3. TOWARDS AUTONOMY-WITHIN-ILLNESS: APPLYING THE TRIADIC APPROACH TO THE PRINCIPLES OF BIOETHICS

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INTRODUCTION

The notion of autonomy has been crucial in the development of bioethics and, particularly, the ethics of health care. Generally speaking, autonomy refers to the capacity of individuals to act in the world in a self-regulated way, "the having or making of one's own laws" (*Oxford English Dictionary*). In this sense, agents are autonomous if their actions are truly their own. In ancient Greece the term was applied to the *polis*, referring to the self-government of city-states; later, modern philosophy extended this to the ethical and political self-determination of human beings (Schneewind 1998). The idea of autonomy as moral freedom already appears in the writings of Rousseau and is central to Kant's philosophy, for which the autonomy of the will is a necessary condition for moral action, and the moral principles or laws that dictate how we must act originate in reason. In this sense, autonomy is understood as the capacity to act in accordance with internal norms, not controlled by others, but also as the obligation established by one's duty to consider others as autonomous beings; that is, their right to be respected as such and therefore, not to be externally manipulated (Etxeberria and Casado 2008). In the field of bioethics, most scholarship has focused on this second meaning of autonomy. In this chapter, however, we argue that the first sense of the term, that is, the *capacity* to be autonomous, needs to be re-examined within a naturalist approach so as to explain what it means for an agent to be autonomous.

For mainstream bioethics, largely developed after the work of Beauchamp and Childress ([1979] 2008), autonomy is a pivotal element in a four-principle account of the ethical issues surrounding health care (the other principles being: beneficence, non-maleficence and justice). Although Beauchamp and Childress consider all four to be of equal weight, for many authors the principle of respect for autonomy is *first among equals* (Gillon 2003), implying that patients' right to make decisions on issues affecting their health should prevail at the end of the day.

However, in considering the obligations that respect for autonomy entails, a large part of the literature has been more concerned with the legal–juridical aspects of the principle of autonomy involved in how to protect a "right", than with the personal subjective aspects that underlie patients' capacity to act autonomously. To take this into account, philosophical analysis and research should address the experience of patients and physicians, and the needs arising from it (Tauber 1999). Thus, in fact, we contend that, to a certain extent, the principle of autonomy developed by mainstream accounts of bioethics has been shaped according to an idealized capacity for autonomy, based on the image of healthy adult individuals who are self-sufficient citizens and are entitled to rights that protect their ability to act. What this view has neglected to address, however, are the particularities that characterize the situation of ill people who are more dependent on others. A better understanding may arise from a perspective focused on how the capacity to be autonomous is grounded in biological, psychological and social factors.

In this chapter we question the validity of the notion of autonomy underlying the mainstream doctrine of the four principles of bioethics, and propose to expand it. Our strategy will be to appeal to the philosophy of medicine and the debate therein on the nature of health and disease so as to work out a richer conception of autonomy-within-illness. If ailments, generically, are conditions that are judged to be "bad" or evaluated as non-healthy, the triadic approach distinguishes between *disease* (an ailment as considered by the medical profession), *illness* (the ailment from the subjective experience of the ill person) and *sickness* (the ailment from the perspective of society's institutions).[1] Of course, an ailment can be considered as a disease by the ill person herself, for example when she is looking at X-rays, or deciding on which chemotherapy to go for, but in that case her judgement is shaped by medical knowledge (something that has been increasingly made possible in our society, where lay people can sometimes access very specialized knowledge) and not limited to her subjective experience. One could also say that sickness and disease overlap, because the medical and health care institutions are part of society's institutions, but although both science and the political system can be considered from an institutional perspective, science and the economic system generate different evaluations of ailments.[2]

A framework similar to the one we adopt was first proposed by David Thomasma and Edmund Pellegrino (1981), who argued that medical ethics must be based on philosophy of medicine. These authors advocated that *beneficence* is the most important principle of medical ethics, and that the triadic model, which pays equal attention to how disease is experienced and conceptualized subjectively by patients, how it is clinically objectivized by medicine and physicians and how it is variously viewed by, and embedded in, society, is a good way of emphasizing the variety of relevant aspects involved in beneficence. It is evident that a consideration of this kind requires a change in the classical perspective of autonomy. As the paragraph below shows, Thomasma's inspiration was taken from the work of Karl E. Rothschuh:[3]

> Health and disease are building blocks of medical logic, but this logic is not exclusively scientific. In fact, as Rothschuh indicates, disease is a *relational structure* between sickness, the sick person, the physician, and society. *The ill person enters three relations – one to the self, another to the physician, and still another to society and environment – all of which are governed by the need for help.* The physician also enters three relations – one of responsibility to the sick person, another to the disease (what is the case? what to do?), and another to society. Society is also involved with individual good for the patient, the common good, and a relationship of aid, prevention, and research on the causes and effects of disease. Rothschuh therefore defines disease as *the presence of a subjective, or social need for help in persons whose physical, psychic, clinical, or psychophysical balance of boundaries in the organism is disrupted*. Health, or well-being, on the other hand, is characterized by the presence of order and balance in the organism and no perceived or actual need for help. This analysis recognizes the primary referent of health and disease as conditions of the body. (Thomasma 2000: 253; emphasis added)
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> Thus, according to these authors, the philosophical analysis of the notions of health and disease obliges us to adopt a triadic perspective and, as regards the relationship between bioethics and the philosophy of medicine, this means that the former cannot be based on a simple account of disease as conceived by the medical profession, but rather upon a careful consideration of other implications also.[4]

Unfortunately, although in a later book Bergsma and Thomasma (2000) provided an account of autonomy in light of the changes that had taken place in health care worldwide, such a comprehensive philosophy of medicine has not yet been completed (Sulmasy 2005: 487–8). Thomasma died in 2002, and few other sustained efforts have been made to link bioethics to the philosophy of medicine, and particularly to the debate on the concepts of health and disease. This chapter aims to make a contribution to this line of research at the intersection between medicine, philosophy and ethics. We claim that bioethics needs to be grounded in the philosophy of medicine and we present an analysis of the problems encountered when analysing some philosophical aspects of the principle of autonomy. We contend that the principle of respect for autonomy requires that the practice and experience of being autonomous in health and illness be taken into account, and that the triad helps conceptualize the complex aspects involved.

The argument presented in this chapter starts with the triadic approach to the concept of disease in relation to debates in the philosophy of medicine regarding the definition of health and disease. In the next section, the "four principles" account in bioethics is considered in light of the triad. Although a relationship is found between disease and the principle of non-maleficence, sickness and the principle of justice and illness and the principle of respect for autonomy, the "four principles" model has not been sufficiently informed by the multidimensional perspective of the triad. In particular, the principle of respect for autonomy needs to be reformulated to account properly for the illness dimension. The final section focuses on the concept of autonomy, and we offer a partial explanation of the reasons why it is unable to make sense of the complexity inherent to the triadic approach if it is understood as in mainstream bioethics, and suggest a new approach.

HEALTH AND THE TRIAD: *DISEASE, ILLNESS AND SICKNESS*

One of the main topics in the philosophy of medicine concerns our understanding of the notions of health and disease; the on-going debate concerns the two different naturalist and normativist views in medicine. For naturalists, disease needs to be described in accordance with natural science (biology), in an objective and reductionist manner, whereas for normativists, judgements on disease cannot be purely objective, since they involve norms and evaluations. Boorse's (1977, 1997) account, typical of the naturalist side, conceives health as the normal statistical functioning of an organism, and disease as an atypical deviation from that normality. For normativists, such as Nordenfelt (1987), health is a matter of well-being, judged according to the standards of the patient. Naturalists and normativists differ also on whether medicine is science or art, understanding that as a science, medicine focuses on studying the nature of disease and possible interventions, whereas as an art, it is concerned with the practical ability to apply that knowledge to individual patients or populations. Medicine has sought legitimacy in laboratory-based science, sometimes at the cost of being less able to pay full attention to the physician–patient relationship (Tauber 1999: 13). Another related issue to consider is whether medicine requires an exhaustive knowledge of the organic nature of diseases (providing that such knowledge is possible), or whether it should limit itself to the practical search for efficacious therapeutic interventions. Although this debate has been going on over recent decades, some authors have recently argued that it has now reached a stalemate that needs to be overcome (Khushf 2007: 27).

A possible way out of the opposing naturalist and normativist positions might be found in an understanding of ailment based on a triad of notions (disease, illness and sickness), capable of encompassing the medical, personal and social aspects of the phenomenon. This triadic conceptualization would not be committed to either naturalism or normativism, but may accommodate features of both. Indeed, disease is usually defined in naturalistic terms, but illness and sickness incorporate insights from the normativist position, thus recognizing the relevance of subjective and social values. In Bjørn Hofmann's (2002) characterization the triad offers a comprehensive way of addressing the conflicting views of basic concepts in health care. His distinction between illness, disease and sickness corresponds to the social structure of health care, since it represents the perspectives of the main stakeholders involved. Furthermore, it genuinely connects evaluative and epistemic aspects, clarifying how these complex issues emerge and can be tackled. This is how Hofmann (2002) defines the triad:

- Disease is a negative bodily occurrence as conceived of by the medical profession.
- Illness is a negative bodily occurrence as conceived of by the person himself.
- Correspondingly, sickness is a negative bodily occurrence as conceived of by society and/or its institutions.

As said before, although the style of thinking of each vortex as disease, illness and sickness could be reproduced by other parties (example.g. patients thinking of their condition in terms of disease), the triadic model tries to characterize the knowledge generated according to the authority that motivates each different system of evaluations.

Hofmann concurs with other authors, such as Nordenfelt (1987), in that both health and disease are evaluative concepts, since values play a role in constituting the concept of "health care". Yet, in contrast to Nordenfelt (1987, 1994) and Twaddle (1994) for whom the starting point is a general or positive notion of health, Hofmann maintains that negative concepts, such as disease, illness and sickness, can be used independently, as they are informative enough. He argues that as a matter of fact, these concepts do exist, even in the absence of a general theory of health; they are not mere names for different "health problems", as Twaddle contends, or "disabilities", as Nordenfelt says, but rather the terms capture three different perspectives on human ailment that are the main focus of medicine and health care.

In Hofmann's view, the triadic distinction between illness, disease and sickness is fruitful both theoretically and practically. For instance, he argues that the term "health care" should be replaced by terms such as "disease control", "illness care" and "sickness rights ascription". Indeed, such conceptual differentiation would correspond better to the different perspectives and would be more explicit regarding how to act and what to expect from the practice of medicine, even if we doubt that it could ever be implemented in practice. The term "health care" has been used for a long time and will be very difficult to substitute. But this is not the most interesting aspect of his use of the triad. When combined, the three perspectives provide an understanding of "normal" or typical health care scenarios, as opposed to ethically problematic situations or "cases". The paradigm of a normal scenario in health care is when a person feels *ill*, the medical profession is able to detect *disease*, and society attributes to him the status *sick*. Illness explains the person's situation from their point of view, disease permits medical attention, and sickness frees the person from ordinary duties of work and provides the right to assistance.

In the typical or normal scenario, negative bodily occurrences, as conceived of by the individual, correspond to those recognized by the medical profession and by relevant social institutions. In other cases, however, conditions deviate from this standard and may be judged as falling under one or two aspects of the triad, but not all three of them (Hofmann 2002: 10–12).[5] Thus, an instance may be judged to be both disease and sickness, but not illness (for example, some mental diseases in which the person does not personally feel afflicted by any condition, or diseases that are asymptomatic for the patient but potentially harmful to others, such as some cases of human papillomavirus (HPV) infections). It may also be the case that a condition is understood as both disease and illness, but not sickness (the common cold or dental caries could fall into this category as far as their social consequences are null), as the individual in question would suffer ailment and be in need of mild medical assistance, but this would not affect their social identity. Other instances could be occurrences of illness and sickness, but not of disease (a typical example of this used to be fibromyalgia, a condition of vast social and personal consequences that for a long time went unacknowledged by the medical system). Currently, we may consider some conditions, such as low and moderate hypertension or lactose intolerance, to be examples of disease, but not of either illness or sickness; other negative bodily occurrences (such as melancholia, feelings of dissatisfaction, unpleasantness or incompetence) might be personally experienced as illnesses even though they are not socially understood as medical conditions (neither disease nor sickness); and some situations may be considered by society as sickness, although they are not counted as either disease or illness (Hofmann mentions in this respect some cases of delinquency, dissidence or homosexuality in certain societies).

An interesting aspect regarding our use of the triad is linked to the significance assigned to the body. Hofmann's formulation tries to avoid the notion of "the body", using the expression "occurrences" to mean processes, states or events. This might be because he wants to avoid difficulties in relation to mental health and illness. But, as we see it, an emphasis on "bodily" aspects is necessary in order to stress that whenever there is disease/illness/sickness, someone is afflicted by it: these concepts predicate an embodied organism. In other words, if we consider, quoting Epicurus, that illness is about "the cry of the flesh", there must be some bodily flesh in order for there to be illness.[6] All disease, be it mental or physical, is embodied.[7] Thus, the triad appears able to integrate controversial cases discussed in the literature (Cooper 2002a, 2002b) and to offer a more comprehensive framework for assessing ailment and analysing difficult cases involving conflicts of moral values and principles.

The triad comprises biopsychosocial elements and possibilities in a holistic approach. In particular, it attempts to address elements of personhood that have no firm objective basis – the social, the emotional, the moral – in a picture of the organism as an integrated, functioning whole, according to which medicine should be holistic in orientation. A similar argument is offered by Alfred Tauber, who claims that the basic purpose of medicine is to recover "the full personhood of the patient to again become an autonomous free-living individual"; therefore, by its very nature, medicine "demands a holistic understanding of the organism and a holistic approach to the care of the patient" (Tauber 2002: 262, 268). Indeed, respecting and promoting the autonomy of patients seems to be connected to the very idea of fighting human ailment in its complexity.

In the next section, we analyse the "four principles" account of bioethics formulated by Beauchamp and Childress in order to observe the relationship between the triadic approach in philosophy of medicine with this bioethical perspective and the notion of autonomy that underlies it.

THE PRINCIPLES OF BIOETHICS AND THE TRIAD

The mainstream doctrine or standard model in biomedical ethics is the well-known "four principles" approach developed by many authors after 1979, when it was introduced by the first edition of *Principles of Biomedical Ethics* (Beauchamp and Childress [1979] 2008). The four principles are respect for autonomy, non-maleficence, beneficence and justice; they were proposed as mid-level norms mediating between high-level moral theory and low-level common morality, and they became very influential in bioethics.[8] As mentioned earlier, for many authors respect for the autonomy of the patient has been the core of this four-element ethical account, but we contend that there is a serious problem in the common understanding of the notion of autonomy as a right, rather than as a capacity that enables physical, psychological and social interactions.

We worry that the "four principles" account, the most salient representative of contemporary bioethics, may sometimes operate with a notion of disease that is simplistic and one-dimensional in comparison with the richness of perspectives opened up by the triad, and by contemporary philosophy of medicine. Thus it is useful to review Beauchamp and Childress's book (hereafter B&C) in light of the account proposed by the triad, in order to consider how to link discussions in the philosophy of medicine with critical bioethical debates, and thus clarify current controversies over the meaning of basic principles, particularly in relation to the principle of autonomy and the obligations that arise from it.

Although the multidimensionality of the notion of disease offered by the triad is absent in B&C's account, there is a sense in which something equivalent appears in the four-principle scheme,[9] and in fact it is possible to establish some parallels that show why similar concerns appear in both conceptualizations. Thus, we may say that the principles of bioethics reflect (to some extent at least) the triad: the principle of non-maleficence may be associated with the perspective of disease, respect for autonomy with that of illness, and the principle of justice with sickness, whereas the principle of beneficence may be linked to all three of them (at least according to some authors, as we mention later). However it is more usual to see this principle being linked to how the medical profession sees the patient's good, something that is often criticized as introducing paternalism. Let us now examine these principles one by one.

The principle of non-maleficence asserts an obligation not to inflict harm on others (Beauchamp and Childress 2008: 113). B&C confine their analysis of this principle to the prevention of harm, which is itself a contested concept. It is true that they do not deny "the importance of mental harms and setbacks to other interests", but they concentrate on physical harm, which in their view can be *objectively* measured (117). Their idea of non-maleficence is to avoid pain, disability and death as much as possible, and to do so by appealing to objective, shared professional standards. They find a specification of the principle in the standards that determine due care in a given set of circumstances: "Due care is taking sufficient and appropriate care to avoid causing harm, as the circumstances demand of a reasonable and prudent person. This standard requires that the goals pursued justify the risks that must be imposed to achieve those goals" (118). Professional standards are set by health care professionals, and are therefore associated with disease in the sense of negative bodily occurrences identified by the medical profession. So, when non-maleficence is invoked, it could be said that it is underlain by the notion of disease.

In what concerns the principle of *justice*, B&C maintain that no single theory can account for the conflicting demands associated to it. Justice fosters questions about "what the people of a nation should expect from their health care system and how the nation can address citizens' needs for increased insurance, long-term care, and the like" (Beauchamp and Childress 2008: 272). Every society, they add, should recognize "an enforceable right to a decent minimum of health care within a framework for allocation that incorporates both utilitarian and egalitarian standards" (272). Those standards, again, are not set by patients alone, but by a number of social agents who identify which negative bodily occurrences are entitled to (or require) health care benefits. B&C specify and balance several principles of justice in particular contexts (227ff.), but in all of them the notion of justice is underlain by this notion of sickness.

When illness is defined as "negative bodily occurrences as conceived of by the ill person", this definition clearly has more to do with conceptions of the good held by patients, and therefore with their *autonomy*, defined by B&C as a "person's right to hold views, to make choices, and to take actions based on their personal values and beliefs" (Beauchamp and Childress 2008: 63). It is true that the principle is still directed at health care professionals, in the sense that it requires action from them, in the form of respectful treatment in disclosing information to the patient and fostering free decision-making. Still, from the perspective of autonomy, illness is the most salient notion.

So far we have argued that non-maleficence is underpinned by the notion of disease, autonomy by illness and justice by sickness. But, what about the principle of *beneficence*? We now turn to this question.

B&C propose a framework of *prima facie* principles, and deny the priority of one over the others (Beauchamp and Childress 2008: 57). They justify the obligation to follow these principles, but acknowledge that their precise demands cannot be precisely settled, but are open to interpretation and specification. Morality, they say, is "rooted no less deeply" in autonomy than in non-maleficence, beneficence or justice (104). "Neither the patient nor the physician has premier and overriding authority, and no pre-eminent principle exists in biomedical ethics, not even the obligation to act in the patient's best interest" (177). This fits well with the triad, according to which absence of health needs to be analysed in three dimensions – medical, personal and social – with none being more important than the other two.

This absence of priority is especially clear when considering beneficence, which requires that agents take positive steps to help others (rather than merely refrain from harmful acts), balancing an action's possible goods against its costs and possible harm. Here lies another reason why the triadic approach looks promising when trying to capture the complexity inherent in the health care relationship: it helps us understand the debates over beneficence, a principle that was initially subject to harsh criticism within bioethics, but which has been recovered by authors such as Tauber (1999) or Pellegrino and Thomasma (1988) as the guiding principle or moral core of the medical profession, provided it is rendered compatible with respect for the patient's autonomy.[10]

DIMENSIONS OF AUTONOMY

We have suggested that, to some extent, a relationship may exist between the principles of bioethics and the triadic notions of disease, illness and sickness. The relationship is not a direct match between the triad and the "four principles" account of bioethics, but similar concerns may underlie both theoretical accounts, in the ethical and in the epistemological domain. Rather than to assume that there needs to be something like a one-to-one link or a many-to-one link, our aim is to see how an epistemological investigation of the triad may help inform an ethical discussion of the principles. In the following section we argue that such a relationship is not adequately emphasized, both in theory and in practice. The four principles of medical ethics are not sufficiently informed by the concerns present in the triad, and in particular the principle of respect for autonomy needs to be reformulated so that it connects better with the illness dimension of the triad and provides an account of the phenomena related to autonomy-within-illness and the associated problems.

On the practical side, our point is that mainstream medical ethics was developed to assist decision-making within a context of acute care, which focuses on decisions that need to be taken in order to restore health. Within this theory, decision-making is conceived to occur related to, and requiring, the kind of autonomy that healthy people may exercise. Thus, ill individuals, who may be thought to be in a categorically different situation from healthy people, are endowed by mainstream bioethics with this idealized form of autonomy.

So, the question is: how is autonomy affected by illness? Patients' experience of illness is shaped by a sense of vulnerability that is both subjective (how patients may perceive themselves) and objective (their susceptibility to external threats, pressures and harm). Yet, as Carel (2009) argues, there is a diverse range of patient responses to illness, and their needs are correspondingly different (for a similar conclusion concerning the diversity of patients' experience of dignity, see Chochinov 2004). Patients' responses to illness are often very personal in nature; they might even be considered as ways of asserting their identity. In this sense, more basic than the capacity to self-rule, and underlying it, autonomy can be observed in how agents manage to maintain a precarious identity with the ability to act so as to ensure the persistence of their agency (Moreno and Casado 2011). In this way, a patient's response to illness, his behaviour, is ultimately related to what he *is* as an agent.

Patients may be more autonomous and less subjectively vulnerable than we believe them to be, although in ways different from those assumed by the standard model and that need to be better characterized. Conversely, nurses (and other health professionals) may be more vulnerable than is generally believed, since they are continually exposed to existential suffering in stressful environments (Carel 2009: 217–18). As a result, bioethics needs to readdress what it means to be autonomous-within-illness; not to deny that ill people can be autonomous – that would be tantamount to advocating an unacceptable return to paternalism – but to take into account that there are different ways of striving to maintain a precarious identity. Many of those might not easily accommodate standard accounts of bioethics; as we will see in what follows, there are alternative ways of looking at autonomy.

Autonomy in illness

In 1988, the Hastings Center published a special report on the ethical dimensions of chronic illness and chronic care, topics which had hitherto been relatively neglected in bioethics (Jennings *et al.* 1988). A common theme in the ensuing literature is that judgements about quality of life change dramatically when one becomes chronically ill (Carel 2008). Reports show that healthy people judge the life of some ill people to be more "unliveable" than the ill people themselves experience it (Menzel 1992; see also Wasserman *et al.* 2011). Philosophers writing on the challenges of disability have similarly complained that "physicians in particular estimate the quality of the lives of their disabled patients to be much lower than do the patients themselves" (Amundson 2000: 46). In other words, the very idea of a *self*, of the agent's identity, acquires different meanings depending on the perspective of the healthy or the ill. Ethics must take into account how being ill alters our selfhood (Tauber 1999). Related to this, we must ask whether our views on the relevance of the principle of respect for autonomy may change in illness, in comparison with how it is conceived in health, just as the capacity to exercise autonomy may vary between health and illness, at least in some ways.

During the last quarter of the twentieth century, the principles of bioethics were conceived to help with fast life-or-death decision-making. However, longer life expectancy and other social and cultural factors have turned the attention of institutionalized bioethics to chronic disease, shifting the focus from emergency medicine to primary, long-term care. The management of chronic disease requires a more comprehensive account of autonomy than that offered by the standard accounts based on acute disease. When the focus shifts from acute cure to chronic care, it becomes clear that bioethics needs an understanding of autonomy-within-illness, rather than relying on a general account of autonomy-within-health. Moreover, the concept of autonomy includes at least three different aspects or dimensions – decisional, executive and informational – which we will discuss in the following section.

Because the concept of patient autonomy was developed in the context of acute care, it has been identified with the *decisional* autonomy of patients or their proxies: whether to accept or reject a proposed treatment. In contrast, primary care, with its focus on chronic disease and palliative care, is an area of medicine where practice must go beyond the disease-laden idea of "fixing bodies" and move towards viewing patients as people, individuals with stories of their own who live in social networks of relatives, friends and fellow citizens. It must move towards illness and sickness.

A perspective like this forces the notion of autonomy to move beyond respect for the autonomy of patients as respecting their freedom of choice. As Eric Cassell (2010: 43) points out, in practice, the principle of respect for autonomy has been translated into something like this: "present the patients with the current and correct information about their clinical situation and offer them the options from which they must choose". Indeed, B&C write about "*substantial autonomy*", expressing a confidence that "Patients and research subjects can achieve substantial autonomy in their decisions, just as substantially autonomous choice occurs in other areas of life, such as buying a house or choosing a university to attend" (Beauchamp and Childress 2008: 60). However, the examples chosen in this quote support our previous criticism of this way of understanding autonomy: buying a house and choosing a university are typical choices for the relatively healthy.

Thus, at least in medical practice, the prevailing notion of autonomy identifies it with the freedom of choice of someone who is rational and able to make such choices. Leaving aside the fact that some people cannot make free choices even if they are not ill (for instance, in cases where the stronger party uses his or her influence to control, manipulate or exploit the other), if a theory of medical ethics does not take into account the very fact that creates the health care relationship, that is, that patients need some form of care that may contribute to sustain their autonomous living, then the theory has a problem. In Cassell's words:

> This discussion of autonomy in medicine must seem a little bit strange and unreal. What happened to sickness? It is as if no one is sick. What we know about sickness – not as doctors ... but merely the everyday knowledge of sickness. Because if people are really sick, with everything that goes with sickness, can they really make the best decisions about their care the way we have described? (Cassell 2010: 44)

We believe that B&C's "substantial autonomy" does not fully consider the particular situation of ill people, because this concept does not come from the "kingdom of the sick", but rather from the "kingdom of the well" (Sontag 1978). In particular, it comes from philosophical and legal conceptions of autonomy, such as those proposed by Harry Frankfurt (1971) or Ronald Dworkin (1988). Although they work in different fields of philosophy, what these authors have in common is that they did not develop their definitions of autonomy for patients, but rather for healthy, "normal" agents or citizens.

To paraphrase Carel (2008: 77ff.), what is needed here is a model of "autonomy within illness" that gives more weight to the subjective, first-person experience. To the extent that chronically ill people report experiencing episodes of well-being or happiness, it is possible to talk about autonomy within illness, but it will not be the kind of autonomy that healthy people are presumed to have. As a matter of fact, autonomy-within-health is also under scrutiny, as recent work in neurosciences (Felsen and Reiner 2011) adds new criticisms to the "standard model" of autonomy based on Frankfurt or Dworkin. This research suggests that human brains are indeed capable of the hierarchical control required for reflective thought, but that decisions conventionally perceived as autonomous may not be rational with respect to the deliberative process itself, and are rarely free from covert external influences. If the capacity for autonomy needs to be redefined in order to align our moral values with neuroscientific naturalism, this is especially relevant for our discussion because patients' autonomy is even more complex and precarious than the one assumed by the standard model (Moreno and Casado 2011).

Three-dimensional autonomy

In bioethics, respect for the principle of autonomy is intrinsically linked to the notion of informed consent for therapeutic actions, with the emphasis usually placed on consent. This suggests that respect for autonomy is mainly understood with an epistemological bias towards disease, towards taking into account the available therapeutic options, and fails to give due consideration to illness and sickness. Here we claim that an adequate account of patient autonomy should include other dimensions in addition to the medical decision-making. As Hofmann notes:

> If the medical profession is the only one identifying negative bodily occurrences, their sensitivity to the interests of the person and society will determine whether they act paternalistic or violate patient autonomy. Additionally, one can question how well a person without illness understands information about diseases that he or she cannot experience. Is there a real informed consent?
> (Hofmann 2002: n12)

As evident in the above quote, Hofmann doubts that a health professional could really *inform* a patient adequately about something he or she does not experience. He is warning us against using a notion of autonomy that is mainly related to the disease angle of the triad. Our understanding of autonomy would improve if we could situate our concern in a more comprehensive perspective that included illness, the more personal subjective dimension, and sickness, the more social dimension. In other words, *patient autonomy is more than decision-making.*

Indeed, some studies have argued that, especially in chronic disease, autonomy extends beyond "punctuate decisions" (Kukla 2005: 35). Patient autonomy cannot be reduced to decisional autonomy: it is not so much a matter of what patients or proxies freely and knowledgeably decide at any given point, but rather an essentially conversational, dialogical *process* (Árnason 2000) in which patients, professionals, relatives and others engage in assuming, assigning and deflecting responsibility within a specific practice. In this process the crucial aspect is not the particular content of the decision, but the *agency* involved – who is accountable in the practice, to whom, and for what. This is an important perspective because it reminds us that society and the state are always present in the patient–professional relationship. Health care is indeed a triangular affair.

In an article published in the *American Journal of Bioethics*, Naik *et al.* (2009) warn that the perspective of mainstream bioethics might be neglecting some important features of what it means for people to be ill. They argue that patient non-compliance (behaviour incongruent with the treatment plan) is interpreted by clinicians as either an autonomous refusal of the physician's recommendations or the result of significant impairments in decisional autonomy that need to be assessed and managed. But some patients with chronic conditions may articulate understanding of the management plan and appear non-compliant when in fact they are unable to implement the steps necessary to meet the treatment objectives. Thus Naik *et al.* argue for an expansion of the concept of patient autonomy to include not only decisional autonomy, but also the patient's capacity to execute complex self-management tasks – what they call *executive autonomy*.

This re-conceptualization of the concept of autonomy should be further expanded in order to supplement its decisional and executive components with a particular approach to other aspects of patient autonomy. For instance, what we call *informational autonomy*: the personal management of health-related information, the right to give or withhold it freely and without pressure, the necessary know-how to communicate with others about illness. This component of respect for autonomy has been traditionally associated more with research or information technology ethics than with health care. However, it has been increasingly addressed by European law and bioethics (Casado 2009b) and deserves further consideration.

The informational and executive dimensions of autonomy presuppose an understanding of human agency as intrinsically temporal and social, embedded in culturally elaborated norms, habits and conversations. There is nothing unnatural about autonomy, but it does require a certain form of self-consciousness, which does not arise without the cognitive and communicative abilities required to enable the attribution of some kind of responsibility, which is assigned (or deflected) by discursive, although not necessarily verbal, social interaction. This emphasis on the relationship between autonomy and human communication is shared by other authors. For instance, Philip Pettit (2001: 177) sees human autonomy or freedom as something depending on persons having "the ratiocinative and relational capacity required for being authorized as a discursive partner: their being conversable, in at once a psychological and a social sense." In this sense, to be an autonomous agent (be it patient or doctor) is simply to be the type of self that can live up to the commitments generated in discursive relationships. Performing an autonomous action means performing it as the type of agent who can be held responsible for reasons. After all, we are not born autonomous: we are *made* autonomous, and therefore responsible, by interacting with other agents, including, of course, the professionals who take care of us.

DISCUSSION: WHAT PHILOSOPHY OF MEDICINE OFFERS TO BIOETHICS

Health care is a complex affair. No single concept of disease is capable of capturing, on its own, the complexity inherent in this kind of human relationship. The immanent triadic character of the definition of health by the World Health Organization (WHO) remains a helpful integrative approach to health and disease but, as we have shown, mainstream bioethics, as represented by the "four principles" approach used by B&C, is not sufficiently informed by the triadic concept of disease. This is primarily because the perspective of the ill patient is not adequately present in the principle of respect for autonomy, both in theory and in practice.

Respect for autonomy requires taking illness, the subjectively lived experience of requiring care, into account. But throughout the world, bioethics is mostly being institutionalized by creating ethics committees in every major hospital, and these committees are mostly made up of health care professionals. In our experience, narratives and complaints put forth by patients themselves do not, for the most part, become "cases" and are not often addressed as such by these committees. In Spain, the involvement of lay participants in such committees is generally seen as something that is desirable but hard to put into practice (this absence of social and patient participation in institutional review boards is identified as a problem by comprehensive studies such as Nicolás and Romeo 2009). There may be other examples of how the perspective pursued by the triad might be useful, but in this paper we have argued that adopting something like it helps us understand why this is happening: by using a concept of autonomy which is modelled on certain presuppositions about the autonomy of healthy, "normal" people, mainstream bioethics prioritizes the health care professionals' point of view to the detriment of the other dimensions appearing from the perspective of people in need of care. This is problematic because in bioethics, there is no such thing as "normal" people: what we have here is autonomy-within-illness, not autonomy-within-health.

This bias towards disease is visible in practice, in the heuristics of how bioethics is practised today. In this chapter we have explored a basic hypothesis about the historical sources of this phenomenon: bioethics was born in a technologically mediated medical culture in which the main focus was on cure, not care. The emphasis was on decision-making, and the decisional autonomy of patients. Other dimensions of autonomy were relatively neglected (how to cope in time – executive autonomy; how to manage communicative exchanges concerning one's health – informational autonomy). This created a bias towards autonomy understood simply as the capacity to decide given certain therapeutic options, which again is more related to the epistemological perspective associated with disease.

Reflecting on the triad of notions disease/illness/sickness can help illuminate and critique the "four principles" account of bioethics. In particular, we have argued that the concept of autonomy should be expanded towards a notion better able to account for the kind of autonomy that ill people could sustain if the appropriate care is provided. This implies a multidimensional stance that takes into account not only the quasi-legal or juridical elements related to decision-making, but also different aspects linked to the executive and informational dimensions of autonomy, in order not to neglect the particularities of what it means for people to be ill. In this chapter we have tried to move beyond decisional autonomy, on the path connecting bioethics and the philosophy of medicine. Much is yet to be done regarding re-conceptualizing patient autonomy along these lines, but the resulting model will undoubtedly be more egalitarian and inclusive than the mainstream one. A consideration of the most neglected aspects of the triad supplements our understanding of what it is like to require health care, and what we should focus on in order to provide it and to advance the autonomy debate in bioethics.

Furthermore, this debate on autonomy in bioethics is related to various other issues that affect the way we conceive of medicine. Canguilhem saw medicine as an *art at the crossroads of many sciences* (1978: 34). However, the characterization of medicine as an art, rather than a science, responds in part to an extremely narrow positivist conception of the nature of science (i.e. as the elaboration of theories that explain phenomena), which does not correspond to the conceptions present in contemporary philosophy of science, for which science is not so much involved in the task of constructing theories, but rather consists of a set of practices (experiments, simulations, classificatory practices, data collection and retrieval, etc.) informed by theories. Thus, many would say that science itself can be conceived as an art, because of the importance of its practical or productive function.[11]

The knowledge style of medicine does not coincide with that of a positivistic science, but that does not mean it cannot be scientific. In this sense, a valid way of characterizing medicine's style of scientific knowledge could be to appeal to the triad of disease, illness and sickness as a means of expressing the need to take the personal, social and biological aspects into account. This broader understanding of ailment based on this triad acknowledges the medical perspective of the phenomenon and aims to encompass the naturalist aspiration to objectivity, while at the same time taking into account the perspectives of both patients and society.

CONCLUSION

An exploration of how the triad of notions disease/illness/sickness fits in with the "four principles" account of bioethics should not simply result in a negative indictment that emphasizes certain deficiencies in the way autonomy has been understood in bioethics. Rather, and to put it in more positive terms, we advocate an alliance between bioethics and the philosophy of medicine through a re-conceptualization of patient autonomy, in terms of the actions – personal, medical and social – that need to be taken to sustain the form of living of those in need of care. This implies a multidimensional stance that takes into account not only the quasi-legal or juridical elements related to decision-making, but also different aspects linked to the executive and communicative dimensions of autonomy, in order not to neglect the particularities of what it means for people to be ill. We have argued that the concept of autonomy should be expanded from the capacity to rule one's life through independent decisions towards an epistemological and ethical account of how people can interactively enhance their ability to sustain a life through appropriate care. By understanding autonomy this way the gap is narrowed between the ethical and the scientific goals of medicine.

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