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Raising competence in psychosocial care


Medical treatment from a patient-centered perspective

How to communicate the invasiveness and time frames for ART procedures?



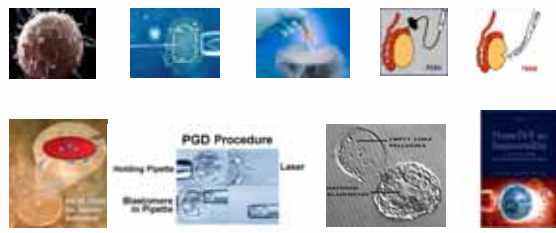
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PATIENT PERSPECTIVE ?

- Nowadays great medical advances within assisted reproduction: IVF/ICSI/PESA/TESE/IMSI/PICSI/PGD/PGS/hatching/vitrification/..



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PATIENT PERSPECTIVE ?

- Nowadays great medical advances within assisted reproduction: IVF/ICSI/PESA/TESE/IMSI/PICSI/PGD/PGS/hatching/vitrification/..
- Care for the emotional aspects more important than ever...



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Introduction: paradigm shift?

Improving the patient's experience of IVF/ICSI: a proposal for an ovarian stimulation protocol with GnRH antagonists

- Patients undergoing IVF/ICSI frequently experience substantial **treatment burden, risk and psychological distress**
- These three related elements contribute to a negative patient experience that can lead to treatment discontinuation
- One approach to minimize these factors is the use of protocols designed to achieve high term, singleton birth rates per IVF treatment started, while improving the patient's welfare

(DeVroey et al Hum Repr 2009)

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Personal background

- University Medical Center Nijmegen
 
- IVF Center St Elisabeth Hospital Tilburg
 

- PhD 'Stress and IVF'

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Overview

- Invasiveness
- Survey
- Stress
- Dropout
- Counselling



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Invasiveness



Experiences, behaviour, attitudes and emotions towards fertility treatments (N=355)

Physical and psychological burden

- Ovarian-stimulation treatment: 55% of patients impact upon daily life, while 31% felt that injections limited their everyday activities
- Most frequent questions from patients concerned fertility drug-related side effects, followed by concerns about application
- The study highlights areas in which improved patient education could help to reduce the psychological burden of IVF treatment

Huisman et al. RBM online 2009

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Invasiveness

Stress level across stages of in vitro fertilization in subsequently pregnant and nonpregnant women

- Negative feedback about treatment communicated to patients responding poorly to IVF (nonpregnant group) may have increased their stress level
- Differences between prospective and retrospective stress ratings may reflect women's attempt to cope with the strain of the **waiting period**

Boivin & Takefman: Fertil Steril 1995

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Invasiveness

Medical waiting periods: imminence, emotions and coping

Stimulation stage = positive affect with a less anxiety
Waiting stage = positive affect and anxiety symptoms
Pregnancy test onwards = depression

- Significant increase in coping activity between the stimulation and waiting stages
- Waiting for medical test results = demanding
- Healthcare professionals can assist by facilitating coping strategies that better fit the demands of the **waiting period** (IVF) and by offering support once outcomes are known

Boivin et al, Wom Health '10

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In summary

Psychosocial care in the Netherlands within ART

- Majority of care not structured
- The need for psychosocial care is known but often no resources (only University clinics)
- Management
nurses play key role



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Dutch nationwide survey

N=60/2009

Who are involved in psychosocial care ?

- Nurses (and doctors) 53%
- Psychologist within fertility team 13%
- Psychologist from elsewhere 23%
- Self help groups/patient communities 11%

Protocol? No=90%



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Dutch nationwide survey

N=60/2009

Availability of psychosocial help?

- Non existent 5%
- Bad 10%
- Neutral 22%
- Reasonable 48%
- Good 14%



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Dutch nationwide survey N=60/2009

When to address psychological help ?

- At intake 30%
- During treatment, if asked for 27%
- During treatment, doctor's initiative 40%
- Not at all 3%



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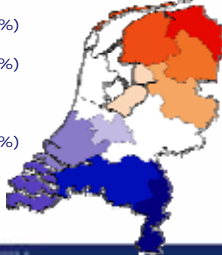
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Dutch nationwide survey N=60 centres

Regarding dropout

- Possibility to monitor the problem (41%)
- Reasons known (24%)
- What measures to avoid dropout ?

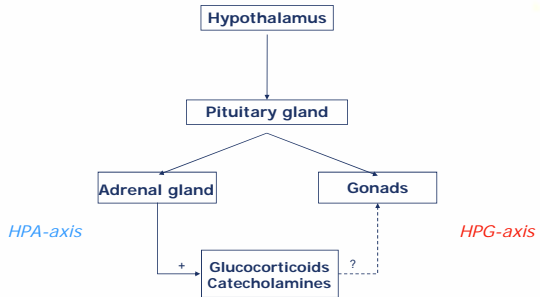
Offering psychological help (52%)



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Influence of stress?



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graph TD
    Hypo[Hypothalamus] --> Pit[Pituitary gland]
    Pit --> Adrenal[Adrenal gland]
    Pit --> Gonads[Gonads]
    Adrenal --> Hormones[Glucocorticoids  
Catecholamines]
    Gonads -.-> Hormones
    
```

HPA-axis

HPG-axis

Selye/1970

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Paracrine effect?

Hypothesis: HPA effect on chance of pregnancy
(IVF population, so HPG is suppressed!)

Time Point	Not pregnant	Pregnant
T1	~1.1	~0.9
T2	~1.0	~1.0
T3	~1.0	~0.7

Stress and outcome success in IVF: the role of self-reports and endocrine variables
Smeenk et al; Hum Repr '04

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Paracrine effect?

Hypothesis: HPA effect on chance of pregnancy
(IVF population, so HPG is suppressed!)

- Direct effect on uterine bloodflow (Schenker et al; EJOG repr 1992)
- Direct effect on granulosa cells; steroids and oocytes (Michael & Cooke; Mol Cell Endo 1994)
- Changing immunological status necessary for implantation (Gallinelli et al; Fertil Steril '01)
- Influence on fertilization and quality of the oocyte (Fateh et al; Fertil Steril 1989)

Stress and outcome success in IVF: the role of self-reports and endocrine variables
Smeenk et al; Hum Repr '04

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Stress & outcome

Stress leads to:

- Oocyte Retrieval (Decreased number of oocytes)
- Decreased Fertilisation
- Fewer Embryo Transfers
- Lower Pregnancy Rates
- Spontaneous Abortion (Miscarriage)
- No Live Birth Delivery

Lifestyle factors (Smoking, Alcohol, Caffeine) also influence:

- Increased Multiple Gestations
- Decreased Gestational Age
- Low Birth Weight

Klonoff-Cohen; Hum Repr Upd 05

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Clinical consequences *doctor's perspective*

Should fertilization treatment start with reducing stress?

- Ample evidence that lower stress levels mean better female and male **natural** fertility
- No conclusive experimental evidence that lower stress levels result in better **fertility treatment outcome**
- First reducing stress may diminish the number of treatment cycles needed, may prepare the couple for an initial failure or even make the more invasive techniques unnecessary

Campagne, Hum Repr 2006

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Clinical consequences *doctor's perspective*

Conclusions

- No evidence to treat *all* fertility patients in order to increase pregnancy results after treatment
- Screening and (online) support of risk groups is feasible (e.g. SCREENIVF: Verhaak et al. Hum Repr '10)
- Patients can be reassured about the overall effect of stress on pregnancy rates after ART treatment

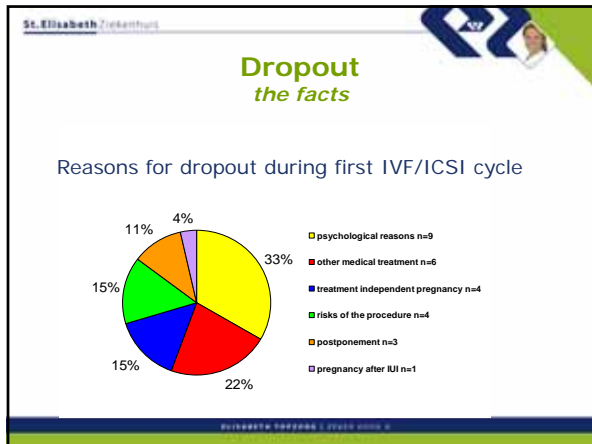
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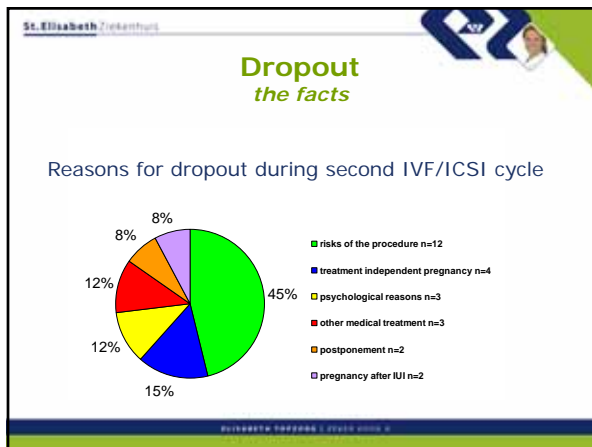
Dropout *the facts*

When and why do subfertile couples discontinue their fertility care? A longitudinal cohort study in a secondary care subfertility population. (N=1391)

- About half of the couples stopped before any fertility treatment
- One-third stopped after at least one IVF cycle
- Main reasons for withdrawal: emotional distress & poor prognosis
- Suggestion: improve quality of patient care by making care more responsive to the needs and expectations of subfertile couples

Brandes et al. Hum Rep 2009





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Clinical consequences doctor`s perspective

- Drop out rates as marker of quality of IVF program
Schröder et al. RBM '04
- High dropout rates in literature (up to 60%)
Emery 1997; Olivius '04; Rajkhowa '06; Domar '10
- Counselling !?

Psychological interference in in vitro fertilization treatment

Journal of In Vitro Fertilization and Embryo Transfer, Volume 15, Number 1, February 2008

Abstract: The aim of this study was to evaluate the psychological impact of in vitro fertilization (IVF) treatment on the couple. The study was conducted in a specialized IVF center. The results showed that IVF treatment has a significant negative impact on the psychological well-being of the couple. The study also found that the psychological impact of IVF treatment is related to the duration of the treatment and the success rate. The study concludes that psychological support is essential for couples undergoing IVF treatment.

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Clinical consequences *doctor's perspective*

Conclusions


- Studies suggest that some patients benefit from psychosocial interventions to diminish dropout *Cousineau & Domar: Best Practice '07*
- The application of a mild treatment strategy and managing patient's expectations might reduce drop-out rates *Verberg et al. Hum Repr '08*
- Top-rated suggestions for patient support were:
 1. written information on how to deal with psychological issues
 2. easy and immediate access to a psychologist or social worker *Domar et al. Fertil Steril '10*

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Clinical consequences *dropout: other side of the coin*

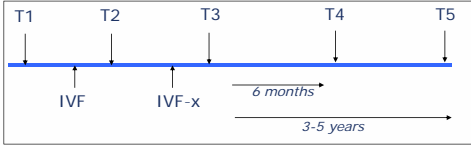
- Single most important reason for dropout from the waiting list was (spontaneous) pregnancy, most within 3 months
- Psychological factors such as stress relief after being placed on the waiting list might be operative *VanDongen et al. HumRepr '10*




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Psychological consequences *what is known?*



- T1: pre treatment
- T2: after first cycle
- T3: after last cycle
- T4: 6 months after last cycle
- T5: follow-up: 3-5 years after last cycle



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Psychological consequences

What is known?

6 months after last IVF/ICSI attempt:

- 20% clinical anxiety
- 25% clinical depression

• Long term: normal anxiety and depression

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Clinical consequences

doctor's perspective

Conclusions

- Majority of patients can handle treatment burden and the outcome of treatment
- Some patients might benefit from psychological interventions to shorten the period of grief
- Fertility team needs to point out the possibilities and screen and refer patients at risk

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Adjustment

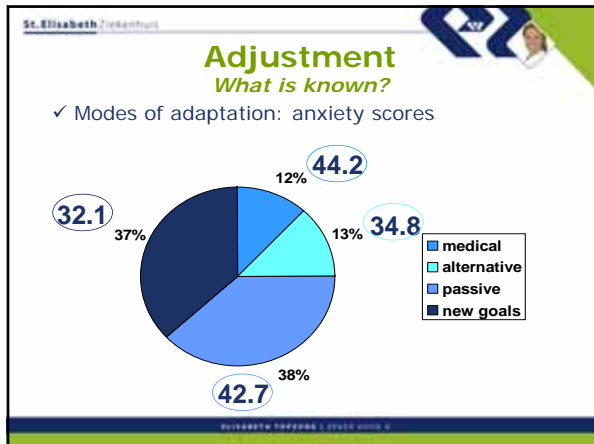
What is known?

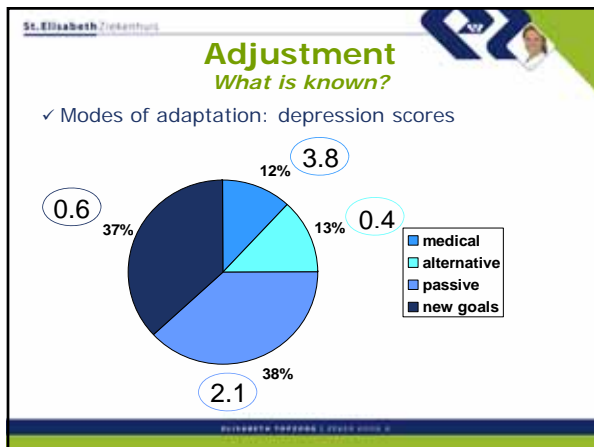
Ways to adjust after failed treatment

- **Medical mode** pursuing medical options
- **Alternative mode** other options
- **Passive mode** not active , still wanting
- **New goals** abandon desire, move on

van Balen & Trimbos-Kemper; J Psy Ob/Gyn 1994

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Clinical consequences

doctor`s perspective

Conclusions

- Way of adjustment is a significant predictor of distress after treatment
- The fertility team should take this into account during and after treatment and screen for it
- Refer for counselling if necessary

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Screening

'quick and dirty'

- Risk factors**
 - personality
 - coping
 - social support
- History taking: *at intake***
 - history of psychological/psychiatric problems
 - combination of treatment with work
 - adjustment/future plans
 - relational aspects
 - communication within relationship/others

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Screening

'team effort'

Refuse treatment?

Moral protocol: since 2010 in the Netherlands

Standardized approach to avoid 'shopping'

- reasonable wellbeing of future child!
- gather relevant information
- multidisciplinary assessment
- transparent procedure

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Counselling

What is known?

ESHRE guidelines

ESHRE Monographs

Basically to be addressed at intake


- Implications of treatment choice
- Sufficient emotional support
- Coping with the infertility experience

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Counselling

What is known?



Who is likely to need counseling?


- patients who use donated gametes, surrogacy and/or adoption
- patients who experience great distress
- patients at risk because of psychological history or profile
- patients who require a form of genetic counselling

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Counselling

What is known?



Review of psychosocial interventions in infertility (N=380)

- Effective reducing negative affect, not interpersonal functioning
- Unlikely to affect pregnancy rates
- Men and women were found to benefit equally

(Bolvin ; Soc Sci Med 2003)

Effectiveness of a psychosocial counselling intervention for first-time IVF couples: a RCT (N=84)

- Results do not support the implementation counselling for all
- Low response rate suggests little perceived need


(De Klerk et al. Hum Rep 2005)

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Counselling

What is known?



Is there too much emphasis on psychosocial counseling for infertile patients?


Emphasis on psychosocial counseling for highly distressed patients in the area of infertility has left the needs of **less distressed patients neglected** and the potential usefulness of alternative methods of intervening with them unexplored

Bolvin, J Ass Repr Gen 97

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Clinical consequences doctor`s perspective




- **Information gathering and analysis**
Help to gather and make sense of all information available
- **Implications and decision-making counselling**
Meaning of information for the individual and highlight consequences
- **Support counselling**
Give emotional support to patients with distress: focus on resources patients have in coping and work out new coping strategies
- **Therapeutic counselling**
Often natural progression from support counselling to therapeutic counselling: refer to specialist

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Clinical consequences doctor`s perspective




- **Avoid 'psychologizing' the patient's symptoms**
Many patients are not psychologically-minded or insightful
- **Shape adequate beliefs rather than challenge misconceptions**
Present the treatment strategy in a positive, collaborative developed plan, rather than last resort
- **Foster realistic expectations about treatment**
Many infertile patients are ill-prepared for the time commitment
- **Clarify other treatment roles**
The infertility counselor should be prepared to educate the patient how psychological treatment will interface with infertility treatment

Belar et al. Psychological Press

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New initiatives..



- Online psychoeducational support for infertile women: a RCT
Cousineau et al. Hum Rep 2008
- IVF patients show three types of online behaviour
Tuil et al. Hum Rep 2008

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Patient centeredness= teamwork!



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The end



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