakes medical decisions where the self-determination of patients could be violated, and they exhibit the complexity needed to investigate the issue of temporising. Dialysis is normally a treatment that goes on for several years—in case the patient is not suitable for renal transplantation—from the moment that a patient is diagnosed with end-stage kidney disease, until the patient dies. Dialysis maintains some of the functions of the kidneys, but not all. With time, the underlying diseases, but also complications of the dialysis, may make life hard for the patient. One reason for choosing dialysis as an example to illustrate temporising in relation to important decisions regarding life-supporting therapy is that it continues for a long time and that patients are awake and conscious during the period of treatment, as opposed to many other life-supporting therapies, such as artificial ventilation in the setting of an intensive care unit. In the present analysis, we will concentrate on cases where patients are already on dialysis treatment, where the decision concerns withdrawal of it and where there are concerns that limited life expectancy and limited quality of life may not justify the burdens of continued treatment.<sup>ii</sup>

The exposition of the article is as follows. In the next section, we highlight some of the reasons that can be given for temporising, focusing on those that are *prima facie* reasonable. In the subsequent section we ask under what conditions temporising is inconsistent with the principle of self-determination because it risks depriving the patient of the opportunity to make the relevant decisions. This will require us to discuss the ways in which a patient can be deprived of decision-making opportunities. We will also need to explore the limits of legitimate risk and uncertainty in connection with such deprivation of opportunity. The article concludes with some brief remarks on the relationship between the issue of temporising and broader debates about patient autonomy.

### TEMPORISING: POSSIBLE REASONS

Various reasons may explain why a physician decides to postpone presenting a treatment decision to the patient. Some overtly conflict with patient self-determination as normally understood. The physician may judge that the patient would consider it burdensome to receive discouraging information about his or her health status and to have to make a choice or that it would be better not to allow the patient to make (what the physician regards as) an unwise decision. Whether temporising ultimately does amount to some kind of paternalism will be explored below, but in what follows we shall not focus on *patently* paternalistic reasons. Nor will we address reasons for temporising, or causes of it, that have nothing to do with effective treatment of the patient, such as feeling uncomfortable about a difficult conversation to be had with the patient, or postponing a decision in order, for example, to leave work early.

<sup>ii</sup>Possible grounds for the withdrawal of dialysis have been described in the literature.<sup>11–14</sup>

### Temporising out of concern for privacy or immediate comfort

On a radical interpretation of the principle of self-determination, once it has been determined or agreed that the patient possesses decision-making capacity, any decision has to be offered to the patient immediately, with no delay whatever. Respect for self-determination, on this account, would mean accepting that decisions may have to be offered in various non-ideal circumstances: for example, when the patient has already started a dialysis treatment session and is therefore tired or distracted, or when the patient is occupied meeting friends or family, or using the bathroom, or is asleep and can only participate by being woken up. Nobody, we assume, would endorse such conduct. This is not only because waiting may be justified all things considered (since other interests, in addition to the right to self-determination, are obviously at stake). It is also because in these kinds of situation, waiting is, intuitively, *not* in conflict with the principle of self-determination as this principle is ordinarily understood. This is not to say, of course, that any decision postponement opted for out of concern for the patient's privacy or immediate comfort would be consistent with self-determination; the point is merely that examples like these are fairly easy to come by and that when we consider them the idea that the principle allows for no delay at all seems rather ridiculous. Such cases of seemingly trivial or harmless temporising suggest that it is, at least, not the passing of time in itself which conflicts with the principle of self-determination.

### Temporising in order to gain even greater clinical certainty

Another possible reason for postponing decision making refers to the as yet uncertain outcome of alternative courses of action and the irreversibility of clinical decisions that restrict future treatment options.<sup>2</sup> While it may not conflict with any professional norms to introduce the relevant treatment decision on the basis of the diagnostic and prognostic information available at the time, the physician may still wish to gather even more information so as to maximise the probability of accurately forecasting the results of different courses of action. A nephrologist, for instance, may wish to temporise in order to find out if a patient who does not seem to be benefiting from dialysis will respond positively to it in due course, as treatment efficiency may change over time.<sup>iii</sup>

At first sight, the purpose of this kind of temporising seems to be to maximise the probability of outcomes that are clinically or in other ways beneficial to the patient, not to protect or promote patient autonomy, and so it would if temporising merely had to do with the physician getting even more certain about what decision to offer to the patient. However, one could also view temporising for greater clinical certainty as a delay tolerated with the aim of raising the probability that the patient will make an *informed choice*. While a decision made on the available evidence would, we may assume, clear the bar of being clinically informed, waiting for additional data could make the decision even better informed. The question is whether such temporising is consistent with the principle of self-determination.

Physicians may, of course, wish to temporise, not only to make the patient's decision more informed from a medical perspective, but to make it more informed in other ways as well. As stipulated, if the earlier choice were to be presented to the patient right away, it would meet the criteria of being a

<sup>iii</sup>An evident reason for this is that withdrawal of dialysis is lethal to the patient and therefore highly irreversible, while in the case of continued treatment, there could be a chance of partial recovery that may be worth taking even if the chance is in some cases very small.

sufficiently informed one, but there is always room to improve the knowledge and experience on whose basis decisions are made. The physician may believe, for instance, that temporising will improve the patient's awareness of his or her situation, and the positive and negative effects of the treatment, and thereby improve the patient's familiarity with the pros and cons of continuing treatment.<sup>iv</sup> It is difficult at the beginning of the dialysis treatment to know what it will be like to go through it for a long period of time—in 4 years with a regular haemodialysis treatment regime, it will amount to about 600 dialysis sessions, with all that this implies regarding dietary restrictions and restrictions on fluids intake, multiple needle insertions in the case the patient has an arteriovenous fistula and other burdens that initially may be hard to fully grasp. Patients may, however, also come to experience the good effects of dialysis treatment on the uraemic symptoms, as well as an enrichment of social life when meeting with other patients and staff at the dialysis ward. It may be felt that temporising in such a situation would make it more likely that patients will make decisions that are fully considered, as over time it may become easier for patients to imagine the rest of their lives on dialysis—or so this line of reflection has it.

### Temporising for greater decision-making capacity

In the kinds of situation under discussion the patient possesses sufficient decision-making capacity, and so he or she could certainly be presented with the relevant options right away. The physician could, however, temporarily withhold the offer of treatment in order to wait for a moment when the patient's decision-making capacity, or autonomy, improves yet further. Above the decided threshold for sufficient capacity, actual decision-making capacity can often be improved.

The negative effects on a patient's decision-making capacity—caused, for example, by the accumulation of uraemic toxins and water as is sometimes the case in end-stage kidney disease—may diminish over time, since the effects of disease are better controlled through the treatment. Whatever the exact reason, there could be significant fluctuations in decision-making capacity as a result of variations in the state of the disease or the effects of treatment and medication.<sup>3–6</sup> Potentially, the task of the physician seeking to optimise patient autonomy will be to time the presentation of the clinical information and decision to the point at which the patient has maximal decision-making capacity.

Variability in the cognitive functioning of patients thus raises the question whether it is morally justifiable for physicians to temporise decisions on the basis of a prediction that the patient will have *better* decision capacity in the near future. Is it possible, for example, that the patient would be able to make a more autonomous decision if one were to wait until he or she is more alert, less distracted or in other ways in greater command of the cognitive repertoire that lies behind decision making? Note that in the situation we are considering the reason for such temporising is not that at the later time the patient will be more likely to make a decision with a better outcome. It is that at the later time the patient's decision will be based on better *processes*, functionally defined, regardless of what the physician and other involved third parties think would be the best alternative for the patient.

<sup>iv</sup>In a recent interview study, this was mentioned as one reason why one might be reluctant to address foregoing cancer-specific therapy.<sup>15</sup>

### Temporising out of respect for the patient's more authentic or deeply held views

Somewhat relatedly, a physician may look beyond the surface of the principle of self-determination and consider what he or she takes to be its underlying values. Surely, this line of thought might go, self-determination is about letting the individual patient's personal goals or values be the ultimate arbiter of what should be done. That being so, while the patient may have decision-making capacity according to the established standards, some temporising may significantly increase the probability that the patient will be able to make, not only a minimally competent decision (bordering on a 'mere, sheer choice'), but a decision that better reflects his or her deeper values, one that can be considered more 'authentic'.<sup>v</sup>

While the different reasons mentioned above seem superficially to describe legitimate reasons for temporising (promoting patient autonomy and the likelihood that 'better' decisions will be made), the question remains whether they genuinely succeed in doing this. In particular, it remains to be established under what conditions temporising for these, or other reasons, is compatible with the principle of self-determination.

### TEMPORISING AND SELF-DETERMINATION

What has so far been assumed is, at most, that a physician will not violate the principle of self-determination *merely* by allowing time to pass. If it is not the passing of time as such, what does make temporising conflict with the principle of self-determination? There is a sense in which this question has no answer. As we have already hinted, the principle, as it is deployed in clinical ethics, is somewhat elusive, and there is no canonical formulation or interpretation to rely on. To that extent, we are obliged to give it the meaning we find most useful, given the historical trajectory of the principle and the shape of the discussion. The principle, we have stated, minimally requires that patients to be given the chance to decide for themselves whether, for example, to continue to receive life-supporting therapy, so any course of action that risks taking that chance away from them would obviously be inconsistent with it. In other words, we suggest that temporising will conflict with the principle of self-determination when it *exposes the patient to a sufficiently great risk of depriving him or her of the opportunity to make the relevant decision*. We now need to explain how this might happen, and then address the relevant notion(s) of risk.

#### Deprivation of opportunity

One potential problem with temporising is that it may deprive the patient of certain opportunities. Although there are many different examples of this, all arguably fall under either of two categories.

#### Loss of capacity

How could a patient be deprived of the opportunity to make the relevant decision simply by postponement of that decision? First, with the passing of time, the patient now judged to have decision-making capacity could lose that capacity.<sup>vi</sup> This could happen

<sup>v</sup>Recent work on authenticity suggests that it might be difficult, or even impossible, to successfully be guided by authenticity as a way to respect patient autonomy.<sup>16 17</sup> We will not go into details, but we conclude that temporising gives rise to precisely the same problems that have been discussed in that work. This is a topic that ought to be pursued further.

<sup>vi</sup>This way of putting it presupposes traditional assumptions about the conceptual and normative role of capacity thresholds: that there is a morally critical dividing line between those who have capacity and those

for any number of reasons. The problem may be the progress of the illness itself, since most chronic diseases progress to a state where decision-making capacity is significantly reduced, due to loss of cognitive functions caused by physiological factors. In the case of patients with chronic kidney disease on dialysis, cognitive impairment is common, especially after a long time on dialysis.<sup>3,5-8</sup> In spite of medical treatments and medications, some of the deleterious effects on cognitive functions with an impact on decision-making capacity can be irreversible.<sup>3,8</sup> However, capacity could obviously be lost for other reasons, too.

If there is a significant risk that the patient will lose decision-making capacity as a result of treatment or developments in the underlying disease, or for any other reason, temporising risks depriving the patient of a right that he or she could have exercised. In addition to making an assessment of the patient's current decision-making capacity, therefore, physicians and other members of the healthcare team, if they are considering temporising, need to predict and monitor any deterioration of capacity in the future. Even with experience and training, such predictions can be very difficult, if not impossible. On the assumption that violations of the principle of self-determination are morally problematic, even the possibility of such deterioration should be taken seriously.<sup>vii</sup>

#### When the decision is no longer the same

Another way in which temporising could deprive the patient of choice may seem less straightforward. As time passes, things may change, as already noted. Actually, this may be what the physician hopes for: positive changes to the patient's decision-making capacity, the patient becoming better informed, better grounds for predicting future treatment effects and so on. However, with time, circumstances may change in such a way that the decision ultimately facing the patient can no longer be said to be the same decision as the one that he or she could have been offered earlier. The most clearly relevant possibility here is that 'external' circumstances will change. For example, due to changes in clinical or other conditions, the options available to the patient may shift. Initially, there could be a wide range of treatment modalities available, but this may cease to be true as time passes and the patient goes through a range of interventions. A patient with chronic kidney disease may begin on a kind of dialysis that is effective when the kidneys still have residual function but not later, after a period on dialysis, when this residual function declines. Even if the options remain the same, the probable outcomes of one of them, or several, may change. With lower residual function, there are dialysis modalities that will not suffice in producing symptom relief and quality of life, and there could be other complications as well. Social relations and support may change too. For example, the treatment may place strains on the patient or his or her family and

who do not. That assumption can be called into question, of course, as it is in the UN Convention on the Rights of Persons with Disabilities (CRPD), art. 12, according to which no one should be denied legal capacity and those with cognitive impairments should instead be offered support in the exercise of their legal capacity. In this new 'support paradigm', the issue of temporising becomes more complex. Is there, for example, a sense in which the principle of self-determination is threatened if temporising significantly risks putting the patient in a situation in which the exercise of his or her right to autonomy will require significantly more support?

<sup>vii</sup>The risk of lost capacity introduced by temporising also raises the issue of whether healthcare, given its commitment to the principle of self-determination, has a *special* obligation in those cases to help patients to retain decision-making capacity, that is, one over and above whatever general obligation it may have in trying to do so.

friends, forcing the patient to take these new circumstances into account when making the (temporised) treatment decision.

In addition to changes in what the possible courses of action are, changes more 'internal' to the patient may also take place, raising the question whether these internal changes risk turning the postponed decision into a substantially different one. Thus, as time goes by, the way in which the patient experiences treatment may be altered. There may be adaptation on the part of the patient, or fatigue may set in. Also, with the new clinical input novel thought processes may ensue: there may be a change not only in preferences, but in will power as well, and other events and issues will compete for the patient's attention, inevitably putting things in a different subjective light. Specifically, the wish to prolong life at a certain cost can vary over time. Perhaps other values come to be considered more important, such as independence and well-being. Arguably, such changes in outlook will not by themselves amount to a change in the decision facing the patient; often they will merely involve a new take on the same decision. However, when the relevant psychological development becomes a significant part of the factual basis on which the decision will be made—when it alters what the patient must reasonably consider when making his or her choice—there is a sense in which the temporised choice facing the patient and the choice he or she would have been presented with earlier are not one and the same. For example, in mentally adapting to new circumstances, the personal costs of continued dialysis may actually decrease, significantly changing the patient's *reasons* for choosing to continue. More generally, the right to make a certain decision may be seen as a right to personally weigh certain (objective) costs and benefits, but those costs and benefits may change notably with the patient's changed subjective perspective.<sup>viii</sup>

As the examples illustrate, circumstances can change in a variety of potentially significant ways. In all of these cases of significantly changed circumstances, the patient may retain a capacity for self-determination, of course, but not with respect to the initial decision that he or she was judged to be able to make. Now, we will not assume that the mere fact that the act of deciding between two alternatives takes place at two different points in time implies that the decisions are different. Nor will we presuppose that any (substantive) change in circumstances, however small, will imply that the postponed decision is a new one. The question is: when are circumstantial changes significant enough to make the (temporised) decision facing the patient a different decision from the one that could initially have been offered to him or her?

Whether decisions arising at different points in time ought to be considered identical is, we maintain, a *moral* matter—not one that could be settled by some independent (metaphysical) account of the individuation of decisions. It is a question of whether circumstances have changed so much *in respects that we care about* that we, from that perspective, ought to consider, say, two decisions separated in time distinct. It is therefore necessary to determine the morally relevant identity criteria for decisions before one can say under what conditions temporising risks depriving the patient of the opportunity

<sup>viii</sup>This, it should be emphasised, is not to say that the viewpoint of the person prior to temporising is in any way superior to the one he or she has post-temporising. In particular, we do not assume that the earlier perspective better reflects the person's 'true self'. As already mentioned, authenticity considerations may or may not rather favour temporising. Temporising is difficult to square with the principle of self-determination not because this principle makes any assumptions about authenticity, but because it requires that persons get to make the relevant decisions when they can still be made.

to make the relevant decision. A thorough analysis of this is clearly beyond the scope of this paper. It is nonetheless important to highlight the relevance of decision identity to the issue of the compatibility of temporising and the principle of self-determination.

### Risks and their acceptability

When a physician postpones offering a treatment decision to a patient because the patient is, at that moment, resting or taking a shower, there is certainly *some* risk that the patient will be deprived of an opportunity to make the relevant decision. After all, circumstances can change dramatically even in very short periods of time. Presumably, however, we can treat this as a de minimis risk—a probability so small that it should not be given further consideration. But when does an insignificant risk of this kind turn into a risk that we should not ignore, on pain of transgressing the principle of self-determination? When does the risk of depriving the patient the opportunity of making the treatment decision become so great that the patient's right to self-determination is seriously threatened? The principle of self-determination, as already mentioned, is not sufficiently well defined to allow an answer to this question. It is compatible with a wide range of views about its moral foundation and importance. Such differences can be expected to correlate with divergent views about how great the risk that a patient will be deprived of a decision-making opportunity needs to be before it excludes self-determination. For example, someone who derives the principle of self-determination from the assumption that this is a basic and absolute human right, trumping most other interests, is likely to be less comfortable with threats to self-determination than someone who takes the principle to be strongly defeasible and grounded in the more pragmatic consideration that most people simply expect to have the last word on what should happen to their own bodies and would object if they were not allowed that.

Now, if autonomy considerations are relevant—as surely, in one way or another, they are to everyone subscribing to the principle of self-determination—it seems natural to take seriously the patient's view of the risk to self-determination. Some patients may accept that risk. They may not feel that the substantial possibility of circumstances changing if the physician temporises conflicts with their right to self-determination. Others, however, might be more risk averse. They might take their right to self-determination to imply that physicians must take no risks at all that the postponed decision will be a different one. Such subjective perspectives on what autonomy demands could be thought to offer some guidance as to how the principle of self-determination should be interpreted.

Understanding the threshold of acceptable risk here as partly subjective is, however, problematic. Patients may not have any views on acceptable temporising-related risks. Even if they do, there will typically be no practical way of eliciting those views. That would require consulting each patient and accessing their opinion, and in many cases, it is very likely to be difficult to ask the relevant questions without at the same time addressing the very treatment issue the physician is considering temporising. If instead it were suggested that a criterion involving hypotheticals should be employed, this would raise many of the difficult issues inherently associated with substituted judgments. Any suggestion that the anticipated risks are consistent with a principle of self-determination when and only when the patient *would* have accepted them raises the question: would have accepted *under what circumstances?*<sup>9</sup>

### The relevance of known unknowns

Whether the patient will be in better shape to make the decision in the future, and whether his or her circumstances will significantly change if the physician chooses to temporise, may be difficult to predict with sufficient certainty, regardless of what one thinks the probability thresholds ought to be. Significant changes may be considered unlikely, but a high likelihood of there not being any substantive changes is seldom equivalent to certainty, and as a rule, the evidence on which the prediction is made is itself associated with (epistemic) uncertainty. This means that temporising amounts to betting on an uncertain outcome and, as such, taking risks with the right to self-determination at stake.

Of course, in medicine, it is often necessary to act on assumptions that are to some extent uncertain, and sometimes risks need to be taken for a payoff. If the physician opts to wait until the patient is even more autonomous, or better equipped to make a wise choice, there may indeed be such a payoff, but the issue now is whether temporising is consistent with respecting the widely accepted patient right to self-determination. Whatever good may be maximised by it, temporising as a result of uncertainty about whether circumstances will change risks depriving the patient of an opportunity to make a decision he or she is considered to have a right to make. To that extent, temporising appears to be in conflict with the principle of self-determination.

### Moral uncertainty

It is not just that the patient's future is uncertain. Uncertainty pertains also to the issue of just how much alteration in the circumstances would turn the temporised decision into one that is relevantly different from the one initially considered. This kind of uncertainty is different from the epistemic uncertainty just discussed. It concerns moral uncertainty (or disagreement). Whether the current decision to withdraw or continue dialysis would differ relevantly from a similar decision next month—when the prognosis would be somewhat clearer and the patient would have a slightly different mindset, having endured some additional suffering or positive quality of life—is hard to say with confidence, because it is not easy to say just what differences between the two decision scenarios *ought to be viewed as important*. Moral reasons can be given in support of drawing the line at this or that place, but reasonable people may still disagree. Therefore, until there is firmer ground to stand on in this regard, the safest approach may well be not to temporise, as the change in circumstances following postponement of the decision may be so significant that the temporised decision ought to be viewed as a new one.

### CONCLUDING REMARKS

The principle of self-determination is central in the practice of modern medicine. It raises many issues, both conceptual and ethical, as the now very extensive literature on it reflects. What has received very little attention, however, is the issue of *when* the self-determining patient ought to be offered his or her clinical choice. In this article, we have explored the question whether waiting for a while before one presents treatment options to a patient with decision-making capacity is consistent with the principle of self-determination. There are certainly reasons why physicians may believe that such temporising is sometimes called for. We have claimed that temporising conflicts with the principle of self-determination when it would expose the patient to a sufficiently great *risk* of depriving him or her of the opportunity to make the relevant decision. Patients can be so deprived if they risk losing decision-making capacity, or if other circumstances

change to such a degree that the ensuing decision situation is essentially a new one. Given the significant uncertainty in any determination of what might happen (and the moral relevance of this) if one postpones offering a treatment decision to the patient, we contend that physicians ought to be very cautious when they consider temporising if their aim is to ensure that they abide by the principle of self-determination.

To say that temporising sometimes conflicts with patient self-determination is not to assert that it is wrong, all things considered. For all that has been argued, in some circumstances, healthcare professionals may be morally justified in disregarding the principle of self-determination. That may perhaps be so if the patient has significant health and welfare interests that cannot be met unless the relevant treatment decision is taken away from him or her. Traditional paternalism is not, however, the only consideration that might trump the principle of self-determination. As we have already remarked, physicians may have to face a choice between respecting decisionally capacitated patients' putative right to make their own decisions and *promoting* patients' self-determination, or autonomy, in some broader respect. In this connection, temporising could perhaps be seen as ethically warranted as long as it significantly raises the chances that the patient will, in the sufficiently near future, be able to make decisions that are more deliberative, independent and anchored in his or her deepest convictions, life goals or the like.

The legitimacy of limiting someone's freedom of choice at a certain moment in time with the aim of increasing this individual's options and ability to act independently in the future is an issue that arises *within* the realm of respect for others' selves. On the one hand, it could be argued that the promotion of future autonomy, by temporising or any other means, is precisely the kind of engineering management of others that the right to self-determination prohibits and that any instrumental take on modifying others' opportunities to decide for themselves, although in the name of prospective self-determination, is anathema to the very idea of respect for autonomy. For example, disrespecting a patient's choice of general practitioner practice on the basis of the prediction that in the future the patient will prefer another one would typically be regarded as clearly conflicting with the principle of self-determination. On the other hand, it could also be argued that part of our responsibility to respect others is to respect them as *persons*, and that, whatever else persons are, they are enduring, or extended in time. From this viewpoint, respecting someone's right to self-determination is not necessarily about respecting the choices of a *time slice* of a person, as it were, but about allowing this extended four-dimensional entity, the person, to shape his or her own life, and from that perspective, temporising in order to promote future choices that are independent and wise could well be consistent with the underlying idea of autonomy. While this kind of tension between different understandings of autonomy has been extensively explored, much work remains.

It is equally clear that to say that a certain kind of temporising is consistent with (the letter of) the principle of self-determination is not to assert that it is consistent with the spirit of this principle—the underlying considerations that made it compelling in the first place. By not seriously risking the possibility that an opportunity to make a decision will be taken away from a patient, a physician could be justified in claiming that his or her temporising meets the principle of self-determination. Still, as already mentioned, on some views of the right to self-determination, any attempt to be a decision-making 'architect' will be at odds with the core value of respect for autonomy. One may disagree, that is, about whether this *attitude* towards others'

decision making is, by itself, inconsistent with the principle of self-determination, but if it is not, it could be argued that this attitude at least does not sit well with the underlying purpose of this principle.

The relationship between the physician and the patient is asymmetrical by nature. Patients are generally in need of care, advice or other forms of help, and often, with their knowledge, skills and mandate, physicians are the only ones who can meet such needs. While some power imbalance between physicians and patients is inescapable, temporising is a manifestation of this imbalance, since it is entirely in the hands of the physician to decide when to present the different options to the patient. To the extent that one takes any significant power difference between equals to be *prima facie* problematic, temporising—even when it satisfies the principle of self-determination, as understood above—could be seen as a missed opportunity to live up to the ideal of human equality, and possibly unwarranted from the perspective of patient autonomy.<sup>ix</sup> Whether a physician could be justified in violating the principle of self-determination, perhaps by appeal to broader autonomy considerations, is a different issue, of course, as is the issue whether it is possible to violate the deeper values underlying this principle while acting in a way that accords with its letter.

Obviously, the ethical issues surrounding temporising need to be further explored. We believe the discussion we have presented could serve as a starting point for the continued study of this and other underaddressed questions about *when* treatment issues should be raised for patients who should be given the opportunity to address them.

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## REFERENCES

- 1 Beauchamp TL, Childress JF. *Principles of biomedical ethics*. 7 edn. New York: Oxford University Press, 2013:459.
- 2 Henrikson NB, Ellis WJ, Berry DL. "It's not like I can change my mind later": reversibility and decision timing in prostate cancer treatment decision-making. *Patient Educ Couns* 2009;77:302–7.
- 3 Burn DJ, Bates D. Neurology and the kidney. *J Neurol Neurosurg Psychiatry* 1998;65:810–21.
- 4 Murray AM, Tupper DE, Knopman DS, et al. Cognitive impairment in hemodialysis patients is common. *Neurology* 2006;67:216–23.
- 5 Thimmaiah R, Murthy KK, Pinto D. Cognitive dysfunction in patients with renal failure requiring hemodialysis. *Indian J Psychol Med* 2012;34:237–41.
- 6 Schneider S, Malecki AK, Boenisch O, et al. Cognitive function at 2443 µmol/l creatinine. *BMC Nephrol* 2012;13:86.
- 7 Dixit A, Dhawan S, Raizada A, et al. Attention and information processing in end stage renal disease and effect of hemodialysis: a bedside study. *Ren Fail* 2013;35:1246–50.

<sup>ix</sup> Alternatively, it could be argued that what is objectionable about temporising, from an autonomy perspective, is the physician getting to choose which version of the patient will be allowed to make the relevant treatment decision. That argument, however, would apply more broadly, as deciding *not* to temporise, could on that basis be viewed as an equally problematic abuse of power. Some power over others may, in the circumstances, simply be inevitable, and therefore (at most) unfortunate, rather than objectionable.

- 8 Schneider SM, Malecki AK, Müller K, *et al*. Effect of a single dialysis session on cognitive function in CKD5D patients: a prospective clinical study. *Nephrol Dial Transplant* 2015;30:1551–9.
- 9 Broström L, Johansson M, Nielsen MK. "What the patient would have decided": a fundamental problem with the substituted judgment standard. *Med Health Care Philos* 2007;10:265–78.
- 10 Volpe RL. Case study. temporizing after spinal cord injury. commentary. *Hastings Cent Rep* 2015;45:8–9.
- 11 Halvorsen K, Slettebø A, Nortvedt P, *et al*. Priority dilemmas in dialysis: the impact of old age. *J Med Ethics* 2008;34:585–9.
- 12 Del Vecchio L, Locatelli F. Ethical issues in the elderly with renal disease. *Clin Geriatr Med* 2009;25:543–53.
- 13 Scherer JS, Swidler MA. Decision-making in patients with cancer and kidney disease. *Adv Chronic Kidney Dis* 2014;21:72–80.
- 14 Van Biesen W, Lameire N, Veys N, *et al*. From curing to caring: one character change makes a world of difference. Issues related to withholding/withdrawing renal replacement therapy (RRT) from patients with important co-morbidities. *Nephrol Dial Transplant* 2004;19:536–40.
- 15 Laryionava K, Heußner P, Hiddemann W, *et al*. Framework for timing of the discussion about forgoing cancer-specific treatment based on a qualitative study with oncologists. *Support Care Cancer* 2015;23:715–21.
- 16 Ahlin J. The impossibility of reliably determining the authenticity of desires: implications for informed consent. *Med Health Care Philos* 2018;21:43–50.
- 17 Sjöstrand M, Juth N. Authenticity and psychiatric disorder: does autonomy of personal preferences matter? *Med Health Care Philos* 2014;17:115–22.