Ethical opinions and personal attitudes of young adults conceived by in vitro fertilisation

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ABSTRACT

Background: Today in vitro fertilisation (IVF) is a widespread and important technique of reproductive medicine. When the technique was first used, it was considered ethically controversial. This is the first study conducted of adult IVF-offspring in order to learn about their ethical opinions and personal attitudes towards this medical technology.

Methods: We recruited the participants from the first cases of in vitro fertilisation in Germany at the Gynaecological Clinic of the University Hospital Erlangen. Our qualitative interview study consisted of in-depth, face-to-face interviews with 16 adults who had been conceived by IVF. Our data was analysed with methods of Grounded Theory.

Results: For these adults, the most important factor influencing their personal attitudes towards IVF was the knowledge that they were deeply wanted children. The artificiality of their conception seemed irrelevant for their ethical opinion. All participants mentioned that it was important for them to be informed about the circumstances of their conception by their parents.

Conclusions: IVF seems to be a medical technique which, although it affects intimate aspects of human existence, can be integrated into the lives of the affected persons without any great difficulties. The findings suggest that parents should inform their children about their fertilisation at an early age and as part of a process over time, not only on a single occasion. Physicians should advise IVF-parents accordingly.

In 1978 the first report appeared of the successful birth of a test-tube baby, Louise Brown. Since then, in vitro fertilisation (IVF) and other artificial reproductive technologies (ART) have achieved widespread acceptance and have become routine medical procedures. In the last 28 years probably more than 3 million babies have been born by means of ART.

Early on, the social, ethical and legal aspects of IVF were widely discussed, and diverse warnings were expressed concerning the dangers to children, parents and society. However, the majority of existing studies of IVF children could show neither physical nor psychological dysfunctioning in the children. Moreover, school achievement, psycho-social functioning and the parent-child relationship were usually within normal limits.

To date there has been no follow-up study of IVF-offspring who are adults today. Moreover, within the ethical debate, the opinions and personal attitudes of the directly affected were never heard. Although initially, the public was warned against the consequences of this completely new dimension of technical intervention into human reproduction:

Here we approach the deepest meaning of in vitro fertilisation. … With in vitro fertilisation, the human embryo emerges for the first time from the natural darkness and privacy of its own mother’s womb, where it is hidden away in mystery, into the bright light and utter publicity of the scientist’s laboratory, where it will be treated with unswerving rationality, before the clever and shameless eye of the mind and beneath the obedient and equally clever touch of the hand.

Pope Benedict XVI, then Josef Cardinal Ratzinger and Prefect of the Congregation for the Doctrine of the Faith of the Catholic Church, emphasised the negative consequences for the individual and society, too:

In reality, the origin of a human person is the result of an act of giving. The one conceived must be the fruit of his parents’ love. He cannot be desired or conceived as the product of an intervention of medical or biological techniques; that would be equivalent to reducing him to an object of scientific technology. No one may subject the coming of a child into the world to conditions of technical efficiency which are to be evaluated according to standards of control and dominion.

Other authors discussed ethical concerns with reference to the personal, especially psycho-social wellbeing of the children: “The new reproductive technologies may jeopardise the psychological and social welfare of the children who result from them. […] These children will view themselves as manufactured products, rather than distinctive individuals born of love between a man and a woman.”

In this study we were not primarily interested in psycho-social aspects of these questions, but in ethical and normative matters. For the first time, we interviewed young adults born in Germany in the 1980s with the aid of IVF about their ethical opinions and personal attitudes. What are their personal attitudes towards IVF? Which individual, possibly identity-defining experiences have they had due to the fact that they were conceived with IVF? How did people around them react? In view of the ethical debates at that time, we also confronted them with the concerns mentioned above. How do they—as directly affected individuals—themselves assess the potential risks of IVF mentioned above? When and under what circumstances did they learn of their IVF? How did they experience the occasion on which they learned about it? What would they advise IVF parents today? What responsibility does the doctor have in this respect and how should he/she advise parents-to-be?
METHODS

Participants
In Germany IVF was successfully carried out for the first time in 1982 at the Gynaecological Clinic of the University Hospital Erlangen. Thus, we were able to contact the very first IVF families in Germany, who were also among some of the first worldwide. The participants in our study had to be older than 18. For that reason we researched the clinic’s medical records for all of the IVF patients with documented successful childbirths from 1982–6. After researching the current postal address, we wrote to these former patients and asked about their willingness on principle to participate in the study and if they would allow us to contact their now adult children. We telephoned the mothers who had declared in writing their willingness to participate. If they gave their consent, they and also their children were informed in detail about the study. Otherwise no further contact took place (see table 1).

Interview appointments were set up with the families at home. Here we report exclusively on the interviews with the children. Before the beginning of the interview we informed the participants once again about the content and purpose of the study and potential risks, and the participants gave their written consent to the participation. The research ethics committee of the Medical School, University of Erlangen-Nuremberg saw no ethical difficulty in carrying out the study.

Procedures
The data was collected by means of face-to-face, in-depth interviews. All interviews were conducted by a 25-year-old medical student (SS), who was supervised by an experienced psychiatrist and medical ethicist (JV). The small difference in age and the similar social status of the interviewer and the interviewee was intended to encourage the interviewee to feel trusting and comfortable. The interviews lasted between 30 and 60 minutes and were tape recorded. Afterwards the recordings were transcribed word-for-word and were submitted to a complete data check. For the analysis we used the software ATLAS.ti V.5.0 (Berlin, Germany).

A half-structured interview guideline served as basis for the interviews. As we were especially interested in the ethical opinions and personal attitudes of the interviewees and due to the lack of specific concepts in that field the guideline was initially oriented on the research questions specified above.

During the interview we first asked open questions to avoid suggestive influences from the interviewer and gain individual opinions from the interviewees in their own words. In a second part of the interview we confronted them with concrete objections and ethical arguments against IVF and wanted to know their personal attitudes. Examples for questions from the first and the second part of the guideline were: “What significance do you think being an IVF child has for you?” and accordingly “Some scientists for example stated, that test tube babies would view themselves as manufactured products. What do you think about that?” Apart from that the questions were posed in the order of appearance in the conversation, and follow-up questions and explanations were built in directly.

The data acquisition ended when gathering more information would not lead to any significant content refinement or contribute to any further development or differentiation of the analysed concepts (theoretical saturation).

Data analysis
Qualitative methods are especially suited to the empirical investigation of personal attitudes, assessments, values and intuitions. We used the techniques of “grounded theory” as an established method of qualitative research for analysing our data. It enables a rapid generation of well-founded new insights for research objectives that until now have been empirically studied to a small extent or not at all. The data analysis started after the first interviews had been conducted.

To analyse interviews using the grounded theory techniques, preliminary categories and concepts are established at the start of the data analysis. This “open coding” is done by intensively investigating the material, and making summaries and comparisons. These first theoretical results were scrutinised on the basis of the next interviews. Then, by combining the preliminary concepts on the basis of a paradigm, new relationships are created (axial coding) and new categories are developed to close the remaining theoretical gaps. Finally, the validation of the relationships takes place as well as the further refinement and development of individual categories on the basis of the data material (specific coding). In this way, the coding scheme was revised and refined over the entire course of the study.

For instance, one of the interviewees stated: “I think I was just a normal kid. It’s not like I had three eyes or two noses or something like that.” During open coding we named this passage “to be normal”. In the course of axial coding we expanded this concept “to be normal” with, for example, specific dimensions of “to be normal”, such as “not to be deformed”. Next, in the specific coding step “to be normal” and its subcategories were refined using further text examples, and we tried to embed this concept on the basis of a story line into a larger overall concept such as “identity”.

An interdisciplinary working group Qualitative Methods, consisting of a psychologist, a sociologist, a physician and several doctoral candidates evaluated the results. To ensure that the concepts we developed were always firmly anchored in the data material, these were presented, discussed and checked at regular intervals. The aim was to achieve consensus referring to the concepts, their relationships and the assignment of the quotations.

RESULTS

Participants
Out of 39 answered letters 18 families stated their willingness in principal to participation. In the end for this study we interviewed 16 young adults aged 19 to 21 years; these included one set of twins and one set of triplets (see table 1). Additional demographic data regarding the interviewees are listed in table 2.

In the following section we exemplify the major concepts we developed from our data material. The most important properties and conceptual aspects of our results are presented by citing characteristic data material.

Knowledge of being a wanted child
The central aspect that marked the attitude of our participants to IVF was the knowledge of being a deeply wanted child:

Table 1 Participant response to letters inviting IVF families to the study

<table>
<thead>
<tr>
<th>Total births after IVF-treatment 1982–86</th>
<th>63</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid addresses</td>
<td>48</td>
</tr>
<tr>
<td>Answered letters</td>
<td>39</td>
</tr>
<tr>
<td>Interest in participation</td>
<td>18</td>
</tr>
<tr>
<td>Interviewed families with children</td>
<td>13</td>
</tr>
</tbody>
</table>

IVF, in vitro fertilisation
Because I think as a child one can be proud of it, when the parents, well, it really is a strenuous process. Not every child can say that he or she was definitely a wanted child. (S202)

These now adult children knew that they were deeply wanted because their parents had undergone IVF treatment. Intuitively, this IVF treatment of the parents was appreciated and evaluated positively. First, they argued that IVF technology enables childless couples to fulfil their longing for a child. Second, according to the interviewees, it is a planned procedure and therefore definitely something intended. It was expressed like this:

Yes, spontaneous pregnancy—well, that happens. And IVF is of course somehow simply a planned thing. If you can’t conceive a child by natural means and then you go the way of IVF, then you of course want a pregnancy to happen. Well, it’s natural, it’s planned. It’s what you wish for. Well, that’s what it is, isn’t it? It’s called ‘wished-for’ child. (S203)

Third, in the context of this treatment the parents had to undergo a lot, which shows the priority of the wish for the child (and thus the priority of the child). One of the interviewees formulated it like this:

Yes. Therefore, my parents deeply wanted a child, no matter what, otherwise they wouldn’t have tried it so many times. That I know. (S205)

From this perspective, the interviewees were not able to comprehend the ethical concerns brought against IVF:

Uh-uh. (shaking head negatively) Not at all. Well, I’d say, if people now, well if that would happen to me, somebody would say, strange, how can you live with that or something like that. If I heard such remarks, uh, then I would say, that person, uh, doesn’t perhaps know, uh, I’d say, the meaning of life, you know? Because, I mean, it’s a beautiful thing if this way you can give a child a life, isn’t it? And if you don’t have any other possibility of doing it. If such remarks came I would know how to defend myself. In any case. But it has never happened to me (pause) that anyone ever looked askance at me or made any comments. (S208)

Often these ethical concerns seem outdated:

Interviewer: “Well, it was conjectured that the children would have to fight against societal prejudices.” - Interviewee: “Yes, well. Maybe it used to be like that. But in the meantime I don’t think there are prejudices any longer.” (S203)

When the interviewees were confronted with moral arguments, these were not seen as applicable:

Interviewer: “I’ll make a few assertions and you give me your opinion on them. “IVF children could see themselves as a product.” - Interviewee: “You’re always the product of something, aren’t you? See myself as a product? True, I’m the product of my parents, sure, what of it, every child is, don’t you think? Is it negative to be a product?” - Interviewer: “It’s hard to cope with being somehow technically created and planned. It’s so mechanical.” - Interviewee: “Mechanical? (laughter) I cope quite well just for that reason, that my parents really wanted me. And because I don’t think of that as artificial, but more like ‘a little help from my doctors’. Next assertion.” - Interviewer: “The process of fertilisation takes place in the bright light of a laboratory, in a Petri dish.” - Interviewee: “And because of the cold Petri dish I’m supposed to have a cool relationship to my parents. That’s not true at all, I would say. And because I was shaken in the test tube I probably have an aversion to test tubes.” - Interviewer: (laughter) “Yes, for instance.” - Interviewee: “That must be the reason why I dropped out of studying chemistry! A light bulb just came on.” (S202)

Lack of interest versus pioneers

We investigated whether, apart from the knowledge of being a deeply wanted child, there were any other specific dimensions of being conceived through IVF that were of any relevance for the IVF children. Did IVF have any impact on their identity or perceptible influence on their life? Does being conceived through IVF have any relevance for their own actions? In this context two types of judgments were exhibited:

Some interviewees stressed that for themselves (aside from the fact of being a wanted child), IVF was relatively insignificant. There was a genuine lack of interest in the circumstances of their fertilisation:

I never thought about it (laughter). To me, I don’t seem to be different, I believe. And now I don’t often think about it. Or really I don’t think about it at all. (S206)

Other interviewees were conscious of their own status as social pioneers and therefore emphasised the specialness of being one of the first test-tube babies in Germany:

Well, when I think about it, there is something special about it. Because of being one of the first test-tube babies. But I really don’t feel special because of it now. I actually feel normal. (S204)

Practical relevance: context of the disclosure

In many cases, the child could not remember the concrete occasion when he or she learned about being conceived with IVF assistance. The IVF of the parents was a part of their parents’ life, and while it was met with certain interest in this context, it was ultimately not considered important for their own life:

Interviewee: “I actually knew all about it from the beginning. They told me the whole story, I grew up with it. For us it was never a taboo topic and actually I was informed about everything that happened.” - Interviewer: “Can you still remember the conversations in which you talked with your parents about this?” - Interviewee: “They weren’t real conversations, but it was simply that in the course of time I understood more, I realised more. I’ve known about this since I was little. I can’t remember a...
specific conversation where they announced, ‘Now we have to tell you something’. It was simply quite normal for us.” (2210)

All participants mentioned that it was crucial for the parent-child relationship that the parents should be the first to inform their child at the earliest possible time and that the child should not be informed by a third person about the circumstances of the conception.

DISCUSSION

Our study supplies the first systematically collected, empirical findings on how IVF is judged and perceived by IVF-offspring. Here, of course, we could only speak with those who had been informed about it, which could not be taken for granted in the early years of IVF. The socio-demographic data of the families (education, vocation, place of residence) do not give any indication of higher than average education or social status of the families. Any possible bias is mitigated in that we did not make any representative assertions in our qualitative study. In contrast to quantitative studies, the aim of this qualitative study was to explore complex values, judgments, identities and social relationships with respect to IVF based on empirically gained and systematically evaluated data from the affected persons. The quality of such a study is not determined by its representativeness or by the size of the random sampling, but rather by the theoretical saturation, intensity and traceability of the performed analysis.22 24 25

In the sometimes very personal and intensive interviews with the first generation of now adult IVF-conceived children, the knowledge of being a wanted child plays an important role. We found plausible causes for the self-perception as wanted child in the fact of IVF-conception itself and the awareness of the great desire of their parents to have a child.

The ethical arguments mentioned above against IVF and the expressed fears of harm to the IVF-child were not supported by the information obtained during our interviews.7 8 20 21 Often these arguments were considered to be antiquated, outdated, or simply incomprehensible. To our interviewees, being conceived in a laboratory was unproblematic, both for their own identity and for their relationships with others, including their parents. Overall, how they were conceived seems to play a very subordinate role in contrast to their lifelong relationships with their parents. The interviewees could not report any negative social effects. On the contrary, some felt that being conceived through IVF made them special in the positive sense.

The results of our study indicate that, from the point of view of the adult children, the knowledge that they were conceived through IVF was quickly integrated into their self-concept, without any major negative effects. We found that IVF tends to have a positive, strengthening influence on the inner cohesion of the family and the parent-child relationship even after the adolescence of the children. Overall, however, the IVF conception of our interviewees had a more subordinate significance for their lives, as many lively and authentic quotations support.

Finally, our findings provide health professionals involved in the care of ART families for the first time with empirically based information and guidance on how the topic should be handled within the family. Without exception, all of the young adults we interviewed endorsed an open, taboo-free handling of the topic of IVF within the family. Most parents told other people close to them about their IVF treatment.22 For all our interviewees it was important that they learned about this topic through their parents and not through a third person. IVF, they stated, should be embedded early on in the life context and should be experienced as a really normal chapter of a family history. Children should be informed about their IVF conception as a matter of course and in a manner appropriate to their age. Many interviewees could not recall one single disclosure conversation, but said that they had always known about it. Experts and lay organisations recommend to provide the information continuously and in a way suitable for children, such as through picture books and stories.26 31 IVF parents-to-be accordingly could be advised accordingly.

Acknowledgements: We thank all participating families. We dedicate this study to the memory of the late Professor Siegfried Trottmann, MD, a pioneer of IVF in Germany.

Competing interests: None.

SS conceived the study, planned the interviews, conducted the field work, analysed and interpreted the data. He wrote the article and saw and approved the final version.

DD helped in acquisition of data and contacting the families. He commented on a draft of the article. He saw and approved the final version.

JV designed and supervised the study and helped analyse the data. He wrote the article and saw and approved the final version.

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