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An open future? The principle of autonomy within medical 'codes of conduct' versus the heteronomy effects of predictive medicine

Review Article

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Abstract: Traditionally, the average code of conduct within Western health care starts from the autonomy of the patient. In addition, medicine today is 'evidence based' and the patient is an 'informed consent'. Yet, the individual autonomy of the patient in health care is not simply enhancing today. Quite a few fundamental changes have and are currently at work within health care, which I will summarize here with the paradigm of *predictive medicine*. One of the characteristics of this paradigm is the increase of medical consults which are not autonomously chosen by an individual. For reasons of public health and diminishing of health risks or for reasons of prevention, on one hand we are dealing with ethical codes centered around the autonomy of patients and the face-to-face relations with health care workers, on the other, we are dealing with a society that takes an increasingly greater medical initiatives. Therefore, the question arises if predictive medicine confronts us with the limits of an ethical code as we know it today. Is there not an urgent need for a *political* code of conduct in health care?

Keywords: *Predictive medicine • Autonomy • Code of conduct • Heteronomy • Ethical • Political*

1. Introduction

Traditionally, the average code of conduct within Western health care starts from the autonomy of the patient, be it the code of physicians, physical therapists or nurses. Medicine today is 'evidence based' and patients must give 'informed consent'. The decision of having any medical treatment or therapy and at what time and place rests on the patient. The individual in medical or clinical practices possess rights and autonomy. In general, the face-to-face relation between health care workers and patients is properly defined to ensure the right application of ethical and juridical principles foreseen within hospitals and medical practices, which are made concrete into transparent codes of conduct, ethical codes or declarations of the rights of patients.

It might be too hasty to conclude that individual autonomy of patients in health care in general is simply enhancing today. Quite a few fundamental changes have and are currently at work within health care, which I will summarize here with the paradigm of *predictive medicine* [1]. The basics of this paradigm are to be found in the fact that a lot a medical consults are no longer the result of an individual initiative, but of an institutional or governmental incentive or requirement: screenings, preventive check-ups, and so on. Predictive medicine as such is not new, but its impact is rapidly increasing today, mostly due to the use and spread of (genetic) screenings. This predictive medicine may possibly have positive effects on the side of autonomy, but also heteronymous effects concerning the position of the individual patient: what about your autonomy if you know at twenty that you will die at forty, to put it somewhat bluntly? While codes of conduct are rather focused on concrete clinical practices and put the accent on the increasing autonomy of the patient, it is the question how to handle this heteronomy originated by health practices with a rather public character? Because of the focus on autonomy in the ethical discussion of medical

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practices, a lot of problems keep out of sight, problems which are most prominent in health care today, mostly caused by the effects of predictive medicine.

In this article, I try to make a sketch of these questions. First of all, I argued that the individual autonomy of the patient is still one of the main focuses of contemporary health care practices. Secondly, I will go deeper into the paradigm of predictive medicine and the changes it can cause within the relation between health care and its 'autonomous' patients. And thirdly, I try to outline how future (ethical) codes of conduct can possibly include a new (political) framework for this changed relation.

2. Individual autonomy

Many codes of conduct for medical professions start from an autonomous point of view when they talk about the patient. In other words, they prioritize the individual relation between a patient and a health care worker or other face-to-face relations within everyday health care. Autonomy seems to be a key term in many of the codes and often it is health care's gateway to show in the patient: "Over the last few decades, it has been widely acknowledged in literature that autonomy has been given substantial priority over the other ethical principles, including beneficence", as King and Moulton write in their interesting survey on the legal foundations of informed consent. Their resolute conclusion is: "Patient autonomy is the most well-known principle of medical ethics". They define patient autonomy "as the ethical principle that preserves an individual's ability to make and carry out informed decisions that arise from unbiased and thoughtful deliberation" [2].

In bioethical discussions in general, an important role is provided for autonomy, as one of the well-known 'four principles of ethics' [3]. The other three principles are *non-maleficence* (the duty not to harm others), *beneficence* (the duty to do well to others) and *justice* [4]. Autonomy is unmistakably a core principle of common sense medical ethics and is mostly translated into concrete ethical guidelines of a code of conduct for health care workers. To give only a few examples of codes of conduct or ethical codes where autonomy is *a* or even *the* central value: the first of the four principles of 'The code of the Australian Physiotherapy Association' from 2001 is "APA members shall respect the autonomy of the individual" (http://apa.advsol.com.au/staticcontent/download/APACodeOfConduct.pdf); in the 'World Medical Association International Code of Medical Ethics', the physician has to "respect a competent patient's right to accept or refuse treatment" (http://www.wma.net/e/policy/c8.htm) [5]. Obviously, the famous principle of 'informed consent' is one of the most palpable outcomes of this focus on autonomy in contemporary clinical practices. This principle or procedure starts from the fact that every medical treatment is preceded by information towards the patient, after which he or she (dis-)agrees with the treatment. An informed patient is meant to make an informed choice. It is "the process by which a fully informed patient can participate in choices about his health care. It originates from the legal and ethical right the patient has to direct what happens to his body and from the ethical duty of the physician to involve the patient in his health care" [6]. In general and theoretically, autonomy and informed consent consequently start from a rather ideal(istic) point of view: a medical treatment is voluntary, chosen by an autonomous patient on a rational and informed basis, and the medical information the subject acquires, enhances its autonomy. The individual subject of informed consent is a steady, self-transparent and rational decision maker that is able to consider all alternatives, after which he makes the decision which suits him most.

This is of course not everyday medical reality and I think we are all aware of it, certainly if one thinks of the huge amount of literature during the last decade that sketches the nuances, difficulties and dilemmas with this principle [7]. This is not the point here. Rather, the question is how the ethical principles operative within medical practice, do not cover medical reality and thus no longer fit as the basis to talk about health care today. Because autonomy is a steady principle within clinical practices, contemporary health care does not necessary enhance our autonomy. I will not develop an empirically more realistic and nuanced concept of autonomy – has this already not been done over and over again? [8] If the ethical objective of autonomy is *unable* to cover the whole of medical practices today, is the question then not how to deal with *heteronomy* in contemporary health care? Even if the objective is and stays 'as much autonomy as possible', what about the fact that more and more medical interventions are not chosen by the individual? What if the potential consequences of predictive medicine will enhance heteronomy rather than autonomy? Should we then not be interested in working out a broader framework within health care which can cope this inevitable heteronomy? Do we not need far more than an ethical 'code of conduct'? Although I am not pleading for heteronomy within health care, I want to ask how we can deal with it, now and in the nearby future.

3. Predictive medicine

Let us start from the actuality within medical practices. In their study *Health politics in a culture of risk* [9], the authors mention two main aspects which they believe to be serious threats to the autonomy of the patient:

1. Threats by powers which can force someone to act undesirably: emotions of the subject, institution, authorities, etcetera.
2. Determinism within human life itself: genetic failure, muscle diseases or other inherited diseases do increasingly limit the individual autonomy as well.

One of most striking illustrations of this threat to the patient's autonomy, is the increase of medical consults which are not autonomously chosen by an individual, but are rather the initiative of schools, factories, institutions or other instances which oblige their employees or students to undergo a medical check-up or screening. A lot of these preventive consults or screenings are prearranged without the manifestation of a medical symptom. They do have a rather public character and differ from the classic relationship between a medicine and a patient. Even if the patient is well-informed, it is not simply up to him to decide whether he needs or wants a medical consult or not. The situation is for more complex than that. What if an even well chosen consult results in the detection of diseases, take for instance a tumor or a cancer? This can determine the rest of a lifetime of the individual and that of his family; it can lead to compulsory discharge at his work, and so on. In short, this *predictive medicine* sheds a new light on the question of autonomy. Of course, predictive medicine can enhance autonomy by informing the patient of the conditions that may affect his future freedom or well-being. It can provide the individual with information that will rationally lead to voluntarily chosen medical treatments or changes in behavior so that illness or disability outcomes that could compromise a person's autonomy can be avoided. On the other hand, not every illness has to do with behavior and not every medical consult is chosen by an individual. Although I can be perfectly informed, since we are dealing with predictions not every outcome can be assured – it is possible that I might get sick but I could also stay healthy – and not every illness can be avoided with a change in lifestyle. Does the fact that I have this information improve my autonomy or does it put me in a situation of heteronomy? If the rise of predictive medicine results in more and more screenings, more individuals will be confronted with ambiguous situations. This is what predictive medicine is also about. If medical consults shift more and more in this direction, do we not need then a thorough consideration upon the question: if autonomy is the objective, do we really want this evolution or not? This consideration can not be framed within an ethical code of conduct which is focused on a one to one relationship between a doctor and a patient; it needs a broader framework to think about it.

3.1. Definition and main characteristics

What is the case? A common twentieth century medical scene started from an individual symptom by which he enters health care to cure the symptom. If there were no symptoms, you were healthy. Health was defined as the absence of physical symptoms. You were healthy, until the opposite was proven. Of course, medical check-ups in school do exist from the beginning of twentieth century and predictive medicine is not a new specialism of our time, rather is it a bundle of new medical practices and relationships within health care: "Predictive medicine implies a significant shift in the societal roles of medicine and in the significance of medicine in the practice of citizenship" [10].

Today, slowly but steadily, a new concept of health and illness has infiltrated the medical scene. More than ever, we are concerned with our health and thus consequently, more than ever we are unhealthy. This paradox seems surprising but is in fact a logic consequence of our concern: the more you want to be sure about your health, the more risks you might be aware of and thus need to be examined in order to be 'sure' you are indeed healthy. Today, medicine is risk-oriented, rather than symptom-oriented.

While I defined health in twentieth century as the absence of symptoms, nowadays it is the other way round: being ill stands for the absence of health. In other words, we are ill until the opposite is proven. By this, I mean that health is no longer the starting point, but on the contrary, the (future) possibility of having a disease. According to this definition, we are ill until we are 100% sure about the opposite. And because this is impossible, we are always in a situation of latent illness and the risks are lurking everywhere, all the time.

On top of that, the concept of illness has widened. Also not being fit, feeling a bit tired or depressed, is part of the condition of not being healthy, or more exactly, of not *feeling* healthy. For the reason we never feel healthy, we never *are* healthy because of the risk we might not be healthy. This risk-oriented medicine, this way of dealing with health and illness, is what I call here *predictive medicine*. Its three keywords are: risk, future and prediction:

- It is oriented at health *risks* and prevention and the search for possible future diseases of the patient, not at a diagnosis of present illness.
- The *initiative* of the medical treatment is no longer

in the hands of the individual, but in those of the 'theatre of institutions': governments, schools, companies, insurance companies, all of them send us to medical check-ups, preventive (genetic) screenings and tests. All this is needed to *predict* possible future diseases.

- Predictive medicine is thus rather *preventive* than curative. It is not a question of a diagnosis of symptoms and a curative therapy; it is all about prevention, advice how to live and eat healthily, to perform enough physical activity, and so on.

Predictive medicine is not exclusively to be identified with genetics. A lot of practices in society in general do have medical prognostic targets. Go to a supermarket and look around: innumerable products are promoted basically because of their healthy ingredients, be it to downsize our cholesterol, be it to upgrade our natural resistance. In the end – besides the fact that industries are trying to seduce us to consume their products [11] – it all comes down to reduce risks, to prevent someone from being ill, without symptoms being already manifestly present: "The types of medical technology that come into play in predictive medicine vary from techniques that detect risks in the body itself, and laboratory techniques to analyze body products, to societal techniques used to chart risks, such as registration, statistics and the dissemination of advice and information. In spite of their differences, all these techniques have in common that they are not primarily focused on diagnosis and treatment but on prognosis and prevention" [12]. The political arena and health insurance and private insurance companies are increasingly promoting mass sports, fitness and a healthy lifestyle. The list of reports, studies and campaigns from political governments in Western Europe, which aim to stimulate their citizens for physical activities and healthy food, is quite impressive. For instance, if we look at the Netherlands from the end of the sixties until now, many large scale campaigns have been funded by the national government [13]. Again, if I can change my lifestyle today in order not to get sick in the future, autonomy is of course enhanced. But if I am informed about a possible outcome of disease which is completely beyond my control, is then heteronomy not the case? Since autonomy does not only include self-determination, but also the value of an open future.

3.2. The contamination of autonomy

What is most striking about predictive medicine is the contamination of individual autonomy. Neither the initiative nor the decision or the future following the prognosis is simply in the hands of the individual subject. It is not just me who decides to visit a hospital or medical doctor. A 'third instance' invites me, offers me incentives or obliges me to enter the medical scene. A lot of contracts (*i.e.*, insurance, job) are only signed after medical tests, and this is certainly not only the case in top sports. With the test, an institution can evaluate the risk it takes by offering me a contract. Although it is my autonomous decision to agree with the test or not, in reality, the situation is far more complex and ambivalent.

In predictive medicine, the prognosis is all about prediction and susceptibility [14] which means there is no absolute guarantee of being ill or not. Prediction means susceptibility, which is hard to interpret and difficult to live with: I might get sick, but also not. The long interval between the prediction and the effective manifestation of a disease, is a hindrance for individual self-realization and personal happiness. How to go on with the idea that you might die of a grave disease within here and fifteen years? And how to live with it when there is even not an adequate therapy for it yet? [15].

Besides these difficulties, a lot of aspects of my personal life are involved: my job, my insurance, my mortgage, the future of my family. If my future employer demands a medical screening or even a brain scan as part of the application procedure, they might refuse me when an inherited failure is discovered. Or even if they only know about the results of a screening I voluntary approved of, the result can be a refusal to get insured or to obtain a loan.

What about my confrontation with the information resulting from the screenings? Information is not only a question of privacy, but also of how to deal with it as an individual. If a screening tells me that I suffer from a genetic deficiency which could cause physical disorder later on, how do I deal with this information I did not ask for? And how to handle information about a possible future disease for which there exists at the moment no adequate therapy? Is this not a situation of radical heteronomy? Yes, I can refuse information, but how to refuse to know something if I don't know the outlines or the subject of what I don't want to know? How to be autonomous when my future is no longer 'open', but determined by the threat of possible illness? Kruijf and Schreuder said: "[…] we should be more aware that autonomy has two sides. The autonomy principle does not only express the value of self-determination, but also the value of an open future. The emergence of predictive medicine compels us to give more weight to the concept of an open future. In predictive medicine, medical intervention, after all, is not only intervention within the body, but in what is. Perhaps. More vague but no less real. Namely, life-expectations or the future. In addition, those that carry out the interventions are not, in fact, only the doctors but a rather fairly diffuse network

of institutions of a less tangible and controllable nature" [16]. This loss of control causes anxiety and agitation, and it is not a coincidence that private companies providing in predictive medicine, trifle with these feelings. To give only one example: "Because…when you stop to think about it…in the future YOU are the one who will have to actually live with how you treat your body today. What you do today may mean the difference between being an 80-year-old in a wheelchair *or* on a tennis court" [17].

Though autonomy is at the heart of the contemporary ethical discourse on health care, the difficulties to make a medical reality of it today can better not be underestimated. As Boenink writes, thinking in terms of autonomy presupposes a ready-to-use technique and a patient which is able to evaluate the pros and cons, if they already are clear to him [18]. But when is this the case? Suppose I can decide autonomously for a screening, what if the test turns out that my children or a member of my family could have the same genetic inheritance? What about this situation? In my family, a nephew has an inherited form of retinopathy, and apparently he inherited it along the bloodline of my mother. The pain and the guilt this caused to my mother were enormous. She felt personally responsible (and thus guilty) for the disease of her grandson. Thinking about contemporary medical practices in terms of autonomy and informed consent falls short here, because the questions raised by predictive medicine do involve many other factors than knowledge, information or making a rational and deliberative decision [19]. Even if all of these conditions are fulfilled, heteronomy can still be the case because the future of my life and that of others is troubled. I can decide upon a consult, not upon the diagnosis. This is not new, but the specificity of predictive medicine, which the amount of uncertainty is far greater than the standard medical consult because the factor of prediction is more significant in this case. While an individual knows he might get sick in the near or far future, possibly no medical treatment can yet get started or even exist when he receives this information. Predictive medicine, far more than a classic medical consult, is all about these possibilities and uncertainties. If a patient is well informed about his uncertain future, the only thing he can do is thinking about his 'future self' and how he would deal with it, how he would live with it, while the evolution of the disease is beyond everyone's control. One could therefore paraphrase here the title of a book of moral philosopher Alasdair MacIntyre: *Whose autonomy? Which decision?* [20].

4. From ethics to politics

4.1. Medicine as a political question

As I argued, the impact of predictive medicine raises many questions towards the limits of the individual autonomy and the face-to-face relations within health care. Predictive medicine puts pressure on the principle of autonomy as the copestone of a right and just health care, and maneuvers medicine within a broader societal framework. Before we can go deeper into the question how to handle this relatively new situation, first of all we need to reflect on the consequences, the actual and potential impact, of predictive medicine on society in general. Since this is all about a broader framework which enters health care, it would be a mistake to limit ourselves to the question of autonomy and the debate in what way exactly autonomy falls short or not in very specific situations [21]. This debate is very interesting, but then we only ask ourselves how to improve the conditions for this autonomy in a very practical and applied way – this is of course a necessary question, but as such, insufficient to overview the whole of the field of problems. Again, it is not the question if procedures are respected and autonomy is guaranteed in clinical practices; rather are we confronted with a kind of medicine which might maneuver a lot of citizens in a situation of uncertainty and heteronomy. As Martin Heidegger wrote, the way you ask a question already determines what kind of answer you can give [23]. Now, if the 'heteronymous' factors at play in health care are not that much to be situated at an individual level, but at the level of society, then we have to change the register of our thinking. Then we have to leave the 'how' question – how to apply specific rules, how to fine tune autonomy, and so on – and go on with the 'whether' question – whether something would be like this or that.

While we must not forget that a lot of medical interventions are still on a curative basis – it is very hard to trace exact numbers or percentages here, at least in the countries I'm working at (Belgium and the Netherlands) –, it is obvious that at the level of society, the amount of preventive screenings have exploded during the last decade; not only the number of screenings or the factors which can be detected, but also the impact of it on health care in particular and society in general. As Rogowski writes in *Current impact of gene technology on healthcare. A map of economic assessments*: "Primarily for screening purposes yet infrequently also for predictive testing in symptomatic individuals, testing for genetic risk factors will be an increasing issue of interest in health care decision making" [22]. Also the World Medical Association is clear on this point: "The

identification of disease-related genes has led to an increase in the number of available genetic tests that detect disease or an individual's risk of disease. *As the number and types of such tests and the diseases they detect increases* […]" (my italics) [24]. And Norman Fost writes in 'Ethical implications of screening asymptotic individuals' that "health supervision and prevention have become a larger part of medical practice. Individual patients are routinely screened for hypertension, diabetes, and urinary tract infection. Mass screening of school children for intelligence, visual problems, and scoliosis are familiar activities" [25]. I could go on like this for quite a while but I think the point is clear: predictive medicine plays a substantial role in today's health care and in society in general.

Risk factors are indeed more and more on top of the medical agenda in contemporary society, but the question is if we can handle them from within the existing medical and ethical frameworks. In clinical medicine, the conditions for autonomy or informed consent are much easier to control and fulfill. As long as there is enough and transparent information, decisions are clearly made by the patients and they are prepared in a democratic way with the health care providers, the situation is well provided for. In predictive medicine, things are different. It is no longer a question of enough information, but also of the way this information is adequate. Given the susceptibility of the prediction and the uncertainty of the future, information can limit my autonomy in a fundamental way and it is very well possible that a prediction of an illness and the advice to change my life style, finally will have been incorrect or even superfluous, due to prospective breakthroughs in medical techniques. The estimation in what way the results of a screening do need a change of lifestyle, is for a layman rather hard to interpret. The patient is dependent on the evaluation of the specialist, and not of his own, autonomous judgment.

The question is thus not only if the prediction is trustworthy, 'evidence-based' or verifiable in a detailed manner. Medical insights evolve so rapidly that within a period of ten years, the advice could be totally different. The reflection on autonomy and how to apply it in a justifiable way, is therefore too narrow to face the problem. It is not simply about improving the decision procedures, although this is also urgent and necessary. What matters is a more broad and general perspective: what are the social and political consequences of predictive medicine and what is its impact on the autonomy of us all? How to organize a society in which more and more people are confronted with individually uncontrollable risks, with predictions and fundamental uncertainties about their future? How to deal with this heteronomy? Can ethical codes of conducts or the right application of procedures face these questions? Kruijf and Schroeder states: "The ethical problems of the culture of risk embodied in a non-symptom based medicine, need a political answer" [26].

4.2. The need for a political code of conduct

What is the situation today? For reasons of public health and diminishing of health risks or for reasons of prevention, on one hand we are dealing with ethical codes centered around the autonomy of patients and the face-to-face relations with health care workers, on the other, we are dealing with a society that takes an increasingly greater medical initiatives. Therefore, the question arises if predictive medicine confronts us with the limits of an ethical code as we know it today. Is there not an urgent need for a *political* code of conduct in health care?

This need is clearly argumented by Henn in *Kommunikation genetischer Risiken aus der Sicht der humangenetischen Beratung: Erfordernisse und Probleme* [27] for very specific cases. They warned us for the urgency by which a legislation for predictive genetic testing is needed, in order to ensure the clients' decision autonomy through adequately informed consent. As said, my concern is broader. Rather than to fine-tune the principle of autonomy, I want to point at the limits of autonomy and of ethical codes based upon it. While ethical codes are prominently present in health care, political codes seem to be absent or not yet fully debated. However, the advent of predictive medicine confronts us with questions that can not be dealt with as individual decisions or respect for autonomy.

Though his study is situated within the area of environmental studies, Craig Summers points at a sore point of ethical codes of conduct: "Codes at present tend to dwell on acts by individual perpetrators. They do not recognize professional contributions to social issues, or problems that are institutionalized in the day-to-day functioning of society such as health risks from environmental and industrial hazards". He continues: "Codes are relevant to social issues given the emphasis they place on human welfare. However, rather than recognizing the involvement of the profession itself in institutiona1ized social issues, the existing ethical standards tend to leave considerations of these issues out of the political and legislative process" [28].

Although generally codes focus on face-to-face relations, a societal perspective is needed. If today we are confronted with medical practices which are not limited to the individual, a code for these practices is necessary. If there are indeed health risks for a population as a whole – smoking, lifestyle, corpulence,

physical activity –, the instances which are authorized to draw medical conclusions and to set up practices and campaigns to prevent people from unhealthy behavior should also be subjected to guidelines and democratic control. Since the conclusions from these instances can lead to a situation where I can lose my right to get insured, where I am forced to undergo screenings or check-ups as a way of getting a job, health care is no longer a situation of an autonomous individual versus a health care worker. Though I may be well-informed, the unrestricted freedom to say yes or no is no longer guaranteed. My 'no' can be a synonym of 'no job' or 'no insurance' or 'no pay back' of hospital bills. Above that, the danger of intertwining of power between government, insurance companies and clinical practices is realistic. My autonomy can impossibly counterbalance the weight of these settled practices authorized by scientific rationality.

It is not only a matter of preventing the data of my medical check-up or screening from being accessible to other instances [29]; it is also a question of who decides on the basis of what. If not the judge but a diffuse network of particular instances can 'punish' me for my unhealthy or undesirable behavior, then the criteria for this punishment have to be transparent, public and verifiable. If for instance – not democratically elected – insurance companies can determine how I should live and do have financial instruments to punish me if my lifestyle does not match their criteria, then health has not only become a public case, 'autonomy' and 'informed consent' will be very ideological instruments to legitimate decisions which are in advance taken by someone else and 'freely' approved by the individual.

By way of conclusion: if health is a political or public issue, then public criteria are needed. What I called here 'a political code of conduct' could be an answer to this need. This code should include at least the following aspects (this is a preliminary list and not exhaustive; it is only a first indication, thus, further research has to be done here):

- Public and democratic control of the criteria in which situations, interventions of predictive medicine or large scale campaigns can be used or for what reasons.
- Guaranteed separation of interests and power of the several instances which are involved in health care.
- A political committee, analogue to ethical committees, to control public and preventive medical interventions and guarantee the right application of the agreed criteria.
- Control on gathering and protection of medical data by an independent instance without particular (financial) interests in health care.
- Criteria for financial punishment based on 'bad lifestyle' (*i.e.*, who, when, …)
- Scientific and evidence-based foundation of medical conclusions to be taken: if corpulence is indeed a great risk for my future health and thus can be punished by refusing to give me an insurance, the scientific evidence for this must be conclusive and well-grounded.
- Transparent criteria for 'right' and 'duty' of information.

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