

QUALITATIVE RESEARCH IN REPRODUCTIVE MEDICINE: FROM DESCRIPTION TO ACTION

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Abstract: Assisted reproduction (ART), particularly that performed using donated gametes, increases the prospect of healthy babies being delivered to increasing numbers of people striving for parenthood. The psychosocial, ethical and legislative issues related both to the donation and receipt of gametes are perceived as extraordinarily complicated. In 2009, a research project aimed at mapping the issues was drawn up and implemented in the Czech Republic. The project should have provided material for consultation purposes, for the work of ethical and legislative bodies, and for better interdisciplinary and international communication in reproductive medicine. Work on the project was affected by several unforeseen events, particularly by the drafting and adoption of a new law on ART (to which the project was initially to have contributed material once concluded). The article describes the dynamic and structural changes occurring within the project due to drafting of the bill as well as the changes and consequences resulting from other circumstances related to the topic researched.

Key words: assisted reproduction; gamete donation; ethical aspects; action research; age limits; legislation; basic research

Introduction

Assisted reproduction (ART) increases the prospects of healthy babies being delivered to increasing numbers of people striving for parenthood. ART enables the manipulation of gametes; it is therefore possible to substitute any absent or low-quality cells with cells from healthy donor(s). Gamete donation allows people who could otherwise not become parents, including post-menopausal women, to have children (the oldest mothers have given birth at an age of about seventy). The psychosocial, ethical and legislative issues related both to the donation and receipt of gametes are perceived as extraordinarily complicated.

ART regulation differs greatly from country to country even within the EU. Sperm donation is perhaps the most widely accepted method within the donation program, but this is not the case everywhere (it is strictly forbidden in Italy for example). The donation of embryos is forbidden in Sweden, Germany and Austria. The most controversial method is egg donation; since the donor undergoes an operation as if she were a hospital patient, i.e.

she is treated with hormones that stimulate the creation of multiple eggs and the eggs are then removed under general anesthetic. Also the demanding nature of the procedure is one of the reasons some countries have forbidden it (e.g. Germany and Austria) or introduced such strict legislation that there is a shortage of donors (e.g. the UK).

Non-anonymous donation or “open identity” i.e. the right of the child, guaranteed in legislation, to know the identity of the donor has recently been introduced. This right can usually be asserted when the child reaches the age of adulthood. Initial research in this area is beginning to emerge. The findings are not unambiguous; some studies warn that this kind of “family secret” may have a negative influence on the parent-child relationship and support “open identity” (e.g. Scheib, Riordan, Rubin 2003; Freeman, Jadvá, Kramer, Golombok 2009), others warn of the potential harm to family relations caused by the addition of a third person or of a change in the donor’s motivation, and state that while the motivation of anonymous donors is altruistic, the motivation of non-anonymous donors is procreative. Also the impact of this kind of motivation on the part of the donor towards a child conceived in this way has to be taken into consideration (Janssens, Simons, van Kooij, Blokzijl, Dunselman 2006).

Where countries have age limits on access to ART, these limits refer to age limits for reimbursement by health insurance companies; the upper limit is usually 39-42 years for the woman. Only a few countries have age limits for those funding the cost themselves. Countries that have banned or restricted the availability of donation procedures do not need age limits because the limits are determined biologically. Countries with more widely available donation procedures are gradually introducing age limits, particularly for women (e.g. 47 years in Belgium and 45 years in The Netherlands).

In the Czech Republic, around 23 thousand series of in vitro fertilization treatment—IVF are performed each year (Řežábek 2011). The oldest “donating” procedure is sperm donation. Due to the emergence of new technologies that enable men who are on the margins of infertility to have a biological child of their own, the number of IVF treatments involving donated sperm is decreasing significantly. There are also few patients undergoing treatment involving donated embryos; at least one kind of gametes belonging to the couple being treated can be used in most cases. On the other hand, treatment involving donated eggs is increasing noticeably: in 2009, the number of series of treatments performed was 2208 in the Czech Republic; in 2010, the figure was similar at 2213, and in 2011, the number may increase to about 3800, based on estimates from the data for the first six months, (Řežábek 2011). Motherhood without medical intervention is exceptional for a woman over 40-42 years of age; this has been confirmed by extensive medical (CDC 2009), demographic (Leridon 2008) and economic (Chambers 2006) research; the considerable increase in the number of treatments involving donated eggs is a result of the postponement of parenthood. The same age limit for female donors was stipulated in both the previous law (valid until 30 March 2012) and the current law (valid from 1 April 2012) on ART in the Czech Republic: “Only a woman who has reached the age of 18 and has not exceeded the age of 35 years can become an anonymous donor.” However, the centers where egg harvesting is conducted prefer donors to be younger than the established age limit. Therefore young women who have yet to plan their own family often act as donors.

Context and design of the research

Legislation in the Czech Republic allows gamete donation and in this regard it is a very liberal country, allowing the use of donor sperm, eggs and embryos. Surrogate motherhood is another method of donation; it is also performed in the Czech Republic but there is no legislation on it. Donation is anonymous by law; the future parents of a donor-conceived child and the child are provided only with non-identifying data on the donor. Due to the wide availability of treatment using donated gametes, the Czech Republic is a very significant target country for foreign patients (Shenfield, de Mouzon, Pennings, Ferraretti, Andersen, de Wert et al. 2010); egg donation is the most popular procedure. The Czech Republic is sometimes perceived as a country that infringes children's rights because donation is anonymous. In 2010, the first two authors of this article began work on a three-year research project entitled "Gamete donation in assisted reproduction: psychosocial and ethical aspects". The aim of the project was to explore the psychosocial issues relating to gamete donation, particularly in relation to the factors influencing the patients' decisions, the development of the relationships of the parents and children born as a consequence of donation, and the donors' decisions. By achieving its basic goals, the project was to have produced new material for consultation services for patients (including patients from abroad) and donors, as well as material for the work of ethical and legislative bodies and better interdisciplinary and international communication in reproductive medicine.

The primary purpose of the project was to identify a whole spectrum of potential answers, i.e. mapping an area hitherto unresearched in the Czech Republic. We chose qualitative research procedures; the target group should have consisted of gamete donors, gamete recipients (patients) and the parents of children conceived in that way. We intended to ask all respondent groups for written statements, to share their experiences, opinions, attitudes and ideas on the relevant issues. We created several versions of a leaflet outlining the purpose of the research and asking for cooperation. The statement should have been relayed anonymously through a website referred to in the leaflet. The motive for selecting this method for acquiring the data statements was based on the research ethics (we consider the topic to be very sensitive) and on the research validity (due to the sensitive nature of the topic, it was necessary to allow the respondents to answer at a time and place of their choosing and to provide statements on what they considered important). The co-author of the project, a physician at an ART center, considered this to be a practical method of data collection; he had the feeling, based on direct contact with patients, that a considerable number of them would readily share their experiences.

At the time the project was being prepared (spring 2009), ART was regulated by Act No. 227/2006 Coll., i.e. it was a relatively new act. ART is an area with rapidly changing technologies and so the laws have to be updated frequently. But there were no indications that the law was to be amended in the foreseeable future. Nonetheless, as the title of our article suggests, sometimes situations develop in ways other than those anticipated by the researcher, however conscientious he or she may be. In the interests of logic, we will categorize the changes by type according to whether they are dynamic or structural; although, of course, they impact on each other.

Dynamic changes—from description to action

The authors had originally planned to undertake descriptive and static research in order to provide expert documentation for a future law and in order to predict the consequences of the potential changes in ART regulation. But in spring 2011, at the beginning of the second year of our research, the Ministry of Health, very unexpectedly, drafted a so-called package of healthcare measures, with the intention of adopting them before the end of 2011. The draft bill on Specific Healthcare Services (now Act No. 373/2011 Coll.) included new legislation on ART. At the same time, the Ministry of Labour and Social Affairs decided to review the situation on substitutive family care (SFC): it started seeking ways to allow the highest possible number of children in care to be placed with families, i.e. to encourage the optimum development of SFC. At the same time, the Ministry of Justice was finalizing preparations for the new Civil Code; we later discovered that the Civil Code also included essential references to ART and SFC. So achieving the goals of our project became urgent: if our goal consisted in providing documentation for regulating ART and for the work of different commissions and experts, we had to provide it immediately. We pondered whether it was legitimate for a researcher to extend the research to include aspects that were absolutely essential in terms of the way in which the situation was developing but that had not originally been planned and whether it was possible to make use of the research findings before they had been finalized and had been subjected to eternal review process. The decision was taken to include elements of action research (in accordance with Hendl 2005).

What should the age limits be for gamete donation?

The most substantial change in the bill on ART was the introduction of an age limit for women seeking treatment, Section 5:

ART may be performed on a woman aged up to fifty-five years at most, based on the written request of the woman and the man who wish to undergo the health care service together (wording from spring/summer 2011).

Until then, there had only been the recommendation set out by the Ethical Commission of the Section of Assisted Reproduction of ČGPS ČLS, suggesting that an upper age limit of 47 years should be applicable to women. In May (18 May 2011), *Mladá fronta Dnes* newspaper printed an article based on evidence from hidden camera recordings indicating that many Czech ART centers did not follow the recommendations and would even accept women who greatly exceeded the suggested age limit for treatment.

Motherhood at a higher age is made possible by intergeneration solidarity: by the transfer of high quality eggs from younger women to older women. The problem with becoming a mother at a later age has nothing to do with the technology or biomedicine per se, but with the social acceptance of the treatment and limits of the social setting within which it is offered. ART experts point out that the opportunities presented by infertility treatment may lead to a conflict of interest between the gamete donors, the couples being treated, donor-conceived children, healthcare centers and society (Dostál 2007). Is the suggested age limit

appropriate? A demographer and a pedagogue joined in the search for the answer to this question. We decided to set out in two directions: 1. Map the opinions and arguments of different groups of people, and 2. Make use of the analysis of the ethical and psychosocial context that was included in the original project and extend it. We had the following initial professional standpoints:

All couples and individuals have the basic right to decide freely and responsibly the number and spacing of their children and to have the information, education and means to do so; the responsibility of couples and individuals in the exercise of this right takes into account the needs of their living and future children, and their responsibilities towards the community (World Population Plan of Action 1974, Article 14(f));

The physician carries joint responsibility for the welfare of the child because of his or her causal and intentional contribution to the parental project (ESHRE 2007);

Removal of organs or tissue from a living person for transplantation purposes may be carried out solely for the therapeutic benefit of the recipient and where there is no suitable organ or tissue available from a deceased person and no other alternative therapeutic method of comparable effectiveness (Convention on Human Rights and Biomedicine 1997, Section VI, Art. 19).

The intermediate results of the analyses led us to the opinion that the limit was too high. We attempted to alter it. There was even an organization through which we could attempt this change: Adam ČR, a nongovernmental organization. Our standpoint was formulated in three stages. First we commented on the bill during the consultation on the draft (May 2011); then we sent the proposed amendments to the Chamber of Deputies (August) and finally also to the Senate (September). More advanced analyses led us to propose lower and lower age limits (May—49 years for the woman; August—47 years for the woman; September—45 years for the woman and the man). Several deputies and senators sent us e-mails stating that they had read our document or that they agreed with our proposals.¹

The act finally passed in an amended form in autumn 2011. The age limit for women was reduced to 49 years by a significant majority of deputies from across the political spectrum. We were probably the only ones to have attempted this change; this surprised us greatly because we were aware that there was relatively strong disagreement over the proposed age limit among the professional and lay public (and, as it turned out, also among the deputies) with the. But the disagreement was probably not strong enough to provoke any kind of reaction.

Abolish the anonymity of donation?

At the beginning of 2012 (year three of the research), the Ministry of Health called on the Commission for Reproductive Medicine (the project researcher and co-researcher were among

¹ The “Adam’s” documents can be found in Czech at the following website: <http://www.adamcr.cz/informacni-odbor/reprodukcnimedicina/etika/stanovisko-k-veku-zeny-pro-art>). We presented our intermediate analyses at conferences (COGI Paris 2011, ART Brno 2011) and in specialized articles (Konečná, Kučera, Suda 2012a, 2012b).

the members) to give its opinion on a deputy's proposal suggesting amendments to the law on ART passed a short time earlier (in force as of 1 April 12). The amendment concerned the introduction of non-anonymous donation in the Czech Republic. The analysis of the situation, based on our intermediate research findings and the findings of the research conducted by SFC (e.g. Konečná, Koubová 2011), which we also have a connection with, became the basis for the minister's rejection of the changes proposed by the deputy. In May of the same year, another similar proposal from another deputy arrived at the Ministry. The Ministry again used the same analyses and they were sufficient to explain the situation to that deputy as well. At present, a publication is being created for healthcare workers who come into contact with complicated parental situations; the publication brings together the issues relating to ART and SFC, explains the problems and draws attention to the myths (Konečná et al. 2012d). It is being published at the behest of the SFC project, which is also funding the cost.

And what about children?

The setting of the age limit at 49 years for the woman did not satisfy some of us; we still considered the limit to be high. Considerations relating to age limits always include those relating to the child's interests; these are also mentioned in documents dealing with ART ethics; they were even referred to in the discussions by the lay public and experts (see below). But as the interests of a child that has yet to be born cannot be explicitly measured, we decided to extrapolate from the interests of existing children. We extended the research group and the data collection methods (see below). At that time, we were invited by the European Society of Human Reproduction and Embryology to participate in formulating the professional position of the "Reproduction and Society" Task Force in April 2012. Much interest was expressed in our presentation of the pilot findings of our study; they are to be reflected in the wording of the mentioned document. The same pilot findings, in conjunction with other project findings, were used in the creation of the "Policy" document of Fertility Europe (FE), a European patient association, under the name of "Equality of Access to Medically Assisted Reproduction" (available on request from the FE secretariat).

Structural changes

We understand structural changes to be changes relating to the way in which the research is constructed and organized (research groups, methods of data acquisition and processing). The changes were prompted mainly by changes to the research context: as reactions to them. But one of the changes was also caused by our poor estimate of the potential for data acquisition.

Extending the research with another research group and another method of data acquisition

Having started work on the project in 2010, we received an unexpected offer: one of the authors of the project was invited to act as the main researcher in the qualitative part of a large three-year project mapping the SFC situation at the Czech "Centre for approaches

to SFC”, based on focus groups with foster and adoptive parents and with SFC experts. As gamete donation is often compared to adoption, it was agreed that the topic of “non-biological parenthood” should be included within the SFC project. The data was to have been acquired through the SFC project and processed as part of the research into the gamete donation. Both research teams, coordinated by Hana Konečná, anticipated that this research would lead to the fruitful addition of a new dimension. This was confirmed in the very first year of SFC research, involving the description and assessment of preparatory courses for SFC applicants, which focused on the issues concerning the development of a child-parent relationship where there is no genetic bond; the “open identity” system of ART also includes professional preparation for future parents and deals with the questions of how and when the child should be told the truth about gamete donation and how it should be further dealt with. The collaboration between the two projects has already been reflected in the very first two publications (Konečná, Koubová 2010 and Konečná, Koubová 2011).

Change to the originally planned methods of data acquisition and processing

In spite of our great efforts to motivate the respondents involved in the gamete donation research, several months into the first year, the results were poor. The physician—project co-author—distributed the leaflets, requesting participation in the research but there was no response. We analyzed the situation and looked for the causes of failure: Was the topic so unimportant that the respondents did not reply at all? Was the topic too sensitive and the respondents unwilling to discuss it? Was the method of acquiring the statements too “unstructured”, so that responding was too demanding psychologically and too time-consuming? Or was the lack of response caused by a general aversion to responding to any project? At that time, we discovered by accident that some colleagues were interested in conducting research in a similar area, but quantitatively and with an emphasis on the demographic characteristics of the respondents. We decided to join forces; our two-member team was expanded by three physicians from ART centers. We moved from a purely qualitative strategy to a mixed strategy. We prepared questionnaires with closed-ended and open-ended questions.

The closed-ended questions were focused on demographic, social and medical characteristics of the respondents (e.g. age, education, therapeutic procedure used) on one hand and on psychosocial topics (e.g. should the child be told about the donation?) on the other hand. The open-ended questions provided the respondents with space to substantiate or expand their answers to the closed-ended questions. We performed two pilot surveys with two different versions of the questionnaire but only the third version was satisfactory as a final version. At present (June 2012) we have about three hundred and fifty questionnaires; about a quarter each from the male donors, female donors, female patients and a quarter from their partners. More than half the female patients and their partners were foreigners. We will have concluded the data acquisition by the end of July and the analysis by the end of September. The strategy chosen seems to be good; the preliminary results are plentiful and interesting (for more details see e.g. Konečná et al. 2012c).

Further extension of the research to include other research groups and methods of data acquisition

Preparations for the new law on ART required that further research groups be included among the respondents and that the range of data acquisition methods be extended. In order to ascertain the opinions and attitudes of those proposing the law, the general public and others, we followed Internet discussions and chatrooms, talked with the deputies, and observed the debates in the Chamber of Deputies and in the Senate. The research into the attitudes of experts and the subsequent analysis constituted a natural part of the original project proposal. We would like to briefly point out here that we were very surprised by the fact that almost no-one mentioned the interests (protection) of the female donors and the ethical side of the donation.

Children as other respondents

For the reasons explained above, in the end we also included children and young adults in the research: with the help of a questionnaire with open-ended questions we ascertained what age they thought parents should be and why. The research was based on a representative sample of 1400 children and young adults aged between 12 and 25 (the upper age limit was determined by financial dependence on the parents; the respondents at that limit were university students). We were very careful not to influence the children's and young adults' answers in the way the questions were formulated or by explanations of the research context. The exact final wording of the questions was as follows:

Thanks to the technological progress of medicine, people can decide freely when to have children. Children cannot choose the age of their parents. But if you had a magic stick and could change the age of your parents, would you change it? How old would you want your mother (father) to be when you are 20 years old? Why? (For children and young adults aged over 15 we set the age limit at 25).

In spite of our expectations, we were surprised by the results of the quantitative analysis: 90% of children wished that their mother would be under thirty and 95% of children and young adults wished that their father would be under thirty-five. The diagrams showing the desired changes in the parents' ages achieved with the help of the magic wand as compared to the real age of their parents are linear and show that they are inverse in proportion: the older the parents, the younger the child made them. At present we are dealing with the qualitative analysis of the statements; we are encoding the types of substantiations, and we will subsequently perform the quantitative analysis as well. Of interest is the fact that even the children who responded that the parents' ages did not matter made their parents younger.

Decision not to approach one of the originally proposed research groups

The original plan involved approaching the parents of children conceived as a result of gamete donation and to ask them to describe their experiences in establishing and developing their relationship with their child, with whom they have no genetic bond. We wanted to send a letter enclosing the leaflet to successful ex-patients of the project co-author. We abandoned

this intention in the end for several reasons. One of them was our poor experiences with the success rate of data acquired in this way; our attempts to approach several of these parents confirmed our skeptical expectations. The second reason was that we had acquired statements of a similar type, but in a more extreme form, through the SFC research. And the third and main reason was that over the course of time we came to the belief that the acquisition of such data would be ethically and methodologically problematic; that, paradoxically, we could be the ones creating the problem (through the letter or question).

Final discussion

Working on the project provided us with a large number of ideas of 1) a methodological nature, 2) of a more specific psychosocial, ethical and philosophical nature 3) and of a more generally philosophical nature.

Methodological considerations

Our research procedure differed from the original proposal: we altered the data acquisition methods, by adding some respondent groups and removing others; and by adding other data processing methods (quantitative analysis was added to qualitative analysis). The way we processed the results changed markedly: originally, they should have been conveyed in the right format to the right places (professional publications) for subsequent practical use; but in fact, we first used the results in practice and only after that did we put them in the right format and publish them. However, the goals of the research did not change in the least. How substantial is the research project? Can the researcher modify it when the situation changes and when it turns out that other factors are in fact relevant to the selected topic and research goals? Our response on behalf of researchers is that the researcher can and must modify the project. We believe that the institution that provided us with the funding for the research project expected our research to make sense and that it assumed we would be able to make responsible and professionally erudite decisions. Our belief is supported by the institution's response: both intermediate research reports were accepted without reservation. What is the researcher's role? Should the researcher stand aside in an "objective", "impartial" position waiting for someone to express interest in his or her work and not enter the public space? Our response is clear from the steps we took: we would consider passivity to be cowardly and unprofessional. Is the researcher able to use or make available for use findings that have not yet been incorporated into the correct format that have not passed the external review process and therefore do not have the "weight" they should have? Our team of authors shares the belief that the researcher can and in principle even must; that the action research has been acknowledged as a valid alternative is proof of this (Hendl 2005). There is of course a risk that results processed under the pressures of time may not have the required validity.

Psychosocial-ethical-philosophical considerations

Both projects, ART and SFC, deal with very complicated questions: "Who can be a parent?", "Whose child is it?" and "What creates the parent relationship between the child

and the adult?" ART differs substantially from SFC in this respect. While SFC deals with the consequences of a situation that exists (resolving the situation of children with no one to look after them), ART is the physical cause of the situation: through the extracorporeal manipulation of gametes, it enables "parent" bonds to be created that would otherwise not be possible (particularly the separation between biological motherhood and genetic motherhood, e.g. in postmenopausal women; but parenthood by homosexual couples is included here too). The objection can be raised that there has always been extracorporeal manipulation of gametes to some degree and that most potential parent combinations have also existed (nobody can be procreated without sperm being released from the male body, and it occurs in the "usual" manner, without technological intervention). That is true, but manipulations of this kind (extra-partner manipulations) do not take place with the support of the system and under its direct assistance. The situation changes completely once reproductive technologies become involved—or more precisely once the legislation making them possible has been adopted: the system (society) no longer deals with the consequences but is directly involved in their emergence, thus it is directly responsible for the situation.

Society is responsible not only for physically enabling the situation to occur; society is also responsible for handling it (through the discourse set, as well as through the terminology and legislation applied). It is responsible for example for the value attributed to donation. For the authors of this article, donation is a demonstration of deep human solidarity with a suffering neighbor. Is the desire to have a child at an age when a person normally cannot have children the manifestation of the deepest human need? What influence do the media have in this regard?

Linking the research into gamete donation with the SFC research meant that both were enriched with further unexpected dimensions and contexts. It is only through linking the two research projects that it becomes evident that parenthood can be legal, biological, genetic and emotional; even intentional parenthood is referred to (a person who seeks a surrogate mother in order to have a child conceived in that way is the parent). The child may have up to five different sets of people who can be considered the child's parents (and these may not always be composed of a man and a woman)—that depends on the legislation of the country in question. Of course, the formation of the parent-child relationship is also dependent on the legislation; if the person who cares for the child does not consider him or herself to be a real parent, and if the child does not recognize the carer as a real parent and, forming the relationship will be more difficult and the stability and certainty of the relationship will probably be weakened. But certainty in a relationship is essential in forming the identity not only of the parent but also (and mainly) of the child; but this is a circular argument. Introducing open identity in ART and abolishing anonymous adoptions in SFC are attempts by the system to resolve the situation in some way: they allow the child to make decisions about his or her relationships (and about his or her identity). The advocates of "open identity" argue that meeting the donor is a decision based on the child's free will and that the child need not take this step (just as an adopted child need not look for his or her biological parents). But it can also be seen as shifting responsibility from the state to the child. If the child has been brought up knowing that he or she has thus far been missing a piece of his or her identity and that the piece will be made available at a specified time, then the child has a black box in his or her hands and cannot not open it. His or her decision-making autonomy

is a myth. We do not think that the child will be negatively affected by the meeting with the donor; however, we consider the many years of waiting (perhaps full of hope) a problem.

This complicated issue was the main reason we abandoned the idea of approaching the parents of children conceived as a result of gamete donation. We felt that by mentioning the problem in the leaflet, we would probably partly create it.

Philosophical considerations

The research project called “Gamete donation in assisted reproduction: psychosocial and ethical aspects” was implemented and is financially supported by the Czech Science Foundation. It supports “basic-research” projects. The Council for Research, Development and Innovations, a professional and advisory body in the Czech Republic, provides the following definition on its website:²

Fundamental (explorative) research—experimental or theoretical work aimed primarily at acquiring new knowledge on the most fundamental causes of phenomena and observable facts, without dealing with questions on the use and utilization of such knowledge,

with the following extended definition:

Basic research can be divided into pure basic research or explorative research undertaken in order to develop knowledge but without the need to relate it to economic or social benefit (not even in the long term) and without the need to make use of the findings in resolving practical situations and without the need to make the findings available to those who are responsible for applying scientific knowledge; applied basic research, conducted with the expectation of creating a broad knowledge base that will probably constitute the basis for resolving problems that have already been identified or assumed (currently or in the future) or for emerging opportunities of use.

The development of the relationship the parent has with the child and that the child has with the parent or the ethical and psychosocial context of newly emerging medical technologies in such a private sphere as the family can certainly be considered to be a basic research topic in the human sciences in the sense of “acquiring new knowledge on the most fundamental causes of phenomena and observable facts”. But can such a base of knowledge for future use be created if the phenomenon is partly created by the current context, by the current circumstances (things will probably be different in a moment)? Is it, under such circumstances, meaningful and ethical to conduct research “without the need to make use of the findings in resolving practical situations and without the need to make the findings available to those who are responsible for applying scientific knowledge” or, according to the extended definition, to be “the basis for resolving problems that have already been identified or assumed (currently or in the future)”?

We are in a closed loop: the potential research findings will emerge only after a certain phenomenon has been enabled, while the enabling of the phenomenon (e.g. in a legislative and organizational sense—the abolition of the anonymity of donation) should result from research findings.

² <http://www.vyzkum.cz/FrontClanek.aspx?idsekce=932>.

We conclude our reflections³ with a quote of Ian Hacking, a Canadian philosopher, who aptly summarizes our feelings:

I am concerned with the human sciences, from sociology to medicine, and they are driven by several engines of discovery, which are thought of as having to do with finding out the facts, but they are also engines for making up people (Hacking 1986; 1995).

References

- Centers for Disease Control and Prevention (2009). *2009 ART Clinic Data. ART – Successrates. USA*. Retrieved February 10, 2012, from http://www.cdc.gov/art/ART2009/PDF/ART_2009_Full.pdf.
- Chambers, G.M., Ho, M.T., Sullivan, E.A. (2006). Assisted Reproductive Technology Treatment Costs of a Live Birth: An Age-Stratified Cost–Outcome Study of Treatment in Australia. *Medical Journal of Australia* 184 (4), 155–158.
- Dostál, J. (2007). *Ethical and Legal Aspects of Assisted Reproduction. Situation in the Member States that Joined the European Union in 2004*. Olomouc: Univerzita Palackého. ESHRE (2007). Task Force on Ethics and Law 13: The Welfare of the Child in Medically Assisted Reproduction. *Human Reproduction* 22 (10), 2585–2588.
- Freeman, T., Jadvá, V., Kramer, W., Golombok, S. (2009). Gamete Donation: Parents' Experiences of Searching for their Child's Donor Siblings and Donor. *Human Reproduction* 24 (3), 505–516.
- Hacking, I. (1995). The Looping Effects of Human Kinds. In D. Sperber, D. Premack, A.J. Premack (Eds.). *Causal Cognition – a Multidisciplinary Debate*. Chapter 12, pp. 351–383. Cambridge: Harvard University.
- Hacking, I. (1986). Making up People. In P. Heller, M. Sosna, D. Wellberry (Eds.). *Reconstructing Individualism*, pp. 222–36. Stanford University Press.
- Hendl, J. (2005). *Kvalitativní výzkum*. Praha: Portál.
- Janssens, P.M., Simons, A.H., van Kooij, R.J., Blokzijl, E., Dunselman, G.A. (2006). A New Dutch Law Regulating Provision of Identifying Information of Donors to Offspring: Background, Content and Impact. *Human Reproduction* 21 (4), 852–6.
- Konečná, H., Kučera, T., Suda, S. (2012a). Upper Age Limit for Access to Assisted Reproduction: Is it Evidence Based or Is It a Never-Ending Discussion? In Z. Ben-Rafael, B.C.J.M. Fauser, R. Frydman (Eds.). *Proceedings of the *14th World Congress on Controversies in Obstetrics, Gynecology and Infertility (COGI)*, 45–50. Italy: Monduzzi Editoriale.
- Konečná, H., Kučera, T., Suda, S. (2012b). Jak příprava zákona otevřela další stránky a zdroje dat zkoumané problematiky aneb Do kolika let je možné umělé oplodnění? In M. Petrjánošová, R. Masaryk, B. Lášticová (Eds.). *Kvalitativní přístup a metody vo vědách o člověku: Diverzita v společenských vědách*. Bratislava: Slovenská akadémia vied. In print.
- Konečná, H., Rumpíková, T., Dostál, J., Mardešić, T., Rumpík, D. (2012c). Interdisciplinarita a smíšený výzkum – prohry a výhry ve výzkumu dárcovství gamet. In M. Petrjánošová, R. Masaryk, B. Lášticová (Eds.). *Kvalitativní přístup a metody vo vědách o člověku: „Diverzita v společenských vědách“*. Bratislava: Slovenská akadémia vied. In print.
- Konečná, H. a kolektiv SNRP (2012d). *O náhradní rodinné péči trochu jinak*. Praha: SNRP. In print.
- Konečná, H., Koubová, L. (2011). Kvalitativa jako prostředek evaluace efektu povinných vzdělávacích kurzů pro rodiče nemající genetickou vazbu k dítěti. In M. Šucha, M. Charvát, V. Řehan (Eds.). *Kvalitativní přístup a metody ve vědách o člověku X. Vybrané aspekty teorie a praxe*, 168–176. Olomouc: Univerzita Palackého.

³ This work was supported by GAČR P407/10/0822 grant.

- Konečná, H., Koubová, L. (2010). *Monitoring příprav na náhradní rodinnou péči v České republice. Popis současného stavu*. Praha: Středisko náhradní rodinné péče.
- Leridon, H. (2008). A New Estimate of Permanent Sterility by Age: Sterility Defined as the Inability to Conceive. *Population Studies* 62 (1), 15–24.
- Řežábek, K. (2011). Data z Národního registru asistované reprodukce (NRAR) za rok 2010. 21. *Symposium ART*, Brno, 8.-9.11.2011.
- Scheib, J.E., Riordan, M., Rubin, S. (2003). Choosing Identity Release Sperm Donors: The Parents' Perspective 13–18 Years Later. *Human Reproduction* 18 (5), 1115-1127.
- Shenfield, F., de Mouzon, J., Pennings, G., Ferraretti, A. P., Andersen, A. N., de Wert, G., Goossens, V., ESHRE Taskforce on Cross Border Reproductive Care (2010). Cross Border Reproductive Care in Six European Countries. *Human Reproduction* 25 (6), 1361-1368.

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