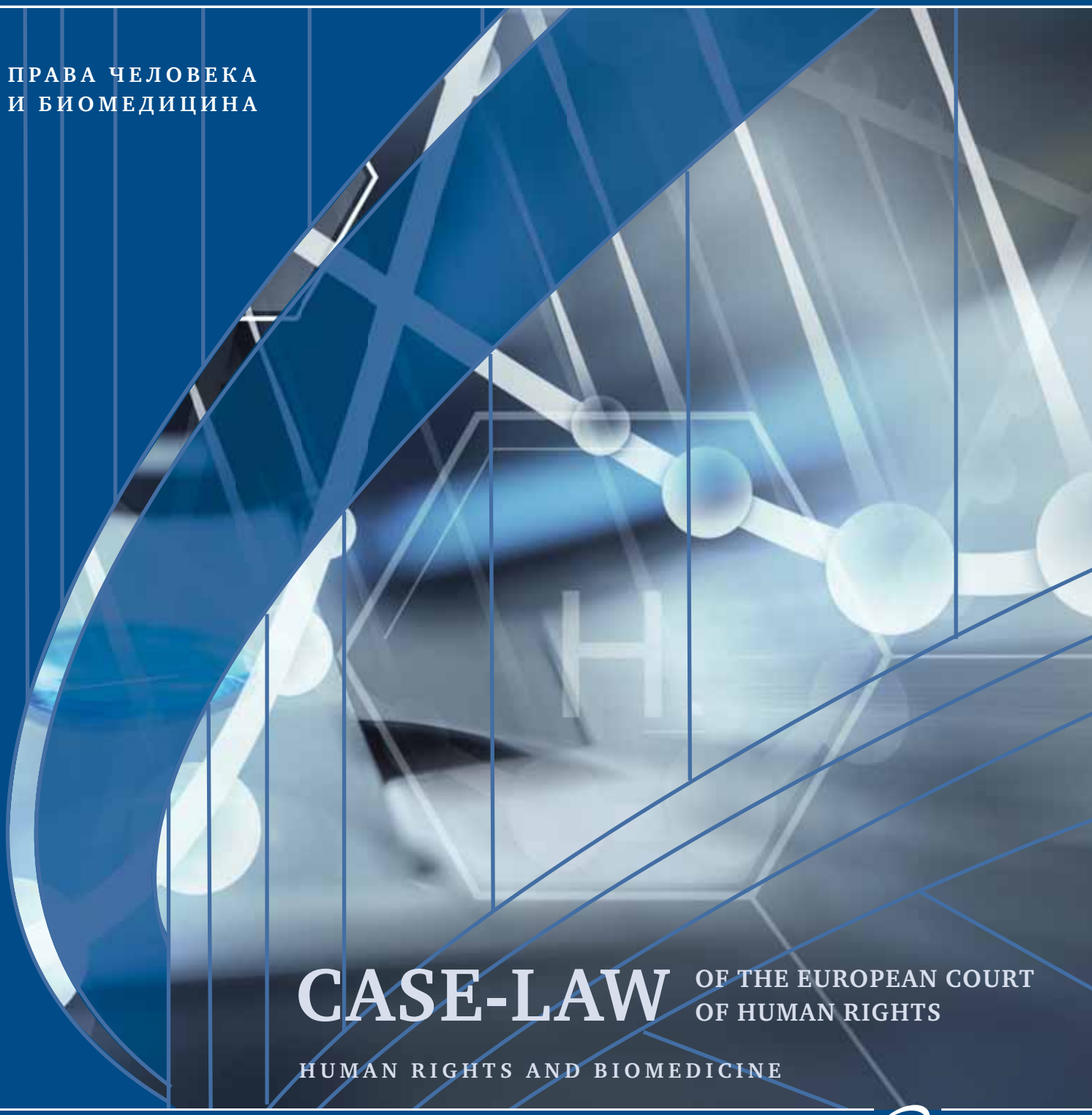
ПРЕЦЕДЕНТЫ ЕВРОПЕЙСКОГО СУДА ПО ПРАВАМ ЧЕЛОВЕКА

ПРАВА ЧЕЛОВЕКА
И БИОМЕДИЦИНА



CASE-LAW OF THE EUROPEAN COURT OF HUMAN RIGHTS

HUMAN RIGHTS AND BIOMEDICINE

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Интересы и благо человека превалируют над исключительными интересами общества или науки

Цена человеческой жизни, предназначение человека и пределы дозволенного вмешательства в создание, развитие и поддержание жизни человека — как никогда актуальные сегодня темы в общественных обсуждениях. И Совет Европы всецело содействует постоянному диалогу о возможностях биоэтики на международном и национальном уровне, проводя конференции, симпозиумы, общественные консультации.

Важную, активную роль в оценке новых этических и правовых вопросов, оказании помощи в повышении уровня информированности общества о правах и свободах в повседневной медицине и в связи с применением биомедицинских исследований играет Комитет по биоэтике.

Неравнодушный, вдумчивый и ответственный подход общества к биоэтике может дать новый позитивный и прогрессивный импульс для развития человечества в целом.

The interests and welfare of the human being shall prevail over the sole interest of society or science

The price of human life, destination of a human being and the limits of warrantable intervention in the creation, development and maintenance of human life are today as relevant as ever topics in public discourse. And the Council of Europe wholly contributes to the ongoing dialogue on the possibilities of bioethics at the international and national level, arranging conferences, symposia, and public consultations.

The Committee on bioethics plays an important, active role in the assessment of new ethical and legal issues, in assistance in raising public awareness on the rights and freedoms in everyday medicine and in relation to the application of biomedical research.

Caring, thoughtful and responsible approach of the society to bioethics can provide a new positive and progressive momentum for the development of humanity as a whole.

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Aspects éthiques et juridiques du consentement éclairé

PHILIPPE BOILLAT

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Direction générale Droits de l'Homme et Etat de Droit (2006—2017)

Aspects éthiques et juridiques du consentement éclairé

Discours d'ouverture de Philippe Boillat, Directeur Général, Direction générale Droits de l'Homme et Etat de Droit*

Mesdames et Messieurs,
Chers collègues,

C'est pour moi un réel privilège et un vrai plaisir de vous souhaiter une cordiale bienvenue au nom du Conseil de l'Europe qui co-organise cette conférence avec le Ministère de la Santé et l'Université de la Justice auprès de la Cour suprême de la Fédération de Russie. Je remercie vivement nos partenaires de l'intérêt manifesté pour cette conférence, mais aussi, plus largement, pour les activités conduites par ma Direction générale Droits de l'homme et Etat de droit.

Cette conférence est consacrée à la bioéthique — en d'autres termes, aux enjeux pour les droits de l'homme soulevés par l'évolution des pratiques et les développements scientifiques et techniques en biologie et en médecine. Des enjeux d'une grande actualité tant les possibilités d'intervention sur la vie humaine se développent. Des possibilités qui sont source potentielle de grandes avancées pour le bien être de l'humanité, mais également source d'inquiétudes quant aux utilisations abusives qui pourraient en être faites, mettant en cause le respect de la dignité humaine.

gnent de l'importance et de l'actualité de la biomédecine et des biotechnologies. Il est donc crucial tant pour les professionnels du droit que ceux de la santé d'examiner et de réfléchir aux différentes questions posées, questions auxquelles ils devront faire face de plus en plus souvent au quotidien.

C'est précisément l'objet de cette conférence, qui se penchera notamment sur des domaines spécifiques tels que le don d'organes et de tissus ou la gestion des maladies contagieuses.

Vous aurez ainsi la possibilité d'examiner les aspects éthiques et juridiques de la mise en œuvre duprincipe du consentementdu point de vue des autorités compétentes, de celui des parties prenantes et organisations concernées, aux niveaux national et international. La promotion de ce dialogue interdisciplinaire et les échanges de bonnes pratiques sont indispensables pour répondre à des préoccupations communes.

Face à la complexité et la sensibilité des questions éthiques dans le domaine biomédical, une approche pluridisciplinaire est essentielle. Il est notamment primordial que les professionnels du droit, mais également ceux

La jurisprudence récente de la Cour européenne des droits de l'Homme, comme celle des cours russes, témoignent de l'importance et de l'actualité de la biomédecine et des biotechnologies

Face à ces développements qui permettent des progrès considérables notamment pour la santé humaine, le respect des principes fondamentaux de protection des droits de l'homme est essentiel pour prévenir les abus.

Ancré dans la Constitution de la Fédération de Russie, le principe du consentement libre et éclairé — qui sera au cœur de vos discussions aujourd'hui — en est un des piliers. Proclamé pour la première fois au niveau international dans la Convention du Conseil de l'Europe sur les droits de l'Homme et la biomédecine — la Convention d'Oviedo, dont nous célébrons les 20 ans cette année — le consentement éclairé est la clé de voute de la protection de l'intégrité de la personne humaine et l'un des droits des patients universellement reconnu.

La jurisprudence récente de la Cour européenne des droits de l'Homme, comme celle des cours russes, témoi-

de la santé, se familiarisent avec les implications des principes essentiels de protection des droits de l'homme qui sont en jeux. Ces deux groupes professionnels ont en effet, chacun à leur niveau respectif, une responsabilité déterminante afin que ces principes soient pleinement respectés.

Il est ainsi de première importance que les professionnels de santé soient sensibilisés à ces questions et comprennent la portée des principes juridiques pertinentstels que le consentement préalable,indispensable à toute intervention.

Autres questions à se poser: quelles informations donner au patient ? Comment recueillir son consentement, notamment dans des situations d'urgence? Comment répondre aux tensions qui peuvent naitre entre nécessité médicale et souhait du patient? Voilà quelques-unes des questions sur lesquelles vous aurez à vous pencher.

De même, les professionnels du droit doivent se familiariser avec la complexité des situations rencontrées dans le

* Conférence organisée par le Ministère de la Santé de la Fédération de Russie, l'Université de la Justice auprès de la Cour suprême de la Fédération de Russie et le Conseil de l'Europe. Moscou, 29 juin 2017.

domaine biomédical, complexité qui ne cesse de s'accroître en raison des progrès de la science et de la technologie.

Aussi, je me félicite que nous bénéficions aujourd'hui de la présence de représentants hautement qualifiés non seulement des deux domaines du droit et de la santé, mais également des domaines de l'éducation et de la formation.

En effet, l'on ne saurait travailler au renforcement du respect des droits fondamentaux et à la prévention des abus en matière de droits de l'Homme sans agir et investir dans l'éducation et la formation. Vous le savez, le Conseil de l'Europe, au cours de ces dernières années, a développé à travers son projet HELP, un large programme de formation en matière de droits de l'Homme, destiné aux professionnels du droit.

J'ai le plaisir de vous informer qu'un nouveau cours sur les principes essentiels de protection des droits de l'homme dans le domaine biomédical va être développé dans le cadre de ce projet. Ce nouveau cours répond à une demande exprimée par les professionnels et les institutions de formation dans les secteurs concernés. Le séminaire qui se tiendra demain à la Faculté de médecine de l'Université de Moscou sera l'occasion de discuter du contenu de ce cours afin qu'il puisse répondre au mieux aux attentes des professionnels concernés. Je vous invite vivement à y participer.

L'approche innovante du Conseil de l'Europe pour l'éducation et la formation professionnelle dans ses 47 États membres, dont la Fédération de Russie, présente deux caractéristiques principales. La première s'appuie sur l'intégration constante et l'enrichissement mutuel des ressources juridiques internationales et nationales. La seconde caractéristique consiste dans son approche pluridisciplinaire du traitement des sujets transversaux, tels que ceux qui relèvent de la bioéthique.

Je suis convaincu que cette conférence et les actions conjointes qui suivront dans le domaine de la bioéthiqueseront mutuellement enrichissantes. Elles contribueront à renforcer notre coopération et faciliteront les travaux préparatoires en cours pour la ratification par la Fédération de Russie de la Convention sur les droits de l'Homme et la biomédecine.

* * *

Mesdames et Messieurs,

Permettez-moi de conclure en insistant à nouveau sur la méthode de travail et l'approche qui sont celles du Conseil de l'Europe. Nous sommes persuadés que le dialogue et la coopération sont essentiels pour atteindre les objectifs définis dans les Statuts de notre Organisation : «ses objectifs sont de réaliser une union plus étroite entre ses membres afin de sauvegarder et de promouvoir les idéaux et les principes qui sont leur patrimoine commun». C'est ce qui fait notre «raison d'être» et notre spécificité. Le Conseil de l'Europe est, en effet, engagé dans une coopération et des interactions directes avec les autorités nationales dans de nombreux domaines, dans le but de promouvoir les bonnes pratiques et faciliter ainsi la mise en œuvre de nos normes juridiques communes.

La coopération technique est une composante importante de la stratégie du Conseil de l'Europe, une de ses valeurs

ajoutées essentielles. La formation des professionnels du droit — et nous l'espérons prochainement également de ceux d'autres secteurs directement concernés comme celui de la santé — joue un rôle croissant à cet égard. Le programme HELP — le seul programme paneuropéen pour la formation des professionnels en matière de droits de l'homme — a été lancé avec succès en 2015 dans la Fédération de Russie. Ma Direction générale apprécie tout particulièrement notre coopération fructueuse avec la Cour suprême, la Cour constitutionnelle, le Bureau du Procureur général, le Ministère de la Justice, le Ministère de la Santé et le Bureau du Commissaire aux droits de l'homme de la Fédération de Russie, ainsi qu'avec les institutions de formation, et tout en particulier l'Université de la Justice et l'Académie du Parquet ici représentées à leur plus haut niveau.

Je forme le vœu que notre Programme HELP se poursuive et se développe avec d'autres partenaires. Les discussions qui auront lieu aujourd'hui à l'occasion de cette conférence et lors du séminaire de demain y contribueront sans aucun doute.

Je vous remercie de votre attention et souhaite à toutes et à tous de fructueuses discussions et d'enrichissants débats.

Le principe du consentement libre et éclairé dans la Convention d'Oviedo

LAURENCE LWOFF
Chef de l'Unité de Bioéthique, Conseil de l'Europe

Le principe du consentement libre et éclairé dans la Convention d'Oviedo

Résumé. Le principe du consentement libre et éclairé est un principe essentiel de protection des droits de l'Homme dans le domaine biomédical. Seul instrument juridique contraignant au niveau international dans ce domaine, la Convention sur les Droits de l'Homme et la Biomédecine définit les conditions essentielles de son application et réaffirme sa pertinence face aux développements dans le domaine biomédical.

Mots clés: bioéthique, Convention d'Oviedo, consentement, Conseil de l' Europe.

Le principe du consentement libre et éclairé est un principe essentiel de protection des droits de l'Homme dans le domaine biomédical. La Convention sur les droits de l'Homme et la biomédecine du Conseil de l'Europe a été le premier instrument juridique à consacrer ce principe au niveau international.

Le travail pionnier du Conseil de l'Europe

Le Conseil de l'Europe, créé en 1949, est une organisation intergouvernementale ayant pour objectif de promouvoir une coopération plus étroite entre ses 47 états membres pour la protection des droits de l'homme et le respect de l'état de droit et de la démocratie.

Dès le début des années 80, le Conseil de l'Europe a initié des travaux sur les enjeux pour les droits de l'Homme des développements dans le domaine biomédical. Ce travail pionnier continue à être unique au niveau international par son approche centrée sur les droits de l'Homme. Un important corpus juridique a ainsi été développé, établissant des principes fondamentaux dans ce domaine. L'instrument de référence à cet égard est la Convention sur les droits de l'Homme et la biomédecine (STE n°164) ouverte à la signature le 4 avril 1997, à Oviedo, en Espagne.

La Convention sur les droits de l'Homme et la biomédecine: un texte de référence au niveau international

Cette Convention — dites Convention d'Oviedo — est le seul instrument juridiquement contraignant dans ce domaine. Elle fait partie intégrante des instruments de référence du Conseil de l'Europe en matière de protection des droits de l'Homme. Si elle n'a pas de lien formel avec la Convention européenne des droits de l'Homme, elle en emprunte de nombreux principes, concepts et termes dans le but de préserver la cohérence du système juridique européen. On peut noter, en outre qu'elle est devenue un instrument de référence pour la Cour européenne des droits de l'Homme (CEDH) dont la jurisprudence dans ce domaine ne cesse de se développer, comme l'a montré un rapport de recherche récent préparé par la Division de la Recherche de la CEDH, sous la direction du Service du Jurisconsulte[1].

La Convention d'Oviedo établie un ensemble de principes applicables à la médecine quotidienne. Pour cette raison, elle est souvent considérée comme le «traité européen des droits des patients». Mais elle traite aussi des secteurs spécifiques soulevant des préoccupations particulières en matière de droits de l'homme que sont la génétique, la recherche biomédicale et la transplantation d'organes et de tissus d'origine humaine. La Convention définit ainsi un cadre commun de protection des droits de l'homme à l'égard des applications de la biologie et de la médecine à l'intérieur duquel les états peuvent développer leur propre législation.

La Convention d'Oviedo a été complétée jusqu'à présent par quatre protocoles additionnels qui en développent les principes dans des domaines spécifiques. Le premier protocole additionnel portant interdiction du clonage d'êtres humains (STE n°168, 1998) n'avait pas été envisagé au moment de l'élaboration de la Convention. La décision d'élaborer ce protocole a été prise à la suite de l'annonce de la naissance de la brebis Dolly, produite par transfert nucléaire. L'adoption de ce protocole dans une période de temps très limitée après cette annonce témoigne d'un très fort consensus politique et d'un accord sur les enjeux pour les droits de l'Homme présentés par cette nouvelle technologie. Ce Protocole est le seul instrument international juridiquement contraignant interdisant le clonage d'êtres humains.

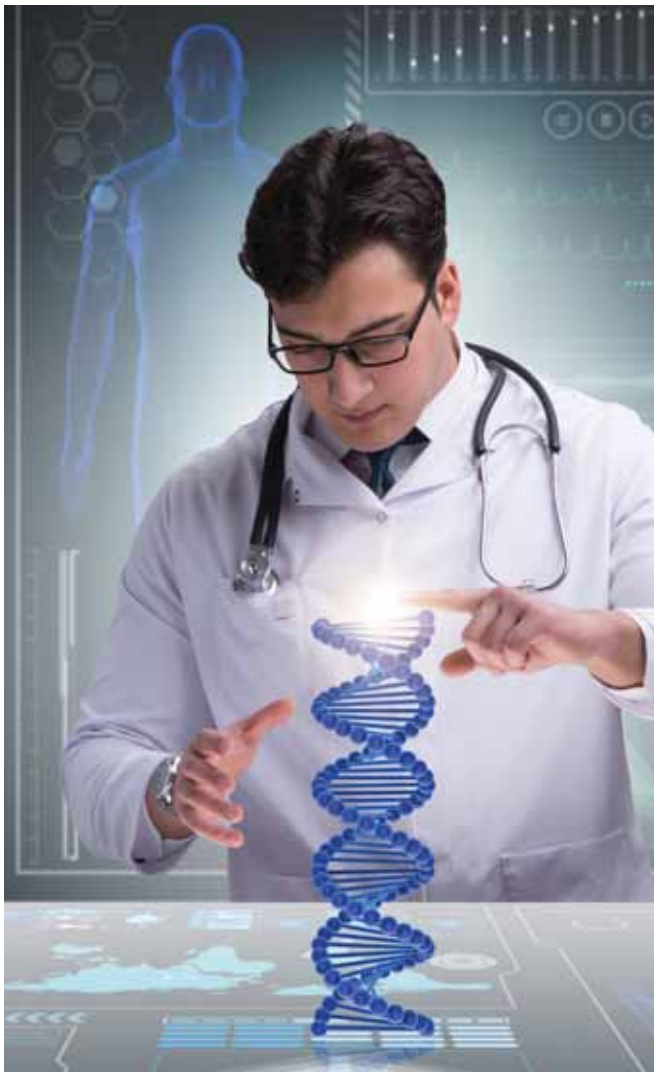
Les trois autres protocoles élaborés jusqu'à présent étaient déjà envisagés au moment de la rédaction de la Convention. Ils couvrent des domaines soulevant des préoccupations particulières pour la protection des droits de l'Homme en raison des interventions particulièrement invasives ou intrusives qui les caractérisent: la transplantation d'organes et de tissus d'origine humaine (STE n°186, 2002), la recherche biomédicale (STCE n°195, 2005) et les tests génétiques à des fins médicales (STCE n° 203, 2008).

Le consentement libre et éclairé — Plus qu'un simple accord, un processus pour permettre un choix

Le consentement libre et éclairé est un principe central dans ces différents domaines d'application de la biologie et de la médecine.

La Convention a consacré, pour la première fois dans un instrument juridique international contraignant, une

[1] Rapport de recherche — Bioéthique et jurisprudence de la Cour européenne des droits de l'Homme © Conseil de l'Europe / Cour européenne des droits de l'homme, 2016 / http://www.echr.coe.int



règle déjà bien établie, à savoir qu'aucune intervention ne peut en principe être imposée à une personne sans son consentement. Il s'agit là de reconnaître l'autonomie de la personne dans sa relation avec les professionnels de santé.

La CEDH a régulièrement rappelé dans sa jurisprudence pertinente, que le droit d'exprimer son consentement à une intervention dans le domaine médical relevait du droit à la protection de la vie privée, en particulier du droit à l'intégrité[2].

La règle générale du consentement est établie à l'article 5 de la Convention d'Oviedo qui précise qu' «une intervention dans le domaine de la santé ne peut être effectuée qu'après que la personne y a donné son consentement libre et éclairé. Cette personne reçoit préalablement une information adéquate quant au but et à la nature de l'intervention, ainsi que quant à ses conséquences et ses risques. La personne concernée peut à tout moment, librement retirer son consentement.»

Le consentement n'est pas ici entendu comme un simple accord donné, mais comme un processus permettant à une personne de faire un choix libre et éclairé par rapport à une intervention envisagée. L'information préalable en est donc une composante essentielle.

La notion d'information "appropriée" renvoie à la fois au contenu et à la forme sous laquelle elle est communiquée. Elle exige du professionnel de santé responsable qu'il fournisse, avant l'intervention, une information objective quant à la nature et aux conséquences possibles de l'intervention envisagée ou de ses alternatives. Cette information doit notamment porter sur les améliorations pouvant résulter du traitement, sur les risques qu'il comporte. Les risques de l'intervention ou de ses alternatives ne doivent pas porter uniquement sur ceux inhérents au type d'intervention, mais également tenir compte des caractéristiques individuelles de la personne, telles que son âge ou l'existence d'autres problèmes de santé.

La personne doit, en outre, pouvoir obtenir des informations complémentaires, si elle le souhaite. Selon l'intervention et le contexte dans lequel elle est envisagée, ces informations devront être complétées; c'est le cas notamment lorsqu'il s'agit d'une recherche[3].

Cette information doit, de plus, être formulée dans un langage que la personne concernée puisse comprendre. Il peut être important de fournir, en plus d'informations orales, des informations écrites pour en faciliter la compréhension. Sauf en situation d'urgence, la personne concernée doit pouvoir bénéficier d'un temps de réflexion. Ce temps nécessaire variera selon la nature et les effets de l'intervention.

La liberté du consentement implique que la personne concernée ne subisse pas de pression ou d'influence indue. Des pressions, même très légères exercées, sur une personne en situation de faiblesse peuvent donner à cette personne le sentiment qu'elle a l'obligation de donner son accord, même si tel n'est pas son souhait. La notion de pression peut également s'appliquer à des situations où il existe une relation de confiance entre la personne concernée et celle qui sollicite le consentement et peut, de ce fait, l'influencer. Cela peut être le cas, par exemple, pour la participation à un projet de recherche, si le médecin du patient est également le chercheur qui sollicite le consentement. Les pressions peuvent également être d'ordre financier ou d'autre nature (par exemple, promotion, notes à un examen qui pourraient dépendre du consentement à participer à une recherche…), mais ayant toute pour conséquence d'influencer la décision de la personne qui, en leur absence, n'aurait pas donné son accord.

La liberté du consentement implique aussi la possibilité de le retirer à tout moment. Le souhait de la personne à cet égard doit être respecté. Dans certaines situations toutefois, en accord avec les normes et obligations professionnelles, le médecin peut être obligé de poursuivre l'intervention entreprise, pour éviter une grave mise en danger de la santé de la personne concernée.

Consentement implicite ou exprès

Le consentement peut, par ailleurs, revêtir différentes formes: implicite ou exprès et dans ce dernier cas, être ver-

[2] P. 42 à 66, Rapport de recherche — Bioéthique et jurisprudence de la Cour européenne des droits de l'homme © Conseil de l'Europe / Cour européenne des droits de l'homme, 2016 / http://www.echr.coe.int

[3] Voir Article 13 du Protocole additionnel relatif à la recherche biomédicale (STE n°195, 2005).

bal ou formulé par écrit. Quelle que soit la forme, l'information préalable appropriée reste un élément essentiel et déterminant pour la validité du consentement. La forme dépendra le plus souvent de la nature de l'intervention envisagée. Le consentement implicite est le plus souvent considéré comme le plus approprié pour les interventions relevant de la médecine quotidienne, sous réserve que la personne concernée ait été, au préalable, suffisamment informée. Dans le cas de procédures médicales invasives, un consentement exprès, consigné par écrit peut être exigé. Lorsqu'il s'agit d'une participation à une recherche interventionnelle ou un prélèvement d'organe sur un donneur vivant, un consentement exprès et spécifique est requis (articles 16 et 19 de la Convention d'Oviedo).

Protéger les personnes n'ayant pas la capacité de consentir…

Certaines personnes, en raison de leur âge, d'une incapacité mentale ou d'un autre motif similaire (coma ou accident, par exemple) peuvent être considérées par le droit national comme n'ayant pas la capacité à consentir à une intervention déterminée. Comme le précise le rapport explicatif de la Convention (par. 42), «il revient à chaque droit interne de déterminer, selon la technique qui lui est propre, si une personne jouit ou non de la capacité de consentir à une intervention en tenant compte du souci de ne priver la personne de sa capacité d'autonomie que pour les actes où cela est nécessaire dans son intérêt.» Il est important toutefois de signaler que lorsqu'un majeur soumis au régime de l'incapacité ne souffre pas, à un moment donné, d'une capacité mentale réduite (par exemple parce que la maladie évolue favorablement), il doit, conformément à la règle générale du consentement (énoncée à l'article 5 de la Convention), donner lui-même son consentement.»

Dès lors qu'une personne est considérée incapable de consentir, il convient de définir les conditions permettant d'assurer la protection des personnes concernées sur lesquelles une intervention et envisagée. Celles-ci sont énoncées à l'article 6 de la Convention d'Oviedo.

La première est que l'intervention envisagée ait pour but un bénéfice direct pour la personne concernée. La recherche biomédicale et le prélèvement de tissus régénérables sont les seules dérogations possibles à cette règle. Elles sont énoncées respectivement à l'article 17 et à l'article 20 de la Convention d'Oviedo.

La seconde condition est l'obtention de l'autorisation du représentant de la personne concernée, d'une autorité ou d'une personne ou instance désignée par la loi.

Il convient de noter qu'il ne s'agit pas alors d'un «consentement au nom de la personne», mais d'une autorisation qui doit toujours être guidée par l'intérêt supérieur de cette dernière.

Comme dans le cas d'une demande consentement, de façon à ce que la personne ou instance concernée puisse prendre une décision éclairée, la personne ou l'instance concernée doit donc pouvoir bénéficier préalablement d'une information adéquate quant au but et à la nature de l'intervention ainsi que ses conséquences et ses risques.

…mais conserver, autant que possible, leur capacité d'autonomie

La capacité d'autonomie en ce qui concerne les interventions doit toutefois être préservée dans toute la mesure du possible. Aussi, dans le cas d'un mineur, son avis doit être considéré comme un facteur de plus en plus déterminant, proportionnellement à son âge et à sa capacité de discernement. Dans certaines circonstances, son consentement à une intervention donnée pourra ainsi être considéré nécessaire, voire suffisant. Comme le rappelle le rapport explicatif de la Convention d'Oviedo, cette condition est en accord avec l'article 12 de la Convention des Nations Unies relative aux droits de l'enfant qui dispose que «les Etats Parties garantissent à l'enfant qui est capable de discernement, le droit d'exprimer librement son opinion sur toute question l'intéressant, les opinions des enfants étant dûment prises en considération eu égard à son âge et son degré de maturité.»

De même, dans le cas d'un majeur, celui-ci doit être associé, chaque fois que cela est possible, au processus d'autorisation. Il conviendra donc de recueillir son avis,

après lui avoir préalablement expliqué l'importance et les conditions de l'intervention.

L'autorisation donnée doit enfin pouvoir être retirée à tout moment, sous réserve des situations exceptionnelles déjà énoncées dans le cas d'une intervention sur une personne ayant la capacité de consentir. Toutefois, un tel retrait doit toujours être effectué dans l'intérêt de la personne concernée. En effet, si une personne capable de consentir a le droit de retirer son consentement même si cela est contraire à son intérêt, il ne peut en être de même dans le cas d'une autorisation dont le retrait ne peut être motivé que par l'intérêt de la personne concernée. En outre, comme le précise le rapport explicatif de la Convention, «le respect des obligations professionnelles impose au médecin d'agir dans l'intérêt du patient. Il est même du devoir du médecin de protéger le patient de décisions que prendrait contre son intérêt, la personne ou instance dont l'autorisation est exigée».

Souhaits précédemment exprimés

Disposition très innovante à l'époque de l'élaboration de la Convention, l'article 9 prévoit qu'une personne puisse exprimer ses souhaits par anticipation d'une situation prévisible où elle ne serait pas en mesure d'exprimer sa volonté. Outre les situations d'urgence, cela peut notamment s'appliquer aux personnes souffrant d'une maladie évolutive comme la démence. Si des souhaits ont été exprimés par rapport à une intervention susceptible d'être envisagée lorsque la situation survient, ceux-ci doivent être pris en compte.

Des exceptions limitées et encadrées

La Convention prévoit des exceptions à la règle générale du consentement dans un nombre limité de situations et sous réserve du respect de critères précis.

Tel est le cas pour une personne considérée comme capable de consentir, mais dont la capacité de prendre une décision quant à un traitement proposé est gravement altérée par le trouble mental dont elle souffre. La Convention prévoit les conditions précises dans lesquelles il peut être procédé à l'intervention visant à traiter ce trouble mental. Pour toute autre intervention, le consentement sera requis.

En outre, il ne sera possible de procéder à l'intervention visant à traiter le trouble mental malgré le refus de la personne concernée que dans des circonstances prévues par la loi, lorsque l'absence d'un tel traitement porterait gravement préjudice à la santé de la personne concernée et «sous réserve des conditions de protection prévues par la loi comprenant des procédures de surveillance et de contrôle ainsi que des voies de recours.» De telles mesures ne devraient être envisagées qu'en dernier recours et en l'absence d'alternative moins intrusive. Dès lors que l'absence de traitement ne constitue pas un risque grave pour la santé de la personne, le traitement sans consentement est exclu.

Une dérogation à la règle du consentement est également prévue en cas de situation d'urgence qui empêche le médecin d'obtenir le consentement ou l'autorisation appropriée. La Convention prévoit ainsi que le médecin puisse, sans attendre le consentement de la personne concernée ou l'autorisation de son représentant légal ou personne ou instance désignée par la loi, procéder à une intervention «médicalement indispensable pour le bénéfice de la santé de la personne concernée». Sans être limitée aux interventions nécessaires à la survie de la personne concernée, cette dérogation ne s'applique que dans le cas d'interventions médicalement indispensables à effectuer sans délai. Pour toute autre intervention, le consentement ou l'autorisation appropriée sera requis. En outre, même dans de telles situations, des mesures raisonnables devraient être mises en œuvre par les médecins pour déterminer les souhaits qui pourraient être ceux de la personne concernée.

Enfin, la Convention prévoit la possibilité de restreindre l'exercice des droits des personnes concernées dès lors que de telles restrictions sont prévues par la loi et constituent des mesures nécessaires, dans une société démocratique, à la défense d'intérêts collectifs (sûreté publique, prévention des infractions pénales, protection de la santé publique) ou à la protection des droits et libertés d'autrui. Ces restrictions reprennent certaines de celles prévues à l'article 8.2 de la Convention européenne des droits de l'Homme. Ces restrictions sont applicables aux dispositions relatives au consentement à une intervention et à l'autorisation dans le cas de personnes n'ayant pas la capacité à consentir, sauf dans le cadre d'une recherche biomédicale (articles 16 et 17), ou d'un prélèvement d'organes ou de tissus sur donneur vivant à des fins de transplantation (articles 19 et 20).

A titre d'exemple, on peut citer notamment l'isolement, si nécessaire, d'une personne atteinte d'une maladie contagieuse sur le fondement de la protection de la santé publique; la protection des droits et liberté d'autrui peut également justifier la réalisation d'un test ordonné par une autorité judiciaire en vue d'établir un lien de filiation, ou pour l'identification d'un personne dans le cadre d'une enquête criminelle.

Consentement libre et éclairé : un principe essentiel dont la mise en œuvre doit être régulièrement réexaminée

Le consentement libre et éclairé est un principe essentiel de protection des droits de l'Homme dans le domaine biomédical. Il est la clé de voute de la protection du droit à l'intégrité protégé notamment par l'article 8 et l'article 3 de la Convention européenne des droits de l'Homme.

C'est avant tout un processus dont le respect des modalités conditionne la validité. L'information préalable appropriée de la personne concernée en est une composante déterminante.

Les développements dans le domaine biomédical exigent d'en examiner régulièrement la mise en œuvre pour prévenir les risques «d'érosion» de son application mettant notamment en jeu le respect de l'autonomie de la personne. Face à l'évolution technologiques et scientifique, il convient également de réfléchir et, le cas échéant, de préciser les conditions de sa mise en œuvre, afin d'en garantir le respect.

Trends in the Russia's case-law on human rights in biomedicine

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Trends in the Russia's case-law on human rights in biomedicine*

Abstract. The paper reviews the case-law on assisted reproductive treatments, and specifically with surrogate motherhood used as a focal point, identifies the core issues in the legal classification of these matters in light of statutory regulation and the realities of modern medical progress, outlines a framework for adjudicating such matters, specifically those involving challenges to a surrogate mother's withholding of consent to the registration of a child's potential (biological) parents as his or her parents.

Key words: biomedicine assisted reproductive treatments, surrogate motherhood, contract for surrogate motherhood, biological parents, parental rights, gender equality principle.

Medicine could not possibly advance without experiments on humans and the use of human organs, tissues and genetic material. Given, however, that such research involves interference with human life, it needs to be mandatorily regulated by law. It is certainly necessary to facilitate medical progress and the development of new treatment options and methods for purposes of preserving human life and health, but protection of rights of those who are affected by these things is a reasonable and legitimate requirement and provides a means, first, to set a balance between the interests of science, society and a specific individual, and secondly, to prevent illegal interference with human life.

Situations that have to be dealt with by the legislature and courts alike and that involve the application of new fertility treatments, transplantation of human organs and tissues, medicobiological experiments on humans and the use of genetic engineering techniques, are quite delicate andoften not exceedingly complex. These days courts see cases that require not only the practical application of law provisions, but also the resolution of a crucial issue such as the balance between provisions of law and standards of ethics. The issue quite often arises, for example, where assisted reproductive technology (hereinafter also referred to as ART) is used in infertility treatments.

As is stated in Article 55 § 1 of the Federal Law of 21 November 2011, No 323-FZ, "On the Public Health Framework in the Russian Federation"[1] (hereinafter referred to as the Public Health Framework Act), assisted reproductive technology provides infertility treatments whereby some or all stages of conception and early foetation are moved outside the uterus (including those using donated and/or cryopreserved donated gametes, reproductive organ tissues and embryos, as well as surrogate motherhood).

In the Russian Federation, legal relations in the area of surrogate motherhood are regulated by Articles 51—52 of the Family Code[2] (hereinafter referred to as the RF FC), Article 55 of the Public Health Framework Act, Article 16 of the Federal Law of 15 November 1997, No 143-FZ, "On Official Records of Births, Deaths and Marriages"[3] (hereinafter referred to as the Births, Deaths and Marriages Registration Act), the order of the Public Health Ministry of the Russian Federation of 30 August 2012, No 107n, "On the Arrangements for Using Assisted Reproductive Technology, Contraindications to and Restrictions on the Use Thereof", (registered with the Russian Justice Ministry on 12 February 2013, No 27010; hereinafter referred to as Order No 107n)[4].

For instance, Article 55 of the Public Health Framework Act lays down the following rules:

— surrogate motherhood is available to a woman aged twenty to thirty-five, with one or more healthy children of her own, with a clean bill of health, who gives her voluntary consent in writing to medical intervention. A married woman can only be a surrogate mother if her husband gives his consent in writing. A surrogate mother may not also donate ovicells (§ 10);

— surrogate motherhood is gestation and delivery (including premature birth) under a contract made between a surrogate mother (a woman who carries a child to term after being implanted with a donated embryo) and potential parents whose gametes are used for fertilization, or a single woman for whom gestation and delivery is impossible on medical grounds (§ 9);

— gametes can be donated by citizens aged between eighteen and thirty-five years, fit and sane, who have passed medical and genetic examination. Where donated gametes and embryos are used, citizens are entitled to information about the results of medical and genetic examination of the donor, his race and nationality, as well as physical characteristics (§§ 7—8).

Article 51 (4) of the RF FC provides that married couples that give written consent to an IVF treatment or embryo implantation and have a child as a result shall be recorded as his or her parents in the register of births.

Married couples that give written consent to embryo implantation in another woman for purposes of gestation can be registered as the parents of the child subject to the consent of his or her birth mother (surrogate mother).

Public registration of the birth of a child delivered by a surrogate mother follows the general rule, subject to the above requirement of Article 51 (2) (4)

* Translated into English by LLC "Development of legal systems".

[1] Rossiyskaya Gazeta. November 23, 2011.

[2] Rossiyskaya Gazeta. January 27, 1996.

[3] Rossiyskaya Gazeta. November 20, 1997.

[4] Rossiyskaya Gazeta. April 11, 2013.

of the RF IC, as well as the provisions of Article 16 of the Births, Deaths and Marriages Registration Act. Specifically, a birth certificate must be issued complete with a document issued by a healthcare provider to evidence that the surrogate mother has given consent to the registration of the couple as the child's parents. Thus, when it comes to according parental rights to genetic (biological) parents, the law essentially gives precedence to the interests of the surrogate mother.

To be sure, the surrogate mother's pregnancy creates a blood bond between her and the child, but one cannot disregard the fact that the child's life is created by an embryo produced by in vitro fertilization of gametes of the genetic parents, so the precedence of the surrogate mother's parental rights is moot. The establishment of such precedence can be detrimental, first of all, to the interests of a surrogate-born child, who not only can be denied a chance to be raised in the family of his or her genetic parents but can be likely to be raised by a single parent.

At the same time, pursuant to Article 3 of the Convention on the Rights of the Child[5], the States parties are required to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her. These provisions are also enshrined in the RF IC, which postulates that family relationships are governed, inter alia, by the principle of precedence of the interests of minors in the family (Article 1 (3)).

Of no less relevance is the issue of safeguarding the rights and interests of the biological (genetic) parents whose gametes were used to fertilize the surrogate mother, the issue of their emotional distress if denied statutory parenthood by the surrogate mother in respect of their child that they could not conceive and deliver naturally.

For example, in 2011, a Russian court heard the matter brought by the spouses Ch. against surrogate mother R. and her former husband to ascertain the origin of a surrogate-born child, expunge the birth record and order them to cease and desist from resisting the registration of the plaintiffs as the child's parents. The claim was denied on grounds that the surrogate mother had not consented to the naming of the plaintiffs, the genetic parents, as the parents of the child born by her in the register of births.

Contesting the constitutionality of Article 51 (4) of the RF FC as regards the arrangements for the registration of a surrogate-born child in the register of births, and Article 16 (5) of the Births, Deaths and Marriages Registration Act on grounds that the above statutory provisions are at variance with Article 19 and Article 38 (§§ 1 and 2) of the Constitution of the Russian Federation because they prohibit the naming of genetic parents in the register of births as the parents of a surrogate-born child unless the surrogate mother consents thereto, the Ch. spouses took the matter to the Constitutional Court of the Russian Federation.

In its Decision of 15 May 2012, No 880-O[6], the Constitutional Court of the Russian Federation dismissed the complaint of the Ch. spouses because it failed to meet the requirements of the Federal Constitutional Law of 21 July 1994, No 1-FKZ, "On the Constitutional Court of the Russian Federation"[7], that govern the admissibility of a complaint to the Constitutional Court of the Russian Federation. In ruling the complaint of the Ch. spouses. to be admissible, the Constitutional Court of the Russian Federation stated that "the statutory right of a surrogate mother to authorize the naming of the genetic parents of a child as his parents in the public record of his or her birth means that she is entitled to name herself as the mother of the child in the birth record, and ipso facto in his or her birth certificate, thus conferring upon the birth mother the rights and duties of a mother (Article 47 of the Family Code of the Russian Federation). While not being the only one possible, the said model of statutory regulation does not exceed the law-making authority of the federal legislature".

Another approach to addressing the balance between the rights of surrogate and genetic mothers was used by a court when hearing the matter brought by M. against the surrogate mother B. and her husband B. to challenge the motherhood of the surrogate mother, establish the motherhood of the genetic mother and edit the birth record.

In granting the claim of the plaintiff M., the court held that the surrogate mother had not demonstrated her intention to have herself registered as the mother of the child born by her because her postpartum behaviour showed no sign of maternal feelings or desire to assume the rights and duties of a mother with respect to the delivered child. The court established that the surrogate mother B. broke off contact with the plaintiff M. a few days before the delivery, kept secret her whereabouts and the state of health of herself and the future child, did not inform M. of the place and time of the delivery, and left the Russian Federation with him (for the Republic of Cyprus) within eight days of the delivery.

The court also stated that legal significance in establishing parenthood in respect of the child born by her is attached to both biological parenthood and to parenting, which was not the case here. The court cited in this context Articles 3 and 7—9 of the Convention

[5] The Convention on the Rights of the Child (adopted by the UN General Assembly on 20 November 1989, entered into force in the USSR on 15 September 1990) // Collected Treaties of the USSR. 1993. No. XLVI.

[6] The Decision of the Constitutional Court of the Russian Federation of 15 May 2012, No 880-O, "On the inadmissibility of the complaint of citizens Ch.P. and Ch.Yu. alleging an infringement of their constitutional rights by the provisions of Article 51 (4) of the Family Code of the Russian Federation) and Article 16 (5) of the Federal Law on Official Records of Births, Deaths and Marriages" // Document not published. Source: ConsultantPlus.

[7] Rossiyskaya Gazeta. July 23, 1994.

on the Rights of the Child, Articles 8 and 14 of the Convention for the Protection of Human Rights and Fundamental Freedoms[8], and said that in this context, given the special circumstances of conception, the defendants deprived the child of his or her right to be with his or her kin, which can be regarded as discrimination. The court took into account that the genetic evidence adduced shows that the surrogate mother and her husband have no genetic link to the child, but establishes a genetic link between M. and the child. A surrogacy agreement was also in place with the surrogate mother, who fled with the child abroad, failed to provide love and care to the child and had no wish to assume parental rights in respect of the new-born child.

However, in view of the procedural irregularities committed in the adjudication of the matter, which the Civil Division of the Supreme Court of the Russian Federation found to be material when hearing the cassation appeal in the case, the judgment was set aside and the case remanded for retrial.

On 16 May 2017, the Plenum of the Supreme Court of the Russian Federation adopted Resolution No.16 "On the application of legislation by the courts when hearing cases involving the establishment of the origin of children"[9] (hereinafter referred to as the Origin of Children Resolution), in which a separate section addresses the adjudication of disputes over the use of ART, including surrogate motherhood.

For instance, item 31 of the Resolution expounds that where a surrogate mother withholds consent to the registrations of potential parents as the parents, this cannot be good and sufficient reason for the dismissal of the claim of the persons affected to recognize them as the child's parents and to give the child to them to raise. For purposes of due process of law, the court is specifically required to check whether a surrogacy contract is in place and what are the terms and conditions thereof, whether the plaintiffs are the child's genetic parents, the reasons why the surrogate mother withheld consent to the registration of the plaintiffs as the child's parents, and having regard to the facts established in the case, as well as to the provisions of Article 3 of the Convention on the Rights of the Child, to adjudicate the matter in the interests of the child.

Another problem in this context is the question of rights and interests of genetic fathers because depriving a genetic father of parental rights at the sole election of a surrogate mother leaves open the issue of

[8] Adopted in Rome 4 November 1950. // SZ RF [Legislative Corpus of the Russian Federation (LCRF)]. 2001. No 2. Art. 163.

[9] Rossiyskaya Gazeta. May 24, 2017.

gender equality in parenthood and a level playing field for the exercise thereof.

Also, as already stated above, Article 55 of the Public Health Framework Act stipulates that assisted reproductive technology is available to men and women, whether married or single. A surrogacy contract can only be made in this context by potential parents or a single woman for whom gestation and delivery are impossible on medical grounds. Single men are not covered by this provision of the Act.

Yet there are lawsuits to set aside the denial by ZAGS [Registry of Births, Marriages and Deaths] agencies to name a single man who entered into a surrogacy contract as the father in the public record of the birth of children, and to challenge a denial of surrogacy services to a single man. The court judgments for single men seeking the recognition of their fatherhood of surrogate-born children as well as specific performance of surrogacy services on the grounds of non-compliance with the gender equality principle are not upheld by the Supreme Court of the Russian Federation.

There are also situations where legal action is taken by grandmothers of surrogate-born children with biological material from their deceased sons, seeking to compel the ZAGS agencies to name the child's deceased father and suing grandmother as the parents in the birth certificate. The courts are right in quashing denials by the ZAGS agencies of public registration of births reasoning that the use of ART is not an infertility treatment here, and the claim of the plaintiff, a biological grandmother of the child, to be registered as the mother of the child and her deceased son as his or her father has delicate ethical dimensions, does not seek an infertility treatment and is at variance with the essence of legal parenthood.

In 2011, the Supreme Court of the Russian Federation examined, as part of judicial oversight over statutes, the matter in the lawsuit by citizen Ms N. to repeal clause 6 of the Protocol on the Application of Assisted Reproductive Treatments for Female and Male Infertility[10] (hereinafter referred to as the Protocol). The clause specified that gamete donors provide their gametes (sperm, oocytes) to others for infertility treatment and do not assume parental duties towards the future child.

The female individual N. believed that the challenged portion of the Protocol was at variance with Article 19 § 2 of the Constitution of the Russian Federation, Article 49 and 80 of the RF FC and violated her right and the right of her daughter born using assisted reproductive technology to establish the fatherhood of the commercial donor who was aware of the implications of his actions and was motivated by the desire to make money therefrom. The claimant also argued that Clause 6 of the Protocol discriminates between her child and naturally born children.

The Supreme Court of the Russian Federation in its Decision of 13 January 2011, No GKPI101-1601[11], dismissed N.'s claim because by law "no in vitro fertilization can be made available to a single woman by licensed medical service providers unless she consents in writing to ART treatments. In this context, the donor's details are statutorily covered by physician–patient privilege and may not be disclosed without the citizen's consent except as provided for in Article 61 of the Framework Legislation [of the Russian Federation on Public Health Care (approved by the Supreme Soviet of the Russian Federation on 22 July 1993, No 5487-1)]. The list of donor details that can be disclosed to a woman who seeks specialist medical care involving ART… is limited to the results of his medical and genetic examination, physical characteristics and ethnicity. By the same token, the donor may not be notified of the results of use of his biological material, and his written consent to IVF treatment is not required.

When seeing artificial fertilization from a medical services provider, a woman enters into a contract with the provider, who shall warn her in advance that the donor disclaims parental duties towards the future child. The donor also enters into a contract with the medical services provider, who, once in receipt of biological material, shall acquire all rights thereto and shall be liable for any misuse thereof.

Thus, the IVF birth mother and the donor have no privity with each other, by virtue whereof the provisions of Article 49 of the Family Code of the Russian Federation regarding the establishment of fatherhood through the courts are inapplicable here and the donor may not be recognized as the father of ART-conceived child".

The above legal position was subsequently endorsed in Clause 32 of the Origin of Children Resolution, which says that "in the meaning of family legislation (Article 51 (4) of the RF FC), a birth where a couple (single woman) used donated genetic material does not create parental rights and duties between the child and the donor, whether known to the child's parents or not (anonymous donor).

In light of the above, the donor of the genetic material may not refer in the context of claims to challenge and/or establish fatherhood (motherhood) to the fact that they are the child's genetic parent.

For the same grounds, claims of individuals recorded as the child's parents (single parent) may not be granted to recognise the fatherhood of the donor of the genetic material used to produce the child.

Bioethical issues arise in numerous areas and can dog individuals as well as their close of kin all their lives, which makes bioethics and biomedicine the borderland between ethics, law and science. Legal regulation and law enforcement practices go some way towards addressing the controversial aspects of human rights in this area.

The Supreme Court of the Russian Federation assigns matters relating to family and children disputes to its family and children bench and lawsuits for health damages, including those involving various medical treatments, to its employment and social bench.

[10] Approved by the order of Public Health Ministry of the Russian Federation of 26 February 2003, No 67, "On the application of assisted reproductive technology (ART) in female and male infertility treatments" (registered with the Russian Justice Ministry on 24 April 2003, No 4452) // Rossiyskaya Gazeta. May 6, 2003. Document repealed by order No 107n).

[11] Document not published. Source: ConsultantPlus.

Consentement présumé au prélèvement d'organes post mortem en droit français et expression du refus

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Consentement présumé au prélèvement d'organes post mortem en droit français et expression du refus*

Résumé. Cet article envisage les modalités du consentement au prelevement d'organes port mortem. Les prélèvements d'organes ont été initialement encadrés en France par la loi Caillavet du 22 décembre 1976, qui a fixé le régime juridique du prélèvement d'organes sur personne vivante ou décédée et les conditions dans lesquelles il peut être pratiqué. Intégrées au Code de la santé publique par les lois de bioéthique de 1994, ces dispositions ont, depuis lors, fait l'objet de plusieurs modifications dont les plus récentes, issues de la loi du 26 janvier 2016 et de son décret d'application du 11 août 2016, portent sur les modalités d'expression du refus au prélèvement.

Mots clés: bioéthique, législation française, corps humain, don d'organes post mortem, consentement présumé, refus, registre national.

En droit français, «des prélèvements peuvent être effectués (…) sur le cadavre d'une personne n'ayant pas fait connaître de son vivant son refus d'un tel prélèvement»[1]. Cette règle de consentement présumé, introduite par la loi du 22 décembre 1976 dite loi «Caillavet» ne vise, depuis son origine, que les personnes majeures capables.

L'article 2 de la loi Caillavet disposait en effet que «s'il s'agit du cadavre d'un mineur ou d'un incapable, le prélèvement à des fins thérapeutiques ne peut être effectué qu'après autorisation de son représentant légal»[2]. Cette différence de régime est toujours en vigueur. L'article L. 1232-1 alinéa 3 dispose en effet que le «prélèvement peut être pratiqué sur une personne majeure dès lors qu'elle n'a pas fait connaître, de son vivant, son refus d'un tel prélèvement» et l'article L. 1232-2 alinéa 1er précise que «si la personne décédée était un mineur ou un majeur sous tutelle, le prélèvement ne peut avoir lieu qu'à la condition que chacun des titulaires de l'autorité parentale ou le tuteur y consente par écrit». Cependant, l'obligation du consentement des deux parents est assouplie en cas «d'impossibilité de consulter l'un des titulaires de l'autorité parentale». En pareille hypothèse, le prélèvement peut avoir lieu à condition que l'autre titulaire y consente par écrit[3].

Fondée sur des considérations pratiques et reflétant l'attitude majoritaire de l'opinion publique en matière de consentement au prélèvement[4] la présomption légale pouvait être aisément renversée. En effet, le décret du 31 mars 1978 précisait que la personne qui entendait s'opposer à un prélèvement sur son cadavre pouvait exprimer son refus par tout moyen[5]. Il s'agissait donc, depuis les origines, d'une présomption simple. C'est au regard de ces dispositions, toujours en vigueur aujourd'hui[6], que la loi du 26 janvier 2016[7] a apporté d'importantes modifications. Depuis le 1er janvier 2017, date d'entrée en vigueur de ces dispositions, la présomption de consentement, codifiée à l'article L. 1232-1 du Code de la santé publique n'est en effet plus une présomption simple, pouvant être renversée par tout moyen, mais une présomption mixte, ne pouvant plus être renversée que selon les modalités prévues par la loi[8] et précisées par un décret du 11 août 2016[9] et un arrêté du 16 août 2016[10]. Le Code de la santé publique retient désormais trois modalités d'expression du refus[11], qualifiant l'inscription sur un registre national automatisé comme le mode

* Ce texte est issu d'une conférence prononcée le 29 juin 2017 à l'Université d'Etat russe de la justice, à Moscou, à l'invitation de celle-ci et du Conseil de l'Europe.

1 Loi n° 76-1181, 22 décembre 1976, préc., art. 2, al. 1er. Auj. C. sant. publ., art. L. 1232-1, al. 3: «ce prélèvement peut être pratiqué sur une personne majeure dès lors qu'elle n'a pas fait connaître, de son vivant, son refus d'un tel prélèvement».

2 Loi n° 76-1181, 22 décembre 1976, préc., art. 2, al. 2. Cette exigence n'était pas requise pour les prélèvements effectués à d'autres fins, scientifiques ou autopsiques : CE, 17 fév. 1988, Époux Camara, AJDA, 1988.366, comm. Azibert et de Boisdeffre p. 329 ; Rec. CE 1988.72; JCP 1990.II.21421, obs. E. Fort-Cardon ; D. 1989.41, concl. B. Stirn.

3 C. sant. publ., art. L. 1232-2, al. 2.

4 Selon une récente enquête d'opinion, une très forte majorité de 84% des personnes interrogées seraient favorables au prélèvement de leurs organes après leur mort: http://harris-interactive.fr/opinion_polls/les-francais-se-declarent-prets-au-don-dorgane-mais-en-meconnaissent-le-cadre-juridique/. Cette position est constante en France depuis de très nombreuses années.

5 Décret n° 78-501, 31 mars 1978 pris pour l'application de la loi 76-1181 du 22 décembre 1976 relative aux prélèvements d'organes, JO 4 avril, p. 1497, art. 8.

6 C. sant. publ., art. L. 1232-1, alinéa 2.

7 Loi n° 2016-41, 26 janvier 2016, de modernisation de notre système de santé, JO 27 janvier, texte n° 1.

8 C. civ., art. 1354: la présomption «est dite simple, lorsque la loi réserve la preuve contraire, et peut alors être renversée par tout moyen de preuve; elle est dite mixte, lorsque la loi limite les moyens par lesquels elle peut être renversée ou l'objet sur lequel elle peut être renversée; elle est dite irréfragable lorsqu'elle ne peut être renversée».

9 Décr. n° 2016-1118, 11 août 2016, relatif aux modalités d'expression du refus de prélèvement d'organes après le décès, JO 14 août, texte n° 16.

10 Arr. 16 août 2016 portant homologation des règles de bonnes pratiques relatives à l'entretien avec les proches en matières de prélèvement d'organes et de tissus, JO 25 août, texte n° 28.

11 Le taux de refus est en France, pour 2015, de 32,5 % (https://www.agence-biomedecine.fr/IMG/pdf/dp_activite-greffe2015_point_presse_fev2016.pdf).

principal (I) tandis que les autres sont désignées comme des modes subsidiaires (II)[12].

I. L'inscription sur le registre national comme mode principal d'expression du refus

La possibilité d'inscription sur le registre national des refus est ancienne. La loi du 26 janvier 2016 a conféré à cette possibilité d'expression du refus la qualité de mode principal (A). Les modalités pratiques de cette expression n'ont été que partiellement affectées par cette réforme (B).

A. Primauté de l'inscription sur le registre

Ainsi que nous l'avons vu plus haut le refus au prélèvement d'organes post mortem pouvait être exprimé du vivant de la personne, depuis 1976, par tout moyen. Pouvant être exprimé librement, ce refus pouvait l'être à tout moment de l'existence, soit oralement, notamment à l'occasion d'une discussion familiale, soit, mais l'hypothèse était plus rare, par écrit. La principale difficulté que posait ce dispositif résidait dans l'administration de la preuve du refus exprimé. Pour faciliter cette preuve, le décret du 31 mars 1978[13] avait institué des registres, tenus par les hôpitaux pratiquant des prélèvements d'organes, sur lesquels les personnes hospitalisées pouvaient consigner leur refus des prélèvements post mortem. Les progrès techniques et organisationnels ont par la suite permis de centraliser ces registres pour aboutir à la création d'un registre national automatisé[14] dont les modalités de fonctionnement ont été prévues par un décret du 30 mai 1997[15]. Les dispositions relatives à ce registre ont été intégrées au Code de la santé publique.

[12] J.-R. Binet, «Refus des prélèvements d'organes post mortem: comment l'exprimer?», JCP N, 2016, Etude 1307.

[13] Décret n° 78-501, préc.

[14] C. sant. publ., art. L. 1232-1, al. 2.

[15] Décret n° 97-704, 30 mai 1997, relatif au registre national automatisé des refus de prélèvement sur une personne décédée d'organes, de tissus et de cellules et modifiant le code de la santé publique, JO, 3 juin, p. 8897.

Depuis la loi du 26 janvier 2016, l'inscription sur ce registre est envisagée comme le mode principal d'expression du refus aux prélèvements d'organes post mortem. L'article L. 1232-1, alinéa 3, du Code de la santé publique dispose en effet que le prélèvement peut être pratiqué sur une personne majeure dès lors qu'elle n'a pas fait connaître, de son vivant, son refus d'un tel prélèvement, «principalement par l'inscription sur un registre national automatisé prévu à cet effet». On peut, en première analyse, s'interroger sur le sens devant être donné à l'utilisation de l'adverbe «principalement». Qu'il existe un mode principal et des modes accessoires n'emporte en effet aucune conséquence juridique. Doit-on y voir un souhait du législateur, à destination des citoyens qui seraient invités à choisir ce mode d'expression du refus plutôt qu'un autre? C'est possible. Toutefois, l'utilisation de cet adverbe doit surtout être envisagée comme le résultat d'une concession.

En effet, alors que le projet de loi[16] ne comportait pas de dispositions relatives aux prélèvements d'organes, c'est un amendement parlementaire qui les y a inclus. Son auteur, M. Jean-Louis Touraine, souhaitait alors faire de l'inscription sur le registre l'unique modalité possible d'expression du refus, écartant ainsi la famille de ces questions hautement sensibles. Lors des débats, cet amendement inquiétant[17] a suscité l'opposition de nombreux parlementaires en raison du «risque de brutaliser les proches qui sont déjà en état de choc»[18] au nom d'une «logique qui consacre un droit de la société, ici représentée par le médecin, sur l'individu et sur son corps, qui appartiendraient, par défaut, à la collectivité?»[19]. En effet, s'il est possible de comprendre que la volonté de lutter contre la pénurie d'organes disponibles puisse fonder un tel renforcement de la présomption de consentement, il est tout aussi légitime de s'inquiéter de voir s'effacer, progressivement, la place de la volonté des personnes au profit d'un critère purement utilitariste[20].

B. Modalités d'inscription et respect du refus

L'article R. 1232-4-4 introduit par le décret du 11 août 2016, prévoit, dans son I, qu'une personne peut refuser qu'un prélèvement d'organes soit pratiqué sur elle après son décès, à titre principal en s'inscrivant sur le registre national automatisé des refus de prélèvement. Les modalités d'inscription sur ce registre sont précisées aux articles R. 1235-5 à R. 1235-14. A l'exception de l'article R. 1235-7, ces dispositions n'ont pas été modifées par le nouveau décret. Selon ces dispositions, toute personne majeure ou mineure âgée de treize ans au moins peut s'inscrire sur ce registre afin de faire connaître son refus. Nous avons vu plus haut que la présomption de consentement ne s'applique pas aux personnes mineures et aux majeurs sous tutelle. Les prélèvements qui les concernent supposent le consentement exprès des deux titulaires de l'autorité parentale ou du tuteur[21]. Le refus exprimé quant au prélèvement permet à son auteur d'effectuer des choix selon la finalité du prélèvement et les organes ou tissus concernés. La personne peut en effet préciser qu'elle refuse qu'un prélèvement d'organes soit opéré sur son corps après son décès soit à des fins thérapeutiques, soit pour rechercher les causes du décès, soit à d'autres fins scientifiques, soit dans plusieurs de ces trois cas[22]. L'article R. 1232-4-5 permet de ne refuser le prélèvement que pour certains des organes ou tissus ou pour l'ensemble des organes ou tissus.

La demande d'inscription sur le registre est faite sur papier libre ou en remplissant le formulaire mis à disposition du public par l'agence de la biomédecine[23]. La solution la plus simple est, à l'évidence, d'utiliser le formulaire en ligne disponible sur le site internet de l'agence[24]. En toute hypothèse, la demande d'inscription doit permettre d'identifier son auteur. Elle doit donc comporter les éléments essentiels de l'état civil[25]. Elle est datée, signée, accompagnée de la photocopie de tout document susceptible de justifier de l'identité de son auteur[26]. Lorsqu'elle est faite sur papier libre, elle est adressée à l'agence de la biomédecine[27] par tout moyen permettant de lui conférer une date certaine de réception[28]. Pour conférer une date certaine à la réception de la demande, celle-ci devra donc, au minimum être remise en main propre contre récépissé ou adressée en recommandé avec demande d'accusé de réception. Quel que soit le moyen employé, l'agence doit envoyer à l'intéressé une attestation d'inscription sur le registre dès l'enregistrement de son inscription, sauf s'il a expressément mentionné qu'il ne souhaitait pas en recevoir[29].

16 Doc. AN n° 2302, projet de loi relatif à la santé, 15 octobre 2014.

17 Agnès Leclair, «Dons d'organes: l'amendement qui inquiète», Le Figaro, 22 mars 2015.

18 Intervention de Denis Jacquat, député LR, lors des débats.

19 Intervention d'Arnaud Richard, député UDI, lors des débats.

20 Mme Monette Vacquin écrit au sujet de la présomption de consentement, qu'elle «ne permet pas au défunt de participer, en tant que personne, par un assentiment exprimé de son vivant, et non en tant qu'objet, à l'usage fait de son corps. Elle a fondé en droit la seule logique de l'efficience, de l'utilitarisme immédiat (…)» (M. Vacquin, Frankenstein ou les délires de la raison, François Bourin, 1989, p. 208).

21 C. sant. publ., art. L. 1232-2.

22 C. sant. publ., art. R. 1232-6.

23 C. sant. publ., art. R. 1232-7, al. 1er.

24 https://www.registrenationaldesrefus.fr/#etape-1

25 Nom, prénom, sexe, date et lieu de naissance, adresse.

26 C. sant. publ., art. R. 1232-7, al. 2.

27 Agence de la biomédecine - Registre national des refus - 1 avenue du Stade de France 93212 SAINT-DENIS LA PLAINE CEDEX

28 C. sant. publ., art. R. 1232-7, al. 2

29 C. sant. publ., art. R. 1232-8.

Le refus de prélèvement des organes est révisable et révocable à tout moment[30]. L'équipe de coordination hospitalière de prélèvement prend alors en compte l'expression de volonté la plus récente. La révocation doit être faite selon les mêmes modalités que celles qui sont fixées pour la demande d'inscription par l'article R. 1232-7. Une attestation de radiation du registre est adressée à l'intéressé, sauf s'il a expressément mentionné qu'il ne souhaitait pas recevoir d'attestation[31]. Si le refus avait été exprimé selon une modalité subsidiaire, le parallélisme des formes impose que sa révocation emprunte la même voie.

Pour garantir le respect de la volonté ainsi exprimée, le Code de la santé publique fait de l'interrogation du fichier national automatisé des refus un préalable obligatoire au prélèvement en des termes clairs: «aucun prélèvement d'organes à des fins thérapeutiques, ou aux fins de recherche des causes du décès, ou à d'autres fins scientifiques, ne peut être opéré sur une personne décédée âgée de plus de treize ans sans interrogation obligatoire et préalable du registre sur l'existence éventuelle d'un refus de prélèvement formulé par la personne décédée»[32]. La demande d'interrogation du registre fait l'objet d'un document écrit, daté et signé par le directeur de l'établissement de santé dans lequel le prélèvement est envisagé ou, à défaut, par un autre responsable de l'établissement expressément habilité à cet effet par le directeur. Il comporte obligatoirement la copie du procès-verbal du constat de la mort, préalable indispensable à toute perspective de prélèvement d'organes[33]. A l'image de la demande, la réponse est faite par un document écrit, daté et signé par un responsable de l'Agence de la biomédecine expressément habilité à cet effet par le directeur général de cet établissement[34].

II. Le recours subsidiaire aux proches du défunt comme mode d'expression du refus

Si l'inscription sur le registre est le mode principal d'expression du refus, devant par conséquent être privilégié, le Code de la santé publique permet encore d'associer les proches du défunt à la décision de prélèvement. Cette participation se traduit par une obligation d'informer les proches (A) qui peuvent alors transmettre la volonté du défunt (B).

A. Information des proches

Auparavant, la loi imposait au médecin de «s'efforcer de recueillir auprès de la famille et des proches, l'opposition au don d'organes éventuellement exprimé de son vivant par le défunt, par tout moyen»[35]. La loi du 26 janvier 2016 a atténué ce rôle. En effet, désormais le rôle du médecin n'est plus de s'efforcer de recueillir auprès des proches le témoignage d'une opposition au prélèvement, mais, simplement, de les informer «préalablement au prélèvement envisagé, de sa nature et de sa finalité». Rien n'est précisé quant aux proches devant être informés. S'agit-il seulement de ceux qui sont présents à l'hôpital? Faut-il ménager une place à part pour les membres de la famille proche (père, mère, époux ou épouse, enfants)? Cette question n'appelle aucune réponse évidente[36], ce qui ne sera pas sans poser problème dans les faits. On peut en effet imaginer la possibilité de dissensions entre les proches, certains étant fermement opposés à un prélèvement et souhaitant témoigner du refus du défunt, les autres y étant favorables. Sans comparer les situations, la question du prélèvement d'organes pourrait tout à fait générer les mêmes problèmes que celle de la décision d'arrêt de traitement en fin de vie. Comme pour les questions de fin de vie, on regrette que le législateur n'ait pas été plus précis en la matière en identifiant les proches devant être obligatoirement consultés, selon leur proximité avec le défunt et en hiérarchisant leur parole. En effet, même si leur rôle tend à s'amoindrir au fil des modifications législatives, les proches conservent une place, résiduelle, en matière d'expression du refus. Cependant, le médecin n'ayant plus l'obligation de rechercher l'éventuelle opposition, on peut craindre quelques difficultés de mise en œuvre et une possible fragilisation au regard de l'article 8 de la Convention européenne des droits de l'homme[37].

B. Rôle des proches dans l'expression du refus

L'article R. 1232-4-4, II du Code de la santé publique prévoit qu'une personne peut exprimer son refus par écrit et confier ce document à un proche. Ce document est daté et signé par son auteur dûment identifié par l'indication de ses nom, prénom, date et lieu de naissance. Le texte envisage également la possibilité qu'une personne en état d'exprimer sa volonté, soit dans l'impossibilité d'écrire et de signer elle-même. En pareille hypothèse, elle peut demander à deux témoins d'attester que le document qu'elle n'a pu rédiger elle-même est l'expression de sa volonté libre et éclairée. Ces témoins indiquent leur nom et qualité et leur attestation est jointe au document exprimant le refus. Ainsi rédigé et conservé par un proche, ce document devra être transmis à l'équipe de coordination hospitalière de prélèvement. Encore faudra-t-il que le proche disposant de ce document

[30] C. sant. publ., art. R. 1232-4-6.

[31] C. sant. publ., art. R. 1232-9.

[32] C. sant. publ., art. R. 1232-10

[33] C. sant. publ., art. R. 1232-11

[34] C. sant. publ., art. R. 1232-12

[35] C. sant. publ., art. L. 1232-1, al. 4, anc.

[36] L'arrêté précité du 16 août 2016 relatif à l'entretien avec les proches n'apporte aucune précision sur ce point.

[37] En effet, dans un arrêt du 24 juin 2014, la Cour européenne des droits de l'homme a retenu une violation du droit à la vie privée et familiale parce que la législation lettone en matière de prélèvement d'organes post mortem n'était pas formulée de manière suffisamment précise et n'offrait pas une protection juridique adéquate contre l'arbitraire (CEDH, 24 juin 2014, Petrova c/ Lettonie, n° 4605/05, RTD civ. 2014, p. 840, obs. J.-P. Marguénaud).

soit prévenu du décès et de l'éventualité du prélèvement et que, d'autre part il sache qu'il doit transmettre le document dont il est dépositaire à l'équipe de coordination hospitalière, ce que l'obligation faite à l'agence de la biomédecine d'informer le public des modalités d'expression du refus ainsi prévues est loin de garantir[38].

Enfin, le III de l'article R. 1232-4-4, prévoit qu'un proche de la personne décédée peut faire valoir le refus de prélèvement d'organes que cette personne a manifesté expressément de son vivant. Ce proche ou l'équipe de coordination hospitalière de prélèvement transcrit par écrit ce refus en mentionnant précisément le contexte et les circonstances de son expression. Ce document est daté et signé par le proche qui fait valoir ce refus et par l'équipe de coordination hospitalière de prélèvement. Cette dernière possibilité revient finalement, à la même chose que ce qui existait antérieurement, à ceci près que le formalisme est alourdi et que, comme pour l'hypothèse visée au II, l'absence d'obligation faite aux médecins de rechercher l'éventuelle opposition au prélèvement risque fort de priver ce droit de toute effectivité dans de fréquentes hypothèses. Dans la pratique, il semble qu'il soit assez difficile d'exiger de telles formalités des proches frappés par le deuil. Il en résulte que les équipes de coordination sont amenées à assouplir les contraintes en se contentant de faire signer un document, assez rarement circonstancié, et rédigé par l'équipe pour soulager la famille. En outre les règles de bonnes pratiques publiées par l'arrêté du 16 août 2016 prévoient une autre possibilité d'assouplissement. En effet, le texte rappelle que «le prélèvement constitue une possibilité ouverte par la loi» et que toute décision de prélèvement comme de non prélèvement «doit tenir compte du contexte dans lequel il est envisagé et doit être analysée tant qualitativement que quantitativement»[39]. L'affirmation, curieusement formulée, permet en réalité à une équipe de coordination hospitalière de ne pas procéder au prélèvement en cas d'opposition catégorique des proches. La grille d'analyse de l'entretien, jointe aux bonnes pratiques, contient d'ailleurs une ligne 49, sous «le défunt ne s'était pas opposé» indiquant que «en raison du contexte le prélèvement n'a pas été possible»[40].

Conclusion. Importance capitale de l'information

L'existence d'une présomption de consentement rend absolument nécessaire une parfaite information de la population. Depuis la loi du 6 août 2004, le législateur a ainsi prévu un ensemble d'obligations d'information au sujet des modalités du prélèvement d'organes. Il s'est agi, à l'époque, d'une véritable rupture car la logique conduite depuis 1976 consistait dans une occultation de l'information au sujet du consentement présumé pour éviter de trop nombreuses inscriptions sur le registre des refus. Cette politique a cependant démontré ses limites car, peu informée, la famille consultée au moment où le prélèvement est envisagé est plus fréquemment hostile au prélèvement que lorsque, en raison de la bonne diffusion de l'information dans la société, une conversation a pu avoir lieu, permettant de clarifier la position de chacun. Ce constat a conduit les pouvoirs publics à lancer de vastes campagnes d'information à partir de la révision des lois de bioéthique intervenue le 6 août 2004. Ainsi informée, la population est donc conduite à pouvoir véritablement s'exprimer en s'opposant, le cas échéant, aux hypothèses de prélèvement post mortem. L'information n'est pas sans effet, comme en atteste l'augmentation très significative du nombre d'inscriptions sur le registre à la suite de la campagne d'information menée à l'hiver 2016-2017 en raison des modifications apportées par la loi du 26 janvier 2016 et le décret du 11 août 2016[41]. Précisons que, depuis la loi du 7 juillet 2011, une mention peut être portée sur le dossier médical personnel ou la carte vitale, précisant que la personne a été informée de la législation relative au don d'organe[42]. La loi française prévoit alors de multiples modalités d'information. Ainsi, le Code du service national impose une information à destination de la jeunesse, lors de la journée défense et citoyenneté[43]. En outre, les médecins doivent s'assurer que leurs patients âgés de seize à vingt-cinq ans sont informés des modalités de consentement au don d'organes à fins de greffe et, à défaut, leur assurer cette information[44]. Pour y procéder, le médecin précise au jeune patient les sources d'information disponibles émanant de l'Agence de la biomédecine, notamment l'existence de son site internet[45]. Il l'invite à accéder lui-même à ce site, et, s'il l'estime souhaitable, lui remet personnellement une version imprimée des pages spécialement éditées par l'agence à destination des jeunes. Il répond, le cas échéant, aux demandes d'information complémentaires[46]. Enfin, une information doit être dispensée dans les lycées et les établissements d'enseignement supérieur[47].

[38] C. sant. publ., art. R. 1232-4-7.

[39] Arr. 16 août 2016, préc., annexe, II, D, in fine.

[40] Arr. 16 août 2016, préc., annexe I, Proposition de grille d'analyse de la conduite de l'entretien, 49.

[41] Depuis le 1er janvier 2017, on assiste à une affluence significative sur le site internet du registre. Les refus, qui étaient de l'ordre de 170 000 avant janvier avaient ainsi doublé à la fin du printemps 2017. Toutefois, si l'on compare ce chiffre aux 10% de la population qui, dans les enquêtes d'opinions, se déclarent opposés au prélèvement d'organes après leur mort, on constate qu'il demeure très faible.

[42] L. 2011-814, art. 9 et 13: C. sant. publ., art. L. 1111-14; (dossier médical personnel) et C. séc. soc., art. L. 161-31, II (Carte vitale)

[43] C. serv. nat., art. L. 114-3, al. 2

[44] C. sant. publ., art., L. 1211-3, al. 3.

[45] https://www.dondorganes.fr

[46] C. sant. publ., art. R. 1211-50, al. 2.

[47] C. éduc., art. L. 312-17-2

Informed consent in the case-law of the European Court of Human Rights

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Informed consent in the case-law of the European Court of Human Rights*

Abstract. This article deals with patients' rights related issues in the case-law of the European Court of Human Rights. It is noted that one of the crucial safeguards of the patients' rights is a requirement of obtaining a patient's consent to any — even minimally invasive — medical intervention. Referring to decisions and judgments of the European Court of Human Rights, the author recites and clarifies criteria which such consents must meet. Moreover, the author describes situations where a medical intervention is permissible without consent of a patient or his or her relatives, and enumerates requirements which such a medical intervention must meet to comply with standards of the European Court of Human Rights in this field and be considered as justified

Key words: bioethics, human rights and biomedicine, free concent, medical intervention.

The European Court of Human Rights (hereinafter referred to as "the Court", "the European Court") has repeatedly addressed the issues of patients' autonomy, freedom of choice and safeguards and dealt with them in light of Article 2 (Right to life), 3 (Prohibition of torture) and 8 (Right to respect for private and family life) of the European Convention for the Protection of Human Rights and Fundamental Freedoms[1] (hereinafter referred to as "the Convention").

The starting point for the review of the relevant category of cases is the Court's adherence to the principle reflecting the very essence of the Convention which is respect for human dignity and freedom[2]. Personal inviolability of the individual, his/her physical, moral and psychological integrity, and personal autonomy are the inherent elements of the rights enshrined in the Convention. In the sphere of medical assistance, this principle is embodied, inter alia, in the requirement to obtain consent of a patient to any, even minimal, medical intervention[3]. Medical intervention against the wishes of a fully responsible adult patient (or, if lacking capacity, against the will of his/her legal representatives) is an infringement against his/her physical security and can be only justified in exceptional circumstances to be discussed below.

The Court has developed a number of criteria for the patient's consent to medical intervention. Specifically, it must be express, free, informed and conscious.

A. Express consent

The patient must clearly express his/her opinion regarding a particular proposed medical procedure.

For example, in the case of Glass v. United Kingdom, the applicant, the mother of a severely mentally and physically retarded child, lodged a complaint in her own name and in the name of her child. The doctors at the hospital where the applicant's son was once again taken to in critical condition, decided to administer diamorphine to him to alleviate his distress despite strong objections on the part of the applicant, who believed that the doctors did that in an attempt to kill her child. By way of defence, the respondent State argued that during one of the boy's previous hospitalisations the applicant had given consent to a specific treatment, including the administration of morphine, which according to the respondent State could be understood as her consent to the administration of diamorphine. The Court rejected that argument, pointing out that, apart from the fact that morphine rather than diamorphine was mentioned in the previous discussions, such talk could hardly have constituted express (or free and informed) consent. Moreover, the doctor's' decision to administer diamorphine despite the applicant's opposition led to the interference with her son's right to respect for his private life, including his physical integrity[4]. Because in the event of disagreement between medical professionals and a patient over a certain treatment, the law of the United Kingdom generally requires a court order for such treatment, and in this case it was not in place, the Court found the above interference to be in violation of Article 8 of the Convention.

B. Free consent

The patient must consent to a medical intervention of his own free will, while being in a position to refuse the intervention. Consent obtained from a patient in a situation with no actual choice but a semblance of it, cannot be deemed free.

* The article reflects its author's views and does not bind the European Court of Human Rights.

Translated into English by LLC "Development of legal systems".

[1] Adopted in Rome on 4 November 1950 // SZ RF [Legislative Corpus of the Russian Federation (LCRF)]. 2001. No 2. Art. 163.

[2] Cf.: ECtHR Judgment of 8 November 2011 in the case of V.C. v. Slovakia (application No 18968/07) (hereinafter referred to as "the V.C. case"). § 105 // ECtHR Bulletin. Special issue, "Selected Judgments of the European Court". 2012. No 2.

[3] Cf.: ECtHR Judgment of 22 July 2003 in the case of Y.F. v. Turkey (application No 24209/94) (hereinafter referred to as "the Y.F. case"). § 33 //http://hudoc.echr.int

[4] ECtHR Judgment of 9 March 2004 in the case of Glass v. United Kingdom (application No 61827/00). §§ 70 and 82 // http://hudoc.echr.int

The Court addressed the issue, specifically, in the cases of Y.F. and Juhnke v. Turkey[5]. The applicants were detained and taken into police custody on suspicion of being involved in the activities of the Workers' Party of Kurdistan (an organisation banned in Turkey). After questioned by the police, they were brought to see gynaecologists for examination in order to protect police officers against potential false accusations of sexual assault on the detainees. The applicants claimed that the examination had been made without their consent, whereas the respondent Government insisted that they could have voiced their objections to the examination in the doctor's office and that it was impossible to perform this procedure without the consent of the patient.

The European Court noted the vulnerable position of the applicants, who were in custody, i.e. under the total oversight of the government, which means that they were hardly in a position to counter the examination. In the Juhnke case, the Court also assumed, having regard to the facts in the case, that the applicant could have been misled about the nature of the examination, had he been told that it was required[6]. In the end, the Court accepted that the examination of the applicants was conducted against their will[7] or without their free (as well as informed) consent[8], which constituted a violation of their right to respect for private life guaranteed in Article 8 of the Convention.

In the case of Konovalova v. Russia, the applicant, who was in her fortieth week of pregnancy, was taken to the hospital of the Kirov Military Medical Academy because she had gone into labour. Upon arrival, she was given the hospital's brochure to read which had a warning that medical care at the hospital was part of the teaching process for medical students and for that matter all the patients were involved in the teaching process. Since her contractions were irregular, and the applicant showed the symptoms of extreme fatigue and distress, the physicians decided to put her into a drug-induced sleep. Later that day, the applicant underwent a number of examinations, during which she was told that the delivery was scheduled for the following morning and that medical students would be present during the procedure. After the examinations, the applicant was again put into a drug-induced sleep. According to the applicant, she said the following morning that she did not want the students to be in present, but the doctors ignored the request. The delivery was witnessed by physicians and students, who were presumably told about the applicant's state of health and the treatment used. Later, the Government referred to the physicians, who denied in the course of domestic litigation that the applicant had voiced any objections.

The European Court noted the very general nature of information provided in the brochure and no explicit reference to the teaching process. Moreover, the wordings in the brochure and those used in the conversations with the applicant made an impression that the students' involvement was mandatory and that the applicant had no option as to whether agree or not to the students' presence during labour[9]. The Court found that the presence of medical students at the time of the child's delivery was at variance with the requirements of legality in the sense of Article 8 of the Convention due to the overly general and indefinite nature pf the provisions in the then effective Russian legislation and lack of adequate procedural safeguards against arbitrary interference with the applicant's rights guaranteed by this Article.

C. Informed consent

The patient must be given full and reliable information about the status of his/her health, the exact nature of medical intervention and the potential risks and consequences, the existing alternatives to the intervention and the implications of declining it. The information must be presented to the patient in a clear and comprehensible language and form. It is forbidden to provide distorted, biased and incomplete information to influence the patient's choice.

In the cases of V.C. and N.B. v. Slovakia, both applicants, ethnic gypsy women, were sterilised during the delivery of their second child by Caesarean section. In both cases the doctors established that there was a danger of rupture of uterus in subsequent pregnancy and delivery, which could result in the death of the mother and child. The applicants were advised that if they wanted to have more children later on, then either they or their children might die, and they were offered sterilisation as the only way to avoid such scenario, so both women signed a typewritten single-phrase request for sterilisation[10].

The Court noted that not only have the applicants failed to receive full information about the status of their health, the nature and consequences of the proposed medical intervention and available alternatives to the procedure, but the information they received was distorted obviously in an attempt to influence their choice. Under the circumstances the applicants' formal consent to sterilisation cannot be deemed free and informed.

The Court also stated that sterilisation constitutes a major interference with a person's reproductive

[5] ECtHR Judgment of 13 May 2008 in the case of Juhnke v. Turkey (application No 52515/99) (hereinafter referred to as "the Juhnke case") // ECtHR Bulletin. 2008. No 10.

[6] ECtHR Judgment in the Juhnke case. § 77.

[7] ECtHR Judgment in the Y.F. case. § 34.

[8] ECtHR Judgment in the Juhnke case. § 77.

[9] ECtHR Judgment of 9 October 2014 in the case of Konovalova v. Russia (application No 37873/04) (hereinafter referred to as "the Konovalova case"). § 46 // ECtHR Bulletin. 2015. No 1.

[10] ECtHR Judgment in the V.C. case. § 117; of 12 June 2012 in N.B. v. Slovakia (application No 29518/10). § 76 and 77 //http://hudoc.echr.int

health status and bears on manifold aspects of the individual's personal integrity, including his or her physical and mental well-being and emotional, spiritual and family life[11]. Given the critical nature of the intervention resulting in the applicant' loss of reproductive functions, their tender age at the time of the intervention (20 and 17 years), serious physical and psychological consequences for both, the Court found that the applicants were subjected to treatment in violation of Article 3 of the Convention.

D. Conscious consent

The patient must be given an opportunity and sufficient time to consider the proposed treatment, weigh all the pros and cons, take into consideration the relevant factors and make a conscious choice. Moreover, the patient must be in a condition that allows a conscious choice. Thus, in the aforementioned cases against Slovakia the Court did not find the consent to sterilisation to be informed, given as it was by women who had by that time been in labour for over several hours, whose mind was clouded by birthing pain and the effect of tranquillisers and painkillers[12]. By the same token, in the Konovalova case the Court noted that, having been informed of the presence of students between two sessions of drug-induced sleep, when she had already been in a state of extreme distress and fatigue for some time, the applicant could have hardly made ameaningful and informed decision[13].

This requirement also imposes on medical professionals the duty of making sure that the patient's choice is conscious and responsible. For example, in the case of Arskaya v. Ukraine, the applicant's son, 42, was hospitalised with pneumonia, tuberculosis, haemoptysis and pulmonary insufficiency; his condition described as serious. The following day the doctors noted that he behaved inadequately and was in an agitated state close to being euphoric. For a few days the patient was given antibacterial, blood clotting and other required medication, which initially improved his general state; however, three times he would refuse bronchoscopy needed for a specific diagnosis to be established and for subsequent treatment to be worked out, he also declined intramuscular antibacterial injections, which was noted (documented) by the attending doctors. The applicant's son was also examined by a psychiatrist, who diagnosed him with somatogenic paranoid disorder. The patient's condition was steadily deteriorating, yet he continued to refuse bronchoscopy and intramuscular injections. The applicant's son died 11 days after hospitalisation.

The European Court emphasised that in ascertaining the validity of a patient's refusal of treatment the key issue is his ability to make responsible informed decisions. In this case, despite the fact that the state of the applicant's son was extremely serious and life endangering and that he demonstrated clear signs of not being compos mentis, the attending doctors simply accepted his refusals of treatment, without even attempting to assess his capacity to make rational decisions regarding his treatment. However, before accepting the patient's refusal of treatment, the doctors were obliged to eliminate the risk that the patient's refusal was given without full understanding of what was at stake[14].

According to the Court, the fact that the question of whether the applicant's son was aware of the implication of his refusal of treatment was not duly ascertained by the doctors largely due to the absence of clear rules in the regulatory and legislative framework for public health care to determine whether the patient's refusal of treatment was valid and binding upon the medical professionals. Specifically, there was no procedure in place to enable the doctors to quickly and objectively assess the patient's ability to make responsible decisions. Therefore, the Court found that in that case the respondent State failed to fulfil its obligations in the area of public health pursuant to Article 2 of the Convention.

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No medical intervention can be upheld by the Court without the patient's consent unless the respondent State proves beyond reasonable doubt that the intervention was medically necessitated, i.e., that there was a threat to the life or major irreparable damage to the health of the patient, and that the decision to undertake a medical intervention without the patient's consent was taken in the context of and with due regard of the statutory safeguards. In this context cases involving the administration of compulsory medical measures to applicants who used to be drug dealers, specifically, packaged small doses in plastic bags and then swallowed them to transport or conceal drugs from the police are mostillustrative.

For example, in the case of Jalloh v. Germany, by the decision of the police a few hours after being taken into custody the applicant was forcefully administered emetics. During the procedure the applicant was held by four policemen and had a tube introduced into his stomach through the nose to administer the medicine. The applicant was also injected with an emetic. The Court found that the applicant had been subjected to inhuman and degrading treatment in violation of Article 3 of the Convention stating that the purpose of the intervention — obviously painful and humiliating — was not to save the life of the applicant, but to obtain evidence in the case for the police; and other more humane alternatives were not considered, such as waiting for the drug leave the body naturally,

[11] ECtHR Judgment in the V.C. case. § 106.

[12] ECtHR Judgment in the N.B. case. §§ 76–77.

[13] ECtHR Judgment in the Konovalova case. § 47.

[14] ECtHR Judgment of 5 December 2013 in the case of Arskaya v. Ukraine (application No 45076/05) §§ 87–89 //http://hudoc.echr.int

and that such procedure presented a health risk for the applicant[15].

Yet, in the case of Bogumil v. Portugal with a similar fact pattern, the Court found no violation of Article 3of the Convention. In that case the applicant was subjected to surgery for the drug to be retrieved from his stomach without his written consent. The Court noted that unlike the Jalloh case, the intervention was motivated not by the wish to obtain evidence in the case, but by therapeutic considerations because the applicant was about to die of intoxication. The applicant was held under observation for 48 hours, and it was not until it became clear that waiting for the drug to be expelled naturally was endangering his life that medical professionals (not the police) opted for surgery[16].

In the case of Bataliny v. Russia, the Court addressed involuntary psychiatric care, as well as clinical tests of new medications. The first applicant (the son of the second and third applicants) was brought to a psychiatric hospital following an attempted suicide. Over the following two weeks he underwent involuntary psychiatric care, which also involved using him as a "scientific research patient", with a new antipsychotic administered to him to study its effects. Having regard to the forensic medical evidence provided by the national authorities, the European Court stated that whereas the initial commitment of the first applicant could be justified by his attempted suicide, his psychological state over the following fortnight could not be described as a severe mental disorder or other acute mental condition and thus did not require involuntary treatment. The respondent Government provided no argument or evidence to demonstrate the medical necessity of such intervention. The Court found that the involuntary psychiatric care of the first applicant, with no convincing proof of medical necessity, which involved using him to test a new drug, constituted inhuman and degrading treatment in breach of Article 3 of the Convention. Given the international standards in place, the Court emphasised that it was unacceptable to do research and test new medicinal products without the consent of thepersons being tested[17].

It is noteworthy that the so-called medical indications do not constitute good and sufficient cause for medical intervention without the patient's consent. In other words, medical professionals do not have discretion to decide what is best for the patient or undertake medical procedures without his/her consent even if they believe that they are acting in the best interests of the patient. For example, in the cases against Slovakia discussed above, the Court emphasised that sterilisation is not a procedure that is needed when performed to save the life of the patient and therefore cannot be undertaken without

[15] ECtHR Judgment of 11 July 2006 in Jalloh v. Germany (application No 54810/00) (hereinafter referred to as "the Jalloh case"). § 82 // ECtHR Bulletin. 2007. No 2.

[16] ECtHR Judgment of 7 October 2008 in Bogumil v.Portugal (application No 35228/03). § 77 // ECtHR Bulletin. 2009. No 2.

[17] ECtHR Judgment of 23 July 2015 in Bataliny v. Russia (application No 10060/07). § 88 // ECtHR Bulletin. 2016. No 1.

the patient's consent, even if another pregnancy can be a threat to life, and even if the patient's history, which shows that the patient did not seek medical care, suggests that the patient will continue to neglect her health[18].

The Court's case-law covers various safeguards for patients who are not in a position to have a say in the medical decisions that affect them. Specifically, in the cases of Lambert and Others v. France, as well as Gard and Others v. United Kingdom, the Court faced very complex and delicate, first of all in moral and ethical terms, issues involving vegetative patients on life support. In the first case, V. Lambert (the son of the first two applicants and stepbrother of the third and fourth applicants), was in a traffic accident at the age of 32 and sustained a severe head injury, which put him in a coma, which lasted for a number of years. Before the accident, he made no arrangements regarding his life support. In the second case, the first applicant (the ten-month-old son of the second and third applicants) suffered from an extremely rare genetic disease — a mitochondrial DNA depletion syndrome — which caused progressive muscle atrophy and brain damage because the child's organs were not supplied by sufficient energy to function normally. According to the attending doctors, the child was unable to see, hear, cry or move, and the brain damage was irreversible. In both cases the doctors saw no likelihood of improvement in the patients' condition and suggested that life support be discontinued; the applicants, however, were strongly against this option. In the end, the matter in each case was referred to the national courts, which after a scrupulous study of all the evidence adduced and examination of numerous witnesses upheld the decision of the doctors.

The European Court emphasised that the issue involved the discontinuation of life support rather than euthanasia, and therefore had to be addressed in terms of the respondent States' performance of their obligations under Article 2 of the Convention[19]. It went on to say that there is no consensus among the Council of Europe's member States regarding the discontinuation of life support, although most States seem to have resolved the issue. It the opinion of the Court that in the matters of start and end of life the States must be given margin of appreciation not only to allow or disallow the discontinuation of life support, but also to take measures to ensure a balance between the patients' rights to life and to respect for their private life, including personal autonomy.

The Court studied the relevant statutory and regulatory framework in place in the respondent States, the extent to which preferences of the patients, their relatives and medical professionals were taken into account; as well as legal remedies available to ensure that decisions be made in the interests of the patients, and found that the framework and decision-making process in both cases met the requirements of Article 2 of the Convention. The Court made special mention of the quality and depth of the examination of the cases by the domestic courts.

Another controversy is a post-mortem organ and tissue donation for transplantation purposes. A number of countries use the presumption of consent in the matter, i.e. the patient is assumed to have agreed to donation upon death unless he/she himself/herself when alive or his/her next of kin after his/her death dispose otherwise. In the cases of Petrova v. Latvia[20] and Elberte v. Latvia, the applicants complained about the post-mortem removal of organs and tissues of their son and husband respectively, done without the consent of the deceased and without the consent of the applicants themselves. The Court emphasised that its task was not to adjudicate which system — one based on presumed or explicit consent — must be implemented by the state, but only to ascertain whether the necessary legal and practical conditions were in place to enable the applicants to exercise their rights in this context[21]. The Court went on to say that although the law in effect at the material time expressly provided for the rights of the person involved or his next of kin to go on record as consenting to or opposing the removal of organs after his/her death, it failed to specify the duties and the margin of appreciation granted in this context to the medical professionals or the competent public authorities. Specifically, it was still unclear how the presumption of consent was practically applied to the situation in which the applicants found themselves and had certain rights as the next of kin, but were not informed of, let alone taken through, the arrangements for the exercise of these rights. Therefore, the Court concluded that a violation of the applicants' right to respect for their private life guaranteed by Article 8 of the Convention was in place.

By way of summary of the foregoing, it must be said that the standards of the European Court in the matter under discussion obviously expect medical professionals to forgo a paternalistic approach to the patient and require them to treat him/her as an adult, capable of assuming responsibility for his life and health and making a conscious choice. The task of physicians is not to make the patient accept any choice they think is the best, but to provide the most complete and accurate information that will allow the patient to himself/herself make a voluntary and informed decision. A deviation from this rule will only be justified in exceptional circumstances, with the respondent Government required to prove every time beyond reasonable doubt the need for medical intervention without the patient's consent and to have effective procedural safeguards and remedies in place for the patient.

[18] Judgment in the V.C. case § 113.

[19] ECtHR Judgment of 5 June 2015 in Lambert and Others v. France (application No 46043/14). § 124 // ECtHR Bulletin. 2015. No 2; ECtHR decision of 27 June 2017 in Gard and Others v. United Kingdom (application No 39793/17). § 79 //http://hudoc.echr.coe.int

[20] ECtHR Judgment of 24 June 2014 in Petrova v. Latvia (application No 4605/05) // ECtHR Bulletin. 2014. No 10.

[21] ECtHR Judgment of 13 January 2015 in Elberte v.Latvia (application No 61243/08). § 110 // ECtHR Bulletin. 2015. No 4.

Russia's topical bioethical issues through the prism of case-law of the European Court of Human Rights

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Abstract. Cases concerning bioethics involve far-reaching interdisciplinary issues, which quite often lie at the junction of law, science and ethics. Such cases are difficult to manage, not least because of the lack of settled national case-law. Taking her cue from the Cherkessk City Court, the author recommends that such cases be adjudicated in light of the legal doctrines developed by the European Court of Human Rights. Specifically, a review is made of certain legal issues that resonate in Russia using as an example similar cases in other Council of Europe member States: the United Kingdom, Italy, France and Czechia.

Key words: bioethics, human rights and biomedicine, margin of appreciation of domestic authorities, balance between private and public interests, IVF, reproductive technologies, embryo, home delivery, establishment of kinship.

The idea to consider some of Russia's topical bioethical issues through the prism of case-law of the European Court of Human Rights (hereinafter referred to as "the ECtHR", or the Court) was prompted by a news item[1] about a case on the docket of a court in the Karachay-Cherkess Republic[2] involving the arrangements for cryopreserved IVF embryos after the separation of spouses, the potential parents. There being no applicable case-law in Russia, the parties and the court had to turn to[3] the ECtHR' case-law, specifically the case of Evans v. United Kingdom[4], which had a fairly similar fact pattern.

Cases concerning bioethics are often fairly unusual and fall outside familiar territory. This largely prevents the emergence of settled case-law on bioethics on a domestic level. At the same time, at the level of the Council of Europe the likelihood of similar cases is significantly higher, which makes it possible to use the experience of other states to save time and resources for the parties' representatives and courts alike.

Given that before coming to the ECtHR and being put before international judges, the case goes through all effective domestic remedies, i.e., is examined by judges of national, including higher courts more than once, the ECtHR's final judgment can be said to be a perfect "legal product", which can be useful.

It goes without saying that this does not mean blind copying of the Court's conclusions because there are no identical situations and no identical domestic laws; we are rather talking about using the Court's approaches. Therefore we propose to look closer at the approaches taken by the ECtHR when dealing with certain bioethical issues, starting with the aforementioned Evans case.

Legal approaches to adjudicating cases involving the legal status of an embryo

A cohabiting couple decided to have children and underwent appropriate treatment. It was revealed that the applicant, Ms.Evans, had serious pre-cancerous tumours in both ovaries, and that her ovaries would have to be removed. Because the tumour was growing rather slowly, it was feasible to extract ovicells for subsequent use in IVF treatment. With the couple's consent, the eggs were extracted and fertilised with the sperm of the applicant's cohabitant, and the resulting embryos were cryopreserved, following which ovariectomy was performed.

It took the applicant about two years to recover. By the time when she was physically ready for the implantation of embryos, the couple had split up, and her former cohabitant notified the clinic of withdrawal of his consent to fertilisation and demanded that the embryos be destroyed. In response, the applicant took legal action to restore the withdrawn consent. Having failed in the domestic courts, she filed an application with the ECtHR, including for violation of the right to life, guaranteed under Article 2 of the European Convention for the Protection of Human Rights and Fundamental Freedoms[5] (hereinafter referred to as "the Convention"), arguing that domestic legislation made it possible for her former spouse to withdraw the consent to the implantation of embryos, whilst she was left with no other option to have genetic children.

* Translated into English by LLC "Development of legal systems".

1 Rodionova, A. Cherkess Court to Set an IVF Precedent [in Russian] // Vademecum. 2017. 22 Feb.: https://vademec.ru/Article/sud_cherkesska_sozdast_pretsedent_v_praktike_eko/

2 Case No 2-1018/2017 (M-109/2017)/ Website of Cherkessk City Court, Karachay-Cherkess Republic: https://cherkessky--kchr.sudrf.ru/modules.php?name=sud_delo&srv_num=1&name_op=case&case_id=800733&delo_id=1540005&hide_parts=0

3 According to a news report of March 17, 2017, the judgment in Evans v. United Kingdom was adduced as evidence in the case //Website of Channel One of Russian television: http://www.1tv.ru/news/2017-03-17/321748-v_cherkesske_byvshie_suprugi_delyat_v_sude_embriony

4 ECtHR's judgment of 10 April 2007 in Evans v. United Kingdom (application No 6339/05) (hereinafter referred to as "the Evans case") // ECtHR HUDOC: https://hudoc.echr.coe.int/eng#{"fulltext":["6339/05"],"itemid":["001-80046"]}, see also the ECtHR's Grand Chamber's Case-Law by Council of Europe member States. 2007. No 10.

5 The Convention for the Protection of Human Rights and Fundamental Freedoms (adopted in Rome 4 November 1950) // SZ RF [Legislative Corpus of the Russian Federation (LCRF)]. 2001. No 2. Article 163.

When examining the case, the ECtHR assumed a wide margin of appreciation left to the national authorities in the delicate matters of ethics and morality, and lack of consensus among the Council of Europe member States over the course of action in such situations.

The ECtHR finds that the national authorities are in a better position to know the needs and preferences of their citizens; therefore, leaving it up for the national authorities to adjudicate the matter on the merits, the ECtHR limited its role to monitoring the decision-making process, including the following aspects:

— whether full consideration was given to the interests of the parties and society at large;

— whether a fair balance was struck between the conflicting interests;

— whether the national authorities exceeded their margin of appreciation.

In the Evans case, accordingly, the domestic courts faced a challenge to ensure a fair balance between the applicant's interests (have biological children and revise the legislation on withdrawal of consent to treatment), the interests of her former cohabitant (not to have children by her and to be entitled to withdraw his consent) and the interests of society at large (legal certainty and consistency of case-law).

It is noteworthy that in that case the Court held that embryos have no independent rights and therefore no right to life in the meaning of Article 2 of the Convention, thus upholding the position formulated three years previously on the right to life of embryos, which was put forward in Vo v. France[6]. The applicant, T.-N. Vo, who was pregnant, came to a women's health clinic for a routine examination. Unfortunately, another patient with the exact same surname had an appointment with the physician on the same day to remove an intra-uterine device. The doctor confused the patients and started the procedure without first examining the applicant, which caused a large loss of amnionic fluid and, as a result, the loss of her child. The applicant, having failed in having the national courts find the physician guilty of unintentionally killing her [unborn] child, lodged an application with the ECtHR alleging a violation of Article 2 of the Convention. However, the Court, referring to the sensitivity of the issue, the moral, cultural and philosophical dimensions of the question as to when life begins, the ambiguous legal status of an unborn child and no consensus among Council of Europe member States, sidestepped the substantive aspect of Article 2 of the Convention, focusing on whether the domestic remedies available to the applicant in that case were consistent with the procedural safeguards under the Article.

Another case, which cannot be overlooked in a discussion about the legal status of cryopreserved embryos, is Parrillo v. Italy[7], which was examined by the ECtHR' Grand Chamber in 2015. In that judgment the Court rehashes the arguments made in the Evans case, although the cases have different fact patterns: namely, after the death of her spouse during the hostilities in Iraq, the applicant decided to make her cryopreserved embryos available for research rather than implanting them.

(Since the question of research is rather broad and goes beyond the scope of this paper, we will leave it aside and will only recommend that those interested in this subject read the working group's special report[8], published on the website of the Bioethics Unit of the Council of Europe, as well as the relevant statutes and regulations[9], including Article 18 of the Oviedo Convention on Human Rights and Biomedicine[10] and Article 18 of the Additional Protocol thereto[11], which cover in vivo testing.)

The case of Parrillo v. Italy is interesting because of the ECtHR's finding regarding ownership of embryos. Domestic courts having denied her request to give the embryos to research, the applicant lodged a complaint with the ECtHR, alleging, among other things, interference with her ownership of the embryos and citing Article 1 of Protocol No 1[12] to the Convention. The ECtHR stated in no uncertain terms that the Article did not apply here because it is impossible to reduce the legal status of human embryos to "possessions" in the economic and physical meaning of the Article.

[6] ECtHR's judgment of 8 July 2004 in Vo v. France (application No 53924/00) // ECtHR HUDOC: http://hudoc.echr.coe.int/eng#{%22fulltext%22:[%22vo%22],%22documentcollectionid2%22:[%22GRANDCHAMBER%22,%22CHAMBER%22],%22itemid%22:[%2001-61887%22]}

[7] ECtHR's judgment of 27 August 2015 in Parrillo v. Italy (application No 46470/11) // ECtHR HUDOC: https://hudoc.echr.coe.int/eng#{"fulltext":["46470/11"],"itemid":["001-157263"]}, see also ECtHR Bulletin. 2016. No 1.

[8] Report by the Working Party on the Protection of the Human Embryo and Foetus (CDBI-CO-GT3) regarding the protection of human embryo in vitro. Strasbourg, 2003 // Bioethics Unit, Council of Europe: https://rm.coe.int/16803113e8

[9] Cf.: Recommendations of the Parliamentary Assembly of the Council of Europe No 1046 (1986), On the Use of Human Embryos and Foetuses for Diagnostic, Therapeutic, Scientific, Industrial and Commercial Purposes, and No 1100(1989), On the Use of Human Embryos and Foetuses in Scientific Research; Resolution the Parliamentary Assembly of the Council of Europe No 1352 (2003), On Human Stem Cell Research // Website of the Parliamentary Assembly of the Council of Europe: http://www.coe.int/t/r/Parliamentary_Assembly/

[10] Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS No 164) (adopted in Oviedo 4 April 1997) // Website of the Treaty Office, Council of Europe: http://www.coe.int/en/web/conventions/full-list/-/conventions/rms/090000168007d004

[11] Additional Protocol to the Convention on Human Rights and Biomedicine concerning Biomedical Research(CETS No 195) (signed in Strasbourg 25 January 2005) // Website of the Treaty Office, Council of Europe: http://www.coe.int/ru/web/conventions/full-list/-/conventions/rms/0900001680083742

[12] Protocol No 1 to the Convention for the Protection of Human Rights and Fundamental Freedoms (signed in Paris 20 March 1952) // LCRF. 2001. No 2. Article 163.

Legal approaches to adjudication of cases involving home deliveries

Home delivery is also a fairly topical issue, specifically for the Russian courts that hear relevant cases on a regular basis. Among the causes célèbres in this context is the case of Yelena and Alexey Yermakov and the Kolybelka [Baby Cradle][13] parenting centre which was arranging home deliveries. According to the Office of the Prosecutor General of the Russian Federation[14], the illegal activities resulted in the death of six infants and injury to the health of two newborns. The court convicted the defendants under Article 235 of the Criminal Code of the Russian Federation[15] (illegal practice of medicine resulting in negligent death) and sentenced them to imprisonment and a large fine.

The relevance of the subject to Russia is also confirmed by social media posts that started last autumn: women use the hashtag "violence in delivery" [насилие_в_родах] to share their unhappy experiences in maternity hospitals, complain against specific physicians, the obstetric arrangements in general, including the unwillingness of certain public health professionals to take into account the opinions of women in labour, also in cases of labour with no complications.

In Dubská and Krejzová v. the Czech Republic[16], the applicants wanted to give birth at home because they did not like the rules that required the child to be taken from the mother right after the delivery for two hours to be examined, weighed and measured. Women were also unhappy about being made to take certain drugs, and disallowed leaving the maternity hospital right after the delivery, even where there were no complications.

When preparing for home delivery the applicants looked for but couldn't find midwives for assistance. However, no obstetric intervention by health professionals is allowed under Czech law unless adequate medical equipment is on hand, moreover, midwifery in a home environment is not covered by health insurance policy and is punishable by a large fine.

Failing to find midwives, one of the applicants opted for home delivery, and the other for the most suitable maternity hospital. At the end of the day, both were unhappy with the quality of the medical services received and applied to the ECtHR alleging a breach of their right to respect for private life under Article 8 of the Convention.

When examining this case, the Court held that its task was not to determine the best framework for obstetric intervention (this is a responsibility of the national authorities), but to ascertain the extent to which government intervention into the private life of the applicants was consistent with the safeguards of Article 8 of the Convention; in other words, whether the actual unavailability of home delivery struck a fair balance between the right to respect for the private life of the applicants, on the one hand, and the public interest in protecting the health and safety of the mother and child, on the other.

In assessing the margin of appreciation of the national authorities, the Court noted that although the problem of home delivery is per se not classified among particularly delicate issues of ethics and morality, yet the margin of appreciation of the national authorities is sufficiently broad here because it falls within the context of national health service system and protection of public health. Also, contrary to the claims of the applicants, there was no consensus among the Council of Europe member States, which could have narrowed the margin of appreciation of the national authorities. Specifically, scheduled home deliveries are regulated by law in 20 out of 47 Council of Europe member States and the choice of delivery mode depends on medical indications. National health insurance covers home deliveries in 15 of those countries only. In the other 23 countries, home deliveries are not sufficiently regulated. None of the member states has an express legislative ban to home delivery assistance by midwives. A very small number of countries, whose statutory regulation was reviewed, have disciplinary or criminal penalties in place for such activities, but these are presumably not often invoked.

It is noteworthy that in this case the Court, having attributed its position to the high infant mortality rate, departed from the conventional wisdom, pointing out that in the context of home delivery the interests of the mother and child do not align.

In the end, given the wide margin of appreciation afforded to the State, as well as the efforts being taken by the national authorities to improve the quality of obstetric intervention, the Court determined that the Czech courts had reviewed, taken into account and balanced the interests of the individual and society in that case, and found no violation of Article 8 of the Convention.

Legal approaches to adjudication of cases involving access to assisted reproductive technologies

Quite recently Moscow courts have heard a case, widely covered by the press[17], that centred on the

[13] Case No 1-123/09, Primorye District Court of St Petersburg, judgment of 25 September 2009.

[14] Judgment was handed down in criminal case against top management of St Petersburg Kolybelka Parenting Centre responsible for death of 6 infants // Official website of Procurator General of the Russian Federation. 2009. 25 September // https://www.genproc.gov.ru/pda/news/news-60764

[15] SZ [Legislative Corpus (LC)]. 1996. No 25. Article 2954.

[16] ECtHR's judgment of 11 December 2014 in Dubská and Krejzová v. Czech Republic (applications No 28859/11 and 28473/12)// ECtHR HUDOC:http://hudoc.echr.coe.int/eng#{«fulltext»:[«dubska»],»documentcollectionid2»:[«GRANDCHAMBER»,»CHAMBER»],»itemid»:[«001-168066»]}, see also Details of ECtHR's judgment of 11 December 2014 in Dubská and Krejzová v. Czech Republic (applications No 28859/11 and 28473/12) // ECtHR Bulletin. 2015. No 3.

[17] https://ria.ru/incidents/20150513/1064234075.html.

access to fertility treatments for families where one of the spouses is in custody, as in the case of Veronica and Nikolai Korolyov[18], with Nikolai serving a life sentence for a terrorist attack at the Cherkizovsky market.

In its fact pattern, the Russian case is very similar to Dickson v. United Kingdom[19], where two inmates got acquainted by correspondence. After the applicant's release, the couple registered their union; the husband, however, had some 8 years more to serve before his first chance to become eligible for parole. By that time, the applicant would have been 51 — an age where the likelihood of natural conception is obviously low. For that matter the applicants, wishing to have a child, asked the authorities to allow them to have an artificial insemination.

The national authorities had to strike a balance between the private interests of the couple and public interests. On the one hand, the IVF treatment was really the only option available to the applicants to have common children. Furthermore, having a child could facilitate the rehabilitation of the inmate. On the other hand, there was the question of protecting the interests of the child, who would have been forced to spend a fatherless childhood, and the child's wealth status: after all, the mother would have been the only breadwinner in the family. Apart from that the national authorities invoked the punitive theory of punishment and submitted that the granting of permission for in vitro fertilisation to a couple where a spouse was in prison can undermine public faith in the correctional system. After all, deprivation of freedom is a punishment for a crime and implies certain restrictions.

In this case, even accepting the state's wide margin of appreciation, the ECtHR found no evidence that the Policy for dealing with inmates' requests for in vitro fertilisation provided for a balance between the aforenamed opposing interests. Moreover, the Policy was not fixed statutorily and thus submitted to the Parliament for debate (by way of contrast, we can revisit the Evans case, where the Court points out that the Human Fertilisation and Embryology Act of 1990[20], which provides, inter alia, for the withdrawal of consent to the implantation of embryos, "is the fruit of much reflection, consultation and debate… as well as desire to ensure a fair balance between the parties to IVF treatment"[21]). Having regard to these circumstances and the number of judgments for the applicant, the Court found that the authorities of the United Kingdom exceeded their margin of appreciation and were in breach of Article 8 of the Convention.

Legal approaches to adjudication of cases to determine kinship and child custody

There was a case[22] involving an alleged kidnapping of a boy in the town of Dedovsk outside Moscow which was extensively covered by the mass media. According to the media[23], a woman who had a miscarriage early in her term simulated pregnancy without her spouse's knowledge of it, kidnapped an infant who was abandoned by its mother from a maternity hospital and passed it as her own. For two years the child lived surrounded by love and care in the family of the alleged kidnapper, and when the offence was investigated, the child was placed in an orphanage and then adopted by a new family.

A similar situation was looked into by the ECtHR in Paradiso and Campanelli v. Italy[24], where an Italian couple circumvented national law by using a surrogate mother from Russia. The applicant travelled to Moscow twice in order to deliver genetic material of her spouse for fertilisation and take the child away with her after birth. In the meantime the surrogate mother signed a consent to surrender the child to the applicants. However, upon their return home, they faced problems in regularising the status of the child because of the illegality of commercial surrogate motherhood in Italy. It came to light at the trial that the child was no kin to either of the applicants. At the same time, social services reported that the applicants' family offered his or her child a congenial environment and the best care. In the end, the child was placed in an orphanage and then adopted by another family.

The national courts ruled this way because there was no genetic link between the child and the applicants and because it was necessary to stop the violation of the domestic law. Recognising that the child would be inevitably affected by the loss of the

[18] Case No 2-7779/2014 (M-7340/2014) // Website of Babuskinsky District Court of the city of Moscow: https://babushky--msk.sudrf.ru/modules.php?name=sud_delo&srv_num=1&name_op=case&case_id=197229934&delo_id=1540005

[19] ECtHR's judgment of 4 December 2007 in Dickson v. United Kingdom (application No 44362/04) // ECtHR HUDOC:http://hudoc.echr.coe.int/eng#{%22fulltext%22:[%22dickson%22],%22documentcollectionid2%22:[%22GRANDCHAMBER%22,%22CHAMBER%22],%22itemid%22:[%22001-83788%22]}

[20] UK Public General Acts managed by the National Archives: http://www.legislation.gov.uk/ukpga/2008/22/contents/enacted

[21] ECtHR's judgment of 10 April 2007 in Evans v. United Kingdom, §§86-89

[22] Unfortunately, we could not find the full details of the lawsuits involved on the websites of the courts; presumably, this is case No 2-3796/2017 (M-2027/2017)// Website of Krasnogorsk Town Court of Moscow Oblast: https://krasnogorsk--mo.sudrf.ru/modules.php?name=sud_delo&srv_num=1&name_op=case&case_id=52096133&delo_id=1540005

[23] Boy kidnapped two years ago from Dedovsk maternity hospital was found, kidnapper facing prison time// Website of Channel One, Russian Television: http://www.1tv.ru/news/2017-01-15/317848-pohischennyy_dva_goda_nazad_iz_roddoma_v_dedovske_malchik_nayden_pohititelnitse_grozit_tyuremnyy_srok;
[D]edovsk baby kidnapper facing criminal charges// Vesti-Moskva: http://www.vesti.ru/videos/show/vid/709490/
[M]atvey, kidnapped in Dedovsk, adopted by new family. By Irina Bobrova // Website of Moskovsky Komsomolets Daily: http://www.mk.ru/social/2017/04/13/matveya-pokhishhennogo-v-dedovske-usynovila-novaya-semya.html

[24] ECtHR's judgment of 24 January 2017 in Paradiso and Campanelli v. Italy (application No 65192/11)// ECtHR HUDOC: http://hudoc.echr.coe.int/eng#{«appno»:[«25358/12»],»documentcollectionid2»:[«GRANDCHAMBER»,»CHAMBER»],»itemid»:[«001-170359»]}

loving family in which it spent all in all 8 months, the national authorities, taking into account the shortness of that period and the tender age of the child, held that the damage would not be irreparable and made arrangements for the child to be adopted by a new family as soon as possible.

In addressing this matter, the ECtHR ascertained whether family ties were created between the applicants and the child. After all, family ties can exist, according to the Court's case-law, even with no biological link or legitimisation. What matters is the quality of the relationship and the length of cohabitation. Having ascertained strong emotional ties between the applicants and the child early in its life, which was supported by the opinions of psychologists and social workers, the national authorities still found that the applicants themselves endangered that relationship by engaging in illegal activities. Therefore, given the shortness of the cohabitation, the absence of a biological link and the uncertainty of the legal status of the relationship, the Court found that the relationship cannot be described as family life, the strength of emotional ties and the applicants' desire to be parents notwithstanding. As for the applicant's argument that he was sure of being the child's father, the Court held here that it was not enough of a factor to establish family life because it cannot compensate for the shortness of cohabitation with the child. Accordingly, the case was examined by the Court in light of the applicants' right to respect for their private life, including the right to personal development through a relationship with a child. A strong emphasis was made on the protection of the child's interests despite the fact that it was not an applicant in this case.

Having established that the Italian authorities acted in accordance with the national laws and pursued legitimate aims, the ECtHR looked at how thoroughly the arguments of the parties were considered to achieve a fair balance between the interests of the state and those of the individuals whose future was directly affected by the decisions made. Given the wide margin of appreciation of the national authorities in delicate ethical issues, the special importance of public interest in protecting women and children from the threats that the Italian authorities believe are presented by commercial surrogate motherhood, the Court found no violation of Article 8 of the Convention in that case, highlighting the scrupulous attention given to the child's interests by the domestic courts.

The reviewed case should be differentiated from the Court's settled case-law in matters such as Mennesson, Labassée v. France etc[25], in which there was a genetic link

between the applicants and children born of surrogate mothers. The situations in those cases are not typical of Russia, so we need not look at them. At the same time, we note that the doctrines formulated in those cases can be useful in the context of issues that frequently arise in Russian courts during custody battles, disputes between surrogate mothers and genetic parents, adoption and guardianship cases, as well as other similar matters, in which the court has to find a fair balance between the interests of children, parents and society at large.

Unfortunately, the format of a journal article does not allow an in-depth review of all topical issues in bioethics, so we invite readers wishing to cover the subject in greater detail to look up a summary of the ECtHR's case-law on bioethics updated by the Research Department of the Court upon request from the Bioethics Unit of the Council of Europe[26].

This summary can be used as a desktop reference guide: it groups cases by the subject matter and gives a brief description of the case and the Court's judgments. For a more detailed study of the case-law on human rights, use the database of ECtHR judgments and decisions[27]on the Court's website.

[25] ECtHR's judgment of 26 June 2014 in Mennesson v. France (application No 65192/11)// ECtHR HUDOC: http://hudoc.echr.coe.int/eng#{«appno»:[«65192/11»],»documentcollectionid2»:[«CHAMBER»],»itemid»:[«001-145179»]} ; ECtHR's judgment of 26June 2014 in Labassée v. France (application No 65941/11)// ECtHR HUDOC: http://hudoc.echr.coe.int/eng#{«itemid»:[«001-145180»]} ; ECtHR's judgment of 21 July 2016 in Foulon and Bouvet v. France (applications Nos 9063/14 and 10410/14)// ECtHR HUDOC: http://hudoc.echr.coe.int/eng#{«itemid»:[«001-164968»]} ; ECtHR's judgment of 19 January 2017 in Laborie v. France (application No 44024/13)// ECtHR HUDOC: http://hudoc.echr.coe.int/eng#{«itemid»:[«001-170369»]}

[26] Bioethical issues in light of the case-law of the European Court of Human Rights: a research report. Council of Europe / European Court of Human Rights, 2016. For a Russian-language text of the report, see: http://www.echr.coe.int/Documents/Research_report_bioethics_RUS.pdf

[27] ECtHR HUDOC:http://hudoc.echr.coe.int/

Artificial insemination in the light of case-law of the European Court of Human Rights

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Artificial insemination in the light of case-law of the European Court of Human Rights

Abstract. This article contains a review and analysis of case-law of the European Court of Human Rights relating to use of the artificial insemination. The author analyses the following issues considered by the European Court of Human Rights: access to the artificial insemination, problems faced by families raising children conceived via artificial insemination and confidentiality of donors and mothers' personal data.

Key words: artificial insemination, medically assisted procreation, right to private life, right to family life.

Nowadays the scientific progress has contributed to the development of new tools which help to prevent aging, extend our lives and improve the health. The developed countries see increase in life expectancy, people are now able to live in comfort and — most importantly — to choose one's own way of life. In the context of private and family life it means that we may freely get married or stay single, decide to have or not to have children. The modern medicine allows single or older women, women with reproductive health problems to get pregnant and homosexual couples to have a child through artificial insemination procedure (hereinafter referred to as "AI").

However, effects of scientific progress, despite all of its benefits, may be unpredictable not only from a medical but also from a social point of view. In the latter case the law is the most important instrument for resolving all possible conflicts and disputes. Globalisation led states to necessity of not only governing any new relations domestically but also of complying with their international obligations, in particular, with obligations incorporated in the European Convention for the Protection of Human Rights and Fundamental Freedoms (hereinafter referred to as the "ECHR" or the "Convention").

The ECHR does not provide intricate medical concepts. Its drafters did not even thought about extending its scope to such specific sphere as medicine, which is quite comprehensible if not to forget that the Convention was adopted in 1950. The Convention contains general provisions on fundamental human rights. However, perception of the ECHR as "a living instrument" allows to interpret its provisions widely, and the European Court of Human Rights (hereinafter referred to as the "Court") played a specific role in developing and successful implementation of this concept.

However, before proceeding to the issue of how to use the ECHR for protecting the rights of those who had recourse to assisted reproductive technology, in particular, to AI, it is necessary to define some terms as AI is not but one of the techniques of medically assisted procreation.

The medical doctors often use the term of medically assisted procreation. A layperson may think that this is the same as the in vitro fertilisation, which is not quite right. Medically assisted procreation is a method of conception based on the manipulation of reproductive cells by medical personnel, in contrast to natural conception, and comprises both in vitro fertilisation (conceiving in vitro, in a laboratory, and introducing an embryo into the uterus) and AI (introducing the donor semen into the uterus). This article deals with the latter procedure.

AI is the simplest method of the medical assisted procreation which has been used for more than two hundred years. In 1785 the first case of successful human AI was documented. In the second half of the nineteenth century, several reports of human AI were published in France, England, Germany and the United States[1]. In 1899 I. I. Ivanov, a Russian scientist, was the first to develop the method, as we know today, in human medicine[2].

Despite the fact that the AI technique has been used for a long time and the domestic courts have had a number of opportunities to tackle this issue when settling disputes between private parties, on the international level such kind of disputes have been rare, and only a small number of cases relating to AI have been referred to the Court over the years. The Court is constantly extending its jurisdiction but is very cautious when it comes to the complaints about new medical techniques and medically assisted procreation and usually provides the States with a wide margin of appreciation on this matter.

According to the well-established case-law, the notion of "private life" is a broad one and does not lend itself to precise definition. This concept encompasses, inter alia, the right to establish and develop relationships with other human beings, the right to "personal development", the right to self-determination as such. It also encompasses elements such as gender identification, sexual orientation and sexual life and the right to respect for the decisions both to have and not to have a child[3].

As to the concept of "family life", it is not confined solely to families based on marriage and may encompass other de facto relationships. When deciding whether a relationship can be said to amount to «family life», a number of factors

[1] Agarwal A. and Allamaneni S.S.R. "Chapter 6: Artificial Insemination"// T. Falcone and W. Hurd (eds.), Clinical Reproductive Medicine and Surgery. Philadelphia: Mosby Inc., 2007, p. 539.

[2] Ombelet W., Van Robays J. History of human artificial insemination // F, V & V in ObGyn 2010; Monograph: 1 — 5, p. 3. URL: http://www.fvvo.be/assets/97/13-Ombelet_et_al.pdf (accessed: 29.06.2017).

[3] See the Court's judgment citing the relevant case-law: S.H. and Others v. Austria [GC], no. 57813/00, § 80, ECHR 2011.

may be relevant, including whether the couple live together, the length of their relationship and whether they have demonstrated their commitment to each other by having children together or by any other means[4].

The question arises whether the issues relating to AI are covered by the concepts of private and family life.

From the one hand, the answer is "yes". For example, in the case S.H. v. Austria the Court held that the right of a couple to conceive a child and to make use of medically assisted procreation for that purpose was also protected by Article 8, as such a choice was an expression of private and family life[5]. In the case Dickson v. the United Kingdom[6] the Court considered the issue of the refusal to provide the applicants — a prisoner and his wife — with facilities for AI. The Court found that the refusal of AI facilities concerned their private and family lives which notions incorporated the right to respect for their decision to become genetic parents.

From the other hand, in J.R.M. v. the Netherlands[7], where a donor requested to provide him with access to a child conceived with his sperm by AI, the Court held that "family life" implied close personal ties in addition to parenthood. In the case at hand, the applicant's contacts with the child had been limited in time and intensity (several months). Furthermore, the applicant had apparently not considered to make any contribution, financially or otherwise, to the child's upbringing. Thus, the applicant's contacts with the child, both in itself and together with his donorship formed an insufficient basis for the conclusion that as a result thereof such close personal tie had developed between them that their relationship fell within the scope of "family life".

Thus, the answer to this question depends on the circumstances of the case. It is likely, taking into account the extension of the Court's jurisdiction, that the complaints relating to AI will be covered by Article 8 or Article 8 taken in conjunction with Article 14 of the ECHR. Even if the Court does not qualify some issues arising out of relations between a donor and a child or between a child's parents as "family life", it will, most likely, consider them as an element of private life.

The following issues relating to the application of the AI technique have already come to the Court's attention: access to AI; relations between members of families with a child conceived via AI; confidentiality issues.

Access to AI

Nowadays AI is available for single women who want to have a child, same-sex couples or heterosexual couples affected by the man's infertility. This issue is governed differently worldwide: some legislators allow to use AI only to married couples (Germany, Switzerland, Hungary), in other countries this procedure is prohibited for use by homosexual couples (USA, Canada, Iceland, Estonia, Sweden, Belgium, Denmark, Spain and the United Kingdom allow homosexual couples to have recourse to AI)[8]. The above-mentioned restrictions are challenged in courts, in particular, in the Court.

In Dickson v. the United Kingdom[9] the Court considered the issue of prisoners' access to the AI. It held that this was an area in which the Contracting States could enjoy a wide margin of appreciation as, while the Court had expressed its approval for the evolution in several European countries towards conjugal visits, which could obviate the need for AI facilities, it had not yet interpreted the Convention as requiring Contracting States to make provision for such visits. Nevertheless, the policy on the issue had placed an inordinately high "exceptionality" burden on applicants for AI as they had to demonstrate both that the deprivation of AI facilities might prevent conception altogether and that the circumstances of their case were "exceptional" within the meaning of certain criteria. Despite the wide margin of appreciation provided to the States, the Court held that the restrictions prescribed by the domestic law went beyond the state's margin of appreciation. In fact, the English law stipulated a huge list of criteria to be complied with: the provision of artificial insemination facilities must be the only means by which conception was likely to occur; adequate length of imprisonment; consent of both parties and approval of the medical authorities; stability of relations; satisfactory domestic circumstances and the arrangements for the welfare of the child; evidence that AI would be in line with the public interest.

In Gas and Dubois v. France[10] the applicants were two French women who had been cohabiting and then had entered into a civil partnership. One of them gave birth in France to a daughter who had been conceived in Belgium by means of AI with an anonymous donor. The second applicant applied for a simple adoption order in respect of her partner's daughter, but her application was refused. The applicants maintained before the Court that there was a difference in treatment under the law depending on whether a couple raising children was made up of two women cohabiting or in a civil partnership or of a woman and a man in the same situation. The Court held that while French law provided that anonymous donor insemination was available only to heterosexual couples it also stated that it was to be made available for therapeutic purposes only. Hence, broadly speaking, anonymous donor insemination in France was confined to infertile heterosexual couples, a

[4] X, Y and Z v. the United Kingdom [GC], 21830/93, 22 April 1997, § 36, Reports of Judgments and Decisions 1997 II.

[5] S.H. and Others v. Austria [GC], no. 57813/00, § 82, ECHR 2011.

[6] Dickson v. the United Kingdom [GC], no. 44362/04, § 66, ECHR 2007 —V.

[7] J.R.M. v. the Netherlands (dec.), no. 16944/90, Commission decision of 8 February 1993, Decisions and Reports 74, p. 120.

[8] Donor insemination (DI), http://fertility.treatmentabroad.com/treatments/donor-insemination-di

[9] Dickson v. the United Kingdom [GC], no. 44362/04, ECHR 2007-V.

[10] Gas and Dubois v. France, no. 25951/07, § 63, ECHR 2012.

situation which was not comparable to that of the applicants. In the Court's view, therefore, the applicants could not be said to be the victims of a difference in treatment arising out of the French legislation in this regard.

In the case S.H. v. Austria the applicants challenge the prohibition under domestic law on the use of ova and sperm from donors for in vitro fertilisation. In its judgment the Court considered, inter alia, whether the prohibition on the use of donor sperm for in vitro fertilisation was justified, especially given that the law allows using donor sperm for AI? It turned out to be quite difficult to find the answer. The case was considered by a Chamber and then referred to the Grand Chamber. In its judgment[11] the Chamber held that the prohibition for use of the donor sperm for in vitro fertilisation was discriminatory while such use was allowed for AI. It held that in vitro fertilisation with donor sperm combined two techniques which, taken alone, were allowed, namely in vitro fertilisation on the one hand and sperm donation for in vivo conception on the other hand. It found that a prohibition of the combination of two medical techniques which, taken alone, were allowed, required particularly persuasive arguments. The only argument which, in the Chamber's view, was specific to that prohibition was that in vivo artificial insemination had been in use for some time, was easy to handle and its prohibition would therefore have been hard to monitor. Such an argument related merely to a question of efficiency, which carried less weight than the particularly important interests of the private individuals involved, and, therefore, the Chamber concluded that the difference in treatment at issue was not justified.

The Grand Chamber disagreed and considered that this issue must be seen in a wider context. The fact that the Austrian legislature, when enacting the law which enshrined the decision not to allow the donation of sperm for in vitro fertilisation, did not at the same time prohibit sperm donation for in vivo fertilisation — a technique which had been tolerated for a considerable period beforehand and had become accepted by society — was a matter of significance in the balancing of the respective interests and could be considered solely in the context of the efficient policing of the prohibitions. It shows rather the careful and cautious approach adopted by the Austrian legislature in seeking to reconcile social realities with its approach of principle in this field. In this connection, the Court also observed that there was no prohibition under Austrian law on going abroad to seek treatment of infertility that used artificial procreation techniques not allowed in Austria and that in the event of a successful treatment the law contained clear rules on paternity and maternity that respect the wishes of the parents.

In both judgments the Court considered the arguments in favour of the prohibition on the use of donor sperm for in vitro fertilisation submitted by the government, such as the risk of eugenic selection and problems stemming from the legitimate interest of children to be informed of their actual descent. Both arguments concern the sperm donation in general and the Court did not ground its decision on these arguments. At the same time, the

[11] S.H. and Others v. Austria, no. 57813/00, §§ 86—94, 1 April 2010.

Grand Chamber's judgment contains better reasoning than the judgment of the Chamber. It is more consistent with the Court's approach adopted when dealing with complex cases and when there is a lack of consensus among the States. In such cases the States should enjoy a wide margin of appreciation. The Chamber's argument according to which where a particularly important facet of an individual's existence or identity is at stake, the margin allowed to the State will be restricted, is not sufficiently reasoned. It is unlikely that the present case concerns "the individual's existence or identity". These two concepts refer rather, in the first case, to the right to life (the Chamber refers to the case of Evans v. the United Kingdom[12] relating to the embryos' right to life, their storage and use) and to a person's understanding of who he or she is (for example, transsexuality issue, the Chamber refers to Christine Goodwin v. the United Kingdom[13]).

Relations in families with children conceived via AI

After the birth of a child conceived via AI, new problems may arise, in particular, the issue of adoption, donor's right of access to the child, etc.

In its earlier case-law the Court made clear distinction between private and family life which limited the possibilities of protecting the relevant human rights. For example, in one of its earliest judgments relating to the adoption of a child conceived via AI by one of the women in de facto marital relationship, the Court held that this relationship did not fall within the scope of the right to respect for family life and, moreover, the law did not prevent the applicants from living together as a family. The positive obligation of the State did not go so far as to require that a woman such as the first applicant, living together with the mother of a child and the child itself, should be entitled to get parental rights over the child. As to the right to private life, it was respected as the statutory impossibility for the first applicant to be vested with the parental authority did not entail any restriction in the applicants' enjoyment of their private life[14].

In the case of Gas and Dubois v. France the Court did not find violation of Articles 8 and 14 due to the refusal to provide a simple adoption order. In their complaint the applicants' main argument was that they — a homosexual couple — had been discriminated and subjected to different treatment as compared to heterosexual couples who were married or in a civil partnership. However the Court disagreed with them. It held that they were not in comparable situation with married heterosexual couples. In examining the applicants' situation compared with that of opposite-sex couples who had entered into a civil partnership, the Court observed that the latter were likewise prohibited from obtaining a simple adoption order. Accordingly, the applicants had not been discriminated against on the basis of their sexual orientation. Moreover, the legal consequences of simple adoption would be contrary to the child's interests, given that the adoption would entail the transfer of parental responsibility to the adoptive parent while depriving the child's biological mother of her rights, despite the fact that she intended to continue bringing up her child. The last argument is particularly important. In dealing with cases involving children, the Court, first and foremost, establishes what is in the best interest of the child. The final decision is dependent on results of this assessment.

In the case of X, Y and Z v. the United Kingdom[15], relating to refusal to register post-operative transsexual as father of child born to partner by AI by donor, the Court analysed the disadvantages suffered by the applicants as a result of such refusal. The applicants alleged that the child would not inherit from his farther; she would be subjected to stress, in particular, when she would have to produce her birth certificate; the child's sense of personal identity and security within her family would be affected. The Court disagreed and held that, first, there was a possibility to make a will; second, it was unlikely that any stigma would be attached to the family if the name of the father was not indicated in the birth certificate; third, the child's non-biological father was not prevented from acting as a father in the social sense: he could provide emotional and financial support to the family and was free to describe himself as her "father", could apply for a joint residence order, which would automatically confer on him full parental responsibility.

Moreover, the Court held that it was impossible to predict the extent to which the absence of a legal connection between the father and the child in such specific situation would affect the latter's development. It reminded that there was uncertainty with regard to how the interests of children in this position could best be protected and the Court should not adopt or impose any single viewpoint. Given that there was no generally shared approach among the Contracting States in respect of transsexuality, the Court was of the opinion that Article 8 did not imply an obligation for the respondent State formally to recognise as the father of a child a person who was not the biological father.

The above judgments concern AI by an anonymous donor. The situation becomes more complicated if a donor is not anonymous. An anonymous donor knows nothing about the recipient and eventual pregnancies. When a donor knows a woman who wants to get pregnant, he may claim his rights in respect of the child. In the case of J.R.M. v. the Netherlands a homosexual couple asked the applicant to be a donor. After the birth, he had participated

[12] Evans v. the United Kingdom [GC], no. 6339/05, ECHR 2007-I.

[13] Christine Goodwin v. the United Kingdom [GC], no. 28957/95, ECHR 2002-VI.

[14] Kerkhoven and Hinke v. the Netherlands (dec.), no. 15666/89, 19 May 1992.

[15] X, Y and Z v. the United Kingdom [GC], 21830/93, 22 April 1997, §§ 48—52, Reports of Judgments and Decisions 1997 II.

in upbringing the child for several months, and then the mother refused him access to the child. The Court dismissed his application. As mentioned above, the Court held that the ties between the applicant and the child were not close enough. It further held that the situation in which a person donated sperm only to enable a woman to become pregnant through AI did not of itself give the donor a right to respect for family life with the child.

Confidentiality

This issue may be considered from two angles concerning confidentiality of information on donor and information on the fact of undergoing the procedure of AI.

In the recent years, a trend toward disclosing information on sperm donor has been recorded. In some countries, for example, in Germany, the legislative amendments providing for creation of a special registry containing information on sperm donor were approved[16].

The right to know one's origin has been developed in case-law of the Court (in cases not related to AI), which held in one of its judgments that respect for private life required that everyone should be able to establish details of their identity as individual human beings and that in principle they should not be obstructed by the authorities from obtaining such very basic information without specific justification[17].

In the case of Odièvre v. France[18], relating to refusal to divulge identity of biological parents and, in particular, the applicant's biological mother who wished to keep her identity secret, the Court held that such restriction of the right to access to information was acceptable. It emphasized that problem of anonymous births could not be dealt with in isolation from the issue of the protection of third parties, essentially the adoptive parents and the biological mother.

In theory, if the Court considers this issue in the context of AI, it will apply the same principles. It will weigh the right of the child to know his or her origin and the right of the biological father to ignore the existence of his child and "the right not to have a child" as the Court stated in the judgment Evans v. the United Kingdom, cited above (§ 90). Many countries provide in their laws that the donorship is anonymous and, in the light of the Convention as interpreted by the Court, the anonymous donorship is in line with Article 8, despite the modern trend — which has not yet acquired sufficient support — toward more openness in family relations.

There is another aspect of confidentiality issue in respect of AI, namely, the right to keep secret both the fact that a person had recourse to AI and information on a person's state of health. For example, in the case of Radu v. the Republic of Moldova[19], the Court held that disclosure by a medical institution to the applicant's employer of information on the applicant's recourse to AI and her state of health was unlawful. It noted that all the relevant domestic and international law expressly prohibited disclosure of such information and, in the applicant's case, no exceptions to this rule were applicable.

The analysis of the Court's case-law shows that it is quite difficult for an international court to resolve disputes in such specific area as medicine and, in particular, AI. In dealing with such disputes, the Court takes into account such relevant factors as particular circumstances of the case, a state of society in the Contracting States and existence of consensus on the relevant issue.

[16] Sperm donor anonymity to be lifted in Germany. URL: http://www.alliancevita.org/en/2017/06/sperm-donor-anonymity-to-be-lifted-in-germany/ (accessed: 05.07.2017).

[17] Gaskin v. the United Kingdom, 7 July 1989, § 39, Series A no. 160. See the review of the case-law on the right to know one's origin: Besson S. Enforcing the child's right to know her origins: contrasting approaches under the Convention on the Rights of the Child and the European Convention on Human Rights // International Journal of Law, Policy and the Family, Volume 21, Issue 2, August 2007, p. 137—159.

[18] Odièvre v. France [GC], no. 42326/98, ECHR 2003-III.

[19] Radu v. the Republic of Moldova, no. 50073/07, 15 April 2014.

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