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APPLICATION OF THE PRINCIPLE OF INFORMED CONSENT IN THE LIGHT OF LEGAL GUARDIANS

1. Introduction

The concept of the right to self-determination is an essential element of the right to protection of physical integrity of every human being. In the framework of the right to self-determination, the rights of patients require the adoption of certain principles and their application in the matters related to consent, i.e. consent to medical intervention. The modern law insists on the right of the patient to decide whether to undergo medical therapy, the type of therapy, and under what circumstances, and to withdraw from the medical procedure at any time.[1] The consent of the patient is a reflection of the respect of the autonomy of the patients' personality and their human dignity. From the legal point of view, each medical intervention represents an invasion of the bodily integrity, and if there is no valid consent, the medical intervention would represent a legally impermissible action. With their consent, therefore, the patients exclude the unlawfulness of such an action. Undergoing medical therapy with valid consent is closely linked to the right of the patient to information on all aspects of medical therapy, the condition of their health, the risks and prospects of each procedure.[2] Hence, in legal practice and in jurisprudence, these two rights are commonly referred to as informed consent. Although the legal validity of consent depends on the level and quality of information to the patient, in some cases there is a deviation from their union. Namely, in emergency procedures for the purpose of the protection of life and health, sometimes the patient is not informed or is superficially informed on the nature of the impending intervention.

2. The child as a patient

In its third part, the Declaration on the Right of the Child to Health Care (1998) ensures the right to consent and the right to self-determination of the child, providing that the child as a patient and the

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[1] Quoted according to Petric S., 'Pretpostavke odstetne odgovornosti davatelja zdravstvenih usluga u pravu Bosne i Hercegovine', *Proceedings on the Topicality of Civil and Commercial Law and Legal Practice* no. 3, Mostar, 2005, pp. 124-125. The right of free disposal of their health and life is an exclusive right of the patients, which means that the physician does not have an independent right to treat, which is in line with the modern concept of doctor-patient relationship.

[2] The third principle of the European Charter of Patients' Rights (2002) prescribes that every individual has the right of access to all information that might enable him or her to actively participate in the decisions regarding his or her health. See at: http://home.online.no/~wkeim/files/europeancharter.htm

parents or legal guardians have the right to active and informed participation in all the decisions regarding the child's healthcare. When making such decisions, the decision- makers must take into account the wishes of the child according to his/her ability to understand. The child, who is, in the opinion of the physician, mature, is authorized to make independent decisions about its health care.[3] The competence of the child as a patient and his parents (legal guardians) includes the denial of consent to a medical procedure or therapy. Although it is assumed that the parents act in the best interests of the child, in reality it is not always the case. When the parents or legal guardians refuse to give consent for the procedure without which the child's health would be put into a grave danger or irretrievably compromised, and there is no alternative to the generally accepted methods of medical therapy, the physician must obtain the appropriate judicial authorization to perform such a procedure or therapy.[4] The child-patient and his/her parents (legal guardians) are entitled to full information on the state of the child's health and medical conditions, provided that it is not contrary to the best interest of the child. Any information shall be provided in the manner appropriate to the culture and level of age and understanding of the recipient. This is particularly important when the information is provided to a child who has the right to access general health information.[5]

Under the influence of the international legal instruments governing the rights of the child to health care, the national legal systems introduce certain frameworks that are not dependent on the legally relevant business/legal capacity or competency to stand trial for the children who are subjects of the law. For example, in the legislation of Great Britain, a physician shall conduct a medical treatment on the child if he considers it in the best interest of the child, provided that: the child is competent to give consent; the parents or persons with parental responsibility have given their consent to the treatment and the court has declared the treatment lawful or necessary.[6] Therefore, chapter 8 (1) of

[3]See Article 9 of the Declaration on the Rights of the Child to Health Care. Except in emergencies (according to Article 12, this is in cases when the child is unconscious or otherwise unable to give consent, or when the parent or legal guardian is not available and the therapy is urgent, the consent to intervention is assumed, unless a clear and undoubted view had been expressed earlier that relevant consent in a particular situation would not be given), informed consent is required before any diagnostic procedure or therapy of the child, especially when it comes to invasive procedures. In most cases, consent is given by the parents or legal guardians. Before such consent is given, it is necessary to consider the wishes of the child depending on his/her ability of understanding (Article 10). The text of the Declaration on the Right of the Child to Health Care (Declaration of Ottawa on the Right of the Child for the Health Care 1998) can be seen at: http://www.wma.net/e/policy/c4.htm

[4]See Article 11 of the Declaration on the Rights of the Child to Health Care.

[5]See Article 9 of the Declaration on the Rights of the Child to Health Care. Exceptionally, some information shall be withheld from the child or the child's parents (legal guardians), if there are strong reasons to believe that the information would jeopardize the life or health of the child or the physical or mental health of any person other than the child (Article 16).

[6]See: Herring J., *Family Law*, Pearson Education Limited, England 2001, 2004, pp. 393-394; Price D., 'Medical Law - United Kingdom', *International*

the Family Reform Act 1969 stipulates that the consent of a minor who is 16 years of age to any surgical, medical or dental treatment … is valid as if the person was adult; when a minor as described in this chapter gives his/her valid consent, the consent of the parents or guardians shall not be deemed necessary. However, examples from the court practice show the following: in the case of *Re W (A Minor) (Medical Treatment: Court's Jurisdiction)* [1993] 1 FLR 1, [1992] 2 FCR 785 CA, the physician has performed medical treatment relying on the parental consent for a minor at an age of 16-17 years, despite the opposition of the child. This decision raised negative comments because the physician has the authority to undertake the intervention if he/she believes it is in the interest of the patient, but it is unusual that the physician decides that it is in the interests of a particular patient to receive medical intervention against his/her will. Even if the physician considers that the treatment is in the patient's best interest, relying on the parental consent, he/she would have to obtain the permission from the court before the medical procedure.[7] Likewise, contrary to the law, by the authority of the court decision, the sixteen years old minor who suffered from anorexic nervosa was involuntarily subjected to treatment in case of *Re C* (Detention: Medical Treatment) [1997] 2 FLR 180, [1997] 3 FCR. In accordance with its authority, the court ordered that C remains in hospital until released by her physician or by another court order. This decision involved the use of certain force so that the minor should remain in therapy. The decision, according to the author Herring, is controversial, given that it is unlikely that it would be lawful to keep C at the clinic if she was eighteen years old.[8] In addition, in the Swedish law related to medical care, and other things related to self-determination and personal integrity of the child, there is an obligation to consider the statement of will of a minor. This means that a physician must always try to determine whether the minor is mature enough to understand the circumstances, as well as the effects of certain medical intervention.[9]

In our legislation, the child who is 15 years old and who is mentally competent has the right to consent to medical procedure.[10]

Encyclopedia of Laws, Volume 3, Herman Nys (ed.), Kluwer Law International, 2002, p. 175.

[7]Ibid.

[8]Ibid.

[9]Although the Swedish legislation relating to medical care does not specify age limits, guidelines can be found in other laws. Thus, according to the Parents and Children Code (Föräldrabalken) Article 6:11 stipulates that the opinion and wishes of the minor shall be considered in accordance with their age and maturity. Moreover, the provisions of the code relating to adoption (Article 4:5 Föräldrabalken) stipulate that a juvenile over the age of 12 cannot be adopted without his/her consent. If the child is 12 years old, but shows a certain level of maturity, his/her wishes shall be taken into account (Article 21:5 Föräldrabalken). This suggests that the medical practitioners have to consider the wishes of minor patients about medical treatment, taking into account their maturity and development. According to Westerhall L., 'Rights and Duties of Physicians and Patients, Sweden', *International Encyclopedia of Laws, Medical Law*, Volume 3, Herman Nys (ed.), Kluwer Law International, 1998, p. 86.

[10]See Article 62 Paragraph 2 of the Serbian Family Law, *Official Gazette of RS* no. 18/05 and Article 35 Paragraph 3 of the Law on Health Protection of Serbia

According to the Law on Health Protection of the Republic of Serbia, if the patient is a minor or is incapacitated, he/she may undergo a medical treatment if his/her legal guardian (parent, adoptive parent, guardian) has been informed and given consent.[11] The patient without legal/business capacity (a minor) actively participates in the decision making process on the consent to a proposed medical measure, in accordance with his/her maturity and ability to reason.[12]

3. A conflict of interest when deciding on the treatment of the child

Medical procedure rules require that parents give consent for surgical or other interventions the child is to undergo, when the child is a minor. However, when the child has reached a satisfactory level of maturity, it is authorized to make a decision on whether or not to consent to the proposed medical treatment. Giving consent for medical treatment of the minor, in practice, can be challenged in two ways. First, there may be a conflict of opinion between the child and the parents as his/her legal guardians, when, as a rule, if there is parental consent, the physician decides to apply the treatment, despite the opposition of the child. In other words, the desire of a competent child to refuse the treatment will be rejected, which has direct implications on the right to autonomy and self-determination. The question that imposes itself is the question of respect for the right of the child to express his or her opinion freely, which is one of the four fundamental principles in the approach to the rights of the child, enshrined in the Convention on the Rights of the Child (1989). As part of the category of the right to participation, the right of the child to express his or her opinion freely means that the child becomes an active participant in the society, while respecting the opinion of the child confirms the right of the child to participate in the decision making process regarding his/her life. Therefore, special attention must be given to the opinion of the child, in accordance with his or her age and maturity. The serious implementation of this principle would require ensuring that the child has access to relevant information appropriate to his or her age, by which he/she could form his/her own opinion. Otherwise, the child in the hospital environment must be informed about who is responsible to communicate the implications of the medical treatment, what are the side effects, what are the options available, what are the consequences of not undergoing the treatment and the like. The child's capacity to make decisions for him/herself depends on the child, but also on how well he/she is informed and how much appreciated by the other participants. It is necessary to be clear as to which aspects of the child's care, education or health he/she may be involved in. In order to provide guidelines to the physicians in determining the competency of the child, in 2001 the British Medical Association published a guide to assist the physicians in determining the maturity of the child. According to the prescribed rules, the physician must first determine whether the child understands the nature of his/her medical condition and the

(hereinafter referred to as LHP RS), *Official Gazette of RS*, no. 107/2005, 72/2009-state law, 88/2010, 99/2010, 57 / 2011.

[11]See Article 35, Paragraph 1 of the Law on Health Care of Serbia.

[12]See Article 35, Paragraph 4 of the Law on Health Care of Serbia.

proposed treatment and possible side effects, and the consequences that may occur if the child does not undergo the treatment. Secondly, the physician must determine if the child is at the age when he/she can understand the moral and family consequences of the situation, i.e. if he/she realizes how much suffering his/her possible death would cause to his/her parents. Thirdly, there is the question of how much life experience the child has. Fourthly, there is a question if there are changes in the mental circumstances of the child, i.e. whether his/her condition fluctuates between ability and disability. Finally, the physician must determine whether the child is able to weigh the information properly to make the right decision.[13]

As a rule, when the child reaches a certain level of maturity, that implies making decisions on matters affecting him/her (and the consent to medical procedure is certainly one of those matters). Therefore, the decisions of the parents are not legally relevant. However, it often happens that this delicate matter creates a conflict of opinion between the child and the parents as his/her legal guardians, when, as a rule, if there is parental consent, the physician decides to apply the treatment, despite the opposition of the child. In domestic law, the responsible medical practitioner who considers that the legal guardian of the patient is not acting in the best interests of the child shall immediately inform the competent authority for guardianship matters.[14] The solution stipulated in the law is in accordance with the European standards, but since the provisions of the relevant law have only been implemented for a short time, there is still no sufficient quantum of cases before the courts that would allow a serious empirical research in our country. On the other hand, major problems may arise when parents disagree with the physician's assessment and the treatment regimen proposed for the child. It should be noted that the conduct of the physician is not an absolute and immutable rule that applies to every specific situation, and that the criteria upon which the decision is made include individual approach to each case by applying the principle of the best interests of the child. In order to obtain an insight into the complex problem of disparity between the medical ethics and protection of the interests of the child as a patient on one hand, and non-compliance of the parents on the other hand, we would like to point to the opinion of the British Court in the famous Gillick[15] case. The case relates to prescribing contraception to a minor

[13]See the article entitled 'Consent and Capacity' at: http://www.bma.org.uk/ap.nsf/Content/Reportoftheconsentworkingparty~Chapter3

[14]See Article 35 of the Law on Health Care of the Republic of Serbia. In Swedish legislation, the Law on the Teams for the Care of Minors (Lag 1990:52 honey Särskilda bestämmelser TV vård av unga) is applied in terms of the interests of minors, providing that when there is a conflict of interest, the physician fulfils his duty by reporting the case to the relevant social services. This justifies the medical care and treatment that are based on the best interest of the society to protect minors. See more in: Westerhall L., 'Rights and Duties of Physicians and Patients, Sweden', *International Encyclopedia of Laws, Medical Law*, Volume 3, Herman Nys (ed.), Kluwer Law International, 1998, p. 87.

[15]See: Gillick v West Norfolk and Wisbech Area Health Authority, House of Lords [1986] 1 AC 112, [1985] 3 All ER 402, [1985] 3 WLR 830, [1986] 1 FLR

under the age of 16. In its conclusions, the Britain's court of the highest instance stated that a doctor can give the minors an advice with regard to contraception without parental consent, provided that she understands the advice. The doctor can proceed in this way, even if he is unable to persuade the minor patient to tell the parents that she is seeking advice on contraception. The advice would be justified (legally provided) if the patient is close to begin or continue to have sexual intercourses without contraceptive treatment. Without the physician's advice, both physical and mental health of the juvenile patient may be threatened and the interests of the patient comply the doctor to give advice even without the consent of the parents. The media popularity of this case influenced the widespread use of the term "Gillick competence" for minors who are mature enough and able to give consent to a medical treatment. In disputes concerning the ability of the child to consent to a medical treatment, the British courts tend to show readiness in terms of approving the proposed treatment by a physician in the cases where the treatment is opposed by the parents.

A precedent in the British courts, where it was decided in favour of the parents and not the medical establishment, is the case of *Re T (A Minor) (Wardship: Medical Treatment)* in which the court did not approve the proposed medical intervention without the consent of the parents.[16] In this case, baby C had a life-threatening liver disease. The medical experts unanimously agreed that without a liver transplant, C would not live longer than two and a half years. The parents, who are experienced health professionals in providing health care for sick children, refused to give their consent. Before the case went to trial, the child C has undergone an operation that resulted in a lot of pain and suffering. In its decision, the Court of Appeal, as an appellate court, relied on the principle of the welfare of the child, on the grounds that the assumption on the extension of the child's life is not the only goal of the court. Judge Ward explained his decision as follows: "according to the latest analysis, the best interests of the child include an expectation that difficult decisions affecting the length and quality of its life will be taken for it by the parents to whom its care has been entrusted by nature." However, regardless of this ruling, the parents later changed their minds and subjected the child to an operation.[17] Through the analysis of the British courts' rulings, we may conclude that there is no generally

224, [1986], at:
http://www.hrcr.org/safrica/childrens_rights/Gillick_WestNorfolk.htm The case proceeded as follows: in 1980, the Ministry of Health and Social Security issued instructions that in "exceptional circumstances," a doctor may give advice on contraception to minors under 16 without parental consent or consultation with them. The girl's mother (Victoria Gillick), a devout Catholic, asked for a review of the legality of the said instructions, seeking assurances that none of her five daughters under the age of 16 will obtain such advice without her consent. In the proceedings before the court of first instance she lost the case, the appellate court unanimously adjudicated in her favour, only to lose again by the decision of the House of Lords (the highest British court).

[16]See Re T (A Minor) (Wardship: Medical Treatment), [1997] 1 FLR 502, [1997] 2 FCR 363 in: Herring J., *Family Law*, op.cit., pp. 397-398.

[17]Ibid.

accepted consensus on the decisions about subjecting children to medical treatments.

3. Conflict of interests when deciding on the treatment of the child in the European Court of Human Rights.

The child as a patient cannot be excluded from the system of human rights guaranteed by the European Convention for the Protection of Human Rights and Fundamental Freedoms (1950). Thus, the protection of the rights of the child as a patient found its place in the European Court of Human Rights in two representative cases: *Glass v United Kingdom*[18] and *Panullo and Forte v France*.[19] Namely, Article 34 of the Convention provides that: " The Court may receive applications from any person, … claiming to be the victim of a violation by one of the High Contracting Parties of the rights set forth in the Convention or the protocols thereto. The High Contracting Parties undertake not to hinder in any way the effective exercise of this right."

In the first case, *Glass v United Kingdom*, the plaintiffs who filed a complaint to the Court 5 in June 2000 are David (the son) and Carol (the mother), British citizens.[20] David Glass was born in 1986 and, due to serious mental and physical defects, he needs twenty-four hour care. He underwent an operation to alleviate the problems with the upper respiratory system and after that, he suffered certain complications, including an infection, which led to a critical situation and him being connected to a respirator. The hospital staff believed that, despite the best care, David was dying and that further intensive care was inappropriate. However, David soon recovered and he was transferred to intensive care at the pediatric ward. Although he was discharged from the hospital, due to the respiratory channels infection, he was hospitalized repeatedly. During one of his hospital stays, the mother Carol expressed her opposition to the use of morphine and other opiates used for pain relief. Also, she stated that in case her son suffers a cardiac arrest, she expected resuscitation (reanimation). The physician in charge had the opinion that it was not in the best interest of the child, because his death was imminent and that they should facilitate it and not revive him. The doctors had determined that David was dying because of a lung disease and that morphine should be used. However, the mother and the rest of the family members objected, arguing that he was not dying and that giving him morphine was jeopardizing his chances of recovery. The hospital insisted on its position and assured the boy's mother that he would be given the lowest dose of morphine.

After receiving the doctor's opinion, the mother expressed her wish to take the child home and the hospital threatened to have the family removed by the police if they kept preventing the physicians from administering morphine. The doctors started the process, despite the fact that the mother insisted that the dose of 1 mg per hour was a dose for

[18]See the decision in the case of Glass v United Kingdom, Application No. 61827/00 [2004] ECHR 103 (9 March 2004), at: http://www.worldlii.org/eu/cases/ECHR/2004/103.html

[19]See the decision in the case of Pannullo and Forte v France, Application No. 37794/97 [2001] ECHR 741 (30 October 2001), at: http://www.worldlii.org/eu/cases/ECHR/2001/741.html

[20]See the decision in the case of Glass v United Kingdom.

adults and therefore excessive for a child of David's age. Without consulting the child's mother, they put the 'Do Not Resuscitate' order in his medical file. The next day, the mother noticed that the child's condition worsened. Alarmed, the family requested termination of morphine administration, while the physician in charge (Dr. Walker) pointed out that this was possible, provided that the family gave consent to the 'Do Not Resuscitate' order. Despite all this, David' condition improved and the boy was discharged on October 21, 1998.[21] In the case of *Glass v United Kingdom*, the Court found that there was a violation of Article 8 of the Convention. According to the Court, the child's mother was authorized to make the decisions in her child's name. The decision on the morphine administration, despite his mother's objections, constitutes a violation of the child's right to privacy and his right to physical integrity.[22]

In another representative case, *Panullo and Forte v France*, Italian citizens, Mr. Vincenzo Pannullo and his wife Caterina Forte filed a petition to the European Commission of Human Rights against the French Government, claiming a violation of the right of respect for their private life (Article 8 of the Convention for the Protection of Human Rights and Fundamental Freedoms).[23] The case proceeded in the following manner: their two-year daughter Erica underwent heart surgery at the Marie-Lannelongue hospital in Le Plessis-Robinson. After a while, the child was admitted to the same hospital for postoperative check up. The following day, after the check up, she got a fever and vomited blood. The doctors diagnosed rhinopharyngitis and prescribed antibiotics. Two days later, the doctors discharged the child from the hospital. In the evening of the same day, the parents phoned the hospital because Erica had got a fever again. The parents (the applicants) took the child to a doctor who diagnosed pneumonia and telephoned the hospital with a request that their child is hospitalized immediately. On arrival, Erica was admitted to the department of cardiology. When she fell into a coma, she was transferred to the intensive care unit. The doctor said that she had a severe infection of the left lung, which was damaging her heart. Unfortunately, Erica died and the investigative judge ordered that an autopsy is performed. The report of autopsy contained the conclusion that Erica had died from an acute respiratory infection. The applicants considered that their right to privacy was violated by the French authorities, because they had retained the body of their deceased daughter for so long (seven months). The European Court of Human Rights ruled in their favour.[24]

Based on the above, it can be stated that a conflict of interest in making the decisions about the treatment of the child, essentially, refers

[21]Ibid.

[22]Ibid. The decision of the Court that favoured parental consent is in accordance with the Convention on Human Rights and Biomedicine (1997), which stipulates in Article 6 Paragraph 2 that when, in accordance with the law, a minor does not have the capacity to give consent to an intervention, the intervention shall be undertaken only with the approval of the legal guardian or the authority prescribed by the law.

[23]See the decision in the case of Pannullo and Forte v France.

[24]Ibid.

to the question of priority in case of a conflict of opinion between the child and the parents, and between medical professionals and parents.

There is no room for doubt that, if the child is able to understand the meaning and the consequences of the medical treatment that is in his/her best interest he/she should make an independent decision. Therefore, the decision on the treatment of the child that is in line with the child's best interests is, by definition, tripartite: a) if the child is aware of the importance and the consequences of the proposed medical treatment, his/her wish shall be decisive; b) the wish of the parents or the persons who have parental rights shall prevail if the child, because of his/her age cannot understand the significance and the consequences of the medical treatment and c) the evaluation and the opinion of competent medical experts in each particular case.

In our opinion, the priority in making the decision, under certain conditions, belongs to the child. However, since the issue is not simple and it regularly involves a combination of different life circumstances, it is appropriate and necessary to approach this matter seriously in our legal and medical tasks. In contrast to the analyzed common law, which is far more advanced in terms of the protection of the rights of the child, the legal status of the child as a patient in the domestic law is still at an early stage of development and it is going to experience the process of continuous improvement and serious confirmation in practice.

4. Conclusion

The interest of the child is a legal standard, which implies that acting in accordance with the best interest of the child means to decide in the manner in which the child would decide for him or herself if he/she were able to. In Serbian law, the child who is 15 years of age and able to understand the significance and the consequences of a medical treatment that is in his or her best interest, decides independently. According to the Law on health protection of the Republic of Serbia, if the patient is a minor or is incapacitated, he/she may undergo a medical treatment if his/her legal guardian (parent, adoptive parent, guardian) has been informed and given consent, bearing in mind that a guardian may decide on a medical procedure for the child only with previous approval from the legal custodian and decision-making authority. The opinion of the child, however, should be taken into consideration as an increasingly determining factor, according to the age and the degree of maturity. Observed in the prism of national level, the right of the child to make decisions about the issues that affect his/her life, which, of course, includes the decision to undergo a medical procedure, is accompanied by certain deviations resulting from the slow changing of the traditional idea with regard to recognizing the right of the child to participate in the decisions that affect him or her.

Summary

The rules of medical procedure require that the parents give consent when their minor child undergoes a surgical or other intervention. However, when the child has reached a satisfactory level of maturity, he/she is authorized to make the decision on whether or not to give consent to the proposed medical treatment.

The decision on medical procedures and grounds for "informed consent" for the persons, who, because of their age or health status, are not capable of giving their consent, is regulated by the Convention on Human Rights and Biomedicine (1996). In that Convention, the status of the most important principle is given to obtaining valid consent for medical intervention in the name of the people who do not have legal capacity to give consent. If, under the law, a minor cannot give consent to the procedure, the procedure can be undertaken only with the consent of the legal guardian or a public authority stipulated by the law. The opinion of a minor shall be taken into consideration as an increasingly determining factor, according to the age and the degree of maturity.

Key words: right to self-determination; child as patient; informed consent; best interest of the child; legal guardians of the child.