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The Limits of Autonomy of a Minor Patient and the Nature of Selected Medical Interventions

Abstract: The aim of the study is to analyze domestic law and selected aspects within international legal regulation connected to the scope of autonomy of a minor patient depending on medical interventions. The starting point is the explanation of the most significant elements of the principle of self-determination: the right to consent and the right to information. It should be pointed out that the scope of patient autonomy is related to typical medical interventions (physical examination, surgery), and it increases when the minor reaches the age of 16. In this context specific regulations are depicted, which provide different solutions as lowering the age to consent (*ex vivo* transplantation), taking into account the minor's actual ability to decide (medical experimentation), or the extended scope of information. To sum up, the principle of autonomy of a minor patient is guaranteed in proportion to the level of the child's development (mainly based on the criterion of age) and under the supervision of a statutory representative or, in some cases, with the court's involvement. This special regulation ensures the rights and interests of minors in an appropriate way.

Keywords: minor patient, patient's rights, patient's autonomy, informed consent

1. Introduction

The paternalistic model of relations between the physician and patient, which was still prevailing several years ago, has gradually evolved into the partnership approach respecting the patient's autonomy who is an active participant of the therapeutic process. However, the principle of self-determination, whose most essential elements contain the right to express consent and the right to information about one's health condition¹, is not of an absolute nature. In order to fulfil the postulate of patient's good/welfare², the principle becomes considerably limited,

1 J. Bujny, *Prawa pacjenta – między autonomią a paternalizmem*, Warszawa 2007, p. 138.

2 *Ibidem*, p. 4.

among others in relation to a special category of patients, i.e. minors. Due to their age, they cannot shape their legal situation themselves, including their conscious decision on medical interventions they are going to undergo. A manifestation of special protection provided to these subjects by the legislator is a formulation of regulation characterized by solutions typical of the paternalistic approach and, in consequence, restriction of the minor patient's autonomy.

A purpose of the article is the analysis of the limits of minor patient's autonomy in the context of provided health services³ with regard to the criterion of a type of applied medical intervention. Due to the limits of the publication, the study does not embrace introductory issues dealing with consent, obligation of information, or considerations on the statutory prerequisites of admissibility to carry out a given service. A starting point for further considerations are regulations of the Act of 5 December 1996 on the Professions of a Physician and Dentist (hereinafter referred to as APP)⁴ and the Act of 1 July 2005 on the Collection, Preservation and Transfer of Cells, Tissues and Organs (hereinafter referred to as ACPT)⁵. A distinct scope of the minor patient's autonomy introduced by the legislator will be analyzed in two levels: the fulfilment of the obligation of information and consent for the provision of a health service. For functional reasons, the issue of informative autonomy of a minor patient will be considered first. Health services analyzed in the above-mentioned aspects have been chosen based on various criteria. This catalogue includes the most common and most frequently performed medical examinations or tests (body examination and physical examination⁶ – routine medical actions that do not considerably interfere in patient's physical integrity and do not entail any risk for the patient⁷), other health services (giving medications, or coating plaster)⁸ as well as surgeries, methods of treatment and diagnosis posing a higher risk. The author has also selected special interventions which do not benefit a minor directly and do not exert a therapeutic impact on them (a minor donor in *ex vivo* transplantation), or pose a greater risk for a minor patient (medical experiments). It should be stressed that analyzed health services are merely examples whereas the review of so many distinct types of them enables to compare the scope of minor patient's autonomy in

3 More about the concept of health benefits: M. Dercz (in:) M. Dercz, T. Rek, Ustawa o działalności leczniczej. Komentarz, Warszawa 2014, p. 43 and following.

4 Consolidated text Journal of Laws of 2015, item 464 as amended [Tekst jedn. Dz.U. z 2015 r. poz. 464 ze zm.].

5 Consolidated text Journal of Laws of 2015, item 793 as amended [Tekst jedn. Dz.U. z 2015 r. poz. 793 ze zm.].

6 T. Dukiet-Nagórska, Świadoma zgoda pacjenta w ustawodawstwie polskim, "Prawo i Medycyna" 2000, No. 6-7, p. 78.

7 M. Safjan, Prawo i medycyna, Warszawa 1999, p. 45.

8 M. Malczewska (in:) E. Zielińska (ed.), Ustawa o zawodach lekarza i lekarza dentystry. Komentarz, Warszawa 2014, p. 604.

typical situations and special cases. Additionally, minors do not constitute a uniform category of entities for the Polish legislator. In this context, individual groups may be distinguished and the ensuing different scope of self-determination depending on the group category. In the conclusions, the author will present legislation regarding the protection of the minor patient's autonomy as well as factors affecting determination of the limits thereof.

2. Minor patient's autonomy in selected acts of international law – a review

Developing patient's rights, the rights of a minor patient were not included therein for a long time, which actually deprived these subjects of any protection⁹. These tendencies changed as late as in the second half of the 20th century, when minor patients were guaranteed minimum standards of autonomy in a therapeutic process¹⁰.

Before considering this issue under Polish law, it is worth presenting solutions emphasizing autonomy of a minor patient within the above context resulting from the acts of international law. The content of Art. 6 par. 2 of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Applications in Biology and Medicine: Convention on Human Rights and Biomedicine of 4 April 1997 (hereinafter referred to as EKB)¹¹, explicitly indicates that where, according to law, a minor does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law. Concurrently, the opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity. Art. 6 par. 4 of EKB sets forth that the representative, the authority, the person or other bodies shall be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. Furthermore, the invoked regulation envisages special solutions on research on a person without the capacity to consent (Art. 17 of EKB) or ex vivo transplantation (Art. 20 of EKB). Apart from general conditions of medical interventions, the above-mentioned

9 More on the subject of the child's legal situation in health care: M. Dercz, *Konstytucyjne prawo dziecka do szczególnej opieki zdrowotnej*, Warszawa 2016.

10 J. Zajdel, *Prawo medyczne dla kardiologów*, Łódź 2009, p. 79.

11 The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine of 4 April 1997 r. (in: T. Jasudowicz (translation and ed.), *Europejskie standardy bioetyczne: wybór materiałów*, Toruń 1998, pp. 3-15. The ECB, adopted by the Committee of Ministers of the Council of Europe, entered into force on December 1, 1999, but it has not been ratified by Poland.

situations also require a written consent for a specific test (recovery/removal) while no objection by the potential donor concerned may be raised. Art. 12 of the Convention on the Rights of the Child of 20 November 1989¹² (hereinafter referred to as KDP) assures to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child. The views of the child shall be given due weight in accordance with the age and maturity of the child, which requires individual approach to each case.

3. A minor patient and the right to be informed about one's health condition in the Polish law

A purpose of the information given to a patient before the provision of a medical service is to enable him or her to express an informed consent¹³. A correct fulfilment of the obligation of information is a necessary prerequisite of recognizing the patient's decision as legally binding¹⁴. The principle according to which a patient is the subject entitled to obtain information about his or her health condition is subject to significant modifications in the case of a minor patient. This right is correlated with the powers (competence) to decide about the scope of medical services being provided.

In the light of the regulated obligation of information within the scope of typical medical services, it becomes apparent that minors are not treated as a uniform group of entities, which has been mentioned in the introduction herein. When a minor person becomes sixteen years old, it is necessary to provide him or her with full information of the minimum scope indicated in Art. 31 par. 1 of APP. This information encompasses various aspects of medical services being provided. On the other hand, when a minor patient is under 16, a doctor is obliged to inform both a statutory representative who has given surrogate consent and the minor patient. However, pursuant to Art. 3 par. 7 of APP, the doctor's obligation with regard to a minor patient has been limited solely to information necessary to assure a correct (regular) course of a diagnostic or therapeutic process, which does not exclude conveying negative information about the minor patient's health condition or unfavourable forecast. Respect for minor patient's autonomy is manifested in the fact that a doctor has to listen to the minor patient after providing him or her with the information. Since a minor patient under 16 has no competence to give consent for the provision of a medical service, it is not binding. Under the present legal

12 The Convention on the Rights of the Child adopted by the United Nations on the 20 of November 1989 (Journal of Laws of 1991, No. 120, item 526) [(Dz.U. z 1991 r. Nr 120, poz. 526)].

13 M. Dercz, H. Izdebski, T. Rek (in:) M. Dercz, H. Izdebski, T. Rek, Dziecko – pacjent i świadczeniobiorca. Poradnik prawny, Warszawa 2015, p. 124.

14 M. Malczewska (in:) E. Zielińska (ed.), Ustawa..., *op. cit.*, p. 592.

state, failure to convey appropriate information does not affect validity of surrogate consent provided by a statutory representative¹⁵. This solution engages minor patients in a therapeutic process to a certain extent. It is underlined that if the child is more mature, the scope of information should be wider¹⁶. Fulfilling the obligation of information, it is especially important with regard to minor patients to convey the information in an accessible way, both the message and its content. To achieve this, patient's individual features and his or her perceptive capacity, which depend not only on age but, most of all, a degree of mental development and current health condition, must be taken into account.

A general catalogue of information to be provided may be modified by the provisions of other Acts. Increased obligation of information, which is manifested in two levels, has been envisaged in the case of *ex vivo* transplantation. The first aspect concerns the extended scope of information to be provided, its accuracy and specially regulated possibility of withdrawing consent (Art. 12 par. 1 point 5 of ACPT). The second element is connected with a group of entities implementing this obligation, which embraces both a doctor taking part in a surgery and a doctor not participating directly in it. A purpose of double obligation of information is making sources of information more objective and more numerous, which is further reinforced by the duty to fulfil it in writing.

Compared to regulations concerning typical situations, including medical experiments, the obligation of information looks different. Standards envisaged in Art. 31 of APP are modified by the catalogue contained in Art. 24 of APP, which extends the scope of the obligation of information by depicting a degree of accuracy of data to be provided, including a possibility of withdrawal from the experiment at any time¹⁷. As far as minor participants of the experiment are concerned, this information should be conveyed to a statutory representative (in the case of surrogate consent), or a statutory representative and minor patient (in the case of cumulative consent).

On the other hand, different from statutory regulations, deontological norms do not envisage the obligation to inform a minor patient about anything regardless of his or her age or perceptive capacity, being limited to the fulfilment of the obligation with regard to a statutory representative or actual guardian, which is set forth in Art. 16 par. 3 of the Code of Medical Ethics¹⁸.

15 M. Świdarska, *Zgoda pacjenta na zabieg medyczny*, Toruń 2007, p. 123.

16 R. Kubiak *Prawo medyczne*, Warszawa 2014, p. 289.

17 M. Nesterowicz, *Prawo medyczne*, Toruń 2016, p. 198.

18 The Code of Medical Ethics, hereinafter referred to as CME, http://www.nil.org.pl/__data/assets/pdf_file/0003/4764/Kodeks-Etyki--Lekarskiej.pdf (accessed: 16 July 2016).

4. A minor patient and consent to intervention in the Polish law

The legislator generally protects the minor patient's interest within the scope of consent to the provision of medical services on the basis of a model of surrogate consent (given by a statutory representative) or a model of cumulative consent (given in parallel by a statutory representative and a minor). The institution of double consent expresses a strengthened tendency to respect patient's autonomy of the will as early as possible¹⁹. With regard to typical interventions (examination, other services, surgeries, diagnostic and therapeutic methods of higher risk), the minor's rights within the impact on the decision depend on the criterion of formal age. Once a minor turns sixteen years of age, the model of parallel consent is revised while the minor is given a tool to co-decide about medical services he or she is provided with. It should be emphasized that a younger patient may not decide about the provision of these medical services regardless of his or her health condition, a degree of personal development or ability of making rational evaluations²⁰. With regard to this group of minor patients, the respect for their autonomy is also expressed in a manner of resolving a collision of wills of both entitled subjects. In the case of conflict of opinions in the form of objection raised by a minor below 16 years old and the consent of a statutory representative, a decision of the guardian court thereon shall be decisive²¹. Moreover, it is worth depicting here instruments of non-assertive impact of a minor below 16 years old, which have been envisaged in the Act of 25 February 1965 – Family and Guardianship Code (hereinafter referred to as FGC)²². B. Janiszewska draws attention to the institution of listening to a minor before giving consent to medical intervention or refusing to make the minor undergo medical intervention depicting the content of Art. 95 § 4 of FGC and Art. 576 § 2 sentence 1 of the Code of Civil Procedure²³. The above quoted regulation expresses the fact that the autonomy of minor patients undergoing medical interventions who may not bindingly decide about medical services they are subject to because they are under 16 years of age is indeed taken into account.

On the other hand, as far as special interventions are concerned, the legislator introduced different solutions. Regardless of the minor's age, admissibility of *ex*

19 M. Świdarska, *Zgoda...*, *op. cit.*, p. 62-63.

20 B. Janiszewska, *Zgoda na udzielenie świadczenia zdrowotnego. Ujęcie wewnątrzsystemowe*, Warszawa 2013, p. 667.

21 Compare art. 32 par. 6 and art. 34 par. 5 APP.

22 Consolidated text Journal of Laws of 2017, item 682 [Tekst jedn. Dz.U. z 2017 r. poz. 682].

23 Por. treść art. 95 § 4 FGC (Parents before making decisions on more important matters matters relating to the person or property of the child will listen to them if his mental development, health, and degree of maturity allow it, taking into account as far as possible its reasonable wishes) oraz art. 576 par. 2 sentence 1 CCP (The Court in matters relating to the person or property of the child will listen to them if his mental development, health, and degree of maturity allow it, taking into account as far as possible its reasonable wishes).

vivo transplantation from a minor donor always requires consent expressed by a statutory representative and guardianship court competent with regard to the place of residence of a candidate for a donor. If a minor donor attained 13 years of age, an entity that is additionally entitled to give consent shall be the donor himself or herself (Art. 12 par. 2 of ACPT); therefore, the structure of triple consent shall be applied. What is more, the above invoked regulation lowers the age limit of a minor entitled to give parallel consent by three years enacting it on the level of 13 years of age, which explicitly increases the scope of autonomy of a minor *ex vivo* donor compared to patients undergoing other medical interventions²⁴. Hence, the age limit obliging a doctor to fulfil the obligation of information fully with regard to such a donor is also lowered. A minor who attained 13 years of age may effectively refuse or object to marrow biopsy. On the other hand, if haematopoietic cells are collected from peripheral blood, then regardless of age, the Polish legislator does not require minor's consent²⁵. The literature points out that there are no reasons provided for the above presented distinction²⁶. The minor patient's autonomy within this context may also be considered in the procedural level. Pursuant to Art. 12 par. 4 of ACPT, court proceedings to obtain permission may also be initiated by the minor's application who attained 16 years of age. However, the court may issue consent only if it has been requested both by the statutory representatives of the minor over 16 years of age and the minor himself or herself²⁷.

The exception thereof in the Polish law is a solution applied with regard to the regulation of medical experiments. Apart from the age prerequisite of a minor participant of a test/experiment, the legislator introduced a factual criterion of acting with sufficient understating as a factor authorizing giving cumulative consent by a minor. Due to interpretative obscurity, this notion requires a pursuit of an individual assessment in every case²⁸. Hence, the structure of parallel consent with regard to medical experiments is also applied to a wider group of individuals than in the case of general regulation or the one resulting from APP. It increases the scope of the minor patient's autonomy also within the aspect of providing him or her with full information. Apart from the minor who attained 16 years of age, an individual under 16 but acting with sufficient understanding is also entitled to the equivalent right to co-decide.

In the light of deontological norms, pursuant to Art. 15 of CME, if a patient is not capable of expressing informed consent, it should be given by his or her

24 M. Świdarska, *Zgoda...*, *op. cit.*, p. 346.

25 J. Haberko, (in:) J. Haberko, I. Uhrynowska-Tyszkiewicz, *Ustawa o pobieraniu, przechowywaniu i przeszczepianiu komórek, tkanek i narządów. Komentarz*, Warszawa 2014, p. 139.

26 J. Duda, *Cywilnoprawne problemy transplantacji medycznej*, Warszawa 2011, p. 138.

27 J. Haberko, (in:) J. Haberko, I. Uhrynowska-Tyszkiewicz, *Ustawa...*, *op. cit.*, p. 136-138.

28 R. Kubiak, *Prawo...*, *op. cit.*, p. 450.

statutory representative or a person who is actually taking care of the patient. As far as a minor person is concerned, a doctor should also attempt to obtain his or her consent if he or she is capable of expressing such consent consciously. What is more, Art. 37 of CME stipulates that marrow may only be collected from a child upon the consent of his or her statutory representative. With regard to a minor person, he or she should also give such consent if he or she is capable of giving informed consent. On the other hand, medical experiments with the participation of a minor may be performed solely if it is not possible to carry out experiments/tests of comparable efficiency with the participation of individuals capable of expressing consent (Art. 44 of CME).

5. Conclusions

In result of the analysis of the minor patient's autonomy in the context of the nature of medical intervention he or she is subject to, the following conclusions have been reached. A special legal situation of a minor patient and necessary additional legislative protection are manifestations of the paternalistic treatment of this group of patients, which is justified by their welfare. Nevertheless, elements expressing the minor patient's autonomy can also be found in the Polish law. A type of a health service is a factor that significantly affects the scope of autonomy of a minor patient. Distinct limits thereof introduced by the legislator can be perceived in two levels. The first one involves determination of a group of individuals entitled to express consent to undergo medical service including the rights of a minor patient. The second aspect, which is considered analogously, refers to the rights to information.

Basically, the minor's rights to express consent to undergo a health service (test/examination, other services, surgeries, and methods of treatment and diagnosis of higher risk) become extended after the minor turns 16 years of age. In such a case, based on the formal age criterion, the legislator reserves the minor patient's autonomy in the model of cumulative consent, i.e. expressed in parallel by the minor and his or her statutory representative. On the other hand, a minor patient may not express exclusive consent by himself or herself. If a minor does not have a statutory representative, or it is impossible to contact them, the guardianship court's permission must be obtained. In the case of collision of wills between the authorized entities, i.e. a statutory representative and a minor over 16 years old, the court's permission is additionally required, which emphasizes subjectivity of a minor patient whose will shall not be changed by a statutory representative but solely by an impartial court. Moreover, as far as the implementation of the right to obtain information about one's health condition is concerned, a doctor is obliged to convey such information fully to a patient who turned 16 years of age, the same as to an adult and not incapacitated patient. On the other hand, with regard to other minors, a doctor adapts the scope and

form of information necessary to assure a proper course of a diagnostic or therapeutic process thus providing him or her with medical services. Next conclusion ensues that the Polish law also contains special norms, in the light of which respect for minor persons' autonomy becomes considerably enhanced. The example thereof is medical intervention undertaken under exceptional circumstances, which is undeniably affected by the following situations: a non-therapeutic purpose of the service, or the fact it does not directly benefit a minor patient or generates a higher risk he or she will be subject to. In effect of the occurrence of the above quoted factors, minors' autonomy is taken into account to a larger extent, which is manifested in the form of various solutions. One of them is a lowered age limit entitling a minor to express parallel consent, which occurs in the case of *ex vivo* transplantation of a minor donor. The Constitutional Tribunal decided that the legislator is not constitutionally obliged to transfer special solutions onto statutory regulations concerning the provision of basic and massive health services²⁹.

What is more, increased autonomy is manifested by the inclusion of not only the criterion of a formal age but also consideration of factual capacity of the subject to express consent resulting from patient's individual features. Furthermore, when exceptional interventions such as medical experiments are undertaken, increased obligation of information in relation to a minor patient is revised, which implies a higher degree of accuracy and a wider scope of information being conveyed as compared to the regulations on the provision of typical health services.

Comparing Polish and international legislations, an essential difference is noticed with regard to a choice of the criterion determining the minor's rights to express consent. Regulations combining the right to make a decision with factual competence, which prevail in the international law, have been replaced by the formal age criterion in the domestic legislation. Nevertheless, the doctrine emphasizes the need to consider a degree of mental maturity and free and sufficient assessment of the situation individually with regard to each patient. The argument raised in support of the above opinion is insufficient protection of minors' rights. On the other hand, however, the application of the factual prerequisite with regard to routine services would be difficult in practice. What is more, the above-formulated postulate would require the inclusion of a special course in medical education concerning methodology of such assessments because not objective and inexplicit factual criterion may lead to arbitrary decisions made by doctors. Nevertheless, even revised (changed) educational programme is not a sufficient solution because the skill of making accurate assessments would, most of all, require considerable experience therein.

29 The judgment of the Constitutional Tribunal of 11 October 2011, K 16/10, <http://ipo.trybunal.gov.pl/ipo/Sprawa?cid=1&dokument=7021&sprawa=6145> (accessed: 17 July 2016).

Summing up, it should be acknowledged that legal subjectivity of a minor patient has been emphasized by providing him or her with the right of self-determination. Yet, its fulfilment has been reserved proportionally to the degree of development (basically assessed with the inclusion of the age criterion) and under the supervision of statutory representatives, and sometimes with the involvement of a court as a guarantor of impartiality.

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