Current developments and their impact on counselling
Special Interest Group Psychology and Counselling

27 June 2010
Rome, Italy
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**Current developments and their impact on counselling**

*Organised by the Special Interest Group Psychology & Counselling*

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What is ESHRE?

ESHRE was founded in 1985 and its Mission Statement is to:

• promote interest in, and understanding of, reproductive science and medicine.
• facilitate research and dissemination of research findings in human reproduction and embryology to the general public, scientists, clinicians and patient associations.
• inform politicians and policy makers in Europe.
• promote improvements in clinical practice through educational activities
• develop and maintain data registries
• implement methods to improve safety and quality assurance

Executive Committee 2009/2011

- Luca Gianaroli - Italy
- Anna Veiga - Spain
- Joep Geraedts - Netherlands
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- Timur Gürgan - Turkey
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- Søren Ziebe - Denmark
**ESHRE Activities – Annual Meeting**

- One of the most important events in reproductive science and medicine
- Steady increase in terms of attendance and of scientific recognition

**Track record:**
ESHRE 2008 – Barcelona: 7559 participants
ESHRE 2009 – Amsterdam: 8132 participants

**Future meetings:**
ESHRE 2011 – Stockholm, 3-6 July 2011

**ESHRE Activities – Scientific Journals**

- *Human Reproduction* with impact factor 3.773
- *Human Reproduction Update* with impact factor 7.590
- *Molecular Human Reproduction* with impact factor 2.537
ESHRE Activities – Campus and Data Collection

• Educational Activities / Workshops
  • Meetings on dedicated topics are organised across Europe
  • Organised by the Special Interest Groups
  • Visit: www.eshre.eu under CALENDAR

• Data collection and monitoring
  • EIM data collection
  • PGD data collection
  • Cross border reproductive care survey

ESHRE Activities - Other

• Embryology Certification
• Guidelines & position papers
• News magazine “Focus on Reproduction”
• Web services:
  • RSS feeds for news in reproductive medicine / science
  • Find a member
  • ESHRE Community

ESHRE Membership (1/3)

• ESHRE represents over 5,300 members (infertility specialists, embryologists, geneticists, stem cell scientists, developmental biologists, technicians and nurses)

• Overall, the membership is distributed over 114 different countries, with 50% of members from Europe (EU). 11% come from the US, India and Australia.
ESHRE Membership (2/3)

<table>
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<th>1 yr</th>
<th>3 yrs</th>
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<tr>
<td>Ordinary Member</td>
<td>€60</td>
<td>€180</td>
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<tr>
<td>Paramedical Member*</td>
<td>€30</td>
<td>€90</td>
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<tr>
<td>Student Member**</td>
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*Paramedical membership applies to support personnel working in a routine environment such as nurses and lab technicians.
**Student membership applies to undergraduate, graduate and medical students, residents and post-doctoral research trainees.

ESHRE Membership – Benefits (3/3)

1) Reduced registration fees for all ESHRE activities:
   - Annual Meeting
     - Ordinary: €480 (€720)
     - Students/Paramedicals: €240 (€360)
   - Workshops
     - All members: €150 (€200)

2) Reduced subscription fees to all ESHRE journals – e.g. for Human Reproduction €191 (€573)
3) ESHRE monthly e-newsletter
4) News Magazine “Focus on Reproduction” (3 issues p. a.)
5) Active participation in the Society’s policy-making

Special Interest Groups (SIGs)
The SIGs reflect the scientific interests of the Society’s membership and bring together members of the Society in sub-fields of common interest

- Andrology
- Psychology & Counselling
- Early Pregnancy
- Reproductive Genetics
- Embryology
- Reproductive Surgery
- Endometriosis / Endometrium
- Stem Cells
- Ethics & Law
- Reproductive Endocrinology
- Safety & Quality in ART
Task Forces

A task force is a unit established to work on a single defined task / activity

- Fertility Preservation in Severe Diseases
- Developing Countries and Infertility
- Cross Border Reproductive Care
- Reproduction and Society
- Basic Reproductive Science
- Fertility and Viral Diseases
- Management of Infertility Units
- PGS
- EU Tissues and Cells Directive

Annual Meeting

Rome, Italy 27 June to 30 June 2010

Pre-congress courses (27 June):

- PCC 1: Cross-border reproductive care: information and reflection
- PCC 2: From gametes to embryo: genetics and developmental biology
- PCC 3: New developments in the diagnosis and management of early pregnancy complications
- PCC 4: Basic course on environment and human male reproduction
- PCC 5: The lost art of ovulation induction
- PCC 6: Endometriosis: How new technologies may help
- PCC 7: NOTES and single access surgery
- PCC 8: Stem cells in reproductive medicine
- PCC 9: Current developments and their impact on counselling
- PCC 10: Patient-centred fertility care
- PCC 11: Fertility preservation in cancer disease
- PCC 12: ESHRE journals course for authors

Annual Meeting – Scientific Programme (1/2)

Rome, Italy 27 June to 30 June 2010

- Molecular timing in reproduction
- Rise and decline of the male
- Pluripotency
- Preventing maternal death
- Use and abuse of sperm in ART
- Live surgery
- Emerging technologies in the ART laboratory
- Debate: Multiple natural cycle IVF versus single stimulated cycle and freezing
Annual Meeting – Scientific Programme (2/2)

- Fertility preservation
- Congenital malformations
- ESHRE guidelines
- Data from the PGD Consortium
- European IVF Monitoring 2007
- Debate: Selection of male/female gametes
- Third party reproduction in the United States
- Debate: Alternative Medicine, patients feeling in control?
- Historical lecture: "Catholicism and human reproduction"

Certificate of attendance

1/ Please fill out the evaluation form during the campus
2/ After the campus you can retrieve your certificate of attendance at www.eshre.eu
3/ You need to enter the results of the evaluation form online
4/ Once the results are entered, you can print the certificate of attendance from the ESHRE website
5/ After the campus you will receive an email from ESHRE with the instructions
6/ You will have TWO WEEKS to print your certificate of attendance

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www.eshre.eu
Current developments and their impact on counselling

Organised by the Special Interest Group Psychology & Counselling

Course coordinators: Petra Thorn (Germany) and Chris Verhaak (The Netherlands)

Course description: This course will present an overview of some topical issues counsellors have to tackle. In the morning session, ethical dilemmas brought about by advances in medical care such as providing ART for couples where one partner is affected by a life-threatening disease or by HIV, will be analyzed and discussed. In the afternoon, a range of up-to-date clinical issues will be presented.

Target audience: Psychologists, counselors, clinicians, nurses and affiliated paramedics, ethicists, nurses, counselors, lab technicians and affiliated paramedics, doctors involved in medically assisted reproduction, ethicists, lawyers, policy-makers

Scientific programme:

08:45 – 09.00  Introduction - Petra Thorn (Germany)

Ethical dilemmas

09:00 – 09:30  Developing parameters for a decision process in difficult situations – the example of deciding access to ART in the case of a progressive and potentially life-threatening disease of one partner - Gisela Bockenheimer-Lucius (Germany)
09:30 – 09:45  Discussion
09:45 – 10:15  New advances in PGD: do they present a dilemma for couples and clinicians? – Guido Pennings (Belgium)
10:15 – 10:30  Discussion
10:30 – 11:00  Coffee Break
11:00 – 11:30  Egg Freezing: ethical and psychological challenges - Lucy Frith (United Kingdom)
11:30 – 11:45  Discussion
11:45 – 12:15  Reproductive needs of men and women living with HIV: implications for family planning counselling - Cornelia van Zyl (South Africa)
12:15 – 12:30  Discussion
12:30 – 13:30  Lunch

Clinical issues

13:30 – 14:00  “Your count is zero” Counselling the infertile man - Tewes Wischmann (Germany)
14:00 – 14:15  Discussion
14:15 – 14:45  Mourning rituals for couples remaining childless - Meredith Wheeler (United Kingdom)
14:45 – 15:00  Discussion
15:00 – 15:30  Coffee Break
15:30 – 16:00 Using the internet for fertility health intervention and research: strengths and limitations – Laura Bunting (United Kingdom)

16:00 – 16:15 Discussion

16:15 – 16:45 Interactive personal health records for IVF patients – can they empower patients? – Chris Verhaak (The Netherlands)

16:45 – 17:00 Discussion
Developing parameters for a decision process in difficult situations –
The example of deciding access to ART in the case of a progressive and potentially life-threatening disease of one partner

Gisela Bockenheimer-Lucius
Frankfurt am Main, Germany

Women/Couples with a progressive and potentially life-threatening disease of the male partner requesting IVF/ICSI.

1. Basic medical and ethical reflections
2. Ethical analysis regarding the four basic moral principles autonomy, beneficence, nonmaleficence and justice (Beauchamp / Childress)
3. Changing perspectives to the point of view of potential parents – Guideline to structure and facilitate counselling and decision making in a specific situation

Combination of circumstances with different ethical implications

a. A man with a progressive malignant disease deposits his sperm for his partner to be used for reproduction. He himself hopes for recovery, but the disease cannot be stopped. In the terminal stage the couple requests ART.
b. A man with a progressive malignant disease in the terminal stage and his partner decide that sperms for IVF/ICSI should be harvested by testicle biopsy.
c. A man lives for a longer time in a vegetative state after brain damage. His partner requests harvesting his semen for IVF/ICSI by biopsy. She claims that this is consistent with his wishes for procreation expressed before his accident.
Basic medical and ethical reflections

Medical problems
• Pregnancy cannot be realized naturally nor by homologous artificial insemination or IVF.
  – Production and quality of sperms already reduced
  – Inevitable exposure to chemotherapy or radiation
• Hope for success by IVF/ICSI
  – Extension of indication for IVF!
  – Nowadays ICSI a worldwide procedure of a high standard, commonly applied method

Within the team uncertainty can arise...
• Genuine and mutual wish for a child?
• Does a desperate situation result in a desire not sufficiently considered and explored?
• Decision under considerable moral pressure?
  ➢ Several times there was need for ethics consultation by the Ethics Committee at the University Hospital of Frankfurt/Main
The crucial ethical problem

- Protecting the physical and psychological well-being of the resulting child - Do no harm!
- Joseph Fletcher: „Choice and responsibility are the heart of ethics […] While it is true that we have no responsibility for our own birth, and therefore no moral stake in it, we do have a moral stake in the conception and birth of others, of those whom we bring into the world […]“
- Not rejecting possibilities of ART
- Not disapproving or violating reproductive autonomy and procreative liberty
- But regarding ability to take responsibility for choices – Ethics of freedom within responsibility

Ethical analysis regarding the four basic moral principles

*autonomy, beneficence, nonmaleficence and justice*

(Beauchamp / Childress)

Regarding the child

*Nonmaleficence*

- Somatic or psychological harm by IVF/ICSI?
- Can probability that the child will grow up without his father justify refusing access to ART?
- Psychosocial harm for the child by a emotionally disturbed mother? Moral impact?)
Regarding the child

**Beneficence**

- As a rule human beings prefer their life to non-existence;
- We can assume that human beings procreated by IVF will approve of their lives as much as naturally conceived persons;
- Being child strongly wished for by the parents could be considered especially valuable by the child.

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Regarding the woman

**Nonmaleficence**

- The female partner is healthy and fertile - There is no indication for ART
- Risks of the procedure
  - Risk of the hormonal stimulation
  - High psychological burden (only 30 % embryo transfer is successful, only 15 % success rate/birth of a healthy child, increased risk for abortion, risk of multiple pregnancy)
- Additional burden resulting from the death of her partner
  - Consequences of the therapy (hormones, disappointment or depression after a failed IVF) coincide with the loss of the partner
  - Mourning phase and emotional adaptation

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Regarding the woman

**Beneficence**

- The ability to have a child wished for
- Bonding to the dying partner by having a child

**Autonomy**

- Freedom of personal life and family planning
- Legitimate, justified wish of a couple to have their own child
- Authenticity of the wish for a child
Regarding the man

**Nonmaleficence**
- Physical illness is the focus of attention; motivation to decide or to act autonomously may be considerably reduced.

**Beneficence**
- The interest to have a child is justified and should be highly valued.

**Autonomy**
- Authenticity of the desire to have a child is important with regard to the fatherhood

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**Excursus: Posthumous Procreation**
- Emergency department and intensive care doctors regularly receive requests from wives (actual or de facto) of dying or recently deceased men for sperm removal.
- Legislation regulates removal of sperm from a dying man, debate surrounds the issue of consent and how it can be proved.
- In Germany harvesting the gametes of a deceased is illegal (Embryo Protection Act ESchG § 4, Abs. 3)

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**Changing perspectives to the point of view of potential parents**

Guideline to structure and facilitate counselling and decision making in a specific situation
(University of Frankfurt/Main, Germany)
Responsibilities

- Reproductive autonomy of the parents and their personal responsibility for the procreation of a child – Ethics of parenthood
- Shared decision-making and the change over to the perspectives of the potential parents does not mean to shift the responsibility from the health care team to the couple.
- Protecting the physical and psychological well-being of all concerned.
- Who has to bear the cost? Considerable expenses - Problems of justice

Guideline for the decision process for access to ART in the case of a progressive and potentially life-threatening disease of one partner

1. Medical problems
2. Is the information sufficient about the risks of the procedure and the chances to achieve success?
3. Authenticity of the desire to have a child
4. Mental health of the mother
5. If the partner is not able to consent: Is there any indication regarding the partner’s attitude towards or willingness for fatherhood?
6. Social environment
7. Is there need for a consultation of the clinical ethics committee?

References

New advances in PGD: do they present a dilemma for couples and clinicians?

Guido Pennings, Ph.D

Precongress course Psychology and Counselling, ESHRE, Rome 2010

I have no commercial and/or financial relationships with manufacturers of pharmaceuticals, laboratory supplies and/or medical devices.

Learning objectives:
- To clarify the differences between prenatal diagnosis and preimplantation genetic diagnosis;
- To elaborate on the patient-clinician relationship and the impact on the conflicts and dilemmas that may be encountered;
- To look in detail at the consequences of microarray screening for the practice of preimplantation genetic diagnosis.

High risk of serious harm: the “medical model”

The goal of a medical application: the prevention of disorders in the future child.
The paradigm of ‘serious disease’ that is used as a standard in prenatal diagnosis:
- untreatable;
- lethal at or shortly after birth;
- (complete) dependence for basic activities.

Risk = seriousness X probability

However, the penetrance of the disease is rarely 100% and the expression is almost always variable (i.e., Marfan’s disease)
Generally accepted rules of PD that are under pressure in PGD:
- PGD can only be applied in case of a high risk of a serious disease in the future child
- The woman (or couple) decides about the final destination of the embryos

Differences between PD and PGD

Presupposition: the burden of abortion prevent the lowering of the indications for selection. However, IVF is arguably an equal barrier to prevent the ‘slippery slope’.

Two different situations:
1. IVF is needed because of infertility so only PGD is extra
   - lowering of the indications
2. No IVF is needed, so IVF + PGD are extra
   - no (or limited) lowering of the indications

Lowering the indications

Specificity of PGD

The availability of several embryos simultaneously maximising principle

When one can choose between a possible person A with a quality of life a and a possible person B with a quality of life a + x, then you should give priority to B regardless how small x is) (procreative beneficence principle)
Mutatis mutandis: when the quality of the embryo and the chances of success are equal.
Deviations from the “medical model”

- Testing for late-onset disorders
- Testing for predispositions / susceptibility for diseases

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- Aneuploidy screening to increase the chance of success of IVF
- HLA typing for hematopoietic stem cells transplantation (saviour siblings)
- Selection of healthy carriers of recessive disorders

In general: carrier status is no reason for selection since every person is a carrier of some serious recessive conditions.

Carrier embryos are not replaced because of the risk for the children of the carriers (grandchildren): 1% for autosomal recessive and 50% for sex-linked conditions for each son of a female carrier.

The selection is not performed for eugenic reasons (cleaning the gene pool) but to avoid difficult decisions and risks for the children of the children.
Differences between PD and PGD

- The contribution of the clinician is larger in PGD. Example: Down syndrome detected after PD and after PGD
- The clinician acts rather than refrains from acting. Acts weigh heavier than omissions in determining moral responsibility.
- In vitro location of the embryos shifts the locus of control partially from the woman to the partner and the clinician. See also conflicts about the destination of cryopreserved embryos.
- The question of whether it is acceptable to abort for a certain disease is replaced by the question of whether it is acceptable to start an IVF/PGD cycle for a certain disease.

Moral responsibility

1. The principals: the intentional parents who start the project and intend to raise the child.
2. The collaborators: the persons who assist the parents when they experience problems in realizing their parental project - persons: gamete donor, surrogate, clinician...
   - actions: inform, diagnose, perform technical acts etc.

Patient-clinician relationship

The evaluation of the parental project is crucial for the evaluation of the actions of the collaborator.

- conflicts arise because patient and clinician use different standards of responsible parenthood.
- main problem: large grey zone
Decisional authority about embryos

- Intentional parents have priority

They choose within a legal and/or institutional framework
i.e. PGD is by law forbidden for social sexing
i.e. the clinic refuses PGD for late-onset disorders

- Within this framework, patients and clinician negotiate

They run through the most likely outcomes during counselling
i.e. preferential replacement of non-carrier embryos

Patients change their minds

- Advance directives: ‘if X happens in the future, than Y must be done’

→ Difficulty:
  - bring the future situation clearly to mind
  - predict new possibilities
  - foresee new possibilities

→ Consequence: advance directives have limited value and patients maintain the right to change their minds

Possible conflict with the clinician

Patients change their minds

- The clinician makes a causal and intentional contribution at the start of a determined project.

- The project serves as the context in which the persons are able to foresee and plan the consequences of their actions.

- The change of mind of the patients is a deliberate human intervention that ‘cuts off’ the clinician’s contributions from the final result.
Patients change their minds

• The clinician may feel abused and betrayed because she has been ‘tricked’ into participating in a project she considers to be morally wrong.
• The feelings may generate a wish to force patients to abide by the original agreement by for instance destroying the embryos.
• However, conscientious objections by the clinician can only regard her own actions and integrity. The clinic has to store the embryos and has to release them for transfer to another clinic.

Conditional treatment

Conditional treatment is ethically problematic because it conflicts with:
• the rule of non-directiveness, and
• the reproductive autonomy of the patient.

The goal of the conditions is to bring the situation in line with the principles of responsible parenthood and/or good clinical practice:
• lower the risk for the child
• increase the chance of success of the intervention

Making non-directiveness an absolute principle ignores the moral responsibility of the clinician (and other collaborators).

Conditional treatment

Nevertheless: minimising risk should not be the sole goal of the clinician. Example: PD after PGD to eliminate the risk of misdiagnosis.

The chance that patients will not respect the original agreement may be fairly high in some situations. Example: 25% did not have a PD to confirm the result of the PGD although they had signed a contract agreeing to do this beforehand.
Microarray screening of embryos

New development: screening embryos by means of microarrays.
- Screening for all chromosomal aberrations and hundreds of genetic disorders simultaneously.
- Testing for susceptibilities for complex disorders (cancer, diabetes, obesity, alcohol abuse, addiction, autism, mental illness ...) and traits (height, eye and hair color ...).

Microarray screening

First question: which goal is served?
Main advantage: more abnormalities can be detected than with older techniques.
Main danger: information overload leading to a situation where autonomous decision making by the parents is not improved or even jeopardised.
Important problem: the clinical significance of the findings may be unknown or unconfirmed.
Solutions for the difficulties that people have in working with probabilities: generic consent, reformulation in terms of below and above average risk, ...

- There is a problem of informed consent when hundreds of diseases and susceptibilities are discovered. How to provide counselling?
- Higher chance of incidental findings
- High risk of false-positive and false-negative results (additional testing, psychological burden etc.)
- In case of late-onset diseases, there will be interference with the right of the child not to know.
- The complexity of the findings makes it very difficult to make pre-test agreements between patients and clinician and thus increase the chance of conflicts.
Microarray screening

The evolution of testing (and especially microarray technology) requires serious thinking, if possible prospectively.

What should be done to make it workable?
- Limit the number of diseases (high risk, serious harm ...)?
- Limit the information provided to the parents?
- Start it and look at what people do and ask for?

Conclusions

1. The clinician carries partial responsibility for the result as a collaborator in the parental project of the parents.

2. If the projects conflicts with the principles of responsible parenthood and good clinical practice, the clinician can impose conditions for her collaboration or can refuse further assistance.

Counselling, discussion and shared decision making before the start of treatment can prevent most conflicts.

Bibliography

Egg Freezing: the ethical and psychological challenges

Dr Lucy Frith (PhD)
The University of Liverpool
UK

Declaration

I have no commercial relationships or other activities that might constitute a conflict of interests in regard to the material presented here

Learning Objectives

• To outline the developments in egg freezing
• To give a broad overview of regulation and professional guidelines
• To consider key ethical and psychological issues raised by egg freezing
  – For use in your own reproduction
New developments

• Oocyte freezing is now possible
• There are two main techniques:
  – slow cooling where eggs are frozen slowly using lower concentrations of cryoprotectants
  – vitrification where eggs are frozen quickly using higher concentrations of cryoprotectants, this is a relatively new freezing method

• Estimated that between 1997-2007 there were 164 live births from frozen oocytes (Edger & Gook, 2007)
• Recent studies:
  – similar fertilization and embryo development rates of vitrified versus fresh eggs (Rienzi et al, 2010).
  – the clinical outcome of oocyte slow-cooling cryopreservation is reduced compared with fresh cycles (Borini et al, 2010).

• In UK 41 (37.5 %) clinics are licensed by HFEA for oocyte storage, 4 lives births with slow cooling method
• ICSI is the preferred method of insemination for cryopreserved oocytes to overcome the problem of cryopreservation-induced zona hardening.
• Further studies are required comparing IVF and ICSI with different methods of cryopreservation.
‘Although oocyte cryopreservation does not seem to have consistent success, it must be remembered that in the early days of IVF and embryo freezing there were many failures, and many were doubtful about the future of these procedures. It is highly likely that oocyte cryopreservation is undergoing the same process.’ (Okty et al, 2010:15)

Why Freeze?

- To use in one’s own reproduction
- To donate to others
- For research

To use in one’s own reproduction

- Women who may have to undergo cancer treatment with the possibility of loss of function of the ovaries after this time
- Women who have a family history of premature menopause
- Women who have ethical or religious concerns regarding freezing of embryos
- Women who wish to delay starting a family
I shall concentrate on this aspect of egg freezing as the use of oocytes for research and for donation are issues not specifically raised by the freezing of oocytes

**Regulation - UK**

- The area is governed by the Human Fertilisation & Embryology Act 2008 (that recently updated the original HFE Act 1990)
  [Details and full text of the Act](http://www.dh.gov.uk/en/Publicationsandstatistics/Legislation/Actsandbills/DH_080211)
- The Human Fertilisation & Embryology Authority (HFEA) grants licenses to all clinics who: provide IVF or donor insemination, stores gametes or embryos, brings about the creation of an embryo and/or carries out research on embryos.

- Regulations state that eggs may be frozen for a basic storage period of 10 years
- This can be extended in certain circumstances for a total time period of 55 years, if:
  - a doctor must confirm in writing that either gamete provider or the intended recipient is 'prematurely infertile'. The doctor's certificate must be renewed before the end of each ten year storage period in order to renew for a further ten years.
American Society of Reproductive Medicine

Oocyte cryopreservation is an experimental procedure that should not be offered or marketed as a means to defer reproductive aging, primarily because data relating to clinical outcomes are limited.

ESHRE

In view of the lack of success and clinical applications in the case of ovarian tissue, this application should not be offered to women as a means to preserve their fertility potential when there is no immediate threat to their fertility. According to similar reasoning, oocyte freezing for fertility preservation without a medical indication should not be encouraged. (2004)

BFS

Oocyte cryopreservation should not be portrayed as a means to counteract age related fertility decline (Cutting, et al 2009)
Ethical issues raised by egg freezing for ‘social’ reasons – to counter act age related fertility decline

Women delaying childbearing

In 2004, for the first time, the fertility rate of women aged 30-34 overtook that of women aged 25-29, according to a detailed analysis of birth statistics published by the Office for National Statistics. Although fertility rates increased in all age groups the trend towards later childbearing has continued.

UK National Statistics, 2005

• One clinic in the UK said, ‘that around a quarter of the 66 woman who have been treated at her clinic have had their eggs frozen as an “insurance policy” in case social reasons mean they need them when they are older.’

• They called them their ‘Bridget Joneses’, career women who delay having babies or who can’t find Mr Right
Arguments for ‘social’ egg freezing

- Reproductive autonomy
- Redresses reproductive gender equality
- Better for child
- Avoids problems of embryo freezing

Reproductive autonomy

- The central claim of this argument is that personal reproductive decisions should be free from interference unless they will cause serious harm to others.
- This argument is sometimes reinforced by claims that reproductive choices are “integral to a person’s sense of being” (Jackson, 2007: 48), any restrictions require even more robust justification than less important choices

- It might be argued that the level of evidence of harm needed to justify restricting reproductive choices should be higher than the level needed to justify less important choices.
- Or it might be argued that as reproductive choice is very important, allowing people to exercise it is a good in itself and this good outweighs the production of a certain level of harm.
- In sum, there is a belief that the more important the particular choice, the stronger the case for restricting it has to be.
Gender equality

• Alleviates gender inequality by allowing women to extend their reproductive years
• There are strong arguments based on equal concern and respect for women which require that women have access to this new technology (Goold & Savulescu, 2009)

‘Self-donation of oocytes has the potential to allow reproductively aging, informed, and determined women who have not yet met their life partner to proactively maximize their chances of passing their own genes on to a child, regardless of their age.’ (Rybak et al, 2009)

Advantageous to the future child

• Better for the child, as gives people more time to prepare, become financially secure, so women not rushing into reproduction
• Can have another (genetically related) child if circumstances change (Goold & Savulescu, 2009)
Avoids embryo freezing

- Avoids problems of embryo freezing
  - Moral problems
  - Empowers women (less reliant on partner if not using donor sperm)
  - Allows her to have a child with her current partner

Arguments against social egg freezing

- Medicalization of reproduction
- Causes harm
- Practical aspects

Medicalization

- Medicalization of reproduction - how do we define ‘social’ as opposed to medical reasons?
  - i.e. Is infertility a disease, are there clear biological markers or a constructed condition?
- Is there a danger of such technologies becoming commercialised (Harwood, 2009) and moving towards meeting social rather than ‘medical’ needs?
'Cryopreservation for social and not medical reasons means that the freezing institution is dealing with a customer and not an infertile patient. The management of customer expectations is radically different from infertile patients as there is nothing 'wrong' with them; they are simply using a service.'

Jim Catt, (Monash) Bionew 494

Causes harm

- Could harm the individuals by giving them unrealistic expectations
- Introducing interventions on healthy women
- Risks, use of ICIS raises issues
- Alter behaviour – delay childbearing
- Risks to future child
- Risks to society

Practical aspects

- Cost – who should pay? Available in UK on the NHS?
- When does it cease to be experimental?
- Ensuring it is carried out ethically (informed consent and free choice)
Counselling

BFS recommends that, ‘Patients presenting at clinics for oocyte cryopreservation should be offered realistic information and appropriate counselling which should include the potential benefits and limitations of the technology.’

Need to make sure consent processes robust so women aware of:
- Success rates
- Pitfalls
- Storage (cost, regulations)
- Psychological aspects of the process (both harvesting, emotional effects of storage and implanting)

• Women must understand the potential benefits, limitations, and risks of the developing technology, thorough pre-treatment counselling must be provided, and documented in the medical record.
• Women with cancer or other illnesses requiring treatments that seriously threaten their future fertility should receive the same thorough counselling. They may have no viable options and may be appropriate candidates for such treatment despite its experimental status. (ASRM, 2008)
### Success rates

The ASRM Practice Committee (2008) stated that a live birth rate per oocyte thawed should be quoted as 2% for slow freezing and 4% for vitrification and that these figures may be lower in women above the age of 35.

### Numbers of eggs

‘If low oocyte numbers are retrieved from a stimulation cycle, patients need to be aware that it may be necessary to undergo further stimulation cycles to gain enough stored oocytes to give a reasonable chance of success.’ (Cutting et al, 2009:132)

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Goold, I & Savulescu, J, In Favour of Freezing Eggs for Non-Medical Reasons.

Harwood, K. Egg freezing: a breakthrough in reproductive autonomy?


Maher, B (2007) 'Little consensus on egg freezing: Latest data fail to resolve debate over safety and efficacy' Nature 449, 958


Reproductive needs of men and women living with HIV/AIDS: Implications for family planning counselling

Cornelia van Zyl, MSc.
Prof. M. Visser
Department of Psychology
University of Pretoria
South Africa
No conflict of interest

Learning observations

• To establish the reproductive needs of men and women living with HIV/AIDS at two critical stages, namely:
  – when testing HIV+
  – being pregnant
• To contribute to more comprehensive HIV/AIDS counseling as well as family planning services in the Public Health System in South Africa

Research Methodology

George Gaskell (2000) stated “the real purpose of qualitative research is not counting opinions or people but rather exploring the range of opinions, the different representations of the issue” (p.41)
**Overview**

- Demographics of participants
- Reproductive needs:
  - Individual interviews
- HIV counsellors’ perceptions:
  - Focus group discussions

<table>
<thead>
<tr>
<th>Demographics</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 HIV+ men: aged 29 to 46 years</td>
</tr>
<tr>
<td>10 HIV+ pregnant women: aged 19 to 32 years</td>
</tr>
<tr>
<td>10 HIV+ non-pregnant women: aged 22 to 38 years</td>
</tr>
<tr>
<td>5 HIV counsellors : aged 23 to 39 years</td>
</tr>
</tbody>
</table>
  - Ante Natal Clinic (ANC) |
  - Voluntary Counselling and Testing (VCT) |

**Reproductive needs**

Aspects explored during interviews:
- Background on subject
- Meaning of parenthood
- Effect of not having children
- Personal need vs. cultural norms
Reproductive needs: continued

Aspects explored during interviews:

• Influence of significant other
• Participation in prevention programs
• Influence of HIV status on private life
• Knowledge about risk-reducing therapy

Reproductive needs:
Background on subject

• HIV+ men
  – All had good knowledge on viral transmission
• HIV+ pregnant women
  – Most women had good knowledge on viral transmission
• HIV+ non-pregnant women
  – Most women had good knowledge on viral transmission

Reproductive needs:
Meaning of parenthood

• HIV+ men
  – Personally and culturally important to all men
• HIV+ pregnant women
  – Personally and culturally important to the majority of women
• HIV+ non-pregnant women
  – Personally important to the majority of women
  – Most women reported parenthood was culturally important to married couples
Reproductive needs:
Effect of not having children

- HIV+ men
  - “You are not man enough”
- HIV+ pregnant women
  - “They are disregarded as women”
- HIV+ non-pregnant women
  - “Your value as a women is determined by your ability to have children”

Reproductive needs:
Personal need vs. cultural norms

- HIV+ men
  - Most men reported their communities did not support HIV+ people having babies
  - Some men wanted another baby regardless of status
- HIV+ pregnant women
  - Most women reported their communities did not support HIV+ people having babies
  - Most women reported that the baby came at a good time
- HIV+ non-pregnant women
  - Most women reported their communities did not support HIV+ people having babies
  - A woman trusted the effectiveness of ARV medication and was not scared of transmitting the virus

Reproductive needs:
Influence of the significant other

- HIV+ men
  - Most partners wanted a baby
  - All men were in supportive relationships
- HIV+ pregnant women
  - Most partners wanted a baby
  - Some women were in supportive relationships
- HIV+ non-pregnant women
  - Some partners wanted a baby
  - Half the women were in supportive relationships
Reproductive needs:
Participation in prevention programs

- HIV+ men
  - Most men did not take part
  - Valuable suggestions were made to improve services
- HIV+ pregnant women
  - Most women took part
- HIV+ non-pregnant women
  - Most women did not take part

Reproductive needs: Influence of HIV status on private life

- HIV+ men
  - The majority were taking better care of themselves
  - Less than ½ of sexual relationships did not suffer
- HIV+ pregnant women
  - Less than 1/3 were taking better care of themselves
  - Less than 1/3 of sexual relationships did not suffer
- HIV+ non-pregnant women
  - 2/3 were taking better care of themselves
  - Less than ⅓ of sexual relationships did not suffer

Reproductive needs: Knowledge about risk-reducing therapy

- HIV+ men
  - The majority had no knowledge on becoming a parent in a safe way or where to get information on risk reducing therapy
- HIV+ pregnant women
  - None of the women knew about becoming a parent in a safe way
  - "They still preach the message of prevention but they do not tell you what happens afterwards"
- HIV+ non-pregnant women
  - None of the women knew about becoming a parent in a safe way or where to go for risk reducing therapy
HIV Counsellors’ perception

Group discussions exploring:
- Attitudes towards clients’ reproductive needs
- Perception of clients’ reproductive needs
- Knowledge on risk-reducing therapy
- Training needs regarding risk-reducing therapy and family planning

HIV counsellors’ perception:
Attitudes towards needs
- Counsellors at the Ante Natal Clinic were all negative in attitude towards HIV+ people having babies
- Counsellors at the Voluntary Counselling and Testing Clinic were all positive in attitude towards HIV+ people having babies

HIV counsellors’ perception:
Perception of clients’ needs
- ANC
  - “They want to have more children even if they are HIV+”
  - “They want another baby before they become sick”
  - “HIV+ women will have another baby because previous baby was healthy”
- VCT
  - “They want to leave something behind when they die”
  - “They are relieved to hear there is a possibility having a healthy child”
  - “They are asking about surrogacy”
HIV counsellors’ perception:
Knowledge on risk-reducing therapy

- ANC
  - Counsellors did not have knowledge on RRT
  - “The focus is on the baby and the mother”
  - Patients are counselled not to have anymore babies
- VCT
  - Counsellors had fairly good knowledge about RRT
  - “Main focus on family planning and prevention of infection”
  - They are referred to the doctor, clinic and Steve Biko hospital

HIV counsellors’ perception:
Training needs

- All counsellors expressed a need for training and more information
- ANC
  - “We never thought about that, we did not think about the future. A course to teach us how to counsel, what are their options and how does it work in the laboratory”
- VCT
  - “We must be given enough information so that we can enjoy our jobs. Counselling HIV should be improved as a whole; managing the disease in terms of their reproductive future”

Summary

- HIV+ men
- HIV+ pregnant women
- HIV+ non-pregnant women
- HIV counsellors
Researcher’s impression

• Aristotle 2300 years ago: “There is always something new coming out of Africa”
• Felt as if coming home from very far away land, although working daily 40 km apart
• Research experience gave a “face” to the disease

The Starfish- Loren Eisley

“Why are you throwing starfish in the ocean?”

“It made a difference for that ONE”

Special Thanks:

• Prof Maretha Visser: supervisor to PhD study at University of Pretoria
• Prof B Pattinson: Head of Department Obstetrics and Gynecology, Kalafong Hospital
• Dr Swanepoel: Head of Department Immunology, Kalafong Hospital
• HIV counsellors at both ANC and VCT, Kalafong Hospital
Selected References


Objectives

✓ Understanding of the psychological impact of infertility and of assisted reproductive technologies on men

✓ Knowledge of methodological considerations concerning studies on infertile men

✓ How to make infertility counselling more attractive for men

✓ Basic knowledge of special topics in counselling men on donor insemination

Introduction

A literature review showed that of 121 papers on infertility (published 1948-1985), 56% referred to women solely, 29% to both partners and only 15% exclusively to the man (Bents 1985).

In a well-known study, 49% of women but only 15% of men considered infertility the most upsetting experience of their lives (Freeman et al. 1987).

For 72.5% of the women and 61.8% of the men, psychological counselling as an aid to coping with involuntary childlessness was considered a viable proposition (P < 0.001) (Wischmann et al. 2001).
Key questions

1. Do men suffer from infertility less than women or do they suffer at all ("sturdy oaks")?

2. What is the psychological impact of male factor infertility on men ("shooting blanks")?

Methodological considerations (I)

The claim women react more adversely to infertility than their partners is overly influenced by outdated gender stereotyping and is unsupported by research data (Edelmann & Connolly 2000).

The results of much of the available research supporting women’s greater overt distress in response to infertility may well reflect differences in the ways in which men and women have been socialized to cope with negative affect (Olwek & Donahue, 1990).

It is obvious that the introduction of ICSI has revolutionized the treatment of male factor infertility and thereby probably also improved the psychological well-being of males (Holter et al. 2007).

Methodological considerations (II)

• Men may be more inclined to deny psychopathology

• Men and women may respond in different ways to stress, e.g., alcohol use or depression

• Any gender differences may reflect more general differences in response to stress rather than being specific to infertility (Edelmann & Connolly, 2000).

• With statistical approaches that keep matched pairs, differences between men and women are much smaller than testing the samples as independent groups (Ehrenwasser et al. 2009).
Stigmatisation of male factor infertility

To be diagnosed with male factor infertility may result in secrecy surrounding diagnosis, sometimes to the point that women take the blame for the couples’ infertility (Carmeli & Birenbaum-Carmeli 1994; van Balen 1996)

The relatives of the (formerly) infertile woman are more likely to be informed about successful treatment with donor insemination than the relatives of the man (Wischmann 2010)

Media reports on “the sperm decline” construct stereotypical masculinity and conflate male infertility with impotence (Gannon et al. 2004)

In a study on 256 Danish infertile men the COMPI group found out that men with male factor infertility did not suffer more than men with infertility due to other causes

Most men in this study, including those with male factor infertility, were open about their fertility problems

Across all diagnostic groups, suffering increased over time when treatment was not successful indicating that suffering was not specific to male factor diagnosis or disproportionate for this group (Peronace et al. 2007)

Stigmatisation of male infertility: a cohort effect?

In a study on 256 Danish infertile men the COMPI group found out that men with male factor infertility did not suffer more than men with infertility due to other causes

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Social support and male factor infertility

When men are affected by infertility, the unfulfilled desire for a child and sexual dysfunction are often believed to be synonymous. Many of those rash enough to tell others about their problem become the butt of merciless mockery and innuendo (“You want me to pay your wife a little visit? This is a job for a real man!”) (Miall 1986; Throsby & Gill 2004)

Women with fertility problems tend to be pitied, whereas men are more likely to encounter insulting slurs on their manhood (Nachtigall et al. 1992)
**Sexual disorders in infertile men**

When an andrological factor is the sole cause of infertility, male probands in a recent study report appreciable impairments to their personal and sexual life quality even if they already have children.

A study on 206 infertile couples (compared to 190 fertile couples) could also show that diagnosed male infertility correlated with the lowest average intimate life satisfaction, both in the groups of women and men.

---

**Every 9th of the probands was unable to produce the sperm needed for a second spermiogram after having been told about sperm quality deficits identified in the first.**

More than twice as many men as in the overall population suffer from erectile dysfunctions. According to some studies, premature ejaculation is two to three times more common in infertile men than in the general population.

As many as 45.4% of 487 men interviewed at a reproductive medicine clinic reported that sex “by the clock” (timed intercourse) is stressful.

---

**Infertility treatment and counselling**

Mental health support is sought by – and offered predominantly to – women.

Although infertility is a couple problem, men and women generally experience treatment as observer and participant, respectively.

Man in particular indicate that they believe they can overcome their feelings alone.
Preparatory information: booklets

This factor would improve knowledge of and passage through an IVF cycle:

<table>
<thead>
<tr>
<th></th>
<th>Women (n = 117)</th>
<th>Men (n = 101)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Booklet of information about practical aspects</td>
<td>54%</td>
<td>50%</td>
</tr>
<tr>
<td>Video about IVF</td>
<td>22%</td>
<td>36%</td>
</tr>
<tr>
<td>Booklet about psychological aspects of IVF</td>
<td>39%</td>
<td>34%</td>
</tr>
<tr>
<td>Bibliography about IVF</td>
<td>24%</td>
<td>29%</td>
</tr>
<tr>
<td>Meetings with a psychologist</td>
<td>26%</td>
<td>22%</td>
</tr>
<tr>
<td>Discussion group</td>
<td>24%</td>
<td>8%</td>
</tr>
<tr>
<td>Information meeting with other couples</td>
<td>13%</td>
<td>13%</td>
</tr>
</tbody>
</table>

(Laffont & Edelmann 1994)

Expectations towards psychosocial support

<table>
<thead>
<tr>
<th>Considered the professional psychosocial services as important</th>
<th>Women (n = 1169)</th>
<th>Men (n = 1081)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Course about childlessness</td>
<td>14.3%</td>
<td>13.9%</td>
</tr>
<tr>
<td>Professionally led support group</td>
<td>11.7%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Psychologist</td>
<td>20.8%</td>
<td>18.7%</td>
</tr>
<tr>
<td>Sex therapist</td>
<td>10.7%</td>
<td>8.9%</td>
</tr>
</tbody>
</table>

Would participate if these services were available

(Immel et al. 2005)

Improving uptake of psychologic counselling

- Introduce the psychologic support before the medical process
- Make personal and direct contact with the patients
- Present counselling as an integral component of the infertility treatment
- Offer support to all patients regardless of their cause of their infertility

⇒ One-half of the male patients took up psychologic group counselling

(Furman et al. 2010)
Making infertility counselling attractive for men

- Provide pretreatment educational brochures (for men) to enhance the participation rate of men.
- Explain the potential benefits of infertility counselling for both partners.
- Testimonials that reflect typical male concerns about counselling may encourage men to seek mental health support. (O'Donnell 2007)

Preparatory information: Booklets

In a group of 250 men enrolling for a fertility workup, mailing of a leaflet with preparatory information about this procedure was associated with lower distress scores and a higher attendance rate compared to a group of men who did not receive this leaflet. (Pook & Krause 2005)

Pre-Counselling checklists

What to consider in couple counselling

- Be careful about appearing to take sides or subtly praise the female client.
- Address man’s ambivalence about help seeking.
- Address masculine/feminine socialisation (e.g. conflict between work life and family life).
- Address man’s discomfort with emotions.
- Accept that men usually need more time in identifying their emotions and finding words for it than women. (Englar-Carlson & Shepard 2005)
"Feeling guilty" is not the same as "being guilty"
Identify allocation of blame on man and replace it with "accepting my part of the responsibility for our common problem"

Change attribution errors and unfavourable coping styles
Change man’s internal attribution ("I’m a failure") to external attribution ("This blow of fate is our challenge")
Strengthen active and meaning based coping styles, replace passive and avoidance coping styles

Normalization of "negative" emotions
Regarding fathers-to-be with envy, or feelings of guilt due to the male factor, are common, comprehensible and acceptable.

Polarization
A woman may want to talk about her pain and sadness, her partner may feel helpless and withdraw.
This circular pattern can result in polarization and isolation, at a time where both partners need each other the most
Bring forward the couple's communication
Identify dysfunctional role allocations ("depressive woman – helpless man") and make them more flexible

Do men suffer from infertility? Yes!
In keeping with masculinity norms, many husbands tend to suppress their emotions in an effort to support their wives.
Withdrawal might be a way of protecting the woman from her partner's pain. (Cousineau & Domar 2007)

Men in Non-Western vs. Western societies

Table IV: Differences from reference population in Symptom Checklist (SCL-90-R)

<table>
<thead>
<tr>
<th>SCL-90-R scales</th>
<th>Women (n = 562)</th>
<th>Men (n = 439)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somatization</td>
<td>51.9 ± 12.2***</td>
<td>51.4 ± 11.5***</td>
</tr>
<tr>
<td>Obsessive/compulsive</td>
<td>50.3 ± 11.4</td>
<td>49.9 ± 11.1</td>
</tr>
<tr>
<td>Interpersonal sensitivity</td>
<td>51.1 ± 12.6***</td>
<td>49.7 ± 11.5</td>
</tr>
<tr>
<td>Depression</td>
<td>51.9 ± 12.2***</td>
<td>49.5 ± 10.6</td>
</tr>
<tr>
<td>Anxiety</td>
<td>52.7 ± 13.4</td>
<td>50.7 ± 10.7</td>
</tr>
<tr>
<td>Anger hostility</td>
<td>55.2 ± 11.9**</td>
<td>50.8 ± 11.2</td>
</tr>
<tr>
<td>Hostility</td>
<td>51.5 ± 14.7***</td>
<td>50.1 ± 11.7</td>
</tr>
<tr>
<td>Psychosocial isolation</td>
<td>50.8 ± 11.6</td>
<td>50.9 ± 11.8</td>
</tr>
<tr>
<td>Global severity index</td>
<td>51.1 ± 12.7</td>
<td>49.2 ± 11.7</td>
</tr>
<tr>
<td>Positive symptom distress index</td>
<td>51.6 ± 10.2***</td>
<td>49.7 ± 7.8</td>
</tr>
<tr>
<td>Positive symptom total index</td>
<td>51.2 ± 12.4***</td>
<td>50.6 ± 12.0</td>
</tr>
</tbody>
</table>

Values are mean ± SD.

P < 0.05, **P < 0.01, ***P < 0.001; reference population: mean = 50, SD = 10.

Boyd 1988, p. 4
Case example

1st counselling session:
Mr. Z., 60 yrs old, has fathered 3 children in his marriage (which broke about 3 years ago). Since 2 years a new partner, a black African woman, about 30 years younger with a strong wish for a child. The diagnosis is male factor infertility, “I’m very annoyed about this infertility!” His sexual life is not affected by this diagnosis.

He wakes up every night, sees his son’s shadow in the house. Mr. Z. reported that his son has committed suicide 3½ years ago. “I feel guilty: Should I’ve noticed it earlier that he is depressive?”

➢ Mr. Z. was referred for individual psychotherapy to facilitate the mourning process.

Case example (ctnd.)

2nd counselling session (with both partners):

➢ Information was given to her about the contents of the first session.

She asked for information about the risks concerning the development of ICSI children. The couple was informed about the chances of success of ICSI.

A short discussion about "plan B" followed. She: “I am religious and I am quite confident that we will stay together, in any case!”

The position of the father after successful ART
Male infertility: Impact of donor insemination

Counselling issues include managing the taboo, social stigma and legal uncertainties, the meanings attributed to the donor for the intended parents and the child, the donor’s anonymity or identifiability as well as sharing the information with the child and significant others.

Development of families after ART and DI

The "European Study of Assisted Reproduction Families" investigated 102 IVF families, 94 families after DI, 102 families after adoption and 102 families with spontaneously conceived singletons.

Between the groups, there were no differences in the parent-child-relationship or in the various variables concerning the psychological development of the child


Development studies: selection biases?

NB:
The response rates in the primary "European Study of Assisted Reproduction Families" from 1996 were 76% for IVF families, 72% for families after adoption, just 65% for families with spontaneously conceived singletons and only 47% for DI families

In the 1996 study, the assessment of education quality was done by interviews with the mothers solely. There were hints for difficulties of the social fathers with their DI children (e.g. overprotectiveness or dissociation)
Long-term psychological effects of infertility

There are only small differences in the quality of life between involuntarily childless couples and parents (Sydsjö et al. 2005, Sundby et al. 2007, Verhaak et al. 2007; Kraaij et al. 2008, Peterson et al. 2009)

NB: One third of the couples are non-responders

A study comparing women and men 4-5.5 years after successful and after unsuccessful IVF with a control group showed that quality of life in men seems more negatively affected by involuntary infertility than reported before:

Their scores in depression and psychological well-being were similar to the women in the unsuccessful IVF group (Johannsson et al. 2010)

Summary

- In general, the emotional impact of infertility is lower for men than for women (women’s loss of being pregnant is not experienced by men) (Mahlstedt 1985)
- At least men with male factor infertility suffer as much as women with female factor infertility, but research results are still inconclusive (Peronace et al. 2007, Holter et al. 2007)
- Male factor infertility seems to be more stigmatized than other infertility diagnoses (Webb & Daniluk 1999)
- Men do indeed experience pain related to their infertility but feel they have few acceptable outlets for the expression of their distress
- A significant selection bias has to be considered in studies on men and their reactions to infertility (Mahlstedt 1985)

Conclusions (I)

- Provide questionnaires to identify infertile men who need psychosocial support (e.g. FertiQol or SCREENIVF)
- Studies on invasive reproductive treatment measures on infertile men (e.g. MESA/TESE) are still missing
- The counselling needs of men and women after (successful or unsuccessful) treatment for male factor infertility have to be investigated
- The same implies to the counselling needs of families after donor insemination and to the development of children born after donor insemination
Conclusions (II)

• The "new" treatment options ICSI / MESA / TESE and also DI: Do they encourage and give hope or do they impede the grieving process in male factor infertility?

• Studies have to differentiate between the psychological impact of infertility on women and men and their respective abilities to communicate about this distress

• The influences of the doctor's gender and of the counsellor's gender on the infertile man's well-being and emotional adjustment during ART have to be studied

• More studies on infertile men in Non-Western societies have to be conducted

Key references


In the end:
Relieving the soul's burdens

Madonna del Parto,
Chiesa di S. Agostino in Campo Marzio, Roma
Mourning Rituals for couples remaining childless

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B.A. Stanford University (USA)
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www.meredithwheeler.org

Learning Objectives:

• To understand the need & purpose of mourning rituals for fertility loss
• To see examples of creative, contemporary rituals
• To understand the core elements of such rituals

Ambiguous Loss

Examples:
• Infertility
• Miscarriage
• Failed fertility treatment
• Terminations
• Birth mothers who give up her child
• Secondary infertility

Characteristics:
• Lack clarity
• Differing assessments as to what or who has been lost
• Has a significant loss even occurred?
Results of Ambiguous Loss

- Social networks do not respond effectively
- Isolation of the mourner

Leading to…

- Disenfranchised Grief—defined as a bereavement that is not or cannot be openly acknowledged, publicly mourned or socially supported
- Complicated Grief—may become chronic, unresolved grief leading to stagnation & illness

Losses (real or perceived) associated with infertility or unwanted childlessness

- Loss of the child genetically-related to both parents
- Death of embryos, early or late miscarriage, stillbirth
- Wound to sense of femininity/masculinity
- Loss of sense of control over life; disempowerment;
- Loss of faith in the proper working of the body
- Loss of experience of parenting/grand-parenting
- Loss of social roles associated with parenting & the connection to the wider community
- Loss of self-esteem; self blame, letting down others (partners, parents, siblings)
- Loss of privacy (from invasive treatment)
- (Perceived) Loss of meaningful stake in the future

Private Ritual vs. Public Ritual

- Examples of private, self-created rituals
- Sanctioned public rituals
Elements of Good Ritual

- Meaningful symbols
- Active involvement
- Variety of methods of participation
- Safe “container”
- Careful preparation
- Follow-up
Feedback

Sanctioned public expression of grief, breaking isolation

“To be able to grieve publicly was a great release. Although the room was filled with people who had been through such pain and suffering, it somehow felt hopeful, perhaps because we all began to realise that we were not as isolated as we had thought.”

Ritual safely “contains” powerful feelings

“A nurturing and healing day…. I felt the atmosphere was containing, grounding and relaxing—enabling me to get in touch with grief without being overwhelmed by personal or collective material.”

Feedback

Time reserved for marking losses

• “This has been a unique opportunity to mark our losses. A very beautiful and healing event. I found it a tremendous comfort and a source of great consolation.”

Catharsis; breaking sense of isolation

• “Tears came and for once they were cleansing. The whole ceremony was very beautiful. Everything was simple and accessible and I really valued being able to participate. It made me feel part of something rather than being separated and isolated and alone.”

Outdoor Rituals
Each participant painted a lantern to carry light.

Detail of the center of the spiral
Outdoor Ritual—the Vision Quest

Elements of Ritual
• Space
• Movement
• Colour
• Silence
• Words
• Music
• Noise
• Vows & Promises

Ritual Activities
• Lighting/Burning something (candle, letter)
• Pouring out/drinking liquid (water/wine/milk)
• Ritual foods or drink, offered or eaten (fruit/bread/sweet & bitter)
• Creating artwork (drawing, collage, sculpting)
• Building a cairn
• Movement (walking, dancing, rocking)
• Writing (poems, memories, letters, naming)
• Deliberating breaking/shattering something (glass, cup, egg)
• Bathing
• Cutting something
• Burying something
• Planting something
• Casting away (off a high point, into water, leaving behind)
Emotions, concerns, issues
ritual can address

- **Anger** (How can I safely express it?)
- **Sorrow** (What has been lost?)
- **Emptiness** (How may I be filled?)
- **Guilt** (How may I be forgiven?)
- **Hurt** (How may I be healed?)

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Full text of a typical Mourning Ritual service plus suggested music & readings appear on the website.

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APPENDIX A

Statement of Purpose (for mourning ritual)

We’ve come together today to recognise and honour the losses associated with infertility, secondary infertility, loss of a pregnancy for any reason, failed fertility treatment, terminations, neonatal death, and unwanted childlessness, whatever the cause.

Most of us are here to mourn those children who are not in life. Some of these children have only lived on the inner level, in our imaginations, hopes and dreams, others were conceived, but are no longer in our world.

There are many losses connected to their absence. Some of us are grieving the lost opportunity to be a parent or grandparent; others are angry about the invasion of our bodies by hi-tech treatments which promised a lot, but haven’t worked; some feel keenly the damage done to relationships with others—our families and friends who may have children, and particularly with our partners which is where much of the strain goes, often eroding our physical & emotional connection.

This ritual is a chance to express grief about events that are past, so that we don’t remain stuck in the pain—so that we can let go of some of the sadness, anger, blame and guilt that linger. And in that letting go, there is the hope that we may free up energy that enables us to move on.
USING THE INTERNET FOR FERTILITY HEALTH INTERVENTIONS AND RESEARCH
STRENGTHS AND LIMITATIONS

Laura Bunting PhD & Jacky Boivin PhD

Learning Objectives

- Identify the advantages and limitations of using the internet in research & health promotion activities
- Understand how to employ the internet in fertility health research

Cardiff fertility studies

- Treatment Decision-Making Study (TDMS) (N=436)
- International Fertility Decision-Making Study (IFDMS) (N=10043)
- Fertility Status Awareness Tool (FertiSTAT) (N=603)
Internet use

- ~25% of World use the internet
  - 50% people in more developed countries (UCLA World Internet Project: Labs, 2004)
  - 70% United Kingdom (Office of National Statistics, 2009)
  - 75% United States (Nielsen//NetRatings, 2004)

Should we use the internet in health research and promotion?

- Ultimate goal of health promotion: Enable people to increase control over their health thereby improving it
  - A review by Whitehead (2007) reported internet use already active in many fields of health
    - Facilitate therapeutic interventions and promote training and education (Elfer, 2006; Teel & Shaw, 2005)
    - Online psychoeducational support for infertile women (Cousineau et al., 2008)
    - Set up and manage patient support groups (Gustafson et al., 2006; Knutis et al., 2006)
    - Infertility networks (e.g., www.infertilitynetworkuk.com)
    - Cancer focus groups (Campbell et al., 2001)
    - Interactive Personal Health Record for IVF Patients (Tuil et al., 2006; 2007)

Strengths of using the internet
Strengths of using the internet

- Empowerment
  - Improve and increase control over a person’s health (WHO, 1986)
  - User decides search technique and information examined
  - Rise in healthism and health literacy
  - Increase control and coping
    - Infertile women exposed to an online program felt more informed about fertility medical decision making and had increased self-efficacy (Cousineau et al., 2008)

Strengths of using the internet

- Empowerment: Knowledge transfer and specificity
  - Increase knowledge (e.g., signs and symptoms of disease)
  - Preparation and informed decision-making
  - Valuable information provided to practitioners about what information people want

Strengths of using the internet

- Accessibility and interactivity (Jensen, 1998)
  - Information at a click at any time, anywhere
  - Direct feedback and real-time communication (Korp, 2006)
  - Internet reaches and engages with a wider range of groups
    - Rural communities (Wheheaad, 2007)
    - ‘Senior surfers’ (Moore, 2005)
    - Disadvantaged teenagers (Walsh & Sword, 2005)
    - People living with disabilities (Knight et al. 2002), depression (Anderson et al. 2005), dementia (Freeman et al., 2005)
  - Support groups
    - Knowledge sharing and community building (Walch, 1999)
**Strengths of using the internet**

- **Accessibility and interactivity**
  - Over 90% of people who are of reproductive age use the internet.

**Strengths of using the internet**

- **Personalised health care**
  - Focus on personal risk is likely to be more effective in promoting change than awareness of general risk (Fischhoff et al., 1993; Greening et al., 2005)
  - Personalising risk is most effective (and less alarming) if coupled with guidance about what to do to reduce risk or seek help (Soames, 1988)

**Strengths of using the internet**

- **Risk categories for lung cancer**:
  - Gender
  - Age
  - Family history
  - Smoking history
  - Environment
  - Diet

[http://www.yourdiseaserisk.wustl.edu/](http://www.yourdiseaserisk.wustl.edu/)
### Efficiency in data collection
- Electronic skip pattern responses make question personally relevant (Smith et al. 2007)
- Creation of electronic database
  - Download data versus hand inputting data
  - Quality of data: Keystroke versus handwritten

### Cost
- Reduction in paper & data entry
  - Internet is at the outset expensive compared to paper but after initial set-up (e.g., website development) and as participants increase the cost switches (Lewis et al., 2010)
  - Millennium Cohort Study - each participant who elected to complete the questionnaire online rather than by paper saved the study approximately $50.00 (estimated saving to date ~$2 million) (Smith et al., 2007)

### Accessibility
- Community samples
  - Expensive, time consuming to set-up and manage
- Clinic samples
  - Missing the 45.3% not seeking medical care?
Potential intervention and research strengths

Cost and accessibility

IFDMS – Paid volunteers
- Google AdWords, Facebook, Babycentre, Clearblue, IPSOS
- 6 months recruitment
- 12 languages
- 18 countries
  - Australia, Brazil, Canada, China, Denmark, France, Germany, India, Italy, Japan, Mexico, New Zealand, Portugal, Russia, Spain, Turkey, UK, USA

FertiSTAT - Majority Free
- www.Askbaby.com, Myspace, Facebook (cost £30)
- 8 months recruitment
- 1 language
- 4 countries
  - UK, USA, Canada, Australia

Potential intervention and research strengths

Cost and accessibility

IFDMS – Paid volunteers
- N = 10,043
  - n=8,352 women
  - n=1,691 men
  - Treated: 7,095
  - No treatment: 2,948
  - Average age: 31.8 (SD=5.9)
  - Time trying: 2.8 (SD=2.9)
  - 33.5% University educated

FertiSTAT - Majority Free
- N = 603 women
  - Pregnant: 424
  - Not pregnant: 179
  - Average age: 29.0 (SD=5.4)
  - Time trying: 1.4 (SD=1.8)
  - 44.5% University educated

Potential intervention and research strengths

Is the FertiSTAT sample comparable to the population?

- Population values include men

- **Marijuana**
  - ≥ 14 units a week

- **Caffeine**
  - ≥ 14 units a week

- **Smoke**
  - ≥ 14 units a week

- **Alcohol**
  - ≥ 14 units a week

- **Anabolic Steroid**
  - ≥ 14 units a week

- **Last 12 months**
  - ≥ 14 units a week

- **Class A drug ever used**
  - ≥ 14 units a week

- **Stress**
  - ≥ 14 units a week

- **Unprotected sexual intercourse with multiple partners**
  - ≥ 14 units a week

- **Overweight**
  - ≥ 14 units a week

- **Lifestyle**
  - ≥ 14 units a week

- **Sexually Transmitted Disease (STD)**
  - ≥ 14 units a week

- **Pelvic surgery**
  - ≥ 14 units a week

- **Period**
  - Menstrual cycle irregular
  - Menstrual cycle more than 35 days
  - Menstrual cycle less than 21 days

- **Pelvic Inflammatory Disease (PID)**
  - ≥ 14 units a week

- **Endometriosis**
  - ≥ 14 units a week

- **Period pains**
  - ≥ 14 units a week

- **Reproductive**
  - ≥ 14 units a week

- **Education (University level)**
  - ≥ 14 units a week

- **Demographic**
  - ≥ 14 units a week

- **Online (%)**
  - ≥ 14 units a week

- **Population (%)**
  - ≥ 14 units a week

Potential intervention and research strengths

- Page 78 of 100
Potential intervention and research strengths

- Anonymity and convenience
  - Valaitis & Sword (2005) found that the internet can help to diffuse embarrassment, feelings of being judged or shyness
  - No concerns about keeping appointments or remembering to put a questionnaire in the post (Stewart et al., 1998)

- Ease of survey construction
  - SurveyTracker, SurveyMonkey

Limitations of using the internet

- Quality control and regulation
  - Quality standards for internet health sites
  - Anyone can upload information onto the internet
  - How do you regulate this?
    - Craigie et al. (2002) reported that experts’ ratings of health information on the internet displayed a low level of consensus between the different experts
  - Impartiality
    - Difficult to determine whether information is providing equal options of information or just those of society (Pitts, 2004)
    - Information can provide commercialised incentives to companies wishing to promote and sell products
Limitations of using the internet

The digital divide

Access varies considerably across the World
- The Internet World Statistics in 2006 ranked North America as having the highest (68% of the population) and Africa lowest (2.5% of the population) internet use

Office for National Statistics (United Kingdom, 2009)

Limitations of using the internet

Percentage of IFDMS respondents with university education according to country

Limitations of using the internet

The digital divide

- Varying navigational and computer literacy skills
- Income level linked to use (Kaye, 2006; Kulchinian et al., 2003; Loader, 1998)
- Age (Smith et al., 2007)
- Gender (Hoaglen et al., 2003)

Note. **The remaining studies used men and women
Limitations of using the internet

- Challenges patient-doctor relationship (Baker et al. 2003; Korp, 2006)
  - Increase provider stress as they may feel patients are challenging their medical authority
  - Cause societal pressure to challenge drug use, costs and availability (e.g., Herceptin availability for breast cancer)

- Balance between healthism and medicalization
  - Fear and anxiety inducing (Kent, 2000)
  - Cancer campaigns criticized for focusing too much on young women when in reality the majority of cases are in older women (Office of National Statistics, 2004)

Potential intervention and research limitations

- Web security
  - Privacy and identity theft may impact on responders willingness to reply

Potential intervention and research limitations

- Reduction of personal care
  - Reduce contact = reduced relationships with participants (Mann & Stewart, 2000)

- Reduction in experimental and practitioner control
  - Repeat participation (Gosling et al., 2004)
  - Environmental distractions
Potential intervention and research limitations

- Costs and design complexity
  - Webpage and questionnaire development
  - Hosting and maintenance
  - Database construction and management

Should we continue to use the internet in fertility health research and promotion?

- Majority of reviews to date assessing internet use and health are positive (Lustria et al., 2009; Strecher, 2007; Whitehead, 2007)
- Internet is a cost effective, reliable, efficient and effective way of recruiting participants in fertility research
- Many limitations are issues in general with health promotion and research biases and not just limited to the internet (Ekman et al. 2006)
  BUT Limitations should be tackled:
  - Researcher responsibility
  - Education
  - Employ mixed methods that are appropriate to the individual, the study and the intervention
  - Male recruitment

Future development using the internet

- FertiSTAT prospective study
  - Released at ESHRE 2009
  - Media picked up online, paper and magazine articles
  - Time 1: N=607
Future development using the internet

- How can we engage people into research?
  - Internet mobile phone applications that link to online databases

Symptom check list

Participant receives personalized feedback (e.g., fertile window, behavioral risk reduction)

Researchers receive prospective risk data to validate FertiSTAT

MANY THANKS.

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References

Online interactive personal health records: Psychological aspects

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the Netherlands

Learning objectives

- To understand possibility for interactive personal health record
- To understand psychological aspects of interactive personal health records
- Insight into different kind of behaviours on internet
- To reflect on psychological issues in online personal health records
- To reflect on future directions

Objectives of the online personal health record

- Patient empowerment
- What is patient empowerment?
  - Knowledge
  - Shared decision-making
  - Self efficacy
  - Patient centered care
  - Satisfaction with care
Interactive online personal health record

- General information
  - FAQ
  - Information clinic
  - Information treatment
  - Links
  - Literature
  - Video

- Personal information
  - Electronic medical record (EMR)
  - Day planner
  - Embryo photo
  - Personal prognosis
  - Correspondence

- Communication
  - Email
  - Forum
  - chat

Shared decision making
Patient participation satisfaction
Coping style

- Active versus passive

- Regarding medical information:
  - Monitors > approaching threat/ information
  - Blunters > avoiding threat/ information
The number of page-views per week after a patient-couple’s first visit to the website.
null
Relationship between online behaviour and psychological factors

<table>
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Conclusions

- Intensively used
- Positively evaluated
- No relationship with psychological outcome
- Relationship online behaviour, emotional impact and coping style needs further elaboration
Mark your calendar for the upcoming ESHRE campus workshops!

- **Basic Genetics for ART Practitioners**
  organised by the SIG Reproductive Genetics
  16 April 2010 - Porto, Portugal

- **Array technologies to apprehend developmental competence and endometrial receptivity: limits and possibilities**
  organised by the Task Force Basic Science in Reproduction
  22 April 2010 - Brussels, Belgium

- **The management of infertility – training workshop for junior doctors, paramedicals and embryologists**
  organised by the SIG Reproductive Endocrinology, SIG Embryology and the Paramedical Group
  26-27 May 2010 - Kiev, Ukraine

- **Preimplantation genetic diagnosis: a celebration of 20 years**
  organised by the SIG Reproductive Genetics
  1 July 2010 - Rome, Italy

- **EIM 10 years’ celebration meeting**
  organised by the European IVF Monitoring Consortium
  11 September 2010 - Munich, Germany

- **The determinants of a successful pregnancy**
  organised by the SfGS Reproductive Surgery, Early Pregnancy and Reproductive Endocrinology
  24-25 September 2010 - Dubrovnik, Croatia

- **Basic training workshop for paramedics working in reproductive health**
  organised by the Paramedical Group
  6-8 October 2010 - Valencia, Spain

- **Forgotten knowledge about gamete physiology and its impact on embryo quality**
  organised by the SIG Embryology
  9-10 October 2010 - Lisbon, Portugal

www.eshre.eu
(see “Calendar”)

Contact us at info@eshre.eu
Keep an eye on our calendar section for more information on

Upcoming events

- **Female and male surgery in human reproductive medicine**
  8-9 October 2010 - Treviso, Italy

- **Promoting excellence in clinical research: from idea to publication**
  5-6 November 2010 - Thessaloniki, Greece

- “Update on pluripotent stem cells (hESC and iPS)” and hands on course on “Derivation and culture of pluripotent stem cells”
  8-12 November 2010 - Valencia, Spain

- **Women’s health aspects of PCOS (excluding infertility)**
  18 November 2010 - Amsterdam, The Netherlands

- **Endoscopy in reproductive medicine**
  24-26 November 2010 - Leuven, Belgium

- **Fertility and Cancer**
  25-26 November 2010 - Bologna, Italy

- **The maternal-embryonic interface**
  2-3 December 2010 - Valencia, Spain

- **GnHR agonist for triggering of final oocyte maturation – time for a paradigm shift**
  3 December 2010 - Madrid, Spain

- **Raising competence in psychosocial care**
  3-4 December 2010 - Amsterdam, The Netherlands