

## **Long term consequences of infertility – are there any?** **By Professor Johanne Sundby , Norway**

Background:

- It is normal to want to have a child or two...
- Infertility is caused by bodily malfunction, it is a disability and maybe even a disease
- Some of the pain of infertility and childlessness is due to the fact that family life is still very much the norm, even if single/career options are there
- In most industrialized as well as developing countries the prevalence of infertility is between 2 and 10 % of all women – because the woman is the measurement unit
- Is the prevalence of infertility increasing? There is no substantial evidence that there is a numerical increase, but.....
- A higher proportion of infertile couples do seek care
- There is a lower tolerance towards using time to become pregnant – people seem to "order" pregnancies at the right time.
- More women get educated, live single lives, wait and see, and panic when the biological "clock ticks" faster than their plan to settle.....
- The psychological and social and medical aspects of infertility is well researched.
- The infertility crisis is described and also used in lobbying for access to treatment
- More people than ever have access to modern ART in industrialized countries

Long term knowledge is lacking:

- How long do people cope with being an infertile couple under treatment?
- Does the infertility sadness and depression continue after medical treatment?
- Do people divorce more often after infertility experience?
- Do infertile couples get their sexuality back?
- Do they need therapy?
- How many get children after treatment cycles?
- How many resort to adoption?
- How many accept to live childless?
- For those who get children, are there any special conditions around their child relationships?

A few older infertile women (age 75-80) interviewed:

- In such interviews, the women emphasize that they have experienced the problem, but there were no viable solutions at the time when they were young. So they remained childless, but have quite vague memories about any trauma. They have created meaningful lives out of what they had. Good marriages continued, a few had good careers as teachers, nurses, even one poet. It was just "one of those things that happened in life".

Long term (7 years) follow up of infertile women, 1988:

- Before IVF, I conducted a 6-7 year follow up of 366 infertile female patients treated 1982. 40 % had given birth to a child. ¾ lived with a child, meaning that 30 % had adopted. Most (80%) lived with the same partner still.
- 2/3 of the women reported that infertility had been a major social and personal trauma at the time of investigation
- Scores on four different mental health instruments (Impact of event: avoidance, intrusion; GHQ; Eysenck), were not any different than reference values for these instruments.
- Determinants of difference in mean scores were: divorce, adoption, low education, time since investigation (intrusion only), while outcome (child) did not pay a significant role.
- A few infertile women are identified as "cases" on psychological instruments – they are more often divorced and more often have short education. They are inherently more vulnerable to life events like infertility, and continue to suffer the consequences.
- Adoption parents score less on psychological problems, maybe because of the selection mechanism to be allowed adoption.

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Long term follow up after IVF; (8 years) 2005, men and women

- I have conducted postal interviews with a random sample of former IVF couples, men and women separately, treated 8 years ago.
- Response rate lower than in 1988 study, but no reminder sent.
- More women than men responded.
- 32 % said that infertility resulted in less desire for an active sex life
- 10 % said that their sex life was not back to satisfactory now (2005)
- 53% said that the investigation influenced their sex life negatively

Some results:

Marital status after 8 years (2005):

Married 68%

Divorced 17%

Living together 14%

Childwish since (mean) 1991,

Married (mean) since 1992

Treatment started (mean) 1993

Actual treatment 1997 – the mean year of ending treatment as well -

Time as infertile patients: 5 years (mean)

82 % had children in 2005

18 % did not have children

How did they get children?

Born not related to treatment 15%

Born after treatment 36%

Adopted 15%

Stepchildren 3%

## Foster Children 10%

Have they told the child about its IVF situation?

- Those who had treatment related childbirth:
- 6 of them have told the child about how it was made
- 24 have not!
- The main reason for not telling is that "nobody in the family knows" and "they are too young, I will tell later" (children are typically 4-7 years)

Who did they communicate on infertility with:

- Colleagues: not at all 24 %, openly 20 %
- Friends: not at all 6%, openly 60%
- Own Mother: not at all 20%, openly 47%,
- Own Father: not at all 26%, openly 30%
- (we also asked about in-laws, and others)
- Friends seem to play a larger role than family! But one specific female family member can be a confidant (aunt, grandmother etc)

Mental health now:

- In this series, the only mental score asked for, was the GHQ.
- This is a Likert type of scale, with scores 1,2,3,4 (very much to not at all, etc).
- Most of the respondents scored 1 or 2 on all items (ca 80%)
- Around 5-6% have a score that reflects a mental problem that would be referred to as "case"
- The results reflect a "normal" population

Somatic health now:

- Own health status: not so good 9 %, quite good 51 %, very good 38 %
- Types of health problems encountered (infertility related): 8 stated depressions, one hormonal disruptions, and one has menstrual problems/fibroids
- Pregnancy complications: preeclampsia, sectio, twins, and "something wrong but it went well" – only 6 cases
- Two sought help with a psychotherapist

Some general comments on ethics, dilemmas and technology:

- The age limit is being pushed by possible egg donation and grandmother surrogacy
- The parent limit is being pushed by all forms of surrogacy (Social, biological and womb mother, social and donor father)
- The marriage limit is being pushed by lesbian motherhood, living together, single motherhood etc
- Infertility must be seen as a social and individual disaster
- The frequency of infertility must be estimated as high
- The ethical concerns regarding treatment options must be minimized
- The alternatives (no child, adoption) must be seen as secondary, or of low value

- Fertility drug companies take on a new role as parent/treatment advisers and support groups. Luxury seminars, workshops, colorful information material etc is available for activists.
- Successful "patients" are invited to speak in public and become "owned" by these companies.
- Independent Consumer Organizations, Patient Support Groups etc. get heavily subsidized by the drug industry. They used to be mental support groups, but now they are lobbying too.

Concluding remarks:

- Adoption is a viable solution for most
- Infertility is depressing, but not forever
- It is possible to live well, even childfree
- We don't know enough on long term implications and consequences, neither for the child nor for the parents
- Not all couples will become pregnant – ever