The problem of individual autonomy and family authority in decision-making in clinical ethics

El problema de la autonomía individual y la autoridad familiar en la toma de decisiones en ética clínica

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Abstract

With the aim of studying some ethical problems related to clinical situations involving the family, a systematic review of this term is presented to understand and define it. Conceived as an organic body in its constitution, structure and organization, this article analyzes the various circumstances in which there is a relationship between clinical ethics and...
the family, mainly emphasizing the difference between individual autonomy and family authority.

Keywords: personal autonomy, clinical ethics, family authority, family clinical practice guidelines.

1. Introduction

Currently there is a prevalence between individual autonomy and the rights involved in family medicine (1), leaving the role of family authority in medical decisions without considering the richness and significance of this category. Family authority is understood as the participation and influence that the family has in the decision-making of its members (2), whether in the medical field or in other types of personal or collective decisions. This participation can range from collaboration to oppressive, abusive and controlling relationships. It is important to point out that for the various authors who address the relationship between personal autonomy and family authority, there is a conflict between the patient and the family, especially due to the difference in values and priorities that can occur between the choices of one and the other (3,4). The position maintained in this paper is to affirm that this conflict exists, particularly when the family is not structured as an organic body. On the contrary, the good of the family implies the good of the patient, since the family is a system that functions in a particular way, i.e., its constitution, structure and organization is guided by values and principles that must be considered in clinical ethical problems.

2. The principle of autonomy: theory and practice

The principle of autonomy as the only moral ethos in clinical ethics has meant for the patient the freedom/right to choose treatment (5)
as opposed to a paternalistic view of health care and the understanding of the patient as a mere recipient of care (2). However, this “liberal-individualistic” consideration does not consider that autonomy also means the responsible use of freedom, for example, in the field of autonomy the responsibility for personal decision must also be considered. The patient (with fear, denial and vulnerability, inherent to a condition caused by a disease), is responsible for the decisions he makes about himself and about those who make up his family.

Autonomy, in the long history of its formulation, has received a variety of considerations (2,6-8), highlighting the difference in the approach presented by principlism and personalism in their definitions. For the principlism current, the definition of autonomy, supported by Immanuel Kant and John Stuart Mill as an ethical principle, refers as:

That all people have intrinsic and unconditional value and, therefore, should have the power to make rational decisions and moral choices, and each should be allowed to exercise his or her capacity for self-determination (9).

Whereas for personalism, respect for autonomy means:

Respecting its freedom, that is, its capacity for self-government [...] (which is found) in the human will, by means of which the moral agent can order his action (10).

This autonomy is not absolute, but relative to “the will and its capacity to will, to understand and desire the good as good, respecting in this the natural law offered to man”(10). Therefore, in personalism, autonomy is understood within the scheme of the classical virtues, the free will and the idea of good, while in principlism, autonomy implies this personal intention of the will and the act of being in itself free, as “the very definition of the human”(10). In principlism, there is this internal struggle between the individual right of freedom against the coercion of others (10).
The family also occupies a preponderant place in the construction of personal individuality, in the first place, because people are born and develop in diverse family contexts. To speak of family, it is necessary to make a distinction of the elements that compose it both *ad intra* and *ad extra*. *Ad extra* we find the extended family, the city, the nation, society, international and global relations. *Ad intra* we find not only its members (father-husband, mother-wife, and child-sibling) but the human being, his history, his circumstances, his integral being. The family itself is a network of relationships between all these actors.

3. What is the place of the family in clinical ethics decisions?

Some authors are on the side of the family and support its importance in medical decisions by defining the family as:

- “A place where the patient recovers his identity that is lost in the disease (utilitarian vision)” (11).
- “An ontological reality that helps to consider the social being (existence) of the patient” (1).
- “A means of recovery of the patient, given that the family provides security, help and assistance in illness or as a group in which the patient’s interests may be subordinated to certain perceived collective interests” (12).
- “The source of authority to authorize the patient’s treatment. The Eastern, Confucian family view” (14). The Eastern reality is one of the most interesting to address. In fact, for Eastern ethics, principles are not only founded for action, but are the embodied and active life of virtue. The principles of Confucian ethics are piety, reciprocity and sincerity.
- The place where the patient regains confidence and security (5), which the disease takes away and leaves the person vulnerable.
• For other authors, the family is a source of authority only when there is an “extraordinary community” (14), defined as one where there would seem to be no conflicts. However, in families there is love, generosity and sacrifice, as well as jealousy, resentment and even hatred. Paraphrasing D. Winnicott, we are before the idea of a sufficiently good family (15), which will come to the rescue of the development of the person in his maturity achievements.

As far as civil law is concerned, we can say that there is also a problem between private law and the possible right of guardians or relatives to decide on the health of the sick (16). However, civil law confirms the autonomy of the individual rather than the role of the family, which comes into play only when the patient is not capable of understanding or wanting to (16). In this case we refer, within the legal context, to patients who are always competent, that is those who can make decisions freely, as opposed to incompetent subjects, where all decisions fall to their relatives or legal guardians.

4. Moral dilemma in diseases directly involving family decisions

A moral dilemma is an “extreme situation of moral conflict in which our agent cannot follow a course of action that is in conformity with his or her two conflicting obligations” (17). This dilemma poses a conflict between individual autonomy and family authority in establishing, who is the legitimate decision-maker? That is, who has the authority to make or guide a decision in certain medical situations to their final resolution? This problem arises when medical decisions involve not only the patient, in his individuality, but also the authority that the family assumes inwardly as a group of relationships and outwardly in its social and caring role. In addition, the individual in his own disease needs the family as this place of return to his
identity, security and freedom, which the disease removes or disturbs. It is in these circumstances that the family recovers its moral ethos in medical decisions.

Below we consider some cases in which the family has a moral right to participate in medical decisions in clinical ethics:

- Genetic studies (related to genetic information) and reproductive conditions.
- Illnesses or medical research on children.
- Organ donation between family members or organ transplantation between non-family members (when the family does not respect the donor's decision, physicians ask the family before starting any surgery) (17).
- Problems of long and costly illnesses (e.g., terminal cancer).
- Disabled patients (e.g., patients with Down syndrome, Alzheimer’s or Parkinson’s).
- Degenerative diseases (e.g., geriatric or mental illness).
- Long-term or dependent rehabilitation process, with assistance from a caregiver.
- In those cultural groups where the family assumes a decisional role in its members or intimates such as Confucian, Latin, Southern, Islamic, Indian families, among others).
- Permanent vegetative state.

5. How to solve the problem between individual autonomy and family authority?

Some authors give answers to the problem between autonomy and family authority.

- Some responses are sociological or psychological, such as narrative bioethics (19). This approach proposes that when the patient or his family tells the story of the disease, the
existential sovereignty lost by the disease is recovered, helping to work on this feeling of vulnerability in those involved.

- Others seek to rethink a community approach that values the relationships between family members as what gives meaning to people’s lives, where individual rights take second place to the generosity experienced in the family as a whole (20).

- Others present the feminist idea of relational identity (2,21-23), which:

  rejects the normality of an individualistic ethic, where social and family relationships are excluded from the construction of the ego. This individualistic ethic reinforces a decidedly masculine vision that does not value family or social relationships (2).

- Others originate in the business world. The partnership model proposes:

  give family members the opportunity to attend meetings with the physician, but also to present their interests and concerns, for example, their financial ability to treat the patient at home or willingness to handle the resulting emotional stress (12,24-27).

- Others such as Hardwig or Blustein argue that medical problems should be solved in meetings between the patient, the patient’s family and the physician, which takes the form of clinical counseling. This family conference (5) or community history (14) is reminiscent of the community approach, but from a clearly organizational and participatory view of decisions.

- In addition, others speak of relational autonomy, where there should be a relationship between intimacy and responsibility that exists within the family, but when this relationship is not present (due to a serious cause or an incapacitating illness), the law must intervene (28). This measure is taken only in extremis, by means of a guardian.
• From a multisystem viewpoint, which includes the psycho-socio-spiritual dimensions, the role of the ethics committees in the ethical-clinical counseling in conflicts between the patient and the family has become more relevant with the passing of time. In these committees, the participation of various agents, not only from the health field, allows for an integrative vision that takes into account the role of the family, the patient and the health care team. Thus, ethics committees have become mediation entities between conflicts.

6. A possible solution to the problem: the family as a body

Considering the family as a body implies establishing a dialogue between Christian anthropological ethics and General Systems Theory (29,30), to establish a decisional process (decision-marking) in clinical cases in the family setting that helps to resolve ethical dilemmas that directly involve family decisions.

In order to establish our working hypothesis, we have considered the following theoretical approaches that address Christian family ethics and General Systems Theory as foundations:

a) the organicist theory that designates the tendency to conceive society as instrumentally like a biological organism, prevalently human, where society appears, therefore, endowed with an organic life that is articulated in differentiated parts, which are constituted by organs. This serves to ensure the primacy of the whole over the parts and to legitimize a hierarchical social order distinct in roles and functions involving coordination and reciprocity (31); b) Biblical theology, which defines the original family as “one Caro” (24), that is, as the source of the common origin of man and woman, a sign of their equality of nature and dignity and oriented to procreation (32). Also to form an ordo amoris (lat. ordered love) and a societas amicalis (lat. amicalis) in marriage (33-36); c) Systemic Family Therapy, which conceives that neither people nor their problems exist in a vacuum, but that both are intimately linked to
broader reciprocal systems, of which the main one is the family (37), and d) the contributions in the definition of the living, by Maturana and Varela, in their formulation of autopoiesis as a definition of the organization of the living (38). Although Varela himself does not mention the family as an autopoietic structure in itself, but as a space of human institutions (39).

Taking into consideration this theoretical framework, the hypothesis affirms that the family is an organic body *sui generis*, which is defined as a network of continuous and permanent production of components that constitute in this process its identity, as a system closed in itself. The family in our interpretation resembles an organic body, in its constitution, structure and organization. This implies attributing to the family some properties of the body, which shape its being and outline its structure. These family properties are: 1) The family has a defined structure and organization; 2) The family is understood as a reality interrelated among its members; 3) The family is born, grows and dies; 4) The family maintains its being and adapts; 5) The family reproduces itself; 6) The family is an organized totality. These elements make up our theory and formulation where the passage from this theorization to ethics is a natural step, since what is a body must act as such. We have called this the passage from the *imperative* (the theoretical concept of the family: should be) to the *vocative* (the acting of this theory: that which is done), that is, the family as a corporal being must be that which it is and which acts, a place where one lives and promotes communion among people. In order to achieve this, a clinical practice guide for decision-making will be presented below, which aims to help discern the ethicity of a family act. This guide is structured in two categories: a) the fundamental value of the family, called *ordo amoris*, and b) the two principles that flow from this ordered love, the principle of responsibility and the principle of totality.

In the family as a body there is an ideal value to be realized, which we have called *ordo amoris*, that is, ordered love. This ordered love explains the relationship between the individual and the family.
If the actions within the family are carried out in view of this ordered love, understood as a good to be achieved, it would then imply that it would be from the vision of Christian anthropology. That is through respect for the three family goods: the good of the children, the good of fidelity and the good of mutual reciprocity of the marriage bond (48).

These goods that describe the relationships and their quality within the family and between spouses, are a potential value since in the family, the ordo amoris is a goal to follow that must consider not only the human limits themselves, but also the contextual elements or circumstances that can aggravate or diminish the goodness or badness of a human act. Therefore, our discernment has as its premise that in each family, this ordo amoris is a reality to be discovered, a vital force that moves the family around two aspects, unity and differentiation.

Therefore, the question that must guide all this discernment applied to a clinical ethical case is: does an ordered love exist in this particular case? For this value of ordered love to be realized within the family as a body, two guiding principles must be realized: the principle of responsibility and the principle of wholeness.

a) The principle of responsibility (40) affirms, within the value of ordered love, the existence of a double commitment within the family. One of a personal type, which affirms the individual freedom and autonomy of its members and another, of a relational type, which affirms the value of the actions or dispositions of the family system in relation to its members and other systems. Both responsibilities help the family system to develop new skills or functions that allow it to evolve and adapt to new situations and needs.

b) The principle of totality affirms the existence within the family as a body, on the one hand, of an individual good, that is, the good of the whole person, guaranteeing his freedom and, on the other hand, a relational good understood as the good of the family in its organic unity, which guarantees its unity.
and its preservation. The function of the principle of totality is to compose these goods by integrating them into the unity of the family body. As it has been said in the family as a whole, one’s own good is realized together with the good of the others; even more, the personal good, depends on and is related to the good of the family as a whole.

The principle of totality for its application requires compliance with both the deontological norm and the teleological corrective. The deontological norm (41) states that within the family one must act in such a way as to respect and love the members. Working in view of this ordered love for the good of the family, while the teleological corrective establishes that within the family one must act in view of this love, out of love for each one and for the good of the family as a whole.

7. Ethical evaluation of moral dilemmas in diseases directly involving family decisions

When physicians or health care personnel have the opportunity to help a patient or his or her family discern about a possible treatment, they become involved in this family relationship as part of the family system’s process of evolving and adapting to new situations and demands. The physician, whether willingly or not, from the moment the patient enters the consultation room, becomes part of this family relationship network, not as a member, but as part of the process of adaptation of the family organism in the search to recover its condition of homeostasis lost by the disease. This involuntary participation of the physician has a series of consequences. From the family there are questions of help; support and advice, but there are also emotions such as uncertainty, worry, anxiety and hope. In this maelstrom of human life, there is also the story of the family itself. As we said before, in the story of the family there is “love, generosity
and sacrifice, but also jealousy, resentment and even hatred”. Therefore, we can also speak of the vulnerability of the family (42).

All this must be confronted with the figure of the sick person, his vulnerability and the loss of identity generated by the disease itself. This reality, in the sick person, is lived in the duality of knowing (when and if he/she is conscious) how weakened he/she is and, of knowing that his/her situation causes suffering in his/her family, how it causes pain in his/her own body. The patient as an autonomous subject must, based on this duality, make decisions that take into account this *ordo amoris*, that is to say, this love for himself and for the good of the family, this is called *teleological correction*.

The hypothesis put forward is then to affirm that this duality between relief of the patient and concern for his condition makes the figures of the family and of the health personnel fundamental. The health personnel must help, to the extent of their technical possibilities, to deal with the difficulties caused by the disease. To bring the patient to a situation of improvement or recovery, when possible, without ever neglecting his care, while the family must, to the extent of their capabilities, welcome the patient’s concerns and accompany him on the road to recovery or care. The family, as part of the patient’s history must, following the *deontological rule*. As to respect and love the members of the family, acting accordingly with this love for the good of the family or in negative one can say avoiding, on the part of the family, any action that causes harm to the integrity of the family members, whether physical, psychological or moral. This is where the organic dimension of the family makes a difference in the clinical ethical evaluation, where all members of this network (including physicians, as a facilitating agent in decision-making) of relationships help the family system to evolve and adapt to new situations and needs.

This is a difficult task to face for health personnel, but it is also an opportunity to assume the richness and significance that the family as an organic body has in the resolution of clinical ethical conflicts. Now, how to determine a criterion for the family to decide in
The problem of individual autonomy and family authority... the face of a moral dilemma? The guide presented below provides some light on how to answer this question, both for patients, family members and health personnel.


The clinical practice guideline for decision-making presented below is the result of discernment under the ethical criteria of the family as a body. Table 1 shows a guide formulated as a checklist, which can help families, health personnel and clinical ethics committees to screen in three areas: ordered value, principle of responsibility and principle of totality, which determines the health of this family body and how it can behave in the presence of an ethical dilemma.

Table 1. Questions for the discernment of cases in the ethics of the family as a body

<table>
<thead>
<tr>
<th>Fundamental value</th>
<th>Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ordered love</td>
<td>• Love is the inner principle, permanent force and ultimate goal; • There are contextual elements that impede the experience of this love; • Personal communion is a visible reality; • The people who make up the family feel identified with this communion; • Within the family, the gratuitousness of actions is an expression of love; • Within the family, the freedom of persons is guaranteed; there are clear roles and functions that follow a definite order: wife-husband/father-children/brothers; • These roles and functions guarantee the good of the members and of the family as a whole;</td>
</tr>
</tbody>
</table>
• There are relationships that do not guarantee these goods;
• The family accepts changes or demands (internal or external);
• The family knows how to overcome crises or problems, discovering its mistakes and proposing solutions.

### Ethical principles of the family as a body

### The principle of responsibility

<table>
<thead>
<tr>
<th>Individual</th>
<th>Common</th>
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<tbody>
<tr>
<td>• Family members feel responsible for their behavior and its consequences;</td>
<td>• The family is able to make decisions responsibly, in view of contingent situations or in anticipation of the future;</td>
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<tr>
<td>• Family members are willing to help with daily chores.</td>
<td>• The level and space of all family members is respected in these decisions;</td>
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<td></td>
<td>• The decisions agreed upon in the family are socially valued;</td>
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<td></td>
<td>• The spouses, in view of their total self-giving, preserve unity, maintain fidelity and strive for indissolubility. There are contextual elements that have an influence;</td>
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<td>• Parents are responsible for the transmission in life;</td>
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<td></td>
<td>• Parents live sexuality as a full condition of human life. There are contextual elements that influence;</td>
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<td></td>
<td>• Parents guarantee the necessary means for the harmonious development of their child-children. There are contextual elements that influence;</td>
</tr>
<tr>
<td></td>
<td>• Parents are responsible for the education of their child-children. There are contextual elements that influence;</td>
</tr>
<tr>
<td></td>
<td>• In the family, care is taken for the needs of the sick, the elderly, etc. There are contextual elements that influence;</td>
</tr>
</tbody>
</table>
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| Forgiveness is lived in the family as a path to communion. There are contextual elements that influence; | The family participates in activities of social commitment. There are contextual elements that influence; | There is a social space for this participation. |

### The principle of totality

#### Common good deontological rule
- The members of the family act in such a way as to respect and love their family members;
- The actions performed or not performed within the family are performed in view of the good of the family or conditioned by internal or external factors, what are these factors?
- One can speak of disinterested actions within the family;
- Actions that cause unjustified harm to family members are avoided;
- The members of the family are informed adequately when it comes to taking any kind of action or foresight.

#### Individual good teleological corrective
- Family members are free to make decisions;
- These decisions are respected within the family, when they are oriented to the good of the person;
- People are valued in their integrity, respecting their legitimate freedom and autonomy;
- Legitimate self-esteem is cultivated and promoted within the family.

Fuente: elaboración propia.

To exemplify our ideas we will present an ethical case that we will try to explain in the light of this ethics of the family as a body. In our analysis, we will present a case in which these principles of ordered love, responsibility and wholeness are violated. This case will be the case of the savior brother or *savior sibling*.
9. The case of the savior brother

Soledad Puertas and Andrés Mariscal (44) are parents of Andrés, their first son, who is 6 years old and was diagnosed a few months ago with beta thalassemia major (BTM), a severe form of thalassemia characterized by intense anemia that requires periodic transfusions of red blood cells. Due to the severity of the disease and to improve the prognosis of the small patient, bone marrow cell transplantation has been proposed. In a first search for compatible hematopoietic cells in the marrow donor banks of the Spanish bone marrow network, no compatible donors were found.

Doctors at the Virgen del Rocio Hospital in Seville propose the possibility of having a second child born genetically selected to be a bone marrow donor for his brother Andrés. The procedure involves the use of assisted reproduction techniques (ovarian hyper-stimulation to obtain eggs for fertilization). \textit{In vitro} fertilization; monitoring of the viable embryos until the third day; on the third day, the embryos undergo preimplantation genetic diagnosis (PGD), in which the embryo is analyzed to determine which one is compatible with the sick sibling by means of a human leukocyte antigen (HLA) test, to avoid any type of rejection. Those embryos compatible with the HLA of the sick sibling are subsequently transferred to the mother.

The parents, informed by the medical team, give their consent to this technique and affirm their desire for their son Andrew to get better, even if it means having a second child. The parents state: “We were a little lost with this subject. We knew that there was some research on stem cells and we started to ask the doctors and, once all the permissions arrived, we decided that it was the best thing for our son” (44).

On October 12, 2008, Javier was born in Seville, the first medical baby, free of hereditary disease and immunologically compatible with his sick six-year-old brother, thanks to the 2006 Spanish law on assisted reproduction techniques, which contemplates the possibility of applying PGD techniques for therapeutic purposes for third parties (45).
Regarding Javier’s birth, Soledad affirms that “everything went very well and that her son, Andres, was looking forward to seeing his newborn brother. According to her words, the six-year-old is aware that the new member of his family can save his life” (44).

It is important to note that the issue of sibling saviors raises not only various technical complications, but also ethical ones. These techniques approved in some countries such as the United States, the United Kingdom, Australia and Spain, imply not only recourse to *in vitro* fertilization (IVF), but also to pre-implantation genetic diagnosis (PGD). Therefore, the selection of compatible embryos not for the good of the embryo—as in the case of the selection of embryos free of serious genetic disease—but for the good of another child (46). This is why the term savior sibling or *savior sibling* is used. The BTM as a condition that allows laboratory testing—so to speak—of embryos affected by this malformation before being transferred to the uterus, avoiding, on the one hand, the existence of undesirable genetic diseases and, on the other hand, ensuring hematopoietic compatibility with the sibling affected by the genetic disease to be cured by PGD. Thus, the child who will be born will be loved according to the good he or she will give to his or her sick sibling. See Table 2 to understand this point of view.

### Table 2. Analysis of a clinical case from the point of view of the ethics of the family as a body

<table>
<thead>
<tr>
<th>Fundamental value</th>
<th>Indicators</th>
<th>Yes</th>
<th>No</th>
<th>Justification</th>
</tr>
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<tbody>
<tr>
<td>Ordered love</td>
<td>• Love is the inner principle, permanent force and ultimate goal;</td>
<td>Yes</td>
<td></td>
<td>There are no previous antecedents (legal, historical or family) to the contrary in the case of the Puertas Mariscal family.</td>
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<td></td>
<td>• There are contextual elements (personal, relational, historical) that impede the experience of this love;</td>
<td>No</td>
<td></td>
<td>No elements are found to prevent this ordered love. There is a distortion of this love. There is a gratuitous love for the first son</td>
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<td>Andrew to the detriment of Xavier, who is loved in view of another.</td>
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<tr>
<td>• Personal communion is a visible reality;</td>
<td>A constituent part of this communion of love is freedom and gratuitousness. In this case, this gratuity is lost, since the other is welcomed into the communion of persons as a means to an end. A means that is based on techniques that foresee the selection of others less fortunate and their elimination. In this case, the communion between persons is not guaranteed.</td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• The people who make up the family feel identified with this communion;</td>
<td>Without judging the parents’ choice, there are some important psychological risks (46) in the sibling rescuer, especially with the identification with the family. In Andrew, feelings of gratitude or aggression may arise, and in the sibling rescuer, feelings of hatred or resentment may arise.</td>
<td>No</td>
<td></td>
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<tr>
<td>• Within the family, the gratuitousness of actions is an expression of love;</td>
<td>These dynamics that speak of the structure within the family would not help to build a family unity, much less a healthy relationship between parents and children, who by defending this intervention endanger the personal identity of one child to the detriment of the other.</td>
<td>No</td>
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<tbody>
<tr>
<td>• Within the family, the freedom of individuals is guaranteed; there are clear roles and functions that follow a defined order: wife-husband/father-children/siblings; No</td>
<td>In the case of the savior brother, this freedom and gratuitousness does not exist, the savior brother is not a gift for the family, but a source of spare parts, wanted not as an end, but as a means (46).</td>
</tr>
<tr>
<td>• These roles and functions guarantee the good of the members and the family as a whole; No</td>
<td>The parents state their bewilderment about their son's treatment: “we were a bit lost with this issue”. This feeling of bewilderment, added to the media expectation, in a short time. It can be an element against assuming an ethical, serious and responsible assessment. Therefore, the actions taken do not guarantee the good of the whole family, but of the weaker part, to the detriment of another, which may be born.</td>
</tr>
<tr>
<td>• There are relationships that do not guarantee such assets; Yes</td>
<td>Illness is never a blessing, but it, like death, is a constituent part of our human existence. Science, in this case, does not take the side of the weakest and most vulnerable: Javier, it is wanted as a means (remedy) for Andres breaking the relationship of this family as a body.</td>
</tr>
<tr>
<td>• The family accepts the changes or demands (internal or external); No</td>
<td>The family, because of the requirement of science, does not accept the changes that the disease of the sibling with thalassemia requires.</td>
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The family knows how to overcome crises or problems, discovering its mistakes and proposing solutions.

Parents establish a tyranny in relationships where the balance is tipped in favor of a humanity that is always weak and in need, but whose expected recovery entails a serious danger for another to be born. This tyranny of a noble will, does not help to solve family problems, it only shifts their focus.

<table>
<thead>
<tr>
<th>Ethical principles of the family as a body</th>
<th>Indicators</th>
<th>Yes</th>
<th>No</th>
<th>Justification</th>
</tr>
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<tbody>
<tr>
<td>The principle of responsibility</td>
<td></td>
<td></td>
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<tr>
<td>Individual</td>
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<tr>
<td>Family members feel responsible for their behaviors and their consequences;</td>
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<td></td>
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<td>Paternal responsibility is the archetype of all responsibility. The father is the caretaker of a being-already and with the impotence of a not-yet-being. This responsibility is contrary to the idea of a father-architect who does not receive the gift of a child, but builds, constructs, plans a child by projecting/selecting its potentialities, and loving it, not for its precariousness, but for its potentialities. This dimension hurts the organic dimension of the family, transforming the family into a technical, manipulable, disposable and reprogrammable body. In this scenario, personal responsibility disappears.</td>
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<tr>
<td>Family members are willing to help with daily chores.</td>
<td></td>
<td></td>
<td></td>
<td>Unspecified.</td>
</tr>
<tr>
<td>Common</td>
<td>The family is capable of making responsible decisions in view of contingent situations or in anticipation of the future;</td>
<td>The parents did not have all the information and if they had had it, they would have been able to judge the consequences of such a decision, beyond being able to save the sick child, which in itself is a noble act.</td>
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<tr>
<td>• The level and space of all family members is respected in these decisions;</td>
<td>No</td>
<td>Within the assumptions, in this case, the decision space of the savior sibling to be or not to be a donor and of all those who died so that this hematopoietically compatible savior sibling could be born is violated.</td>
<td></td>
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<tr>
<td>• Decisions agreed upon in the family are socially valued;</td>
<td>Unspecified.</td>
<td></td>
<td></td>
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<tr>
<td>• The spouses, in view of their total self-giving, preserve unity, maintain fidelity and strive for indissolubility;</td>
<td>Unspecified.</td>
<td></td>
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</tr>
<tr>
<td>• Parents are responsible for the transmission in life;</td>
<td>No</td>
<td>From the personalist point of view: the use of IVF and PGD shows us that parents are not responsible for the transmission of life, when it comes to respecting the nature and purpose of marital acts, in order to promote authentic conjugal love.</td>
<td></td>
<td></td>
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<tr>
<td>• Parents live sexuality as a full condition of human life;</td>
<td>No</td>
<td></td>
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<tr>
<td>• Parents guarantee the necessary means for the harmonious development of their child-children;</td>
<td>Unspecified.</td>
<td></td>
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</tbody>
</table>
Parents are responsible for the education of their children;

In the family, the needs of the sick, elderly, etc. are attended to;

Forgiveness is lived in the family as a path to communion;

The family participates in social engagement activities;

A social space exists for this participation.

The principle of totality

Common good deontological rule

Family members act in such a way as to respect and love their family members;

In this family, the principles are distorted. First, the common good is reduced to the good of one person, that of the sick sibling. This centralization neglects for a possible treatment - the personal good of both the parents - subjected to IVF - and that of the savior sibling created for the good of another and of those who died because of PGD.
The problem of individual autonomy and family authority...

<table>
<thead>
<tr>
<th>• The actions taken or not taken within the family are in view of the good of the family or conditioned by internal or external factors, which are these factors?;</th>
<th>The savior brother is instrumentalised as a spare part, being valued as a means to an end. The members of the family act for the good of Andrés, since this good has phagocytized the good of the whole family. Causing, as a matter of principle, an illicit act. In this case, the family homeostasis and unity will be determined and subjugated to the needs of the individual, taking expressiveness away from the other constituent structures of this group.</th>
</tr>
</thead>
<tbody>
<tr>
<td>• It is possible to speak of selfless actions within the family;</td>
<td>The actions of this family are motivated and encouraged by the medical staff to save Andrés from his illness. We can speak here of relationships not oriented in view of the family as a body, unity and reciprocity, but centered on an individual: Andrés, who self-generates egocentric relationships in view of his needs.</td>
</tr>
<tr>
<td><strong>Individual good</strong></td>
<td><strong>Family members are free to make decisions;</strong></td>
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<td></td>
<td><strong>Such decisions are</strong></td>
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<td></td>
<td><strong>to be respected within the family, as</strong></td>
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<td></td>
<td><strong>long as they are oriented to the good of</strong></td>
</tr>
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<td></td>
<td><strong>the person;</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Family members are adequately informed</strong></td>
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<td></td>
<td><strong>when it comes to taking action or making</strong></td>
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<tr>
<td></td>
<td><strong>plans.</strong></td>
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<td></td>
<td><strong>They avoid taking any action that may</strong></td>
</tr>
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<td></td>
<td><strong>cause unjustified harm to family members;</strong></td>
</tr>
<tr>
<td></td>
<td><strong>No</strong></td>
</tr>
</tbody>
</table>
- People are valued in their integrity, respecting their legitimate freedom and autonomy;

We could define this type of family as technical families, where what shapes its structure and determines its organization is will, instrumentalization, utilitarianism and onerousness. In this case, the family is not structured in view of relationships, but it is the individual who self-generates egocentric relationships in view of his needs.

- Legitimate self-esteem is cultivated and promoted within the family.

In this technical family, not only is the value of legitimate love not promoted, but it does not solve the problems it aspires to solve, since they are born not in its structure, but in demands that go beyond its organization. Demands that demand freedom and gratuitousness, but avoid responsibility in their formula. In view of our moral question, is there in this particular case an ordered love? We can say that neither there is no ordered love, since the principle of responsibility nor the principle of totality is respected.

### 10. Discussion

The family is a natural reality that has accompanied humanity since its origins. This gives the family two important elements: its polysemic manifestation in history and its close relationship with the
human. The human family, as a natural reality, is the product of decisions made in determined contexts, mediated by intelligence, individual will and cultural, religious and historical conditioning factors. The family is a natural institution in accordance with human nature, since:

Marriage—the origin of the family—responds to the personal structure of the human being, which is expressed in the sexual difference and complementarity between man and woman, in such a way that through the union of the spouses a new life can be generated (49).

The family, which is born with marriage, is the form that responds in a natural way to the personal structure of the human being.

With advances in reproductive medicine, cultural changes and changes in mentalities, the family has seen a transformation in its structure and functions. Artificial insemination and surrogacy have contributed in part to the change in the traditional concept of family, giving rise to diverse and new types of family configurations that seek civil and legal recognition. Each of these new configurations seeks to be legally and socially recognized as families with rights and duties, a situation that is strongly opposed by some sectors of society. If we were to ask people today what constitutes a family, the answers would be as diverse as philosophies, ideologies or cultures, but all these people would reaffirm that no matter what constitutes the family, it is an important place for man and for society.

Considering the importance that the family has for our hypothesis, the concept that it assumes as a body, brings with it an imperative and a vocative. On the one hand, the family must be the place of the human and, on the other, be what it should be, that is, a place where communion between people is lived and promoted.

The analogy of the family as a body implies an ethic centered on ordered love as a fundamental value oriented under the principles of responsibility and totality. If analogy is a reality halfway between the univocal and the equivocal, comparing the operations of the family with the operations of a body is a possible and viable reality. In the
family, being a communion of persons, it is similar in its doing since the relationship between its members shapes its structure and determines its organization. This bond in itself forms a cohesion between people where it is born from conjugal love and invites others to join; forming a network of conjugal, parental, filial and fraternal relationships whose mission is to form a family entity to the extent that these links form a network of continuous and permanent production.

For the value of ordered love to develop within the family as a body, it is necessary that two guiding principles be fulfilled: the principle of responsibility and the principle of totality, as we have already mentioned. A correct evaluation of a family moral act should consider not only both principles, which express the value of this ordered love, but also the deontological moments and the teleological corrective. In our hypothesis this is a continuous process, since in family ethics as a body, the realization of the deontological norm implies of itself the realization of the teleological norm and vice versa. There is no struggle between goods, but a reciprocal relationship. The principle of totality guarantees this harmonious relationship between the individual good and the family good as two moments of the same movement.

If the family as a natural reality lives in this logic of ordered love, respecting the principles of totality and responsibility in its decision-making, we can affirm that the struggle that exists between family authority and individual autonomy, in our theoretical formulation, ceases to exist. In a family that is structured as a body, acquiring through ordered love, a family autonomy of its own. Therefore, both autonomies (the family and the individual) would have as values and principles common elements, that is, the good of both the persons that integrate the family and the family in all its corporeality. Both issues would be tensioned towards the same good.

With the clinical case, we have learned that there are two positions that go against an ethics of the family as a body, considering people as means to an end or considering the family as private property. Both positions relativize the difference or the family unit in
view of its utility or functionality. These positions arise when the child is transformed into medicine, in the case of _savior siblings_, or when the family is transformed into a scenario for satisfying desires or frustrations, such as in cases of domestic violence or abuse.

To speak of the family as a body also implies, within the theory of speech acts or performative theory (47), that to say something is also to create a reality. This understanding of the family as an organic body can be fruitful within health teams as well as within the various instances that have to solve family clinical ethical problems since it implies the valuation of all family members in their own individualities, but also the consideration of their relationships as an organic whole.

The last step in our discussion is to consider the performative fecundity (47) of this hermeneutics of the family as a body. With performative fecundity, we understand that, when speaking of the family as a body, not only is a fact described, but at the same moment of its description this definition accomplishes what it describes. When resolving clinical cases, conceiving the family as a body can help us make decisions not only aimed at saving the health of the sick individual, but also at understanding that both disease and medicine imply a systemic relationship of the entire family body: family members and patient, who suffer with the disease and want the integrity of all their members. Talking about the family as a body, makes it possible to consider the various agents involved in medical decisions: parents, children, siblings and others who are considered family members, who together with the patients, can and should have an opinion in the recovery of the sick and in medical decisions taking this ordered love as value and as principles to be respected: responsibility and totality.

### 11. Conclusion

The analogy of the family as a body, values not only the natural elements present in the family, such as the personal will to share a life...
The problem of individual autonomy and family authority... project, represented in the value of ordered love, but also, through the principles of responsibility and totality, respects personal freedom and at the same time values its interpersonal relationships as a network of relationships, which form an organic totality. This theoretical definition requires an ethical application: that which is a body must act as such. The clinical practice guide presented here responds to this theoretical need: to move from the imperative to the vocative. When the family is formed as an organic body, it must act as the place where one lives and promotes communion between people. The conflict between diverse autonomies disappears and this whole network of relationships tends to achieve common goods and goals.

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