

The attitudes of IVF patients treated in the Czech Republic towards informing children born after gamete donation

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Background. In recent decades gamete donation has received growing attention. Data from the Czech National Registry of Assisted Reproduction show that the number of cycles using donated oocytes has been increasing every year. According to Czech law, gamete donation is anonymous. Since 2011, some members of the Czech parliament have repeatedly made requests to revoke the anonymity but anonymity is one of the preconditions for such donation in this country. The aim of this study was to find out how the gamete recipients feel towards informing their child about the circumstances of their conception and their access to the identity of the donor.

Methods. A total of 195 recipients (122 women undergoing treatment - 43 Czechs, 79 foreigners (Western Europe and the USA) and 73 male partners - 28 Czechs, 45 foreigners) participated in this survey. The data were obtained by anonymous questionnaire.

Results. A significant difference between the attitude of the future Czech and foreign parents regarding disclosing the mode of conception was found ($P = 0.003$). The vast majority of Czechs were against disclosure. The foreign recipients were somewhat more divided. Regarding the donor's identity, there was no difference in attitude between the groups. Recipients rarely consider that the knowledge of the donor's identity will be important for their child. The recipients overall, were convinced that the psychological aspects of parenting are far more important to the child than genetics, and see no reasons for disclosing the donor's identity.

Conclusion. While the the foreign recipients were less adamant about non-disclosure, the overall finding was in accord with the current Czech law on anonymity and not in agreement with the proposed abolition. The recipient's attitudes towards disclosing were also culturally determined. The fact that some countries have revised their rules towards open identity is not a rationale for such change in the Czech Republic.

Key words: gamete donation, anonymity, open identity, parenting, donor's offspring

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INTRODUCTION

The number of births originating from donated gametes and embryos is on the rise, where there is no genetic link between the child, the father or the mother, or both¹. Due to women delaying motherhood, oocyte donation from healthy donors has become one of the most frequently used techniques². Data from the National Registry of Assisted Reproduction³ show that the number of cycles using donated oocytes has been increasing every year in the Czech Republic. In accordance with the most recent Czech Act on Specific Health Services (Act No. 373/2011 Sb.), only anonymous donation is allowed. All authorized clinics in which assisted reproduction is performed are responsible for maintaining the anonymity and the prospective parents of the child and the child will obtain only non-identifying information about the donor. Identifying information about the donor's record must be kept for at least 30 years following the use of gametes.

A very important ethical issue is the well-being of children born as a result of this treatment. Should these chil-

dren know about the way they were conceived? Do they have the right to know? Do recipient-parents have a duty to tell their donor-conceived child about their genetic origins? In the earliest days of sperm donation treatment, the common practice was to keep information about donor's identities confidential⁴. In the past few decades, knowing his/her genetic origin has been considered a child's right. Contributing factors to this are the increasing importance of genetics in medical decision-making, a change in social openness and an increased societal acceptance in the matter of reproductive donation. A growing number of countries have legislated for open-identity donation, in which donor-conceived offspring are given access to the donor's identity once the child has reached maturity^{5,6}. The first country to abolish donor anonymity and introduce a new law in favour of children's right to know the truth about his or her genetic makeup was Sweden in 1985. Other countries with a non-anonymous donation system are for example the UK, Germany, Norway, the Netherlands, Finland, Switzerland, New Zealand and Australia⁷.

In countries where anonymity has been abolished,

Table 1. The background characteristics of the recipients of donated gametes; P-values represents hypothesis testing based on Pearson Chi-square test.

Recipients characteristics	MC		FC		MF		FF		Totals together		P	
	n	%	n	%	n	%	n	%	n	%		
Age(years)	23 - 27	1	3.57	2	4.65	1	2.22	1	1.32	5	2.60	< 0.001
	28 - 32	9	32.14	17	39.53	6	13.33	6	7.89	38	19.79	
	33 - 37	7	25.00	6	13.95	6	13.33	15	19.74	34	17.71	
	38 - 41	3	10.71	9	20.93	15	33.33	24	31.58	51	26.56	
	42 - 45	2	7.14	5	11.63	6	13.33	12	15.79	25	13.02	
	46 - 49	3	10.71	4	9.30	5	11.11	18	23.68	30	15.63	
	50 - 53	2	7.14	0	0.00	0	0.00	0	0.00	2	1.04	
	54 and more	1	3.57	0	0.00	6	13.33	0	0.00	7	3.65	
	Answers available	28	100.00	43	100.00	45	100.00	76	100.00	192	100.00	
Education	Technical/Trade graduate	8	28.57	6	13.95	2	4.44	2	2.53	18	9.23	< 0.001
	High school graduate	11	39.29	24	55.81	9	20.00	7	8.86	51	26.15	
	College graduate	9	32.14	13	30.23	34	75.56	70	88.61	126	64.62	
	Answers available	28	100.00	43	100.00	45	100.00	79	100.00	195	100.00	
Marital status	First	21	75.00	34	79.07	34	75.56	49	64.47	138	71.88	0.308
	Second	7	25.00	9	20.93	11	24.44	27	35.53	54	28.13	
	Answers available	28	100.00	43	100.00	45	100.00	76	100.00	192	100.00	
Parental status	Have child	11	39.29	10	23.26	8	17.78	20	25.97	49	25.39	0.226
	Childless	17	60.71	33	76.74	37	82.22	57	74.03	144	74.61	
	Answers available	28	100.00	43	100.00	45	100.00	77	100.00	193	100.00	

parents are recommended to be open with their children and inform them about their conception using donated gametes⁸⁻¹⁰. Although disclosing the details of the child's conception is becoming more common, a significant number of parents delay the intention of disclosing or decide not to tell their child at all¹¹⁻¹³. In cases of anonymous donation, one of the reasons mentioned is the fact that the child cannot obtain any identifying information about the donor anyway^{14,15}. One found that a half of the parents who chose anonymous donation, had done so to maintain confidentiality¹⁶. Many couples who were determined to maintain secrecy, expressed fears of social stigma surrounding this method of conception¹⁷. Others wished to protect the offspring from potential negative consequences for the family^{7,18}. Not knowing the donor to help the children establish clear boundaries between everyone involved and avoid interference of the donor in the future parent-child relationship^{16,19}. A large group of parents believe that the psychological and social aspects of parenting are far more important to a child than genetics, as proven by some well-known psychologists about psychological deprivation Bowlby^{20,21}, Matejcek^{22,23}. As observed in some studies^{17,19,24} recipient-parents believed their decision - disclose or not disclose - to be in the best interest of the child.

In the Czech Republic, the ethical issues associated with the gamete donation have never been closely investigated. The aim of this study was to provide insight into who the IVF patients in the Czech donation program are and what are their opinions on psychological issues regarding gamete donation.

MATERIALS AND METHODS

Respondents

This study on recipients treated by donate gametes was performed in two Czech IVF centres between the years 2012 - 2015 and was based on an anonymous questionnaire. We decided to use a mixed research strategy; a combination of qualitative and quantitative questions to capture as much opinion from each side as possible. In addition to the basic socio-demographic aspects of the recipients, we focused on the ethical problems, especially on the issues connected with informing the child about their conception.

Participants

A total of 195 recipients participated in this study. Out of this sample, 122 were women undergoing treatment - 43 from the Czech Republic, 79 from foreign countries. The remaining 73 were partners of the patients - 28 Czechs, 45 foreigners. Although the questionnaire was given to both partners, more women filled it out than men.

Data gathering

An anonymous questionnaire with open and closed questions was designed. For the closed questions a simple scale which consisted of three choices: agree, don't know and disagree was used. The closed questions were focused on both the socio-demographic (non-identifying) characteristics of respondents (age, education, marital and parental status), as well as some ethical topics closely connected to gamete donation. The recipients were asked about their attitudes toward secrecy or disclosure of the method of conception towards the child, what type of

Table 2. The couple's main attitudes towards openness or secrecy concerning the mode of conception to the child grouped by gender and nationality. Male Czech (MC), female Czech (FC), male foreigner (MF) and female foreigner (FF) are considered; relationship was evaluated using Chi-square test.

Question	Answer	MC		FC		MF		FF		Totals together		P
		n	%	n	%	n	%	n	%	n	%	
1. Should offspring be informed about the circumstances of their conception?	Yes	5	17.86	4	10.00	16	35.56	29	40.28	54	29.19	0.003
	No	23	82.14	30	75.00	27	60.00	38	52.78	118	63.78	
	Don't know	0	0.00	6	15.00	2	4.44	5	6.94	13	7.03	
	Answers available	28	100.00	40	100.00	45	100.00	72	100.00	185	100.00	
2. Do you intend to tell to your child that he/she was conceived from donated gametes?	Yes	4	14.29	4	10.00	15	34.09	30	44.12	53	29.44	0.001
	No	23	82.14	30	75.00	27	61.36	35	51.47	115	63.89	
	Don't know	1	3.57	6	15.00	2	4.55	3	4.41	12	6.67	
	Answers available	28	100.00	40	100.00	44	100.00	68	100.00	180	100.00	
3. Is it important for your child to know who the donor is?	Yes	2	7.14	1	2.44	2	4.44	7	9.09	12	6.28	0.370
	No	26	92.86	38	92.68	42	93.33	70	90.91	176	92.15	
	Don't know	0	0.00	2	4.88	1	2.22	0	0.00	3	1.57	
	Answers available	28	100.00	41	100.00	45	100.00	77	100.00	191	100.00	

information should the child have access to – identifying or non-identifying – and whether they intend to inform their child about his/her origin. The open questions then offered space to justify the extent of the respondent's answer to the closed question. When filling out the questionnaire the respondents were guaranteed anonymity. The recipients and their partners filled out the questionnaires separately during their treatment at the clinic. This study was approved by the Ethics Committee of the Institution.

Data analysis

The basic socio-demographic data were collected - age, education, marital and parental status. The age, due to the anonymity was sorted into the following categories: a: 18-22 years, b: 23-27 years, c: 28-32 years, d: 33-37 years, e: 38-41 years, f: 42-45 years, g: 46-49 years, h: 50-53 years, i: 54 years and more for recipients. In accordance with the law of the Czech Republic only women up to 49 years of age can undergo IVF treatment, therefore the age scales h: 50-53 years and i: 54 years and more were created for men only. The education of the respondents was divided into three groups - technical/trade graduate, high school graduate or university degree, the marital status was formed of two groups - first and second marriage/relationship and the parental status was formed of two groups as well - have children and childless. The outcomes for each of the main attitudes were stratified by gender crossed with nationality (female – recipient of donate gamete (Czech-FC, foreigner-FF) or male – recipient of donated gamete (Czech-MC, foreigner-MF)). For assessing the attitudes and perspectives of the recipients a three point scale was used (agree, disagree and neutral or “don't know”).

The associations between the demographic factors were analysed using the Chi square test. All the statistical analyses were performed using the Dell Statistica programme, version 13 (Dell Inc. (2015)). A *P*-value < 0.05 was considered significant.

RESULTS

The socio-demographic characteristic of the recipients

The data are presented in Table 1.

The most prevalent characteristics among the Czech recipients were secondary education (49%), first marriage (78%) and childlessness (70%). The foreign recipients characteristics were higher education (84%), first marriage (69%) and childlessness (77%). The foreign recipients undergoing treatment with donated gametes were older than the Czech recipients (*P* < 0.001).

The recipients' basic attitudes towards disclosing

The opinions of the recipients on informing the child about their genetic origin, their intention to disclose and their opinions on the importance of donor's identity for the child are summarized in Table 2.

Question 1. Of all of the recipients responses (n=185), almost two thirds – 118 (64%), refuse to inform the child about the circumstances of his/her conception, 54 recipients (29%) were for disclosing and 13 recipients (7%) were hesitant. There was a significant difference between the Czech and the foreign couples regarding disclosing the mode of conception to their child, $\chi^2(6, n = 185) = 19.69, P = 0.003$. The vast majority of the Czechs (82% of men and 75% of women) thought that the child should not be informed about the circumstances of their conception, whereas for the foreigners this attitude was less pronounced (60% of men and 53% of women).

The opportunity to expand on their answer was taken by some of the recipients, especially by foreigners. Each respondent had the opportunity to express one or several motives. All the reasons were included in our analysis and each was rated separately. The qualitative data gave us a more detailed view of the reasons behind these recipients' decisions. In parentheses is cited how many Czechs (MC, FC) / foreigners (MF, FF) responded.

Out of the parents who chose to inform their child, the most cited reason by the Czechs was “the genetic uncertainty” (medical reasons). The child should know that he does not share genes with his parents due to possible future genetically conditioned diseases (2 MC, 3 FC/ 1 MF, 1 FF). Amongst the foreigners, the most cited reason was “the honesty in the parent-child relationship” (7 MF, 15 FF) and „to avoid a potentially detrimental effect due to secrecy within the family“ (6 MF, 9 FF), the second most cited reason was “the child has a right to know” (1MC/ 7 MF, 7 FF) and thirdly, “the correct formation of the child’s identity” (3 MF, 4 FF). Another described reason was “to avoid the risk of an accidental disclosure” (1 FC/ 5 FF, 5 MF). Some of them mentioned concerns relating to organ donation, blood testing or genetic profiling which might cause the information to be revealed in the future. Other reasons include “recommendations by the authority” (1 FF) and “to avoid the risk of consanguinity” (1 MC). Some felt that knowing about the conception would show the child “how wanted they were” (1 MF, 2 FF).

The most cited reason for not to inform was “the uselessness of such information” that is not at all important for child’s life (1 MC, 3 FC/ 2 MF, 3 FF). According to some recipients it could be harmful to the child to disclose the circumstances of conception because “such information could confuse the child and could complicate the formation of his/her identity“ their child would not feel ‘normal’ if they were told and they wanted them to have a normal childhood (1FC/ 4 MF, 5 FF). Some recipients admitted concerns about “the negative effect of disclosure on the relationship between the child and their parents”, in particular the non-genetic parent. They were afraid of weakening the non-genetic parent-child relationship (1 MC / 4 MF, 3 FF). Other recipients who are against telling the child also felt “the fear of social stigmatization”, because gamete donation in their country is not so socially acceptable (2MC, 2 FC/ 1 MF, 2 FF). Some emphasized “their own substantial contribution to the conception of the child“ (2 MF, 2 FF). One of the reasons against informing the child was the “religion” of the recipients (1FF). Unfortunately, only a minimal number of respondents substantiated their answers. The foreigners expressed their attitudes more often than the Czechs.

Question 2. Parents’ intentions to tell, mostly balanced with their general view of informing the offspring about their genetic origin. The Czechs (68%) were clearly in favour of not telling the truth to the child in the future whereas the foreign respondents were more open to disclosing the mode of conception, and 40% of them planned to inform their offspring in the future. There were significant differences between the Czech and foreigner recipients’ intentions to tell the child, $\chi^2(6, n=180) = 21.92, P=0.001$.

The respondents generally considered the time when they will explain the situation to their child. Most foreigners reported that they would begin “to explain to a child from infancy” (10 MF, 17 FF). The Czechs wanted to begin “to explain around puberty” (2 MC, 3FC). Some

recipients wrote that they would “explain when the child can understand” (5 MF, 10 FF) and others did not know when and how to explain to a child (3 MF, 5 FF).

Question 3. The recipients rarely considered that the knowledge of the identity of the donor is important to a child. The vast majority - 176 (92%) believe that it is not necessary for the child to know the identity of the donor. Only 12 recipients (6%) called for obtaining identifying information and 3 recipients (2%) were still unsure. There was no difference between the Czechs and the foreigners, $\chi^2(6, n=191) = 6.50, P=0.370$.

DISCUSSION

The practice of gamete donation has received growing attention due to an increasing number of individuals and couples who have resorted to gamete donation¹. Patients considering the use of donated gametes in fertility treatment have to face several psychological, social and ethical issues. Perhaps the most important of these is whether or not to inform the child of their genetic origin and whether disclosure really is in the child’s best interests. The findings from many studies show that one of the main reasons parents give when explaining why they chose to disclose is that they want to be honest with their child and that they feel that the child has the right to know about their origin^{13,14,18,25}. Many people consider the importance of knowing their own genetic origin in relation to the future health of the person concerned. Family history ignorance or accidental consanguineous marriage are thus usually overestimated^{26,27}.

According to several authors, providing identifying information about the donor is important in terms of developing the child’s identity²⁸⁻³⁰. But is genetics really the main creator of personal identity? And is missing identifying information about the donor vital for personal identity development? We found no study, in this context, describing what the meaning of “identity” is. There are many theories concerning identity which are often contradictory^{31,32}. A genetic-essentialist understanding of oneself and identity is misleading. It overstates an individual’s genetic makeup and downplays other factors that are critical in the development of identity, especially the role of the family, society and the environment³³. Another complicated term is “parent”.

In the Article 7 of the Convention on the Rights of the Child is mentioned: The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and as far as possible, the right to know and be cared for by his or her parents. Parenthood can be defined genetically (origin of gametes), biologically (pregnancy and birth) or psychosocially. The legal framework of the parenthood is related to each state’s legislation. Some countries consider a new layout of the birth certificates where all possible parents may be mentioned. Extensive research in the field of child developmental psychology, above all “attachment theory” of Bowlby^{20,21} and the “psychical deprivation theory” of

Matejcek^{22,23} clearly answer that psychosocial solid ties are crucial for positive child development.

There is no supporting evidence to the claim that a child needs to know the identity of the donor to create his/her own identity. Knowing one's donor is not in itself a necessary condition for healthy mental development and general well-being of the child³⁴. This is consistent with studies showing that children who do not know about their donor conception are doing as well as non-donor-conceived children in terms of general emotional, social and behavioural development^{17,35,36}. Likewise, other studies found no differences in the children's psychological well-being and the parent-child relationships between the disclosing and the non-disclosing families^{14,37,38}.

Our survey disclosed the attitudes of future parents on various aspects of "disclosure". Of all the recipients' responses (n=185), almost two thirds (64%) tended toward refusal to inform the child about the circumstances of their conception, less than one third (29%) were for disclosing and 7% were hesitant. There was a significant difference between the attitude of Czechs and foreigners, $P=0.003$. The vast majority of the Czechs (82% of men and 75% of women) thought that the child should not be informed about their genetic origin, whereas within the foreigners this difference was not obvious (60% of men and 53% of women). But there was no differences between the Czechs and the foreigners in disclosing of the donor's identity. Recipients rarely considered that the knowledge of the identity of the donor is important for a child. Only 6% of them called for obtaining identifying information.

Human sciences like sociology and psychology take reality as a socially conditioned phenomenon^{39,40}. However, there is not just one social reality as Ian Hacking reminds us³⁹. We are convinced that the current "disclosure trend" is culturally and socially determined and the decision about disclosure of the mode of conception is entirely up to the parents. The fact that some countries have revised their rules towards open identity is not the reason for such change in the Czech Republic. Reproductive tourism is growing, due to different conditions within countries, both financial and legal.

Concerning infertility treatment conditions, foreign patients are well informed about Czech legislation. It is their own decision, their own responsibility and their free choice to come for infertility treatment and gamete donation to the Czech Republic or to any other country offering anonymous gamete donation.

CONCLUSION

This survey showed that almost two thirds of respondents – 118 (64%), refuse to inform the planned child about the circumstances of his/her conception, 54 recipients (29%) were for disclosing and 13 recipients (7%) were hesitant. There was a significant difference between the Czech and the foreign couples regarding disclosing the mode of conception to their child, $\chi^2(6, n=185) = 19.69, P=0.003$. The vast majority of the Czechs (82%

men and 75% women) thought that the child should not be informed about the circumstances of their conception, whereas for the foreigners this attitude was less pronounced (60% of men and 53% of women). The recipients in this survey were predominantly convinced that the psychological and social aspects of parenting are far more important to the child than genetics and they can see no reasons for disclosing.

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