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PECULIARITY OF INDIVIDUAL RIGHT TO HEALTH DATA WITHIN THE FAMILY

According to the Universal Declaration of Human Rights the family is the natural and fundamental group unit of society and is entitled to protection by society and the State. Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution. At the same time the family as well as a particular individual is protected against any interference in privacy issues, notably, no one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honor and reputation. Everyone has the right to the protection of the law against such interference or attacks¹.

By this article we are drawing attention to the right of person to marry and to found a family and the right of person to the privacy in health issues, the balance between these rights, situations when one right may prevail upon the other, ways of resolving the existing disputable issues in the current law of Ukraine.

To research and resolve the above we are going to analyze the right of person to marry and to found a family and the right of person to the privacy in health issues according to the Law of Ukraine; to analyze the right of person to marry and to found a family and the right of person to the privacy in health issues abroad; to reason when the right to found the family may prevail over the right to the privacy or vice versa, that is to find the balance of the said rights when necessary; to offer amendments to the law of Ukraine to improve the existing legal norms and to overcome the probable ambiguity in the above mentioned relations.

In order to do the complete and interesting research a combination of approaches are used. The descriptive analysis of a number of technical rules helps to organise and characterize the legal rules related to the sphere of the research. The sociological approach includes both qualitative and quantitative research methods. As we are comparing the national law with the EU existing best practice and the practice of other countries, the comparative analysis approach is used as well.

The research of the above mentioned issues is of urgency as family life and individual privacy play a great role in the everyday life of a person and at the same time influence greatly the public law aspects. Moreover, according to the requirements of the Association Agreement between the European Union and its Member States, of the one part, and Ukraine, of the other part, one of the requirement for Ukraine is ensuring respect for common EU values, achieving convergence with the EU in a number of areas including the legal one, that is to reinforce the rule of law and respect human rights and fundamental freedoms and to meet other requirements relating to the Law referring to e-communication in all the spheres of Ukrainian life and health sphere including². In conformity with the Strategy of firm development “Ukraine – 2020” the reform of the health care system is one of the main targets aiming to approximate to the values and standards stipulated by the “European health strategy – 2020”³.

In terms of philosophical and theoretical grounds and “support” for our research we have analyzed the works of Georg Wilhelm Friedrich Hegel, Tom L. Beauchamp and James F. Childress, John Hardwig, Ruslan Stefanchuk, Oksana Kashyntseva, Geraldine van Buren and other researchers. Moreover, International documents, norms, precedents are studying and evaluating by us as indisputable rich sources of information and practice that rule and direct our research.

According to the law of Ukraine right to found a family is the individual non property right ensuring the natural life of the person. The family consists of persons living together, having the common everyday life, mutual rights and obligations⁴. The number of mutual obligations is imposed to husband and wife in conformity with the current Family Code of Ukraine. For instance, the husband and the wife shall resolve the family issues together with the equal opportunities; the husband and the wife are entitled to object to inequality in family issues’ resolution. They shall bring together the family relations on the ground of love, respect, friendship and mutual help⁵.

Despite all the above mentioned general norms regulating the equality of the rights of husband and wife, their rights to share family problems in order to resolve them together, there is no any legislative explicit obligation of resolving the health issues of each other together, nor of sharing health information. On the one hand, the reasons of this are clear – we shall respect the individual privacy issues, guaranteed by the Universal Declaration of human rights and by the norms of national legislation, the Constitution of Ukraine included⁶. On the other hand, we see some sort of contradictions in this aspect on the national level. To be more precise, the article 30 of the Family Code of Ukraine states that the fiancés shall share with each other health information; moreover, the legislator confirming that the result of medical check-up of the fiancés is the confidential information but may be shared with fiancés. It means that the health information of the each of fiancé is to be disclosed to the both of them. Taking the above into consideration, we see the inconsistency of the Ukrainian legislator. First of all, according to the national law the fiancés are persons who has an intention to marry and who filed application for marriage registration⁷. It means that according to the law persons who have already made decision to marry shall share health issues with each other and

during twenty days they are offered to do the medical check-up. But, as health information is considerable and highly important issue that may influence greatly the decision to marry or not to marry, we believe that the said information shall be shared before the couple makes the decision to marry and file the application for marriage registration. Moreover, twenty days may be not enough to have the detailed medical check-up done and it may be too late to do it just before the marriage. Taking into consideration the above, it seems to be highly advisable to modify the current law referring to the said aspect of the Family Code of Ukraine. We believe that it would be more appropriate to legally instruct persons who plan to marry to share health information before filing of the application for marriage registration. To update health information the persons may do the medical check-up. Nevertheless, the results of the said medical check-up are confidential and shall be opened to the couple upon the consent of each member of the couple to the disclosure. So, we are of the opinion that disclosure of the health information of the capable mature person, in any marital status, shall be eligible upon the consent of the said person to the disclosure, except the situations stipulated by law and referring to the ensuring and protecting the public health and counteraction against spread of HIV and other diseases.

In regards to the health information of married couple, as it is mentioned above, the Ukrainian legislator does not explicitly oblige the husband and the wife to share their health data, nor shall other member of the family share their information within the family. It is fair to mention that this issue is very disputable in legal and ethical aspects. Some researchers believe that this kind of information must be shared within the family. For instance, John Hardwig in his paper "What About the Family? – The Role of Family Interests in Medical Decision Making" states that it is highly important to give an opportunity to the family to participate in decision making process relating to the ill member of the family and its treatment as "there is no way to detach the lives of patients from the lives of those who are close to them" and as the decision made by one member who is ill may or "will have dramatic and importantly impacts on the lives of the whole family"; family according to John Hardwig does not necessarily mean immediate family member but also "those who are close to the patient"⁸. In our opinion this scientific view is very close to the communitarian values – values of the social and political philosophy that emphasizes the importance of community in the functioning of political life, in analysis and evaluation of political institutions and in understanding human identity and well-being⁹. This approach is very interesting and gives the food for the scientific thought.

As for the Ukrainian law regulating the private health information and family relations issues, considering the private nature of family relations and life it should be advisable for the married couple to share health information. So, we believe that it would be better if the law could give as a general rule an opportunity to the physician or other medical officer to provide the mentioned health information to the married couple upon the consent of each member of the said couple. In this situation one of the principles of Biomedical Ethics developed by Tom L. Beauchamp and James F. Childress – principle of respect for autonomy meaning the respecting decision-making capacities of autonomous persons; enabling individuals to make reasoned informed choices¹⁰ would be respected and at the same time the interests and rights of the other member of the married couple could be protected.

To summarize the above, in our opinion, it would be more appropriate to legally instruct, by the Family Code of Ukraine, persons who only plan to marry rather than persons who have already filed application to marry (fiancés) to share health information. To update health data the said persons shall have the opportunity do the medical check-up. The results of the said check-up are confidential and shall be advised to the couple upon consent of each member of the couple to disclose the health information. Moreover, in our opinion, considering the private nature of family relations and life it should be advisable for the married couple to share health information. So, we believe that it would be accurate if the law could outline an opportunity to the physician or other medical officer to provide the health information of one of the members of the married couple or of both of them to the said couple upon their consent to the above disclosure.

¹ The Universal Declaration of human Rights. [Online access]. – Online link: <http://www.un.org/Overview/rights.html>

² The Association Agreement between the European Union and its Member States, of the one part, and Ukraine, of the other part. [Online access]. – Online link: http://eeas.europa.eu/ukraine/docs/association_agreement_ukraine_2014_en.pdf

³ Strategy of firm development "Ukraine – 2020" [Online access]. – Online link: <http://zakon3.rada.gov.ua/laws/show/5/2015>

⁴ The Family Code of Ukraine. [Online access]. – Online link: <http://zakon2.rada.gov.ua/laws/show/2947-14>

⁵ The Family Code of Ukraine. [Online access]. – Online link: <http://zakon2.rada.gov.ua/laws/show/2947-14>

⁶ The Constitution of Ukraine. [Online access]. – Online link: <http://zakon2.rada.gov.ua/laws/show/254%D0%BA/96-%D0%B2%D1%80>

⁷ The Family Code of Ukraine. [Online access]. – Online link: <http://zakon2.rada.gov.ua/laws/show/2947-14>

⁸ John Hardwig. "What About the Family? – The Role of Family Interests in Medical Decision Making". [Online access]. – Online link: <http://web.utk.edu/~jhardwig/family.htm>

⁹ Encyclopedia Britannica. [Online access]. – Online link: <http://www.britannica.com/topic/communitarianism>

¹⁰ Tom L. Beauchamp and James F. Childress. Principles of Biomedical Ethics. 5th edition. [Online access]. – Online link: https://books.google.de/books/about/Principles_of_Biomedical_Ethics.html?id=_14H7MOW1o4C&hl=ru

Резюме

Чабан О. А. Особливості реалізації права на таємницю про стан здоров'я залежно від сімейного стану.

Стаття присвячена аналізу права особи на шлюб, а також права на таємницю про стан здоров'я; досліджені основні права та обов'язки подружжя та наречених в аспекті інформації про стан здоров'я особи; випадки розкриття такої інформації і збе-

реження її конфіденційної. Для вирішення наявної законодавчої неузгодженості в досліджуваному аспекті запропоновані зміни до Сімейного кодексу України.

Ключові слова: право на таємницю приватного життя, інформація про стан здоров'я, право на шлюб, розголошення, конфіденційність, чоловік, жінка, повага автономії волі, біомедична етика.

Резюме

Чабан Е. А. Особенности реализации права на тайну о состоянии здоровья в зависимости от семейного положения.

Статья посвящена анализу права на заключение брака и права на тайну о состоянии здоровья; изучены основные права и обязанности супругов, а также помолвленных лиц в отношении информации о состоянии здоровья в Украине и за рубежом. Для разрешения существующих спорных вопросов в законодательстве предложены изменения в Семейный кодекс Украины.

Ключевые слова: право на тайну о личной жизни, информация о состоянии здоровья, право на заключение брака, раскрытие информации, конфиденциальность, супруг, супруга, уважение автономии воли, биомедицинская этика.

Summary

Chaban O. Peculiarity of individual right to health data within the family.

The article is dedicated to the analysis of the right of the person to marry and to found a family, and the right of the person to the health data privacy; the main duties, obligations and rights of the married couple and fiancés in terms of the disclosure or non-disclosure of the health information of each of the member of the couple are researched on national and international levels. To resolve the existing ambiguity in aspect of balancing of the above mentioned rights the amendments to the current Family Code of Ukraine are offered.

Key words: right to the privacy, health information, right to marry and to found a family, disclosure, confidentiality, husband, wife, respect for autonomy, biomedical ethics.

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СТРАХУВАННЯ ЯК СПОСІБ УПРАВЛІННЯ РИЗИКАМИ В СФЕРІ ОХОРОНИ ЗДОРОВ'Я

Одним із шляхів підвищення ефективності та якості надання медичної допомоги є впровадження системи управління ризиками, що дає змогу виявити та оцінити негативні наслідки, спланувати стратегію протидії, яка була б спрямована на зменшення випадковості подій, які завдають фізичної та моральної шкоди медичному закладу, його персоналу та пацієнтам.

На європейському ринку медичних послуг страхування вже давно розглядається як ефективний метод управління індивідуальним соціальним ризиком, що забезпечує компенсацію шкоди (відшкодування шкоди). Проте страхування є ефективним інструментом управління ризиками лише у поєднанні з іншими формами організації управління ризиками, які спрямовані на виявлення та чітке окреслення як очевидних джерел небезпеки (ятрогенної патології), так і прихованих (неочевидних) джерел небезпеки та заходів протидії. В іноземній практиці впровадження систем управління ризиками сформувало багатий досвід, який повинен бути використаний Україною в процесі реформування системи охорони здоров'я¹.

Незважаючи на те, що система контролю якості медичної допомоги в Україні існує, аналіз узагальнення судової практики та наукової літератури свідчать про її неефективність у частині відшкодування шкоди здоров'ю пацієнтів внаслідок різних подій^{2, 3, 4, 5}.

Світовий досвід демонструє ефективність прийняття уніфікованих стандартів, що допомагають медичному закладу вибрати найбільш оптимальну форму побудови системи безпеки пацієнтів. Цьому сприяють створені в різних країнах національні агентства з безпеки медичної допомоги. Системний аналіз проблеми управління ризиками свідчить про її комплексність. Причини виникнення помилок мають вагомий людський фактор та системний компонент⁶. Дослідження показали, що людський чинник відіграє важливу роль у виникненні дефектів у наданні медичної допомоги, частота помилок персоналу варіює від 30 % до 80 %^{7, 8}. Доведено, що стимулювання персоналу до уважності й обережності найчастіше не є ефективним механізмом запобігання дефектам надання медичної допомоги – людські помилки невідворотні. Як зазначає у своїй роботі Дж. Ризон: «...ми не в змозі змінити суть людей, але ми в змозі змінити суть організацій, в яких працюють люди»⁹.

Наприклад, якщо існують помилки у виборі лікарських засобів, що мають схоже упакування і які розташовані в одному місці, то з позиції підходу, орієнтованого на людських фактор (людиноцентричний підхід) вирішення проблеми лежить у площині навчання персоналу, покарання за недбалість чи халатність. Як протилежність людиноцентричному підходу є значно ефективніший системний підхід, орієнтований на зміну умов – два препарати повинні зберігатися в двох різних місцях, мати різне кольорове маркування¹⁰.