THE SEPARATION OF CONJOINED TWINS – ETHICAL DILEMMAS

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Abstract
The conjoined twins are those twins who have several body parts united, this situation being one of the most challenging malformations. Some pairs, depending on degree of conjunction, can be surgically separated. The way in which one should divide these organs between the two organisms is still a critical ethical issue, the decision being extremely difficult both for the family and for the medical team. In the first part of the paper we will present some practical considerations derived from the personal experience of one case of conjoined twins. The second part of the paper will describe the general ethical aspects that physicians will have to face when treating the conjoined twins. That is why in order for the surgical treatment of conjoined twins to be successful an experienced team in a tertiary center of pediatric surgery with access to all of the related specialties indicated in the therapeutic strategy of such serious malformations and obviously in collaboration with specialists in bioethics.

Key words: conjoined twins, bioethics, surgical separation.

The purpose of this paper is to tackle one of the most difficult clinical situations from a medical ethical and social perspective that is, the issue of conjoined twins. In the first part of the paper we will present some practical considerations from the personal experience of a case of conjoined twins, and in the second part we will describe the general ethical aspects we could face when treating the conjoined twins.

The child with serious malformation represents a major problem for a wide segment of the society: families, physicians, nurses and for the whole care system, for the staff of the educational network and also for the members of the communities in which the child has to integrate.

Surgeons who treat a child with serious malformation have to deal with situations related to the surgical practice (the diagnosis, treatment and the and the
follow-up of results), and but also situations of professional ethics. An important example is the conjoined twins, a malformation with an incidence of 1:200,000 newborns. From the very first description of the „Biddenden Virgins”, in the year 1100 BC, the conjoined twins have been fascinating both law makers and the medical world (1, 2, 3, 4).

The authors of this article bring into discussion the particular situation of two female conjoined twins united in the region of the pelvis (ischyopagus twins) and who faced the surgical team with a new situation. Our department has not been at the first experience of such pathology: in 1983 two female conjoined twins, Lina and Gherghina were cared about initially and after the separation operation carried out in Switzerland two German girls joined in the thoracic region which were diagnosed and were accompanied at the surgical operation by dr Gabriel Ionescu who was also part of the surgical team.

In our most recent case, the two conjoined ischyopagus twins, which were entrusted to us immediately after birth presented the feature that the twin A presented the cephalic extremity, neck and thoracic cavity (without the upper limbs) but with some serious cardiac malformation (bicameral heart). Twin A was sharing with twin B the pelvis and the lower limbs. At the age of 11 days the status of twin A, who was in fact a parasite twin, died and the separation surgery has been performed by emergency. The organs shared by the two twins were preserved during the surgery (bladder, ileum, colon, uterus and ovaries) and were allocated to twin B.

When one of the twins is physically and mentally affected, the choice is easier, as the common organs will be redirected towards the healthy patient, in order to facilitate the chance of survival of this latter.

The similar problem of the organs division would have been interesting and extremely difficult to solve if the family had a different opinion or if both twins had the same chance of survival. This problem although interesting, would hardly be solvable (5).

In the cases when we need to perform a surgical separation there are two options:

1. to separate the twins in two distinct individuals that are able to adapt to the extraterrestrial environment (the condition is to have separate organs for each twin without „sharing” organs from one twin to another);
2. to separate the twins by sacrificing one of them, depending on the „shared organs”. This second situation is one of the most difficult decisions to make from both medical and moral point of view in medicine and respectively in medical bioethics.

In this case, the main ethical issues envisaged by the medical team were: could the two conjoined twins be considered two separate human beings and legally entitled, even if one of them seems to be parasite without the organic equipment necessary for survival? What is the right attitude regarding the common organs?

The situation seems to be better when one of the twins is affected (parasite or deceased). The situation in which a twin has deceased for different reasons is totally different from that in which one twin is deliberately sacrificed in order to save the life of the other (6). When one of the twins is physically or mentally affected, the choice is easier as the common organs can be redirected to the
normal twin in order to make his life better.

When we speak about the treatment of conjoined twins we have to take into consideration aspects regarding the individual autonomy, quality of life, risks taken by the physician and by the patient, the benefits of the patients, etc (7).

The decision must always be individualized and must be very carefully made. Generally speaking, conjoined twins are considered to be a tragically situation and this pathology is the most difficult to be treated (8). Therefore, in order to successfully treat conjoined twins, it is necessary to have an experienced pediatric surgery team, in a level III pediatric surgery department, with direct access to all related specialities recommended in the treatment of such serious malformations (9). Even so, there are many ethical aspects, obviously in the case of the accurate prenatal diagnosis and which allows for the family to be informed which may be affected by the presence of this malformation (10).

One of the most important sources of ethical dilemmas in pediatrics is represented by the clinical situations that involves life and death decisions-making which have an extraordinary impact both on the patient and his family and on the physician and on the medical team.

Treating a child does not mean treating a small adult. A child is a micro-universe itself, a combination of self potential, genetic legacy, environmental influences and ... the parents' hopes. But we are not aware of these things until „our” own personal universe collapses due to the child disease. When using the word „our” we meant two possibilities: doctors who are treating a seriously ill child or parents of a dying child.

If in the case of an adolescent, it is relatively easy to understand the purpose of a surgery, the intention of „saving a life” by a surgical intervention, even what is an imminent death, for a newborn, these aspects have no meaning. In western societies parents are considered to be entitled to make the decision. In eastern societies, the family comes at first in many cases and its decision is sometimes more important than the decision of the patient himself (in our case of the family). In transitional societies, where the shift from the paternalistic model dominated by the physician’s authority in any decision, to the liberal model dominated by the patient' sovereignty, is very slow, it is hard to say who has the final word: the patient or the physician? In a society in transition like the Romanian one, the values are not well defined, patients are willing to express their autonomy but they do not dare to make decisions (they are still under the „spell” of „Doctor, you know what is the best for me!”) and the doctors want to share the responsibilities of decision with the patient, even when the patient is not a coherent partner able to deliberate over the medical options (11).

Regarding the case of conjoined twins, there are several dilemmas. First of all, the question whether the conjoined twins represent one organism or two is a fundamental issue that will not be given an answer too soon. Could we consider a twin with no lungs and heart for their own, as a legally entitled human being? Could the twins separation be considered „homicide” from a legal perspective? Do physicians have the right to take a life of one of them in order to preserve the other’s life? Could we accuse parents of homicide if they refuse the surgery and both twins die? Whose interests should prevail: the child’s best interest, the
parents’, the doctor’s or the public interest? Who should make the decision of separation of conjoined twins? According to what values should one make such a decision?

In the case of the ischyopagus twins (joint only at the pelvic region), both parents and doctors consider that the most important thing is the existence of two separate brains that work independently. Even The Court of Appeal in United Kingdom considers that twins with independent heads and two separate parts of body are two human beings (12).

In case the two conjoint twins are considered to be two separated organisms and we have in view their separation we should take into consideration the principle of „double effect”, an extremely important concept in the surgical treatment related to the separation of coinjoined twins consisting in the fact that any action in such situations has both favorable and unfavorable effects (13). Management for such cases has to be individualized and the problem of attributing organs to one twin is difficult to solve especially when there are no medical differences between them. Choosing among the „sharing organs” and designating to one or another must be performed after consulting the parents (14).

Saving a life by sacrifying another is far from being morally acceptable even when one life is at the beginning and the other at the end, like in a case of heart transplant between brothers, one of them dying (potential donor) and the other with a cardiac malformation and severe cardiac failure (potential receptor). The situation of conjoined twins is probably the only one in bioethics in which the separation could be morally acceptable. The decision is extremely difficult for the parents who have the perception of two children, that looks almost normal, and who might feel guilty for the condemnation to death of one of them (regardless of the motivation). In order to minimize the mother’s feels of guilt, a solution could be to transfer the responsibility of the final decision to the medical team (of course, in agreement with the family wish or at their request). In this situation, in Engelhardt’s view, the respect for patient’s autonomy becomes the principle of permission, according to which, in a secular pluralist society, the authority for actions regarding other people is based only on their permission. It is therefore a procedural principle which is based on a empty moral: it cannot tell us what to do in a concrete situation but only how to proceed in order to come to an agreement with all the others in particular situations (15).

The Catholic Church considers the separation surgery of conjoint twins as „morally unacceptable” and the argument is that „someone cannot perform something wrong from which to result something good” and „deliberately killing an innocent child is always wrong” (16). While respecting the religious arguments which cannot be apart from any complete ethical dicourse, we may argue that the intention of surgical separation is not to kill, but to save a life of a human being. We can also speculate around the fact that one twin would have been dead anyway if it has not been joint with the other, and of course preserving one life is better than losing two. We do not want to fall completely into an utilitarian perspective, but only to underline the fact that if we have the possibility to save a life, then we even have the moral duty to do it.

Some questions still remain: what are the criteria to draw „the limit” between two human beings? The presence of two
heads (even if there is only one heart, one abdomen, one pelvis)? The presence of two heads and two hearts, meaning in a symbolistical way… two separate souls?

Physicians will always find some medical criteria for tracing the limit. It’s the same like in organ transplant when we have two potential compatible candidates, but one of them will always be „better” than the other. In conjoint twins, the genetic potential of one will definitely be „better” than that of his brother. Is it enough for the genetic lottery to give the verdict?

**Conclusions**

Life faces us with some decisions … that are not only hard … but extraordinary.

In order to make the right decision, we have to understand life, death and… human vocation.

Without wanting to conclude with more questions than answers, we can say that the result of the medical act will never be satisfactying as long as the patient or the family is not an integrative part of the medical decision-making. The physician and the patient represent a „couple” in which the two are forcedly put together and in which common values do not exist but… a common target: fulfilling the life value and not that of the science. Even when this life means prolonging it or just improving its quality…

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