

Autonomy in Bioethics

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Acknowledgments

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Mariangela Giovanzanti

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Il saggio finale si propone l'obiettivo di analizzare le varie concezioni di autonomia dei pazienti in relazione al livello e verità che ricevono durante e prima il trattamento medico che ricevono, e come questi due concetti siano collegati.

Nella storia della pratica medica, dire la verità interamente ad un paziente non è una pratica diffusa. Solo negli ultimi anni, istanze che richiedono procedure analoghe al consenso informato, sono state adottate. Le motivazioni che hanno spinto a questa conversione sono molteplici, tra le quali sicuramente vi è un aspetto legato alla responsabilità legale dei medici e degli infermieri, ma secondo alcuni degli autori che ho preso in esame, la responsabilità è da attribuire all'importanza che ha acquisito il concetto di autonomia dell'agente in bioetica, nell'ultima decade.

Il concetto di autonomia in bioetica è di difficile declinazione, dato che l'autonomia è un concetto nato in un contesto politico nell'antica Grecia; autonomia significa infatti, legge auto-conferita, quindi la capacità di ognuno di autoregolarsi; questo tipo di regole sono regole morali, la parola autonomia quindi è una parola che si riferisce alla sfera morale dell'individuo.

L'applicazione del concetto in bioetica è un uso relativamente nuovo; il concetto necessita quindi di diverse specificazioni e contestualizzazioni che sono l'oggetto dello studio degli autori che ho preso in esame.

La declinazione del concetto nell'ambito scientifico della medicina implica che vengano poste delle caratterizzazioni alle modalità di applicazione; il concetto di autonomia in sé per sé è un concetto estremamente olistico e politico.

In generale, infatti, "l'errore" commesso dagli autori è un errore di contesto; gli autori tendono ad applicare le categorie politiche del concetto di autonomia al contesto della bioetica per intero. L'approccio che personalmente difendo è quello contestuale. L'applicazione del concetto in bioetica implica quindi, l'incorporazione del metodo sperimentale nell'analisi del concetto stesso e l'analisi di casi specifici.

La relazione biunivoca tra il concetto di autonomia ed il concetto di rivelazione della verità risulta quindi problematico sotto diversi punti di vista.

Durante la storia della pratica medica, non era stata mai sollevata fino alla metà dello scorso secolo, la necessità di formulare una lista di diritti della scienza medica, la disciplina della bioetica.

Beauchamp e Childress, nel loro "I quattro principi della scienza biomedica" dispiegano questa lista completa ma non comprensiva di quattro principi; beneficenza, non-maleficenza, giustizia ed autonomia. Nelle prime edizioni del libro i quattro principi erano elencati e spiegati in questo ordine; nella quinta edizione gli autori specificano che il valore dell'autonomia è quello al quale si deve guardare con più riguardo. La motivazione, ovviamente, è il fatto che la teoria bioetica in quel periodo si stava concentrando sulla materia del mantenimento della autonomia del paziente nei confronti degli specialisti della medicina. Tra i diritti del malato quindi, emerge prorompentemente il diritto ad un giusto trattamento morale oltre meramente il diritto

alla “cura” medica e quindi all’erogazione di un “giusto” servizio. La giustizia morale del medico quindi passa in secondo piano; il medico come agente morale passa in secondo piano. Il paziente al contrario arriva a essere paritetico a livello morale rispetto al professionista medico: la sua pariteticità morale risulta quindi in una maggiore richiesta di considerazione della propria integrità di agente.

I quattro principi forniscono una guida utile per individuare i diritti del malato e i doveri del medico nell'operare; il giuramento di Ippocrate è sicuramente contenuto ed aggiornato nei quattro principi; beneficiabilità e non-maleficienza possono essere riassunti nel diritto al mantenimento e miglioramento della salute; giustizia è il principio secondo il quale, il trattamento di cui si ha bisogno debba essere somministrato, senza discriminazioni; il principio di autonomia implica il mantenimento ed aumento della capacità di libero arbitrio dei pazienti durante il rapporto con i medici e durante la cura. L'appello al principio di autonomia è una risposta allo spopolare nella storia e nel mondo, del modello di cura paternalistica; prima della lista di Beauchamp e Childress, i medici dovevano fare il bene dei pazienti e i pazienti dovevano fidarsi ciecamente dei medici. Questo tipo di pratica nonostante sia ancora maggioritaria nel mondo, ad oggi è guardata con molto dispetto nell'occidente individualista e cultore del libero arbitrio.

Porre l'attenzione sul principio di autonomia invece che su quello di beneficiabilità implica automaticamente porre l'accento sul soggetto paziente e sulla sua futura capacità di azione invece che sui benefici che la terapia gli arreca.

I problemi che l'approccio principlistico ha sono molteplici; per prima cosa esso non prende in esame le possibili differenze culturali; il secondo problema è che non vi è una chiara gerarchia di applicazione dei principi in caso essi siano in conflitto anche solo temporaneamente; il terzo problema è che la lista non è neanche lontanamente comprensiva e completa.

Uno dei massimi filosofi degli ultimi decenni, Gerald Dworkin, scrive un saggio intitolato “Teoria e Pratica dell'Autonomia” alla fine degli anni 80. Nella sua opera egli fornisce una definizione di autonomia che può essere utilizzata ampiamente data la sua versatilità ovviamente è anche la sua stessa debolezza dato che una definizione versatile è spesso incompleta o generica. La definizione da lui fornita è la seguente: “L'autonomia è una capacità di secondo ordine di riflettere criticamente sulle preferenze e i desideri di primo ordine, e l'abilità o di identificarsi con essi o di cambiarli in vista di un più alto ordine di preferenze e di valori. Esercitando questa capacità definiamo la nostra stessa natura, diamo significato e coerenza alle nostre vite e ci prendiamo la responsabilità delle persone che siamo e diventeremo¹”. Questa definizione presenta diversi problemi, come già menzionato precedentemente; la sua applicazione in bioetica, essendo la definizione così nebulosa, potrebbe comportare anche un atteggiamento paternalistico o quantomeno leggermente paternalistico da parte dei dottori.

¹ Dworkin, Cambridge, 1988.

La concezione di autonomia di Onora O'Neill, nel suo "Autonomia e Fiducia in Bioetica"² è più analitica e tende ad evitare i problemi che storicamente hanno caratterizzato la definizione dell'autonomia. I più eminenti tentativi della filosofia moderna sono quelli di Mill e Kant. Il primo da una spiegazione fenomenica o naturalistica dell'autonomia, l'altro invece basa il concetto di autonomia nella cornice dei diritti umani.

Le concezioni di Mill sono intuitive e la divisione che egli opera è funzionale; l'autonomia naturalisticamente giustificata è quella che viene conferita agli uomini in quanto naturalmente dotati di libero arbitrio; l'autonomia fenomenica invece si manifesta quando un soggetto compie un atto autonomo affermando la sua individualità. La concezione di Kant, basata sui diritti umani invece, è una concezione che basa nell'esistenza della morale individuale l'esistenza dell'autonomia; se un soggetto è in grado di pensare moralmente, quell'individuo deve quindi essere autonomo. Uno dei problemi di questo tipo di approccio al concetto è che ammettendo la coincidenza tra autonomia morale e fisica, si esclude che chiunque non goda della libertà e quindi dell'autonomia, non possa godere dell'autonomia morale richiesta, o addirittura della capacità morale stessa.

Il più grande problema, che si trasforma in una incongruenza se preso in esame a fondo, è il legame tra sviluppo dell'autonomia e rivelazione della verità, anche nelle tesi della O'Neill.

Chiunque può decidere di essere a conoscenza o meno di un fatto pur mantenendo, anzi esercitando la sua autonomia; al contrario una persona che non conosce la verità su un determinato aspetto della realtà può agire autonomamente.

In più l'impiego della nozione di autonomia in maniera assoluta tende a svalutare valori come la fiducia, che al contrario, sono fondanti nelle relazioni interpersonali e nello sviluppo dell'autonomia dei soggetti.

Dopo aver analizzato le diverse fallacie dei vari approcci degli autori presi in esame, e dopo aver enumerato numerosi esempi, la conclusione alla quale giungo alla fine della tesi è quella che il protagonismo del principio di autonomia dovrebbe essere soppiantato dalla superiorità del principio di beneficenza. Il principio di beneficenza, infatti, è il principio che deve sottendere la pratica stessa della disciplina medica. Il giuramento ippocratico già contiene la centralità dell'argomento. Tuttavia, non è un ritorno alle origini ciò che auspico, ma una rivalutazione delle priorità che la medicina ed i medici dovrebbero avere.

Rivelare la verità a tutti i costi ad un paziente può essere un atto non meramente controproducente ma addirittura doloroso: la verità non deve al contrario diventare uno strumento da manipolare a proprio piacimento in modo da circuire le volontà del paziente da parte del medico. Tuttavia il valore della verità rivelata si può quantificare solamente se viene valutato il miglioramento della condizione del paziente e la sua disposizione d'animo. La verità in sé non ha un valore liberatorio ed autonomizzante nel caso della medicina; ci sono casi in cui la rivelazione della verità è addirittura deleteria per la cura per paziente o nel meglio dei casi è inutile. Se un malato terminale viene informato o no della sua condizione di vita fa poca differenza per la sua autonomia nel lungo termine. Sarebbe anche interessante vedere in che modo rappresenterebbe una

² O'Neill, Cambridge, 2002.

violazione dei diritti il fatto che la verità venisse rivelata prima ai parenti piuttosto che al malato stesso e che siano loro a decidere. Al contrario se sapessimo che il malato terminale in questione vuole compiere un viaggio in Africa e che ha spettato tutta la vita per fare questo viaggio, forse il valore dell'atto di rivelare la verità cambia sostanzialmente.

Al contrario, se si è a conoscenza che il paziente in questione è una persona particolarmente fragile psicologicamente, sembra intuitivo pensare che non si rende certo necessario far presente la possibilità di un eventuale sintomo di una malattia letale; questo è uno dei casi dove il principio di beneficiabilità deve soverchiare quello del rivelare la verità per mantenere la salute del paziente ed anche la sua futura autonomia. Se infatti si causa un grande stress emotivo ad un individuo la sua capacità di riprendersi da una malattia potrebbe diventare ancora più ridotta.

Il fattore psicologico è quello più importante in una serie di malattie e rivelare la verità non può essere deleterio a tal punto da peggiorare la condizione del paziente.

La conclusione del saggio si può sintetizzare in un approccio più relazionale alle questioni di autonomia in scienza biomedica. L'autonomia va contestualizzata in modo da poter delegare una parte di essa per mantenere un certo livello di protezione nei confronti di soggetti vulnerabili come chi sta subendo una condizione di malattia, quindi intrinsecamente di stress psicologico.

La verità è un fattore importantissimo del rapporto dottore-paziente; un paziente deve avere la certezza che il medico gli stia dicendo quantomeno una quantità rilevante di verità. La verità è la base della fiducia tra medico e paziente. Quello che accade tra paziente e dottore, è una cessione di un certo livello di autonomia per acquisire un maggiore livello di benessere; tutto ciò avviene se il paziente decide di affidarsi alle cure del medico.

Non vi è nulla di innaturale o errato in questa pratica, dato che ha tenuto in piedi la scienza della medicina per millenni.

Introduction

The problem of autonomy: Overall, in the 20th century, in the practice of medical ethics there has been a proportional incorporation of the preponderance of the values of the patients with regard to the treatment received. Only within a society in which all the individuals are held as equals (at least theoretically) can envisage the space for individual rights within an intrinsically paternalistic practice such as medicine. The relevance given to individual rights has led automatically to the incorporation of several moral stances into

different disciplines that had not, in their history, any moral foundation in themselves. Medicine, for example has always been thought as a discipline, which implied two different agents that were clearly on a different moral stance: the patient, not aware of their condition; and the doctor, with their intention being the wellbeing of the patient as a whole.³

In this context then, the need for some kind of clarification has emerged during the 20th century. In the history of medicine of this past century there has been an increase overall in the law system concerning the directives to be given after a patient's death as well as laws concerning the visits of relatives at the hospital or the disposal of internal organs of an individual made from their relatives.

This may appear like a deformation of the principle of the habeas corpus: this paper aims to demonstrate that these procedures like informed consent (which can be regarded as the most relevant amongst all of them) are in fact an extension of the principle of personal autonomy instead of being a reduction of individual deliberation.

In the context of the new rights emerged in medical ethics during the last thirty years, there can be seen the striking necessity to embed new individual and personal rights in contexts which are not favorable to the development of personality or individuality in a sheer sense. Medicine has always been seen as totally subject to the discretion of the physician's opinion; no one should have dared to question the nature of the physician's actions and thus the extent to which a physician can influence the life and the choices of a patient. No one especially would have questioned to give an objective opinion about the amount of information that a doctor shall display, as default, to any given patient, regardless of the characteristics of the patient in itself and regardless of the prejudices of the doctor concerning the situation of the patient.

In general, several authors in the past decades have stated their take on the role of the medical practice with regards to patients within an ethical framework.

The function of medical care has been put most succinctly by Charles Fried⁴. The doctor's prime and basic function is not so much the prevention of death (which is not in his power) but the preservation of life capacities for the realization of a reasonable, realistic life plan. As in peculiar cases, conflicts arise and decisions must be made between various capacities and between the risk of death and the impairment of various capacities, the doctor must see himself as the servant, not of life in the abstract, but of life plans of his patients. This kind of accounts of autonomy help explain why medical decisions are a matter of autonomy and not of technical expertise.

To suppose that they are matters of expertise, decisions to be taken by experts, represents a denial of autonomy that is particularly damaging for two reasons. First, one's body is irreplaceable and inescapable; in addition,

³ For the sake of simplicity, I will not consider, during my paper, the possibility that a doctor uses their paternalistic actions in order to create damage to a patient or to the society as a whole.

⁴ Fried, "An Anatomy of Values: Problems of Personal and Social Choice", Harvard University Press, 1971

because my body is me, failure to respect my wishes concerning my body is a particularly insulting denial of autonomy. The coincidence of autonomy of the body with autonomy of the subject needs to be underlined, since the agency is within the body and the body consists of agency, we can never split the reasoning made for the autonomy of the agency and that of the body of the agent. Decisions that seem to have only theoretical implications for subjects, such as treatment or truth, eventually have effects on the body integrity of the agent and thus autonomy is both of the body and of the soul, in the sense that doctors, not only have the responsibility towards the morality of patients but also towards their future bodily possibilities.

In a very famous book, O'Neill⁵ draws the origins of the modern Kantian approach in bioethics (and in several other social sciences, especially about any political consideration). O'Neill argues for a principled account of autonomy of the patient with regards to the physicians' decisions: what O'Neill argues is, that there is an intrinsic moral characteristic of the patient as an agent that binds the doctor to consider him as a moral equal, and thus to entitle them with full autonomy as an agent, even within a situation of distress.

Chapter 1

Autonomy and Trust in Bioethics

1.1. O'Neill's approach to autonomy and criticisms

In her book, "Autonomy and Trust in Bioethics" O'Neill gives different accounts of autonomy, tracing back to the father of the different approaches. She analyses the birth of the concept in political philosophy and then

⁵O'Neill, "Autonomy and Trust in Bioethics" Cambridge, 2002.

applies the categories to bioethics. She first states that the concept of individual autonomy is a fairly new concept since the great ancient Greek philosophers, creators of all the possible philosophical categories, did not consider this concept as a necessary one, since autonomy was only conceived as the autonomy of a city with respect to other cities, so autonomy was relational and collective in its definition, not ontological and individual, like the modern political philosophers conceived⁶. This reveals to be a crucial point even for what regard the concept in bioethical field, as I will argue further in this chapter.

In her book she further analyses the different approaches according to which the relationship between autonomy and trust have been used in history of the bioethical field; the parts taken into account in my analysis are merely the first ones, where there can be found her statement of principles and her theoretical approach, and thus the criticisms moved have to be addressed only to the parts just mentioned. Her analysis goes further in the explanation of the different approaches to autonomy undertaken in the different bioethical field, like genetic manipulation and abortion. Issues concerning informed consent and thus autonomy of the patients in these particular instances are not the object of my research and of my thesis statement.

1.2 Individual autonomy in a naturalistic setting: Mill

According to O'Neill, individual autonomy can be considered as the means through which men contribute to improvement of societal well-being⁷. So autonomy is a functional attribute; not really applicable in the case of bioethics, since it is not that enables the well-being of the patient, but informed action, thus through the doctors' interference, which could be seen eventually as a violation of autonomous action. She then further analyses the contemporary account of autonomy in bioethics; choosing is autonomous when the first-order desires that it satisfies are backed by second-order desires. In this case even informed consent to which a patient arrives paternalistically induced by a doctor would respect the requirements of an autonomous act; the doctor makes the agent act in accordance to its first order desires, get healed, through the way she considers best, thought her cure. The account of autonomy that should be taken into account in medical ethics are the ones that regard the procedures through which a patient reaches a decision, not the enabling nature of the decision itself.

1.2.1 Definition of consent according to O'Neill

⁶O'Neill, Cambridge, 2002.

⁷O'Neill, Cambridge, 2002.

The concept of consent goes hand in hand with the concept of patient autonomy and its implication with a notion of trust towards the physician; O'Neill thus analyses the concept of consent and its requirements in order to preserve the patients' autonomy. She states that at best we may hope that consent that is given by patients in the maturity of their faculties, although not based on full information, will be based on a reasonably honest and not radically or materially incomplete accounts of intended treatment, and that patients understand these accounts and their more central implications and consequences to a reasonable degree⁸.

This notion of consent may seem intuitive but theoretically it grounds consent on the potential lack of full information, and if we are to intend autonomous action and action performed on full information in order to properly affect future circumstances, then the grounding of consent are very different from the grounding of autonomy and thus autonomy itself cannot be based on consent given by patients.

O' Neill is here proposing a threshold model of autonomous action in order to escape all the theoretical failures that the theorists of autonomy as a concept requiring certain tenets have fallen into. According to her then, an action is autonomous if it does meet the requirements of a non-autonomous act; if it had the basic features of an autonomous action and can be adduced to the will or first-order or second-order desires of the individual. Acknowledging to an extent the implicit limitation contained in this definition or in this theoretical account, she then tries to found autonomy in the concepts of human rights as obligatory.

According to Simone Weil⁹, she states, “The notion of obligations comes before that of rights, which is subordinate and relative to the former. A right is not effectual by itself, but only in relation to the obligation to which it corresponds, the effective exercise of a right springing not from the individual who possesses it, but from other men who consider themselves as being under a certain obligation towards him.”

The doctor through the obligation to give information about the procedure to be executed can perform the exercise of a patient's autonomy. Thus, informed consent is the enabling act of autonomy performed by a doctor. If patient autonomy is labelled as a negative obligation of the patient, it is much easier to ground its practice in medical care. If we try to define the features of autonomous actions and frame it within informed consent the account we are giving will always be incomplete. Here is her theoretical point: “Individual autonomy fits cozily into views that give priority to rights, and some hope to justify rights solely or largely on the basis of their supposed contribution to individual autonomy. However, when we talk about obligations we immediately have to focus on relationships between obligation bearers and right holders, between obligation bearers and beneficiaries. We do not know what our obligations are if we cannot specify to whom we owe them (or, in the case of obligations without specified claimants, what types of action are needed if they are to

⁸O'Neill, Cambridge, 2002.

⁹As reported in O'Neill, Cambridge, 2002.

be well carried out). Agents may have some obligations to all others, such as obligations not to torture or not to enslave; other obligations to individual persons, such as obligations to keep promises to those to whom they were made; and other obligations to persons who are not individuated but merely specified by one or another description – for example, to other road users, to nearby others in present danger, to neighbors or colleagues.”

1.3 Principled approach to autonomy: Kant

She then proceeds spelling out the second main approach to autonomy present in modern philosophy; implicitly the Kantian one, here explained is the one at the basis of the previously stated conception of human rights as obligations. “Kantian autonomy is manifested in a life in which duties are met, in which there is respect for others and their rights, rather than in a life liberated from all bonds.¹⁰”. The reason to hold a principled view of autonomy is that: “The minimal interpretation of individual autonomy as informed consent provides plausible but very incomplete ethical guidance; more robust interpretations of individual autonomy offer more complete but very implausible ethical guidance. Nor, as disputes about ‘reproductive autonomy’ show, can ethical issues be well resolved merely by limiting the pursuit of individual autonomy by a requirement not to harm¹¹.” Principled autonomy requires us to act in a way that is fair to the autonomy of all and in a way that can represent a universal code of conduct.

1.4 The limits of truth telling in bioethics and its relationship to patient’s autonomy

1.4.1 Definition of autonomy by Gerald Dworkin; The weak theory of autonomy

Gerald Dworkin, at the beginning of his book, “The theory and Practice of Autonomy” states a comprehensive but not too broad definition of autonomy that can be used instrumentally on many grounds. The definition he gives is the following: “Autonomy is a second-order capacity to reflect critically upon one's first-order preferences and desires, and the ability either to identify with these or to change them in light of higher-order preferences and values. By exercising such a capacity we define our nature, give meaning and coherence to

¹⁰O'Neill, Cambridge, 2002.

¹¹O'Neill, Cambridge, 2002.

our lives, and take responsibility for the kind of person we are.”¹² Due to its versatility, this notion of autonomy will be referred as “weak”.

This first part of my argument has been directed to showing that a weak notion of autonomy is connected to central parts of ethical reasoning. It is also linked to important metaphysical and attitudinal features of moral agents. Our idea of who we are, of our self-identity, is linked to our ability to find and refine ourselves. The exercise of the capacity of autonomy is what makes my life mine. Moreover, if I am to recognize others as equal persons, there is a requirement that I give weight to the way they define and value the world in deciding how I should act. One argument, then, for the value of autonomy is that we have a conception of persons that is deeply rooted in our world view, and that this conception is worthy of respect and admiration. A full analysis of why the capacity for autonomy is worthy of respect would require a general theory of value (worth) and of morality (respect). I have neither but I shall make some comments about the value of autonomy.

1.4.2. Instrumental and intrinsic value of autonomy

To give a complete account of autonomy has been a never-ending task, which eventually has come to the level of understanding by philosophers and experts, that it does require a division of the concept. The two basic divisions of the concept have been the instrumental explanation of autonomy and the intrinsic value of autonomy.

On instrumental grounds, being able to shape one's own choices and values makes it more likely that one's life will be satisfying than if others, even benevolent others, do the shaping. Nevertheless, there is value connected with being self-determining that is not a matter either of bringing about good results or the pleasures of the process itself¹³.

This is the intrinsic desirability of exercising the capacity for self-determination. We desire to be recognized by others as the kind of creature capable of determining our own destiny. Our own sense of self-respect is tied to the respect of others - and this is not just a matter of psychology. Second, notions of creativity, of risk-taking, of adherence to principle, of responsibility are all linked conceptually to the possibility of autonomous action.

These desirable features of a good life are not possible (logically) for non-autonomous creatures.

In general, autonomy is linked to activity, to making rather than being, to those higher forms of consciousness that are distinctive of human potential.

¹²Dworkin, "The Theory and Practice of Autonomy" Cambridge, 1988

¹³O'Neill, Cambridge, 2002

Chapter 2

The taxonomy of autonomy: specification of the concept in the bioethical field

2.1 Definition of a general approach to autonomy in bioethics

In order to give a precise account of autonomy in the bioethical context, there needs to be some specification of the concept of autonomy and which conception of it must one take into account.

Too often, indeed, autonomy in bioethics is equated to full information and thus to the preservation of a patient's autonomy goes hand in hand with full disclosure of the medical truth by the doctor. The process of disclosure of full information is thus the trickiest one. Consider a case in which two twins want to be tested for a reproductive genetic disease. Twin A gets the results and thus chooses their life partner as one who does not have the recessive gene of their disease and thus assures that their sons will not have that specific condition. The result of the genetic testing of twin B get mixed up, so they receives a negative result: they are thus convinced that they does not have the abovementioned condition and thus their life choices accordingly. Let us suppose the twins never spoke to each other about the test for a random reason. Could we infer in this case that twin B is not acting autonomously, even though the direction in which they are

operating is clearly misled by a false information? The autonomy of the subject does not depend on the quality of the specific information they receive (and thus on the degrees of truth contained in that specific information), but on the relevance that is given to that information in one's life choices and on the degree to which the information acquired affects future choices. Consider another case: two twins are informed that they may have inherited a gene that brings along a disease. Twin C decides to get tested and finds that they has the gene of that disease and gets preventive care; the preventive care they receive give unexpected side effects, since it is an experimental cure, and they dies from the side effects of the cure, the cure to a disease that they had not contracted yet. Twin D decides not to be tested after their sibling's experience; they eventually contracts the disease and are cured and their life is saved. Which of the two choices was more autonomy enabling? In the short term, the disclosure of the truth to twin C gives them the chance to get preventive care, which was supposed to be lifesaving; their choice was thus autonomy enabling in the short term.

The choice made by twin D was not autonomy enabling in the short term, on the other hand, they choose not to know, conventionally thus, performing an act which is autonomy inhibiting. In the long term though, their decision appears to be unwillingly autonomy enabling since this decision to postpone their autonomous decision reveals to be a life-saving strategy. They did not purposely avoid the experimental preventive cure because they rationally considered the risks of a non-fully-tested medicine; they merely decides not to know if one day they may die from one specific disease they were genetically prone to. Twin D non-commitment to truth thus is the best autonomy enhancing decision in the long term.

These two cases clearly define the framework of the need for a deep reflection on the link between full information and autonomy, which has been utterly stressed and taken as a given in modern bioethical philosophy. They demonstrate that truth telling to a patient is not always autonomy enabling. The ultimate choice remains on the subject in the second case, since they choose not to know for their own psychological wellbeing. In the first case they choose according to a casual mistake; a wrong response to an exam can cause the failure to produce a right diagnosis and thus the impossibility of a subject to truly act within the boundaries of full information. In this case, the subject act in the context of false information and thus presumes that their choices are autonomous even though they are based on false beliefs.

The relational value of autonomy is the one that needs to be safeguarded in the bioethical field; a patient needs to be autonomous not compared to the objectivity of the truth, but by the selection of truth provided to them by the doctor. This account of patient autonomy appears to be rather "spiritual" and "idealistic" since a patient can be autonomous with regards to a physicians proposed cure, only if the patient has a good level of education in general, a deep knowledge of his medical condition and the cold mind necessary to perform rational choices in a context that may be cause of distress and depression.

Consider an even more controversial case concerning patient's autonomy. A future mother is told that her

child may bear a genetic malformation after an echography is performed. Further exams shall be undertaken in order to ascertain the condition, but those exam would take a long time and she would not be allowed to legally get an abortion after the exams are done. After proper medical counseling, she decides to abort nevertheless. The autopsy done on the fetus reveals that the malformation was a false positive and that the fetus was completely healthy. The full disclosure of information here corresponds to the full voicing of a doubt that reveals to be unfounded. Is this kind of disclosure mandatory? Wouldn't the doctor better ascertain their opinion before talking and causing distress to a future mother?

Truth disclosure is a hard task to be undertaken by a health professional since most of the time truth is not revealed as it is but rather as it is thought to be. The commitment to full disclosure of the truth is a commitment to full opinion disclosure and opinion is clearly subjective while medical truth is not. Patient's actions must be guided by the analysis of medical truth not of mere medical opinion. If the mere medical opinion is sufficient to an influence in patient behavior, we are for sure witnessing a paternalistic action performed by the medical professional.

2.2 Defense of the principle of autonomy within truth telling; updating autonomy

Practically the approach and analysis that O'Neill decides to use is not apt to succeed since she tries to base autonomy only within human rights. If analyzing only human rights, indeed, the main issue is that there is no objective way to prove that human rights are natural and thus obligatory. If the obligation related to the inexpugnable existence of human rights cannot be stated, then, human rights are not to be stated objectively as obligatory and then her whole argument is fallacious as all the other authors that she criticizes.

The main way to ascertain the existence of an objective right to autonomy is then to base it within human actions and not human principles; autonomy of agents can then be verified within a given set of agents and recipients of principled action. The attempt that I am about to delineate is related to the set of action pertaining the sphere of medicine, of medical action and of truth telling performed in that context; all the other sets of actions need to be verified specifically. In this frame then the three sets of different actions that are envisaged are the omission of information (involuntary), the voluntary hiding of the truth, the contraction of the principle (the one that shall be regarded as superior (like beneficence)), and lastly obviously a lie. Only if these actions are analyzed in different context then, there can be framed a difference between all the cases in which truth telling makes sense and the other cases in which truth telling does not make sense, in general, since a different principle within medical ethics must be applied.

The only case that is concerned with the principle of truth telling in bioethics is the case pertaining the sentient

and willing non-disclosure of the truth by the doctor.

2.3 Breaking the link between autonomous action and truth telling: not always lack of full information means lack of autonomy

Other accounts of the wrong parallelism made between autonomy and truth telling in medical ethics are represented by the fact that absolute truth telling is far from possible in the actual sense of the phrase. As will be discussed, the expectations on doctors' behavior is more ideal than realizable. The tradition of trusting your physician to do your own good dates back in bioethics. Patients do expect doctors to tell them the truth in order to be able to fully trust them and set their own lives in the doctors' hands. There is a never-ending tension between the traditional approach to medical care and the modern tradition, which underlines the patients' right to know all the truth that regards his condition.

The most common case, which is easily brought up in our mind is the end of life case, strictly speaking the one concerning consent to a potentially meaningless treatment. In this case the dying patient should be informed that the treatment she is about to undertake will not in any case improve his condition but will only ease his departure from life. In these cases, it is cogent to comply with consent rules, since no patient can thoroughly consent to a treatment if she is not informed of her condition.

My position is that, if the information on the patients' own condition does not make her epistemically better off about possibilities of improvement, consent must not be achieved and the doctor is thus allowed to act paternalistically towards the patient according to the doctors' conception of the patient good. The conception of the good of one subject from a subject, which by structure hold a higher epistemic standing, is to be held as sufficient to provide information to the patient. In the case of dying patient, we can never talk about competent patients signing full consent. The doctor must choose for them instead. Among the circumstances that make the release of proper consent impossible, there surely is the condition of being a dying patient. This brings about the issue: is being truthful the only enabling act towards the fulfillment of the requirements of full patient autonomy and thus is truth the highest value to be preserved in the doctor-patient relationship? The answer according to a utilitarian point of view is no: the highest value to be preserved is the beneficence principle between doctors and patients: any action performed by any doctor must increase the wellbeing of the patient, even disclosing the truth must have an instrumental value and it is not an absolute value in itself if disclosing the truth causes despair or extreme distress in a patient. What is to be absolutely safeguarded is the trust that the patient has that the actions performed by the doctor will increase the patients' good and her overall condition. The patient does not have any right to hold the doctor accountable for the provision of the

blunt truth. Informed consent is only a procedure in order to delay penal responsibility, not an epistemic justification of the doctors' actions; the need to ensure consent to a procedure is due merely to the attribution of the undertaking of risks from the patients, it is not at all bound to the procedure of truth provision. We know for sure, in fact, that the submission of truth to a distressed patient could cause even further distress to the subject and thus there are for sure bioethical cases in which the truth may be withheld from the patients in order to provide them with the good they are entitled to given their condition as patients.

Furthermore, there are cases in medicine in which the truth needs to be withheld for good reasons; think about medical trials and experimentation. The patient which is being delivered the placebo cannot know if the treatment she is receiving is effective or not and is not entitled to know if her clinical indicators have been modified during the treatment. This is surely a case in which the patient has to withhold her right to know the truth and trust that the doctor will tell her if there is something utterly going wrong or a drastic measure to be undertaken. The patient cannot hold her right to the whole management of the true information otherwise, she would be denied the treatment. This is a situation, which is considered unusual only within the context of medicine: in any other social context, we are not distressed at all, if we are brought about to the realization that truth is always thoroughly avoided. Absolute blunt truth in most of the cases, including the medical ones annihilates any kind of hope and thus truth itself must be regarded in its instrumental value much more than in its absolute value. The doctors, due to their epistemic privilege towards their patient do hold the right to withhold the whole truth to patient if this disclosure of truth negatively affects the patients' overall beneficence. Doctors hold this right since they own the right to be subjective truth holder agents. No doctor withholds the whole objective truth; they own their own subjective perception of it. In addition, if they do not own the objective truth they are certainly not bound to disclose it as being the objective truth. So doctors being subject to a degree of uncertainty regarding the objective truth are not bound to full disclosure of truth. This can be considered to a certain extent a detailed version of the uncertainty objection to truth telling provided by Higgs ("Truth Telling" Oxford Handbook of Bioethics, 2009). His account though if far more factual since it concerns the actual amount of information possessed by the doctor as inferior to the ones present in objective reality of the patients' condition: it is a quantitative objection, while mine is a qualitative objection to the conception of objective truth concerning the impossibility to perceive objectivity with a structurally subjective mind. Therefore, the inevitable human bound to subjectivity allows the doctor to withhold a certain amount of information, consciously or unconsciously concerning a given patient condition perceived in the present.

2.4 Incorporation of Beauchamp and Childress beneficence principle as overarching over autonomy

All these practical reasons represent the justification for the fact that the authors of the four bioethics' principles, Beauchamp and Childress have listed the principles in a certain order, and beneficence and non-maleficence come before respect for autonomy, and thus truth telling in a blunt, sometimes enabling manner. One of the most redundant cases cited when trying to state beneficence over truth telling is the paradoxical case in which a patient does not want to receive a certain medical information. In that case, the good of the patient, so not receiving the information must be respected. There is no harm made if a consent not-to-know is stipulated between the two subjects. The principle of beneficence also bounds a doctor towards a vitally important side information that he may come to know while enquiring on a condition on which the patient has consented not to know about. Consider if searching for cancer cells a doctor finds a bronchitis, he will of course reveal it to the patient even though he may have asked not to know of his cancer condition. Therefore, the principle of beneficence becomes in this way the disclosure of vital, potentially life-saving information. Autonomy cannot be considered a sufficient tenet to which one practitioner should abide if the thing, which is at stake, is the life of the patient itself. Autonomy can be an overarching principle in moral stances, not in practical ones. If autonomy is to be literally and always respected, the proper cure of a subject cannot take place completely and quickly enough; and timing is crucial in medicine.

Furthermore, the principle of autonomy as stated by Beauchamp and Childress also includes a certain degree of authorized paternalism, which implicitly states the supremacy of beneficence over autonomy; according to them, the principle of autonomy is made up of five tenets:

1. Tell the truth
2. Respect the privacy of others
3. Protect confidential information
4. Obtain consent for intervention over patients
5. When asked, help others make important decisions.

This last point justifies medical paternalism when the patient delegates to the doctor the choice for his best health. Seen on from a literal point of view this is a delegation of autonomous action properly stated. The principle of autonomy stated by the authors is indeed a negative principle; it consists of "not depriving a subject of its own freedom" and it does not have all the theoretically enabling characteristics of formal full autonomy.

Chapter 3

Omission of autonomy of reason and of the individual in itself; one and only entity

The principle of autonomy with which O'Neill has dealt so far can be reduced to the principle of autonomy of the individual action of to the principle of autonomy of the will of a given agent. O'Neill does not deal with this crucial difference, and this ultimately results as the failure of her approach to the subject.

If individual autonomy is to be dealt holistically then, the definition of O'Neill can be said to be fallacious; if autonomy of the will of a given agent is to be safeguarded, on the other hand, then only, the author can be taken literally. The crucial difference between autonomy as a political concept and autonomy as a functional concept is totally disregarded by O'Neill and thus there comes with it the need to distinguish the concept as a political concept from the operational value of autonomy.

The concept of autonomy is a dynamic and complex concept and thus autonomy is to be dealt with on a phenomenological account, at least in the case of bioethics. Whenever the concept of autonomy is mentioned in bioethics, the concept has to be considered on a case based account and thus, the comprehensive account attempted by O'Neill results as fallacious. If autonomy is dealt with on a merely operational ground then, the framework given by Beauchamp and Childress is the best available one. On that ground, autonomy has to be seen as a function of the principle of beneficence, as mentioned in the utterly famous "four principles" of bioethical actions.

Now that I have delineated clearly the theoretical criticisms moved to O'Neill, I will proceed to enumerate the objective criticisms to be moved as well.

3.1 O'Neill's approach; criticisms

The inexpressible link between patient's autonomy and truth disclosure is shadowed by the benefit of the doubt that should be considered in a physician's pronouncement. The weaker the physiological condition of the patient (due to diverse factors as distress or education level) the tinier is the possibility to grasp the full capability to fail and subjectivity of a doctor's diagnosis.

In her book "Autonomy and Trust in Bioethics" O'Neill stresses several aspects of autonomy and its implications with truth telling trying to face all the criticisms. She starts with a definition of autonomy that can be used validly in this field.

Autonomy has had various definition; the field in which there is more consent on the definition of autonomy is bioethics. A complete definition of autonomy may be "a matter of independence or at least as a capacity for independent decisions and actions". This conception of autonomy has several features; it is a relational definition in the sense that it is considered as autonomy from something; it is selective, since individuals can be autonomous on certain fields but not on others; it is a graduated definition since, individuals may have a greater or smaller degree of independence.

The link between autonomy and independence brings about matters of trust between individuals; when individuals are independent; they value their own opinion a lot and are self-centered and not inclined to trust others. If the main aspect of autonomy that is stressed is independence, its incompatibility with trust comes up crystal clear. Individual autonomy cannot be seen merely in terms of independent action from other; if we only take this stance in consideration, autonomy can have also trivial value indeed.

Among the various accounts of autonomy that have been given by several authors, the one which is more fitting to the bioethical discipline is the one which individuates a minimal account of autonomy of the patients in the practice of informed consent. Informed consent though, has several problems within itself since the circumstances and state of mind of the patient that signs it may invalidate the practice in itself. Consider for example the distress to which a patient is exposed when she comes to know about her serious health condition. On the other hand, though, it is hard to define the boundaries of validity of informed consent since in the majority of the cases the patients that sign an informed consent do not have the medical knowledge or the rational capacity to analyze and take into account viable alternatives to the treatment proposed by the physician; once again in this case we are face with a "forced" or at least "driven" consensus, and thus, even if the practice is perfectly respected formally, the actual autonomy of the patient is not only not respected, but indeed limited.

There is though, a more modern account of informed consent and its relationship to autonomy; the consumer choice approach. It evaluates informed consent in a libertarian fashion and thus it becomes merely a tool for offering "necessary and sufficient ethical justification".

In the conclusion of O'Neill's argument, the triumph of informed consent aver other bioethical principles is "an unsustainable illusion". Her proposal is to take into account a Kantian rather than a Millian conception

of autonomy. This change of ideological paternity implies a shift from the personal account of autonomy as individual independence and thus individualism to a more ancient and relational account of autonomy. In the Kantian, sense autonomy needs to be address as the capacity of agents to provide themselves with moral principles upon which actions have to be performed. The Kantian approach to autonomy regards rights as obligations and requirements towards others rather than ideal or aspiration. In this sense, the right to autonomy is the right to act within a framework of moral imperatives that assure everyone with their rights. The difference between the two conceptions can be seen as follows: the Kantian approach points out the practical reason of the principle of autonomy, while the Millian approach is more of a general appeal to the idea of personal autonomy without a specific normative framework. The first one is the one that justifies a political change towards a more democratic regime, in search for a conception of autonomy that implies widespread respect for every subject's autonomy; the second one could also exist within an aristocratic regime, since it does not entail the equality on moral grounds on the entire subject who are to exercise autonomy.

In short Kant's approach to autonomy is non-relational; Kantian autonomy is manifested in a life in which duties are met in which there is the respect for others and their rights rather than in an individual life liberated by all bonds; it is non graduated, since it does not accept any kind of lesser degree of right since it is inalienable and framed in a context of categorical imperative; it is not a form of self-expression since autonomy is not seen as an attribute of a subject who can act without boundaries; it is seen as the identification of morality as self-law. Autonomy, from the Greek *autos* and *nomos* literally translated as self-law but self-moral law.

In this framework, a principled autonomy driven action is an action whose principle could be adopted by all other agents.

Given this specific account of autonomy, that stresses the relational side of the concept, it becomes redundant to state the supremacy of the principle of autonomy in biomedical ethics. This principle is indeed important but its implications are contained in the principles of justice and beneficence if we are to consider as biomedical principles the ones listed by Beauchamp and Childress.

The principle of justice towards a patient implies the respect of their relational autonomy, but it does not bound the doctor to the full disclosure of a truth, which is not relevant, like the cases above. The principle of justice implies that the patient be treated justly and justly may also mean that some truth may be concealed from them of that some truth may be distilled and revealed in a second moment after some more testing. Treating a patient according to a principle of justice then, requires a full-fledged respect for their psychological integrity. When you picture the professional relationship between a psychologist and their patient, for example, the physicians may be aware of conditions that are threatening the current health of the subject or may have come to know some aspects of their condition that are extremely private and may be

disastrous if revealed all of the sudden to the patient. Imagine, in this context, the case of the schizophrenic patient who undergoes regular psychotherapy. The patient may be convinced that certain areas of their life are haunted by a spirit, or may personify an inhuman object or may hear voices that reveal information that do not exist; these features are constitutive of the patient's reality and crumbling these certainties would be of great impact to the life of the subject. A patient like this cannot be inflicted forceful truth telling in the name of the respect of a close-minded medical ethics. In a case like the aforementioned, the beneficence and the justice principle impose to the professional to withdraw from truth telling and on the contrary to secure justice and the preservation of the fragile harmony of the patients' mind.

3.2 Why the problem is not solved: the futility of the distinction between autonomy and truth telling in the function of the good of the patient

Limits to truth telling in bioethics do exist and have been outlined. What is not to endeavor is to define the significance of truth telling and the reason why truth telling have been so overarching over the principle of beneficence and autonomy in medical practice. The ultimate resort to truth telling is, in fact, an erroneous statement, since the prerogatives it has are included in the concept of full respect of autonomy.

This is the main reason why the theoretical approach of O'Neill, in order to become more objective, has become more fallacious. Since the introduction that the author does to the weight of truth telling tends to "weight" on her argument even more that how much paternalism would weight on an argument made in favor of the predominance of beneficence of the patient in the medical field, the momentousness is, in the end, just a heavier burden.

3.3 The ultimate limits of truth telling in bioethics and its relationship to patient's autonomy

Gerald Dworkin, at the beginning of his book, "The Theory and Practice of Autonomy,"¹⁴ states a comprehensive but not too broad definition of autonomy that can be used instrumentally on many grounds. The definition he gives is the following:

Autonomy is a second-order capacity to reflect critically upon one's first-order preferences and

¹⁴ Dworkin, Cambridge, 1988

desires, and the ability either to identify with these or to change them in light of higher-order preferences and values. By exercising such a capacity, we define our nature, give meaning and coherence to our lives, and take responsibility for the kind of person we are.¹⁵

Due to its versatility, this notion of autonomy will be referred to as “weak”.

The first part of my argument has aimed to show that a weak notion of autonomy be connected to central parts of ethical reasoning. It is also linked to important metaphysical and attitudinal features of moral agents. Our idea, of who we are, our self-identity, is linked to our ability to find and refine ourselves. The exercise of the capacity of autonomy is what makes my life mine. If I am to recognize others as equal persons, there is a requirement that I give weight to the way they define and value the world in deciding how I should act. One argument, then, for the value of autonomy is that we have a conception of persons that is deeply rooted in our worldview, and that this conception is worthy of respect and admiration. A full analysis of why the capacity for autonomy is worthy of respect would require a general theory of value (worth) and of morality (Respect). I have neither but I shall make some comments about the value of autonomy.

3.4 Instrumental and intrinsic value of autonomy

To give a complete account of autonomy has been a never-ending task, which eventually has come to the level of understanding by philosophers and experts, that it does require a division of the concept. The two basic divisions of the concept have been the instrumental explanation of autonomy and the intrinsic value of autonomy.

On instrumental grounds, being able to shape one's own choices and values makes it more likely that one's life will be satisfying than if others, even benevolent others, do the shaping. However, there is value connected with self-determination that is not a matter either of bringing about good results or the pleasures of the process itself¹⁶.

This is the intrinsic desirability of exercising the capacity for self-determination. We desire to be recognized by others as the kind of creature capable of determining our own destiny. Our own sense of self-respect is tied

¹⁵Dworkin, Cambridge, 1988

¹⁶O'Neill, Cambridge, 2002

to the respect of others – and this is not just a matter of psychology. Second, notions of creativity, of risk-taking, of adherence to principle, of responsibility are all linked conceptually to the possibility of autonomous action.

These desirable features of a good life are not possible (logically) for non-autonomous creatures. In general, autonomy is linked to activity, to making rather than being, to those higher forms of consciousness that are distinctive of human potential.

3.5 Role of autonomy in health care

Charles Fried has put the function of medical care most succinctly. The doctor's prime and basic function is not so much the prevention of death (which is not in his power) but the preservation of life capacities for the realization of a reasonable, realistic life plan. When conflicts arise and decisions must be made between various capacities and between the risk of death and the impairment of various capacities, the doctor must see himself as the servant, not of life in the abstract, but of life plans of his patients. This kind of account of autonomy helps explain why medical decisions are a matter of autonomy and not of technical expertise.

To suppose that they are matters of expertise, decisions to be taken by experts, represents a denial of autonomy that is particularly damaging for two reasons. First, one's body is irreplaceable and inescapable; in addition, because my body is me, failure to respect my wishes concerning my body is a particularly insulting denial of autonomy. The coincidence of autonomy of the body with autonomy of the subject needs to be underlined, since the agency is within the body and the body consists of agency, we can never split the reasoning made for the autonomy of the agency and that of the body of the agent. Decisions that seem to have only theoretical implications for subjects, such as treatment or truth, eventually have effects on the body integrity of the agent and thus autonomy is both of the body and of the soul, in the sense that doctors not only have the responsibility towards the morality of patients but also towards their future bodily possibilities.

3.5.1 The two sides of the coin: waiver and therapeutic privilege

Therapeutic privilege may be conceived as the opposite side of the coin of waiver. In waiver, the patient decides that certain information will be harmful or cause distress and that he would be better off not having it. In therapeutic privilege, the doctor decides that securing informed consent would be harmful to the patient and that he is better off not having it.¹⁷ It is a privilege because it allows exemption from a duty; it is therapeutic because it is intended for the benefit of the patient. This exception raises the clearest conflict between the value of autonomy and what is considered to be the best interest of the patient. Using the framework of seeking general agreement by all the relevant parties, the issue becomes what powers to ignore our consent we can agree to grant health professionals when they claim that seeking such consent would be harmful to us. It is useful to consider a spectrum of positions ranging from weak to strong powers.

The weakest position is that autonomy may be denied only in the interests of the autonomy of the patient. This exception would allow a doctor to withhold information only when a special harm would (be likely to) follow from the disclosure of information, namely, that harm that would result in the patient's being unable or being less able to make an autonomous decision about his treatment.

The stronger version is the view that failure to disclose was always justified because "risk disclosure poses such a threat of detriment to the patient as to become unfeasible or contraindicated from a medical point of view."¹⁸ Here, one can distinguish two ways in which such information might be contraindicated. In one case, the disclosure has a direct harmful effect on the emotional state of the patient. He is distraught when he learns he has cancer or Hodgkin's disease. In the other kind of case, the harm operates primarily via its effect on the treatment decision made by the patient. The doctor believes that disclosure would lead the patient to choose a form of treatment that is not optimal or perhaps even detrimental. Note that this is not equivalent to asserting the patient cannot make a rational or autonomous decision; it is a claim that the decision is wrong or mistaken.

Conclusion

¹⁷Bortolotti, "The Relative importance of Undesirable Truths", *Medical Healthcare and Philosophy*, 2013

¹⁸Sep, van Osch, van Vliet, Smets, Bensing, "The power of clinicians "affective communication": How reassurance about non-abandonment can reduce patients' psychological arousal and increase information recall in bad news consultations. An experimental study using analogue patients" *Patient Education and Counseling*, Elsevier, Utrecht, 2013

This work was an attempt to comprehend so many and complex theoretical tenets that it not surprising it probably did not complete its own task.

The first chapter was focused on the relationship between autonomy and truth telling according to the different possible accounts of autonomy that can be used in the bioethical context.

The second chapter focused on the book by O'Neill and after critical analysis, I confronted some of the concepts presented by Beauchamp and Childress and their relationship to O'Neill's work.

The third chapter summarized the different approaches to autonomy in bioethics and then applies the original paradigm I invented in order to deal with the concept of autonomy in bioethics.

For sure, again, the work could have been much more in depth and much longer, but for the purposes of this thesis, I decided to break down the subject in a linear and intuitive way. The theoretical references to Mill and Kant were necessary in order to ground the concept of autonomy at least in modern philosophy, but a deeper analysis surely could have included medieval and ancient accounts of autonomy much more in depth.

As far as what concerns O'Neill's book, it was only partially taken into account, since all the other issues like, reproductive autonomy and genetic engineering that she deals with, would have required another thesis.

Same discourse is valid for Dworkin; his book is a philosophical account of autonomy as a theoretical and a practical matter, while I took into account merely the theoretical work of synthesis he operated.

I can thus assure that all the analysis and selection was made with the intent of safeguarding the original meaning the author wanted to confer to their book and that any imprecision is due to a lack of comprehension rather than a lack of integrity.

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