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MINOR PATIENTS' AUTONOMY. RECOGNIZING THE DIGNITY TO CREATE CAPABILITIES

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Abstract: The current health legislation recognizes minors' capacity to make decisions or, at least, to take part in those that affect them, according to their age and maturity. But this capacity is not promoted. Capacitating minors to make their own decisions is still a challenge, because it requires something that today is not happening: autonomy has to be understood not as a state, but as a process that needs support. Our proposal is that this support should be based on recognizing minors as vulnerable persons, that is to say, as persons with emotional needs, who are the subjects of rights and duties, and who have social needs of self-fulfillment. All in all, autonomy has to be understood as a process based on recognizing minors' dignity as a previous condition to help them acquire those typical capabilities of autonomous persons. This concept of support requires, in the first place, a change of the social view of minors.

Keywords: *autonomy, minor patient, recognition, capabilities, empowerment, pedagogy*.

INTRODUCTION

Respect for patient's autonomy has become a fundamental bioethics principle, which has brought about legislative and paradigm changes. However, the previous pedagogy needed to develop yhat principle has not been implemented yet. A pedagogical process of autonomy forging that begins with the assistance relationship with children and adolescents is necessary in order to have autonomous adults. Furthermore, this process requires something that goes beyond the pediatrician surgery. The social view of minors has to change in all areas: family, school and society as a whole.

Thus, our proposal of minors' capacitation needs two questions to be answered: In which sense does the traditional view of minors have to change in order to promote autonomy? And, from this view, how can minors' autonomy be encouraged in the health care field?

THE FRACTUOUS VIEW OF MINORS

The western culture has traditionally assumed that minors are not autonomous, because they are neither moral agents nor subjects of rights. This culture states that the faculty of making moral judgments is linked to reason and that children do not have the same capability of moral reasoning than adults. In other words, minors are not mature. Let's have a historical overview of the social conception of minors.

In prehistory the elderly are beloved because they are the tradition's bounders and transmitters and thus they become the cohesive force of the family life. In this context, minors are thought to have the opposite characteristics as those attributed to elderly: impotence, ignorance, rashness.

The first great attitude change takes places in Greece (De los Reyes Lopez, M., Sánchez Jacob, M. (Eds.)., 2010).[1] The Greek culture is naturalistic: moral is identified with natural. It is considered that nature achieves physical and moral perfection in maturity, which is the stage in which certain virtues are acquired. In Greece both children and elderly are flawed, because they are in an intermediate state between health and illness. The old are flawed to excess, because they are de-

[1] Ch. 4 and introductions of Ch. 5, 40.

crepit and minors are so by default, because they are immature. They are not subjects, but objects. They are their parent's possessions. That is why minors are seen as physically and morally flawed, apart from incomplete, defective and thus in some way ill (*in-fermus*),[2] frail, unable to look after themselves. The childhood is a period that has to be overcome as soon as possible and in the best possible way.

With Rousseau and the Romanticism culminates the second great attitude change. Now the paradigm of perfection is the child-adolescent. Rousseau claims (1970 and 1985) that children are the only healthy ones and that humanity is to be found in childhood and adolescence: the child is naturally good (acts rightly). Evil and unfairness arise in social relationships. That change of conception is put down to minors' school enrollment, which makes children to be non-anonymous and the center of the family life. They are beloved by their families and do not have an inferior status anymore. Childhood is just one stage in human life and probably better than the others in terms of happiness.

Nowadays the earlier stages of the human being's life are the most beloved ones. Childhood is considered to be the personality blooming period and the one of identity reassertion. Values and attitudes, and thus a lifestyle and a vital project, are built up over it. During second half of the twentieth century, the absolute and paternalistic protection of minors is mitigated and the ownership of some of their rights is recognized. Laws that give and grant rights to minors are passed. One example is the Declaration of the Rights of the Child (UN, 1959).

However, this situation leaves a lot to be desired. Although the rights' ownership of minors is recognized, there are some areas in which their capacity to exercise them is still not recognized, because neither is their maturity, beyond exceptional cases[3]. In general terms there is a fractuous view of minors: professionals that have to respond to minors' needs often reduce them to the dimension each one takes care of. Teachers reduce minors to minds that have to be completed

[2] In Spanish the word 'ill' is translated as 'enfermo', which comes from '*in-fermus*', meaning not solid.

[3] It happens in the health care area, in which minors from 12 years old can be 'mature minors', that is to say, they can make their own decisions regarding their health, but this possibility is exceptional: minors are immature as long as the physicist does not prove the contrary.

with knowledge; politicians consider them to be citizens that have to respect the rules of social coexistence; the media consider them consumers....

But the person cannot be reduced to just one of its dimensions. Eric Cassell states that the person is a joint of "me" (me as a child, as a pupil, as a son...), so everything we do implies the person as a whole. He defines it as "*a human, bodily, thinking, reflective, sensitive, emotional and relational individual*" (Cassell, 2009:15-16). Mounier (1976:59) defines it as "*a spiritual being, which is composed of a form of subsistence and independence that is maintained by joining a values hierarchy, freely lived and responsibly assimilated and in a constant correction. All unified in a free and creative activity.*"

Therefore a comprehensive view of minors is needed for integrating all dimensions in an autonomous subject with a vital project, as a biopsychosocial and spiritual being. Obviously, minors do not have all dimensions as developed as adults, they still do not have its vital project forged, because they are neither fully nor always autonomous. Minors are thus a biopsychosocial and spiritual being, but vulnerable. Professionals that take care of minors' needs have to support them in their autonomy development process, each one from his area, but without losing perspective: the ultimate goal has to be to help them to develop their autonomy as a complete, biopsychosocial and spiritual person.

CLARIFYING CONCEPTS

This comprehensive view implies that supporting minors' autonomy development process means to satisfy their expectations of recognition, which is the opportunity they need to develop the capabilities required to be autonomous. The idea of recognition is explained by Axel Honneth and the capabilities are proposed by Martha C. Nussbaum. Before going deeply into it, though, some concepts need to be clarified.

The first one is 'minor'. Minors are people under 18, or under 16 in health care. Anyway, the age-group between 0 and 10 years is called childhood and at 12 years adolescence begins. The age-group between 10 and 12 years can be childhood or adolescence depending on the child's maturity.

The second concept to be defined is 'health'. Jordi Gol Gorina[4] defines it as the personal, caring and joyful autonomy. The WHO defines it as the state of full physical, psychical and social wellbeing. Both definitions may seem presumptuous and difficult to put into effect, although they stress an important idea: there is not a clear delimitation between health and illness, but there are degrees of health that one loses and wants to regain. Therefore, a healthy growth is not one without illness, but one based on an appropriate dealing with health conditions, which makes prevention to be extremely necessary.

The third concept is 'autonomy'. It has two dimensions: moral and functional. The moral autonomy is the capability to make decisions according to one's own set of values and personal goals (Beauchamp and Childress,1979). The functional autonomy is the possession of basic abilities to be self-sufficient in the daily-life activities. Although both dimensions are significant for minors' growth, we will focus on the moral one and it will be understood as synonym of maturity.

It has to be said that autonomy is not opposed to 'vulnerability'. Several authors (Honneth, 2009; Buttiglione, 1999; among others) claim that the human being is vulnerable by definition, because he is dependent on his relationships with others. Thus vulnerability (as dependency) is not a weakness, but a condition of the possibility to acquire autonomy. That is why support is so important.

Without avoiding the complexity of defining 'dignity', we will stay confined to the intuitive idea of the inner value that every person deserves just because of being a person. Dignity, on the contrary of autonomy, has no degree: either one has it or not. Autonomy can be partially or totally lost, but dignity remains.

The last concept that needs defining is 'justice'. It will be understood as equal opportunities in order to develop capabilities. Consequently, injustice is the infringement of equal opportunities.

SUPPORT AS VULNERABILITY RECOGNITION

Recognition (Honneth, 2009; and Costa-Alcaraz, 2012) is mutual respect based on the equal dignity of all human beings. That is why the struggle for recognition begins when expectations of recognition are in-

[4] X Congress of Catalan Physicists and Biologists (Perpignan, 1976).

jured. Injuring them is a moral crime that generates feelings of injustice, whereas satisfying them helps to transform conflictive relationships into cooperative ones.

Honneth proposes three recognition spheres. The first one is love, which is defined as having lived within a family and having been accepted as one is. That makes interpersonal relationships easier. Injuring the expectation of emotional recognition means a physical humiliation, which makes self-confidence decrease. The second sphere is law and is defined as becoming a subject of rights and duties and thus in having a shared identity as a member of society. Injuring the expectation of legal recognition means a limitation of individual rights, which makes self-respect (moral responsibility) decrease. The third sphere is solidarity, which is defined as respecting the positive contributions. Injuring the expectation of social recognition means a degradation of self-fulfilling possibilities, which makes self-esteem decrease.

The ultimate goal of recognition is the personal identity forging, as long as others help to it: the recognition by others allows self-recognition, which makes to have the conviction of the own moral and social value. The acquisition of self-confidence, self-respect and self-esteem helps person to forge a vital project in which he/she conceives herself as autonomous and individualized[5].

Let's extrapolate this approach to minors. Minors are a social group that cannot become a lobby, because they meet none of its three requirements: they are aware neitherof their own vulnerability, nor of the power of the fight and thus they do not fight. The others (family, teachers, physicians, society as a whole) are the ones that have to fight on their behalf.

That is why recognition cannot be reciprocal, but adults have to recognize that minors are more dependent on others than them, that is, more vulnerable. So the recognition is based on equal dignity of minors with regard to adults. Minors' dignity has to be recognized as a previous step to permit (and support) their autonomy to develop. Traditionally minors were not considered to be autonomous, because they were not considered to be mature. Now it appears that they were not considered to be mature because their dignity was not recognized. And the way to recognize it is by fighting on their behalf, by not injur-

[5] Other authors have similar thoughts to those of Honneth, i.e., Ricoeur (1966) or Lévinas (2000).

ing their expectations of recognition[6] in order to establish a cooperative relationship with them.[7]

Regarding the three spheres of recognition, the emotional one is the recognition from parents, as long as they are the minors' first and most significant moral standards. That makes them to be self-confident and also their relationships with others (teachers, physicians, other adults or other minors, who can also become moral standards) are facilitated.

The legal recognition is the recognition of minors' ownership of rights and –according to their cognitive development– their capacity to exercise them. But minors have to be also recognized as subjects of duties.

Social recognition is the respect for the degree of autonomy that minors have in each situation. That respect can be shown by helping them to choose their moral values and to forge their vital project (or questioning inappropriate behaviors with assertiveness) and also by having them participate in the decision-making process, letting them assume responsibilities according to their age and cognitive development.

Lastly, recognition helps minors to forge their identity in a more decisive way than in adults, because they are just beginning to define both it and their vital project, and the beginning can determine the process and the end. The fact of having their moral and social value recognized or not and thus that they believe it or not, will determine their personality to a large extent and, ultimately, whether they will tend to recognize others or not. The three spheres of recognition, therefore, will make minors to conceive themselves as immersed in the forge of their vital project, that is, in the process of developing their autonomy and forging their own individuality.

SUPPORT AS CREATION OF CAPABILITIES

Recognition is the opportunity that minors need to develop those capabilities needed to be autonomous. According to Martha C. Nussbaum

[6] Expectations can be created and directed, minors do not have them by themselves. That is why, when exaggerated, expectations can be injured (educated). But here we are talking about expectations of recognition.

[7] Relationships are a very important quality of life's constituent, which has three dimensions: objective (real), subjective (perceived) and social (relational). If minors' relationships are conflictive, unhealthy or null, their global quality of life will be very deficient, no matter how good are the objective and subjective ones.

(Nussbaum, 2007 and Gough 2007/08) a fair society has to be based on equal opportunities in order to develop capabilities. Capabilities are what people are capable to do and to be, depending on an intuitive idea of what a life in accordance with human dignity is. However, Amartya Sen (Dréze I Sen, 1997)[8] states that everybody has different needs and different abilities to transform their capabilities into results, that is, into a dignified life. Therefore, equal opportunities means equal possession of all basic capabilities from an appropriate minimum threshold and up to the maximum possible, for each person and each capability. Below that threshold a dignified life is not possible. The idea is to make a list of capabilities and ask what would be the minimum capability compatible with human dignity for each area of activity of a typical human life. All in all, it means asking what each person is capable to do and what is not, and help him/her to acquire those capabilities that he/she lacks.

Nussbaum's list contains ten capabilities, but she says it is only a tentative and reviewable proposal. They are: life; bodily health; bodily integrity; senses, imagination and thought; emotions; practical reason; affiliation; other species; play; and control over the environment. Practical reason and affiliation are the main ones. But, according to Nussbaum, health assistance (in a comprehensive meaning) is a basic citizens' need. It is not one more capability, but the basis of the whole capabilities spectrum. In the health care field, because of patient's dependency (especially the minor patients), the main capabilities are life, bodily health and bodily integrity.

Similarly as in Honneth's theory of recognition, Nussbaum's capabilities approach is based on the defense of individuality, which wants to overcome –among others– the traditional view of minors as no-faced individuals, that is, individuals without a significant identity. The children's right to achieve the minimum threshold of capabilities in order to have a dignified life is due yo often hampered (due to lack of recognition, be for overprotection).[9]

[8] Amartya Sen does not agree with Nussbaum's list of capabilities, but both philosophers are the first ones to deal with quality of life and also both deal with opportunities and liberties.

[9] Appelbaum and Grisso propose four capacities that specify the Nussbaum's 'practical reason' and 'senses, imagination and thought': understanding of relevant information, appraisal of the situation, manipulation of information and capability to communicate a maintained choice in time. Piaget and Kohlberg, despite of being branded as excessively Kantian and harshly criticized by Carol Gilligan, also specifies

MEDICAL CONSULTATION AS A SPHERE OF EMPOWERMENT

In the health care area the fractuous view of minors becomes a biocentric view. Physicians reduce people with health conditions to their biological dimension and understand them as broken bodies that need repair. Traditionally this view has meant that ill people were not considered to be members of society. Nowadays that does not happen anymore because bioethics –and specifically the bioethics principle named 'respected for persons'– has returned the condition of persons to ill people. However, the biocentric view of patients still remains and consequently the relationship between patients and physicians is often merely informative (Emmanuel & Emmanuel, 2010). Furthermore, it can be said (Engel, 1977) that health care has become an industry, because the planning and the funding of health care services depend on the technologies available and as a result everything does: diagnosis is based on tests that are carried out by machines or in labs... All in all, nowadays an evidence-based medicine is being imposed. It has to be overcome in favor of a comprehensive view of illness as a situation with psychosocial determinants, that is, in favor of a comprehensive view that conceives patients as biopsychosocial, spiritual and vulnerable persons, and minor patients as biopsychosocial, spiritual and doubly vulnerable persons.

In order to change the view of illness, its experience has to be understood. Illness is experienced as a threat (Laín Entralgo, 1984: 316; Chapman and Gravin, 1993; Bayés, 2001:47-68). The threat generates suffering and alters the person's time, because it interrupts his/her vital project. Suffering is wider than pain, which is only one of its causes, and the person suffering is subjected to time instead of having it at his/her disposal. So, the physician has to synchronize his professional subjective time (present, accelerated time) with the patient's subjective experiential time (future, slow time of diagnosis and prognosis). In minors this experience is more serious, because they are not used to face adversity (neither have they enough resources to do so), they want immediate solutions to

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the 'practical reason' in those capabilities of an autonomous moral, which could be five: critical thought to weight up alternatives, reflection on one's own moral values, appropriate management and use of resources, empathy, and information management. Apart from capabilities, autonomy also requires attending to the decision's seriousness (Drane's scale shows that the more serious a decision is, the more capacity is needed to make it) and to the environment (familiar, cultural,...). (DE LOS REYES, M., SÁNCHEZ JACOB, M. (eds). (2010) pp., 40-47, 361-364, 368-369).

problems and they exaggerate the frustration of not having their expectations satisfied. In any case, the vital project is interrupted, because the person's world becomes disordered and lose sense. The person is disconnected from his/her world and loses the sensation of indestructibility. That is why it becomes necessary to have a relationship of confidence with the physician, in which context he helps patients not to lose moral autonomy, by trying to make their decisions coherent with their moral values and vital project. Minors are still forging their vital project and developing their autonomy, so the effects of an illness are even more devastating and they will need more than ever a relationship of confidence with caregivers,[10] so that they together with the parents help them to define their moral values and the kind of vital project they want to forge.

Now, in this context, how should recognition of minors be understood? First of all, caregivers have to recognize them as doubly vulnerable (because of being minor and ill). Recognizing minors as having equal dignity as adults means recognizing that similarly as what happens with adult patients, minor patients are still persons, no matter what the effects of the illness are. That is why the forge of a cooperative relationship with physicians that allows the supported decision-making[11] needed.

There are also three spheres of recognition in health care. Emotional recognition is obtained in the relationship between minors and physicians, which has to be based on confidence. Physicians have to rely upon minors by recognizing them as valid speakers, which will make them rely upon physicians and facilitate their relationship with other caregivers. Legal recognition means enacting rights and duties for minor patients, as it happens for adults. And social recognition means respecting each minor's degree of autonomy, by listening to and educating their opinions, but also assertively questioning inappropriate attitudes and behaviors. Similarly, it means making them part of the decision-making process, by letting them assume responsibilities in accordance with their age and cognitive development.

Caregivers, ultimately, help to forge minor patients' identity, because they empower them in being responsible for their health (in terms of both healing and prevention) and in using health care resources appro-

[10] Caregivers are any professionals from the health care system that may treat a minor during his life (family doctor, specialists, nurses, psychologists, social workers...).

[11] 'Supported' seems more appropriate than 'shared', because decisions are individual. What is shared is the previous deliberation.

priately. Here the vital project is specified in a lifestyle: caregivers help minors to develop their autonomy, by helping them to forge a healthy lifestyle.

From this idea of recognition, how are capabilities needed for autonomy translated? Nussbaum's list can be applied to the health care field: life (quality of medical attention); bodily health (personal hygiene); bodily integrity (intimacy); senses, imagination and thought (creativity in solving attainable medical problems, such as remembering the time to take medicines); emotions (capacity to show fear or doubts about the illness); practical reason (reasoning on consequences of attainable medical decisions, such as whether or not a medicine has to be taken despite of disliking its savor); affiliation (affective ties with the physician of reference and the caring team); other species (therapeutic effects of having pets or taking care of pets as an exercise of responsibility assumption); play (promotion of playing among minors admitted to hospital); and control over the environment (familiarity with the medical establishment, the surgical instruments...).

At this point, how can recognition be settled in the medical consultation in order to allow capabilities to develop? The answer is by making the medical consultation[12] be a sphere of empowerment with several characteristics (Catalonia Bioethics Committee, 2009) that can be classified in four steps. The first one is familiarization with the environment and basic procedures (national health clinic, caregivers, set of instruments and procedure to make appointments).

The second and most important step is to create a sphere of recognition, which should have several characteristics: it should be based on mutual confidence; the caregiver has to avoid both paternalism and placing adult responsibilities on minors; he/she has to assist minors' vulnerability not as a weakness, but as a chance for their empowerment, which has to be achieved through the ethics of care[13]; he/she has to synchronize his/her professional time with the minors' experiential time; he/she has to listen to the minors' account of their problem; he/she has to assist minors' needs

[12] The medical consultation does not need to be a physical room neither be located in the national health clinic (i.e.: 'Health and School' program, in Catalan 'programa Salut i Escola') or it can be a phone call (Samaritans). The medical consultation thus is the circumstance in which a minor addresses a caregiver to share a health problem with him (in a comprehensive sense of health).

[13] To know more on this concept read Carol Gilligan (1982), Sheila Benhabib (1992) or Francesc Torralba (2002).

and detect any lack of family recognition (first sphere); all this leads to a supported decision-making process based on an attentive listening; and therefore all this needs communication abilities, such as empathy and compassion. As to this last point it would be positive to have caregivers trained in vulnerability management as there are in diversity management.

The third step is education for health. Assuming that minors and their families' personal options have to be respected, physicians have to take an educative role. This role should have several dimensions: healing, illness prevention and risk prevention. It should have as well a previous condition: an appropriate information, which has to be complete, truthful, continued, adapted to minors' cognitive development and contrasted with their experience. Education includes the *knowledge* (having information), the *know how* (choosing ethical criteria to act) and the *know how to be* (how to be responsible, how to forge one's identity and vital project). Parents should have an intermediary role, but never an interlocutor one (they have to help, but not to substitute minors, who are the subject of the health condition).

The last step is getting unhealthy behaviors back on track. Caregivers should wield an assertive authority so that minors do not lose confidence with them and at the same time modify those behaviors voluntarily.

PROMOTING AUTONOMY FROM A NEW VISION OF MINORS

This paper maties a proposal of minors capacitation based on understanding autonomy as a process that needs support, which firstly requires a change in the social view of minors. This proposal aimed at answering two questions: In which sense does the traditional view of minors have to change in order to promote autonomy? And, from this view, how can minors' autonomy be encouraged in the health care field? Now both can be anwered.

The social view of minors should be modified in favor of a comprehensive one that does not fracture them but conceives them as a whole –a vulnerable, developing whole. This new vision has to consider the experience of illness as that of a threat, which generates suffering and slows down the minors' time, because it interrupts their vital project and thus it makes a relationship of confidence with caregivers necessary. This relationship should help minors forge their autonomy, by helping them choose their moral values and the kind of vital project they want. All in

all, the new vision as to be one that conceives minors as biopsychosocial and spiritual, vulnerable, beings.

This new comprehensive view will allow caregivers to promote minors' autonomy, that is, to support them in the autonomy development process. Firstly, caregivers should grant minors the opportunity they need to develop basic capabilities. This opportunity is the emotional, legal and social recognition of their dignity, which means relying upon them, respecting them and loving them, so that they can have self-confidence, self-respect and self-esteem. This recognition will transform the medical consultation into a sphere of empowerment to help minors develop the ten basic capabilities of an autonomous person. In that way minors will forge a healthy lifestyle as a significant part of their vital project.

Obviously, this is a theoretical proposal that needs to be translated into a practical usable tool for caregivers working with children, to allow them to transform the informed consent process into a supported elaboration of each minor's health problem. It should be done according to the narrative ethics and the ethics of care. But that would mean another paper.

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