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HEALTH AND AUTONOMY: A REVIEW FOR STUDYING PATIENT DECISIONS

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Abstract: *The purpose of this paper is to synthesize the meaning of two important concepts in the literature on sociology of health: health and autonomy. The review presented here has been performed as part of a research on patient's decision-making and it is meant to reveal differences in definitions which are likely to change the underpinning perspectives of patient decisions.*

Keywords: *sociology of health, decision-making, patient decisions, autonomy, health diagnosis*

In researching various topics in the sociology of health, there are several important terms which require thorough differentiation and analysis before the commencement of any study. For example what makes something a treatment cannot be answered without first looking at what *health, disease* and *illness* are. On the other hand, *autonomy* does not have a clear-cut definition in various philosophical perspectives. Each different conception of autonomy is likely to bring new insights and explanatory power to research which takes it into consideration, as opposed to the institutional definition of autonomy as the capacity to give consent in an informed manner. Therefore, this part will first present and critically analyse various definitions of health, disease and illness. The concept of diagnosis will then be presented. The third part will describe several perspectives on autonomy. The concluding part of this paper synthesizes the theories presented above with respect to patient decisions.

What is health?

The notion of health is rarely defined in health research, especially when it comes to subjective health (Stefanescu & Stefanescu 2012), public health policy (Stanciu & Jawad

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2013) or the standard of social justice and equity (Eliassen 2013). Still, the term has evolved throughout time together with the scientific evolution of thought and humanity's perception of the good life (Turner 2000). Its definition is intertwined heavily with notions of illness and disease. Between the times of the "doctrine of specific aetiology as disease" (Dubos [1959]1961: 90, cited by Sills, 1968: 331), to the conception of disease with multiple causes, from illness as "imbalance between the person and his external environment", to illness caused by sins in Christianity (p. 322) many patients have suffered of have been cured as a consequence of these philosophical perspectives. In another perspective, health is a standard to which a person can aspire and more importantly, one that is rarely met. Sills (1968) uses the term "asymptotic concept" of health to denote the tendency to express health as an endeavour and journey upon which individuals need to embark on throughout their life. This belief is based on the belief that the individual should preserve an equilibrium between his physiological, mental and metaphysical components and the environment. Modern environmental conceptions of health empirically establish connections between the health of societies and the state of their environment (Mete & Liu 2008), but not in the sense of asymptotic health. On the other hand, there is another conception of health that Sills (1968) points out to, called the "elastic concept" of health. It is based on the assumption that disruptions in the ideal healthy state that individuals are born into are a natural evolution of the body. As a consequence, preventive and preparatory measures should be taken from the very beginning of ones life, such as "restricting the water intake of children" (Sills, 1968: 333) in order to prepare and allow them to be adapted for the worst. The third conception of health proposed by Sills (1968) is called the "open-ended concept" of health and it is based on "positive mental health" (p. 333). Open-ended health touches areas thought to be out of the medical domain, such as nonconformity and moral norms (Freidson, [1961]1962, cited by Sills, 1968) and weakened religious values entering the area of mental health (Brewster Smith, 1961, cited by Sills, 1968).

In modern medicine, however, the multiple causes of disease are acknowledged. However, some causes remain to be disputed in light of scientific evidence, such as mental or psychological patterns that may favour the development of physical dis-ease. At the same time, cures are directed towards symptoms, rather than "the person" (Pott 1992). This critique of modern medicine bares with it the dichotomy between the cure of separate parts of the body, as performed in each specializations of modern medicine and the holistic perspective over the body and illness. However, there is another possible interpretation of this critique, which opposes treating the cause of illness as opposed to treating only the symptoms which are effects of illness.

In 1984, the World Health Organization adopted a new policy on health which introduced the notion of *healthy life* as opposed to prolonged, but unhealthy life. The slogan of the proposed policy was "Adding life to years" (Asvall 1992: ix). The goal of this policy was that "[b]y the year 2000, people should have the basic opportunity to develop and use their health potential to live, socially and economically fulfilling lives" (Asvall 1992). Health at this point is no longer an un-attainable goal, but a "resource for everyday life -- not the objective of living" (p. xii). In this context, individuals should change their perspectives over their health and maximize their health potential, however great or small it may be. Pott (1992) criticizes the view that chronically ill people should first of all accept their illness, as a concept based on increasing productivity of the least productive group in a society: the chronically ill. She reminds about the fact that people with chronic illnesses first of all need to be recognized as such, as "suffering human beings" (p. xiv). The utilitarian perspective of illness tries to see the "full part of the glass" and to neglect the essence of chronic illness which is premature death. Accepting that chronic illness implies a premature death would also mean accepting that a person's life potential has not been fulfilled. But, by accepting illness and aiming to produce as much as possible during the period of life affected by illness, it will be possible to fulfil the goal of utilitarian maximization.

Unlike the individualistic notions of health, the institutional definitions provide a different set of problems. The World Federation for Mental Health describes health of groups, communities, societies (nations), species and of ecological systems (Sills 1968). They are usually criticized for disregarding individual survival and health to the benefit of the group, society or of "life in general" (Sills 1968; Kukla 2015). However, there is a difference between the definitions of health derived from social justice studies and the institutional ones. Kukla (2015) divides definitions of health into three categories: scientistic, social-justice and institutional. The scientistic definitions regard health as a physical deviation from the "normal" functioning of the body, while social-justice ones are normative in essence and regard the way in which healthy life should be conducted (Kukla 2015). On the other hand, the institutional definition that Kukla provides herself is very similar to the laws that have lead to the death of Socrates: "A condition or state counts as a *health condition* if and only if, given our resources and situation, it *would be best for our collective wellbeing* if it were medicalized - that is, if health professionals and institutions played a substantial role in understanding, identifying, managing and /or mitigating it. In turn, *health is* a relative absence of health conditions (and concomitantly a relative lack of dependence upon the institutions of medicine)" (p. 524) Has Socrates condition been medicalized by having him drink the hemlock?

The diagnosis

The decision of medicalizing or not a certain health condition, to use Kukla's terms requires naming the set of symptoms that require a doctor's attention or finding a cure. In 1964 and in 1971, the psychologist Schachter (1964; 1971, cited by Mumford, 1983b) wrote: “Given a new, strange or ambiguous bodily state, pressure will act on the individual to decide exactly what it is that he feels and to decide how he will label these feelings”. It is the spectrum of personal beliefs about health, illness and disease, as well as the beliefs about what is considered as acceptable symptoms in a certain situation that help the person decide upon a label for the feelings of unease (Gillespie, 1999; Mumford, 1983a). Kleinman (1980, cited by Gillespie, 1999) proposed the notion of 'explanatory model' to refer to “a cognitive framework, drawing on a person's belief system, in which an individual makes sense of their illness experience, or health problem. An [explanatory model] may relate to cause, onset, patho-physiology, course and treatment, and it constitutes the subjective interpretation of an illness episode” (Gillespie, 1999: 107). Lay person's ability to decide upon a label for the feelings of unease has been compared with that of health professionals and doctors. The traditional view is that doctors are much more proficient in finding the appropriate label for a series of symptoms (Mumford, 1983d). Other researchers have argued that doctor's ability to do so is not necessarily different than that of lay people (Gillespie, 1999).

Provided that the bodily feelings described by Schachter are not recognized or considered as something to be expected, the pressure to decide and label them may lead a person to search for possible answers, either from family, peers or from a recognized professional, such as doctor, therapist, shaman or healer, (Mumford, 1983c). Lay-referral systems, as defined by Friedman cited by Gillespie (1999:109) are social networks consulted by a person prior to seeking medical help. Lay referral systems have been shown to influence the decision to seek professional care (Gillespie, 1999; Mumford, 1983b). Clearly, many other factors influence the decision to seek medical help, such as education, income, social class, physical proximity to a clinic, costs of treatment, in terms of money, time and even effort (Mumford, 1983:52), the social acceptance of the symptoms, their persistence in time and their interference with daily activities and many others (Mechanic, 1968, cited by Gillespie, 1999).

The main point of this discussion is that the pressure to label feelings of unease or even different types of pain is part of the doctors' tasks, called *diagnosis*. In ancient and current medicine, naming the problem and its cause made reference to a system of beliefs, each one specific to places and times (Mumford, 1983c). For example, in Chinese medicine, disease is explained as an imbalance between the two energies of Yin and Yang which is determined by the untroubled flow of energy within the main energetic points of the body (Mumford, 1983c). But in medical dictionaries a diagnostic is "the determination of the nature of a disease" (Mumford, 1983d). However, as Stedman (1976, cited by Mumford, 1983d: 64) shows, there are many types of diagnoses:

1. "clinical diagnosis is a determination based on a combination of physical signs, such as heart rate, temperature, respiration, and symptoms the patient describes or demonstrates, such as pain, swelling or nausea. In diagnosis by exclusion, the doctor goes over the array of diseases to which the symptoms could point and then rules out all but the one that seems consistent with all symptoms.
2. differential diagnosis is the weighing of alternatives to decide which one of two or more diseases best fits the similar signs and symptoms that the patient seems to suffer.
3. laboratory diagnosis is based on chemical, microscopic, bacteriological, or other instrumented study of secretions, discharges, blood or tissue
4. physical diagnosis is a diagnosis made by means of physical sounds, sights, and smells. The doctor feels for an enlarged liver or gland, listens to the heartbeat, takes a pulse, or taps a knee to see whether there is normal knee-jerk reflex.
5. pathological diagnosis is the examination of tissue obtained through biopsy or at a post-mortem examination"

Still, Mumford (1983d:64) points out that a diagnostic "may only be a medical label for an as yet little-understood cluster of symptoms that have been described as occurring together". Such a label is likely to disperse anxiety both for the doctor as well as for the patient. The responses that patients give to the receipt of a diagnosis may be very different from one person to another. They have been categorized as: denial, mastery and dependency (Mumford, 1983). These reactions are described with respect to acute as well as chronic diseases. Some diseases have acute and chronic phases, which purport different handling by both the doctor as well as the patient.

What is autonomy?

According to Dworkin (1988) *autonomy* is different from liberty in two ways: autonomy requires information or knowledge in order to be different from liberty, while freedom needs a "preference about desires, values and wishes" to be different from autonomy, as well as a preference for the way in which the desires, values, wishes have been acquired. Dworkin (1988:105) defines liberty as: "the ability of a person to do what he wishes and to have significant options that are not closed or made less eligible by the actions of other agents or the workings of social institutions", in line with both the view of Thomas Hobbes and John Stuart Mill and that of Jean Jacques Rousseau and T.H. Green about freedom. To emphasize the two differences between autonomy and liberty he describes two cases, the first from John Locke and the second, from the story of Odysseus. The first case is that of a prisoner who is locked into a cell which has multiple doors. The guards go through the drill of locking all doors, but one of the doors is damaged and cannot be locked. Not knowing about this, the prisoner remains confined and does not try to escape. In this case, Dworkin (1988) suggests, the freedom of the prisoner is not affected, but his autonomy is. The second case presented is that of Odysseus, when he orders his men to chain him and ignore all his further orders in order to prevent him from steering his ship towards the sirens and into the rocks, at the sound of their enchanted song. In this case, Odysseus decides to limit his freedom in order to preserve his autonomy, given that the song of the sirens is likely to create a false or externally driven preference in his mind. In this case, Odysseus has a preference about his preferences, as Dworkin (1988) suggests and he also has a preference about the cause of his preferences.

In light of these arguments, Dworking (1988b) suggests that autonomy encompasses both a reflexive behaviour about ones own beliefs, as well as the ability to change these should they not reflect what he calls a second-order preference: "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". He goes on to argue that "[b]y 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" (p. 108). In light of this perspective, Dworkin (1988) points out that the content of the choice for autonomy is not given: "Someone who wishes to be the kind of person who does whatever the doctor orders is as autonomous as the person who wants to evaluate those orders for himself" (p. 108-109). He acknowledges himself that this view is not shared by most authors, such as R. P. Wolff. While I agree with his definition of autonomy and the differentiation that he makes between this concept and that of liberty, I find it difficult to see how responsibility for ones actions is directly implied from the concept of autonomy. I would argue that responsibility for ones actions is a distinct concept which is not at all trivially connected to either autonomy or freedom, in a world in which knowledge is imperfect. The consequences of an action come may be based on the laws of nature, from the psychological costs of an action and from the sanctions of others who are affected by the individual's actions in a negative way. When laws of nature give the consequences of ones actions, responsibility is clearly implied by autonomous action. When psychological costs of ones' actions appear, the individual cannot be accounted for any impact upon the others. Hence responsibility is shared. If direct reactions of others constitute costs of ones' actions, then responsibility is shared, since it depends upon the ability of others to know about the autonomous actions, to identify the actor responsible for this action and for coordinating their effort regarding the sanction, etc. However, if responsibility means accepting the causal relation between one's actions and any consequence, however small, unlikely or new, and irrespective of the other's implication then, autonomy indeed, always implies responsibility.

In the bioethics literature, autonomy is defined as self-determination, which basically means “the interest of ordinary persona in making significant decisions about their lives for themselves, according to their own values or conception of a good life, and in being left free by other persons, at least within limits, to act on those decisions.” (Broke 2001: 232). In Broke's vision, choosing to follow no treatment at all is part of the alternatives of an autonomous person: “It is important to recognize that sometimes patients may make treatment choices in the exercise of their self-determination that are bad, foolish or irrational and do not best serve their well-being even as determined by their own values. The importance of self-determination implies that even bad choices of competent patients must be respected” (p. 232). Young (2001) points out that in medicine autonomy and self-determination is put into practice through *informed consent.* Still, this implies that the patient is *competent* and is able to *understand* the information that is relevant for her decision.

Not all health-care professionals agree with self-determination in the form discussed until now. The main argument behind this idea is that the experience of a health-care worker should add more value to the medical decision, but this simply disregards the fact that for the patient more life is not always better than less life and on the other hand, that decisions differ upon their framing, in terms of the probability for “extending life” or for “resulting death”. Young (2001) emphasizes the fact that “the practitioner must alert the patient to the values underlying the framing of the information provided” (p. 444), however impractical this may be.

Nevertheless, the lack of influence or coercion is almost impossible to measure sociologically. As long as autonomy has no predetermined content, as Dworking (1988) suggests, it may be impossible to measure. In other words, if an autonomous action cannot be identified with a certain choice (for example, not to listen to the doctor in treatment choices), then what would make an indication of an autonomous action? There are however, two general ways to measure autonomy: directly and indirectly. The direct measurement would require the use of a measurable definition of autonomy. Faden, Beauchamp and King (1986) suggest that autonomy should be a characteristic of an action, not of a person. In this way, Faden et al. (1986: 235) defines "autonomous actions" by three aspects:

- "intentionality
- understanding
- non-control from influences" (p. 238)

Intentionality and understanding can be evaluated empirically, but the absence of exterior influences is hardly a concept that can be evaluated. Influences can generally be categorised based on several criteria:

- from the point of view of the sources of the influence: doctors, family, friends, internet, social norms, religious beliefs, etc.
- from the point of view of the awareness / lack of awareness of the influence
- from the point of view of the way in which the sources exercises their influence: by coercion, by manipulating information, by rewarding certain behaviours, etc.
- from the locus of the influence: internal (chemical for example) or external to the decision-maker.

On the other hand, a person may clearly accept a well documented opinion issued by a different person, in a logical manner. Is any change of opinion resulting from a logical inference presented to the decision-maker by a different person, an influence? I think that in a strict sense, this is an influence, indeed, but by the manner in which it has been exercised, it does not endanger the autonomy of the decision-maker. Should an opinion formed based on a logical inference presented to the decision-maker be an influence, does this mean that the decision-maker should not learn a way to solve his/her health problem? At this point Faden et al. (1986) point out that a certain source of influence should not exercise control over the individual. In other words, the source of an influence should not condition the action of the decision-maker by other means than those of logical action. And more importantly, the source of influence may be either external or internal (like mental illness or some form of addiction as Mackenzie (2015) points out). In order for logical action to take place, understanding of all logical connections resulting from the relevant information should take place. This is why Faden et al. (1986) propose that while intentionality is a dichotomous variable, understanding and controlling influences are continuous variables. Thus, the degree of understanding and the degree of control of a decision-maker's actions lead to the degree of autonomy of the action, conditional upon it being intentional.

To use Faden et al.'s (1986) framework, the main question is not what are the main characteristics of a patient that lead to an autonomous action, but *under which conditions are patient's actions autonomous*? Ensuring that the conditions of autonomy are met (i. e. that actions are intentional and that the decision-maker possesses the capacity to understand relevant information and that no individual or source of influence controls the decision-maker's choices), does not automatically lead to an autonomous choice. In my opinion, if autonomy is not valued by the decision-maker, creating the conditions for autonomy will not lead to an autonomous decision. A person that has been under the influence of others for a long time and values such influence will not know how to behave and what to do under conditions in which autonomy is encouraged. It is the case of slaves that have been suddenly released and do not know what to do with their newly acquired freedom and autonomy, or of former totalitarian regimes who require accommodation and learning in order to become autonomous. In a similar line of thought, Mackenzie (2015) argues that when some health-behaviour needs to be changed and some aid is required (support, additional motivation, etc.), such aid can be viewed as influence from other people, and autonomy would thus be endangered. But, in light of Dworkin's (1988) excerpt from Odysseus, it is only the freedom of an addicted person that is limited, in order to preserve autonomy, provided that the restriction of freedom has been a previous choice of the decision-maker.

Implications for decision-making

This paper has departed from various definitions of health, diagnosis and autonomy in order to understand how different conceptions of these terms could shift decision-making perspectives in the area of patient decisions. Health evolved from single to multiple-cause perspective, as well as from an unattainable goal to an aspect of life that will decrease in time, with certainty and to a resource for increasing productivity. It also oscillates between an individualistic utilitarian perspectives, to a socially and institutionally defined concept. On the other hand, ensuring health requires naming the problem in a process of diagnosis, itself a socially defined process. Diagnosis and finding a cure are based on an explanatory model of the disease or illness which differ with each culture and in time. However, patients' choice of a treatment assumes that she is autonomous and free to do so. As it has been shown in the third part of this paper, autonomy can be empirically measured with difficulty. Still, the framework proposed by Faden, Beauchamp and King show great potential for application in patient decision-studies, as opposed to considering only the institutionally defined informed consent.

In Rational Choice Theory (for a review, see Gheondea-Eladi 2013) the individual is assumed to decide. This implies that she is autonomous. However, in rational choice and in single-criterion decisions, in general, bad decisions are thought to exist. Usually the accuracy of the decision (with respect to a known 'correct' solution) had been thought to be one in which the individual ends up dying or in great suffering as a direct result of her choices. But, from the point of view of multiple-criteria decisions, it is possible to have several solutions to the same problem or to be in an impossibility to formulate a solution (Keeney & Raiffa 1976; Roy 1996; Lootsma 1992). Multiple-criteria decision-making also requires the autonomy of the individual. The attainment of good-health is usually the goal of most patient decisions, despite the World Health Organization's conception of health as a resource for life. This means that even if decisions are placed in a single- or multiple-criteria decision-making framework, the alternatives of action depend primarily upon the definition of health. As has been seen in the first section the definitions of health can be based on pshysio-pathology or on institutional and societal values, all framed by the explanatory model in which the individual places herself. When the definition of health as the goal of patient-decisions is socially defined, the autonomy of the decision-maker may be placed under debate. Consequently, the evaluation of patient decisions in terms of improving health and maintaining autonomy depends greatly on the framing of the decision. The person or the institution generating that framing therefore holds an influence over the individual. To conclude, when considering studies on patient decisions, the way in which autonomy and the improvement of health enter the decision-making process should be critically and reflectively evaluated. In essence, rational choice theory and multiple-criteria decision analysis depend on the clear formulation of health as a goal and of autonomy as a second-order preference.

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