ADDICTION, VOLUNTARY CHOICE, AND INFORMED CONSENT: A REPLY TO UUSITALO AND BROERS

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ABSTRACT
In an earlier article in this journal I argued that the question of whether heroin addicts can give voluntary consent to take part in research which involves giving them a choice of free heroin does not – in contrast with a common assumption in the bioethics literature – depend exclusively on whether or not they possess the capacity to resist their desire for heroin. In some cases, circumstances and beliefs might undermine the voluntariness of the choices a person makes even if they do possess a capacity for self-control. Based on what I took to be a plausible definition of voluntariness, I argued that the circumstances and beliefs typical of many vulnerable heroin addicts are such that we have good reasons to suspect they cannot give voluntary consent to take part in such research, even assuming their desire for heroin is not irresistible. In a recent article in this journal, Uusitalo and Broers object to this on the grounds that I misdescribe heroin addicts’ options set, that the definition of voluntariness on which I rely is unrealistic and too demanding, and, more generally, that my view of heroin addiction is flawed. I think their arguments derive from a misunderstanding of the view I expressed in my article. In what follows I hope therefore to clarify my position.

INTRODUCTION

Can heroin addicts voluntarily consent to take part in research which involves giving them a choice of free heroin – assuming, of course, they are neither intoxicated nor suffering from withdrawal symptoms at the time of consent? The question arises in connection with research on the effectiveness of heroin prescription as a treatment alternative. In the bioethics literature the answer has standardly been assumed to depend on whether or not heroin addicts’ possess the capacity to resist their desire for heroin. Since there appear to be empirical reasons to think that they possess this capacity, some have concluded that no special problem attaches to the voluntariness of heroin addicts’ consent.1 In an earlier article in this journal, I questioned this claim on the grounds that circumstances and beliefs sometimes appear to exert a controlling influence on persons, causing them to feel pressured into performing certain actions (like enrolling in clinical trials, for example), independently of whether or not they have lost their capacity of self-control.2 What if the question of the voluntariness of heroin addicts’ consent is considered more broadly, based on their actual circumstances and beliefs rather than hard-to-verify claims about their capacity of resistance? To investigate this, I suggested using a definition of voluntariness from Olsaretti (1998).3 What if the question of the voluntariness of heroin addicts’ consent is considered more broadly, based on their actual circumstances and beliefs rather than hard-to-verify claims about their capacity of resistance? To investigate this, I suggested using a definition of voluntariness from Olsaretti (1998).3 A person’s choice is voluntary, according to this definition, if she does not make it because she believes she has no acceptable


alternative, that is, if she makes it either because she believes she has at least two options, both of which are acceptable, and chooses one of them because, all things considered, she prefers that to the other, or because she believes she has at least one option that she wants or likes so much that she chooses it because of that, whether or not she believes she has any acceptable alternative. Whether a person’s choice is voluntary, then, depends crucially upon her motivation, and hence upon her beliefs about her options; the relevant condition that undermines voluntariness would be the absence of an acceptable alternative – where the standard of acceptability is an objective standard of well-being. Based on this definition, I argued that there are several good reasons why we cannot simply presume that the heroin addicts in the target group (which includes addicts who are vulnerable in the terminology of research ethics) can give voluntary consent to take part in research which involves giving them a choice of free heroin. That is because their motivation might undermine their sense of having a meaningful choice other than participation even if they possess the capacity to resist their desire for heroin. One reason for thinking that their sense of having a meaningful choice might be undermined, I argued, could be that the wider social and psychological circumstances typical of these addicts are such that they could plausibly shape their beliefs, leading them to think they lack any acceptable alternative to taking part in research.

Uusitalo and Broers are unpersuaded. They think that my claim ‘rests on a flawed conceptualization of heroin addicts’ options,’ a false assumption ‘that people always choose on the basis of their own well-being’ and a ‘too demanding and unrealistic’ conception of voluntariness. In their words, ‘If we decided to stay with Henden’s account, major adjustments would be required to set clinical research and treatment to an ethically acceptable level in many situations’ (p. 8). I think their arguments derive from a misunderstanding of the view I expressed in my article. In what follows I hope therefore to clarify my position.

1. HEROIN ADDICTS’ OPTIONS

Uusitalo and Broers think that drug-oriented motivation in vulnerable heroin addicts does not adversely affect the voluntariness of their capacity to consent to take part in research into heroin-assisted treatment. Many other considerations apart from access/no access to heroin are likely to be relevant to how they perceive their options, they say. For example, participation might be seen as a step toward accessing proper treatment. I agree with Uusitalo and Broers that considerations other than access/no access to heroin might affect how heroin addicts perceive and weigh their options. Our disagreement concerns the significance of offering free and legal heroin to vulnerable individuals addicted to heroin. An important premise of my description of heroin addicts’ options-set, faced with a decision to take part in such research, is of course, that heroin addicts have something important in common: they care intensely about heroin. That is what distinguishes them from people who are not addicted to the drug. In addition, especially vulnerable heroin addicts might (perhaps because of multiple treatment failures in the past) be in a situation in which achieving abstinence seems unlikely or downright impossible. They may therefore perceive the prospect of free and legal heroin as a particularly salient feature of their choice situation – or at least, it would seem implausible to rule out this possibility. Now, there is, in fact, plenty of evidence of addicts paying selective attention to drugs and drug-associated stimuli, often leading them to lose sight of their longer-range goals. It has been commonly observed, for example, that addicts tend to ignore or downplay the costs of taking drugs while greatly exaggerating the benefits of so doing. Drug-related attentional bias has been demonstrated in users of a variety of different drugs, including alcohol, cannabis, cocaine, heroin and tobacco. Can it be ruled out that especially vulnerable heroin addicts, who are given the choice of taking part in heroin trials, might assign disproportionate weight to the prospect of obtaining free and legal heroin while deliberating their decision? Uusitalo and Broers seem to believe that it can, but offer nothing in support of their belief. Given the attentional biasing evidence just mentioned, however, it is extremely plausible that many heroin addicts are influenced by considerations arising from such a prospect and that they, as a result, may find it difficult to properly assess their own rational motivations. That, of course, need not rule out that other considerations also might matter to them (e.g. that taking part in the study might eventually result in proper treatment). Even if the standard description of heroin addicts’ options (on which I relied in my article) may not reflect the full empirical details of their actual deliberation (details which anyway are bound to vary immensely), the important point is that it plausibly reflects one particularly salient feature in their perception of the choice situation and it is the potential effect of that feature that has the greatest bearing on considerations of whether or not their consent is voluntary.


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2. THE STANDARD OF WELL-BEING

One of the problems facing my view is, to quote Uusitalo and Broers, that ‘Heroin addicts might have a variety of different reasons for using heroin [. . .] improving well-being is probably common, but surely not the only reason. In fact, it is dangerous to presume that people always choose on the basis of their own well-being’ (p. 5). They illustrate their point with an example of a woman who faces a decision between dying of cancer in one month or participating in research on a new treatment that has unpleasant side-effects but will postpone her death by a couple of months. About this woman, Uusitalo and Broers say: ‘Her decision may depend on how she sees the situation as it affects her well-being; but it could also depend on an altruistic reason, i.e. whether she wants to help the clinical research, or on some other issue that for instance concerns her family’ (p. 5). Here Uusitalo and Broers appear to attribute to me a view of ‘well-being’ according to which it is a special kind reason having to do with promoting one’s own pleasure, satisfaction, or happiness. This is a misunderstanding, so let me say how I used this notion in my article. There I assumed (along with standard philosophical usage) that ‘well-being’ – how well life goes for a person – is the name of a prudential value that grounds reasons for actions and choices. The idea is that the justification of choice must be understood as comparisons of the alternatives with respect to some prudential value. That is, without some prudential value there will be no common basis on which the comparison of alternatives can proceed. This value has been given different names (‘utility,’ ‘pleasure,’ ‘satisfaction,’ ‘happiness,’ ‘well-being,’ ‘welfare’ etc.) and there are different theories about what it consists in. What this means is that ‘well-being’ as used in my article, is not a kind of reason at all, but a standard for the evaluation of options that gives reasons their justificatory force. That is, things matter to agents in terms of how they affect their well-being. Now, as I made clear in the article, I rely on Olsaretti’s (1998) account of voluntariness. This account assumes a hybrid theory of well-being, i.e. a theory that incorporates both an objective value constraint and a pro-attitude constraint.7 Hybrid theories are ‘objectivist’ in the sense that things that are part of a person’s well-being are thought to be irreducible to mental states promoting her feelings of pleasure, satisfaction or happiness. At the same time, it is assumed that such mental states can also be components of a person’s well-being. Of course, space does not permit a detailed account of prudential value, i.e. what this value consists in. And anyway, it is a task for value theory. Olsaretti (along with e.g. Parfit) seems to treat it simply as a generic or unspecified sort of objective value but of course, other views are possible, including various forms of perfectionism.8 For present purposes, what should be borne in mind, is that by accepting an objective standard of well-being (as I say I do in the article), well-being on my view includes much more than a person’s own feelings of pleasure, satisfaction or happiness. For example, it can include the well-being of other people whose well-being that person takes for her own.9 How well life goes for a person often depends on the status of other people’s well-being. It is therefore incorrect to assume, as Uusitalo and Broers do, that the view of well-being on which I rely in my article rules out that heroin addicts can have ‘altruistic reasons for their actions’. More generally, given my view of well-being, it does not make sense to speak of well-being as a special kind of reason at all.

3. THE CONCEPT OF VOLUNTARINESS

According to Uusitalo and Broers, the account of voluntariness I relied on in my article is ‘unrealistic’ and ‘too demanding’ since ‘there is a considerable number of cases of informed consent which would fall outside the scope of voluntariness in medical and healthcare settings’ (p. 8). To support this claim they give two examples. One is the case of voluntary euthanasia; the other a case of a woman with treatment-resistant aggressive cancer who faces a choice between dying in one month or participating in a trial for a new treatment that has unpleasant side-effects but which will postpone her death by a couple of months. They also give a more direct argument why I am mistaken in claiming that we should not presume that vulnerable heroin addicts can give voluntary consent. Let me consider these in turn, starting with the case of voluntary euthanasia.

According to Uusitalo and Broers, voluntary euthanasia would be an oxymoron on my account since ‘cases of voluntary euthanasia are hardly cases in which one chooses euthanasia for the reason that it brings one’s well-being to such high a level, by [an] objective standard, that one chooses it for that reason. Nor do people voluntarily consenting to euthanasia typically have two


8 See e.g. T. Hurka. Perfectionism. Oxford: Clarendon Press; 1993. It is certainly possible to reject the view of well-being I assumed in my article. Perhaps this is Uusitalo and Broers’ position. The problem is that they neither explain why they want to reject it nor suggest any alternative theory of prudential value.

acceptable options available in this sense’ (p. 7). Uusitalo, Broers and I can certainly agree that it would be rather implausible to claim that someone who chooses euthanasia does it because she believes it will significantly improve her well-being. It seems considerably less implausible, however, to hold that she might choose it because, all things considered, she prefers it to the alternative. On my view, if a person chooses something voluntarily she does not choose it only because she thinks she has no prudentially acceptable alternative. Which means, of course, that she might choose it precisely because she prefers it to the alternative. Exactly what prudential value a person’s alternative will have when euthanasia is considered an option will, of course, depend on her particular circumstances, motivation and beliefs. Uusitalo and Broers seem to assume (without substantiating their assumption) that if one chooses euthanasia one cannot have any prudentially acceptable alternative. But why should that be true? It seems perfectly possible, for example, to imagine palliative care and good nursing as an acceptable alternative to euthanasia for a person who knows she will soon die from an incurable illness. Clearly, not everyone knowing of their imminent death from incurable illness would settle on euthanasia if given the choice. But suppose, instead, the alternative to euthanasia was a lingering, extremely painful death. It is easy to imagine the person rejecting this option as unacceptable. Euthanasia, of course – though she might consider it acceptable in the circumstances – is not an option that she either wants or likes so much that she would choose it for those reasons. Rather, it is an option that is forced upon her by the dire circumstances in which she finds herself. That is, she chooses it only because she can see no other way, because her circumstances make her believe she has no prudentially acceptable alternative. In this situation, her choice will be non-voluntary on my view.

Let me move on to the case of the woman with an aggressive form of treatment-resistant cancer. Uusitalo and Broers ask us to imagine her facing a decision between dying of cancer in one month or participating in research on a new treatment that has unpleasant side-effects, such as nausea, but which will postpone her death by a couple of months. If she rejects that latter option, she will die sooner. According to Uusitalo and Broers, if she does choose that option, I would have to say (implausibly in their view) that she cannot have chosen it voluntarily since she has no acceptable alternative and because the new treatment ‘does not promote her well-being over a threshold to such high a degree that she would want to choose it because of that’ (p. 7). But, of course, I need not say this. Once again, Uusitalo and Broers assume (without argument) that for a person who knows that cancer will soon take her life, dying of cancer in ‘one month’ cannot be a prudentially acceptable alternative to dying of cancer in ‘a couple of months’. But why should that be accepted? The point is the same as above: whether or not it is an acceptable alternative for her will depend on her particular circumstances, motivation and beliefs.

Finally, I argued in my article that we should not simply presume that vulnerable heroin addicts can give their consent voluntarily, since it cannot be ruled out that they believe they have no prudentially acceptable alternative. The reason for this, I argued, is that it cannot be ruled out that they lack the capacity to abstain from heroin, that their current situation on the street is intolerable and, therefore, unacceptable in the sense that it would not be reasonable to expect them to choose it, and that taking part in research is their only acceptable option. It is their belief that they don’t have any acceptable alternative to taking part in research that, on my view, undermines the voluntariness of their consent – even if this belief might be false since they might in fact possess the capacity to abstain from heroin. Against this Uusitalo and Broers object that ‘If the research offers addicts an option that they believe to be an acceptable option in their situation in terms of well-being, it does not change if the addicts suddenly think there are more acceptable options. There could be an implicit assumption that abstinence is always a better option than the treatment offered in the research’ (p. 7). If I have understood this correctly, their point here is that if the addict were to realize that she has an acceptable alternative to taking part in research (e.g. she realizes that she does in fact possess the capacity to abstain from heroin), that would not change anything with respect to the voluntariness of her consent since it need not change her belief that taking part in research was an acceptable option. But, of course, even if it does not change her belief that taking part in research is an acceptable option (e.g. by making it less acceptable), it would change the voluntariness of her consent on my view since realizing that she has in fact an acceptable alternative means that she might choose that option (or refuse to choose it) because she prefers it to the alternative (or prefers this alternative to that option) – rather than choose it only because she believes she has no prudentially acceptable alternative. And that, on my view, is precisely what it means to say that she chooses it voluntarily. Once again, the relevant condition that undermines voluntariness is

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the absence of an acceptable alternative. I fail to see that Uusitalo and Broers have given any convincing reasons why the requirement that research subjects should have such an alternative when asked whether to take part in research is ‘too demanding’ or ‘unrealistic’. On the contrary, not making sure they have understood they have such an alternative seems unethical. This leads me finally to consider the more positive suggestion Uusitalo and Broers make about heroin addiction and informed consent.

4. ADDICTION AND AUTONOMY

In their article, Uusitalo and Broers seem to assume that the notion of voluntariness is the same as the notion of autonomy. Heroin addicts, they assert, ‘can always choose not only whether to participate but also to opt out from research insofar as they are acknowledged self-governing agents. The generally accepted model for consenting to research or treatment in bioethics is the procedural account of autonomy’ (p. 5). In their opinion, the problem with the sort of view I defended in my article is that ‘it requires that heroin addiction is considered to undermine the agent’s autonomy and that it is heroin as a substance, or the agent’s dependence on that substance, that undermines autonomy. In light of evidence, however, this drug-centred view of addiction seems too narrow’ (p. 6). The ‘evidence’ Uusitalo and Broers appear to have in mind here, is that ‘heroin prescription seems not only to work as a factor that maintains physical dependence but also provides stability in the addict’s life’ (p. 6). Heroin prescription provides a means to promote addicts’ well-being (p. 6). Their main objection to my argument that we should not presume that vulnerable heroin addicts can give voluntary consent thus seems to be that heroin-assisted treatment is likely to undermine heroin addicts’ autonomy.

This objection is confused for several reasons. First of all, in my article I did not express any opinion on whether prescribing heroin therapeutically is an effective way of treating heroin users. That must be determined empirically. Whether heroin-assisted treatment in the end should be recommended for some groups of heroin addicts depends on whether the benefits of such treatment outweigh the costs. Second, while I find it difficult to understand how heroin-assisted treatment could possibly promote heroin addicts’ autonomy with respect to their drug-oriented choices and actions (since it maintains their addiction to heroin), I am not ruling out that it may promote their autonomy with respect to those areas of their lives most affected by these choices and actions (e.g. work or social relations). However, that is besides the point. It does not make any difference to whether their consent to take part in research on such treatment is voluntary or not since they are not asked to consent to take part after the treatment’s conclusion, but before it starts. Third, Uusitalo and Broers seem to assume that voluntariness and autonomy amount to more or less the same thing, and that since there is no problem with heroin addicts’ autonomy, there should be no problem with the voluntariness of their consent. I think they are mistaken on both counts.

First, voluntariness is not the same as autonomy. Doing something voluntarily means that one has a choice whether to do it or not. But someone may have a choice whether to do something or not without doing it autonomously. The standard example from the autonomy literature is, of course, the case of adaptive preferences, famously illustrated by Thomas Hill’s Deferential Wife who voluntarily chooses to serve her husband thereby demonstrating her lack of autonomy. In the medical context, impaired decisional capacity (e.g. diminished reasoning abilities) does not necessarily rule out a capacity to consent voluntarily to a treatment option (or indeed reject it), but it might plausibly rule out a capacity to make this choice autonomously. Equally, someone may do something autonomously without having any choice in the matter. An example here could be the case in which one anticipates loss of self-control at some time in the future and initiates steps to avoid this eventuality by arranging circumstances so as to remove the possibility. A drug addict who wants to quit, for example, might move on her own initiative to a place where she knows she cannot get hold of the drugs. After having moved there, however, she may not be refraining from drugs as a voluntary act. But that does not mean that she does not do it autonomously. Arguably, her choice to move is precisely what makes refraining an autonomous act. Diachronic self-control, of which this is an illustration, is plausibly an important component of autonomy since it supports the connections and continuities which make up our personal identity and hold us together as agents.

What this means is that assessments of heroin addicts’

11 Uusitalo and Broers do not say what they think is the relation between well-being and procedural autonomy.
12 As I made clear in a footnote, one way of getting around the problem of consent if the benefits of heroin-assisted treatment greatly outweigh the costs (including ethical costs) might be to appoint some surrogate authority (e.g. family member) or perhaps relax competence-defining criteria. See Henden, op.cit. note 2, p. 4.
voluntariness in the context of research should be conducted separately from assessments of their autonomy.

Second, I argued in my article that we cannot rule out that the voluntariness of heroin addicts’ consent is compromised by the social and psychological circumstances created by their addiction to heroin. Neither, therefore, can we rule out that their autonomy is compromised (since non-voluntariness in this case would clearly entail diminished autonomy). More generally, there are plenty of good reasons to think that being addicted to a drug diminishes autonomy with respect to drug-related choices and actions. In fact, the very idea of ‘being addicted to a drug’ plausibly implies ‘impaired control over drug-oriented behavior’ and hence diminished autonomy. It is difficult to understand, therefore, what it could possibly mean to be ‘addicted’ if not to have impaired control with respect to behaviour involving the object of one’s addiction. From an empirical point of view, there is, of course, plenty of evidence that addicts do in fact have impaired control with respect to their drug-related choices and actions. Thus, addicts self-consciously cause significant harm to themselves, including emotional distress, health problems, financial problems, disruption of family and other interpersonal relationships. They often report feeling miserable and wanting to quit. Since it is plausible that no one autonomously chooses to engage in behaviour they believe to have such negative consequences, it seems a reasonable assumption that addicts must have impaired autonomy.

However, even if addiction plausibly impairs addicts’ autonomy it is a different matter to explain how addiction impairs their autonomy. One complicating factor is that the notion of ‘autonomy’ is used in so many different ways by different philosophers, and that there are many theories of autonomy (also of ‘procedural autonomy,’ which is the variant Uusitalo and Broers highlight in their criticism of my view). It is beyond the scope of this short reply to discuss the issue of addicts’ autonomy. Nevertheless, I think an important clue to this explanation has been mentioned already: as pointed out in the first section, there is plenty of evidence that addicts’ attention is biased toward drug-associated stimuli, something that makes them lose sight of their longer-range goals, to ignore or downplay the costs of taking drugs and to greatly exaggerate its benefits. Many addiction researchers believe that such bias plays an important part in explaining the maintenance or escalation of drug-oriented behaviour, including relapses among users who have quit and are attempting to stay clean. Since it is plausible that directed attention, the capacity to voluntarily manage the focus of our thoughts, is a necessary condition of autonomy, and because there is evidence that addiction persistently disrupts addicts’ directed attention, a reasonable hypothesis could be that addicts’ autonomy is impaired by drug-related attentional bias. This hypothesis requires, of course, much more development and defence than I can provide here. However, it does lend support, in my opinion, to the view that we should not simply presume that consent given by heroin addicts to take part in research is valid until proven otherwise.

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16 I think that those who, like Foddy and Savulesv (2006), argue that addiction does not impair autonomy in effect are denying the existence of such a thing as ‘addiction’. Perhaps that is Uusitalo and Broers’ view too. However, as far as I can see, they don’t provide any arguments for it.