Notifying family court about the matters of threatened underage patient’s life: ethical and social context

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ABSTRACT

The rights of child are the areas of particular interest in contemporary societies. Convention on the Right of Child, that was enacted nearly thirty years ago, led to the important change in the recognition of rights and freedom of an underage. Such problems are many times directly related with the protection of young patient’s life. In such contexts, both opinions of physicians caring for a child and its parents are taken into account. A conflict arising between such parties sometimes takes place. It is most often related with alternative opinions on life and health protection requirements for a child. In the half of 2017 year, similar situations took place in Great Britain and Poland. The first case concerned withdrawal from the activities described as medical futility. Whereas, the second case concerned parents contradicting medical interventions pursued by a personnel for theirs new-born child. Such cases were extensively reported by mass media. They were motivating factors for the following key questions: Are any limits for parental authority? Can medical personnel intervene into parental authority? What does the best interest of a child mean? Can it be defined? Can it be secured with means of a judicial decision? Are there any proved methods of solving a dispute between parents of a child and hospital physicians, in which such a child is diagnosed and treated?

Keywords: rights of a child, rights of a patient, medical futility, parental authority, family law

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Initial notes

In summer, 2017, public opinion was notified about two interesting cases of conflict arising between the medical personnel and parents of a child. First such case took place at territory of Great Britain. It concerned so called Charlie Gard’s case. It pertained to a boy in the age of several months with diagnosed rare mitochondrial disease. According to the physicians, this boy was in terminal status, what constituted the basis for a motion that was filed to the court, in order to get consent for disconnection from respirator. Following lacking consent from parents of the boy for such activities, as well as subsequent demand for boy’s discharge to home, hospital personnel decided to refer this case to family court (Lawler, 2017). Similar decision was made by Polish paediatricians in the case occurring in the Bialogard hospital. In turn, this case pertained to lacking parents’ consent for any medical activities towards theirs newly born child. In both cases physicians decided to refer the case to the family court1 (also check: Wood, 2012). In both cases, in Great Britain and Poland, the court had to decide on future child’s lot.

Purpose and methodology

Similar cases induce strong social emotions. On the one hand, it is demonstrated that the parental authority does not has absolute character, and a child’s life and health are values of particular character. On the other hand, it is underlined that the state cannot enter in brutal way into the guaranteed parental rights for upbringing and care for own child (Kmieciak 2017). Therefore, who has rights in the stipulated cases? Can it be objectively demonstrated? Maybe there is a chance for adverting the important and lacking element, that could solve similar disputes? Can mediation be such an element? The purpose of presented papers is to give response to similar questions. Analysis of formal documents concerning rights of a patient, as well as the events presented by media in summer, 2017, will be made. (Łaska – Formejster, 2016)

Charlie Gard’s case

The Charlie Gard’s case has been presented in e.g. worldwide mass media for several weeks. The following problems were particularly deliberated:

- Can be disconnection from respirator treated as euthanasia on small child?
- Can be the experimental therapy successful in such case?
- How should the physicians and parents proceed?2 (also check: Crespi, 2014)

A significant dispute occurred between the parents of small boy and hospital authorities. According to the parents, there was a chance for experimental therapy. Whereas, the physicians recognised quick disconnection from respirator as required. According to them, only in this way the boy could die in dignity. They added, that the genetic disease experienced

by the boy involved muscular dystrophy, that significantly increased pain suffered by small patient. Several courts opined the Charlie’s case, including the European Court of Human Rights. (Van McCrary, 2009, Landor et. all. 1994) ³

Thus, hospital decision on referring the case to the court was not astonishing. A significant conflict presently took place: on the one hand, parents required respecting theirs rights of contact with own son and decision on his health. Charlie parents claimed for his transportation to home, in order to enable his death at home. On the other hand, we had the medical personnel activities that knew the patient’s health state. Designated experts stated that subsequent therapy does not make sense, it will only strengthen the suffering of the boy. It was also recalled, that transportation of the boy to home could have only additionally increased such suffering. Therefore, objection of parents - despite theirs empowerment - could lead to the problems of medical personnel, who feared for the patient’s safety. Physicians and nurses, basing on own knowledge and following lacking parents’ consent for particular interventions, may fear for objective damages and patient’s suffering arising from such fact, who is presently a child. (Document, 2017)

Charlie Gard’s case was finally solved in the court, where the conflict has intensified. The media informed that during the court proceeding boy’s mother shouted on the judge. In turn, the judge underlined the ultimatum for parents at particular stage of proceeding, who should search for mutual activities with hospital authorities concerning the method, in which the boy will be disconnected from the respirator. The boy was disconnected from the respirator in the end of July, 2017. (also check Moratti 2010) ⁴

**Polish perspective**

Similar cases to the above, in which Charlie Gard was a hero, occured also in Poland. They most often take place when parents do not give consent for life-saving surgical therapy, following own beliefs. Prof. Janusz Skalski, cardiac surgeon from Cracow, recalled in the book “I am brave enough to tell about the miracle”, that such phenomena occur very often in the case of the Jehovah’s Witnesses. It all concerns the surgical operations required for children, i.e. cardiac surgery, during which blood transfusion is mandatory. Skalski underlines, that physicians do not have problems with consent of guardian courts for application of a particular therapy in a child. Whereas, in such situations the consent of court is most often insufficient. Nevertheless, the conflict between parents and medical personnel still exists. Physicians still present the standpoint, that a child’s life should be firstly saved. Whereas, parents underline that such intervention is in breach to theirs beliefs. The court most often adjudicates the child’s life saving procedure, against the will of parents. (Kmieciak, 2016)

The elaborated problems in relations between a child who is a patient, a child’s parents, physicians and court, returned in Poland in the beginning of September, 2017. At that time, the media notified the public opinion about a new-born child kidnapped from the hospital by parents, who did not give consent for any medical procedures just after the birth. According to the representatives of Bialogard hospital, it pertained to “...drying a child, warming under the

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⁴ Court judgment, 3 In the High Court of Justice Family Division, Neutral Citation Number: [2017] EWHC 1909 (Fam)
heat lamp, cleaning the vernix caseosa, bathing a child in the ward, intra-muscular or oral administration of K-vitamin, protective vaccination, eventual feeding the child, as required, screening tests, prevention for anterior uveitis (also known as Crede treatment)\(^5\) (also check: Antommaria, Weise, 2013).

Assuming the parents proceedings as completely rational is hard, from the perspective of medical personnel activities. Physicians caring for young mother recalled, that they did not foresee such reaction of her. When she was pregnant, she completely accepted the proposed tests and medical interventions. After giving birth, she did not give consent with her father for the activities referred above. Following such condition, the hospital decided to notify the court. (Galant, 2017, Rodriguez, Pattini, 2016)

In the elaborated case, several important facts can be discerned. On the one hand, intentions of parents are hard in recognition. They opposed to all medical personnel propositions, that are standard caring procedure for a newly born child. On the other hand, it is also hard to understand the activity of physicians. Neonatology State Consultant, prof. Ewa Helwich directly pointed out, that notification of court was groundless. She added in conversation with Polish Press Office, that “in the case of new-born from Bialogard hospital, referring the case to family court was groundless. Patience and calm talks between personnel and parents were in shortage\(^6\). When elaborating the case referred above, a perspective other than the perspective demonstrated by prof. Skalski is clearly visible. Cardiac surgeon paid caution to the endangered child’s life. In the Bialogard case, all probably pertained to the case of health threat. Polish Act on the Physician and Dentist Profession reserves the right of guardian court notification. However, such activity is pursued in several cases. It all pertains to the cases, in which a child in the age of 16 or above or an incapacitated person has other opinion being in contradiction to parent’s or custodian’s opinion. Antommaria, Weise, 2013) In the Bialogard case, physicians probably plead to art. 34, par. 6 of act referred above. According to its wording, “when a custodian for underage, an incapacitated person or a person incapable of conscious expression of own consent does not give consent for the activities stipulated in par. 1 and pursued by a physician, that are required for the elimination of life threat or severe health damage, such physician may pursue such activities after the consent of guardian court.”\(^7\) When acknowledging with the opinions of hospital representatives, parents of the child and prof. Ewa Helwich’s, making a conclusion of child’s life threat or severe health damage in the case referred above is hard. The child was not in such state, it was so called late preterm. Physicians did not want to introduce a therapy, they tried to pursue standard preventive procedures, instead.

**Discussion**

The reaction of Bialogard parents may be firstly seen as unaccountable. On the other side, the upper court agreed with theirs standpoint. Whereas, one question still remains: Did parents have chance of defence for own rights in the presence of the court? Polish Physician’s

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\(^7\) Act on the Profession of Physician and Dentist, December 5, 1996 (Journal of Laws, 1997, no. 28, item 152)
Profession Act (in contradiction to i.e. the Mental Health Protection Act) does not provide the chance for meeting between the family court judge and parents, who do not give consent for medical activities. The court collects explicitly the hospital opinion, what places such parents on lost position. According to the media, in the referred case the hearing took place at territory of hospital.

When thinking about it, we may consider the physicians decision on submitting the case to the court as wrong. We may assume that they acted dogmatically, with breach to the parents’ rights. On the other hand, when all medical interventions are negated, a natural fear may rise in them, that is related with the child’s health and eventual criminal liability. Parents have legal competences related with a child’s health state, following the pursued role. Whereas, the parental authority should be pursued in relation to its objective good. These parents declared, that they wanted to act exactly in this way. When the vaccination obligation was negated by them, it does not stand in contradiction to it. It is more and more often pointed out, that the intensive vaccination schedule for new-borns is in contradiction to medical care standards. But we do not know theirs attitude in the whole case. We also do not know, whether the physicians wanted to listed to them or not. Thus, probably the only missing factor was actually conversation. (check also, Hardin, 1998)

We may produce a similar conclusion when analysing the Charlie Gard’s case. We should remember, that boy’s parents received ultimatum in the elaborated case. This word is unfortunately key factor proving the fact, that unfortunately the judicial procedure did not bring the expected results. Both the hospital and parents of the boy did not find the expected results. (Winright, 2017)

It should be recalled in such context, that the hospital was not in contradiction to parents of the boy. Generally, hospital activity was oriented on the ways, according to which the child functioned. This boy finally died in a hospice, according to judicial decision. Making a conclusion that hospital wan the process is hard. Undoubtedly, the case was lost by boy’s parents. Not only that theirs postulates were not fulfilled, but generally they were recognised by numerous people as enemies to own child. Whereas, when observing theirs fight, such state of affairs can be hardly taken for truth. (also check, (Muirhead, 2004)

Towards mediations

Both the case of small boy from England and the case of parents from Polish Bialogard demonstrate, that worldwide discourse of the medical world on the medical mediation is important. (Thorpe, 2011)

Mediating a dispute is something different from judicial decision. When a case is solved in the court, the result will never satisfy both parties. It may lead to a case, in which both parties are not satisfied. This method of solving a dispute provides a chance for consensus for both parties. It appears that in the cases of Charlie Gard and Bialogard child, a mediator should be involved, who is completely neutral, instead of the court. It is presently an expert, who does not automatically take the standpoint of hospital or postulates submitted by parents. Such a person should be so called third party, who enters into the conflict. Such a person should manage the negotiations, that many times evolve into emotional quarrels. Similar cases are perfectly pursued with means of the mediation activities (D.C. Heltzer, et al., 2011). A common value for all parties, presently a child’s good, may be easily found.

In the medical world, so called medical mediation is more and more strongly heard. In Poland, mediation regulations can be found in i.e. the legislation stipulating the principles of Chamber of Physicians operation. Legal representatives handling with patient’s rights more and more often pursue the mediation proceedings in hospitals. Such activities are also found when solving the cases of alarming medical events. The Charlie and Bialogard case also demonstrate one more area of insight.

It generally involves the clinical mediation, the establishment of new group of experts who will enter into the centre of conflicts at territory of hospital ward or clinic. It can be the case of admission to the hospital or principles of treatment, and many more. Such activities may also pertain to the cases related with last moments of a patient’s life. The mediator must be an expert and a person, who supports the agreement of both parties. The mediator must also take care for presentation of standpoints by parties in mediation. Such expert should be independent from hospital.9

Conflicts in medical world occurred in the past, and will be in the future. Whereas, such conflicts are of unique character. They involve key values in every society, presently: human life and health. The Charlie Gard case and the Polish Bialogard case realises, that a proportion of disputes can involve not only a patient’s life, but also his health and death. Similar cases cannot be completely solved in the court. A judge cannot completely eradicate a particular problem with means of a sentence. Thus, a problem of medical mediation is worth of deliberation, that may give insight into the importance of agreement in the special cases, such as a patient’s life, health and death, that occur in current reality.(check also, Nelson 2003).

References


