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Freedom, Consent and Autonomy in Bioethics:

Justifications for Enforced Medical Treatment and its Refusal

Keywords: Autonomy, Consent, Freedom, Enforced Treatment, Bioethics, Biopolitics

Ph.D. Dissertation Summary

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“Much writing on bioethics fails as philosophy because it takes for granted some of the institutions of practices of particular cultures or times.”

O’Neill, O., *Autonomy and Trust in Bioethics*, CUP, 2002, p. X.

“The right to refuse medical treatment is at the core of individual autonomy. It enables an individual to retain physical integrity of his body, and to determine whether there are considerations more important than the preservation of his health or even life. The administration of blood transfusions against religious objection, a caesarean section operation imposed over the objections of the woman in labour, force-feeding of an adult anorexic patient and a non-consensual sterilisation operation on a mentally handicapped woman with the sole purpose of preventing any future pregnancies, [...] go to the very essence of our choices as how to live.”

Wicks, E., *“The right to refuse medical treatment under the European convention of human rights”*, *Medical Law Review*, 9, spring 2001, p.17.

“Rules governing doctor-patient relations must rest on the premise that anyone’s wish to help a desperately pained, apparently helpless person is intertwined with a wish to hurt that person, to obliterate him from sight. It is not accidental that the injunction to “take care of” someone has a two-edged meaning in popular speech.”

Burt, R., *Taking care of strangers*, the Free Press, 1979, Introduction, p. vi.

Introduction

In the course of this thesis, I will foreground cases in which the supposedly objective way of portraying autonomy has been in fact applied in rather different ways in relatively similar cases occurring in the Western world. More specifically, I will focus my attention on the US, the UK and Italy.

The current approach used in bioethics, and more specifically medical ethics, gives a prominent role to the notion of autonomy when dealing with sensitive issues related to the patient's future. This central notion of autonomy was necessary for the construction of the premises of the ethical revolution that shook the Western medical world after WWII.

As a response to the atrocious medical experiments carried out by German and Japanese doctors, the Western world wanted to ensure greater protection for the patient such that he might be better able to defend himself from treatment forced upon him in the name of [pseudo] science. This was achieved via the implementation of the notion of informed consent, through which the decisional power of the patient increased drastically, the results being seen on many occasions in direct improvements to the possibility for affirmation of autonomy, freedom of choice. In recent years, however, the nature of such improvements has been called into question.

A second foundational element of the role of autonomy in Western bioethics has been one particularly important shift in medical ethics over the past twenty years: the patient-doctor relationship has moved from a paternalistic model -whereby doctors were expected and entitled by law to enforce on patients their judgement on the presumption of "knowing best"- to a new system where a patient's authority over her body is central. This qualitative change to the patient's decisional power has in itself increased the (quantitative) weight of autonomy in specific bioethical controversies. Gradually, society has modified its perception of autonomy in medical contexts, moving from a concern with the best possible option for the patient -for whom any deviation from this path only served to further negate his autonomy due to a putative lack of competence- to an increasing respect for the patient's autonomy on condition of sufficient proven competence. The growing acceptance of the patient's will as a sufficient moral justification for ensuring, or withdrawing, treatment has created a number of controversial cases in relation to the patient-doctor relationship.

Thus, as a starting point I will consider the current Anglo-American legal system -whereby the

notion of respect for patient's autonomy has increasingly gained more relevance vis-à-vis the previous paternalistic approach that was dominant in the patient-doctor relationship. Paternalism had assumed that physicians were to be allowed to interfere with a person's freedom of action, a person's autonomy, on the grounds that it is for the good of the person, her liberty thus being legitimately restricted.

The growing number of debated cases of refusal of medical treatment and its denial on the grounds of impermissibility in the name of the patient's best interest has underlined the need for our attention to be refocused on the actual disappearance of paternalism from bioethical debates.

The crucial switch in power relations is characterised by an acknowledgement that -under satisfactory conditions of competence- the patient is the best judge for providing -or rejecting- informed consent over a medical procedure concerning her. Prior to this conception of "patient knows best" there existed a dogmatic view of doctors as the best judges by definition. After all, what can the patient be expected to understand about the procedure that she may or may not decide to undergo? Eventually, it was realised that doctors are as imperfect as any other professionals, and though generally more informed than their patients, doctors can fail just as every other human being engaging in any practical activity can. The *a priori* justification of valuing the nobility of having chosen a profession where an irreversible mistake can be noticed was no longer satisfactory. The more this knowledge of fallibility spread in society, the less people were willing to trust doctors, resulting in a need, gradually expanded, for an increase in the patient's decisional power, or, in more technical terms, in greater respect for her autonomy.

This reform brought innovations in the capability of the patient directly to shape her [medical] destiny. This was seen as a positive change in biomedicine but also more broadly in society, because, despite often being underestimated, the interconnection between "medical politics" and "real politics" is direct enough to allow one to influence the other in significant ways.

It is on these grounds that this work should be considered: through the analysis of the unconvincing application of the notion of autonomy in some specific cases, it is my intention to broaden our perspective on how we should evaluate an inconsistent use of this central concept.

In bioethics there exists a tendency to assess autonomy (or practical autonomy) as the function we can -or cannot- have within a given system. My idea is that we must abandon the mental state that puts a barrier between the sphere of bioethics -and biopolitics as a result- and the

broader political scheme within which certain interpretations can be questioned. In understanding the inadequacy of such a premise in current debates, we must be ready to dissolve it progressively by the acceptance of its anachronism. This questioning our own stance on many delicate issues is a necessary means to avoid a situation in which the inconsistency present in the two spheres of justice (political and bioethical) produces such unhappiness -through the biased use of autonomy as a tool functional to power and not to individuals- that the very groundwork of the current Western society could be shaken by a violent outburst of anger towards authorities, the state and the status quo more generally. If we are to defuse this tension, we are thus required to provide a less drastic change (operated within the current system), yet we need also to realise the urgent need for innovative examination of the role granted to autonomy in Western society.

In order to reveal the central goal of the present investigation, I will attempt to cover a range of different cases exhibiting a certain commonality yet also varying along other important axes. This will allow for the gradual broadening of the reader's perspective, ultimately demonstrating the interconnection of all of the specific cases (related by the use of autonomy as their basic principle of justification) and their political contexts.

In Chapter 1 of this thesis, I will explore standard accepted versions of the notion of autonomy in Western contexts, particularly those of Kant and Mill. I will then consider more recent representations and applications of such a notion, underlining the difficulty in reaching a precise agreement on the definition of autonomy even before applying it to a particular case. Indeed, this initial ambiguity is what leaves room for different interpretations of the notion depending on the circumstances. A fundamentally important aspect that should be understood from the beginning is that, when referring to the incoherence of the application of the notion of autonomy in this work, I will not aim to point out a tension between the Kantian and Millian versions, as I do not contend that one is exclusive of the other. I am aware that these two conceptions could be used in parallel without undermining the consistent application of the wider notion. My critical analysis of how autonomy is subject to contingent interpretations will instead be centred upon a malfunctioning use of its definition according to Kant's description. It is within that version of autonomy that I will foreground the incoherence to which I refer.

To give my critique a more precise and detailed frame of reference, in the subsequent three chapters I will focus my attention on four specific contexts in which the concept of autonomy (and its related sub-definition of competence) has been applied in an inconsistent and therefore

questionable manner. In concluding Chapter 3 I will provocatively sustain that in future cases resembling those considered, the medication of mentally ill death-row prisoners scheduled for execution should be avoided as it would be the only way to ensure a more coherent way of applying the principles that we -as a society- claim to defend. The reasoning behind such a provocation will bring into the equation the direct relevance of politics in defining our ways of dealing with this bioethical case.

As a final step of this work, in the last chapter I will provide a more satisfactory insight of why is it necessary to analyse the mentioned cases through the use of biopolitics. This last part of the thesis will therefore continue with the incorporation of Robert Burt's input into this work's discussion of autonomy before considering also Onora O'Neill's contribution and the value of their respective approaches to understanding autonomy.

I will first of all analyse a practical aspect of the current way of dealing with autonomy, underlining -in line with Burt- that the autonomy of one individual might sometimes be necessary for another to affirm himself as a free agent. In other words, I will highlight that the interdependence that two individuals have in assessing their own autonomy, or competence, is rather too frequently given insufficient consideration. This problematic awareness will bring us back to the question of why there exists a tendency to stress independence as the key feature of autonomy, given that the actual autonomous status of an individual might be more dependent upon others than currently assumed.

The next and final step will be to affirm that -in light of the cases considered, as in others arising in the field of bioethics- we are now in a position to renegotiate our conception of and approaches to autonomy in both bioethical and bio-political contexts.

Having realised the structural limits of the individual-centred version of autonomy that governs the bioethical and political world, as well as all the problems related to its misuse as a natural reaction preserving the very system that we live in, we have the moral duty -and we should have the political wisdom- to reshape the autonomy discourse towards a more communitarian conception that will help us deal with future cases. In order to ensure the relevance of this thesis in progress towards this end, however, some important premises to my work must be made.

First of all, I am aware of the fact that each of the cases considered could produce sufficient material for a thesis of its own. However, I urge the reader to understand that despite its

intriguing appeal at theoretical level, the option of expanding the analysis further for each case would have led the thesis to sacrifice breadth in favour of depth given the practical constraints of this work; while focusing on a single case also represented a valid option, this would not have allowed for a wider evaluation of the role of autonomy. The payoff is the ability to consider what is common to these different (and yet sufficiently similar) situations.

Indeed, this relates to the main objective of this work: to reconnect the discussion over autonomy taking place in the field of bioethics to its political context, interrogating the current conviction that bioethical cases should be evaluated as a separated field altogether.

In this respect, I think it would important for the reader to understand how this thesis developed into its current form, as the research process itself has undoubtedly played a central part in the shaping of the work.

Initially, my research was centred upon Anorexia Nervosa and the debate over the acceptability of refusal of naso-gastric treatment by patients suffering from this unique mental disorder. My perception of the problem was that if we accept that autonomy is the evaluating factor upon which we should base the moral and legal permissibility of an action, all we had to do was to establish if anorexics are autonomous. As will be explained in Chapter 2, this debate is related specifically to the assessment of the presence of competence and/or capacity (the terms with which we connote autonomy in medical contexts), two related concepts whose definition is problematic in itself.

However, what became gradually more obvious to me was that, if I wanted truly to understand what made cases of Anorexia Nervosa so controversial, focusing the argument only on the assessment of competence as the way of resolving its controversial status would have provided only a temporary answer.

To grasp the depth of the issues at stake, I had to increase the challenge to case-specific analyses and move the investigation to more structural questions regarding autonomy and its role in Western bioethics. The decision to broaden the coverage of my research allowed me gradually to question my initial idea of the assessment of competence in Anorexia Nervosa as a sufficient guide to the permissibility of medical treatment (or its refusal).

Firstly, I encountered a case involving schizophrenia and capital punishment (exposed in

Chapter 3) that quite drastically contrasted with the common idea of forcing medical treatment on a person to keep them alive, as in this case the notion of autonomy was used to justify enforced medical treatment to kill -albeit indirectly- the person that should supposedly have benefited from the treatment.

This strikingly different way of defining how we as a society should decide to respect autonomy provoked further questions in me. I came increasingly to doubt the absolute to which we refer when talking about autonomy, understanding that ultimately it is its interpretation (related to human beings within a predefined political structure and thus subject to power relations) that really makes a difference between being forced to stay alive and being allowed to die.

For this reason, in Chapter 4, I decided to broaden even further the spectrum of the cases, taking into account a number of comparable situations where respect for the patient's autonomy had been inconsistent.

The need to consider these cases was vital to the strengthening of the validity of the critical analysis engaged in up to that point: after having introduced the reader to the complexity of conceptions of autonomy in Western bioethics through the contrast of enforced treatment in cases involving mental illness (and thus competence), I realised that considering contexts in which the lack of mental competence was less of a central issue might underline even more clearly the fact that the real entitlement to use one's autonomy is a function of its political acceptability.

This biopolitical strand of the thesis (through a reading of the similarities and differences of the cases) allowed me to point out that -contrary to the tendencies of much of the American bioethical community- bioethics cannot, and should not, be considered as a different field from the rest of philosophy. And, most importantly, we should not think that the autonomy to which we refer when debating a certain given practice or policy is not affected by the political context in which it develops, takes place and becomes a bioethical reality.

As already noted in passing, due to the structural limits of scope associated with a Ph.D. thesis, not every tangential point worthy of attention could be exhaustively explored, and for this reason I unhesitatingly acknowledge that (as in every research project) my choices as to what is relevant and what is not are open to challenge and to criticism. Given the intention of this work to link various subjects not commonly considered in such close proximity, there is at once a

greater risk of undervaluing certain dimensions of the problems tackled and building in structural faults from the outset. Nonetheless, I believe that I have managed to produce a coherent and linear argument that is not jeopardised by the necessary underdevelopment of certain peripheral topics.

Some final clarifications should be made before proceeding into the main body of the thesis. Firstly, I have voluntarily chosen to use -even in cases of major authors- a limited number of sources from which to derive quotations and direct references. The reason behind this decision is the conviction that applying a more balanced and equal representation of the work of both the more and the less well-known philosophers used herein will prevent the reader from becoming distracted by the potential inputs that each of them might have had if moved into a more central role. My priority is rather to ensure that none of the sources applied in this context obfuscates the central argument of this work.

Hence, the use of Foucault, for example, is limited in terms of utilisation both of space and of literature, but there are two reasons for this. The space given to his work is limited because I did not want to make this thesis a Foucauldian one, but only to use some of his more valuable insights in support of my project of reconnecting bioethics to its philosophical roots. Foucault proved very useful and apt in this enterprise, yet I did not want the thesis to be absorbed by his ideas.

That is why -especially in Chapter 4- I refer mainly to one text of his. Without wanting to deprive him of his well-deserved renown nor deny the validity of his broader analysis of power relations, my intention was to treat him as all of the other authors used in the thesis are treated. That is, using their ideas only where they serve to develop the work towards its intended trajectory.

Lastly, I want explicitly to affirm that the interchangeability of “she/her” and “he/him/his” is also intentional. This decision might not satisfy every reader in stylistic terms, but it is the most convincing way for me to ensure that the thesis remains gender neutral without depriving the individuals considered within (sometimes not directly named but still existent) of their humanity.

CHAPTER 1

On Autonomy

Introduction

In order to enter the specificity of the debates related to the application of the notion of autonomy in current bioethical contexts, I shall first construct a more general framework within which the cases presented in the following chapters will be evaluated. Starting from a historical analysis of autonomy, I will then apply it to biomedical contexts, drawing a critical map of the current inconsistencies in its application to cases of enforced treatment (be it by not allowing withdrawal or by forced continuation depending on the circumstances), suggesting ultimately that a possible solution for properly identifying possible improvements in our approach could come from an investigation of the political meaning and value of the choices made by (medical) authorities.

To start my critical analysis, I will follow the structure suggested by Tom Beauchamp and James Childress in their influential book *Principles of Biomedical Ethics*, focusing first on Kant and Mill first to give a more historical view of the path that Western society has taken to arrive at its current conception of autonomy. Subsequently, I will consider important works that have been published in recent decades and that, due to the appearance of bioethical problems that were unthinkable until recent years, have provided new inputs to our understanding of autonomy and brought into question the validity of the previously dominant definition. This part of the thesis will consider, amongst others, the views of Onora O'Neill, Simona Giordano, Robert Paul Wolff, Thomas Szasz, Bruce Jennings and Ronald Dworkin.

Conclusion

This first chapter has shed more light on a topic which is itself plagued by ambiguity. The need for changes in our approach to delicate matters concerning autonomy (be it that of the patient or of the doctor) is inalienable from the times we live in. The level of uncertainty regarding how best to judge and legislate for the ever-increasing number of controversial cases in bioethics is so high that debates on these issues are no longer limited to academic contexts. On the contrary, it is more and more common to find articles or TV programmes attempting to address or explain

problematic cases, in which, as has been pointed out throughout the chapter, the notion of autonomy is frequently central. This social reaction is symptomatic of a period of “reassessment of values” which calls for the attention of experts in the field of biomedical ethics, above all academics. Our response should certainly not bend to what the masses want to hear in order to preserve power, but should instead attempt to understand the core of the problem: namely, we lack a just approach when dealing with subtly yet importantly differentiated cases concerning the freedom of the individual. Especially in instances of *pro-life* versus *pro-choice* conflicts, or, as explained at the outset, where respect for autonomy and medical paternalism are juxtaposed. In the course of this chapter, I have explained the evolution of the notion of autonomy from antiquity to the present day, highlighting a number of modern interpretations of the notion. Subsequently, I argued that over the past twenty years the increasing importance in biomedical decisions of individual autonomy has served as a tool towards the preservation of the *status quo*. The final section of the chapter reflected on the legitimacy of affirming mental illness as an objective medical assessment, since it is also subject to the same dynamics of power and control. The proceeding chapters will shift our analysis to a more practical level, beginning with a more thorough examination of controversial cases of AN.

CHAPTER 2

Anorexia Nervosa: enforcing medical treatment to keep a person alive

Introduction

In order to introduce the main problems present in debates over the [mis]use of enforced medical treatment, I will begin my specific analysis of controversial cases involving this issue by focusing on Anorexia Nervosa (AN). The particularly controversial nature of the current way of dealing with AN stems from the question of whether or not we should consider anorexics autonomous enough to refuse medical treatment, given that AN is generally classified as a mental disorder. In this chapter I will more closely consider this approach, attempting to establish whether or not AN can be classified as a mental illness. Further, that being the case, I will ask to what extent this aspect can undermine the patient's competence when reaching decisions over the acceptance or refusal of naso-gastric treatment. Before moving into the philosophical sphere of the discussion, however, a more accurate examination must be carried out of how and in which ways this epidemic condition affects its sufferers.

Conclusion

In the course of this second chapter we have moved the analysis of the notion of autonomy in bioethical cases from a more theoretical discussion towards a more empirical, fact-based approach. More specifically, our focus has turned to controversial cases of enforced naso-gastric treatment in AN, developing further -and in greater contextual depth- the concepts of competence, autonomy and mental illness relevant to all of the cases considered in this work. Through an investigation that has brought to the fore the medical peculiarity of ED -and more specifically AN- when evaluated in terms of autonomy and competence, it has been pointed out that patients suffering from AN cannot be so easily separated from their illness as can those undergoing most other medical procedures. As shown with the arguments sustained and convincingly articulated by Giordano, we have shifted the debate over the legitimacy of enforced treatment in AN into a field that questioned more vigorously the limits that authority can (or should) have in relation to the values of individual. In doing so, we have reinforced the conviction that, while AN might not jeopardise the level of the patient's competence to such an extent that enforced treatment can take place under current legal and moral standards, the unacceptability of the refusal of treatment in AN is related to the impact that such an acknowledgement would have on wider societal values. The inconsistent use of autonomy as a

function of its political context will be further analysed in the next chapter.

CHAPTER 3

The Singleton case: enforcing medical treatment to put a person to death

Introduction

In the course of this chapter I will highlight a very controversial way of implementing the notion of autonomy as previously considered. In October 2003 the Supreme Court of the United States allowed Arkansas officials to force Charles Laverne Singleton, a schizophrenic prisoner convicted of murder, to take drugs that would render him sane enough to be executed. On January 6 2004 he was killed by lethal injection, raising many ethical questions. By reference to the Singleton case, this chapter will analyse in both moral and legal terms the controversial justifications of the enforced medical treatment of death-row inmates. I will begin by providing a description of the Singleton case, before highlighting the *prima facie* reasons for which this case is problematic and merits attention. Next, I will consider the justification of punishment in Western society and, in that context, the evolution of the notion of insanity in the assessment of criminal responsibility during the past two centuries, both in the US and the UK. In doing so, I will take into account the moral justification used to enforce treatment, looking at the conflict between the prisoner's right to treatment and his right to refuse medication where not justified by reasonably foreseeable positive outcomes for the individual. Finally, in contrast with some retributivist arguments in favour of enforced treatment to enable execution, I will propose a possible alternative, necessary if we are to consistently uphold the notion of autonomy. It will be argued that, within the current Anglo-American legal framework, in cases of capital punishment where the inmate was competent at the moment of sentencing, the death penalty should be carried out as normal, since the immutability of the sentence makes it impossible to justify enforced treatment in either legal or moral terms.

Conclusion

In conclusion, I have tried to show that within the current Anglo-American legal system the justification for forcible medical treatment of death-row inmates is difficult to defend on either moral or legal grounds. On the one hand, the impossibility of changing the prisoner's sentence makes it problematic to claim that involuntary drugging would represent a better option for him. On the other hand, the will to re-establish competence in the patient in order to ensure that his suffering is fully proportionate to the crime committed is difficult to accept.

To broaden the perspective on how we should deal with future cases similar to that of Singleton, a historical analysis of the idea of punishment in the Western tradition was taken into consideration, with a special emphasis on the evolution of the role of insanity in law. Subsequently, to highlight the diverse interpretations that insanity has had in different contexts, various landmark cases were analysed, giving rise to important questions about the consistent application of the principles and justifications underpinning their final judgements. In order to critique the current acceptance of the position evident in the Singleton case, I employed Barry Latzer's influential work, ultimately going beyond it in proposing an additional way out of the Singleton quandary.

In considering the three options suggested by Latzer, I agreed that option C would certainly be the most tempting from a “humanitarian” point of view as this option would have the law allow a possible readjustment of the death sentence after the enforced medical treatment (perhaps to lifelong imprisonment). In this way, the claim that enforced treatment serves the best interest of the patient could be justified, but this possibility naturally flags up the related issue of the inequality of treatment between prisoners who develop mental illness while on death row and those who do not. This would leave competent death-row inmates paradoxically hoping to develop some kind of mental illness in order to avoid capital punishment. As a result, I concluded that all three options, including the one (option A) used by Latzer to legitimise the legal and moral acceptability of the decision taken in the Singleton case, are indeed unsatisfactory on both moral and legal grounds.

Synthesising the analysis carried out in this chapter, I conclude that the only reason for such a treatment would be based on its political value, and the need to re-establish competence is only related to the desire of the relevant authorities not to allow a “soft message” to filter out from this case. I do not aim to question the acceptability of such a justification here, but it should become apparent at this stage that the enforcement of treatment has been based on fictional principles such as consideration of the prisoner's best interest. This distinction between the hidden message of the sentence and its “politically correct” version is what, in my opinion, makes its moral foundations inevitably unstable. As a result, to support this kind of approach in future cases similar to that of Singleton seems unjustifiable.

Rather, to avoid the continuation of such injustices in future, I suggested a new approach to cases resembling that of Singleton. I argued that it would be more coherent to hold that, once the agent is established to have been indisputably competent at the time of the death sentence, the

authorities should continue with the capital punishment procedure without any further hesitation related to the mental condition of the prisoner.

Alternatively –should this option be regarded as inhumane- we would have to find a new and more consistent way of dealing with cases involving autonomy and competence. Before doing that, however, in the next part of the thesis a contrasting use of enforced treatment will be considered: namely, its use to keep a person alive even when they are considered to be competent.

CHAPTER 4

The inconsistent use of autonomy: additional cases and doubts

Introduction

In order to substantiate the claim made in Chapter 3, the attention of this thesis will now shift towards a further two controversial cases relating to the [mis]use of the notion of autonomy. The first case relates to the forced treatment of a burns victim desirous of death, and despite dating back nearly three decades, it remains very topical, raising important questions pertinent to the current study. Indeed, the relevance of this case is such that it is amongst the most frequently examined in bioethics courses at US institutions.

The second case is rather more recent and focuses instead on the absence of forced treatment of a hunger striker in Italy. Given that this project aims to provide an accurate perspective of autonomy in Western contexts beyond strictly Anglo-American boundaries, the geopolitical element of this case constitutes an additional reason for including it in the work. Compared to other issues within the European Union (EU), hunger strikes (HS) have been of relatively minor importance. However, a recent case occurring in Italy has focused attention on the issue, underlining a general uncertainty within the EU with regards to the topic and suggesting that a more firm and consistent standpoint is required.

Amongst the member-countries of the EU there is still little clarity over the approach that the law should take towards respect for patient autonomy. There are a number of reasons for this: first of all, approaches to the notion of autonomy can differ substantially if tackled against a more secular or more religious backdrop. These differences are noticeable in many contexts, and they surely represent an interesting theme worthy of investigation. In this chapter, however, the focus will be directed instead towards a specific representative of the [more religious] southern member-states of the EU, namely Italy, and the application of the principle of autonomy within that context.

The reason why these two cases figure within the same chapter is simple: differently from the two situations considered previously, in both of the cases foregrounded in this chapter the presence of a mental illness is far from given. Nonetheless, strong claims are made as to the *temporary* competence of the people involved in them. What is particularly interesting when comparing these relatively similar circumstances is, once again, the absence of uniformity in

affirming when and how a person is autonomous –or, to use a term more strictly related to the psychiatric dimension: competent. The current analysis aims to raise additional doubts as to the appropriateness of disparities of treatment justified in the name of the same notion of autonomy.

Conclusion

In the course of this chapter, we have explored one case that might be considered a cornerstone of American bioethics, namely that of Dax Cowart. We studied once again questions regarding the objective applicability of the notion of autonomy in that context, affirming that –even if perhaps the best choice was made– the justification for enforced treatment lacked both moral and legal grounds within the current framework that allows a competent patient to refuse treatment. In order to stress further the inconsistency, we then contrasted the Dax case with the recent fatal HS of Sami Mbarka in Italy. To understand the complexity of the issues at stake in HS, a deeper analysis of the principles involved in its acceptance and permissibility was carried out, juxtaposing these principles the notion of sanctity of life and the moral duty of authorities to preserve it at all costs.

Through the use of different HS cases a broader perspective on the topic has been presented, stressing the differential application that the same principles have had in otherwise similar circumstances.

The argument of this chapter affirms that the reason for a differential prioritisation of certain principles over others in relatively similar contexts stems from the biopolitical value of each case. As a result, while the preservation of life would be the main priority of authorities in order to avoid the martyrdom of an individual (with all the destabilising implications that such an action would produce), in Mbarka's case the principle of autonomy was given primacy in deciding how to proceed in that context. The unconvincing supremacy of autonomy over sanctity of life (a particularly unusual value-hierarchy in Italy) leaves more than a little doubt over the authenticity of the authorities' decision. In addition, the rushed attempt to save Mbarka's life at the last moment, was symptomatic an inconsistent approach towards respecting the patient's desire or lack thereof to be rescued from certain death.

If future cases similar to that of Mbarka or Dax are to escape the biopolitical reading that accuses the relevant authorities of discriminatory behaviour, we should aim to arrive once and for all at standard positions with respect to HS, DF and forced treatment in general.

Throughout this chapter additional controversies related to the use of the notion of autonomy in bioethical and legal contexts have been highlighted. Especially towards the end of the chapter, a biopolitical reading of the facts has been foregrounded, affirming that certain distinctions in bioethics are in fact functional to their political value. The next chapter of the thesis will look to provide a deeper engagement with the biopolitical dimension linking all of the cases considered in this work.

CHAPTER 5

A more consistent notion of Autonomy in relation to refusal of treatment

Introduction

Having analysed different situations in which the notion of autonomy has been evoked as a justification for either forcibly treating a person or not depending on the specific circumstances, this thesis went on to present a biopolitical reading of such dynamics, affirming that the awareness of this uneven approach to such controversial cases should push society towards a change in its engagement with them.

In this final chapter, this work will provide a reformulation of autonomy that might function as a starting point for future policy, but –beyond that- as a new way of understanding and experiencing our interaction with the community around us, be it the impersonal relation with the state or -more importantly- the way we deal more directly with our fellow human beings.

To this end, I will first analyse the attitude that Western bioethicists have towards the implementation of the notion of autonomy in current debates relating to the cases described thus far. It will be shown that, at present, the precondition that allows for disparity of treatment is mostly based on the fiction that objectivity is achievable in such delicate cases, and that autonomy is its direct interpretation.

In criticising this dogmatic view I will look at Robert Burt's approach to autonomy: it needs to be thusly individual-centred because it is at one and the same time the result and the product of a cyclical dynamic present in (and vital to) our society. To escape this recursive process I will focus my attention on Onora O'Neill's work, adapting her concerns over the proper societal role of autonomy to cases of enforced treatment. The aim will be to suggest that O'Neill's innovative understanding of Kantian autonomy (*principled autonomy*) is a consistent means of escaping the unsatisfactorily uneven treatment of patients in relatively similar bioethical debates, including dramatic examples of overriding refusal of medical treatment by enforcement.

Conclusion

Certainly, the issues highlighted above constitute but part of the reason for which a reconfiguration of the concept of autonomy in biomedicine proves so difficult and so

unappealing to the authorities involved. More generally, such a change would reveal the numerous flaws dogging our current system. A partial solution, however, might be the reduction of the political power of doctors and -less directly at first- of authorities. The focus of my investigation has been the theoretical change that should be implemented *a priori* when considering the impact of autonomy in bioethical contexts. The solution for a more stable way of dealing with increasingly controversial cases where the interpretation of autonomy is at stake must be found at a more fundamental level than the current case-by-case approach allows. In the same way that informed consent gained relevance as a response to the atrocities of WWII and allowed humanity to progress, it is now time for autonomy to be reshaped in accordance to the evolution of medicine and technology. In conclusion, the consideration of O'Neill's version of Kantian autonomy through the use of arguments both supportive and critical of her suggested move towards *principled autonomy* provides a viable alternative in cases where notions of autonomy, consent and freedom are inconsistently adapted and applied to suit authorities rather than the best interests of the patient.

Conclusion

In conclusion, and in answer to the question raised by the title of this thesis, it appears clear that the line between being forced to be medically treated and being allowed to refuse medical treatment is indeed very thin. This already minimal distinction becomes even fuzzier when we bring into the picture the interdependent terms of freedom, consent and autonomy, themselves used interchangeably by various actors in bioethical and political contexts.

Informed consent -a notion introduced to Western bioethics with the successful aim of enhancing the rights of the patient vis-à-vis enforced treatment- presupposes a level of competence that will allow the individual to process the information provided and subsequently to make an autonomous decision regarding her treatment.

Competence (or capacity, technically speaking) is the term used to denote our level of autonomy, a concept near-impossible to grasp in an objective, “scientific” way. With the rise of this concept, patients were guaranteed more power over decisions concerning their health, and thus their freedom. In fact, a person has come to be allowed to exercise her freedom by autonomously choosing what to do with her life as long as she is deemed capable of making certain decisions, comply with certain tasks, and so forth. However, despite the undeniable improvements that this innovation has brought about, this thesis has considered various cases where the supposed objectivity that is at play in the evaluation of an individual’s level of competence is, in fact, deeply entrenched in politics.

In order to highlight the complexity of such interactions it was necessary to provide an analysis of the current role of autonomy in Western bioethics, developed at two parallel levels: on the one hand, there existed a need to foreground specific cases (with their unique problems) so as to give the critique a more “real-world” edge and to flag up inconsistencies in the application of autonomy in various Western contexts (US, UK and Italy), demonstrating the urgent need to find a more satisfactory way of dealing with similar cases in the future.

On the other hand, autonomy had to be considered in a broader sense that would not limit its analysis to the field of bioethics. Hence, in order to contextualise our critique of the current way of inconsistently applying the notion of autonomy, the first step taken by this work was to provide a general understanding of the historical development of autonomy within the Western tradition, as well as the standard approaches utilised to define it.

The initial premise of the thesis was that the advent of bioethics created new challenges for the way in which we understand and deal with autonomy. Since its incursion into philosophical debates, autonomy has needed constant readjustments in line with discussions over its appropriate definition and precise meaning, limits and value. In this process, the Anglo-American bioethical community has increasingly defined autonomy as a self-standing notion insulated from its political context, capable of being applied in different ways to relatively similar cases.

This thesis has examined the validity of such an approach by bringing to the fore bioethical cases that clearly highlight the fictional status of the Anglo-American notion of autonomy in a vacuum. I have argued that we live in an era where everything is fast-paced. Unavoidably, this also affects the approach that doctors have towards their patients, and so the room for dialogue has often been reduced. Yet, it is important to realise that some medical practices are already failing to comply with the current standard Western approach in bioethics that entails an unwavering application of the individual-centred notion of autonomy.

Such exceptions prove once more the subjugated status of bioethics in relation to its political context. We need to take this opportunity to pause and -using Onora O'Neill's reading of Kantian autonomy- reshape the notion of autonomy in bioethical contexts with the intention of producing positive effects also in the political arena.

In order to support this vision, the thesis followed a structure that, having broadly defined autonomy in bioethics and politics, began with the controversial adaptation of this concept to a specific case of refusal of life-saving medical treatment, before gradually expanding on doubts over the legitimacy of its [mis]use.

Hence, in Chapter 1, we described how autonomy is currently defined in Western bioethics by reference to the two mainstream authors central to discussions of autonomy: Kant and Mill. Subsequently, autonomy was considered through the eyes of more recent and contemporary positions so as to prepare the ground for a debate over the validity of certain interpretations in counter-position to others, and, most importantly of all, to analyse what might incline us to accept (if at all) its differential application in different contexts.

After this introduction to general understandings and applications of autonomy in political and bioethical contexts, in Chapter 2 the reader's attention was directed towards practical cases where controversy over how autonomy should be -and indeed is- applied to real life instances is most

tangible. The focus on cases of refusal of naso-gastric treatment by patients suffering from Anorexia Nervosa constituted the first of these examples because it forces us to question the objective validity of certain presumptions that Western society tends to have regarding issues of this kind. Beginning with these controversial cases also helped us point out a very important aspect that needs to be considered if a convincing assessment of the definition of competence is to be achieved.

The standard argument against compliance with the refusal of naso-gastric treatment is based on the idea that the autonomy of an individual should always be preserved and respected as long as it is possible to affirm that the individual is sufficiently competent to be deemed autonomous. The validity of this tautological approach, criticised thoroughly by the work of Giordano, was called into question, pointing out that we cannot categorically deny that, even if incompetent in relation to food, anorexics can still be considered competent enough to make decisions regarding their quality of life. Taking this position as reasonable, the justification for not accepting a refusal of treatment on the grounds of respecting an individual's autonomy becomes rather weak. Indeed, it becomes weaker still if this hesitancy on the part of authorities involved in the decision turns out to be related to a well-defined political message concerning the necessary preservation of life itself.

To establish the veracity of such a critical reading of cases of Anorexia Nervosa, in Chapter 3 I introduced an additional case where enforced treatment was instead carried out in order to allow a killing to take place. The Singleton case extended the reach of discussions relating to the distinction between the theoretical realm and the practical question of what society should do in order to preserve and encourage respect for the autonomy of the individual, including in its practical implementation in current law. The biased application of categorisations of mental illness raised further questions over the function of defining certain individuals as competent or not in relation to how this limits their potential for action within a given system. In stark contrast with the previously explored cases of Anorexia Nervosa, in fact, Singleton was forcibly treated against his will in order to enable his execution.

The “preservation of life at all costs” attitude applied in cases of Anorexia Nervosa (based on the dominant view in Western bioethics that the sanctity of life must be defended where possible), seemed to have dissipated so as to make room for the conflicting societal desire to ensure that the necessary continuity of retributivism would not be jeopardised by one exceptionally complicated case. In further analysing this disparity, it was suggested that the enforced treatment suffered by

Singleton could not be -and should not have been- justified even in conventional medical terms, as it appears obvious that curing someone only to kill him can hardly be described as “acting in his best interest” -the standard Hippocratic approach in Western medicine.

Having explored the above situations as examples of a strategic use of autonomy in relation to cases involving mental illness, I then went on to consider other cases where the incompetence of the patients was not inherently implied in the condition of the person in question. In Chapter 4, the Dax case and the Mbarka case brought to the fore some additional doubts over the real nature of uneven treatment on the part of the authorities in relatively similar bioethical cases. These doubts compounded concerns over the relationship between the misuse of autonomy in bioethical cases and their political dimensions.

Through an analysis of the unconvincing justification of enforced treatment (for Dax) and of its more or less complete absence (in the Mbarka case), Chapter 4 underlined more vehemently the need to understand these cases not as standalone exceptions to a well-functioning rule, but rather as signs of reinforcement of a certain biopolitical agenda.

Once again the crucial distinction between the two cases was related to the contrast between the disparity of application of the same notion: while for Dax the assessment of temporary incompetence led to a prolonged forced treatment, Mbarka’s enforced treatment was deliberately delayed on the grounds that respect for his autonomy had to be ensured, despite the fact that Hunger Strikes have been proved to produce temporary incompetence towards their final stages. I argued that, contrary to what in fact occurred, this awareness should have prompted authorities to apply the same care for Mbarka as they did in other circumstances (including Dax’s), a change in approach which did not occur because of the political salience of the case.

In comparing the two cases towards the end of the chapter, I utilised the work of Foucault to provide a biopolitical reading of the distinctions made in the two instances, affirming once again that it is impossible to ignore the political weight that each of the cases had in its specific context.

In this respect it should be clear to the reader that -as explained in the introduction- owing to the conscious choice of this work to utilise a number sources to support the critical reading of autonomy that it hopes to have achieved, it has been necessary to limit the depth with which these various positions have been explored.

The Foucauldian analysis employed here proceeded along the same lines. To be fair towards both his work and mine, it is important to understand that although my application of his theory refers to the discussion over autonomy with the intention of destabilising one of its interpretations in favour of another, I am aware that a more complete coverage of Foucault's point of view would have required discussion of power relations even in the new scenario.

In other words, differently from this thesis's objective, Foucault's critical analysis cannot be satisfied by the idea of principled autonomy as a concept free of power schemes and dynamics. I do not wish to contest the validity of such a view here, but it is important to acknowledge that I am aware of its existence and relevance.

Finally, in Chapter 5 the biopolitical critique was expanded through the complementary application of Robert Burt's work, underlining that the independent description of autonomy commonly recognised as an objective truth, is in fact fictional. This inaccurate definition of the way human beings interact with each other serves the specific political systems characteristic of Western society, requiring individuals independent in their choices to decide autonomously to consume whatever the market provides.

As reiterated throughout this work, the definition of autonomy within the current individual-centred system cannot provide reasonable grounds upon which to override refusal of treatment in cases of Anorexia Nervosa (as preferable to the political and medical authorities), instead favouring enforced treatment in other contexts where the ultimate aim is to *not* preserve a life, such as the Singleton case.

This acknowledgement should not prevent us from seeking more consistent alternative applications of the notion of autonomy. On the contrary, it is through this increased understanding that we should realise that autonomy could be used in a more consistent way if we were to apply the non-individualistic variant of it suggested by Onora O'Neill, which incorporates notions of duty and obligation towards the community. This may represent the best way of redefining the current Western approach to autonomy without falling into an inconsistent application of it: we are free to choose individualistically as long as our choice does not significantly affect society (be it the family, the state or the community). Where it does affect society, authority comes into play and reaffirms what can and cannot be tolerated.

Obviously, this restriction of one's freedom in favour of authority is already present in the

biopolitical dimension criticised throughout this work. My proposal for reducing the misuse of power is to enlarge the gamut of actors involved in decision-making so to ensure a more valuable form of dialogue, genuinely driven by the intention to serve the best interests of the person rather than a potentially malicious biopolitical agenda.

A practical outcome of this reform might be the rethinking of the role of authorities in relation to individual autonomy. The increase in respect for the patient's informed choice has undeniably been a positive achievement for the whole society, but it is perhaps time for us to state more clearly our need to reemphasise responsibility as suggested by O'Neill. The upshot of this would be the difficult acceptance of the legal implications of such an innovation in bioethics, which would in themselves mark the first reduction of the autonomy of the individual in the past twenty years. In fact, in relation to this point, we should not forget that Kant's and Mill's standard interpretations of autonomy would not leave much room for the permissibility of enforced treatment on a competent adult. As such, the person in question should be entitled to choose freely how to pursue her own understanding of happiness, which for anorexic patients might mean the end of the repetitive, demoralising procedure that naso-gastric treatment represents. The only way that a possible justification could be found -and this is indeed the method used in the current legislation to prevent the interruption of treatment- has to focus on Kant. That being the case, some of the less considered aspects of his view should be given greater relevance in order to rebalance the current bioethical crisis that we are faced with. Within the wide range of possible ways of reading Kant, the application of O'Neill's approach to cases of refusal of treatment in Anorexia Nervosa may be the only way that will finally allow us to escape the unsatisfactory application of Categorical Imperatives currently favoured by our society. If bioethics is willing to keep on using the term "autonomy" without inconsistency, substantial changes will have to be made to its interpretation.

Having acknowledged this link, I then suggested that O'Neill's approach to autonomy also reduces the "inconsistency-gap", such a remedy to current disparities of treatment could function as an inspiration to other fields as well.

To conclude, and even if unable to substantiate the practical outcomes of such a suggestion in this instance, I believe that, in more practical terms, that Italy could represent an ideal state in which to implement this new less exclusively individual-centred version of autonomy.

If we consider the fact that the Italian context (unlike the Anglo-American tradition) has never

made such a neat switch towards that unquestioned prioritisation of the individual-centred variant of autonomy described in this thesis, we could hardly disagree that this aspect (presupposing agreement on the validity and necessity of a change in approach regarding autonomy) has created the perfect conditions for Italy to represent an example of how Western bioethical debates could be reshaped.

Going back to the critique considered in Chapter 1, where Bruce Jennings argued against O'Neill's suggestion that a detachment from the individual-centred form of autonomy is deeply unrealistic given its deep embeddedness in American society, we could affirm that by the same logic Italian society represents a far more conducive context in which to put into practice the concept of *principled autonomy*. Given that Italy is a liberal country that has never quite embraced the variant of autonomy criticised in this thesis, it remains in the advantageous position of not being destined to follow the same path towards the structural injustices manifest in other contexts, injustices bound to degenerate if not properly tackled, as evidenced by the unacceptable, politically driven resolution of the Mbarka case.