"Counselling in fertility treatment: changing content and measuring effectiveness"

SPECIAL INTEREST GROUP
PSYCHOLOGY AND COUNSELLING

7

28 June 2009
Amsterdam
The Netherlands

PRE-CONGRESS COURSE 7

Organised by the Special Interest Group Psychology and Counselling

Table of contents

Program overview **Page 3**

Speakers' contributions

The right to reproduce versus the welfare of the child: should formal assessment be a part of counselling? - ***Eric Blyth (United Kingdom)*** **Page 5**

The right to reproduce: should some patients be excluded because of age, sexual orientation, intellectual impairment or mental illness – ***Andrea Mechanick Braverman (USA)*** **Page 15**

Evidence based interventions: what exists and what is successful? – ***Jacky Boivin (United Kingdom)*** **Page 31**

The effect of psycho-social interventions: How to measure? – ***Christianne Verhaak (The Netherlands)*** **Page 53**

3 workshops:

- Training and supervision for infertility counsellors: who is qualified? - ***Linda Applegarth (USA)*** **Page 66**
- Clinical hypnosis for infertility – ***Philip Reilly (United Kingdom)*** **Page 77**
- Genetic counselling - ***Alison Lashwood (United Kingdom)*** **Page 83**

Presentation of the conclusions of the workshops

- Training and supervision for infertility counsellors: who is qualified? - ***Linda Applegarth (USA)*** **Page 99**

• Clinical hypnosis for infertility – ***Philip Reilly (United Kingdom)*** **Page 101**

• Genetic counselling - ***Alison Lashwood (United Kingdom)*** **Page 103**

Debate: Lifestyle and fertility treatment: Should women be excluded from treatment for smoking, obesitas, and eating disorders?

- pro: ***Human Fatemi (Belgium)*** **Page 105**
- 1 con: ***Jan Norré (Belgium)*** **Page 110**

Notes **Page 116**

PRE-CONGRESS COURSE 7 - PROGRAM

Counselling in fertility treatment: changing content and measuring effectiveness

Organised by the Special Interest Group Psychology and Counselling

Course co-ordinators: Patricia Baetens (Belgium) and Petra Thorn (Germany)

Course description: The integration of psychological counselling into reproductive medicine is a continuous process. The psychological concerns about the welfare of the child conceived with fertility treatment have changed, and will therefore change the practice of counselling. Moreover, the increasing importance of an evidence based approach in reproductive medicine obliges to develop procedures to assess the effectiveness of psychological counselling

Target audience: Counsellors involved in psychosocial guidance of couples having fertility treatments

09:00 - 09:30	The right to reproduce versus the welfare of the child: should formal assessment be a part of counselling? - ***Eric Blyth (United Kingdom)***
09:30 - 09:45	Discussion
09:45 - 10:15	The right to reproduce: should some patients be excluded because of age, sexual orientation, intellectual impairment or mental illness – ***Andrea Mechanick Braverman (USA)***
10:15 - 10:30	Discussion
10:30 - 11:00	**Coffee break**
11:00 - 11:30	Evidence based interventions: what exists and what is successful? – ***Jacky Boivin (United Kingdom)***
11:30 - 11:45	Discussion

11:45 - 12:15	The effect of psycho-social interventions: How to measure? – ***Christianne Verhaak (The Netherlands)***
12:15 - 12:30	Discussion
12:30 - 13:30	**Lunch**
13:30 - 14:30	3 workshops: • Training and supervision for infertility counsellors: who is qualified? - ***Linda Applegarth (USA)*** • Clinical hypnosis for infertility - ***Philip Reilly (United Kingdom)*** • Genetic counselling - ***Alison Lashwood (United Kingdom)***
14:30 - 15:00	Presentation of the conclusions of the workshops
15:00 - 15:30	**Coffee break**
15:30 - 16:30	Debate: Lifestyle and fertility treatment: Should women be excluded from treatment for smoking, obesitas, and eating disorders? *Moderators: Patricia Baetens (Belgium) and Petra Thorn (Germany)*
15:30 - 15:40	Introduction by the moderators
15:40 - 15:50	1 pro: ***Human Fatemi (Belgium)***
15:50 - 16:00	1 con: ***Jan Norré (Belgium)***
16:00 - 17:00	Discussion
17:00 - 17:30	Business meeting of the Special Interest Group Psychology and Counselling

The right to reproduce versus the welfare of the child: should formal assessment be a part of counselling?

Eric Blyth PhD

Professor of Social Work University of Huddersfield and
Hong Kong Polytechnic University
e.d.blyth@hud.ac.uk
http://www2.hud.ac.uk/hhs/staff/shumedb.php

Learning Objectives

1. The impact of assisted conception procedures on children
2. Professional and legislative provisions to safeguard the welfare of children
3. Operationalisation issues relating to child welfare requirements
4. Autonomy and the right to found a family
5. Safeguarding children's welfare through ensuring their non-existence
6. Equitable welfare of the child assessment
7. The role of counselling in welfare of the child assessment

Children born following assisted conception

1. More than 3.5 million children born worldwide as a result of IVF and other assisted conception procedures
2. >200,000 births p.a.(1%-4.2% of all births)

Remarkably little known about children

1. Leese: “the evidence base is not as robust as it should be. The field has been largely techniques driven . . . and the underlying science has to catch up, and we were struggling against the lack of good evidence, of safety and efficacy”.
2. Edwards: “accidental” discovery of ICSI, “. . . and within three months it was crossing the world . . . There was never any foresight in what might happen to that”.
3. Medical Research Council: “The evidence [that current assisted conception procedures are generally safe], particularly in terms of long-term safety, is relatively weak when compared to other similarly well-established clinical techniques”.

Legislative requirements 1

1. Canada Assisted Human Reproduction Act 2004 - children’s “health and well-being” to be given “priority”.
2. New Zealand Human Assisted Reproductive Technology Act 2004 - “children’s health and well-being” = an “important consideration”.
3. South Australia Reproductive Technology Act 1988 - children’s “welfare” to be treated as “paramount”.
4. Western Australia Human Reproductive Technology Amendment Act 2004 children’s “welfare” to be “properly taken into consideration”.

Legislative requirements 2

1. Victoria Infertility Treatment Act 1995 + Assisted Reproductive Treatment Act 2008 - “welfare and interests of persons born or to be born” to be treated as “paramount”.
2. New South Wales Assisted Reproductive Technology Act 2007 - “protection” of the interests of a person born as a result of assisted conception.
3. UK Human Fertilisation and Embryology Acts 1990 + 2008 - account to be taken of the welfare both of the child to be born and of “any other child who may be affected by the birth”.

Difficulties in operationalisating child welfare requirements

1. welfare requirements focus on a child who does not yet exist and therefore any assessment has to be made and decisions taken in the absence of direct evidence relating to the specific child.

2. welfare requirements promote discriminatory behaviour

Autonomy and the right to found a family 1

Reproductive autonomy = highly-prized human liberty

Jackson: "the freedom to decide for oneself whether or not to reproduce is integral to a person's sense of being, in some important sense, the author of their own life plan".

Autonomy and the right to found a family 2

Reproductive autonomy may no longer be restricted to the choice about having or not having a child. For some individuals at least, reproductive autonomy may mean the ability to choose the type of child they will have.

"Although I believe the desires of people with disability to use technology to deliberately choose to have a child with disability is wrong, I believe that if we are serious about respecting people's procreating autonomy, we should respect those decisions" (Savulescu, 2004: 104).

Reproductive autonomy and human rights

Universal Declaration of Human Rights

European Convention on Human Rights and Fundamental Freedoms

"respect for private and family life"

right "to marry and found a family"

Protecting individuals from unwarranted intervention

Interference permitted so long as it is:

not "arbitrary" (Universal Declaration of Human Rights)

"necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others" (European Convention)

Limits to reproductive autonomy

1. Individual does not have complete freedom to marry anyone he or she chooses or to have children.

2. No obligation on others to help individual to build a family.

3. 'the concern to protect the interest of the child …. can justify refusal of access to artificial procreation to persons not constituting a heterosexual couple or not living as a couple ….. Any right to give life which might flow from Article 12 could only operate in the context of a couple consisting of a man and a woman" (Council of Europe, 1989: 10).

Discrimination against those reliant on assisted conception

Since the state chooses not to restrict the reproductive autonomy of adults who are able to conceive a child without assistance, the selective interference in the reproductive autonomy of those who are reliant on assisted conception procedures to conceive a child = "invidious and opportunistic invasion of [their] privacy" (Jackson, 2002: 182).

Safeguarding children's welfare through non-existence

Harm must be so serious and the life to which a child is likely to be exposed "so bad it is not worth living" (Savulescu, 2002: 772).

"To give the highest priority to the welfare of the child is always to let that child come into existence, unless existence overall will be a burden rather than a benefit" (Harris, 2004: 77).

Problems with non-existence thesis

While individuals can display resilience, enjoy meaningful lives and even thrive in adversity or in spite of disadvantageous life situations, there is no justification in facilitating the birth of children into circumstances where their welfare would be in serious jeopardy.

"There is no such thing as the harm of non-existence …. No one is denied anything if there is no person who exists – there is no abandoned pre-existing soul" (Campbell, 2000: 38).

Equitable welfare of child assessment 1

Potential “contraindications” of eligibility for assisted conception services:
1. age
2. marital status
3. sexual orientation
4. serious mental health condition
5. life threatening illness
6. significant learning or physical disability
7. alcohol or drug misuse
8. conviction for a sexual or violent crime
9. child protection measures taken regarding an existing child(ren)
10. unwillingness to commit to disclosure of donor conception

Equitable welfare of child assessment 2

1. General presumption to provide services

2. Service providers to take all reasonable steps to satisfy themselves that child is unlikely to experience significant medical, physical or psychological harm or neglect.

3. Decision to deny treatment must be fair, transparent, founded on “substantial” evidence and subject to independent appeal

4. No unjustified discrimination on grounds of age, disability, gender, race, religious belief or sexual orientation

Equitable welfare of child assessment 3

Reasons for suspending “presumption to offer services”:
1. previous conviction relating to the harming of children;
2. child protection measures in respect of existing children;
3. previous conviction for a violent or sexual offence;
4. serious mental or physical condition;
5. drug or alcohol misuse;
6. medical history indicating that the child to be born is likely to suffer from a serious medical or physical condition.

Trigger for thorough evaluation of circumstances + risk assessment - not presumption NOT to provide service.

Counselling in welfare of child assessment 1

1. Undertaking assessment of parenting competence fundamentally inconsistent with "non directive" counselling approach?

2. Clients may be "less open" in counselling and less ready to discuss any concerns

3. Focus of discussion may be geared more towards personal deficits and potential risks to any child rather than towards strengths

4. Expectations regarding counsellor-client confidentiality may be compromised

Counselling in welfare of child assessment 2

1. Identification of risk factors may have positive impact on counsellor-client relationship.

2. May provide a clear focus for discussion and identification of areas and issues on which the client may need to work in order to improve emotional well-being and/or to avoid risks to themselves/child.

3. So may contribute to a more holistic counsellor-client relationship than merely serving a "gatekeeping" function.

Counselling in the United Kingdom

Lord Mackay:"...... [T]hrough counselling and discussion with those responsible for treatment [single women seeking treatment] may be dissuaded from having children once they have fully considered the implications of the environment into which their child would be born or its future welfare".

King's Fund Committee: "it will be impossible to separate the process of counselling from consideration of the welfare of the child".

Human Fertilisation and Embryology Authority: "in deciding whether to refuse treatment, the centre should take into account the views of all staff who have been involved with caring for the patient(s)".

BICA: Should be clear separation between the provision of professional counselling services and welfare of the child assessments.

Ethics Committee of American Society for Reproductive Medicine

Possible need for "evaluation by a mental health worker" if questions about the child-rearing capabilities of prospective parents arise.

Counselling in Victoria

1. Woman undergoing an assisted conception procedure and - where applicable - her partner, must first receive counselling from an "approved" counsellor.

2. Counsellor has statutory obligation to treat as "paramount" the "welfare and interests of persons born or to be born".

3. Where concerns arose about potential risk to a child or of parental capacity: "case-by-case" approach - decision to offer treatment "..discussed by a team of doctors, counsellors, a lawyer, and anyone else who may have an interest".

4. Assisted Reproductive Treatment Act 2008 (S 11) explicit requirement on counsellor to state that (s)he has sighted a criminal records check in relation to the woman and [if any] her partner."

Conclusion

While assessment may not be a generally accepted aspect of infertility counselling, the involvement of counsellors in undertaking welfare of the child assessments seems an entirely legitimate activity.

Furthermore, counsellors can make a positive contribution to ensuring that such assessments are undertaken in a manner that respects the legitimate interests of all parties.

Thank you

REFERENCES:

- Adamson, G., de Mouzon, J., Lancaster, P., Nygren, K.G., Sullivan, E. and Zegers-Hochschild, F. (2006) World collaborative report on *in vitro* fertilization, 2000. *Fertility and Sterility.* 85: 1586-1622
- Blackburn-Starza, A. (2008) Survey reveals concerns over new fertility procedures. BioNews 468: 28 July http://www.BioNews.org.uk/
- Brazier, M. (2004) *Minutes of Evidence taken before the House of Commons Science and Technology Select Committee: Human Reproductive Technologies and the Law.* 27 October. Ev. 119. In House of Commons Science and Technology Committee (2005) 'Human Reproductive Technologies and the Law' Fifth Report of Session 2004-05. Vol II: Oral and Written Evidence. http://www.publications.parliament.uk/pa/cm200405/cmselect/cmsctech/7/7ii.pdf
- British Fertility Society (1999) Recommendations for good practice - welfare of the child. *Human Fertility* 85. 2
- British Infertility Counselling Association (2004) Memorandum from the British Infertility Counselling Association to the House of Commons Science and Technology Select Committee: Human Reproductive Technologies and the Law. Appendix 32. Ev 292-294. In House of Commons Science and Technology Committee (2005) *op cit.*
- British Medical Association (2004) Memorandum from the British Medical Association to the House of Commons Science and Technology Select Committee: Human Reproductive Technologies and the Law, Appendix 12. Ev 225. In House of Commons Science and Technology Committee (2005) *op cit.*
- Campbell, A. (2000) Surrogacy, rights and duties: a partial commentary. *Health Care Analysis*, 8, 38.
- Council of Europe (1950) *Convention for the Protection of Human Rights and Fundamental Freedoms*, Strasbourg, Council of Europe. http://conventions.coe.int/treaty/en/Treaties/Html/005.htm
- Council of Europe (1989) *Human Artificial Procreation*, Council of Europe, Strasbourg.
- Donor Conception Network (2004) Memorandum from the Donor Conception Network to the House of Commons Science and Technology Select Committee: Human Reproductive Technologies and the Law, Appendix 47. Ev. 334. In House of Commons Science and Technology Committee (2005) *op cit.*
- Dworkin, R. (1993) *Life's Dominion*. London: Harper Collins.
- Edwards, R (2004) *Minutes of Evidence taken before the House of Commons Science and Technology Committee: Human Reproductive Technologies and the Law*, 24th November. Ev. 148. In House of Commons Science and Technology Committee (2005) *op cit.*
- Ethics Committee of the American Society for Reproductive Medicine (2004) Child-rearing ability and the provision of fertility services. *Fertility and Sterility* 82(3): 564-567.

- European Society for Human Reproduction and Embryology (2001) *Guidelines for counselling in infertility*. Grimbergen: ESHRE. www.eshre.com/file.asp?filetype=doc/04/005/003/psyguidelines.pdf
- Harris, J. (2004) *On Cloning: Th inking in Action*. London: Routledge.
- House of Commons Science and Technology Committee (2005) *Human Reproductive Technologies and the Law. Fifth Report of Session 2004–05.* Vol I . London: House of Commons. http://www.publications.parliament.uk/pa/cm200405/cmselect/cmsctech/7/7i.pdf
- Human Fertilisation and Embryology Authority (2005) *Tomorrow's Children: HFEA Report of the Policy Review of Welfare of the Child Assessments in Licensed Assisted Conception Clinics.* London: Human Fertilisation and Embryology Authority. http://www.hfea.gov.uk/docs/TomorrowsChildren.pdf
- Human Fertilisation and Embryology Authority (2009) Code of Practice (Draft 8th edn). London: Human Fertilisation and Embryology Authority.
- Jackson, E. (2007) Rethinking the pre-conception welfare principle. In Horsey, K. and Biggs, H. (eds) *Human Fertilisation and Embryology: Reproducing Regulation.* London: Routledge-Cavendish.
- Kennedy, R (2004) *Minutes of Evidence taken before the House of Commons Science and Technology Committee: Human Reproductive Technologies and the Law*, 8th December. Ev. 168. In House of Commons Science and Technology Committee (2005) *op cit*.
- King's Fund Centre (1991) *Counselling for Regulated Infertility Treatments: the report of the Counselling Committee*. London: King's Fund Centre.

- Mackay, Lord (1990) *Official Report*, House of Lords, 6th March, col. 1098
- McClure , N. (2004) Oral Evidence to the House of Commons Science and Technology Select Committee: Human Reproductive Technologies and the Law.14 June. Ev. 12. In House of Commons Science and Technology Committee (2005) *op cit*.
- Medical Research Council (2004) *Assisted Reproduction: A Safe, Sound Future*. London: Medical Research Council. http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC002393
- Merricks, W. (2004) *Minutes of Evidence taken before the House of Commons Science and Technology Committee Human Reproductive Technologies and the Law*, 30th June. Ev. 32. In House of Commons Science and Technology Committee (2005) *op cit*.
- Mumford, S. E., Corrigan, E. and Hull, M. G. R. (1998) Access to assisted conception: a framework of regulation. *Human Reproduction* 13(9): 2349-2355.
- Royal College of Obstetricians and Gynaecologists (2004) *Minutes of Evidence taken before the House of Commons Science and Technology Select Committee: Human Reproductive Technologies and the Law*. Ev. 283. In House of Commons Science and Technology Committee (2005) *op cit*.
- Savulescu , J. (2002) Deaf lesbians, 'designer disability', and the future of medicine. *British Medical Journal* 325: 771-773.

- United Nations (1948) *Universal Declaration of Human Rights,* Geneva: United Nations.
- Victorian Law Reform Commission (2007) *Assisted Reproductive Technology and Adoption: Final Report.* Melbourne: Victorian Law Reform Commission. http://www.lawreform.vic.gov.au/CA256902000FE154/Lookup/Assisted_Reproductive_Technology_and_Adoption/$file/ART%20&%20Adoption%20Report%20FINAL.pdf
- Williams, D. and Irving J. (1998) Counselling is not assessment *Journal of Fertility Counselling* 5(1) 13-15.

The right to reproduce: should some patients be excluded because of age, sexual orientation, intellectual impairment or mental illness

Andrea Mechanick Braverman, Ph.D.
Director of Psychological and Complementary Care
RMA NJ

Nothing to Disclose

Who Decides Access? And on what basis?

- Individual
- Practice
- Individual Practitioner
- ESHRE or ASRM
- Mental Health Professional Groups
- Federal Government
  - not yet in the United States but exists on individual state level
- Insurance Companies - Financial

Where are the data to decide?

Personal Values vs. Social Values

- Offering services to patients may conflict with personal or social values
  - Single parents
  - Age limits
  - Gay and lesbian couples
  - Gender selection/family balancing
  - Public assistance participants
  - History of medical or mental illness
  - Criminal History
- National differences and/or regional differences

Program's Beliefs about Screening Candidates

Statement	% Agree or Strongly Agree
Everyone has a right to have a child	59
It is wrong for me to help bring a child into the world to be cared for by a parent who would be unfit in some way	62
It is acceptable for me to consider a parent's fitness before helping them conceive a child	70
I do not have right to try to stop anyone from attempting to conceive a child	43
I do have the right to decide who is and is not a fit parent	44
I have the responsibility to consider a parent's fitness before helping them conceive a child	64
Gurmankin, Caplan & Braverman, 2004	

% Programs Allowing Relatives to Be Gamete Donors

Gurmankin, Caplan & Braverman, 2004

Relation to Donor	% Allowing Donor
Man's brother (has children)	73
Man's brother (no children)	67
Woman's sister (has children)	87
Woman's sister (no children)	79
Woman's mother	18
Man's father	29

Arguments for unlimited access:

- Procreative liberty (Robertson)
- No harm to child or society
- Fairness – spontaneous conception does not have selective access
- Bringing a loved and desired child into society

Arguments for selective access:

- No medical problem that is being treated (single parents or gay parents)
- Resources
- Clinic or individual beliefs that conflict with choice
- Yuck factor? (parenting over an older age)

Slippery Slope with the Yuck Factor

To me, old age is always fifteen years older than I am.
Bernard Baruch

ASRM Ethics Committee (2004)

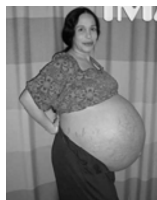
- Fertility programs may withhold services from prospective patients on the basis of well-substantiated judgments that those patients will be unable to provide or have others provide adequate child-rearing for offspring

Whose judgments and with what basis for decision-making?

ASRM Ethics Committee (2004)

- Fertility programs should develop written policies and procedures for making determinations to withhold services on the basis of concerns about the child-rearing capacities of prospective patients

Concerns personally/culturally biased



Clinics Have the Right

- To set policy
- To make judgments
- To be profitable

Patients Have the Right To

- Access to services
- Professional care
- Unprejudiced treatment

These two sets of rights can end up being a wrong

to the patients, treatment team, offspring or society

Remember that….

Resistance to Regulation

- American culture emphasizes individual choice
- Individuals and clinics have set the parameters for acceptance & rejection
  (Gurmankin, Caplan & Braverman, 2004)
- Procreative liberty (Robertson, 1994) is reflective of societal support for individual liberty

Pros of National Regulations and/or Guidelines

- Equal treatment for all individuals & couples pursuing treatment
- Protect the individual from dangerous or unethical treatment
- Protects society's interests (e.g. multiple births)

Cons of National Regulations and/or Guidelines

- Unfair burden on individuals/couples who have a medical issue creating a dual standard for parenthood
- Can increase costs for services & can limit access
- Specter of eugenic policies
  (Gurmankin, Caplan & Braverman, 2004)

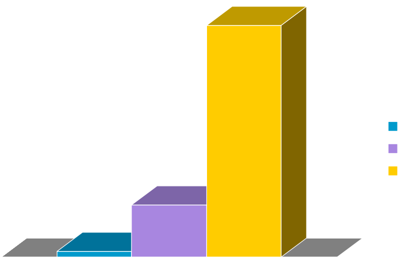
Current practices: USA

- Majority of programs do not have formal policy for screening candidates
- Majority of program directors agree that they have a responsibility to screen candidates
- Majority of programs are "very" to "extremely likely" to turn away candidates under certain circumstances
- Average of 4% turned away annually

Gurmankin, Caplan & Braverman, 2004

If we do decline, who is doing the declining?

Non-Medical Consultations for Candidates

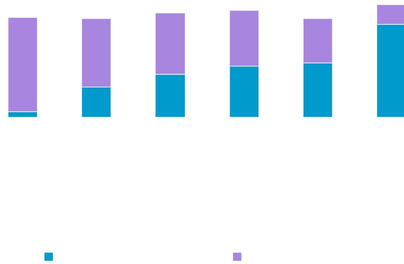


Gurmankin, Caplan & Braverman, 2004

And are we certain of our professional judgment?

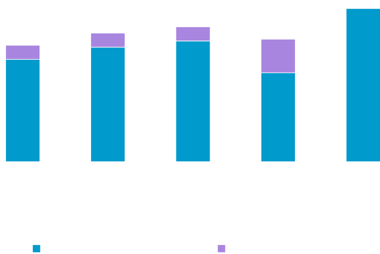
Programs' likelihood of turning away hypothetical candidates

Gurmankin, Caplan & Braverman, 2004



Programs' likelihood of turning away hypothetical candidates

Gurmankin, Caplan & Braverman, 2004



What's the Evidence for our Decisions?

- There are data for certain mental illness diagnoses and parenting outcome, e.g. untreated schizophrenics
- However, it is not evidence based medicine we're practicing in many cases

Biases in Decision-Making

- Personal yuck factor
- Group yuck factor
- Religious background
- Social and socioeconomic factors
- Cultural factors

One person's genius is another person's folly….

So for example….

How Old is Too Old?

How old is too old?

	% comfortable	% uncomfortable
Intended Parents <45	82.1	9.9
Intended Parents >50 but <55	16.6	70.2
Intended Parents >55 but <60	10.1	69.7

Braverman, Scott & Fraterrelli, 2007 ASRM

Data on Older Parents

- Compared matched mothers in 30's, 40's & 50's
- Mental functioning higher in 50's than 30's & national female scores
- Physical functioning non-significant among groups but n.s. lower in 50's than 30's
- Parenting stress low in cohort

Steiner AZ & Paulson RJ (2007)

Who is okay to be a parent?

	% comfortable	% uncomfortable
Recipients of different religions	88.7	5.3
Recipients with terminal illness	26.4	48.0
Recipients with psychiatric diagnosis	21.9	48.4

Braverman, Scott & Fraterrelli, 2007 ASRM

How Comfortable Are We With Same Sex Couples and ART?

	% Comfortable
Same sex female couple: using sperm donation	76.8
Same sex female couple: using IVF one providing eggs, one carrying	64.9
Same sex male couple: using IVF and gestational carrier	53.6

Braverman, Scott & Fraterrelli, 2007 ASRM

Who makes the decisions about access?

- Should we deny access for mental health status?
- Should we limit number of children per parent?
- Should donors be told the outcome of their cycles?
- Should we do transgenerational donations?
- Who decides age limits for recipients?

Is litigation the way to make policy?

"The men are excited about getting to shoot a lawyer."

Access to Services: Who Decides?

- Single parents
- Age limits
- Gay and lesbians
- Public assistance participants
- History of medical or mental illness
- Criminal History

Who decides?

- The fox guarding the hen house…...
- Whose agenda?
  - Physician
  - Mental Health
  - Politician
  - Clergy
  - Consumer

"Then it's moved and seconded that the compulsory retirement age be advanced to ninety-five."

How to Limit?

- Should we limit services to those who have no children or only one child? (the more children, the less financial resources available….)
- Who determines the burden on society by age or ability to support the children
- Should economic status be a consideration for individuals or couples?
- *Are not informal assessments done all the time by nurses and/or doctors?*

And Whose Burden?

- Limitations on the number of embryos transferred?
  - "Yes" in many countries but "no" in others. What burden is then conferred and on whom?
- Society has the burden of the neonatal care, special education services, etc.
- Insurance companies or government have economic impact of the multiples (passed on to the consumer?)

February 11, 2009
The New York Times

Aspects of the yuck factor or reproductive wrongs?

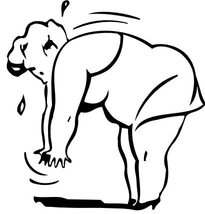
- Sense of responsibility to the offspring vs. individual right to procreative choices
- How do we measure the yuck factor?

Virginia student has fathered 120 children… so far

What is Emotional & Mental Fitness for Intended Parents or for Gamete Donors?

- Measure psychopathology = heritability?
- Measure psychopathology = compliance?
- Measure psychopathology = parenting ability?
- We screen gamete donors for fitness
  - (but different for sperm & egg donors)

But what is mental fitness????



Mental Fitness

Ability to make independent, informed decisions for donors?
OR
Ability to parent for recipients?

If we are judging on mental fitness as ability to make informed & independent decisions then….

- Age is no longer an issue (within reason)
- Finances are no longer an issue
- Don’t worry about sexual preference

How crazy is too crazy?

If psychotropic medication usage is the measure then….

What percentage of the room can raise their hands…

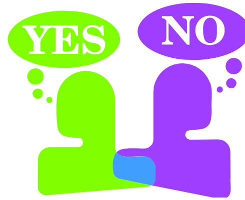
- 34 million American adults with depression
- Women 2x greater than men to have depression
- 19 million American adults with anxiety

We must be careful when asking…

Policies for Determining Emotional & Mental Fitness

The slope is slippery

- Attitudes have changed over the decades
- Cultural norms are different
- We are a world of many cultures, religions and beliefs



Evidence-based interventions: What exists & what is successful

Jacky Boivin, Ph.D., CPsychol
School of Psychology
Cardiff University

ESHRE
Amsterdam, 2009

1

Disclosure

- ASRM, ESHRE and Merck-Serono jointly sponsored the FertiQoL project

Learning objectives

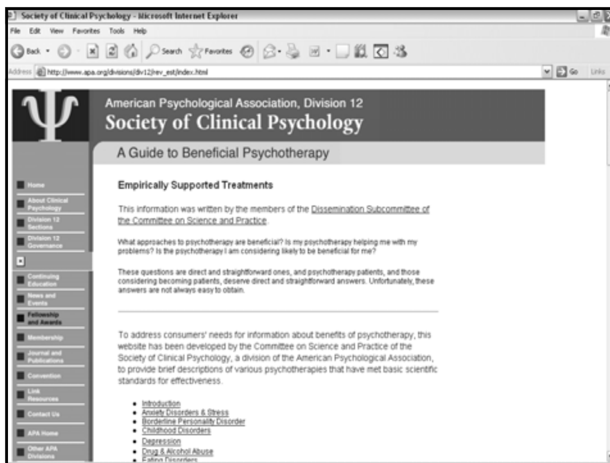
- Understand context of evidence-based psychosocial interventions
- Describe the types of interventions that exist in infertility and their effect on well-being and pregnancy rates
- Learn about interventions tailored to the treatment environment
- Identify gaps in knowledge about effective interventions

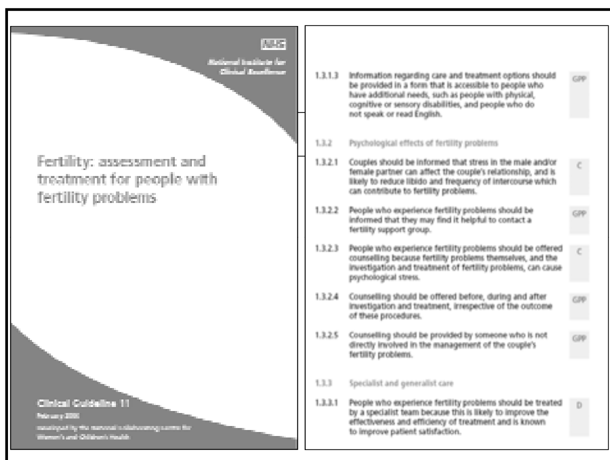
3

Evidence based interventions aim to formalise intuitive knowledge about what works in practice

- Experience ("gut feeling") and clinical judgement
  - Observed & patient reported improvement
  - Referrals & demand for services
- Clinically oriented methods of monitoring
  - Case supervision
  - Consultation with colleagues
- Science-based methods of evaluation
  - Observational cohorts
  - Randomised controlled trials

4





Chronology of psychosocial interventions

- Psychosomatic interventions
- Infertility Counselling
- Pre-treatment assessment
- Mind/body programs
- Life style modification

7

"Infertility is a crisis with many dimensions"

Barbara Eck Menning (1980) The emotional needs of infertile couples. *Fertility Sterility*, 34, 313-319.

Promoted interventions to help people cope with childlessness

8

Effects of childlessness…

- Mood: depression, anxiety
- Self-esteem
- Psychological adjustment
- Marital adjustment
- Sexual adjustment
- Social Adjustment
- Femininity/Masculinity
- Psychiatric symptoms
- Attributions & life meaning

- As a function of…
  - Gender
  - Ethnicity
  - Parity
  - Age
  - Diagnosis
  - Stages or type of Tx
  - Duration infertility
  - Repeated Tx
  - Tx success

Wright et al., 1989; Greil, 1997

9

Tasks & goals of psychosocial approaches in infertility counselling

- Couples encouraged to identify, “work through” and thereby resolve the syndrome of feelings that accompany infertility/childlessness

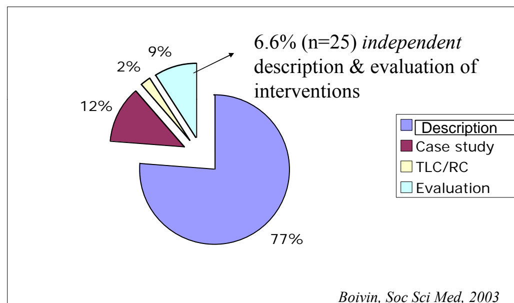
Menning, 1979; Mahlstdedt, 1985

- Reduction of distress
- Improve interpersonal relationships, especially marital
- Motivation, attitudes and expectations re: parenthood
- Address grieving process
- Cope with failure, childless future

Ningel & Strauss (2002)

10

N=380 studies recommending psychosocial interventions in infertility



Boivin, Soc Sci Med, 2003

1

Studies	Type of intervention	Duration (weeks)	Format	Follow-up time
Counselling				
• Holzle et al. 2002	Infertility couns	7	Couple	3 months
• Strauss et al. 2002	Infertility couns	9	i/c	not stated
• Emery et al. 2001	Infertility couns	1	couple	1.5 months
• Christie & Morgan, 2000	Psychoanalytic	not stated	group	no stated
• McNaughton-Cassill et al. 2000	CBT	3	group	immediate
• Wischmann et al. 2001, 2002	Infertility couns	2 or 10	couple	3 months
• Kemeter & Fiegl, 1999	Psychodynamic	1 or 2	couple	immediate
• Pengelly et al. 1995	Infertility couns	3	couple	not stated
• Connolly et al. 1993	Infertility couns	3	couple	1.5 months
• Liswood, 1995	CBT	6	couple	immediate
• Bents, 1991	CBT	15	couple	4 months
• Brandt & Zech, 1991	Infertility couns	4	couple	10 months
• Sarrel & deCherney, 1985	Psychodynamic	2	couple	18 months
• Ellenberg & Koren, 1982	Psychoanalytic	32	individual	36 months
• Bresnick & Taymor, 1979	Psychodynamic	5+	i/c	not stated
Focussed educational programs				
• Tuschen-Caffier et al. 1999	Sex therapy	32	couple	6 months
• McQueeney et al. 1997	Coping training	6	group	18 months
• Stewart et al. 1992	Support/stress red	8	group	immediate
• Takefman et al. 1990	Prep information	12	couple	6 months
• Wallace 1984, 1985	Prep information	1	individual	1.5 months
• O'Moore et al. 1983	Autogenic training	10	group	two months
Comprehensive educational				
• Domar et al. 2000a, 2000b	Mixed	10 weeks	group	12 months
• Domar et al. 1990	"	"	"	6 months
• Domar et al. 1992	"	"	"	"
• Clark et al. 1995, 1998	Mixed	24 weeks	group	12 months

Table 1:Boivin, Soc Sci Med 2003

Intervention effects on all outcomes (■ = positive intervention; □ no intervention effect).

Counselling	1	2	3	4	5	6	7	8	9	10	11	12	13
• Holzle et al. 2002							□		□				
*• Strauss et al. 2002							□		□		■	■	□
*• Emery et al. 2001	□			□									□
• Christie & Morgan, 2000													
• McNaughton et al. 2000												■	
* Wischmann et al. 2001 -02							□		□		■		□
• Kemeter & Fiegl, 1999													
• Pengelly et al. 1995												■	
*• Connolly et al. 1993			□	□	□	□			□	□		■	
*• Liswood, 1995							□		□	□			
• Bents, 1991								■	■		■		
• Brandt & Zech, 1991													
*• Sarrel & deCherney, 1985													■
• Ellenberg & Koren, 1982													
• Bresnick & Taymor, 1979											■		
Focussed education program													
*• Tuschen-Caffier 1999									■			■	
• McQueeney et al. 1997	■							■			■	■	■
*• Stewart et al. 1992	■	■					■					■	
*• Takefman et al. 1990	□			□					□		■		□
*• Wallace 1984, 1985			□	■	□							■	□
• O'Moore et al. 1983				■									
Comprehensive educational													
*• Domar et al. 2000a, 2000b	□	□	□	■	■				■			■	
• Domar et al. 1990			■	■	■								
• Domar et al. 1992			□	■	■								
• Clark et al. 1995, 1998		■				■							

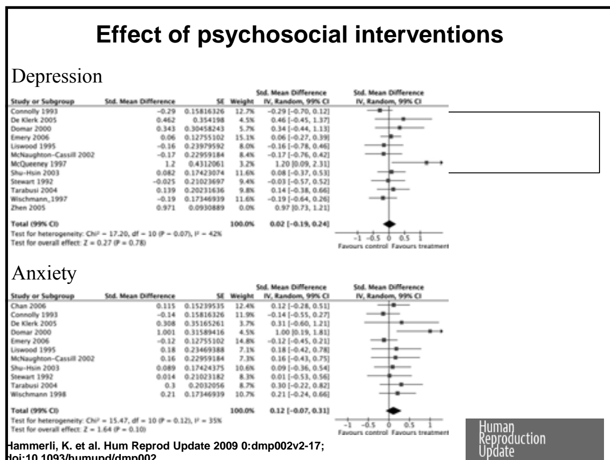
Table 1: Boivin, Soc Sci Med 2003

Table 5 Intervention effects on pregnancy rates and effect sizes (r-statistic).

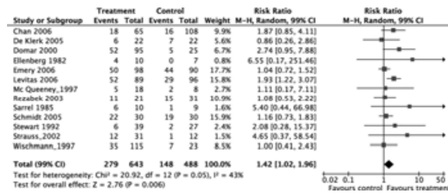
Studies	Pregnancy rate	Effect size (r)
Counselling		
• Holzle et al. 2002	excluded	
*• Strauss et al. 2002	□	.285
*• Emery et al. 2001	□	.039
• Christie & Morgan, 2000	excluded	
• McNaughton-Cassill et al. 2000		
*• Wischmann et al. 2001, 2002	□	.016
• Kemeter & Fiegl, 1999		
• Pengelly et al. 1995		
*• Connolly et al. 1993		
*• Liswood, 1995		
• Bents, 1991		
• Brandt & Zech, 1991	excluded	
*• Sarrel & deCherney, 1985	■	.506
• Ellenberg & Koren, 1982	excluded	
• Bresnick & Taymor, 1979		
Focussed educational program		
*• Tuschen-Caffier et al. 1999	■	.928
• McQueeney et al. 1997	excluded	
*• Stewart et al. 1992	□	.177
*• Takefman et al. 1990	□	.000
*• Wallace 1984, 1985		
• O'Moore et al. 1983	excluded	
Comprehensive educational		
*• Domar et al. 2000a, 2000b	■	.258
• Domar et al. 1990		
• Domar et al. 1992		
• Clark et al. 1995, 1998	excluded	

Excluded = Did not use a Control condition/RA

Boivin, Soc Sci Med 2003



Effect of psychosocial interventions on pregnancy rates



Study or Subgroup	Treatment Events	Treatment Total	Control Events	Control Total	Weight	Risk Ratio M-H, Random, 99% CI
Chan 2006	18	65	16	108	9.9%	1.87 [0.85, 4.11]
De Klerk 2005	6	22	7	22	5.6%	0.86 [0.26, 2.86]
Domar 2000	52	95	5	25	6.7%	2.74 [0.95, 7.88]
Ellenberg 1982	4	10	0	7	0.8%	6.55 [0.17, 251.46]
Emery 2006	50	98	44	90	17.7%	1.04 [0.72, 1.52]
Levitas 2006	52	89	29	96	15.8%	1.93 [1.22, 3.07]
Mc Queeney, 1997	5	18	2	8	2.7%	1.11 [0.17, 7.11]
Rezabek 2003	11	21	15	31	10.9%	1.08 [0.53, 2.22]
Sarrel 1985	6	10	1	9	1.6%	5.40 [0.44, 66.98]
Schmidt 2005	22	30	19	30	15.9%	1.16 [0.73, 1.83]
Stewart 1992	6	39	2	27	2.4%	2.08 [0.28, 15.37]
Strauss, 2002	12	31	1	12	1.5%	4.65 [0.37, 58.54]
Wischmann, 1997	35	115	7	23	8.5%	1.00 [0.41, 2.43]
Total (99% CI)	**279**	**643**	**148**	**488**	**100.0%**	**1.42 [1.02, 1.96]**

Test for heterogeneity: $Chi^2 = 20.92$, $df = 12$ ($P = 0.05$), $I^2 = 43\%$
Test for overall effect: $Z = 2.76$ ($P = 0.006$)

Hammerli, K. et al. Hum Reprod Update 2009 0:dmp002v2-17; doi:10.1093/humupd/dmp002

Copyright restrictions may apply.

Human Reproduction Update

Interventions to change unhealthy lifestyle habits

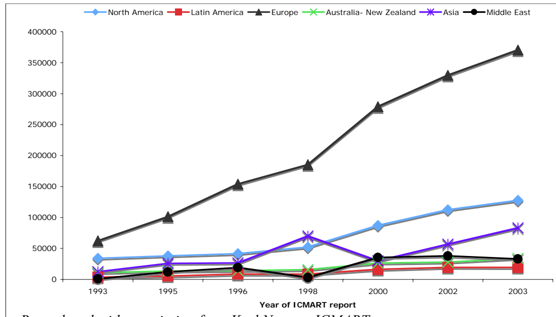
Type	hMG dose	Peak E2	No.oocytes
Non-smokers	29	1869	16
Passive smoker	32	1720	12
Active smoker	37	891	8

Paskowski et al. 2002

New psychosocial challenges

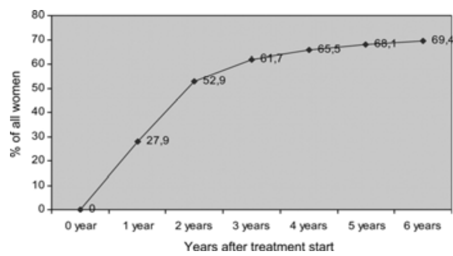
- Helping people initiate treatment and tolerate an optimal number of cycles
  - Fertility awareness & treatment initiation
  - Treatment burden
    - Treatment stress
    - Treatment dropout
  - Ending treatment

Worldwide increase in ART cycles



Reproduced with permission from Karl Nygren, ICMART

Cumulative percentage of the initial cohort in the 1338 women (study population I) with at least one delivery after 5 years of follow-up based on complete follow-up data from the National Medical Birth Register



Pinborg, A. et al. Hum. Reprod. 2009 24:991-999; doi:10.1093/humrep/den463

Copyright restrictions may apply.

Human Reproduction

Chronology of interventions

- Psychosomatic interventions
- Infertility Counselling
- Pre-treatment assessment
- Mind/body programs
- Life style change
- Public health fertility awareness campaigns
- Online information and support interventions
- Brief coping interventions tailored to demands of treatment

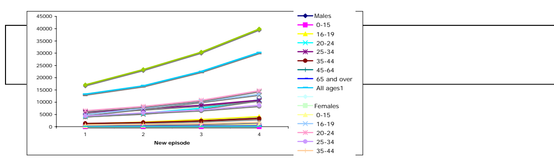
21

People do not behave optimally when it comes to their fertility

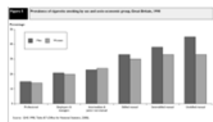
- People do not take care of their fertility
- People do not seek medical treatment when they have a problem

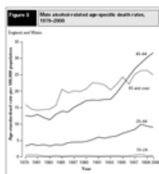
22

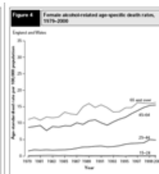
People do not take care of their fertility



Source: UK Public Health Laboratory Service, Table 7.7; 1995, 1997,1999, 2001







Source: UK Office National statistics, 2003

Public health campaigns about the risk factors for fertility problems

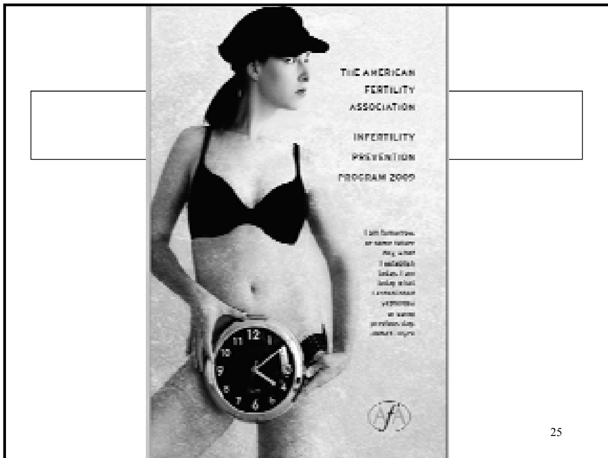
ADVANCING AGE DECREASES YOUR ABILITY TO HAVE CHILDREN.

PRACTICING SAFE SEX NOW, PROTECTS YOUR ABILITY TO HAVE CHILDREN LATER.

IF YOU SMOKE THIS MIGHT BE YOUR ONLY USE FOR A BABY'S BOTTLE.

AN UNHEALTHY BODY WEIGHT MAY PREVENT YOU FROM HAVING CHILDREN.

ASRM ≈2006

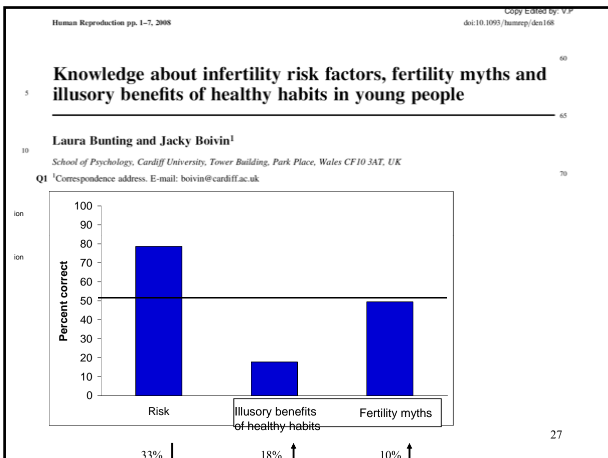


What fertility knowledge do people have?

- Respondents believed women were fertile till 46 years of age (Lebanon: Prevalence, biology: Heyman et al., 2006)
- 50% were unaware of the age-related decline of female fecundity (Sweden: General: Lampic et al., 2005)
- Modest knowledge about human reproduction (Africa: Dyer et al., 2002)
- Only 38% believed infertility was a medical problem (Prevalence: Adashi et al., 2000)
- 72% did not consider 'trying for more than one year' warranted seeking treatment (Chile: Fuentes and Devoto, 1994)

26

Bunting & Boivin (2008)


Human Reproduction pp. 1–7, 2008

doi:10.1093/humrep/den168

Knowledge about infertility risk factors, fertility myths and illusory benefits of healthy habits in young people

Laura Bunting and Jacky Boivin[1]

School of Psychology, Cardiff University, Tower Building, Park Place, Wales CF10 3AT, UK

[1]Correspondence address. E-mail: boivin@cardiff.ac.uk

Can public health campaigns be made more personally relevant?

Ps (n ≈ 60) randomly assigned to:
- General threat words (fatal, accident)
- Fertility threat words (miscarriage, barren)
- Neutral words (desk)

- Stroop interference task

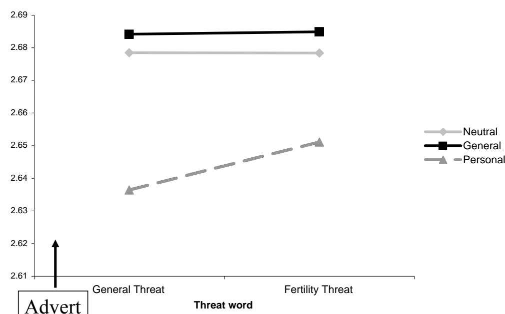
[ ] Tick here if you have unprotected intercourse with multiple partners

[ ] Tick here if you smoke more than 10 cigarettes a day

[ ] Tick here if you are more than 13 kilos overweight

Original advert:ASRM ≈2006

Making adverts more personally relevant captures attention & produces task interference on fertility threat words



29

Human Reproduction Vol.22, No.6 pp. 1506–1512, 2007
Advance Access publication on March 21, 2007
doi:10.1093/humrep/dem046

NEW DEBATE

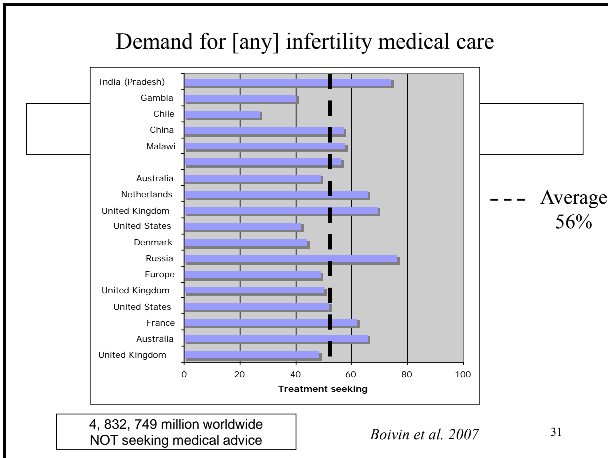
International estimates of infertility prevalence and treatment-seeking: potential need and demand for infertility medical care

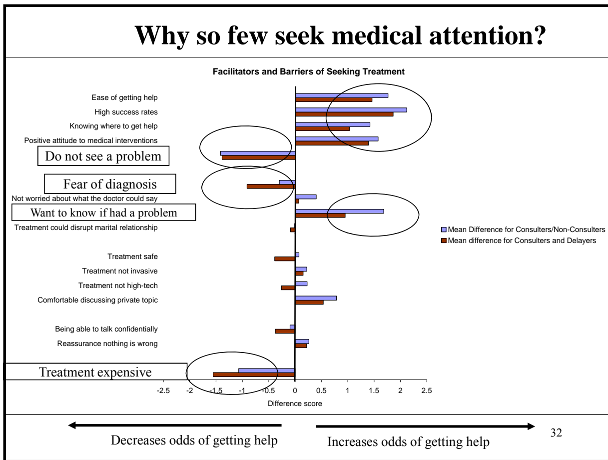
Jacky Boivin[1,4], Laura Bunting[1], John A.Collins[2] and Karl G.Nygren[3]

[1]School of Psychology, Cardiff University, Tower Building, Park Place, Wales CF10 3AT, UK; [2]Department of Obstetrics and Gynecology, McMaster University, Hamilton and Department of Obstetrics and Gynaecology, Dalhousie University, Halifax, Canada; [3]IVF-Clinic, Sophiahemmet Hospital, Stockholm, Sweden

[4]Correspondence address. Tel: +12920876707; Fax: +12920874858; E-mail: boivin@cardiff.ac.uk

30





What interventions needed here?

- Lack of knowledge about effective treatment
- Manage fears about diagnosis

33

Partner with advocacy groups delivering information about pathways to conception

34

Do I have a fertility problem?

- ***What are the benefits of seeking medical advice?***
- ***What are the disadvantages of seeking medical advice?***
- ***Will the doctor want to help me?***
- ***Will the doctor tell me I can never have children?***
- ***Is medical intervention for me?***
- ***Useful websites***

35

Conclusions (1)

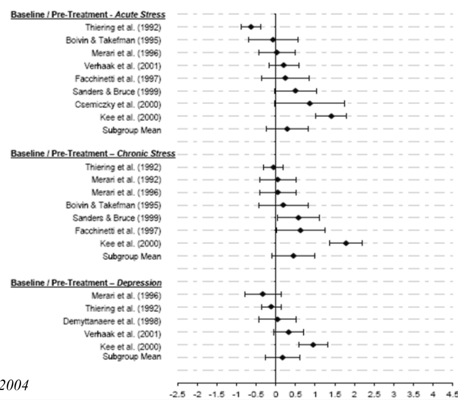
- Psychology has effects BEFORE people attend fertility clinics
- Practitioners must be active in public health domains to overcome:
  - Lack of treatment knowledge
  - Inability to understand risk in a personal context
  - Help people overcome fears of diagnosis

36

Psychological burden of treatment

- Reduces treatment success
- Increases chances of premature treatment dropout

37



Mumford, 2004

Psychological factors predict premature treatment dropout

Investigation & Initial treatment → IVF/ICSI

% ending treatment

5.3% - 40% Diagnosis, IUI, DI	**12.2% to 62%** IVF, ICSI, etc
Malcolm & Cummings, 2004: 16.9 - 39% Gleicher et al, 1996: 25 - 40% Goverde et al. 2000: 15 - 16% Guerif et al. 2003: 5.3-25%	Olivius et al. 2004: 53.8% Goverde et al. 2000: 42% Osmanagaglu et al. 1999: 25-40% Smeenk et al, 2004: 12.2-18.3% Schröder et al. 2004: 39-62%

39

Other psychological variables must be involved

- "Psychologically too stressful" (Osmanagaoglu et al. 1999)
- "Psychological burden" (Olivius et al. 2004)
- "Psychological reasons" (Smeenk et al. 2004)
- "Emotional costs" (Hammarberg et al. 2001)
- "Reached limit" (Brew et al. 2001)
- "Emotional exhaustion" (Daniluk, 2001)

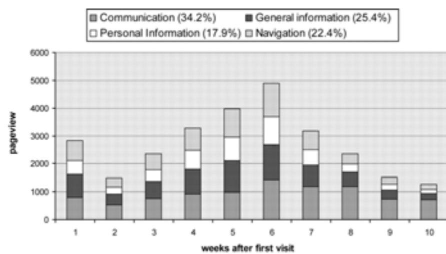
40

Implications

- Interventions to reduce distress during treatment

41

The number of page-views per week after a patient/couple's first visit to the website



Tuil, W.S. et al. Hum. Reprod. 2006 21:2955-2959; doi:10.1093/humrep/del214

Copyright restrictions may apply.

Information seeking style during IVF

Table II. Correlations after the varimax rotation between the three behavioural styles that were identified using factor analysis and the 14 types of content of the website.

› Return to article

Content type	Individual information style	Generic information style	Communication style
Medical records	**0.89**	0.23	0.30
Treatment information	**0.89**	0.30	0.30
Personalized prognosis	**0.80**	0.31	0.22
Frequently asked questions	**0.67**	0.40	0.12
Downloadable documents	**0.67**	0.39	0.29
Day planner	**0.46**	0.41	0.23
Literature	0.20	**0.71**	0.17
General information	0.45	**0.62**	0.23
External links	0.25	**0.62**	0.17
Website help	0.20	**0.61**	0.13
Hospital information	0.48	**0.60**	0.23
Bulletin board (viewing)	0.38	0.24	**0.86**
Bulletin board (posting)	0.14	0.14	**0.83**
Chatroom	0.24	0.25	**0.62**

This table is also called the 'Factor matrix'. Bold figures indicate the highest correlation to a behavioural style.

Tuil, W.S. et al. Hum. Reprod. 2006 21:2955-2959; doi:10.1093/humrep/del214

Prevalence of information seeking styles in IVF

Table III. Prevalence of the (combination of) behavioural styles.

› Return to article

	Combinations of styles			*n* (%)
	Individual information style	Generic information style	Communication style	
None of the styles	○	○	○	411 (35.7%)
One of the styles	•	○	○	195 (17.0%)
	○	•	○	156 (13.6%)
	○	○	•	52 (4.5%)
Two of the styles	•	•	○	138 (12.0%)
	•	○	•	66 (5.7%)
	○	•	•	60 (5.2%)
All three styles	•	•	•	72 (6.3%)

•, having the behavioural style; ○, not having the behavioural style.

Online viewing behaviour

Table I. The usage of the PHR developed at Radboud University Nijmegen Medical Centre in terms of the number pageviews per type of content during the patients first IVF/ICSI treatment cycle (n = 1150 patient couples).

› Return to article

Content type	Pageviews[1]	Average[2]	Mean[3]	SD[4]
Forum viewing[5]	366 175	318.4	44	632.1
Treatment information	60 838	52.9	42	46.2
Medical records	43 513	37.8	29	36.0
Day planner	25 453	22.1	7	34.0
Chatroom[5]	22 155	19.3	2	57.9
Personalized prognosis	18 860	16.4	13	14.2
Downloadable documents	11 984	10.4	8	11.0
Forum posting[5]	11 774	10.2	0	26.7
Hospital information	9424	8.2	4	11.3
Frequently asked questions	7917	6.9	5	7.4
General information	7380	6.4	4	7.8
External hyperlinks	1211	1.1	0	1.8
Literature	1209	1.1	1	1.4
Website help	994	0.9	0	1.4
Total	588 887	512.1	191	801.3

Tuil, W.S. et al. Hum. Reprod. 2006 21:2955-2959; doi:10.1093/humrep/del214

Online support intervention

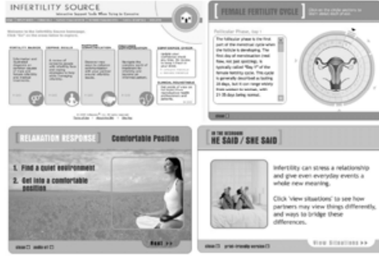


Figure 1: Infertility source web images

Cousineau et al. 2008

46

Person & intervention fit

Online support for infertile women

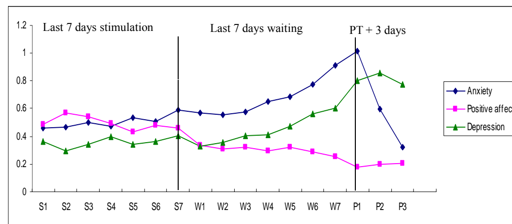
Table IV. Participant characteristics as moderators of the intervention.

Moderator	Intervention result	Test statistic, degrees of freedom, P-value and effect size
Anxiety/high[a]	Lower sexual concern	t[illegible] = −2.46, P = 0.018, d = 0.71
Treatment cycles ≥4	Lower sexual concern	t[illegible] = −2.01, P = 0.05, d = 0.61
	Lower rejection of childfree lifestyle	t[illegible] = −3.35, P = 0.002, d = 1.01
Explained infertility[b]	Lower sexual concern	t[illegible] = −2.01, P = 0.049, d = 0.50
	Higher self-efficacy	Z meta-analysis = 1.93, P = 0.05, d = 0.48
Higher income (>$75 000)	Higher self-efficacy	t[illegible] = −2.45, P = 0.02, d = 0.60
	Lower sexual concern	t_{72} = −2.38, P = 0.02, d = 0.56
	lower rejection of child free living	t[illegible] = −2.60, P = 0.01, d = 0.71
	Lower social concern	t[illegible] = −1.97, P = 0.05, d = 0.48
	Lower global FPI stress	t_{72} = −2.05, P = 0.04, d = 0.48
WOC/high escape-avoidance	Lower rejection of childfree lifestyle	t[illegible] = −2.52, P = 0.047, d = 0.75
	Lower social concern	$t_{28.1}$ = −1.98, P = 0.049, d = 0.75
WOC/low planful problem solving	Lower sexual concern	t[illegible] = −2.86, P = 0.006, d = 0.78
	Lower social concern	t[illegible] = −3.22, P = 0.002, d = 0.95
	Higher self-efficacy	$Z_{meta-analysis}$ = 2.14, P = 0.033, d = 0.63
WOC/high distancing	Higher global FPI stress	F(1, 181) = 8.51, P = 0.004, d = −0.42
	Higher sexual concern	F(1, 181) = 8.32, P = 0.004, d = −.39
WOC/ low distancing	Lower global FPI stress	F(1, 181) = 8.51, P = 0.004 d = 0.48
	Lower sexual concern	F(1, 181) = 8.32, P = 0.004, d = 0.50

[a]High anxiety, STAI score of 43.5 or greater; [b]Explained infertility, male, female, or male and female factor infertility known to study participant. WOC, Ways of coping subscales.

47

Anxiety, depression and positive affect during IVF



S = stimulation
W = waiting
P = Pregnancy test

Boivin & Walker, 1997

48

Psychological demand of two-week waiting period

- Effects manifest in short-time period
- Self-administered
- High appeal to patients
- Component geared to dealing with negative emotions and intrusive cognitions
  - "try not to think about" versus "stay positive"

49

The Positive Reappraisal Intervention Card

- Ten statements
  - Rationale explained to women
  - "prime" positive redefinition associated with positive adjustment
  - Instruction to read once in the morning, once in the evening and any other time needed

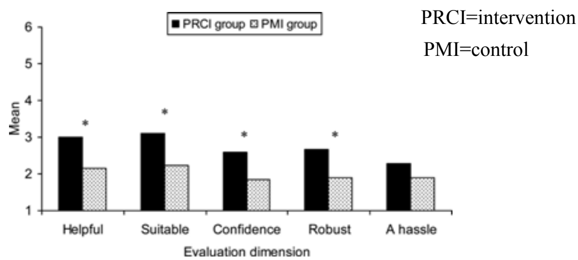
During this experience I will:

Try to do something that makes me feel good
See things positively
Look on the bright side of things
Make the best of the situation
Discover what is important in life
Focus on the positive aspects of the situation
Find something good in what is happening
Try to do something meaningful
Focus on the benefits and not just the difficulties
Learn from the experience

50

Lancastle and Boivin. *Hum Reprod* 2008.

Ratings of the acceptability of the interventions by group

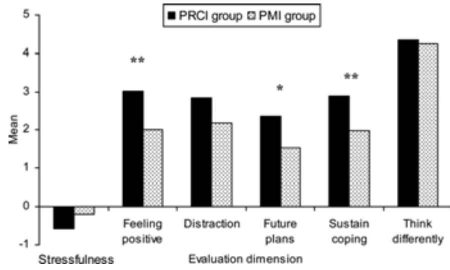


PRCI=intervention
PMI=control

Lancastle, D. et al. Hum. Reprod. 2008 23:2299-2307; doi:10.1093/humrep/den257
Copyright restrictions may apply.

Human Reproduction

Ratings of the perceived psychological effects of the interventions by group

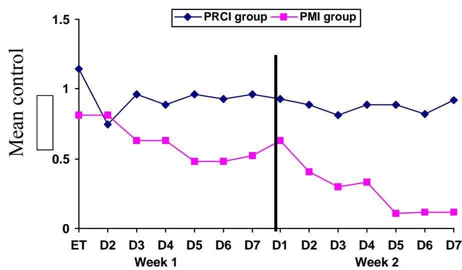


Lancastle, D. et al. Hum. Reprod. 2008 23:2299-2307; doi:10.1093/humrep/den257

Copyright restrictions may apply.

Human Reproduction

Feasibility and acceptability trial of positive reappraisal coping intervention



PRCI=intervention
PMI=control

Lancastle & Boivin, in prep

53

Conclusion (2)

- Protracted period of medical intervention requires bespoke psychosocial interventions
- Must identify relevant and easily implemented interventions for all stages of medical process
- Common measurement method useful for comparisons across studies

54

FertiQoL

The first internationally validated instrument to measure quality of life in individuals experiencing fertility problems

Professionals can download **FertiQoL** **FREE OF CHARGE**

www.fertiqol.org

eshre

MERCK SERONO

Available in 17 languages

55

FertiQoL International

Optional Treatment Module

Have you started fertility treatment (this includes any medical consultation or intervention)? If Yes, then please respond to the following questions. For each question, kindly check (tick the box) for the response that most closely reflects how you think and feel. Relate your answers to your current thoughts and feelings. Some questions may relate to your private life, but they are necessary to adequately measure all aspects of your life.

	For each question, check the response that is closest to your current thoughts and feelings	Always	Very Often	Quite often	Seldom	Never
T1	Does infertility treatment negatively affect your mood?	☐	☐	☐	☐	☐
T2	Are the fertility medical services you would like available to you?	☐	☐	☐	☐	☐

	For each question, check the response that is closest to your current thoughts and feelings	An Extreme Amount	Very Much	A Moderate Amount	A Little	Not At All
T3	How complicated is dealing with the procedure and/ or administration of medication for your infertility treatment(s)?	☐	☐	☐	☐	☐
T4	Are you bothered by the effect of treatment on your daily or work-related activities?	☐	☐	☐	☐	☐
T5	Do you feel the fertility staff understand what you are going through?	☐	☐	☐	☐	☐
T6	Are you bothered by the physical side effects of fertility medications and treatment?	☐	☐	☐	☐	☐

	For each question, check the response that is closest to your current thoughts and feelings	Very Dissatisfied	Dissatisfied	Neither Satisifed nor Dissatisfied	Satisfied	Very Satisfied
T7	Are you satisfied with the quality of services available to you to address your emotional needs?	☐	☐	☐	☐	☐
T8	How would you rate the surgery and/or medical treatment(s) you have received?	☐	☐	☐	☐	☐
T9	How would you rate the quality of information you received about medication, surgery and/or medical treatment?	☐	☐	☐	☐	☐
T10	Are you satisfied with your interactions with fertility medical staff?	☐	☐	☐	☐	☐

Many trajectories in trying to conceive

Start trying to conceive

Conceive

Fail to conceive

Do not seek treatment

Seek treatment

Adopt

Remain childless

Conceive

Fail to conceive

Own gametes

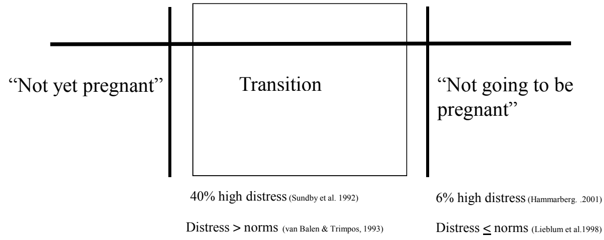
Donated gametes

Adopt

Remain childless

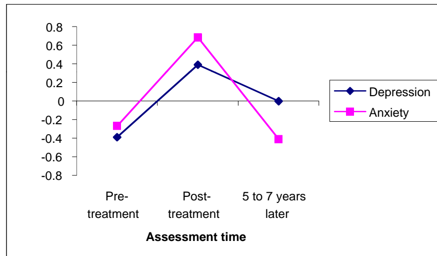
57

Psychological distress during transition of ending fertility treatment



58

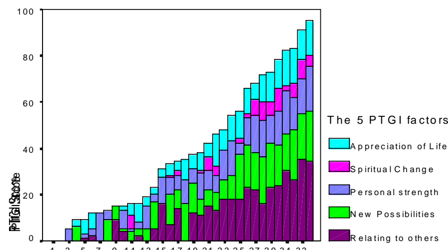
Anxiety & depression, before and after treatment and five to seven years later



Brew, 2002

59

Benefit-finding in infertile populations



Individual values of the 5 PTGI factors for survey participants

60

Challenges in ending treatment and adapting to childless future

- Fear of not being able to cope with end of treatment
- Fear concerning survival of the marital relationship
- An inability to imagine a happy and contented life without children

Boivin, Takefman & Braverman, 2005 61

How do you know when you have done enough? Putting "what if…" to rest

- **Questions couples should ask themselves & discuss with practitioner**
  - Are we confident that we received the best medical advice?
  - Within the limits of what we could afford, did we follow the recommendations of the specialists?
  - Within the limits of what we could both live with, did we pursue all the available treatment alternatives that had a reasonable chance of success?
  - Did we give each treatment option our best effort?

Daniluk, 2001 62

General Conclusion

- Psychology makes a difference to the care of people with fertility problems
- Important to find ways of matching interventions to specific people and specific problems
- Need to expand and diversify psychological services in reproductive psychology

63

Bibliography

- Tuil et al. Human Reproduction 2006 21(11):2955-2959; doi:10.1093/humrep/del214
- Boivin, J. (2003). A review of psychosocial interventions in infertility. Social Science and Medicine, 57 (12), 2325-2341.
- Clark, A.M., Ledger, W., Galletley, C., Tomlinson, L., Blaney, F., Wang, X., & Norman, R.J. (1995). Weight loss results in significant improvement in pregnancy and ovulation rates in anovulatory obese women. *Human Reproduction, 10*, 2705-2712.
- Cousineau et al. Human Reproduction 2008 23(3):554-566; doi:10.1093/humrep/dem306 Daniluk, JC. Reconstructing their lives: A longitudinal, qualitative, analysis of the transition to biological childlessness for infertile couples. J Counsel Devel 2001;79: 439-49.
- de Liz TM, Strauss B. Differential efficacy of group and individual/couple psychotherapy with infertile patients. Human Reproduction 2005;20:1324–1332.
- Domar, A.D., Clapp, D., Slawsby, E.A., Dusek, J., Kessel, B., & Freizinger, M. (2000a). Impact of group psychological interventions on pregnancy rates in infertile women. *Fertility and Sterility, 73*, 805-811.
- Hammarberg, K., Astbury, J. & Baker, H.W.G. (2001). Women's experience of IVF: A follow-up study. Human Reproduction, 16 (2), 374-383.
- National Institute of Clinical Excellence. Treatment Choice in Psychological Therapies and Counselling: Evidence Based clinical Practice Guidelines. London:Department of Public Health, 2001.
- Ningel, K. & Strauss, B. (2002). Psychological diagnosis, counselling and psychotherapy in fertility medicine. In B. Strauss (Ed.) *Involuntary Childlessness: psychological assessment, counselling and psychotherapy* (pp. 19-34). Seattle: Hogrefe & Huber Publishers.
- Sackett, D., Straus, S.E., Richardson, W.S., Rosenberg, W. & Haynes, R.B. (2000). *Evidence-based medicine: How to practice and teach EBM* (2nd ed.). Edinburgh: Churchill Livingstone.
- Smeenk, J.M.J., Verhaak, C.M., Stolwijk, A.M., Kremer, J.A.M., & Braat, D.D. M. (2004). Reasons for dropout in an in vitro fertilization/intracytoplasmic sperm injection program. Fertility and Sterility, 81 (2), 262-268.
- Throsby K. No-one will ever call me Mummy: Making sense of the end of IVF treatment. New Working Paper Series, 2001;5:
- Tuil et al. Human Reproduction 2006 21(11):2955-2959; doi:10.1093/humrep/del214
- Tuschen-Caffier, B., Florin, I., Krause, W. & Pook, M. (1999). Cognitive-behavioural therapy for idiopathic infertile couples. *Psychotherapy and Psychosomatics, 68*, 15-21.
- van-Rooij FB, van-Balen F, Hermanns JMA. A review of Islamic Middle Eastern migrants: Traditional and religious cultural beliefs about procreation in the context of infertility treatment. Journal-of-Reproductive-and-Infant-Psychology. 2004;22:321-31
- Wampold, B.E., Mondin, G.W., Moody, M., Stich, F., Benson, K., & Ahn, H. (1997). A meta-analysis of outcome studies comparing bona fide psychotherapies: Empirically,
- Wischmann, T., Stammer, H., Scherg, H., Gerhard, I. & Verres, R. (2002). Couple counselling and therapy for the unfulfilled desire for a child: The two-step approach of the "Heidelberg Infertility Consultation". In B. Strauss (Ed.) *Involuntary Childlessness: Psychological assessment, counselling and psychotherapy* (pp. 127-150). Seattle: Hogrefe & Huber Publishers.

64

Research collaborators

- Janet Takefman
  Centre for Reproductive Health, McGill University
- Lone Schmidt
  Institute of Public Health, University of Copenhagen
- Kathy Sanders
  School of Anatomy & Biology, University of Western Australia
- Dr Deborah Lancastle
  Medical Genetics, Cardiff University
- Dr Laura Peronace
  School of Psychology, Cardiff University

- Laura Bunting
- Mareike Stiel
- Marie-Anne Durand

65

The effects of psychosocial interventions
How to measure?

Chris Verhaak PhD
UMC Radboud Medical Psychology
Nijmegen the Netherlands

Learning objectives

- Insight into pros and cons of evidence based practice
- Knowing to differentiate between different kind of psychosocial interventions and its different effects
- Able to differentiate between aims of psychosocial interventions
- Understanding possibilities for screening
- Tools to implement outcome assessment in dailiy clinical practice

Scope of the problem

- One out of four patients with fertility problems suffer from psychosocial problems
- 66% of patients drop out of treatment; half of them because of psychosocial reasons

Eysenck 1952

- Traditional forms of psychodynamically based psychotherapy led to no greater improvement than spontaneous remission
- Provided an impetus for rigorous research into the effectiveness of psychosocial interventions

Does counseling work?

- We are satisfied, so are our patients

Need for evidence based practice

- Objectivation of emotional aspects of treatment
- Information about effects of treatment
- Financial aspects

Psychosocial burden of fertility problems

- Widely recognized
- Many clinical reports > focus on emotional problems; those who do not adjust well
- Many systematic studies > more focus on successful adjustment: maladjustment in part of the patients

Recommendation of psychosocial care

- Psychosocial care available for all patients
- Psychosocial care on request
- Psychosocial care based on screening

Need for treatment

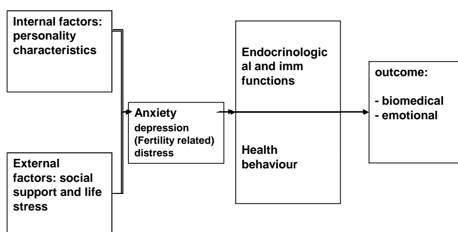
- Only partly related to individual psychosocial burden

Mental health professionals in reproductive care

- Promoting biopsychosocial approach in treatment for subfertile couples
- Explaining psychosocial burden of subfertility
- Treating psychosocial problems in sub fertile couples
- Coaching couples on life style issues

Effect of psychosocial interventions

- Different goals:
  - Stimulate adaptive coping
  - Helping cognitive restructuring
  - Stimulating social support
  - Support in stress management
  - Changing life style related to subfertility



Biopsychosocial model of subfertility

UMC St Radboud Nijmegen, the Netherlands

Focus on psychosocial adjustment

- General psychosocial adjustment in terms of anxiety and depression
- Fertility specific psychosocial adjustment

How to assess

- Different ways to assess anxiety and depression
- Different ways to assess sub fertility related distress

General and disease specific assessment

- Possibility to compare with norms
- Validity in terms of disruption daily life
- Risks for psychopathology
- Sensitivity for specific burden of subfertility
- Sensitive to change for psychosocial interventions

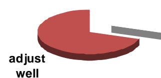
Type of outcomes

- Psychosocial wellbeing
- Process variables: coping and cognitive aspects
- Inter- and intra personal factors: social support; partner relationship

Screening patients

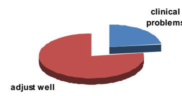
What is known about emotional impact of IVF?

- Most women seem to adjust well to IVF



What is known about emotional impact of IVF?

- Most women seem to adjust well to IVF
- Considerable part of the women develops emotional problems
- Emotional impact of IVF is greater in women than in men



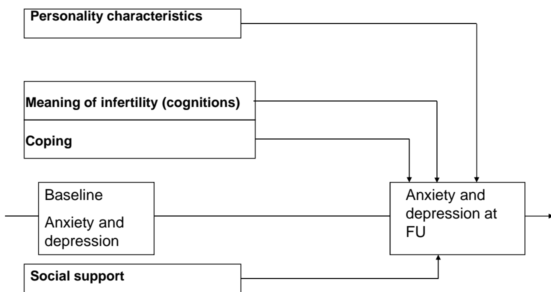
Aims of screening

- Identify risk groups
- Offer tailored interventions in time to those at risk
- Prevention of future emotional problems

How do you know who is at risk?

- Starting point: general risk factors in health psychology
- Investigate the predictive value in IVF patients
- Develop screening tool based on predictors
- Test validity of tool in new sample of IVF patients

Prediction of the emotional response



Risk factors

- High levels of anxiety and depression
- Meaning of fertility problems: more helplessness and less acceptance
- Lack of social support

Anxiety and depression

- 10 items of STAI-state anxiety
- Depression: BDI-pc version: 7 items

Meaning of fertility problems:

Helplessness

- My infertility makes me feel helpless
- My infertility limits me in everything that is important to me
- My infertility controls my life
- Because of my infertility I miss things I like to do most
- My infertility makes me feel useless at times

Acceptance

- I can accept my infertility well
- I can cope effectively with my infertility
- I've learned to live with my infertility
- I can handle the problems related to my infertility
- I've learned to accept the limitations imposed by my infertility

Social support

- 7 items on perceived social support
  - If I'm sad there is someone to talk to
  - If I need practical help there is someone to assist me

Screening beleving van vruchtbaarheidsproblmen

Stemming

Hieronder vindt u een aantal uitspraken, die mensen hebben gebruikt om zichzelf te beschrijven. Lees iedere uitspraak door en zet dan een kringetje om het cijfer rechts van die uitspraak om daarmee aan te geven hoe u zich de afgelopen week heeft gevoeld. Er zijn geen goede of slechte antwoorden. Denk niet te lang na en geef uw eerste indruk, die is meestal de beste. Het gaat er dus om hoe u zich de afgelopen week heeft gevoeld.

	bijna nooit	soms	vaak	bijna altijd
1 Ik voel me prettig	❑	❑	❑	❑
2 Ik voel me tevreden	❑	❑	❑	❑
3 Ik pieker te veel over dingen die niet zo belangrijk zijn	❑	❑	❑	❑
4 Ik ben gelukkig	❑	❑	❑	❑
5 Ik word geplaagd door storende gedachten	❑	❑	❑	❑
6 Ik voel me veilig	❑	❑	❑	❑
7 Ik ben tevreden	❑	❑	❑	❑
8 Er zijn gedachten die ik moeilijk los kan laten	❑	❑	❑	❑
9Ik neem teleurstellingen zo zwaar op dat ik ze niet meer van mij af kan zetten	❑	❑	❑	❑
10 Ik raak helemaal gespannen en in beroering als ik denk aan mijn zorgen van de laatste tijd	❑	❑	❑	❑

Kruis bij de volgende vragen het antwoord aan dat het meest op u van toepassing is. Ook nu gaat het weer om hoe u zich de afgelopen week heeft gevoeld.

1. ❑ Ik voel me niet verdrietig
   ❑ Ik voel me verdrietig
   ❑ Ik ben voortdurend verdrietig en kan het niet van me afzetten
   ❑ Ik ben zo verdrietig of ongelukkig dat ik het niet meer verdragen kan
2. ❑ Ik ben niet bijzonder moedeloos over de toekomst
   ❑ Ik ben moedeloos over de toekomst
   ❑ Ik heb het gevoel dat ik niets heb om naar uit te zien
   ❑ Ik heb het gevoel dat de toekomst hopeloos is en dat er geen kans op verbetering is
3. ❑ Ik voel me geen mislukkeling
   ❑ Ik heb het gevoel dat ik vaker iets verkeerd heb gedaan dan een gemiddeld iemand
   ❑ Als ik op mijn leven terug kijk zie ik alleen maar een hoop mislukkingen
   ❑ Ik heb het gevoel dat ik als mens een volledige mislukking ben
4. ❑ Ik beleef overal net zoveel plezier aan als vroeger
   ❑ Ik geniet niet meer zoals vroeger
   ❑ Ik vind nergens nog echte bevrediging in
   ❑ Ik heb nergens meer voldoening van; ik vind alles vervelend
5. ❑ Ik voel me niet teleurgesteld in mezelf
   ❑ Ik ben teleurgesteld in mezelf
   ❑ Ik walg van mezelf
   ❑ Ik haat mezelf
6. ❑ Ik heb niet het gevoel dat ik slechter ben dan iemand anders
   ❑ Ik heb kritiek op mezelf vanwege mijn zwakheden of fouten
   ❑ Ik geef mezelf steeds de schuld van mijn gebreken
   ❑ Ik geef mezelf de schuld van al het slechte dat er gebeurt
7. ❑ Ik overweeg absoluut niet om een eind aan mijn leven te maken
   ❑ Ik overweeg wel eens om een eind aan mijn leven te maken, maar ik zou dat nooit doen
   ❑ Ik zou een eind aan mijn leven willen maken
   ❑ Ik zou een eind aan mijn leven maken als ik de kans kreeg.

Geef aan in welke mate u het eens bent met de volgende uitspraken

	Niet	Een beetje	In sterke mate	Helema
8. Door de onvruchtbaarheid mis ik datgene wat het meest belangrijk voor mij is.	❑	❑	❑	❑
9. Ik kan de gevolgen, die de onvruchtbaarheid met zich mee brengt aan.	❑	❑	❑	❑
10. Ik heb met de onvruchtbaarheid leren leven.	❑	❑	❑	❑
11. De onvruchtbaarheid beheerst mijn leven.	❑	❑	❑	❑
12. De onvruchtbaarheid geeft mij soms het gevoel nutteloos te zijn.	❑	❑	❑	❑
13. Door de onvruchtbaarheid is mijn leven niet compleet.	❑	❑	❑	❑
14. Ik heb de onvruchtbaarheid leren aanvaarden.	❑	❑	❑	❑
15. De onvruchtbaarheid heeft invloed op alles wat belangrijk voor mij is.	❑	❑	❑	❑
16. Ik kan de onvruchtbaarheid accepteren.	❑	❑	❑	❑
17. Ik denk dat ik de problemen van de onvruchtbaarheid aan kan, zelfs als ze niet opgelost worden.	❑	❑	❑	❑
18. Door de onvruchtbaarheid voel ik me vaak hulpeloos.	❑	❑	❑	❑
19. Ik kan goed met de onvruchtbaarheid omgaan.	❑	❑	❑	❑

Steun van anderen

	bijna nooit	soms	nogal eens	vaak
20. Als ik me gespannen voel of onder druk sta, dan is er altijd iemand die mij helpt.	❑	❑	❑	❑
21. Als ik iets leuks meemaak, dan is er iemand met wie ik dat kan delen.	❑	❑	❑	❑
22. Als ik pijn heb, dan is er iemand die me steunt.	❑	❑	❑	❑
23. Als ik verdrietig ben, dan is er iemand met wie ik dat kan delen.	❑	❑	❑	❑
24. Als ik hulp nodig heb bij karweitjes, die ik niet alleen kan uitvoeren, dan is er iemand die me daarbij helpt.	❑	❑	❑	❑

Validation study

- N=512 IVF patients
- 8 IVF centers in the Netherlands
- Assessment before and six weeks after first cycle

- At risk: 1 ½ sd above norms on at least one risk factor

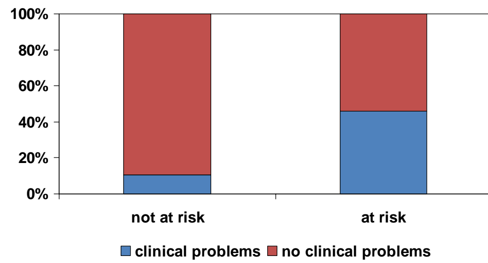
Results

- Screening tool explained
  - 47% of the variance in post treatment anxiety
  - 36% of the variance in post treatment depression

- 34% patients were at risk at pre treatment

- 22% patients showed clinical problems at follow up

Clinical problems at FU by risk group



Results for whole sample

	No emotional problems at FU	Emotional problems at FU	
Not at risk	**302**	36	396
At risk	94	**80**	116
	338	174	512

Psychometric characteristics of the tool

	All women	Non pregnant women
Correctly predicted	74%	75%
Sensitivity	69%	70%
Specificity	79%	87%

Implementation

- Screening of all couples starting fertility treatment
- Offering psychosocial care to those at risk
- Provide access to psychosocial care for those who need

Feedback on screening

- Based on the results of the screening, we see no signs of psychosocial problems
- Based on the results of the screening, we inform you that you might benefit from additional psychosocial support because of….

- The distress you experience
- The mood problems you reported
- The way your fertility problems effect your daily life
- The lack of social support for your fertility problems

Screening

- Tool to identify patients at risk for emotional problems
- Baseline assessment for psychosocial interventions
- Starting point for goal formulation in therapy

Effect measures

- Screening is starting point for assessment of treatment effect
- Repeated assessments during and after treatment
- Feedback on results of your intervention

Challenges

- Develop validated instruments to assess different aspects of emotional burden
- Reach consensus about use of assessment instruments

Training and Supervision for Infertility Counsellors: Who is Qualified?

Linda D. Applegarth, Ed.D.
Clinical Associate Professor of Psychology
Weill Medical College of Cornell University
New York, New York
USA

Learning Objectives

At the end of this presentation, participants should:

1. **Gain a broader understanding of the important roles of mental health professionals working in reproductive health.**
2. **Learn specific qualification guidelines or standards for mental health professionals doing effective infertility counseling; and, understand pitfalls to effective practice.**
3. **Learn ways to obtain or provide supervision and continuing education in the field.**

Introduction

Globally, the infertility counsellor is playing an *increasingly important role* in reproductive health psychology and reproductive medicine.

- This role has expanded in response to ongoing technological advances, legal requirements, and complex psychosocial issues confronted by infertility patients.
- There is also an ongoing need for skilled and trained infertility counsellors to assist patients and healthcare providers.
- Knowing how best to obtain the necessary training and skills, and to assess the qualifications of infertility counsellors is critical to the provision of appropriate and high quality patient care.

The Need for Infertility Counselling

- The complex relationship between the psychosocial and medical components of infertility indicates the need to include infertility counsellors on the treatment team.
- In some countries, infertility counsellors are required by law to be a part of reproductive treatment services.

Role of the Infertility Counsellor

- Covington (1999) notes that the role of infertility counsellors in reproductive healthcare now extends beyond 'advising and comforting.'
- Infertility counselling includes *psychological evaluation* and *assessment*, *psychotherapeutic intervention,* and *psycho-educational support.*
- The infertility counsellor may also conduct *research,* and provide *consultation with the medical staff.*

Clinical role of the Infertility Counsellor

There appear to be two distinct aspects in the clinical role of the mental health professional in infertility: ***counsellor*** and ***evaluator***. (Covington, 1999)

As counsellor, the mental health professional may advise and guide patients about treatment decisions and parenting options. The counsellor must not only have solid clinical knowledge and skills, *but also fully understand reproductive medical treatments and their implications.*

1. Counselling and Support

Silman(1995) also delineates three areas of infertility counselling:

1. Helping patients determine what it is they seek;
2. Exploring the implications of that desire, both physical and emotional that might not be fully considered in the quest for a baby; and
3. Supporting the decision with realistic information.

Counselling and Support

The infertility counsellor may also provide supportive services through:

1. Psycho-education
2. Resources and Referrals

2. Evaluation and Assessment

The infertility counsellor may:

a. Perform psychological screening of individuals and couples participating in assisted reproductive technologies (ART).

b. Evaluate specific groups of patients who may be vulnerable to medical procedures or exploited by those seeking reproductive assistance or healthcare providers.

c. These assessments may or may not involve the use of standardized psychological measures.

Evaluation and "Gatekeeping"

- As an evaluator, the mental health professional may be asked to recommend patient inclusion in or exclusion from treatment.
- The infertility counselor must be explicit regarding the role they will play in working with the patient.
- The infertility counsellor who has an ongoing therapeutic relationship with the patient should not attempt to change his/her role to evaluator.

Additonal Roles of the Infertility Counsellor

- Research
- Consultation to Medical Staff

Who is Qualified?

There is a important need for *special training and experience* in order to provide adequate and appropriate infertility counselling services.

Both psychological and medical aspects of infertility need to be integrated as part of the treatment continuum.

Qualification Guidelines

- In 1995, the Committee on Infertility Counseling Guidelines of the Mental Health Professional Group (ASRM) set forth guidelines to help determine training and qualifications.
- These general guidelines are dependent on specific laws and requirements of each country, but provide a clear framework for defining the necessary types of skills and training.

Qualification Guidelines

A. Minimal qualifications and training:

1. Graduate degree in a mental health profession; and

2. License or certification/registration to practice.

Qualification Guidelines

B. Training in the Medical and Psychological Aspects of Infertility: *A Medical Understanding of….*

1. Basic reproductive physiology
2. Testing, diagnosis, and treatment of reproductive problems
3. Etiology of male and female infertility
4. Assisted reproductive technologies

Qualification Guidelines

C. The infertility counsellor should have training in the psychology of infertility indicating ***a knowledge of…..***

1. Medical and family issues associated with infertility, and the impact on sexual functioning, and
2. Approaches to the psychology of infertility including (but not limited to) psychological assessment, bereavement/loss, crisis intervention, post-traumatic stress, and typical/atypical responses.

Qualification Guidelines (cont'd)

3. Family-building alternatives
4. Psychological and couples treatments
5. The legal and ethical issues of infertility treatments
6. How and where to access to resources and referrals

Qualification Guidelines (cont'd)

D. Clinical Experience

According to MHPG/ASRM guidelines, the infertility counsellor should have "a minimum of one year clinical experience providing infertility counseling, preferably under the supervision of or in consultation with a qualified and experienced infertility counselor."

E. Continuing Education

To insure continued growth in knowledge and skills. Regular attendance at programs and courses designed to provide ongoing education in both psychological and medical issues in reproductive healthcare.

Counter-transference & Gender Issues in Infertility Counselling

Counter-transference

How does the personal experience of infertility impact the counsellor's response to patients?

Gender

Does the gender of the counsellor impact treatment considerations or access to treatment?

International Perspectives on Infertility Counselling: Who is Qualified?

- "Mandated infertility counselling" in some countries
- Counsellor shortages and/or questionable infertility counselling qualifications.
- Despite stated qualification guidelines and legislated counselling, are there sufficient vehicles available for training and supervision?

Infertility Counsellor Training and Credentialing

Haase & Blyth (2006) note that there are limited opportunities for specific infertility counsellor training, including geographic and financial considerations.

Counsellor Training and Supervision

With the absence of formal graduate programs or broad systematic training protocols in infertility counselling, additional educational experience may come through:

- University-based Internship/Fellowship opportunities
- Research
- Consumer Organizations
- Individual supervision with an experienced infertility counsellor

Infertility Counselling Organizations offering Professional Development

- BICA – United Kingdom (+HFEA licensed clinics)
- ANZICA/FAS – Australia/New Zealand
- MHPG/ASRM – USA
- BKiD – Germany
- GLASMI/FLASEF- Latin America
- JAPCRM – Japan
- PSIG/ESHRE – Europe
- FertiForum/SGRM – Switzerland
- CSIG/CFAS – Canada
- GIP/SEF - Spain

International Comparison of Standards/Guidelines for Infertility Counsellors

See attached Appendix

Haase J and Blyth E in *Infertility Counseling: a Comprehensive Handbook for Clinicians* Covington & Burns (ed.) 2nd Edition, Cambridge Press, 2006

Reprinted with Permission

Summary

- **Infertility counselling is a specialty area that integrates the fields of psychology and reproductive healthcare and medicine.**
- **The role of infertility counsellors in reproductive medicine requires specialized skill, knowledge, and training in the complex interface between the medical and psychological components of infertility.**
- **Although qualifications have been delineated, there continues to be a need for clearer definitions of professional standards, overcoming resistance from other professionals, & establishing training programs in the field of infertility counselling. (Jennings, 1995)**

- REFERENCES

- American Society for Reproductive Medicine, Mental Health Professional Group: *Qualification Guidelines for Mental Health Professionals in Reproductive Medicine*. Prepared by the Committee on Infertility Guidelines, September l995
- Baird BN. *The Internship, Practicum, and Field Placement Handbook: A Guide for the Helping Professions*, 5th edition. New Jersey: Pearson/Prentice Hall, 2007.
- Bradley LJ, Ladany N. *Counselor Supervision: Principles, Process, and Practice.* 3rd Edition. New York: Routledge -Taylor & Francis Group, 2000.
- British Infertility Counselling Association (BICA): Becoming an infertility counselor. www.bica.net/becoming-infertility-counsellor and www.bica.net/training_programme, 2008.
- Covington, S. Integrating infertility counseling into clinical practice. In Burns LH, Covington SN (eds.) *Infertility Counseling: A Comprehensive Handbook for Clinicians*. New York: The Parthenon Publishing Group, 1999; 475-490.
- Haase JM, Blyth E. Global perspectives on infertility counseling. In Covington SN, Burns LH (eds.) *Infertility Counseling: A Handbook for Clinicians*, 2nd edition. New York: Cambridge University Press, 2006.
- Jennings SE, (ed.) *Infertility Counselling*. Oxford: Blackwell Scientific Publications, 1995
- Silman R. What is infertility counseling? In: Jennings, SE, (ed.) Infertility Counselling. Oxford: Blackwell Scientific Publications, 1995; 205-13.
- Storr A. *The Art of Psychotherapy*. New York: Methuen, Inc., 1980.

From: Covington SN, Burns LH (eds) "Infertility Counseling: A Comprehensive Handbook for Clinicians," 2nd Edition. New York: Cambridge University Press, 2006.

APPENDIX 2

International Comparison of Standards/Guidelines for Infertility Counselors

JEAN M. HAASE AND ERIC BLYTH

APPENDIX 2. Comparison of standards/guidelines for infertility counselors

Country or jurisdiction	Legislation or guidelines	Degree required or recommended	License to practice	Disciplines providing counseling	Professional counseling association	Training/professional development offered
United Kingdom	Legislation	Required: diploma level or above in counseling, psychology, social work	Regulations recommend membership in regulated profession	Psychology Social work Counseling	BICA [British Infertility Counseling Association]	Courses through BICA www.bica.net
Australia/ New Zealand	Legislation varies but accreditation guidelines apply to all	Required: Bachelor, Masters, or Doctorate	Required membership in ANZICA	Psychology Social work MD	ANZICA/FAS [Australia/New Zealand Infertility Counseling Association of Fertility Society of Australia]	Courses through ANZICA, FAS; and government (donor linking counselor training) www.fas.org
United States of America	Guidelines ARSM and MHPG	Recommended: graduate level degree	Required to practice in every state	Psychology Social work Marriage/family therapy Nurses (psychiatric) MD (psychiatrist)	MHPG/ASRM [Mental Health Professional Group of American Society of Reproductive Medicine]	Annual courses at ASRM www.asrm.org
Germany	Guidelines BKid	Recommended: training in psychosocial discipline and training in counseling or therapy	MD	Psychology Social work Counseling MD (psychiatry, ob/gyn with counseling credentialing)	BKiD [Beratungsnetzwerk Kinderwunsch Deutschland]	Courses through BKiD www.bkid.de

(continued)

APPENDIX 2 ***(continued)***

Country or jurisdiction	Legislation or guidelines	Degree required or recommended	License to practice	Disciplines providing counseling	Professional counseling association	Training/professional development offered
Latin America	GLASMI Guidelines	Recommended: graduate level degree	Varies between countries	Psychology MD (psychiatry)	GLASMI/FLASEF [Grupo Latinamericana de interes en salud mental en infertilidad/Federacion Latinamericana de sociedades de Esterilidad y Fertilidad]	Courses through FLASEF, ASRM, ESHRE
Japan	JAPCRM Developing guidelines	Recommended: Masters or doctorate degree	Psychologists	Psychologists Nurses MD (psychiatry)	JAPCRM [Japan Association of Psychological Counseling for Reproductive Medicine]	Courses offered through JAPCRM
Europe	ESHRE Guidelines	Recommended: graduate level degree	Varies among countries	Psychology Social work Counseling Nurses MD (psychiatry, ob/gyn special counseling credentialing)	PSIG/ESHRE [Psychosocial special interest group of European Society of Human Reproduction and Embryology]	Annual courses at ESHRE www.eshre.com
Switzerland	Legislation	Recommended: graduate level degree	Psychologists, MD (psychiatry, ob/gyn special counseling credentialing)	Psychology Social work Family planning Counselors MD	FertiForum Special Interest Group of Swiss Society of Reproductive Medicine (SGRM)	Members attend Swiss Society of Reproductive Medicine, ESHRE www.sgrm.org
Canada	Legislation	Recommended: graduate level degree	MD	Psychology Social work Marriage/family Therapy Nurses MD (psychiatry)	CSIG/CFAS [Counseling Special/Canadian Fertility and Andrology Society]	Members attend CFAS, ASRM, ESHRE, ANZICA, BICA www.cfas.ca/csig
Spain	Guidelines in development	Recommended: graduate level degree	Required in every state	Psychology Social work	Grupo de Interes de Psicologia SEF	Courses through SEF www.sefertilidad.es

(Reprinted With Permission)

Clinical Hypnosis for Infertility

P R Reilly MA
Fertility counsellor

The London Bridge Fertility Gynaecology and Genetic centre, London

The aim of this presentation is to show how Hypnosis can be used as an aid and adjunct to support patients throughout fertility treatment .

Hypnosis can be used for:

- Anxiety about fertility, medical and surgical interventions.
- Depression.
- Bereavement, miscarriage, termination.
- Stress related issues, eating disorders, needle and other phobias.
- Sexual dysfunction and disorders.
- Relaxation… ….etc. etc.

Literature search

- There are 581 research documents relating to the benefits of hypnosis all for a variety of health issues and published on Pub Med.
- However only 20 specifically relate to infertility.

One of the most informed of these is:

Impact of Hypnosis during embryo transfer on the outcome of In Vitro Fertilisation

Eliahu Levtas. Fertility and Sterility, vol.85, no. 5, May 2006

Patients: Infertile couples undergoing IVF.

98 undertook hypnosis during ET were matched with 96 who did not.

Main outcome: Measure the clinical pregnancy and implantation rates of the two groups.

Results:

53-1% CP with hypnosis ,

30-2% CP without.

My specialist field using hypnosis : Overseas egg donation programmes

- I accompany patients abroad every 8 weeks.
- Giving continuity of care at all stages.
- Number of couples undertaking treatment per programme is 29.
- Patients have their own differing emotional needs, levels of anxiety and fears.
- To support these I offer group relaxation through hypnotic intervention.

This includes

- Sensory awareness
- Relaxation
- Ego strengthening

Those who attended expressed new-found optimism with reduced fears surrounding their treatment.

The success rate of the programme overall is 49% life birth. The average age of patients being 45.

How does this work

- Well – lets look at this firstly by asking

What is Hypnosis??

In practice two components

"Trance" and "Suggestion"

Trance

- Focussed attention.
- Disattention to extraneous stimuli.
- Absorption in some activity, thought or feeling.
- An everyday experience :
- Lost in thought, absorbed in a good book.
- Often accompanied in time distortion.

“Hypnotic” induction procedure facilitates “Trance”

Suggestion.

- Classic hypnotic suggestions are not “spontaneous”.
- They are produced by suggestion (explicit or implicit).
- Are experienced as involuntary
- And are all reversible.

“Hypnotisability”

can anyone be hypnotised
Research data suggests 70% of all of us are hypnotisable

Measurement scales determining these are:

- Harvard group scale. (HGSHS: A. Shor & Orne, 1992).
- Barber Suggestibility scale. (BSS: Weitzenhoffer & Hilgard, 1992).
- Group scale. (GS: Hilgard 1965).

Hypnotic Induction and Deepening

Induction:

- Discuss procedure (script) - Facilitate insight and identify any psychodynamic issues related to stress.
- Focussed attention
- Eye closure
- Occupies conscious mind
- Facilitated disassociation with outside world
- Focus on internal experience

Deepening and awakening

Deepening

- Follow on from induction.
- Descent – safe place.
- Further absorption into inner experience.
- Mental and physical relaxation.
- Increase responsiveness for suggestions.
- Facilitate talking during hypnosis.
- Assent.
- Awakening.
- Encourage to share experience.

Further reading

Hypnosis consciousness and suggestion
A descriptive model:
Oakley, D.A. (1999).
Hypnosis and Consciousness: A structural model. Contemporary Hypnosis, 16, 215-223.

A Cognitive psychological version of the model:
Brown, R.G. & Oakley, D.A. (2004)
An Integrated cognitive theory of hypnosis and high hypnotisability.

Conclusion

In my work Hypnosis is used successfully to support patients through the varying issues they may have

WORKSHOP

Would you like to try a simple relaxation procedure ??

ESHRE Pre course congress
Psychology & counselling

Genetic counselling

Alison Lashwood (MSc. RGN, RSCN, DipHV)
Consultant Nurse
Centre for PGD, Guy's Hospital, London

Learning objectives

By the end of the session delegates will have an appreciation of:

- what genetic counselling is and its relevance to assisted reproductive technology & preimplantation genetic diagnosis
- how it differs from or is similar to therapeutic counselling.
- what specific issues affect those individuals & families with genetic disorders

What is "genetic counselling"?

"A communication process which deals with the human problems associated with the occurrence, or risk of occurrence, of a genetic disorder in a family…."

(Ad Hoc Committee on Genetic Counselling, American Society of Human Genetics, 1975)

It involves an attempt to help the individual or family……..

- Comprehend the medical facts about a disorder
- Appreciate the way in which heredity contributes to the disorder and to the risk of recurrence

- Understand the options for dealing with the risk of recurrence
- Choose the course of action which seems most appropriate to them
- Make the best possible adjustment to the disorder in an affected family member

Who needs genetic counselling?

- Those with a genetic condition
- Those with a family history of a genetic condition
- Parents with an affected child/pregnancy
- Those who request a diagnostic opinion
- Those in consanguineous partnerships

- Couples with recurrent miscarriages
- Ethnic background indicates an increased genetic risk
- Pregnant couples/individuals who fall into any of the above categories.

Roles in Genetic Counselling

Genetic Counsellor

- 'Non-directive'(*Kessler 1997, Michie et al 1997*)
- Provides information
- Offers genetic tests
- Counsels
- Supports
- Offers follow-up

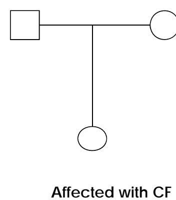
Patient

- Makes the decisions
- Lives with the consequences

The consultation

Case history

- Ellie has cystic fibrosis- diagnosed after birth
- Sue & John had no family history of CF
- Couple want to have more children



Affected with CF

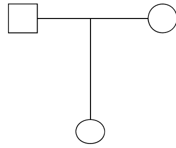
So what do we do?

Let the couple…….

- Tell their story
- Ask what questions they have
- Acknowledge their feelings i.e. grief, anger etc.

Discuss

- Recurrence risks
- Future options
- Other support?



Affected with cystic fibrosis

Specific issues

1. Grief
2. Impact on family *(James et al 2006)*
3. Perception of risk *(Marteau et al 1991)*

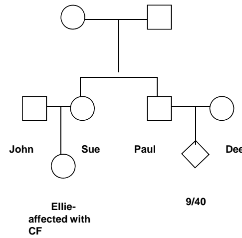
1. Grief

- Loss of health of self
- Loss of reproductive freedom
- Loss of health of family
- Guilt
- Fear

2. Impact on family

Case history

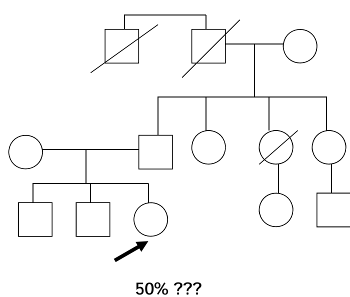
- Dee & Paul are 9/40 pregnant
- Different agendas- no/yes prenatal diagnosis
- Differing views
- Impact of guilt- remember grandparents



2. Perception of risk

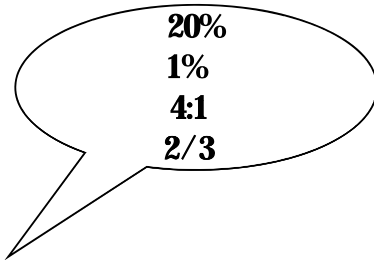
- Evaluation of risk will vary widely.
- Family myths "it only happens to boys in our family"
- Past experience

You will never convince this family.........



- Risk figures can be a difficult concept *(Michie et al 2005)*
- Risk figures need to be presented in different ways
- Both positive and negative presentation of risk

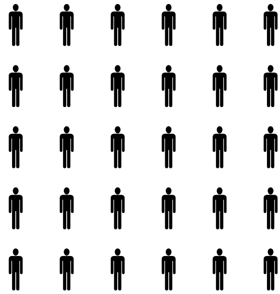
What do risks mean?



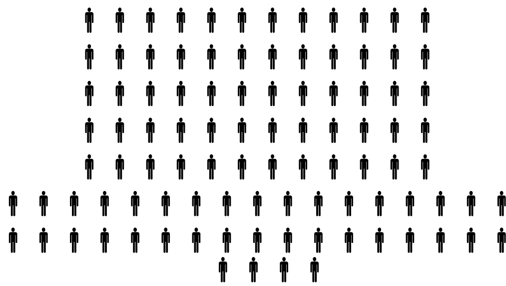
High or low?

- 1 in 200
- 1 in 100
- 1 in 10

20% or 1 in 5



1% or 1 in 100



Visual presentation can help

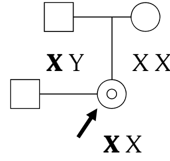
Difficult issues in genetic counselling

1. Confidentiality
2. Late onset disorders *(Went et al 1994)*
3. Testing in pregnancy

1. Confidentiality

Case history

- Donald has Becker muscular dystrophy
- X linked inheritance
- Daisy is an obligate carrier
- Daisy is asking for PGD to avoid having an affected son

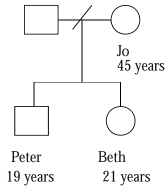


Issues raised

- Neurologist informs genetic counsellor that Daisy's parents used donor insemination to conceive her
- Father does not want Daisy to know
- On testing Daisy is not a carrier
- Who has the right to confidentiality?
- Outcome..................???

2. Late-onset disorders and presymptomatic testing

Presymptomatic testing: Case history



- Jo has Huntington Disease
- Beth and Peter at 50% risk
- Both want to be tested
- Outcome……

Beth has –ve test result
Peter has +ve test result

Implications of presymptomatic testing

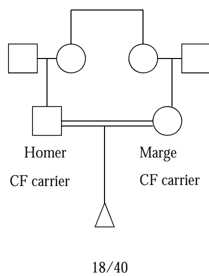
- Impact of result when HD is an untreatable, incurable, late-onset genetic condition *(Tibben et al 1993)*
- Social and psychological impact
- Practical impact e.g. jobs, insurance
- Survivor guilt

3. Genetic testing in pregnancy

Issues to consider

- Impact of time frame for testing
- Do couple understand implications of testing?
- Is decision making compromised by emotion?
- Potential for multiple bereavements

Case history



- Homer and Marge-1st cousin partnership
- No family history of note
- On testing found to be cystic fibrosis carriers
- Prenatal diagnostic test-affected fetus
- TOP

Issues raised by the case

- Request for reassurance
- No previous knowledge of CF
- Late stage of pregnancy urgency of making a decision
- Loss of a much wanted pregnancy.
- “Confirmation” of family fears

Genetic Counselling & PGD

PGD Genetic counselling offers a couple:

- An opportunity to review the genetics of the disorder
- Discuss reproductive options again.
- Talk through their previous experience

PGD Genetic counselling offers a clinician:

- A chance to clarify why the couple have requested PGD
- Time for full discussion of the procedure involved.

Why couples request PGD?

- Prenatal diagnosis and TOP not acceptable
- Knowledge of having an unaffected child from conception
- Avoidance of further miscarriage
- Genetic disorder and fertility problems

Factors affecting request

1. Previous experience
2. Expectation of success
3. Perception of fertility

1. Previous experience

- Prenatal diagnosis and experience of termination of pregnancy
- Health of the couple's affected child
- Death of affected child-when did this happen
- Belief in genetic risk

2. Expectation of success

- Do the couple understand the success rate of PGD *(Gossens et al 2008)*
- Do the couple understand the impact of a PGD cycle
- Limitations of PGD
- PGD reduces risk rather than eliminates it

3. Perception of fertility

- Delayed spontaneous conception
- Do the couple have concerns over their fertility?
- Recurrent miscarriage, is this due to the chromosome abnormality?

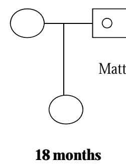
Special counselling issues in PGD

- Affect of PGD treatment on previous children
- Welfare of the child *(HFEA 1990)*

Impact on affected children

Case history

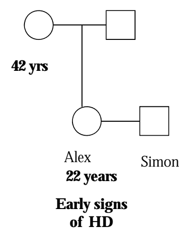
- Matt carries a balanced reciprocal translocation
- Sophie has inherited an unbalanced version
- Severe developmental delay and now on dialysis
- Potential impact of OHSS and multiple pregnancy.



Welfare of the child

Case history

- Alex +ve HD gene test
- Early signs present
- Onset of HD likely to affect child care abilities
- Simon will be dual carer
- Impact of this on the couple



Genetic counselling after PGD cycle

- Support if treatment unsuccessful
- Discussion around confirmatory prenatal testing.
- Confirmatory testing at delivery- conveying results
- Follow up of babies born

In summary

- Genetic counselling is an important part of a clinical genetics and an assisted reproduction service.
- Knowledge and understanding of what is involved is important
- Genetics often raises complex issues for both individuals and families.
- Many of the basic skills it employs are transferable to other specialities.
- PGD should include genetic counselling to meet the needs of a good quality treatment programme.

Bibliography

Ad Hoc Committee on Genetic Counselling American Society for Human Genetics (1975) Genetic Counselling. American Journal of Human Genetics 27:240-242 Clinical Genetics Society (1994)

Donnai P, Charles N, Harris N. Attitudes of patients after "genetic" terminations of pregnancy. *British Medical Journal*, 1991; 282:621-622

Flis-Treves, M., Achour-Frydman, N., Kerbrat, V., Munnich, A., Vekemans, M., Frydman, R. (2003). Preimplantation genetic diagnosis and its psychological effects. *J Gynecol Obstet Biol Reprod* (Paris). Apr; **32** (2): 127-31

Goossens, V., Harton, G., Moutou, C., Scriven, P.N., Traeger-Synodinos, J., Sermon, K. and Harper, J.C. ESHRE PGD Consortium data collection VIII: cycles from January to December 2005 with pregnancy follow-up to October 2006. *Hum. Reprod* 2008;23:2629-2645

Human Fertilisation and Embryology Act 1990. HMSO publication, London 1990
www.hfea.gov.uk/

James, CA., Hadley, DW., Holtzman, NA., Winkelstein, JA. (2006). How does the mode of inheritance of a genetic condition influence families? A study of guilt, blame, stigma, and understanding of inheritance and reproductive risks in families with X-linked and autosomal recessive diseases. *Genet Med.* **8** (4):234-

Kessler S (1997) Psychological aspects of genetic counselling.XI.Non directiveness revisited American Journal of Medical Genetics 72 (2):164-171

Korenromp, MJ., Christiaens, GC., van den Bout, J., Mulder, EJ., Hunfeld, JA., Bilardo, CM. Visser, GH. (2005). Long-term psychological consequences of pregnancy termination for fetal abnormality: a cross-sectional study. *Prenat Diagn.* **25** (3): 253-60

Marteau, T.M., Kidd, J., Cook, R., Michie, S., Johnston, M., Slack, J., Shaw, RW. (1991). Perceived risk not actual risk predicts uptake of amniocentesis. *Br J Obstet Gynaecol.* **98 (**3): 282-6

McAllister M. (2003). Personal theories of inheritance, coping strategies, risk perception and engagement In hereditary non-polyposis colon cancer families offered genetic testing. *Clin Genet* **64** (3): 179-89.

Michie, S., Bron, F., Bobrow, M,. Marteau, T.M. (1997). Nondirectiveness in genetic counselling: an empirical study. *Am J Hum Genet* **60** (1): 40-7.

Michie, S., Lester, K., Pinto, J., Marteau, TM. (2005). Communicating risk information in genetic counselling: an observational study. *Health Educ Behav* **32 (**5): 589-98

McAllister, M., Payne, K., Nicholls, S., Macleod, R., Donnai, D., Davies, LM (2007) Improving service evaluation in clinical genetics: identifying effects of genetic diseases on individuals and families. *J Genet Couns.* **16 (**1): 71-83.

Sorensen, J.R., Swazey, J.P., Scotch, NA.,Kavanagh CM., Matthews, DB. (1981). Reproductive pasts, reproductive futures. Genetic counselling and its effectiveness. *Birth Defects Orig Artic Ser.* **17** (4): 1-19

Palomba, M L., Monni, G., Lai, R., Cau, G., Olla, G., Cao, A. (1994). Psychological implications and acceptibility of preimplantation diagnosis. *Hum Reprod* 9 (2): 360-36

Thornhill et al (2005) ESHRE PGD Consortium "Best practice guidelines for clinical preimplantation genetic Diagnosis (PGD) and preimplantation genetic screening (PGS) Human Reproduction 20:35-48

Tibben, A., Frets, P., van de Kamp, J., Niermeijer, M., Vegtervan der Vlis, M., Roos, R., Rooymans, H., van Ommen, G., Verhage, F (1993). On attitudes and appreciation 6 months after predictive DNA testing for Huntington's disease in the Dutch program. *Am J Med Genet* (Neuropsychiatric Genetics) **43**: 103-111

Went et al (1994) On behalf of a joint committee from the International Huntington's Association and World Federation of Neurology Research Group on Huntington's Chorea.Guidelines for the molecular genetics predictive test in Huntington's disease. Journal of Medical Genetics 31:555-559

Books for general background reading:

Skirton, H & Patch, C (2002). *Genetics for Healthcare Professionals. A lifestage approach* Pub: BIOS Scientific Publishers Ltd. Oxford ISBN:1 85996 043

Harper, P. S. (2003) Genetic counselling: an introduction. *In Practical Genetic Counselling*, 5th edition: London: Arnold.

Training and Supervision for Infertility Counsellors: Who is Qualified?

Workshop Summary

The Expanded Role of the Infertility Counsellor

- This expanded role is based on the complex relationships between psychosocial and medical factors that underscore the need for mental health professional involvement in the infertility treatment team.
- The role includes: evaluation and assessment, psychotherapeutic intervention, psycho-education, research, and consultation to the medical staff.

Who is Qualified?

There is the need for specialized training and experience that includes:

1. Minimal educational qualifications and training –
   a. *basic graduate training in mental health; and,*
   b. *license or certification/registration to practice in the mental health field as required by state or country.*

Who is Qualified?

2. Training in the psychological and medical aspects of Infertility –

   a. *basic reproductive physiology*;

   b. *testing, diagnosis, and treatment of reproductive problems*;

   c. *etiology of female and male infertility*; &

   d. *knowledge of assisted reproductive technologies*.

Who is Qualified?

3. Training in the psychology of infertility to include a knowledge of:

   a. *Medical and family issues as well as impact on sexual functioning*;

   b. *Treatment approaches that include assessment, bereavement/loss, crisis intervention, stress management, typical/atypical responses*;

   c. *Family-building alternatives*;

   d. *individual and couples' treatment*

   e. *Legal and ethical issues*

   f. *How and where to access resources & referrals.*

Infertility Counsellor Training and Credentialing

- Despite mandated or well-defined roles of the infertility counsellor as well as qualification guidelines, there continue to be discrepancies regarding the medical clinic's appropriate use of the mental health professional.
- There are often counsellor shortages and as well as those with questionable training.
- There are often limited training opportunities for counsellors, unclear professional standards, and resistance - issues that make appropriate infertility counsellor training and supervision challenging.
- Infertility counselling organizations are attempting to establish & clarify appropriate professional counsellor training & development on a global level.

SUMMING UP

(5 additional slides)

Misconceptions

- Induce sleep
- Impairs memory
- Lead to unwilling disclosures
- Is a treatment in its self
- Can get stuck
- Can go into unwanted state of consciousness
- Is abnormal

Why fertility treatment

When can it be used

- At all stages of treatment and beyond
- Stress reduction
- Reducing weight Eating disorders
- Phobias (injections)
- Embryo transfer
- Difficulty in sleeping (Insomnia)
- Empowerment

Hypnosis as an adjunct

It is used to support therapies such as Cognitive Behavioural Therapy (CBT)

Kirsch, L. Mongomery, G and Sapirstein, G. (1996).
Hypnosis as an adjunct to cognitive-behavioural psychotherapy:
A meta-analysis.
Journal of counselling and clinical Psychology. 63, 214-220

Mind Map of Using Hypnosis as an adjunct to Psychotherapy

ESHRE Pre course congress
Psychology & counselling

Genetic counselling

Plenary session
Summary slides

Summary- slide 1

- Genetic counselling has a specific clinical goal.
- Can it truly be “non directive”?
- It is undertaken by specialists trained within the field, why is this necessary?
- Where is the boundary between therapeutic & genetic counselling?

Summary slide 2

Genetic counselling needs to take account of:
- The family history &experience of the disorder
- The level of risk to the family

Patients may express grief, concern over impact on family and struggle with their perception of risk.

These issues often create barriers to genetic counselling and genetic counsellors must be aware of these and respond accordingly.

Summary slide 3

- Patient confidentiality is sometimes challenged. Is it ever acceptable to breach confidentiality?
- Testing for late onset disorders can create multiple practical and psychosocial issues for patients. Should this type of testing be available?
- Prenatal testing raises issues in relation to termination of pregnancy and short time frame for decision making. Does this create unnecessary and difficult issues for patients?

Summary slide 4

- Is there a need to employ genetic counselling for PGD patients?
- Why is genetic counselling for PGD patients any different to other that used for other genetics patients?
- Issues to be addressed include that alternative reproductive options have been discussed and couples understand fully the implications of the procedure.
- It is an opportunity to ensure that PGD will meet patients' perceptions of treatment e.g. likelihood of success, extent of information available in embryos.

Summary slide 5

There are special issues that need discussion with couples before they start treatment:

- Should we be responsible for considering the welfare of children born following PGD? What if there is a high likelihood that the parent with a genetic disorder will deteriorate or die?
- What about the impact of PGD on living children with a genetic disorder?

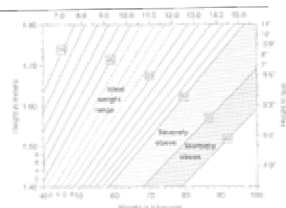
Lifestyle and infertility treatment

Human M.Fatemi, MD,PhD
Centre for reproductive medicine
Brussels/Belgium

Define "Life style"

- BMI
- eating disorders
- smoking
- Alcohol consumption

BMI



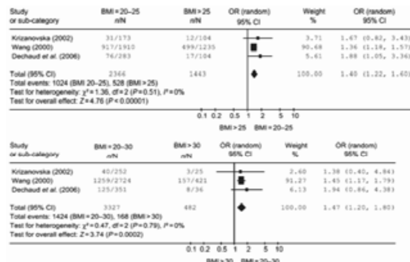
Balen, 2008

Table 4.4 Body mass index (BMI) and percentage pregnant after 12 cycles

BMI	% pregnant after 12 cycles
< 20.0	40
20.1–25	48
25.1–30	48
> 30	18

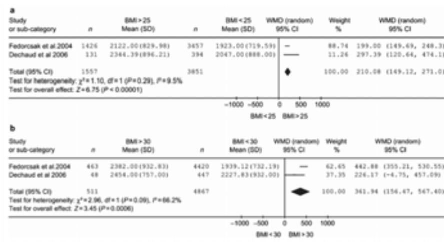
Zaadstra et al., 1993

BMI & ART?



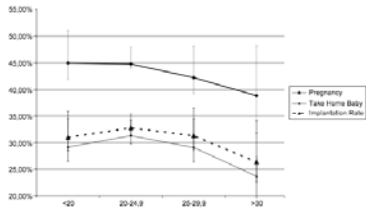
Maheshawari et al., 2007

BMI & ART



Maheshawari et al., 2007

BMI & Pregnancy after ART



Bellver. Obesity, embryo quality, and IVF outcome. Fertil Steril 2006.

BMI & Pregnancy

- Obesity and increased odds
  - → neural tube defects (OR, 1.87; 95% confidence interval [CI], 1.62-2.15),
  - → spina bifida (OR, 2.24; 95% CI, 1.86-2.69)
  - → cardiovascular anomalies (OR, 1.30; 95% CI, 1.12-1.51),
  - → septal anomalies (OR, 1.20; 95% CI, 1.09-1.31),
  - → cleft palate (OR, 1.23; 95% CI, 1.03-1.47),
  - → cleft lip and palate (OR, 1.20; 95% CI, 1.03-1.40)
  - → anorectal atresia (OR, 1.48; 95% CI, 1.12-1.97)
  - → hydrocephaly (OR, 1.68; 95% CI, 1.19-2.36), and
  - → limb reduction anomalies (OR, 1.34; 95% CI, 1.03-1.73).

Stothard et al,2009 (JAMA)

- Eating behavior and pregnancy outcome
  - → Women with disordered eating were shown to be at greater risk of delivering term SGA infants (Conti et al., 1998)
- Smoking and ART?
  - → The available biologic, experimental, and epidemiological data indicate that up to 13% of infertility may be attributable to cigarette smoking.(ASRM, educational Bulletin, 2008)
  - → Smoking appears to accelerate the loss of reproductive function and may advance the time of menopause by one to four years.(Baron et al., 1990)
    - FSH up to 66% higher i active smokers than in nonsmokers (Cooper et al., 1995)
  - → Smoking is associated with increased risks of spontaneous abortion and ectopic pregnancy. (Ness et al., 1999)
  - → Gamete mutagenesis is one possible mechanism whereby smoking may adversely affect fecundity and reproductive performance.(Tang et al., 1999)
  - → Results of a meta-analysis examining the outcome of ART cycles indicate that smokers require nearly twice the number of IVF attempts to conceive as nonsmokers.(Klonoff et al., 2001)
  - → Semen parameters and results of sperm function tests are generally poorer in smokers than in nonsmokers (Stillman et al., 1986)
  - → Clinicians can facilitate smoking cessation by providing education, monitoring, and consistent individualized support.

Smoking and pregnancy

- Placental complications
  - → For placental abruption, a 1.4–2.4 relative risk
    - including degenerative and inflammatory alterations in the placenta, and premature rupture of membranes (Einarson et al., 2009)
    - For placenta preavia, studies have generally shown a 1.5–3.0 relative risk.
      - due to hypoxia: placental enlargement (Einarson et al., 2009)
- Fetal growth restriction
  - → Infants born to women who smoke during pregnancy are, on average, 200 g lighter (Jauniaux et al., 2007)

Smoking and pregnancy

- Relative risks for preterm delivery 1.2 to 1.6 (Shah, 2000)
- Oral-facial cleft: a relative risk of 1.2–1.3 (Little et al., 2004)
- SIDS: a 2.0–3.0 relative risk (Mitchell et al., 2006)
- Other risks
  - → craniosynostosis, clubfoot, childhood respiratory disease, attention deficit disorder, and childhood cancers (Einarson et al., 2009).

Do patients know this?

Public knowledge of the risks of smoking.

Smoking risk	Knowledge of risk
Lung cancer	99%
Respiratory disease	99%
Heart disease	96%
Miscarriage	39%
Osteoporosis	30%
Ectopic pregnancy	27%
Infertility	22%
Early menopause	17%

ASRM Practice Committee. Smoking and infertility. Fertil Steril 2008.

Alcohol and ART

Klonoff-Cohen, 2005

Conclusion

- Knowing the evidence based medicine on this subject, the fertility physician should refuse to treat patients with a certain life style.

- Once the patients seeks advise/professional help to adjust their life style, the treatment should be allowed.

13 titel 08/17/2007

DEBATE: LIFESTYLE AND FERTILITY TREATMENT

Jan Norré
Master Clinical Psychology
Master Sexuology
Psychotherapist

ESHRE Amsterdam, 28 juni 2009

THE QUESTION

SHOULD WOMEN BE EXCLUDED FROM TREATMENT FOR SMOKING, OBESITY AND EATING DISORDERS ?

THE ANSWER IS **NO**

- WHY ?
- HOW TO DEAL WITH ?

THE QUESTION

SHOULD **WOMEN** BE
EXCLUDED FROM TREATMENT
FOR SMOKING, OBESITY AND
EATING DISORDERS ?

Leuven Institute for Fertilty and Embryology

Feministic perspective

THE WOMAN IS TO BLAME !

Leuven Institute for Fertilty and Embryology

THE QUESTION

SHOULD WOMEN BE
EXCLUDED FROM TREATMENT
FOR SMOKING, OBESITY AND
EATING DISORDERS ?

Leuven Institute for Fertilty and Embryology

THE HEALTH CARE PERSPECTIVE

- What do we do with medical diseases who reduce fertility ?
- What do we do with life style issues who reduce fertility ?

THE QUESTION

SHOULD WOMEN BE EXCLUDED FROM TREATMENT FOR **SMOKING**, OBESITY AND EATING DISORDERS ?

LIFE STYLE ?

What do these behaviors reflect ?

- Smoking
- Alcohol
- Drugs

PSYCHOPATHOLOGY ?

- Addictions
- Mood Disorders
- Personality Disorders

Leuven Institute for Fertilty and Embryology

THE QUESTION

SHOULD WOMEN BE EXCLUDED FROM TREATMENT FOR SMOKING, **OBESITY** AND EATING DISORDERS ?

Leuven Institute for Fertilty and Embryology

OBESITY ?

- RECOGNIZED AS DISEASE
- RISK OF PSYCHIATRIC COMORBIDITY

Leuven Institute for Fertilty and Embryology

PSYCHIATRIC COMORBIDITY

- BINGE EATING DISORDER
- MOOD DISORDER

Leuven Institute for Fertilty and Embryology

THE QUESTION

SHOULD WOMEN BE EXCLUDED FROM TREATMENT FOR SMOKING, OBESITY AND **EATING DISORDERS** ?

Leuven Institute for Fertilty and Embryology

EATING DISORDERS

- EDNOS
- ANOREXIA NERVOSA
- BOULIMIA NERVOSA

Leuven Institute for Fertilty and Embryology

INFLUENCE OF PREGNANCY

Life style issues:

- Eating patterns
- Weight
- Post natal mood

Leuven Institute for Fertilty and Embryology

HOW TO DEAL WITH ?

Stepped care treatment

- Treatment of lifestyle or psychopathology
- ART, if necessary
- Continuation of psychotherapy

Leuven Institute for Fertilty and Embryology

NOTES

NOTES

NOTES

NOTES

NOTES

NOTES

NOTES

NOTES