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"The beast of burden":

how to manage the burden of fertility treatment

Special Interest Group Psychology and Counselling

6

1 July 2012
Istanbul, Turkey

"The beast of burden": how to manage the burden of fertility treatment

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Organised by
the Special Interest Group Psychology and Counselling

Contents

Course coordinators

Chris Verhaak (The Netherlands) and Uschi Van den Broeck (Belgium)

Course description

The burden of fertility treatment multidimensional and contributes to treatment outcome and to satisfaction with care. In this course, burden of treatment will be addressed from different perspectives. In addition, tools to alleviate burden will be offered. Actual knowledge from research will be translated into practical recommendations.

Target audience

· Medical doctors
· Nurses and paramedical staff involved in patient care
· Counsellors and other professionals involved in psychosocial care

Scientific programme

Chairmen : Chris Verhaak (The Netherlands) & Uschi van den Broeck (Belgium)

09.00 - 09.30	Treatment discontinuation and treatment burden: a balancing act – **Sofia Gameiro (Portugal)**
09.30 - 10.00	Different treatment protocols, different burden of treatment? – **Cora de Klerk (The Netherlands)**
10.00 - 10.30	Burden of treatment in Turkey – **Aygul Akyuz (Turkey)**
10.30 - 11.00	Coffee break
11.00 - 11.30	The use of internet and other online resources and its impact on the burden of treatment - **Neil Coulson (United Kingdom)**
11.30 - 12.00	The burden of unsuccessful treatment and stopping treatment: the long and winding road – **Uschi van den Broeck (Belgium)**
12.00 - 12.30	Burden of treatment and your sex life – **Hester Pastoor (The Netherlands)**
12.30 - 13.30	Lunch
13.30 - 14.15	What's in a word? The impact of patient and healthcare provider communication on the burden of treatment – **Judith Prins (The Netherlands)**
14.15 - 15.00	Quality of Care and burden of treatment – **Willianne Nelen (The Netherlands)**
15.00 - 15.30	Coffee Break
15.30 - 17.00	Round table discussion: how to diminish burden of treatment in daily practice?
17.00 - 17.30	Special Interest Group Business Meeting

TREATMENT DISCONTINUATION AND TREATMENT BURDEN: A BALANCING ACT

SOFIA GAMEIRO, PHD

ESHRE Pre-Congress Course 6
Istanbul, 1st July 2012

Disclosure

- I have no conflicts of interest

Summary

1. What is discontinuation and why should we talk about compliance (instead)?
2. How does treatment burden affect compliance?
3. When is burden too much burden?
4. How can psychosocial support be implemented to promote compliance?

Learning objectives

- Understand how compliance relates with treatment success
- Be aware of current problems in defining and measuring compliance and how if affects rates estimated
- Understand how the onerous aspects of treatment may impact on treatment compliance
- Differentiate between different types of discontinuation from treatment (desired versus undesired)
- Identify patients in need of counselling support for compliance decision-making
- Lear how to promote compliance by implementing continuous psychosocial support

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What is discontinuation?

- The decision to opt out of (further) treatment, despite a favourable prognosis and ability to cover the costs of treatment

Boivin et al., 2012

- Discontinuation occurs at all stages of treatment
  - From workup to end of a typical ART programme (i.e. 3 cycles)
  - Rates & reasons for discontinuation vary across stages

Brandes et al., 2009

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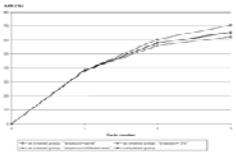
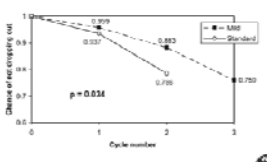
What is compliance?

- Treatment adherence
  - "the extent to which a person's behaviour follows medical advice or corresponds with recommendations from the health care provider…"

WHO, 2003, p. 3





Verberg et al. 2008; Verhagen et al., 2008

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Why should we talk about compliance?

- Guidelines focus only on treatment success rates
  - But efficacy of treatment cannot be accurately estimated when ignoring discontinuation

⇩

Compliance information is essential for informed consent

Addressing causes of non-compliance can help more people become parents

Compliance as a way of auditing treatment delivery at clinics (NICE, 2004)

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Problems in measuring compliance

- Conceptual
  - Definition of compliance
    - Passive versus active censuring, clinic surfing, treatment delay
- Methodological
  - Length of follow-up
  - Treatment protocol ...
- Practical / logistic
  - a precise assessment of compliance implies monitoring patients' long-term treatment trajectories

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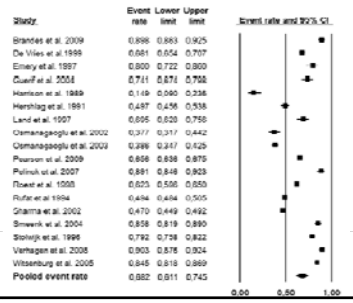
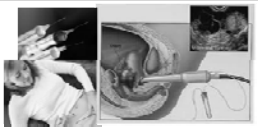
Compliance in Assisted Reproduction

- 68.2% (95%CI 61.1 – 74.5)



Gameiro et al., under review.

Treatment burden



Physical

Personal & relational ⟷ **Clinical / organizational**

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Treatment burden

Physical burden of treatment

I could not stand all the **injections**; I could not stand **side effects of medication**; physical burden; physical discomfort; poor tolerance to physical side of treatment; **retrieval too painful; side effects** from treatment; treatment too aggressive for partner

Physical

Personal & relational ⟷ **Clinical / organizational**

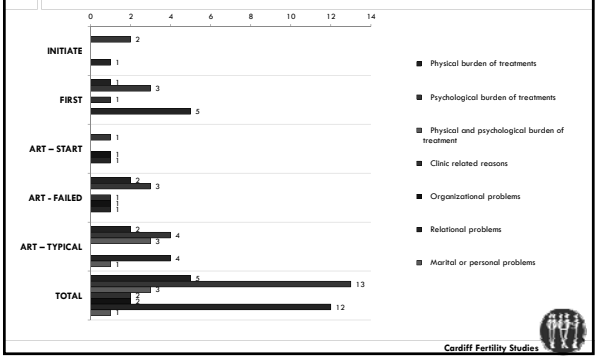
Psychological burden of treatment
can't stand it; emotional distress; emotional stress; psychological burden; psychological reasons; **too anxious or depressed to continue**; too much stress

Relational problems
divorce; **infertility taking too much of a toll on our relationship**; marital problems subsequent to start of treatment; relationship; separated; separated/divorced; separation of couple

Clinic related issues
clinic reason; **insufficient or poorly formulated explanations** about healthcare or fertility problem; **poor management of psychological aspects**

Organizational problems
language problems; **therapeutic programme difficult to integrate with work**

Studies investigating burden



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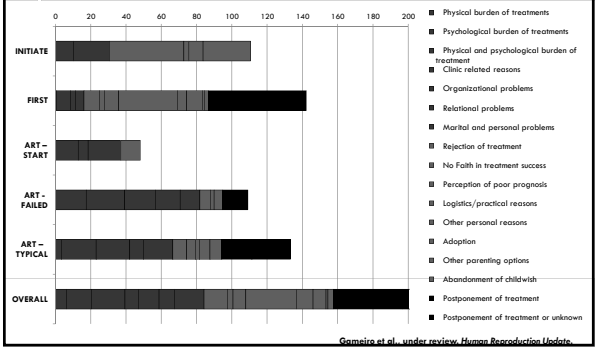
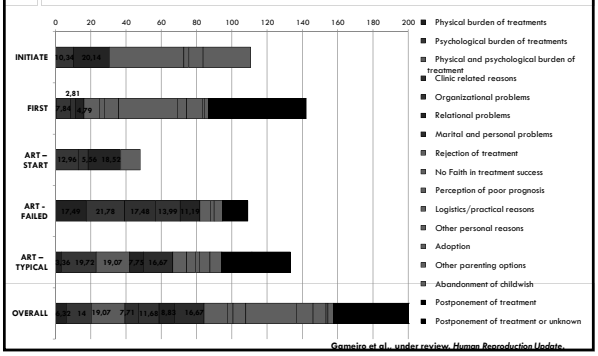
Patients' reports on burden



Gameiro et al., under review, *Human Reproduction Update*.

Patients' reports on burden



Gameiro et al., under review, *Human Reproduction Update*.

Do we know what causes burden?

- Personal & relational
  - despair after repeated unsuccessful cycles of IVF
  - relational conflict around treatment options & management of practical issues
  - differentiate between 'doing enough' & 'doing too much'
  - unable to decide: open-ended decision
- Clinic / organizational
  - abandoned by staff at the end of treatment
  - generic information, not specific to each couple
  - given false hope of success whilst on treatment
  - lack of patient-centered care
    - no continuity, lack of empathy from staff, lack of information / communication skills
- Other
  - social and professional opportunity costs

Boden, 2007; Peddie et al.,2005.

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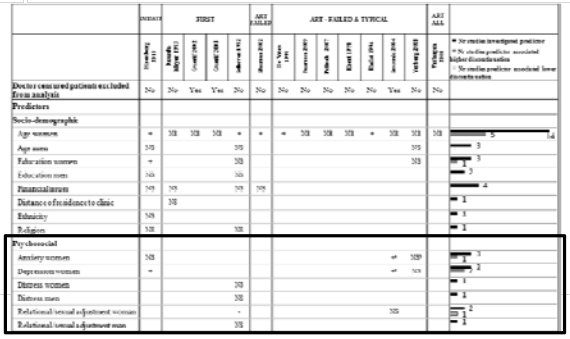
Do we know what causes burden?



Gameiro et al., under review, *Human Reproduction Update*.

Desired versus undesired discontinuation

- Desired
  - based on patients' values and preferences
    - My religion beliefs do not allow me to use ART
    - I decided to adopt
- Undesired
  - as a result of uncontrollable barriers and/or burden
    - I was not able to cope with another treatment cycle
    - I was convinced that treatments would work at my first trial and was too put down by failure to think about continuing
    - I wasn't satisfied with care at clinic

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When is burden too much burden?

STAFF:

1. does not like the doctor or vice versa
2. is disruptive with staff and consistently demanding preferential and/or exceptional treatment
3. has mental health problems that are disruptive to medical treatment
4. needs extensive support that is beyond the ability and expertise of medical staff

COUPLE:

1. communication problems and conflicts about treatment
2. partners at different stages in the grief process and/or different goals

INDIVIDUAL:

1. feeling 'stuck' or that treatment is futile
2. feeling resentful about medical appointments or treatment
3. feeling disappointed when the doctor offers new treatment
4. feeling the need to move on with life versus continuing to invest one's time, energy, and money in infertility treatment
5. feeling relieved when one's spouse or doctor suggests quitting or taking a treatment holiday
6. feeling that one has already mourned the loss of one's biological child

Hammer-Burns, 2004.

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Patients desire continuous support

- 'I hadn't thought about stopping treatment until today. I suppose it's made me confront issues that I should have addressed a long time ago.'
- 'We were prepared for our final appointment with every question you could possibly think of (…). I got more information about my medical condition than I ever had before, and I wondered why this hadn't come earlier'

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Clinics provide insufficient support

Table III. Quality of information provision by clinic doctor.

	The doctor gave me information about this			
	Yes	No	Not sure	Not applicable Max n = 71
Advantages of stopping treatment	17 (24%)	35 (50%)	7 (10%)	12 (16%)
Disadvantages of stopping treatment	13 (18%)	36 (51%)	5 (7%)	17 (24%)
Options other than IVF	24 (33%)	28 (40%)	4 (6%)	15 (21%)
Advantages of options other than IVF	17 (24%)	34 (48%)	5 (7%)	15 (21%)
Access to independent counsellor	48 (68%)	8 (11%)	4 (6%)	11 (15%)
Access to other options (e.g., adoption and fostering)	14 (20%)	42 (59%)	4 (6%)	11 (15%)

Peddie et al., 2004.

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Providing psychosocial support

Type of support	Who	Before treatment	During treatment	After treatment
PCC	ALL STAFF	**-Information about treatment** - success & compliance rates - preparatory **-Information about alternatives** **-Screening & referral**	**-Interventions to decrease treatment burden** **- Tailor to individual needs** **- Screening & referral** - psychosocial support - decisional aid	**- Screening & referral** - psychosocial support - decisional aid
Counselling	Physicians & MHPs	**-Information about treatment & alternatives** **-Decisional-aid** **- Shared DM**		**-Information about treatment & alternatives** **- Decisional-aid** **- Shared DM**
Psycho therapy	MHPs	Crisis intervention Psycho / psychiatric therapy		

In summary

- Clinics should strive to monitor & promote treatment compliance
  - Monitoring of long term treatment trajectories
- Promotion of treatment compliance should be done by
  - Implementing interventions to diminish treatment burden
    - Much more research is needed to infer causal links
  - Providing patients with adequate psychosocial support
    - Information provision and decisional-aid

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Additional information

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FACULDADE DE PSICOLOGIA E DE CIÊNCIAS DA EDUCAÇÃO UNIVERSIDADE DE COIMBRA

Relações, Desenvolvimento & Saúde

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

School of Psychology

Erasmus MC
University Medical Center Rotterdam

ESHRE Istanbul 2012
SIG Psychology and Counselling

Different treatment protocols, different treatment burden?

Cora de Klerk, PhD
Research Psychologist ~ Assistant Professor
Reproductive Medicine ~ Medical Psychology & Psychotherapy
Erasmus MC ~ Rotterdam ~ The Netherlands

Learning objectives

Participants will:

- Be aware of the existence of different definitions of IVF treatment success
- Understand how traditional definitions of treatment success lead to the use of complex, burdensome ovarian stimulation protocols in IVF
- Know about the strengths and weaknesses of a mild IVF approach
- Be able to identify patients who may benefit from a mild IVF approach
- Know how to empower patients to make an informed decision about which IVF treatment strategy to use

Treatment burden in IVF: multiple causes Boivin *et al.*, 2012

- Patient factors
  Individual, couple
- Clinic factors
  Health care providers, environment
- Treatment factors

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Conventional IVF approach Verberg *et al.*, 2009

Aiming for high number of oocytes and embryos:

- Complex stimulation regimes
- Time consuming
- High patient discomfort
- Complications: ovarian hyperstimulation syndrome (OHSS)
- Multiple pregnancies
- High dropout rates
- High costs

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Traditional measures of IVF treatment success

- Numerator:
  - Number of follicles
  - Number of oocytes
  - Number of embryos
  - Implantation rate
  - Pregnancy rate
- Denominator:
  - Started cycle

➢ Ovarian stimulation protocols aiming for maximum number of oocytes

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Novel definition of IVF treatment success Heijnen *et al.*, 2004

- Patient perspective:
- Success = healthy baby

▪ Traditional paradigm:	pregnancy	per cycle
▪ Alternative paradigm:	term life birth	per time period

➢ Milder and shorter ovarian stimulation protocols
➢ Single embryo transfer (SET)

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Mild IVF approach Verberg *et al.*, 2009

Aims:

- Complexity ↓
- Duration ↓
- Patient discomfort ↓
- Complication risk ↓
- Multiple pregnancies ↓
- Dropout rates ↓
- Medical costs ↓

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Mild ovarian stimulation for IVF

- Definition:
- "The administration of low doses (fewer days) of exogenous gonadotrophins in GnRH antagonist co-treated cycles, and/or oral compounds (like anti-oestrogens, or aromatase inhibitors) for ovarian stimulation for IVF, aiming to limit the number of oocytes obtained to less than eight"
- Fauser *et al.*, 2010

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Research methods in psychology

Quantitative research methods:

- Search for causal explanations → prediction
- Narrow focus, outcome oriented
- Numbers

Qualitative research methods:

- Exploration of people's experiences → understanding
- Broad focus, process oriented
- Narratives

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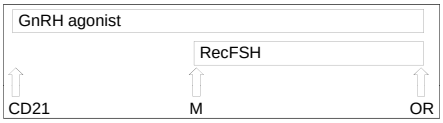
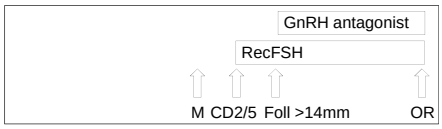
Comparing treatment protocols Eijkemans *et al.*, 2006

Conventional stimulation



Mild stimulation



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Characteristics of study participants Eijkemans *et al.*, 2006

- Indication for IVF or ICSI
- No unsuccessful previous IVF treatment
- Aged younger than 38 years
- Menstrual cycle length of 25-35 days
- Body Mass Index of 18-28 kg/m^2
- Fluent in Dutch

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Side-effects of GnRH Agonist treatment de Klerk *et al.*, 2006

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Side-effects of GnRH Agonist treatment de Klerk *et al.*, 2006

- Depressive mood
- Physical complaints
  Headache, lower back pain, muscle pain

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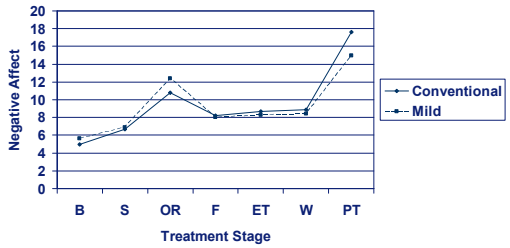
Negative affect during 1st IVF cycle de Klerk *et al.*, 2006



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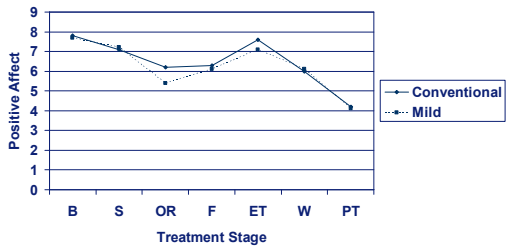
Positive affect during 1st IVF cycle de Klerk *et al.*, 2006



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Patient perspectives on single embryo transfer Højgaard *et al.*, 2007

Double embryo transfer is often preferred over SET:

- Patients' may wish to minimize the amount of IVF cycles
- Twins are preferred over singletons
- Lack of counselling on risks

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Patient perspectives on mild IVF 1 Payne *et al.*, 2012

Access and costs

- Not recommended by physicians
- No information on mild IVF
- Trying different IVF strategies is more effective
- Not cheaper than conventional IVF
- Costs are not a decision factor

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Patient perspectives on mild IVF 2 Payne *et al.*, 2012

Working with nature

- Using the natural menstruation cycle is more effective
- Less medical intervention
- Better quality embryos

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Patient perspectives on mild IVF 3 Payne *et al.*, 2012

Time

- Shorter timeframe makes daily injections bearable
- Less intrusive into day-to-day activities
- Less time spent waiting for results
- Less emotional burden
- Shorter overall treatment period

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One-year follow-up Heijnen *et al.*, 2007

Conventional approach

2 embryos	2 embryos	2 embryos

Mild approach

1 embryo	1 embryo	1 embryo	1 embryo

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Mild vs. conventional IVF: 1-year results Heijnen *et al.*, 2007

- Cumulative rates of term life births ↔
- Number of cycles ↑
- Cancellation rate ↑
- Cumulative rates of patient discomfort ↔
  Anxiety, depressive mood, physical complaints, sleep quality
- Multiple pregnancy rates ↓
- Costs ↓

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Reasons for IVF dropout Brandes *et al.*, 2009

- Emotional distress
- Poor response
- Relational problems
- Doubt about treatment efficacy
- Health problems

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Mild IVF and dropout

- Anxiety and depressive mood are risk factors for dropout
  Smeenk *et al.*, 2004
- Less dropout in mild IVF than in conventional IVF Verberg *et al.*, 2008
- Less dropout in patients with pre-existing anxiety using mild IVF than in patients with pre-existing anxiety using conventional IVF

➢ Patients with pre-existing anxiety may benefit from the use of mild IVF

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Screening

- Hospital Anxiety and Depression Scale (HADS)
- IVFSCREEN Verhaak *et al.*, 2010

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Mild IVF: Strengths Fauser *et al.*, 2010

- Live birth rates per started treatment ↔
- Complexity ↓
- Patient discomfort ↓
- Dropout ↓
- Risks ↓
- Medical costs ↓
- Oocyte/embryo quality ↑

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Mild IVF: Weaknesses Fauser *et al.*, 2010

- Lower pregnancy rate per cycle
- Excessive ovarian response still possible
- Medication costs still high
- Excellent laboratory performance required
- Fewer embryos for cryopreservation
- Not tested in women aged >38
- Programming IVF cycle is difficult
- No models for individualizing FSH doses
- Lack of robustness

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Mild IVF: Challenges Fauser *et al.*, 2010

- Clinicians prefer conventional IVF
- Traditional IVF success outcomes
- Fixed price per IVF cycle
- Fixed number of reimbursed cycles

➢ Patients may not have a choice regarding treatment strategy
➢ Counsellors could enable informed decision-making in patients

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Enabling informed decision-making Sage *et al.*, 2008

- Explain about informed consent and treatment choices
- Explain patients' rights
- Explain the differences between conventional and mild IVF
- Give information about procedures, benefits, risks and expected outcomes
- Explain the risks associated with multiple pregnancies
- Explore contributing factors of unassertiveness
- Identify and challenge unhelpful thoughts
- Help patients formulate helpful alternative thoughts

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Unhelpful thoughts about assertiveness Sage *et al.*, 2008

- Catastrophic thoughts about negative consequences of assertiveness
- Over-generalization of previous negative consequences of assertiveness
- Jumping to the conclusion that the doctor will not listen anyway
- Labelling oneself as not important enough to be listened to by the doctor
- Wanting to be a "good patient"
- Wanting to avoid conflict or cause negative feelings in others

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Challenging unhelpful thoughts Sage *et al.*, 2008

- Understanding its origins
- Usefulness and benefits
- Alternative perspectives
- Proportion and distortion
- Consistency
- Logical reasoning
- Influence and persuasion
- Examine the facts
- Belief or knowledge
- Predicting the future

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Ellen Klinkert	Prof. Egbert Te Velde

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33

Burden of Treatment in Turkey

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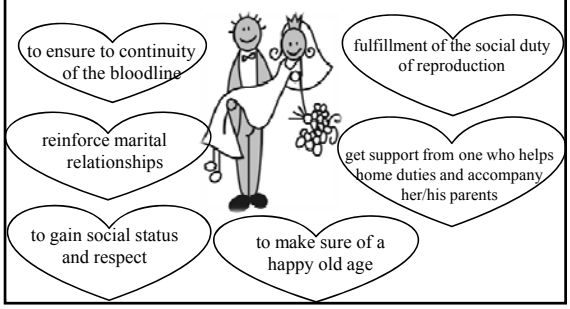
Welcome to Istanbul, Turkey.
The Bosphorus Bridge connects two continents, Europe and Asia.

Learning Objectives

Burden of infertility diagnosis

As many countries, in Turkey,
one of the main purposes of marriage is to have a baby.



Being an infertile wo(men)

✓ About 15 percent of the married couples are not be able to have a baby because of infetility.

✓ When a married couple do not fulfillment of the social duty of reproduction involuntary, they would not fulfill social role of "***being family***".

✓ For the couple, not having a baby means that ***the loss of a social position*** and emotional ***crisis.***

Having a baby; is a social responsibility rather than an instrinsic motivator

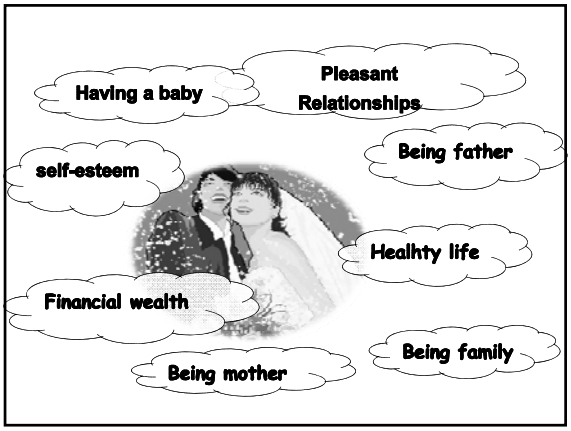
What would like to be when you grow up?

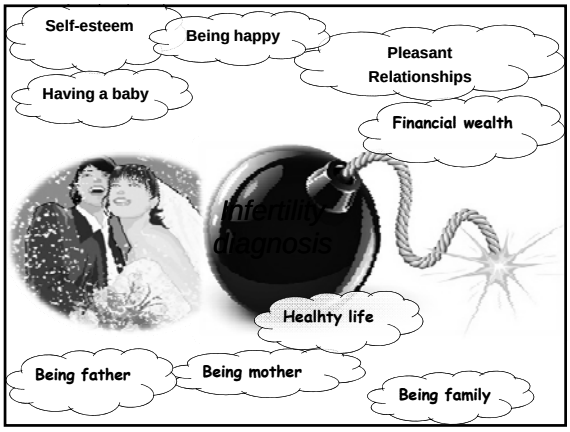
Doctor, Nurse, Teacher, ….. .

MOTHER

Doctor, Soldier, Engineer, Pilot, ……

FATHER





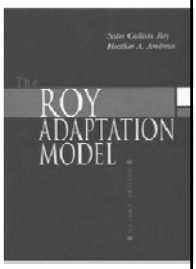
- Individuals remain healthy when he/she lives in accord with her/him physical, psychological, and social environment.
- For the reason that the couples would not fulfill one of their social roles regarding infertility diagnosed, they ***do not adapt to*** physical, psychological, and social changes in their life.

According to Sister Callista Roy ,

Impairment of adaptation is impairment of the health.

According to the Roy Adaptation Model:

Adaptation refers to the process and outcome whereby thinking and feeling people as individuals or in groups, use conscious awareness and choice to create human and environmental integration."



Burden of an infertility; diagnosis

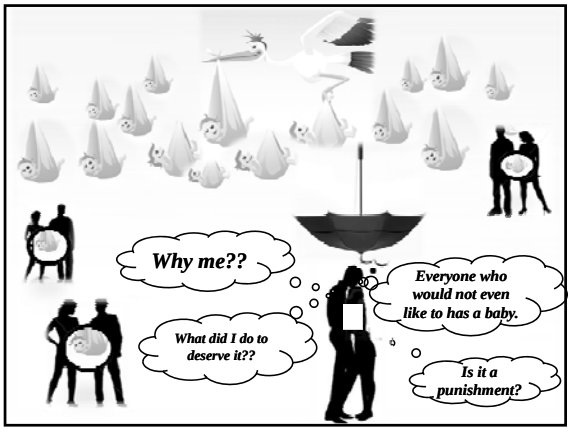
RAM comprises four Adaptive Modes as

- Physiologic Needs
- Self Concept
- Role Function
- Interdependence

Roles are functioning unit of society

" Role is a name that given to individual and social expectations should be done to maintain this name.

When the couples fulfillment of a social duty of being family, being mother /father, their adaptation is impaired, and than they search for adaptation mechanisms.



Burden of an infertility diagnosis

How regularly do your periods occur, and how long do they last?

How often do you have intercourse?

Amount of bleeding in a period

How often do you have masturbate?

What contraceptive methods do you use?

Do you experience any erection or other sexual problems during intercourse?

Which positions do you have intercourse?

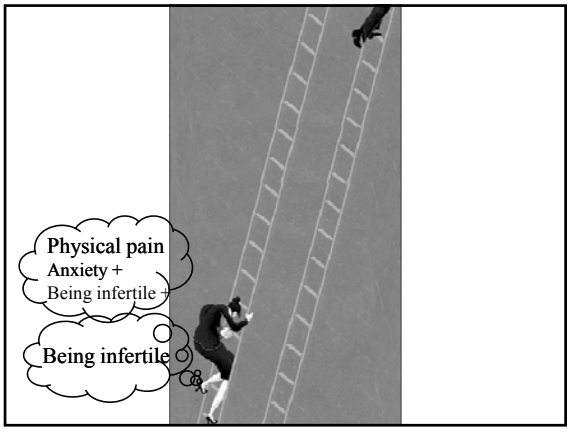
When do you have intercourse?

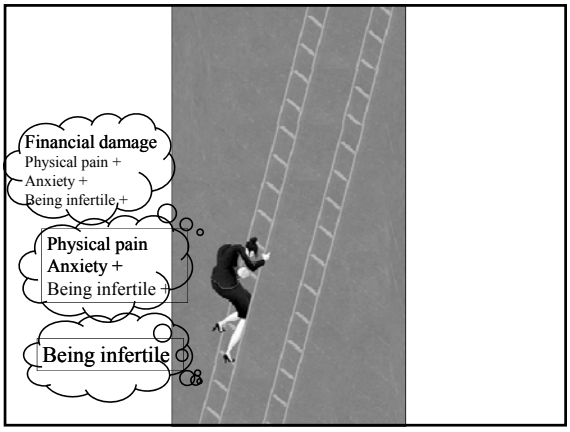
In the diagnosis process, to share the most intimate details of their lives with their health care providers entail stress and anxiety on couples .

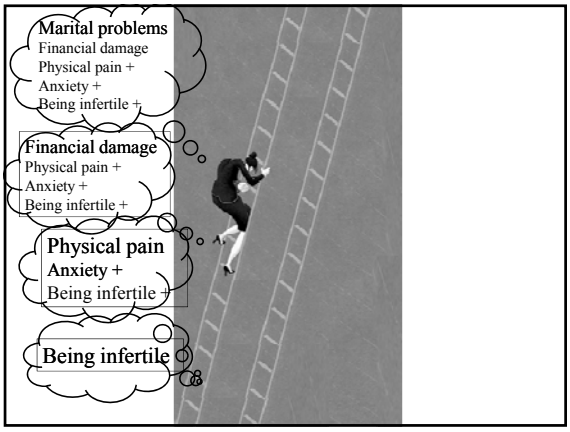
Burden of an infertility diagnosis

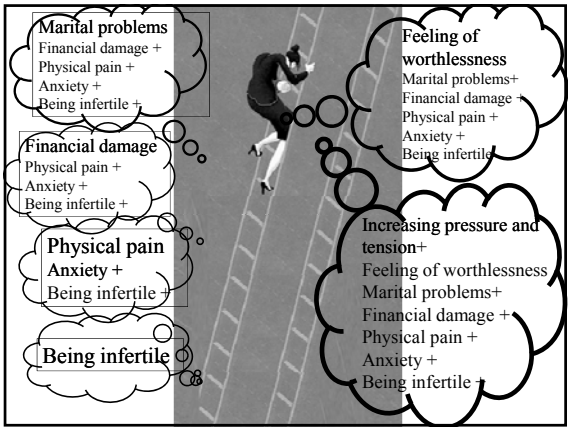
Infertility is conceptualized as a major crisis in life. A crisis evokes emotional reactions that are classified into four main phases:

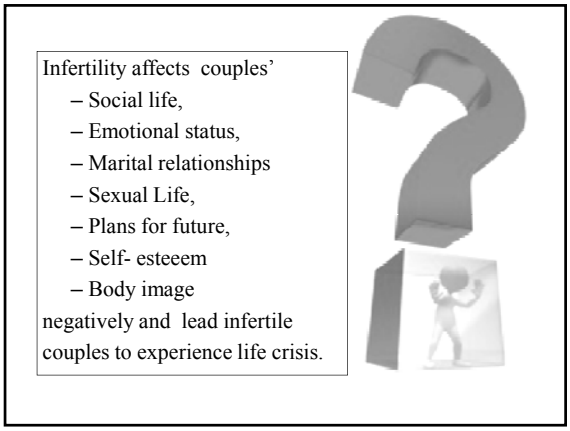
- ✓ The initial phase (shock, surprise, denial)
- ✓ The reactive phase (frustration, anger, anxiety, guilt, grief, depression, isolation)
- ✓ The adaptive phase (acceptance) and
- ✓ A resolution phase (planning for future solutions)

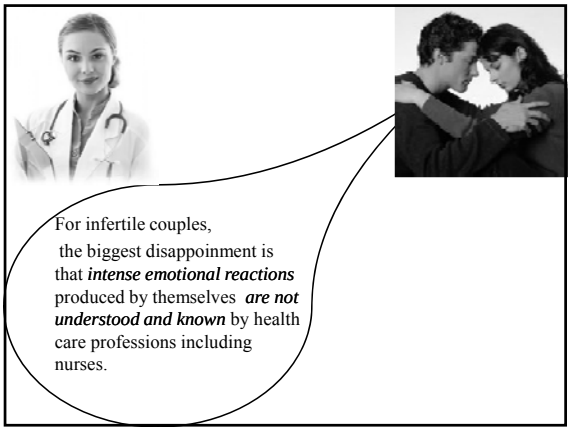




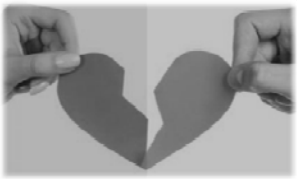

Marital problems
Financial damage
Physical pain +
Anxiety +
Being infertile +
Financial damage
Physical pain +
Anxiety +
Being infertile +
Physical pain
Anxiety +
Being infertile +
Being infertile


Marital problems
Financial damage +
Physical pain +
Anxiety +
Being infertile +
Financial damage
Physical pain +
Anxiety +
Being infertile +
Physical pain
Anxiety +
Being infertile +
Being infertile
Feeling of worthlessness
Marital problems+
Financial damage +
Physical pain +
Anxiety +
Being infertile +
Increasing pressure and tension+
Feeling of worthlessness
Marital problems+
Financial damage +
Physical pain +
Anxiety +
Being infertile +


Infertility affects couples'
– Social life,
– Emotional status,
– Marital relationships
– Sexual Life,
– Plans for future,
– Self- esteeem
– Body image
negatively and lead infertile couples to experience life crisis.



- ✓ Infertility is considered one of the most stressful events by couples worldwide.
- ✓ However, women and men may response differently to infertility and its treatment process.



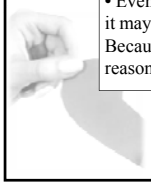
Burden of infertility on women

- Couples' experiences of infertility are significantly affected by their sex and gender role expectations.
- Women who desire children are more likely than men regarding role of motherhood mother and when compared to their partners, ***women have more difficulty adapting*** to infertility.

Burden of infertility on women

• As most procedures related to infertility diagnosis and treatments are performed on the woman, recurrent cycles and side effect of used medicine lead women to be exhausted physically after a while.

• Even though women is not diagnosed as an infertile, it may be interpreted as "inability to get pregnant". Because they have to receive infertility treatment by reason of male infertility problems.



Burden of infertility on men

- ✓ Infertile men typically suffer tremendous grief, a challenge to their identity, and interpersonal struggle related to their "inability to have a biological child" or "failure in sexual life".
- ✓ Male infertility has more devastating effects than female infertility on each couples.
- ✓ However, most women think that infertility is "a destructive role failure", men can think that it is "disturbing, but it is just a situation that do not need to make it a tragedy".

Psychological Assesment of the infertile Couple

When the previous studies regarding infertility are searched, it was found that to determine psychosocial effects of infertility treatment on infertile couples;

- ✓ Beck Depression/Anxiety Inventory
- ✓ The Satisfaction with Life Scale,
- ✓ Quality of Well-Being Scale
- ✓ Appraisal of Life Events Scale,
- ✓ The spiritual Well-Being Scale,
- ✓ General Health Questionnaire
- ✓ Spielberg State-Trait Anxiety Inventory etc …. have been used.

Psychological assesment of the infertile couple

On the other hand, the number of special scales targeted to determine the level of distress experienced by infertile couples and included all aspects of psychosocial effects caused by infertility on life are very scarce.

- ✓ The Sickness Impact Profile;
  (*infertility- related emotional complaints)*
- ✓ The Fertility Problem Inventory
- ✓ The Infertility-Specific Distress scale ……

"Infertility Distress Scale for Turkish Women" was developed by Akyüz et al. (2008)

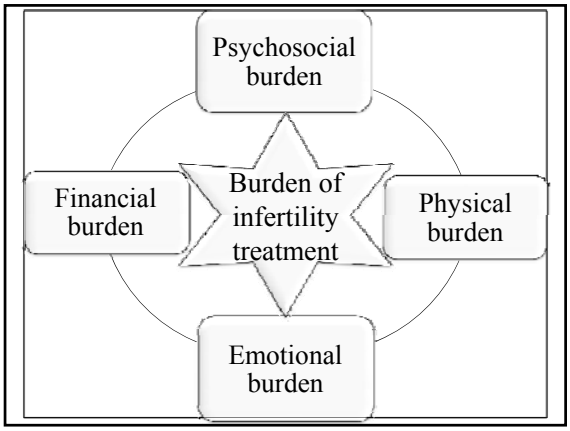
Development and Validation of an Infertility Distress Scale for Turkish Women

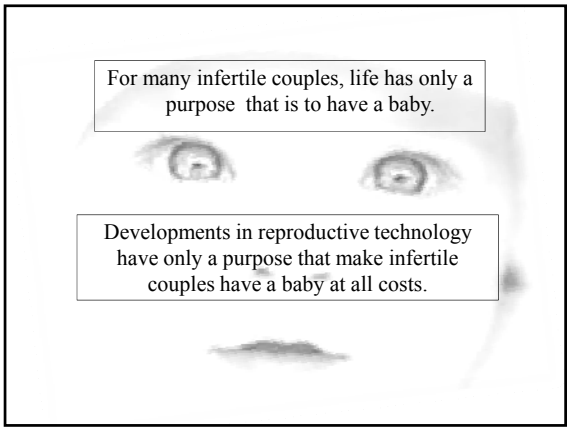
It is important to determine the psychosocial status of couples during diagnosis of infertility and its treatment process.

1. I feel as if I were alone in the World
2. I feel myself excluded out of my family and friends
3. There are people around me to whom I can admit when I am bored
4. I have no more power to resist and struggle
5. I feel myself useless
6. I feel myself unhealthy
7. I feel myself anxious and nervous continuously
8. I have no pleasure from any of my Works
9. I feel myself continuously tired recently
10. I much more take care of myself when compared to previous time
11. I avoid to talk about not being able to have a child
12. I would't like being asked questions about not being able to have a child
13. My husband and I easily talk about not being able to have a child
14. I easily have friendship with families who have children
15. I think people around me accuse me of not being able to have a child
16. I think my husband accuse me
17. That I cannot have a child affects sexual partnership with my husband
18. I feel anger to my husband
19. I think my husband does not currently love me as mush as previously
20. Relationship between me and my husband has been affected negatively
21. My husband is interested in me much more than before

"Infertility distress scale for Turkish Women"

Burden of infertility treatment





Burden of infertility treatment

- When a couple is diagnosed as infertile, they would like to avoid negative feelings and psychological problems that infertility diagnosis entails.

Therefore,
the best coping strategy is
to have infertility treatment.

Burden of infertility treatment

- Disappointment that is rised by getting infertility diagnosis may turn to hope, when the couples learn to have a treatment chance to have a baby.
- Akyüz (1996) stated that when the couples learned needing to IVF to have a baby, they were disappointed as other people as they well as were happy for having a treatment chance .

Burden of infertility treatment

İnfertil Kadınları Psikolojik Olarak Etkileyen Faktörler

"Factors Affecting Infertile Women Psychologically"

There was a statistically significant linear relationship between the Mean Infertility Distress Scale (IDS) score and age, marriage duration and duration of desire to have a child.

Women who were primary school graduates, did not work, had no social security benefits or from low socioeconomic status had significantly higher mean IDS scores.

Burden of infertility treatment

Some reasons such as;

- ✓ Increased treatment options
- ✓ Increasing infertility rates
- ✓ Decreased treatment duration for having baby... lead to decrease negative impacts of infertility diagnosis.

Burden of infertility treatment

In the process of infertility treatment, women only focus on getting pregnant and many of them believe that when they get pregnant, they would be so happy.

Therefore, women consider infertility treatment options to have a baby in this process at all cost.

Burden of infertility treatment

"Effect of desire to have a baby on risk acceptance in Turkish infertile women" Akyüz (2008)

Side effect due to infertility treatment were present in 49.6% of infertile group. However, 93.8% of the women did not consider discontinuing the treatment due to side effects they experienced.

•Furtermore, approximately two thirds of the infertile women stated that they would use infertility drugs even if they increased ovarian cancer risk.

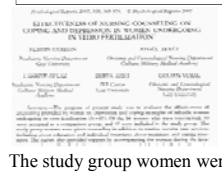
–Psychosocial – Burden of infertility treatment

"Association of depression and anxiety with oocyte and sprem numbers and pregnancy outcomes during invitro fertilization treatment"

A significant correlation obtained between depression on women's oocyte pick-up data and number of oocytes, showed that low oocyte numbers were associated with higher depression.

Women with high anxiety score on the oocyte pickup day had significant lower pregnancy rates, a did those with higher depression.

–Psychosocial – Burden of infertility treatment



"Effectiveness of nursing counselling on coping and depression in women undergoing in vitro fertilization."

The study group women were given counselling in addition to routine nursing care, including group education and individual interviews about treatments and coping strategies.

All of the women were using emotional coping and had moderate depression prior to the study. There was no statistical difference between the control and study groups before and after the counselling in respect to depression and coping strategies.

-Psychosocial -
Burden of infertility treatment

In our study that is in publishing process,
"Infertility history: Is that a risk factor for marital violence against Turkish women?"

There has been determined that there is a statistically significant difference between the infertile and fertile women for the total score of violence in marriage.

The emotional, economic and sexual violence scores were higher in the infertile group. However, the verbal violence score was lower.

-Financial -
Burden of infertility treatment

The budget implementation instructions and in accordance with changes made in 2008 in TURKEY:

"ART can be done for women who over the age of 23, younger than 40 years and results could not be obtained within the last three years for women by other treatment methods, and limited to a maximum of two applications

Families who have one or more children spontaneously or through ART , after that due to male or female infertility, If they receive ART to have children, the costs of IVF treatment is not covered by the goverment budget.

-Financial -
Burden of infertility treatment

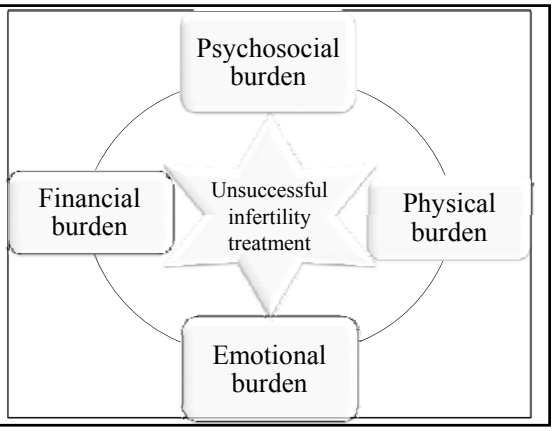
Social insurance only partially covers treatment cost in Turkey and the couples have spent approximately five times their monthly income for treatment.

(Akyüz et al. 2009)

–Financial –
Burden of infertility treatment

"Reasons for infertile couples to discontinue in vitro fertilisation (IVF) treatment"

The most important three reasons for discontinuing IVF-ET treatment for ***THE WOMEN***;
'Unsuccessful treatments and fear of coping'
"Psychological and physical burden"
'Depletion of financial resources'



- Unsuccessful treatment means that reloading of all burdens rest of previous treatment

But, with some extras;
- *Rest of burden of the previous treatment(s),*
- *Downhearted*
- *Decreased hope*
- *Decreseased financial resource vs.*

The results of my thesis conducted to investigate the nursing care, which had been applied according to the Roy's Adaptation Model (RAM) during the IVF treatment and its efficiency to adopt the women who experienced IVF failure show that,

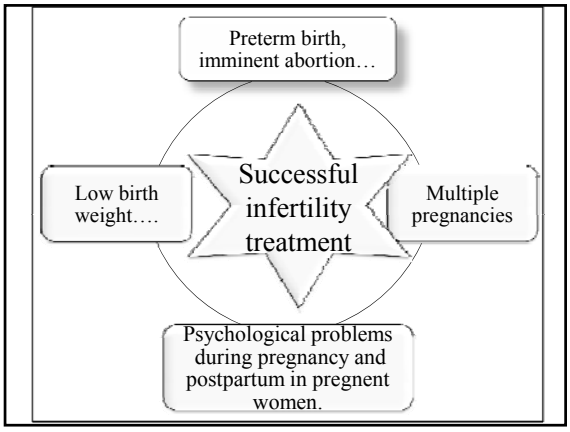
- When the pregnancy test results were negative, depression and anxiety level had increased where as the body image level had decreased.
- It was also determined that the women, one month later after the pregnancy test, in both groups had higher level anxiety, depression and lower level body image while compared with the pre-treatment test level.

Anxiety, Depression

Body image

Other studies state that ;

Lack of self-esteem, feelings of inferiority, depressed mood, memory/concentration, anxiety and fears, as well as for self-perceived attractiveness in comparison with other women and social isolation are often reported by women who are involved in infertility treatment.



Psychological Problems during pregnancy and postpartum

- Studies and clinical experiences show that women with previous infertility have high level of anxiety and depression during pregnancy
- It is also stated that women with previous infertility may be at risk for developing depression during pregnancy and postpartum period.

The Transition From Pregnancy to Postpartum in Previously Infertile Women

"Infertility history ; Is it a risk factor for postpartum depression in Turkish women."

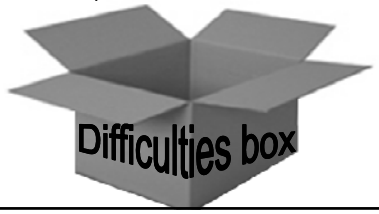
The probability of developing postpartum depression in the infertile group is 1.352 times higher than that in the fertile group.

Additional risk factors such as health issues during pregnancy, the notion that pregnancy causes a decrease in libido and negative body image, the infant's gender, pain from incision or infection, and dyspareunia were manifest in the fertile women, but not in the infertile women.

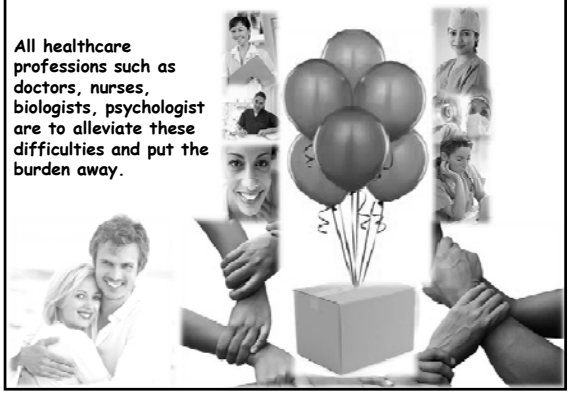
It is difficult;

- to start to infertility treatment once again
- to be happy with pregnancy news o
- to realize and explain why I c pregnant after infertility treatment
- to be afraid of making g infertility treatment.
- to take the dru y treatment
- to receiv eatment.
- to ood, while waiting for being pregnant.
- e to share the most important secrets in own life

It is difficult to be an infertile



All healthcare professions such as doctors, nurses, biologists, psychologist are to alleviate these difficulties and put the burden away.



Thank you for your attention

aygulakyuz@yahoo.com

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The use of the Internet and other online resources and its impact on the burden of treatment

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Learning objectives

- To explore the role of the Internet as an informational and support tool for couples living with infertility
- To consider both the advantages and disadvantages of infertility online support communities and reflect on advice which may be given to patients about their use
- To consider the development of web-based multimedia interventions and their efficacy as an informational and support tool

Background

- Individuals faced with infertility have access to numerous websites focussing on:
  - Infertility, infertility testing and infertility treatment options
- Websites often include support communities either through asynchronous formats (e.g. forums) or synchronous (e.g. chat rooms)
  - "Infertility" 36.4 million hits
  - "IVF 5.5 hits"
  - "infertility treatment" 9.43 million hits
  - "infertility support group" 6.81 million hits

INFORMATION SEEKING ONLINE

Internet use

- In excess of 40% of infertility patients search for infertility-related information online
- Huang et al., (2003)
  - Examined Internet use in couples seeking infertility treatment (total N = 200)
    - 178 (89%) used the Internet for general purposes
    - 89 (44.5%) fertility-related issues
  - Reasons for Internet use?
    1. Better understanding of the medical condition & options
    2. A second opinion
    3. Dissatisfaction with information received from health professionals

Internet use

- Weissman et al., (2000) – two clinics in Toronto
  - Among the study population, 42% of couples had used the Internet in relation to their fertility problems
  - Predominantly females (76%)
- Reasons for using the Internet for infertility problems?
  - 84% searched for medical information on infertility diagnosis and therapy
  - 51% evaluated fertility clinics
  - 25% searched for self-help groups
  - 19% used it to purchase fertility drugs

Does it help?

- There is *some* evidence that searching for infertility-related information online is helpful
- Greil & McQuillan (2004)
  - A third of Internet users in their sample of 33 infertile women described the infertility information they obtained online as 'very useful'
- Weissman et al., (2000)
  - Reported that 30% of patients in their study found that the Internet was helpful in their decision-making process
- Haagen et al., (2003)
  - Found that 64% of users reported that the Internet had improved their knowledge about fertility issues

A note of caution

- A number of authors have expressed concerns about the quality of content available in various infertility websites (Epstein & Rosenberg, 2005; Huang et al., 2005; Marriott et al., 2008; Okamura, Bernstein & Fidler, 2002)
- Marriott et al., (2008)
  - In a review of 107 infertility-related websites retrieved via a Google search, most scored relatively low on predefined criteria assessing credibility, accuracy and ease of navigation

ONLINE SUPPORT COMMUNITIES

What are they?

- Collections of people who interact with each other about a mutually interesting health or illness-related topic in cyberspace i.e. online
- Sometimes called:
  - Online support/self-help groups
  - Computer-mediated support groups
  - Virtual support communities
- Many websites offer communication features and these have helped foster the development of online support communities

Reasons for popularity

- Transcend geographical and temporal constraints
  - 24 hrs a day, no travel time, convenient
- Greater degree of anonymity
  - No cues regarding gender, age, ethnic background etc
  - May facilitate discussion of sensitive topics
- Access to diverse perspectives, experiences, opinions and sources of information
  - Group composition may be more diverse than traditional support networks
- Important learning opportunity for non-members
  - Potential new members, relatives, friends, health professionals
- Control over what is said

Infertility online support communities

- Malik & Coulson (2008)
  - 95 patients reported their experiences (both good and bad)
  - Using thematic analysis (Braun & Clarke, 2006) 5 emergent themes were identified:
    - "unique features of online support"
    - "improved relationship with partner"
    - "reduced sense of isolation"
    - "information and empowerment"
    - "negative aspects of online communities"
- A range of important benefits but also some potential disadvantages

Therapeutic potential?

- Growing literature which suggests that online support communities may facilitate many of the therapeutic exchanges that occur in face-to-face self-help and support groups
- Limited application in the context of infertility
- Notable exception: Malik & Coulson (2010)
  - Content analysis of 3500 messages posted to infertility bulletin boards
  - Messages generated by 778 members

Sub-board	Main purpose of sub-board
Starting out	A support and discussion forum for people new to infertility treatment and individuals wishing to introduce them to the group
2-week wait	To provide a discussion and support forum for infertile couples who are on the 2-week wait between ovulation/intra-uterine inseminations/in vitro fertilization etc and pregnancy testing
Negative cycle	To provide support to individual and couples who have experienced a negative treatment cycle
Inbetween treatment	To provide a discussion forum for those people between fertility cycles
Trying for another miracle	To provide support to parents of children conceived by infertility treatment, hoping for another miracle
Pregnancy loss	To provide support for individuals and couple experiencing pregnancy loss
Moving on	To provide support to those individuals for whom there are no longer available any options regarding successfully achieving a birth child of their own, or for those whom the chance of this is slim

Evidence for self-help mechanisms?

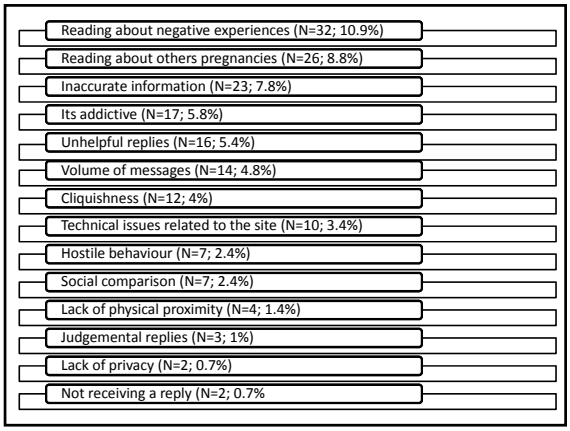
- Support or empathy (N=1591; 45.5%)
- Requesting information or advice (N=238; 6.8%)
- Providing information or advice (N=558; 15.9%)
- Sharing personal experience (N=1588; 45.4%)
- Creative expressions (N=7; 0.2%)
- Universality (N=169; 4.8%)
- Friendship (N=345; 9.9%)
- Chit-chat (N=329; 9.4%)
- Gratitude (N=436; 12.5%)

Problematic aspects

- Anonymity may lead to deindividuation?
  - Hostile, aggressive or uninhibited behaviour
- Asynchronicity
  - May be a time lag to responses
- Accuracy of medical information
  - Particularly if there is no professional involved to moderate
- Addictive
  - Could it actually increase social isolation?

Disadvantages of infertility online support communities

- Malik & Coulson (2010)
  - A total of 295 members of infertility online support communities completed an online questionnaire
  - Mean age = 34 (SD=4.9)
  - majority UK (89.4%)
  - The average time since diagnosis 4.8 years (SD=3.6) with a range of 0.25 to 25 years
- Did anyone experience any disadvantages and if so, what were they?
  - 170 (57.8%) reported experiencing disadvantages to infertility online support communities



- Experiencing disadvantages was found to be related to less overall satisfaction with the online experience
- More educated participants were more likely to report experiencing disadvantages
  - More critical about information quality and therefore report more disadvantages and concerns than others?

OTHER WEB-BASED RESOURCES

- Increasing interest in the potential for web-based multimedia to educate and provide support to medical patients
- Such interventions may be an effective adjunct to routine clinical care and may facilitate – rather than detract from – the ability of health professionals to play an important part in supporting infertility patients

Example

- Cousineau et al., (2008)
  - 190 female patients recruited from 3 US fertility centres and randomised into two experimental and two no-treatment control groups
  - Brief online education and support programme
  - Psychological outcomes included: infertility distress, infertility self-efficacy, decisional conflict, marital cohesion and coping style
- Key findings: Women exposed to the online programme improved significantly in the area of social concerns related to infertility and felt more informed about a medical decision with which they were considering

Conclusions

- The Internet has an increasingly important role in the burden of infertility treatment
  - Access, convenience, lack of information and support
- Emergence of peer to peer online support communities (including Facebook groups)
  - Both advantages and disadvantages
  - How should health professionals respond? What advice should they offer?
- Potential for more complex web-based interventions
- More research is needed in all aspects of infertility online

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UZ LEUVEN

The burden of unsuccessful treatment and stopping treatment: the long and winding road

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I have nothing to disclose

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Learning objectives

- To gain insight into the psychological factors that determine the burden of unsuccessful treatment
- To obtain knowledge on the grieving process of couples and individuals associated with unsuccessful treatment and ending treatment
- To understand the practical implications of the burden of treatment for mental health professionals, medical doctors and the fertility unit
- To have knowledge of a framework to refer patients during treatment

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Overview

A) General psychological framework

1. Infertility treatment: *against the odds*
2. Psychology of pregnancy and loss: *between something and nothing*
3. Treatment failure: *the winding road and how to walk it*
4. Trying again: *the roller coaster ride*
5. Intervention Model: *reading between the lines*

B) Ending infertility treatment

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A) General psychological framework

1. Infertility treatment:
   against the odds
2. Psychology of pregnancy and loss:
   between something and nothing
3. Treatment failure:
   the winding road and how to walk it
4. Trying again:
   the roller coaster ride
5. Intervention Model:
   reading between the lines

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**To understand any living thing,
you must creep within
and feel the beating of its heart.**

W. Macneile Dixon

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1) Infertility treatment: *against the odds*

- Success rates IVF: 30%
- Unsuccessful treatment : 70%
- Fertility unit mostly deals with 'failure and trying again'
- Feeling of 'against the odds' often unanticipated

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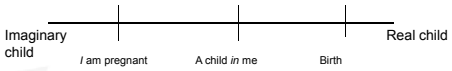
2) Psychology of pregnancy and pregnancy loss
Unfulfilled wish for a child

Continuum:



- wish for a child: process of attachment and growing towards an 'imaginary' baby and confronting reality
  e.g. the 'wished' for child versus the 'actual child'
- attachment and interpretation of the child wish can differ:
  e.g. woman who became pregnant spontaneously versus woman who has been in infertility treatment for 5 years before pregnancy
  e.g. man who's not sure he wants to be a father versus man who has always dreamed about fathering a child and teaching his son football

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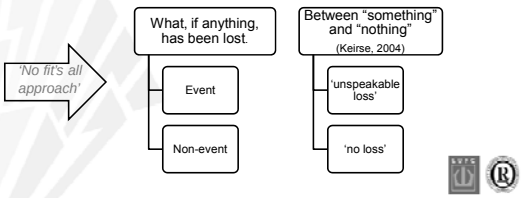
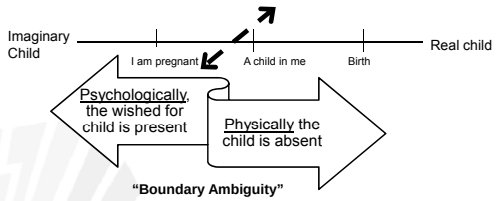
'Unsuccessful treatment and pregnancy loss'
=
"Ambiguous Loss"
(Rosenblatt, 1987)





- Grieving = normal, healthy, dynamic, universal and individual response to loss
- Mourning = healing process

3) Treatment failure: *the winding road?*

- Options if treatment fails:
  1) **No Hcg:**
     - try again >< stop treatment
  2) **Grey area: Biochemical pregnancy**
     - Pregnancy
     - Miscarriage
  3) **The end of the biological line:**
     - 3rd party reproduction
     - Adoption
  4) **Ending infertility treatment: challenges**

Treatment failure: the winding road and how to walk it…

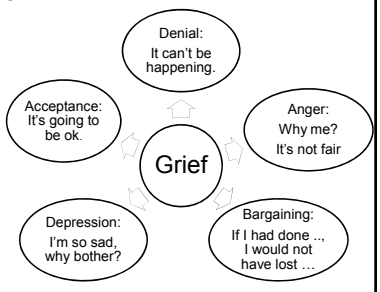
- Treatment failure can evoke a number of emotional and physical reactions:
  - Sadness, disappointment, anger, numbness,crying, ….
  - Headache, muscle tension, stomach problems, …
- Grieving occurs often, but not always

→Individual differences in coping
→Gender differences

3) Stages of grief

(Elizabeth Kübler-Ross, 1969)

- Steps not necessarily linear.
- Diverse individual differences.
- Normalize grief experience + easy to recognize
- Newer grief theories: process models
- From severing bonds to maintaining bonds
- Focus on cognition and meaning making in addition to emotion
- Challenges concept of endpoint



3) Unique aspects of grief

(in infertility, biochemical pregnancy, miscarriage,…)

- Multidimensional loss:
  - Loss of a 'baby'
  - Loss of self-esteem as a parent
  - Feelings of failure as a woman
  - Loss of 'pregnant status'
  - Fear of loss of reproductive capacity
  - Fear of loss of health
  - Fear of loss of control

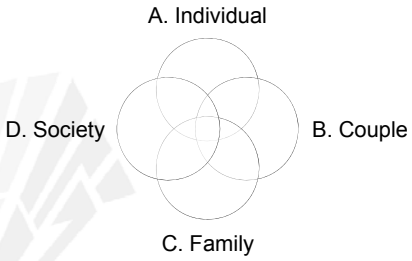
Unique aspects of grief in infertility, pregnancy loss…

- Grieving is difficult because
  - Prospective nature of the loss:
    - o *'pain of not ever knowing'*
    - o *mourning for the hopes, wishes and fantasies of the future baby*
  - 'Invisible' loss
  - Few socially acceptable avenues for mourning
  - Often lack of social support
    - o *intensifies shame and feelings of failure*
    - o *'permission' to grieve*

Unpredictable pattern of perinatal grief

- Tidal wave: growing and cresting, then reclining + repetitive waves
  - recurrent grieving throughout life span
- Shadow grief: reminders/triggers that rekindle the feelings of loss (Peppers & Knapp, 1980)
- Expressions of grief:
  - **Emotions:** shock, numbness, guilt, anger, anxiety, self-blame, depression, …
  - **Physical symptoms**: headache, shortness of breath, heartache, lack of appetite, sleeping problems,…
  - **Cognitive symptoms:** dreams, memory problems, impaired decision making, intrusive thoughts about fetus, hallucinations of hearing baby cry
  - **Social symptoms**: isolation, withdrawal

Grief … in the eyes of the beholder…. A systemic approach



Grief … in the eyes of the beholder…. A systemic approach

- Fertility unit: working with 'patients'
- Outside of the fertility unit:
  not a vacuum for our patients
  → larger system
- We don't work with the system,
  but we do have to deal with it.

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4) Trying again: *the roller coaster ride.*

Mixed feelings and motivations:

- ***Trying Again Right Away***
  - The Need To Be Pregnant Again Right Away
  - The Desire To Get On With Life
  - The Desire To Have Something To Look Forward To Again
  - The Fear Of Never Being Able To Have Another Child
- ***Deciding To Wait***
  - The Need To Grieve
  - The Fear Of Having Another Baby Die
  - The Desire To Let Certain Milestones Pass Before Becoming Pregnant Again

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4) Trying again: *the roller coaster ride.*

- It takes time to process information
- It takes time to process emotions

→Anxiety and wish to fix the problem >< careful consider of short term and long term implications of treatment decisions

→Factors influencing decision making

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4) Trying again: *the roller coaster ride.*

- Treatment decision making:
  - **Situational factors**: physical invasiveness, financial costs, commitment, short- and long term consequences of interventions and drugs used, probability of successful outcome
  - **Personal factors**: beliefs and values about importance of parenthood, morality and ethics involving treatment option, religious beliefs, ethnic and cultural values
  - **Other factors**: age, gender role identity, emotional well-being, self-esteem, locus of control, …

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4) Trying again: *the roller coaster ride.*

"Health care professionals appear to exert significant influence in the determination of couples' treatment decision" (Frank, 1989)

- Ranked 3rd after personal and partner's beliefs
- Ranked higher than degree of emotional stress, probability of success, opinions of family and friends, legal ramifications, religious beliefs

→ Important to recognize our own bias in acceptability and viability of treatment options
→ Non-verbal communication!
→ Need to empower patient to make decision within the context of their lives

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5. Intervention model (Jack Annon, 1976): *reading between the lines*

P	L I	S S	I T
↓	↓	↓	↓
Permission	Limited Information	Specific Suggestions	Intensive Therapy

Differential model of treatment:

not everyone needs the same things at the same time

→ sensitive and tailored interventions

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5) Intervention model : caveat

- Every couple is unique !
- Be sensitive !
- Keep your eyes open !
- Listen, don't judge !
- Remember yourself !
- Remember your place !

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B) Ending infertility treatment

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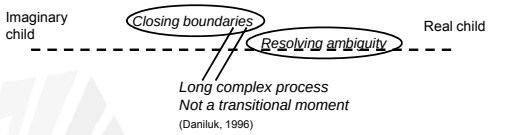
B) Ending infertility treatment

'not yet pregnant' **'not going to be pregnant'**



Long complex process
Not a transitional moment
(Daniluk, 1996)

- Infertility = major loss, often unrecognized and socially 'unspeakable'
- Ambiguous and open-ended loss - hard to find closure
- Impact on identity - intrinsic to adult female and male identity

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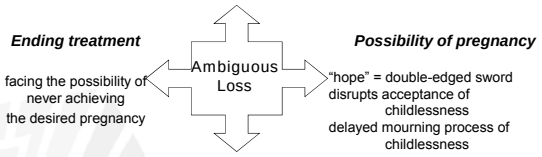
"When enough, is enough."



'In limbo' never-ending-treatment-cycle

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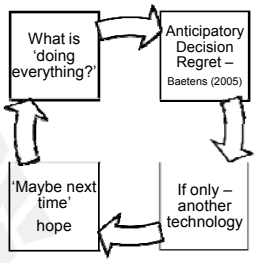
"When enough, is enough."



- Routes into IVF are clear, out of it more obscure.
- Subjective end point, determined by many factors

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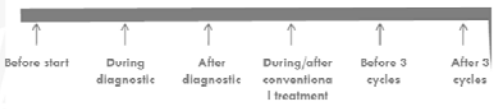
Continuing and discontinuing

- What is "drop-out"?
  - No consensus
  - 'stopping premature' – 'ending' – 'treatment failure'
  - No clear definition



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Continuing and discontinuing

- Methodological problems
  - Heterogenity in different countries and centres – cost, insurence/reimbursement, accessibility of centres
  - Lack of uniform operationalisation
    1. Number of treatments before 'dropout'
    2. Judgement of doctors/team on 'dropout' being 'fit' → subjective judgement
    3. Combination of 1 and 2
    4. Couples who never start treatment → qualitative difference in patients who start or do not start treatment?

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Continuing and discontinuing

- **Patient view versus doctor/clinic view**
  - Passive dropout (patient stops treatment himself/herself)
  - Active dropout (patient is censored by team/doctor)
  - Non-neutral terminology that fails to recognize the interactive nature of the decision to continue or discontinue treatment
  - Tendency to focus on positive outcomes and succes rates rather than focus on 'silent' or 'invisible' patient that disappears out the door (bias)

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Continuing and discontinuing

- **Dropout is not always negative!**
  - Medical point of view:
    passive drop-out needs to be avoided or reduced because of its impact on cumulative succes rates
    → drop-out = negative
  - Psychological point of view:
    drop-out can be seen as a rational, positive and healthy decision of the couple
    → drop-out ≠ negative

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Continuing and discontinuing

- **Impact of psychological factors on dropout is considerable, even in insured patients** (Domar, 2004)
  - The Netherlands
    - 62% (cumulative dropout % after 3 Rx) – 14% active censoring (Land, 1997)
  - Sweden
    - 65% did not complete 3 reimbursed treatment cycles after a failed treatment (Olivius, 2004)
  - Australia
    - average number of started cycles 301 per patient whereas 6 cycles are reimbursed (Hammerberg, 2001)

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- Why stay in treatment?
  Majority (about 70%) of couples achieve pregnancy after 3,5 treatment cycles within 5 years

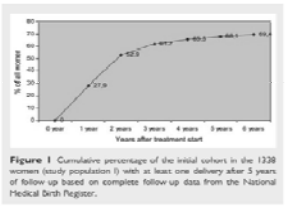

Figure 1 Cumulative percentage of the initial cohort in the 1338 women (study population I) with at least one delivery after 5 years of follow up based on complete follow up data from the National Medical Birth Register.

Pinborg et al. 2009. Human Reproduction, 24(4), 991-999.

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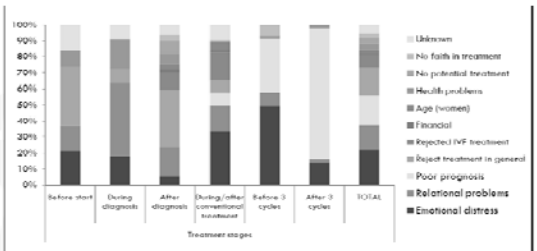
Reasons to drop out from IVF/ICSI



Boivin et al. 2009. Human Reproduction, 24(10), 2377-2384

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What factors play a role?

- Individual factors (coping,cognitions, depression, anxiety, ...)
- Relational factors (partner support, friends, family, …)
- Treatment/clinical factors: prognosis, mild stimulation protocols, phase in treatment, …
- Organisational factors: quality of care, technical and patient-centered aspects

Verhaak et al., 2005; Lowyck et al., 2009; Boivin et al., 1998; Verberg et al., 2008; Lund et al., 2009; Schmidt et al., 2005; ...

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Factors impacting the end of treatment (Takefman, 2006)

Sociodemographic Factors
- Parity
- Age
- Gender
- finances

Interpersonal Factors
- Relationship beliefs
- Expectations about 'family life'
- Uncertainty about future
- Couple congruence

Emotional factors
- Optimism
- Psychological distress
- Having done all you can – 'no regrets'

Fear Factors
- Not being able to cope
- Childless life is unfulfilling
- Relational anxiety

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Ending infertility treatment sessions

Routine session ???
On demand ???
Mandatory ???

- Opportunity to talk about it normalizes experience
- Couple-aspect underlined
- Part of the infertility process and not giving up
- Openness to discuss fears, doubts, etc.

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Ending treatment sessions

'The winding road…'

- Review and reflect on infertility experience emotionally, cognitively,… to help reduce blame
  - 'we've done all we can'
- Assumptions and expectations on entering treatment: 'fix things'
- Emotional and physical impact: disappointments become more difficult to deal with and 'bounce back', feelings of personal failure
- Repeated unsuccessful treatment: loss of control as well as the feeling that infertility takes over and invades most areas of your life
- Stance of the doctor: hopeful or not?
  - 'carrot' dangling in front of you
  - treatment = gamble, addiction

Ending treatment sessions

'Getting lost and stuck – along the way'

- 'All for nothing' if treatment ends without desired outcome
- Belief that persistence will pay off eventually:
  'If at first you don't succeed, try again – try harder.'
- Losing sight of yourself or the reasons for starting treatment
  - desire turns to despair
  - wish for a child becomes a need for a child (Demyttenaere, 1998)
  - getting pregnant becomes a goal in itself
- Avoiding grief work by continuing treatment

Preventing drop-out?

- Depends on decision making
  - Couple can make healthy decision to discontinue based on medical, personal, relational and emotional reasons
  - → No need to prevent drop-out
  - → Stimulate and help decision making process of patients (e.g. medical and psychological counseling, …)
  - → Research needed into determinants of decision making process of couples in ART

Preventing drop-out?

- Depends on decision making
  - Couple can't make healthy, rational decision but experiences burden of treatment +++, doubts about treatment, …
  - → Decision making becomes difficult
  - → Preventing drop-out is needed in order to ensure that couples make the right decision at the right time for them
  - → Sensitive and tailored care is needed!
  - → Research is needed on factors that influence drop-out

How to prevent drop-out?

- Tailor care to individual patients
- Prepare patients for what to expect (treatments, medication, prognosis, information,…) → medical and emotional, couple aspects
- Address different treatment stages differently (beginning versus waiting period versus after results,…)
- Consider organisational issues → invest in quality of care

Thank you for your attention!

Any questions?

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Thank you for your attention.
Questions?

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Erasmus MC
University Medical Center Rotterdam

Burden of treatment and your sex life

ESHRE 2012, pre-congress course, SIG Psychology & Counselling

1st July 2012
drs. Hester Pastoor
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psychologist, sexologist, systemic therapist

Conflict of interest

- None to declare

Content

- Learning objectives
- Are sex and reproduction related?
- Definition sexual health & sexuality
- Literature overview
  - Infertility diagnosis → sexuality
  - Fertility treatment → sexuality
  - Donorgametes
- Case example
- Hypotheses
- Recommendations

Learning objectives

- Acquire knowledge about:
  - Sexual dysfunction causing infertility
  - Infertility diagnoses causing sexual dysfunction
  - Fertility treatment causing sexual dysfunction
- Develop a biopsychosocial view

Erasmus MC

Are sex and reproduction related?

Erasmus MC

Are sex and reproduction related?

- **YES**
- Sex can cause conception
- Dysfunctional sex causes infertility
- Infertility can cause sexual dysfunction
- ART can cause sexual dysfunction

Erasmus MC

Are sex and reproduction related?

- **NO**
- Sex is not a necessity for reproduction nowadays
- Contraception
- Pleasure

Erasmus MC

Sexual health

- Sexual health is a state of physical, emotional, mental and social well-being related to sexuality; it is not merely the absence of disease, dysfunction or infirmity.
- Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.
- For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.

- *Source: WHO Draft working definition, October 2002*

Erasmus MC

Sexuality

- Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual
- orientation, eroticism, pleasure, intimacy and reproduction.
- Sexuality is experienced and expressed in thoughts, fantasies,
- desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these
- dimensions, not all of them are always experienced or expressed.
- Sexuality is influenced by the interaction of biological,
- psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.
- *Source: WHO Draft working definition, October 2002*

Erasmus MC

Case example

- Janet (43) and Martin (44)
- Partners for 20 years
- ART for 8 years, no conception
- Counselling: decision making (ending ART)

- Sexual problems:
  - Diminished sexual desire
  - Dyspareunia
  - 'Trapped' in fertile period of cycle
  - Sexual repertoire: coitus

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Male infertility

'Firing blanks' **(Read, 2011)**

- ***Related tot diagnosis (before and after)***
- 1. Abnormal semen analysis after 1st semen collection without problems
  - 11% unable to produce 2nd semen sample (*Saleh 2003)*
    - 20% responded to vibratory stimulation
  - Severe anxiety during attempts to masturbate and partnersex in all men

- 2. Reduction sexual satisfaction 52.5%
  - pos corr coitus freq p=0.01, neg corr educat level p=0.05
- Reduction in sexual desire + sex satisf 45.4%
  - No corr with andrological status *(Ramezanzadeh, 2006)*

- 3. Perceived male subfertility
  - Higher sexual impact in male only group, *p=0.004*
    - less sex satisf, more sex failure, less enjoyment *(Smith, 2009)*
  - Higher personal impact in male only group, *p=0.04*

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Male infertility

'Being less than a man' **(Gurkan, 2009)**

- ***In general***
- 1. Erectile dysfunction
  Avoiding sexual activity (*Gurkan, 2009)*

- 2. 61.6% ED (*Khademi, 2008)*

- 3. Less pleasure
  Sex for reproduction (*Elia, 2010)*

- 4. ED 36 % infert vs 11% control p=0.005
  ADAM 39% vs 21% p=0.009 (*O'Brien 2005)*

- 5. Lower self-esteem, sexual self-esteem higher than in women
  Lower sexual QOL compared to controls (*Tao 2011)*

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Female infertility

'I am not a real woman' **(Read, 2011)**

- ***Related to diagnosis (before and after)***
- 1. Primary infertility 64.8% sexual dysfunction) *p=0.003*
  Secondary infertility 76.5% sexual dysfunction *9.5x risk*)
  - Arousal *p=0.04* Orgasm *p=0.005*
  - Satisfaction *p=0.01* total FSFI *p=0.02*
  - *Predictors: income level, educational level, partner age, depression* *(Keskin, 2011)*
- 2. Decrease in sexual self-esteem higher in women than in men
  Sexual satisfaction changed most during treatment
  - *Lower sexual satisfaction than men*
  Female factor: females less sex satisfaction (*Tao, 2011)*

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Female infertility

'I am not complete'

- ***In general***
- 1. Less sexual satisfaction (*Gurkan, 2009)*
- 2. 40% sex dysf vs 25% controls
  desire, arousal, freq intercours, freq mast, satisfaction *(Millheiser, 2010)*
- 3. Orgasm + satisfaction problems (*Hentschel, 2008)*

4. Sexual dysfunction:
  22.8% org 33.3% desire
  71.6% arousal 80.2% lubr
  48% pain (*Khademi, 2008)*

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The couple

'Are we meant to be together?' **(Read, 2011)**

- ***In general (women)***
- 1. Most studies show a decline in sexual functioning in women and men
  - SD consequence of infertility (10-60%), not cause
    - 2/3 deterioration
    - 1/3 initial intensification *(Wischmann, 2010)*
- 2. Female sex functioning is pos correlated with male sex functioning
  - 26% SD FSFI
    - *desire, org, arousal, satisf*
      - *pos corr IIEF p=0.01*
      - *neg corr depr p=0.06* (*Nelson, 2008)*
- 3. Control vs infertility group
  - Control more enjoyable sex life *p= 0.005*
    - (arousal p0.001, orgasm p0.004, dysp p0.03) (*Drosdzol, 2008)*

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The couple

'You should find another partner' **(Read, 2011)**

- ***In general (men)***
- 1. Male partner less sexual satisfaction ict female partner
  - Male factor: Relationship instability
    - Sexual satisfaction lower *(Tao, 2011)*
- 2. Men more SD infertile couples, compared to sterilization couples
  - *Intercourse not spontaneous (timing, purpose)*
  - *Decline in arousal*
  - *Failure, uselessness : decline sexual desire*
  - *'interference' of medical team in the bedroom* *(Wischmann, 2010)*
- 3. Male lower QOL than norm group *p<0.05*
  - 23% depression *(no diff norm)*
  - 22% Erectile Dysfunction
    - *pos predicted bij female sex functioning p=0.01 r=0.27* *(Shindel, 2008)*
- 4. 20% ED in infertile couples
  - *duration of infertility* *(Quintero, 2005)*
- 5. Men lower scores vs norm:
  - desire *p=0.01*, intercourse satisf *p=0.04* (vs norm)
  - ED 23.9% vs 13.7% *p=0.01* *(Drosdzol 2008)*
    - *Corr with infert diagn p=0.006*

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Fertility treatment

'*Emotional rollercoaster*' **(Wischmann 2010)**

- 1. All fertility treatments are invasive and potentially emotionally distressing
  - Vaginal examination, oocyte retrievement
  - Semen collection
  - Use of medication
    - Decapeptyl: E decline
      - desire, dyspareunia, mood swings
- 2. Not being able to produce sperm: cancelling treatment cycle
  - Failure, guilt
- 3. 53% says wish for a child is incompatible with a satisfactory sex life
  - Loss of sex spontaneity
  - Freq of sex intercourse 50% (in 30% of couples) *(Wischmann 2010)*

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Donorgametes

- ***Oocyte donation*** *(Carter 2011)*
- Heterosexual women, N=50
- 47% sexual dysfunction in receiving women
  - Depression 33%
  - Distress 59%

Semen donation *(Bomeskog, 2012)*

Lesbian couples, N= 166 couples

Sexual relationship was rated better when higher educational level *(.045)*

Known vs not-known sperm donor: no impact relationship quality

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Hypotheses

▪Sexual dysfunction is related to:

- 1. ***Sexual aspects:***
- Loss of sexual pleasure
- Focus on conception (coitus only on fertile days)
- Men: Loss of masculinity
- Women: sexual function positively correlated to male sexual function *(Tao 2011)*

- 2. ***Psychosocial aspects:***
- Depression, anxiety
- Distress in general
- Self-esteem
- Marital distress *(Millheiser 2010)*

- 3. ***Fertility aspects:***
- Medical team symbolically present in bedroom
- No conception: failure, uselessness, less desire, less enjoyment

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Good to know

1. Social, sexual and relationship concerns
   predict depression and marital dissatisfaction *(Millheiser, 2010)*

2. Some studies show improvement
   because of shared stress, coping jointly
   → more satisfacton, intimacy *(Tao, 2011)*

3. Fertility stress → decreases intercourse freq
   → influence on conception *(Tao, 2011)*

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Recommendations

- 1. Multidisciplinary approach *(Gurkan, 2009)*
- 2. Professional support *(Gurkan 2009)*
- 3. Holistic approach on sexuality in infertility *(Tao, 2011)*
- 4. Acknowledge & normalise *(Read, 2011)*

- ***In general:***
- A. Check knowledge about reproduction
- B. Ask questions about sexuality (before, during, after ART) in more detail, e.g.
  - Does intravaginal ejaculation occur?
    Is coitus possible?
    Do you experience sexual problems?
- C. Advise the couple to separate sex from reproduction
- D. Silfdenafil citrate can be useful *(Boorjian, 2007)*
- D. Refer to a (sex) therapist when necessary

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Case example

- Janet (43) and Martin (44)
- Partners for 20 years
- ART for 8 years, no conception
- Counselling decision making (ending ART)

- Sexual problems:
  - Diminished sexual desire (m/w)
  - Dyspareunia (w)
  - 'Trapped in' fertile period of cycle (w)
  - Sexual repertoire: coitus (m/w)

- **Sexual problems turn out to be primary**

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Case example

- ***Psychosexual therapy:***
- Psycho-education about sexual functioning (desire, arousal, pain)
- Cognitive behavioral therapy (myths, mourning)
- Couples therapy (communication, time/attention)
- Sensate focus (desire, arousal, repertoire)
- Pelvic floor relaxation

- ***Results*:**
- 10 sessions
- Improvement in sexual functioning and partnerrelationship
- Ritualised goodbye to the child

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Thank you for your attention!

Questions?

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What's in a word?

Patient-professional communication and burden of treatment

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professor and chair of Medical Psychology

University Medical Centre St Radboud
Nijmegen, the Netherlands

Pre-conference course ESHRE conference, Istanbul, 1 july 2012
(no conflict of interest or commercial relationships)

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Learning objectives - Information

Participants will learn about:

- How (distressed) patients react to complex information
- General principles of patient-professional communication in the biopsychosocial model
- Specific characteristics of patient-professional communication in fertility treatment

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Learning objectives - Skills

Participants will learn how to:

- Deliver medical information in a way acceptible for patients
- Communicate in different phases of fertility treatment: pre-treatment, during treatment, waiting for results, post results
- Communicate identification of burden of treatment, psychological vulnerability, relational strain

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How (distressed) patients react to complex information?

How physicians may deliver medical information
in a way acceptible for patients.

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Medical information in general

40-80% does get forgotten or cannot be recalled accurately (Kessels et al. 2003)

Explanations:

- *Doctor*: technical jargon, doctor-centered communication
- *Information*: only verbal or written
- *Patient*: older age, anxiety, distress

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Improve retention of medical information

➔Reduce amount of information (Kessels et al. 2003)

➔Check for patient comprehension

➔Ask to put into their own words what they have been told

➔Correct inaccuracies (Braddock et al. 1997)

➔Provide written materials with pictures (Houts et al. 2006)

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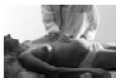
Improve retention of medical information

➔ Present medical information simultaneously through different senses

- Auditive (verbal information)
- Visual (non-verbal expression, printed material, pictures)
- Tactile (bodily sensations)



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Medical information in fertility treatment

Takefman et al. 1990

➔Adapt the quantity of information to the needs of a particular treatment phase

➔Too much information decreases the uptake of educational information in the diagnostic phase

Caveat: too much information

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A double problem with medical information

Information not retained, but also…..

Information not offered

- Only 57% of patients in a fertility clinic received detailed information recommended by guidelines (Mourad et al. 2009)

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General principles of
patient-professional communication
in the biopsychosocial model

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Purposes of medical communication

- Good doctor-patient relationship
- Exchanging information:
  integration of patient-centred and doctor centred approach
- Medical decision making:
  the patient has as much information as wanted before the final decision

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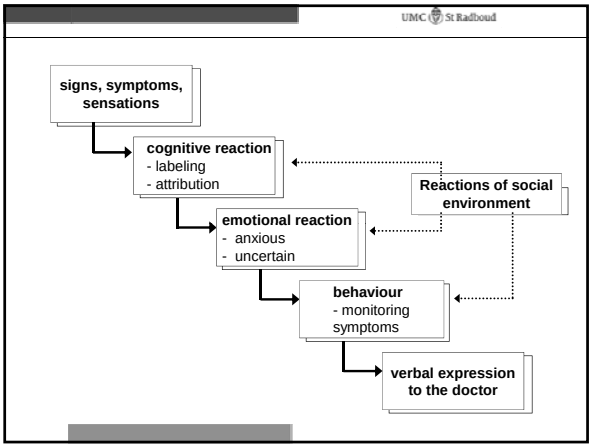
Most common communication behaviours of doctors

1. Giving information and instructions
2. Asking questions, however…..
   exchange of facts rather than sharing emotions
   (Bensing et al. 2003)

But, there's a whole patient history before the first contact and doctor-patient communication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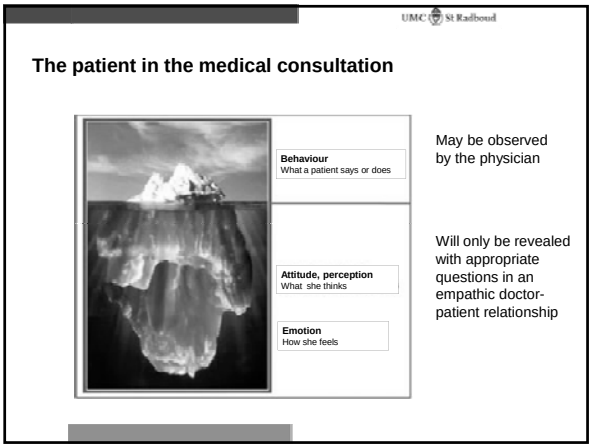
signs, symptoms, sensations
cognitive reaction
- labeling
- attribution
Reactions of social environment
emotional reaction
- anxious
- uncertain
behaviour
- monitoring symptoms
verbal expression to the doctor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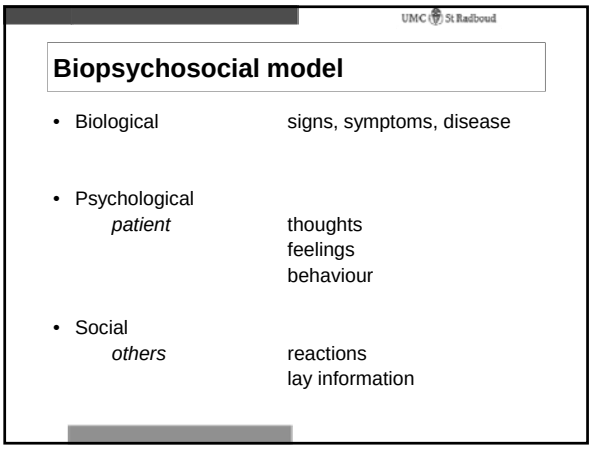
The patient in the medical consultation
Behaviour
What a patient says or does
Attitude, perception
What she thinks
Emotion
How she feels
May be observed by the physician
Will only be revealed with appropriate questions in an empathic doctor-patient relationship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Biopsychosocial model
• Biological signs, symptoms, disease
• Psychological
patient thoughts
feelings
behaviour
• Social
others reactions
lay information

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First medical consultation

PATIENT, PARTNER	PROFESSIONAL
A special day, n=1	Day-to-day, n>10
Focus on outcome	Focus on technique
Pre-existing subjective beliefs	Need for objective information
Uncertainty	Control
High expectations	Normal expectations
New information	Standard knowledge
Limited working memory capacity	Deliver necessary information
PSYCHOSOCIAL perspective	MEDICAL perspective

➔ discrepancy in perspectives
➔ caveats for a good doctor-patient relationship

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Skills needed in the pre-treatment phase

- Empathic
- Respectful
- Non-judgemental
- Sensitive to concerns
- Aware of impaired attention to medical information
- Use of silence
- Aware of non-verbal behaviour

The first consultation is crucial
in the patient-professional relationship

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Outcomes of better doctor-patient communication

Teutsch, 2003

- Better emotional wellbeing
- Resolution of symptoms
- Improved functioning
- Better physiological measures
- Better pain control

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Verbal and nonverbal behaviours related to better patient outcomes

Verbal
- Patient-centered questioning
- Empathic responses to patients
- Summarizing information
- Clarifying information

Non-verbal
- Open and direct posture
- Leaning towards patient
- Nodding when appropriate
- Friendlyness
- Courtesy
- Longer consultations

(Beck et al. 2002)

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Specific characteristics of patient-professional communication in fertility treatment

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Quality of interactions between patients and fertility staff

Systematic review (Dancet et al. 2010)

- Lack of empathy
- Negative interactions with staff
- Poor listening skills
- Poorly formulated explanations of healthcare plans

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What do patients expect from communication with treating physician in the fertility clinic?

- Reassurance (Palumbo et al. 2011)
- Shared decision making (Peddie et al. 2004)
- Identification of treatment burden
- Addressing patients' fears or worries
- Feedback about treatment progress (Boivin et al. 2000)

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Gender differences in doctor-patient communication

In general:

➔Female physicians are more likely to engage in patient-centered behaviours

➔Patients speak more in consultations with female physicians

Hall & Roter, 2002; Roter & Hall, 2004

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Gender differences in doctor-patient communication

However, a reversal of this pattern in studies conducted in obstetric/gynaecological settings

➔Male physicians engaged in more emotion-focused talk and elicited more affective information

Hall & Roter, 2002; Roter & Hall, 2004

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How to communicate
in different phases
of fertility treatment

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Different communication skills in particular phases of fertility treatment

- Pre-treatment: empathy, shared decision making, exchange of information
- During treatment: address patient's fears or adherence
- Waiting for results: empathy, brief interactions
- Post results: feedback on progress, giving bad news

➔ Challenges for health care professionals

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How to communicate positive identification of
burden of treatment
or psychological vulnerability?

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Communication concerning burden of treatment

Psychological burden is caused by
- Patient history (psychological vulnerability)
- Demands of treatment

Identify at-risk fertility patients with short tools and refer to mental health professional for support plans during treatment (Boivin et al. 2012)

Caveat: Communication of a positive screen between identification and referral

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How can the doctor communicate a positive screen of psychological vulnerability?

Do's
- Prepare a separate interview
- Allow yourself the time,in a private setting
- Focus on the expected burden of treatment
- Acknowledge strong emotions
- Focus on support needed to improve the fertility treatment
- Negotiate a mutually acceptable plan
- Explain unexpected outcomes (provide a safety net)

Don'ts
- During the routine consultation
- No extra time for reactions
- Stop or ignore emotions
- Stigma of dysfunctional behaviour or psychopathology
- Focus on referral to psychologist
- Order the patient how to handle during treatment
- Threat of stopping fertility treatment

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Problems
in doctor-patient communication
as an extra source
of burden of treatment

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Reactions of patients

- Feeling hurt or let down resulting in depressed mood
- Anger as emotion
- Aggression as behavioural response
- Anxiety resulting in hypervigilance or increase of control

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Helpful responses of doctors

- Empathy and understanding of these strong emotions
- Let the patient talk and vent emotions
- Communicate about the problems in communication (meta-communication)

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Feritility treatment at risk for communication problems

- Complex medical technologies demand the attention of doctors
- Rapidly changing discipline puts high demands on doctors in keeping up their expertise
- Patients with high expectations and with strong emotions
- Relational strains between patients and partners require expert communication skills

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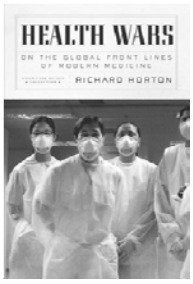
Richard Horton (2003): patient versus technology

Trust between doctors and patients has defined the practice of medicine since the time of Hippocrates. But can it endure in an age of complex medical technologies, ever-increasing demands on doctors, and new threats to health?

Horton sees medicine as a fractured and rapidly changing discipline under unprecedented social, political, financial, and scientific pressures. But he insists that it should be guided above all by one ideal: the dignity of an individual in the face of illness.



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Communication in fertility treatment

PATIENT, PARTNER	PROFESSIONAL
A special day, n=1	Each patient is unique
Focus on outcome	Focus on expected outcome
Pre-existing subjective beliefs	Check the health beliefs
Uncertainty	Express understanding
High expectations	Discuss realistic expectations
New information	Repeat, reduce and check information
Limited working memory capacity	Deliver requested information
PSYCHOSOCIAL perspective	BIOPSYCHOSOCIAL perspective

➔ a good doctor-patient relationship

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How can psychologists and counselors
in the fertility team
attribute to the prevention of problems
in doctor-patient communication?

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Feedback, educational activities and research

- Feedback of observed emotional distress in patients
- Feedback of negative staff-patient communication
- Encourage respectful communication of patient problems
- Organize focus groups of patients and partners
- Staff training in fertility specific communication themes (patient-centered communication, giving bad news)
- Research of psychosocial responses of patients and partners

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Take home messages

- Each encounter with a patient is a unique experience
- Listen to this unique patient and her partner
- Be empathic and understanding
- Reduce information and check comprehension
- Adress fears and worries
- Give feedback about treatment progress
- Identify treatment burden and emotional distress
- Respond non-judgmental

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Quality of care and burden of treatment

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Declaration of Interest

- "Conflict of interest – None"

Content

- Burden of treatment
- Quality of care
  - Relation
- Conclusion and recommendations

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Burden

Infertility and treatment

- Vulnerable/stigmatized/frustrated/losing control
- Treatment time consuming
- Treatment needs scheduling
- Concern side effects of treatment
- Fear self-injecting
- Lack of control
- Balance hope – fear after insemination/embryo transfer
- Threat of definitive childlessness

Redshaw et al. 2007 Hum Reprod
Boivin et al. 2011 BMJ
Domar et al. 2012 Hum Reprod

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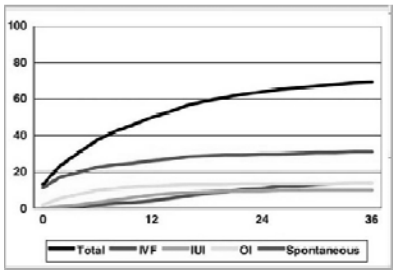
Burden

Infertility and treatment



Brandes et al. 2010 Hum Reprod

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Burden

Infertility and treatment

- Depression
- Anxiety
- Reduced Quality of Life
- Less self-esteem
- Marital issues
- Drop out
- Productivity Loss

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Burden

Infertility and treatment

- Depression
- Anxiety

- twice the prevalence of depressive symptoms relative to fertile women
- 1:5 subclinical forms of anxiety/depression
- Most stressful: oocyte retrieval and pregnancy test

Boivin et al. 1995 Fert Steril
Verhaak et al. 2005 Hum Reprod
Cousineau et al. 2007 Best Pract Res Clin Obstet Gynaecol

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Burden

Infertility and treatment

- Reduced Quality of Life (55 score out of 100) measured by FertiQoL
- Less self-esteem (~ 50% women)

Boivin et al. 2011 Hum Reprod and Fert Steril
Domar et al. 2012 Hum Reprod
Chachamovich et al. 2010 J Psychosom Obstet Gynecol

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Burden

Infertility and treatment

- Marital issues (e.g. relationship, sexual satisfaction, intimacy)
- Inconclusive
- Marital distress – marital adjustment

Cousineau et al. 2007 Best Pract Res Clin Obstet Gynaecol

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Burden

Infertility and treatment

- Drop out
- Prevalence 8-89%
- 'controlled studies' 24-35%

Land et al. 1997 Fert Steril
Malcolm et al. 2004 Fert Steril
Smeenk et al. 2004 Fert Steril
Olivius et al. 2004 Fert Steril
Schröder et al. 2004 RBM Online
Rajkhowa et al. 2006 Hum Reprod
Verberg et al. 2008 Hum Reprod
Verhagen et al. 2008 Hum Reprod
Van Dongen et al. 2010 Fert Steril
Brandes et al. 2009 Hum Reprod

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Burden

Infertility and treatment

- Productivity Loss

- Overall absence IVF/ICSI cycle on average 33 hours
- Costs ~€ 600 per woman/cycle

Bouwmans et al. 2008 Acta Obstet Gynecol

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Burden

Risk factors increasing burden

- Women
- Longer duration infertility
- More unsuccessful treatment cycles

- Diagnosis
- Female age

Boivin et al. 1995 Fert Steril
Ragni et al. 2005 Hum Reprod
Chachamovich et al. 2010 J Psychosom Obstet Gynecol
Ogawa et al. 2001 BPS Med

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Quality of care

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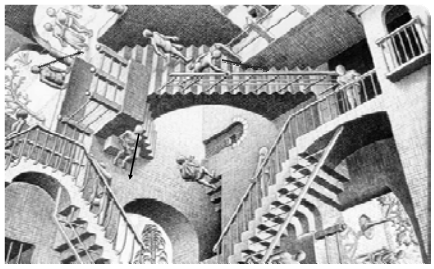
Quality of Care



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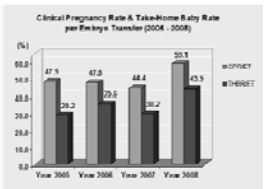
Quality of care

Professionals



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Quality of care

Professionals

ISO 9001

DIN

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Quality of care

Insurance companies and Ministries

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Quality of care

Patients or care users

Experiences
Organisation
Privacy
Work
Relation

Dancet et al. 2011 Hum Reprod
Dancet et al. 2012 Hum Reprod
Souter et al. 1998 Hum Reprod

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Quality of care

ISO certification

- *Advantages*
  - Third party assessment
  - International recognition
  - QM system
  - Efficiency ……..
- *Disadvantages*
  - Does not guarantee better quality
  - Focus on certification
  - Frequent audits ……..

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Quality of care

Implementation QM system

- Requires effort
- Patients and professionals profit
- Is recommended
- Not per se better quality
- Unknown relation with burden of treatment

Helbig et al. 2008 Int J Health Care Qual Assurance
Shaw et al. 2010 Int J Qual Health Care

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Quality of care

Satisfaction

- *Advantage*
  - (seems) easy to measure

Degree of congruence between *patients' pre-existing* expectations *of care and the accomplishment through the* actual care service *received*

Pascoe. 1983 Eval Program Plann

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Quality of care

Satisfaction

- Low expectations - satisfied with deficient care

Example:

- Satisfaction and actual fertility care - information provision
  - 1499 couples
  - 28 recommendations
  - 94% couples (very) satisfied
  - received 57% of the recommended information (10-96%)

Mourad et al. 2009 Hum Reprod

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Quality of care

Satisfaction

- *Disadvantages*
  - Overoptimistic
  - Large discrepancy satisfaction – health care quality
- Patients' experiences with specific care aspects more useful
- Could guide care improvement

Jenkinson et al. 2002 Qual Saf Health Care

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Quality of care

Institute of Medicine

- Effectiveness
- Cost-effectiveness
- Equity of access
- Timeliness
- Patient centredness
- Safety

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Quality of care

Effectiveness

- Service based on scientific knowledge
- Refraining from providing service to those not likely to benefit

Institute Of Medicine. 2001 Crossing the quality chasm

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Quality of care

Effectiveness

- Monitoring/Registration

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Quality of care

Effectiveness

- Monitoring/Registration

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Quality of care

Effectiveness

- 
Assisted reproductive technology in Europe, 2006: results generated from European registers by ESHRE†

J. de Mouzon', V. Goossens, S. Bhattacharya, J.A. Castilla, A.P. Ferraretti, V. Korsak, M. Kupka, K.G. Nygren, A. Nyboe Andersen, and The European IVF-monitoring (EIM) Consortium, for the European Society of Human Reproduction and Embryology (ESHRE)‡

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Quality of care

Effectiveness

- 
World Collaborative Report on Assisted Reproductive Technology, 2002

International Committee for Monitoring Assisted Reproductive Technology (ICMART): Jacques de Mouzon[1,3], Paul Lancaster[2], Karl Gosta Nygren[2], Elisabeth Sullivan[4], Fernando Zegers-Hochschild[5], Ragaa Mansour[6], Osamu Ishihara[7], and David Adamson[8]

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Quality of care

Effectiveness and burden

- Anxiety and depression
  - Unsuccessful treatment → levels negative emotions ↑
  - 2-fold increase suicide
  - Pregnancy → negative emotions disappeared
  - → stress is related to treatment outcome

Johansson et al. 2010 Acta Obstet Gynecol
Verhaak et al. 2007 Hum Reprod Update
Kjaer et al. 2011 Hum Reprod

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Quality of care

Effectiveness and burden

- Quality of Life
  - Unsuccessful treatment → satisfaction with life/QoL ↓
  - Women lower QoL scores than men
  - → more effective treatment would reduce burden (of treatment) for couples

Johansson et al. 2010 Acta Obstet Gynecol
Ragni et al. 2005 Hum Reprod
Hammarberg et al. 2001 Hum Reprod
Chachamovich et al. 2010 J Psychosom Obstet Gynecol

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Quality of care

Cost-Effectiveness

- Avoiding waste
- Superior after comparative analysis in terms of costs *and* effectiveness
- Ideal: more effective and lower costs
- Examples:
  - Vasectomy reversal vs. IVF with sperm retrieval
  - Single vs. double embryo transfer
  - Purified human menopausal gonadotrophin vs. rFSH

Institute Of Medicine. 2001 Crossing the quality chasm
Drummond et al. 2004 Methods of the economic evaluation of health care programmes

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Quality of care

Cost-Effectiveness and burden

- Less infertility studies on cost-effectiveness
- Studies on cost-effectiveness and burden rare
- Those available: cost-effective strategy no effect on depression/anxiety/sleep quality/drop out

Cost-effectiveness

- Mild ovarian stimulation IVF
- Shared decision making SET/DET
- Laparoscopy unexplained infertility

Heijnen et al. 2007 Lancet
Van Peperstraten, et al. 2010 BMJ
Mogveri et al. 2009 Fert Steril

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Quality of care

Cost-Effectiveness and burden

- Special attention to time horizon in cost-effectiveness studies
- Time to pregnancy is associated with QoL

- → More cost-effective treatment → more resources → more people be helped → less burden

Ragni et al. 2005 Hum Reprod
Chachamovich et al. 2010 J Psychosom Obstet Gynecol

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Quality of care

Accessibility

- Care that does not vary in quality because of personal characteristics
  - Ethnicity, socioeconomic status, geography

- Since 1994 International Conference on Population and Development (Cairo)
- Since 1995 World Conference on Women (Beijing)

- More attention to reproduction in women's health and live, but ……

Institute Of Medicine. 2001 Crossing the quality chasm

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Quality of care

Accessibility

- Reimbursement system
- Law and regulation

- IFFS Surveillance
- (104 countries)

Jones et al. IFFS Surveillance 2010

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Quality of care

Accessibility

- Legislation varies
  - PGS and PGD
  - Oocyte donation/sharing
  - Treatment of lesbian couples/single women
- Legal or other access issues reason for cross border care (CBC)

Ziebe et al. 2008 Fert Steril
Nygren et al. 2010 Fert Steril
Blyth et al. 2010 Fert Steril
Inhorn et al. 2012 Curr Opin Obstet Gynecol
Ferraretti et al. 2010 Reprod Biomed Online
Shenfield et al. 2010 Hum Reprod

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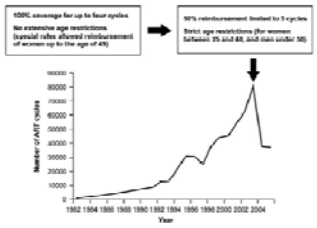
Quality of care

Accessibility

- Financial burden barrier for seeking fertility treatment
- 2004 Germany 50% co-payment IVF/ICSI



Domar et al. 2012 Hum Reprod
Ziebe et al. 2008 Fert Steril
Connolly et al. 2009 Hum Reprod

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Quality of care

Accessibility and burden

- Studies on accessibility and burden rare
- Those available:
  - high burden infertility in developing countries
  - CBC despite difficulties (language, travels, additional costs) positive experiences → 50% success rate
- → Better accessibility → more people be helped → less burden

Dhont et al. 2011 Hum Reprod
Wiersema et al. 2006 J Transl Med
Blyth et al. 2010 Fert Steril
Inhorn et al. 2012 Curr Opin Obstet Gynecol

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Quality of care

Timeliness

- Reducing waits and harmful delays
- Reducing unnecessary care

- Example:
  - Use of prediction models for treatment (in)dependent pregnancy

Institute Of Medicine. 2001 Crossing the quality chasm
Leushuis et al. 2009 Hum Reprod Update

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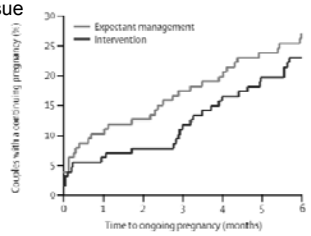
Quality of care

Timeliness

- Prediction model for treatment independent pregnancy (Hunault et al.) unexplained infertility
- TTP no issue



Hunault et al. 2004 Hum Reprod
Steures et al. 2006 Lancet

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Quality of care

Timeliness and burden

- Effects of using such models on burden is unknown
- Patients' appreciation of expectant management on average 5,7 (out of 10)

Barriers to treat timely

- Lack of confidence in natural conception
- Need for more instructions or information material for the expectant period
- No management of expectations

Leushuis et al. 2009 Hum Reprod Update
Van den Boogaard et al. 2012 Hum Reprod

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Quality of care

Timeliness and burden

- Effects of timely treatment is unknown
- → More timeliness → more resources → more people be helped or less treatment needed → less burden

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Quality of care

Patient centredness

- ≠ patient satisfaction
- ≠ patient friendly
- ≠ psychosocial care
- ≠ being nice to patients
- ≠ customer is king

Institute Of Medicine. 2001 Crossing the quality chasm

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Quality of care

Patient centredness

- Provision of care that is respectful of and responsive to individual patient preferences, needs and values …
- System and human factors

Institute Of Medicine. 2001 Crossing the quality chasm

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Quality of care

Patient centredness

System factors	Human factors
Information provision	Attitude of staff
Competence staff	Communication
Coordination and integration	Patient involvement
Accessibility	and privacy
Continuity and transition	Emotional support
Physical comfort	

Dancet et al. 2011 Hum Reprod
Dancet et al. 2010 Hum Reprod Update

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Quality of care

Patient centredness

System factors

Information provision	*concrete, general, personal, channels, timeliness*
Competence staff	*clinical expertise, good order, file*
Coordination and integration	*waiting times, financial, holidays*
Accessibility	*telephone, emergency, flexibility*
Continuity and transition	*continuity of staff, consistent policy*
Physical comfort	*pain medication, accommodation*

Dancet et al. 2011 Hum Reprod
Dancet et al. 2010 Hum Reprod Update

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Quality of care

Patient centredness

Human factors

Attitude of staff	*friendly, sensitive, respectful, relationship, behavior, appearance*
Communication	*taking time, understandable, bad news*
Patient involvement	*shared decision making, access to*
and privacy	*health record, personalized care*
Emotional support	*daily care and specialized staff, contact co-patients*

Dancet et al. 2011 Hum Reprod
Dancet et al. 2010 Hum Reprod Update

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Quality of care

Patient centredness

System factors		Human factors
Information provision		Attitude of staff
Competence staff	⟹	Communication
Coordination and integration		Patient involvement
Accessibility	⟸	and privacy
Continuity and transition		Emotional support
Physical comfort		

Dancet et al. 2011 Hum Reprod
Dancet et al. 2010 Hum Reprod Update

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Quality of care

Patient centredness
- Measurement by experiences

Need for
- Couple-centred approach
- More (written) information
- Assignment of one staff member for questions/problems
- More emotional support

Souter et al. 1998 Hum Reprod
Schmidt et al. 2003 Hum Reprod
Van Empel, et al. 2010 Hum Reprod

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Quality of care

Patient centredness
- Measurement PC Questionnaire Infertility
- Validated instrument
- 46 items
- Distinction 'weak' and 'strong' performing clinics
- European instrument is coming!

Van Empel, et al. 2010 Hum Reprod

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Quality of care

Patient centredness and burden

- Anxiety and depression (n=427)
- PCQ Infertility and HADS in unpregnant women
- Multilevel regression analyses
- Lower levels of anxiety or depression significantly associated with perceptions of more patient-centred care

Aarts et al. 2012 Hum Reprod

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Quality of care

Patient centredness and burden

- Quality of Life (n=427)
- PCQ Infertility and FertiQoL in unpregnant women
- Multilevel regression analyses
- Higher levels of quality of life significantly associated with perceptions of more patient-centred care

Aarts et al. 2012 Hum Reprod

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Quality of care

Patient centredness and burden

- Marital stress and benefit
- Questionnaires (COMPI) program 1013 (un)pregnant women and 886 men
- Multivariate regression analyses
- Less marital stress and more marital benefit significantly associated with perceptions of more patient-centred care

Schmidt et al. 2003 Hum Reprod

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Quality of care

Patient centredness and burden

- Relation between patient centredness and burden
- causality dilemma
  'which came first, the chicken or the egg?'

Patient centred care → less burden

←

Patient centredness and relation drop out?

→ More patient centred care may reduce burden

Aarts et al. 2012 Hum Reprod
Schmidt et al. 2003 Hum Reprod

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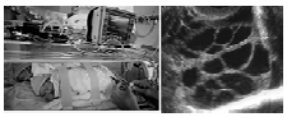
Quality of care

Safety

- Avoiding injuries from the care that is intended to help them



- Examples:
  - OHSS
  - Infection
  - Bleeding
  - Congenital anomalies
  - Multiple pregnancies

Institute Of Medicine. 2001 Crossing the quality chasm

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Quality of care

Safety and burden

- Multiple pregnancies
- Pregnancy related morbidity and mortality
- Severe parenting stress (22%)
- Felt depressed first year (47%)
- Felt social stigmatized
- Lower quality of life
- Lower marital satisfaction

- →More safe treatment → less burden

Fiddelers et al. 2009 Hum Reprod
Pinborg. 2005 Hum Reprod Update
Ellison et al. 2003 Fert Steril
Damato. 2005 Newborn Infant Nursing Reviews
Roca-de Bes et al. 2009 Fert Steril

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Conclusion and recommendations

Quality of care and burden

- There is burden by infertility and fertility treatment
- Effective fertility care reduces burden
- Quality of care is more than effectiveness of care
- Cost-effectiveness, Accessibility, Safety and Timeliness of care in relation to burden scarce, but plausible relation
- Patient centred fertility care related to less burden, but direction of relation unclear

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Conclusion and recommendations

Quality of care and burden

- Improvement quality of care gives a reduction of burden
- Not all dimensions of quality of care easy to improve
- Patient-centredness of care most suited

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Conclusion and recommendations

Quality of care and burden

- In accordance with, reduction of burden by a tailored and integrated approach
  - Patient/couple level (e.g. education, lifestyle or psychological intervention)
  - Organisational level (e.g. waiting times and rooms, flexibilities appointments)
  - Treatment level (e.g. milder stimulation, pen injections)

Boivin et al. 2012 Hum Reprod

Mark your calendar for the upcoming ESHRE Campus events

- Basic Semen Analysis Course in Greek Language
  4-7 September 2012 - Athens, Greece
- Basic Genetics for ART practitioners
  7 September 2012 - Rome, Italy
- Regulation of quality and safety in ART – the EU Tissues and Cells Directive perspective
  14-15 September 2012 - Dublin, Ireland
- Basic Semen Analysis Course in Spanish language
  18-21 September 2012 - Galdakano,Vizcaya
- GnRH-antagonists in ovarian stimulation
  28 September 2012 - Hamburg, Germany
- The best sperm for the best oocyte
  6-7 October 2012 - Athens, Greece
- Basic Semen Analysis Course in Italian language
  8-11 October 2012 - Rome, Italy
- Accreditation of a preimplantation genetic diagnosis laboratory
  11-12 October 2012 - Istanbul, Turkey
- Endoscopy in reproductive medicine
  21-23 November 2012 - Leuven, Belgium
- Evidence based early pregnancy care
  29-30 November 2012 - Amsterdam, The Netherlands

www.eshre.eu
(see "Calendar")

Contact us at info@eshre.eu

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