



Current developments and their impact on counselling

Special Interest Group Psychology and Counselling

9

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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ESHRE – European Society of Human Reproduction and Embryology

What is ESHRE?

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

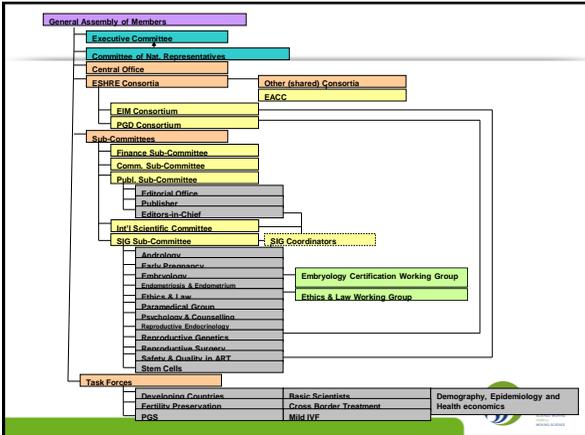
- promote interest in, and understanding of, reproductive science and medicine.
- facilitate research and dissemination of research findings in human reproduction and embryology to the general public, scientists, clinicians and patient associations.
- inform politicians and policy makers in Europe.
- 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

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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 2010 – Rome, 27-30 June 2010
 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)

	1 yr	3 yrs
Ordinary Member	€ 60	€ 180
Paramedical Member*	€ 30	€ 90
Student Member**	€ 30	N.A.

*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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PRE-CONGRESS COURSE 9 - Programme

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

**Current Developments
and their Impact on Counselling**

Special Interest Group Psychology and Counselling

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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...**

- **Genuin 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 an 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.

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

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

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)

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?

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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)



Differences between PD and PGD

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



Lowering the indications

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



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
-
- 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



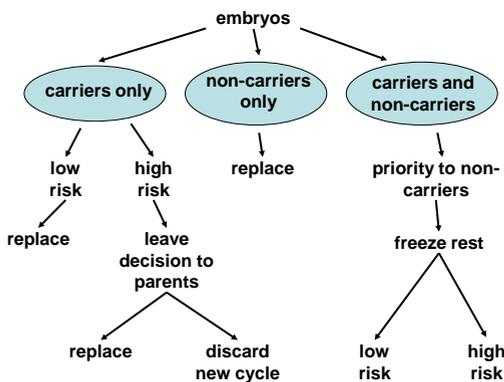
Deviations from the "medical model"

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'

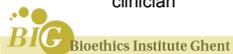
→ Difficulty:

- 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

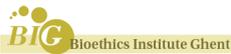
Conditional treatment is ethically problematic because it conflicts with

- a) the rule of non-directiveness, and*
- b) 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, ...



Microarray screening

- 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.

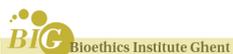
2. If the projects conflicts with the principles of responsible parenthood and good clinical practice, the clinician can impose conditions for her collaboration or can refuse further assistance.

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



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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.’ (Oktay 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)

http://www.dh.gov.uk/en/Publicationsandstatistics/Legislation/Actsandbills/DH_080211 (Details and full text of the Act)

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

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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

Demographics

- 10 HIV+ men: aged 29 to 46 years
- 10 HIV+ pregnant women: aged 19 to 32 years
- 10 HIV+ non-pregnant women: aged 22 to 38 years
- 5 HIV counsellors : aged 23 to 39 years
 - 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 ½ 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"

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- Northern Sotho - Ke a leboga
- Shona - Tatenda
- isiXhosa - Ndiyabulela Enkosi
- Setswana - Reyaleboga
- isiZulu - Siyabonga, Ngiyabonga
- Siswati - Ngiyabonga
- Xitsonga - I nkomu
- Tshivenda - Ndo livhuwa
- isiNdebele - Ngjyanithokoza
- Sepedi - Ke a leboga

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"Your count is zero" – Counselling the infertile man

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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

University Hospital Heidelberg – Institute of Medical Psychology – T. Wischmann – ESHRE, Rome 2010

2



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 (Bentz 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)

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3



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 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

(Webb & Daniluk 1999)

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)

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

(Holler 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
- With statistical approaches that keep matched pairs, differences between men and women are much smaller than testing the samples as independent groups

(Edelmann & Connolly 2000)

(Charamovitch 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)



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 man 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)



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!")

(Mall 1986; Thorsby & 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 (Smith et al. 2009)

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 (Drozdziel et al. 2009)



Every 9th of the probands was unable to produce the sperm needed for a second spermiogram after having been told about spermquality deficits identified in the first (Saleh et al. 2003)

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 (Shinderl et al. 2008, Gurkan et al. 2009)

As many as 45.4% of 487 men interviewed at a reproductive medicine clinic reported that sex "by the clock" (timed intercourse) is stressful (Grieb et al. 1997)



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 (O'Donnell 2007)

Preparatory information: booklets

This factor would improve knowledge of and passage through an IVF cycle:	Women (n = 117)	Men (n = 101)
• Booklet of information about practical aspects	54%	50%
• Video about IVF	22%	36%
• Booklet about psychological aspects of IVF	39%	34%
• Bibliography about IVF	24%	29%
• Meetings with a psychologist	26%	22%
• Discussion group	24%	8%
• Information meeting with other couples	13%	13%

(Laffont & Edelmann 1994)

Expectations towards psychosocial support

Considered the professional psychosocial services as important	Women (n = 1169)		Men (n = 1081)	
• Course about childlessness	14.3%	13.9%	8.6%	8.9%
• Professionally led support group	11.7%	10.0%	5.4%	4.1%
• Psychologist	20.8%	18.7%	8.3%	7.5%
• Sex therapist	10.7%	8.9%	6.6%	5.7%

Would participate if these services were available

(Schmidt et al. 2003)

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



Psychosoziale Beratung bei unerfülltem Kinderwunsch: die BKID-Checkliste für Paare

Liabes Paar mit Kinderwunsch,
 sich ein Kind zu wünschen und darauf lange warten zu müssen, dies wird von vielen Paaren und vor allem Frauen als starke psychische Belastung wahrgenommen. Häufig wird der Kinderwunsch Anderen gegenüber verbalisiert, da das Thema immer noch tabuisiert ist. Wenn dazu noch eine aufwändige und auch nicht in jedem Fall erfolgreiche medizinische Behandlung hinzukommt, kann diese Situation selbst ein ansonsten emotional stabiles Paar an den Rand der Belastungsfähigkeit bringen. Spätestens jetzt sollten Sie sich überlegen, eine psychosoziale Kinderwunschberatung in Anspruch zu nehmen, wie sie von den BeraterInnen von BKID angeboten wird. Die folgende BKID-Checkliste kann Ihnen helfen, ob Sie diese Beratung anfragen sollten.

<input type="checkbox"/> „Als Paar haben wir kein anderes Thema mehr als den Kinderwunsch und die medizinische Behandlung.“	<input type="checkbox"/> „Ohne eigenes Kind empfinde ich mein Leben als steinlos.“
<input type="checkbox"/> „Wenn ich Schwangeren oder Frauen mit Baby begegne, möchte ich am liebsten die Straßenseite wechseln, Familienfeste besuchen mich inzwischen oft.“	<input type="checkbox"/> „Da der Befund bei mir liegt, denke ich darüber nach, mein/e PartnerIn freizugeben, damit der/ihre Kinderwunsch in neuer Partnerschaft erfüllt werden kann.“
	<input type="checkbox"/> „Wir haben uns von früheren“



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.

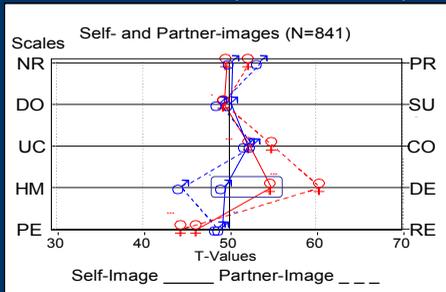
Polarization

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



Polarization in couple's relationship



Legend:
 NR=negative response DO=dominant UC=uncontrolled HM=hypomanic PE=permeable
 PR=positive response SU=submissive CO=compulsive DE=depressive RE=retentive

(from: Wischmann et al. 2002)



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 & Donnar 2007)



Your count is zero

"One in seven couples today have a problem with fertility. While medical techniques for helping some couples continue to advance, for others there is no hope. For those of us in the latter category it is an inexpressible nightmare punctuated with operative procedures, probing personal questions, and frightful expenses. It is also the death of a dream." (Boyd 1988, p. 4)



Men in Non-Western vs. Western societies

Table II Mean T scores among antenatal clinic with their partners

SCL-90-R scales	Study group ^a
Somatization	53.6 (11.6)
Obsessive compulsive	57.9 (11.4)
Interpersonal sensitivity	59.7 (10.8)
Depression	58.7 (10.3)
Anxiety	56.2 (11.9)
Anger—hostility	55.7 (10.9)
Phobic anxiety	58.2 (11.1)
Paranoid ideation	59.8 (10.0)
Psychoidism	58.9 (10.5)
Global severity index	59.7 (10.7)
PSDI ^b	56.9 (10.7)
Positive symptom total	58.2 (9.0)

^aValues are unadjusted mean T scores (SD); ^bmean confidence interval.
^cPSDI = Positive Symptom Distress Index.

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

Symptom Checklist 90-R Scales	Women (n = 562)	Men (n = 539)
Somatization	51.9 ± 12.2***	51.4 ± 11.5***
Obsessive/compulsive	50.3 ± 11.4	48.9 ± 10.1*
Interpersonal sensitivity	51.1 ± 11.8**	49.7 ± 11.5
Depression	51.9 ± 12.2***	49.3 ± 10.6
Anxiety	52.7 ± 13.4***	50.7 ± 10.7
Anger-hostility	51.2 ± 11.9**	50.8 ± 11.2
Phobic anxiety	51.5 ± 14.7***	50.1 ± 11.7
Paranoid ideation	50.8 ± 11.9	50.9 ± 11.8*
Global severity index	51.1 ± 12.7*	49.2 ± 11.7
Positive symptom distress index	51.6 ± 10.2***	49.7 ± 7.8
Positive symptom total index	51.2 ± 12.4**	50.6 ± 12.0

Values are mean ± SD.
*P < 0.05; **P < 0.01; ***P < 0.001; reference population: mean = 50, SD = 10.
Psychoticism scale disregarded.

Wischmann et al. 2001



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



Lesley and Louise Brown with her son Cameron and Professor Robert Edwards at Bourn Hall - 12 July 2008 © Bourn Hall



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.

Human Fertility, June 2009; 12(2): 73-80

PSYCHOSOCIAL COUNSELLING

PART V. THIRD-PARTY REPRODUCTION		
17	Recipient Counselling for Donor Insemination Petra Thorn	305
18	Recipient Counselling for Oocyte Donation Patricia L. Sachs and Linda Hammer Burns	319
19	The Donor as Patient: Assessment and Support Linda D. Applegarth and Sheryl A. Kingsberg	339
20	Embryo Donation: Counselling Donors and Recipients Linda D. Applegarth	356
21	Surrogacy and Gestational Carrier Participants Hilary Hanafin	370

(From Covington & Hammer Burns 2009; Thorn & Wiedmann 2009)

German guidelines for psychosocial counselling in the area of gamete donation

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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

(Golombok et al. 1996, 2002, 2004)

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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

(Golombok et al. 1996, McWinnie 2001)

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)

(McWinnie 2001)

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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)

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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) (Mahstedt 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, Holler et al. 2007)
- Male factor infertility seems to be more stigmatized than other infertility diagnoses
- Men do indeed experience pain related to their infertility but feel they have few acceptable outlets for the expression of their distress (Webb & Daniluk 1999)
- A significant selection bias has to be considered in studies on men and their reactions to infertility

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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

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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



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Thank you for your attention!

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

Meredith Wheeler

B.A. Stanford University (USA)

Dip. Psych, Centre for Counseling & Psychotherapy
Education (UK)

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

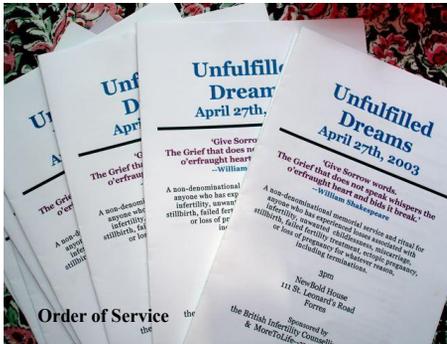


- Examples of private, self-created rituals
- Sanctioned public rituals

Elements of Good Ritual



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



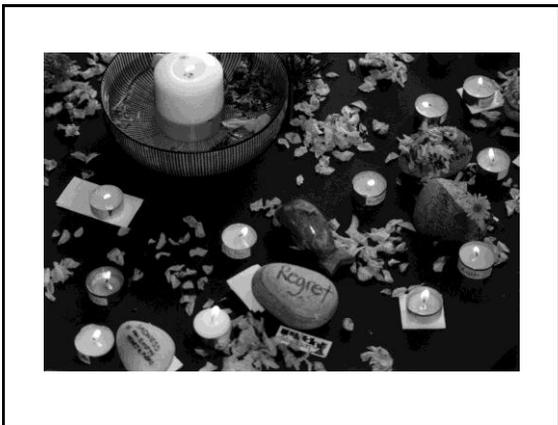
Order of Service



Ritual Space







Central Altar



Ritual Burning







Ritual object



Ritual Burning

Ritual Stones









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





Spiral ritual



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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Meredith Wheeler: www.meredithwheeler.org

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—with 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.

Appendix B

Silent prayer/meditation
Group Ritual—Give Sorrow Words

Music—Song for Athene
John Tavener

Reading: *The Prophet*
by Kahlil Gibran read by Jill

Reading: from a speech by Ted Mosney

Medical Interlude—Lean on Me

Prayer

Silent Prayer/Meditation

Blessing

Concluding Remarks

References will be covered in the Minutes.

BICA runs a referral service for anyone looking for a local counsellor knowledgeable about fertility issues. (www.bica.org)

Unfulfilled Dreams April 26th, 2009

Give Sorrow words.
The Grief that does not speak whispers the
overfought heart and bids it break.
—William Shakespeare

A non-denominational memorial ceremony for anyone who has experienced loss associated with infertility, unwanted stillbirths, miscarriage, stillbirth, neonatal death, failed fertility treatment, ectopic pregnancy or loss of pregnancy for whatever reason.

6:15pm

North Bank
28 Pages Lane
London

2

Appendix C

Welcome Meredith Wheeler

Dedication—Lighting the Candle

Musical Interlude—Carmina Burana Carl Orff

Reading—Once upon a Time
written and read by Hazel Hodge

Reading—Chance
a poem by Kurt Vonnegut read by Diana

Reading—The Pastoral Visitor
written by Harry Foadick read by Tomia

Musical Interlude—Prayin’
Eric Burdon

Statement of Purpose

Responsorial
Various participants read one line.

Everyone is invited to join in on the lines marked

All, in bold face.

I feel sorrow

What has been lost?

my baby

my child

my dream of the future

my chance to achieve

my chance to inherit

my grandkids

(silence)

I feel empty

All: We hoped to give love.

We meant we lost children.

Sometimes I feel like I’m being punished

So sometimes I punish my partner.

my family.

my friends.

myself

All: Help us be kind to each other and to ourselves.

I feel anger

I feel pain.

All: We pray for healing here.

I feel guilty.

Where will I find forgiveness?

All: We offer forgiveness to each other.

We seek to forgive ourselves.

We pray for forgiveness from the Creator of all life.

May our hearts be opened with compassion, not

closed in bitterness by our resentment.

All: We pray for the well being of all children,

everywhere, including those who came and went to

us.

All: May we all find healing.

May we all find peace.



USING THE INTERNET FOR FERTILITY HEALTH INTERVENTIONS AND RESEARCH

STRENGTHS AND LIMITATIONS

Laura Bunting PhD & Jacky Boivin PhD





Learning Objectives

2

- **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

3

Treatment Decision-Making Study (TDMS) (N=436)

International Fertility Decision-Making Study (IFDMS) (N=10043)



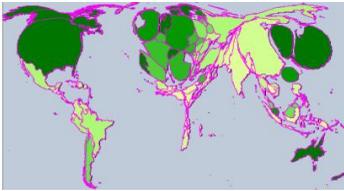
Fertility Status Awareness Tool (FertiSTAT) (N=603)





Internet use

4



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

www.davechaffey.com/Internet-Marketing/C3-Macro-environment

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Should we use the internet in health research and promotion?

5

- 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 (Etter, 2006; Teal & Shaw, 2005)
 - Online psychoeducational support for infertile women (Cousineau et al., 2008)
 - Set up and manage patient support groups (Gustafson et al., 2006; Kralik 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)

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Strengths of using the internet

6

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Strengths of using the internet

7

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)



<http://www.infertilitysource.com>

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Strengths of using the internet

8

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



http://s3.hubimg.com/u/21242_f520.jpg

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Strengths of using the internet

9

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 (Whehead, 2007)
 - 'Senior surfers' (Moore, 2005)
 - Disadvantaged teenagers (Valaitis & Sword, 2005)
 - People living with disabilities (Knight et al. 2002), depression (Andersson et al. 2005), dementia (Freeman et al., 2005)
- Support groups
 - Knowledge share and community building (Walch, 1999)

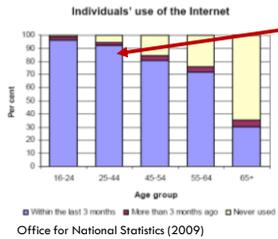
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Strengths of using the internet

10

Accessibility and interactivity



Over 90% of people who are of reproductive age use the internet

Office for National Statistics (2009)

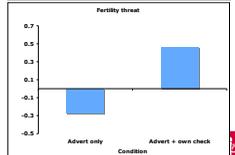
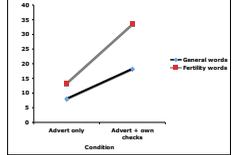


Strengths of using the internet

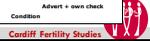
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Personalised health care

- 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)



Boivin et al. (In Prep.)



Strengths of using the internet

12

Personalised health care

Risk categories for lung cancer:

- Gender
- Age
- Family history
- Smoking history
- Environment
- Diet

Your Disease Risk
http://www.yourdiseaserisk.wustl.edu/

Results: Lung cancer
Compared to typical men your age, your risk is **very much above average**.

Screening Tip: There is no specific screening test for lung cancer. However, you should see your doctor if you have a cough that does not go away, or you have shortness of breath, chest pain, or coughing up blood.

Your Risk is: **Very much above average**

Keep up the good work!
You should think about things to lower your risk:
• You eat 5 or more servings of fruits and vegetables per week. [Learn more](#)



Potential intervention and research strengths

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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



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Potential intervention and research strengths

17

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

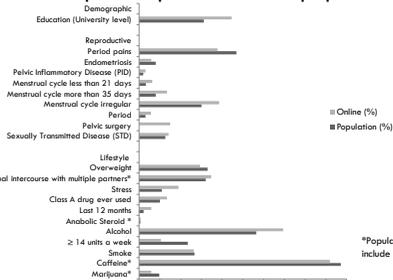


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Potential intervention and research strengths

18

Is the FertiSTAT sample comparable to the population?



Bunting & Balvin (2010) Human Reproduction doi:10.1093/humrep/dec087

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Potential intervention and research strengths

19

- 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, Survey Monkey



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Limitations of using the internet

20



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Limitations of using the internet

21

- **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



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Limitations of using the internet

25

- **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 criticised for focusing too much on young women when in reality the majority of cases are in older women (Office of National Statistics, 2004)

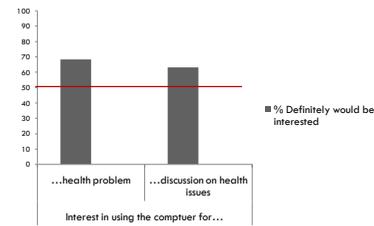


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Potential intervention and research limitations

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



Mattson et al. (2002)



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Potential intervention and research limitations

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- **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

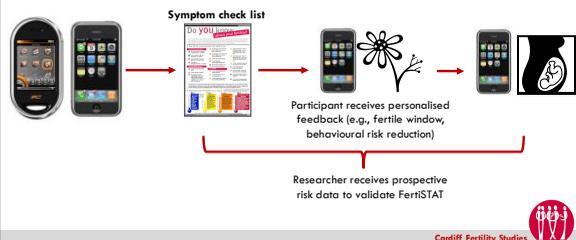


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Future development using the internet

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



MANY THANKS.

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Online interactive personal health records: Psychological aspects

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Wouter Tuij, PhD
Jan Kremer, PhD, MD
UMC Radboud Nijmegen
the Netherlands



Learning objectives

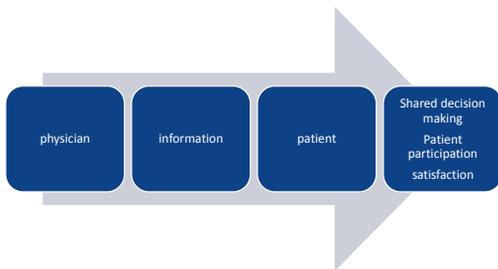
- To understand possibility for interactive personal health record
- To understand psychological aspects of interactive personal health records
- Insight into different kind of behaviours on internet
- To reflect on psychological issues in online personal health records
- To reflect on future directions

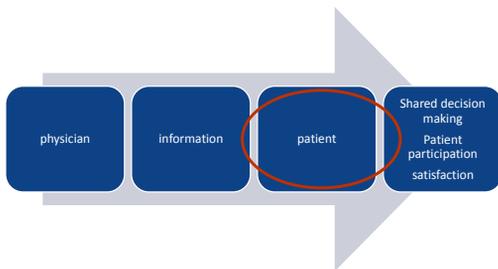
Objectives of the online personal health record

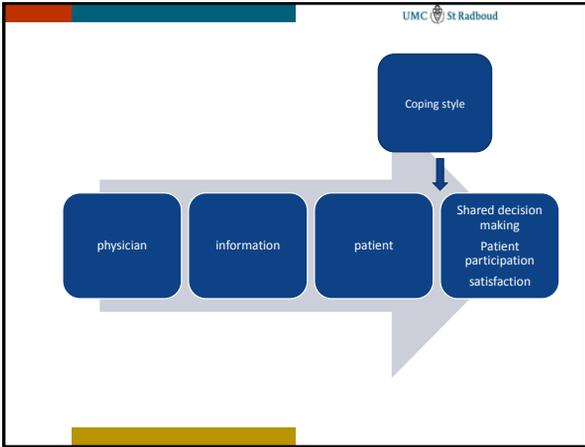
- Patient empowerment
- What is patient empowerment?
 - Knowledge
 - Shared decision-making
 - Self efficacy
 - Patient centered care
 - Satisfaction with care

Interactive online personal health record

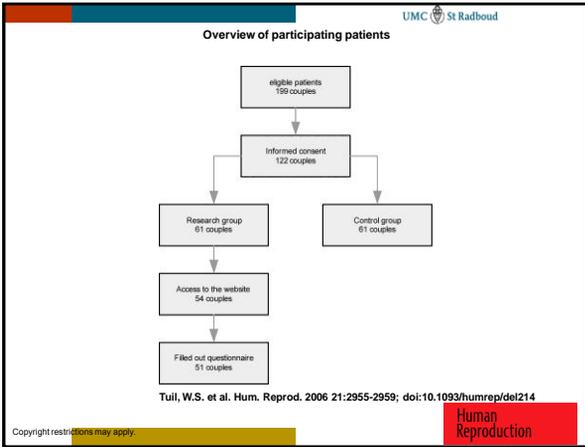
- General information
 - FAQ
 - Information clinic
 - Information treatment
 - Links
 - Literature
 - Video
- Personal information
 - Electronic medical record (EMR)
 - Day planner
 - Embryo photo
 - Personal prognosis
 - Correspondence
- Communication
 - Email
 - Forum
 - chat

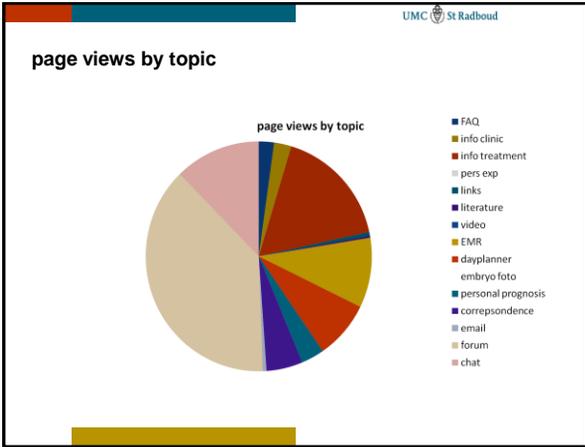


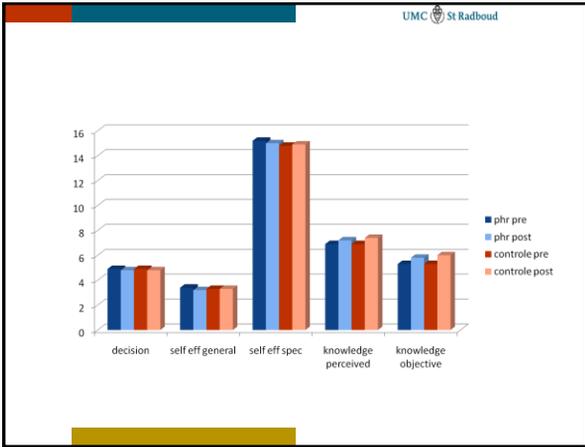


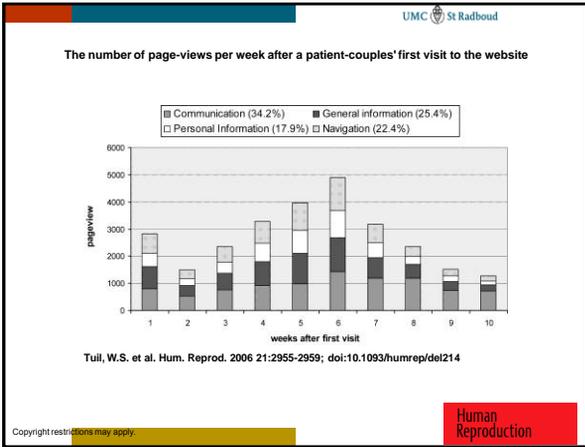


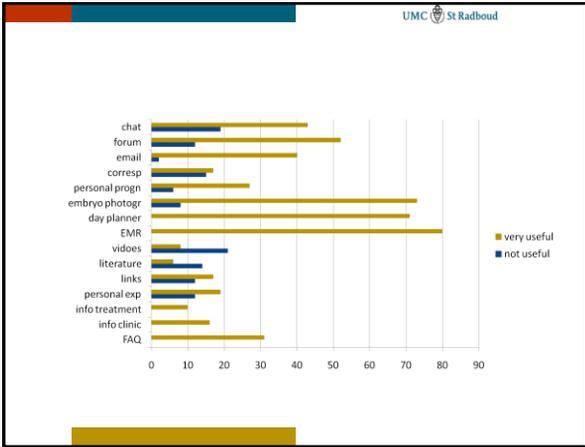
- UMC St Radboud
- ### Coping style
- Active versus passive
 - Regarding medical information:
 - Monitors > approaching threat/ information
 - Blunters > avoiding threat/ information

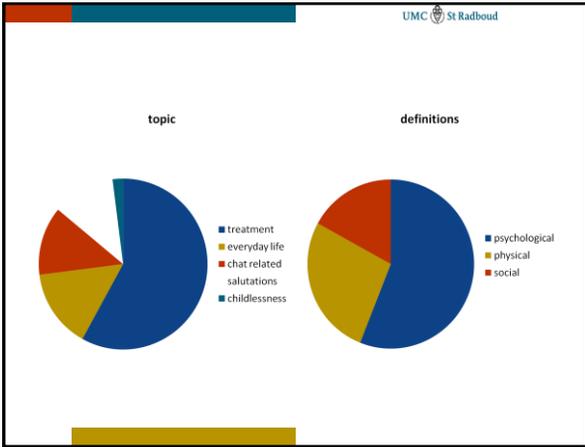










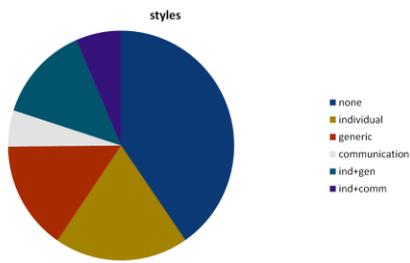


Content type	individual	Generic information	communication
Medical record	0.89	0.23	0.30
Treatment info	0.89	0.30	0.30
Personal prognosis	0.80	0.31	0.22
FAQ	0.67	0.40	0.12
Download docs	0.67	0.39	0.29
Dayplanner	0.46	0.41	0.23
Literature	0.20	0.71	0.17
General info	0.45	0.62	0.23
External links	0.25	0.62	0.17
Website help	0.20	0.61	0.13
Hospital info	0.48	0.60	0.23
Forum views	0.38	0.24	0.86
Forum posting	0.14	0.14	0.83
Chat	0.24	0.25	0.62

Relationship between online behaviour and psychological factors

	individual	Generic	Communication
Active coping			
Sharing emotions	--		
Cognitive coping			
Denial			
Anxiety depression			++

Combination of styles by number of patients



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 SIGS 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

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(see "Calendar")

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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

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