

PRE-CONGRESS COURSE 6

**High standard psychosocial
care in your clinic;
how to implement
new guidelines.**

Special Interest Group Psychology and Counselling
London - UK, 7 July 2013



SCIENCE MOVING
PEOPLE
MOVING SCIENCE



High standard psychosocial care in your clinic; how to implement new guidelines

**London, United Kingdom
7 July 2013**

**Organised by
The ESHRE Special Interest Group Psychology and Counselling**

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Course coordinators

Chris Verhaak (The Netherlands) and Uschi Vandebroek (Belgium)

Course description

Supported by the ESHRE guideline group, new guidelines for psychosocial care are developed by psychologists, counsellors, nurses and gynaecologists. The guidelines are focused on implementing psychosocial care in different aspects of daily clinical care. The workshop is aimed to facilitate implementing the guidelines in daily practice.

Target audience


Doctors and nurses, psychologists and counselors

Scientific programme

Chairman: Christianne Verhaak - The Netherlands

Chairman: Uschi Van den Broeck - Belgium

- 09:00 - 09:30 Tackling the burden of ART, a practical guide for clinical staff
Jacky Boivin - United Kingdom
- 09:30 - 09:45 Discussion
- 09:45 - 10:15 Guidelines and then: how to implement psychosocial care in daily practice
Nathalie Vermeulen - Belgium
- 10:15 - 10:30 Discussion
- 10:30 - 11:00 Coffee break
- 11:00 - 11:30 The implementation of tailored expectant management in reproductive medicine
Noortje Van Den Boogaard - The Netherlands
- 11:30 - 11:45 Discussion
- 11:45 - 12:15 How can mental health professionals work with other clinic staff to implement psychosocial support?
Sofia Gameiro - Portugal
- 12:15 - 12:30 Discussion
- 12:30 - 13:30 Lunch
- 13:30 - 14:00 How doctors could implement psychosocial care
Christos Venetis - Greece
- 14:00 - 14:15 Discussion
- 14:15 - 14:45 How to support patients in the waiting period?
Deborah Lancaster - United Kingdom
- 14:45 - 15:00 Discussion
- 15:00 - 15:30 Coffee break
- 15:30 - 16:00 Screening on distress in ART patients; theoretical background and practical implications
Angelique van Dongen - The Netherlands
- 16:00 - 16:15 Discussion
- 16:15 - 16:45 Supporting patients in changing lifestyle. Rotterdam Lifestyle interventions
Geranne Jiskoot - The Netherlands
- 16:45 - 17:00 Discussion



Tackling the burden of ART:
A practical guide for clinical staff

Jacky Boivin, PhD, CPsychol

School of Psychology
Cardiff

CARDIFF UNIVERSITY
HEALTH SCHOOL
CARDIFF ESHRE, London, 2013
Boivin J, et al. / J. In Vitro Fertilisation Embryo Development
https://doi.org/10.1007/s10815-013-0000-0

Disclosure (past three years)

- Speaker fees, honorarium and/or research funding from Merck-Serono S.A., Weber-Shandwick, EMD Serono Inc

Cardiff Fertility Studies

Learning objectives

- Discover interchange between psychology-medicine
- Learn the Integrated Approach to Infertility Care (IPA Care)
- Describe what is required to take into account clinic issues for compliance and patient quality of life
- Identify work stress and patient difficulty in interactions between staff and patients
- Identify potential impact of taking into account clinic issues

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History and evolution

Psyche → Infertility Infertility → Psyche Assessment Monitoring Follow-up Intervention Evaluation Compliance Systematic reviews

1940: Karl Menninger, Helen Deutsch. "Infertility as a psychic conflict taking under a gynecological flag" Menninger, 1943.

1977: Mahabadi 195. "Working through" & grief & loss therapies.

1978: Assessment Monitoring Follow-up.

2003: Intervention Evaluation.

2009: Compliance Systematic reviews.

Year	% unexplained	% range
< 1960	34.0	(Stand et al. 1955)
1960 - 1969	21.84	11.2 - 30.5
1970 - 1979	16.13	10.0 - 27.0
1980 - 1982	12.1	8.6 - 15.4

Unexplained infertility (Templin et al. 1982)

Barbara Eck Menning Nurse led, Patient Advocacy

IVF & ART

Evidence-based Medicine

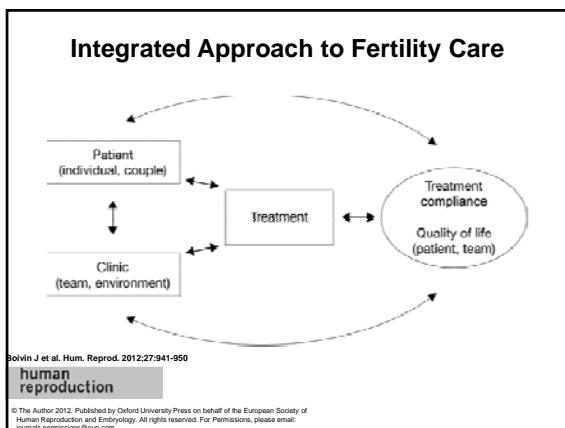
"Drop-out" in ART (Brandes et al. 2009)

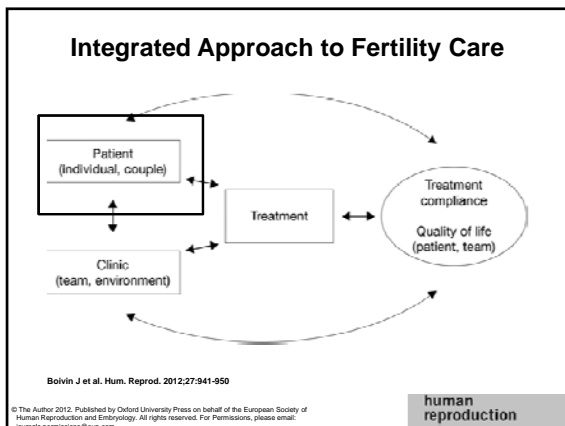
Human Reproduction, Vol.27, No.4 pp. 941-950, 2012
 Advance Article published on January 18, 2012 doi:10.1093/humrep/der467

human reproduction OPINION

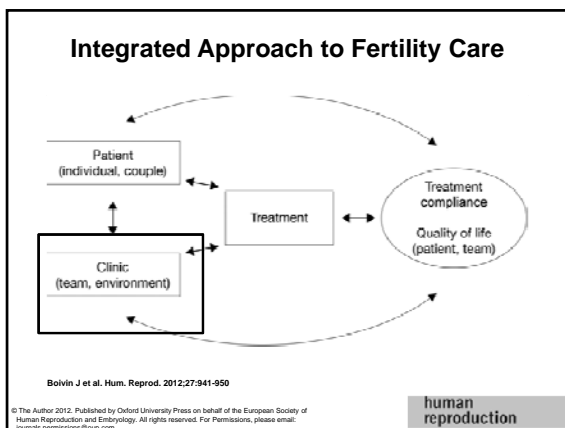
Tackling burden in ART: an integrated approach for medical staff

Jacky Boivin^{1,2}, Alice D. Domar², Daniel B. Shapiro¹,
 Tewes H. Wischmann¹, Bart C.J.M. Fauser³, and Christianne Verhaak⁴





- ### Patient targets (speaker Gameiro)
- **Fear and negative attitudes to treatment**
 - ▣ Education (pre-treatment, treatment changeover)
 - **Psychological vulnerability & ability to withstand demands of treatment**
 - ▣ High-risk referral (pre-treatment), coping interventions (throughout) treatment and beyond
 - **Relational strain**
 - ▣ High-risk referral (pre-treatment); partner involvement; decisional-support (treatment change-over)
- Cardiff Fertility Studies



Practical guide for staff

- Needs assessment
- Intervention development
- Impact assessment

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Recognise issues for fertility teams

TABLE 2

Results of the fertility practice management and workload survey.

Shanafelt et al. 2012: Ob/Gyn – 8/25 specialities on rate of burn-out; 50% at least 1 symptom

Question	Physician	Administrator	Staff
Practice management and workload survey	80.5%	87.5%	77.8%
Staff workload was reduced on two to six days per week	80.5%	87.5%	81.5%
Practice workload survey about what is going on	91.2%	91.8%	78.2%
Staff is satisfied with changes in workload	95.8%	91.1%	88.9%
Workload is high	88.8%	84.7%	83.5%
The physician workload is too high	84.8%	82.8%	83.5%
The administrator workload is too high	84.8%	82.8%	83.5%
The staff workload is too high	84.8%	82.8%	83.5%
Staff is adequately compensated	87.2%	86.7%	77.1%
Staff workload is too high	87.2%	86.7%	77.1%
Staff workload is too high	87.2%	86.7%	77.1%
Physicians were engaged with patients	90.0%	90.0%	81.0%
Administrators satisfied in appropriate	85.0%	89.0%	74.0%
Staff satisfaction in appropriate	85.0%	89.0%	74.0%
Staff satisfaction in appropriate	85.0%	89.0%	74.0%
A high level of patient satisfaction	88.5%	84.0%	81.0%
Staff is satisfied and open	93.0%	89.0%	74.0%
The work environment is stressful	88.0%	75.0%	85.0%
The patient in the practice was positive	95.0%	95.0%	95.0%

% agree/strongly agree:
"Work environment is stressful"

Physician: 48.9
Administrator: 73.7
Staff: 63.9

N=112 ART centres in USA
Gerson et al. 2004 Fertil Steril

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Staff perspectives


- "Holding it together" (Payne & Goedeke, 2007)
 - Emotional/physical experiences of patient AND roles/care experiences of specialist teams
- Change in primary responsibilities (Morris, 2001)
 - Patient centered care Vs medically-orientated responsibilities
- Dealing with disappointed patients (Simpson et al. 2001)
 - Insufficient time to support distressed patients
- Quality of care perceived differently than patients (Aarts et al. 2011)
- How care should be delivered perceived differently than patients (Allan, 2002)
- Difficulty making changes toward patient centered care Huppleschoten et al. 2013

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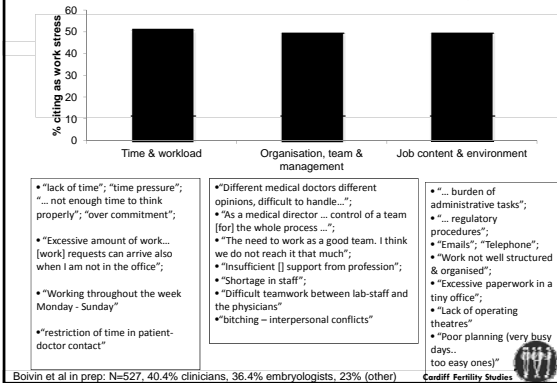


ESHRE survey

- N=527 members of ESHRE
- Provided text responses to three questions
 - "What are the top three factors that make your work stressful?"
 - "What are the top three factors that make working with patients difficult?"
 - "Which top three factors ... would you be most willing to attend a workshop to resolve"
- Textual analysis based on grounded theory (categories & broad themes)
- Sample composition
 - Clinical - 40.4% clinicians, 36.4% embryologists
 - Other - 8.4% administration, 8.4% nurse/mid-wife, 3.4% academic, 2.3% mental Health

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Sources of workplace stress in fertility staff



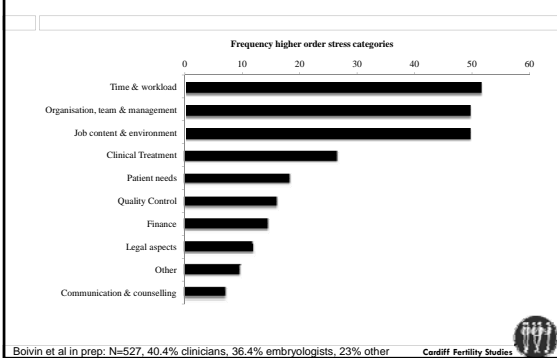
- "Lack of time"; "time pressure"; "... not enough time to think properly"; "over commitment";
- "Excessive amount of work... [work] requests can arrive also when I am not in the office";
- "Working throughout the week Monday - Sunday"
- "restriction of time in patient-doctor contact"

- "Different medical doctors different opinions, difficult to handle...";
- "As a medical director ... control of a team [for] the whole process ...";
- "The need to work as a good team. I think we do not reach it that much";
- "Insufficient [] support from profession";
- "Shortage in staff";
- "Difficult teamwork between lab-staff and the physicians"
- "bitching - interpersonal conflicts"

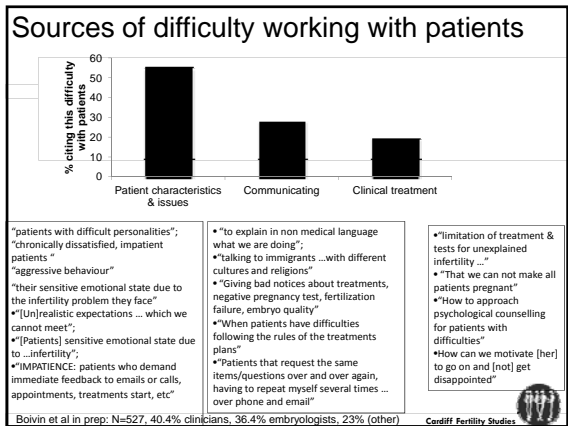
- "... burden of administrative tasks";
- "... regulatory procedures";
- "Emails"; "Telephone";
- "Work not well structured & organised";
- "Excessive paperwork in a tiny office";
- "Lack of operating theatres"
- "Poor planning (very busy days... too easy ones)"

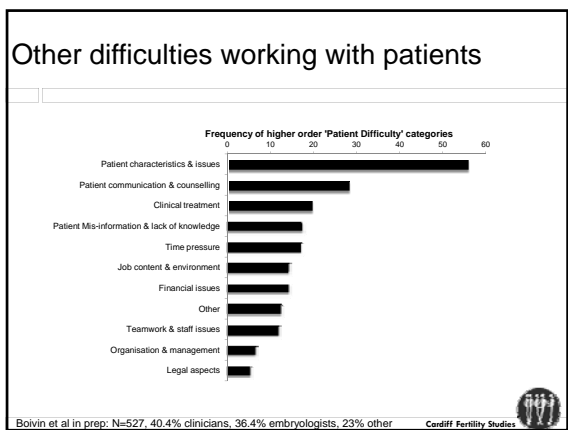
Boivin et al in prep: N=527, 40.4% clinicians, 36.4% embryologists, 23% (other) 

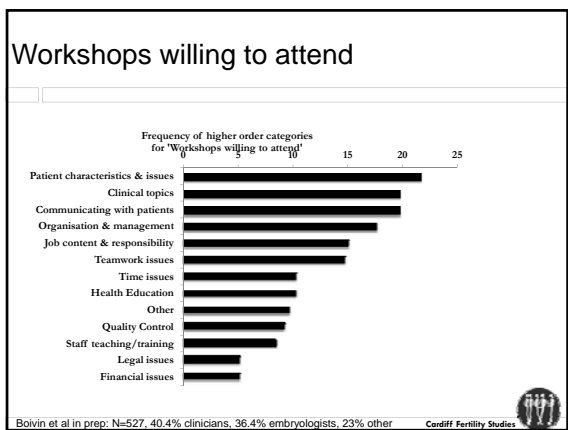
Other workplace stressors



Boivin et al in prep: N=527, 40.4% clinicians, 36.4% embryologists, 23% other 





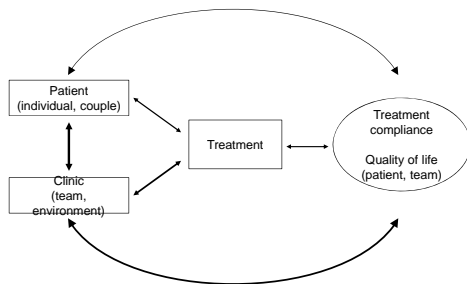


Broad themes

- Work stress: "Time & lack of time trade offs"
- Patient difficulty: "Keep calm and carry on"
- Workshops: "A little of everything"



Integrated Approach to Fertility Care



Bolvin J et al. Hum. Reprod. 2012;27:941-950

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human reproduction

TABLE 9.1
Items With Meta-Analytic *R*s That Are Generalizable Across Organizations

Item	Turnover	Customer	Productivity	Profit
Know what is expected	x	x	x	x
Materials and equipment	x	x	x	x
Opportunities to do what I do best	x	x	x	x
Recognition/praise	o	o	o	x
Cares about me	x	x	x	o
Encourages development	o	x	o	x
Optimistic about	o	x	x	x
Mission/purpose	o	o	x	x
Commitment—quality	x	o	x	x
Best friend	x	x	o	x
Talked about progress	o	o	o	x
Opportunities to learn and grow	x	x	x	x

Notes: o = Positive, generalizable relationship.
x = Strongest generalizable relationships.

TABLE 9.2
Probability of Business Unit Success as a Function of Employee Engagement

Employee engagement Percentile	Success rate (within companies) ^a	Success Rate (across companies) ^b
99	75%	78%
95	67%	71%
75	57%	59%
50	50%	50%
25	43%	41%
5	35%	39%
1	27%	32%


^aSuccess rate (within) = percentage of business units with composite performance above the median of business units within a company.
^bSuccess rate (across) = percentage of business units with composite performance above the median of business units across companies.

11

Corey et al. 2003


Conclusions

- **Discover interchange psychology-medicine**
 - Psychology responds to innovations...
- **Learn the Integrated Approach to Infertility Care (IPA Care)**
 - ...but innovations create need
- **Describe what is required to take into account clinic issues for compliance and patient quality of life**
 - More attention needs to be devoted to staff needs in fertility clinics and how best to address them
- **Identify work stress and patient difficulty in interactions between staff and patients**
 - Time trade offs and need to deliver service despite demanding context important challenges for fertility staff
- **Identify potential impact of taking into account clinic issues**
 - Threats and potential benefits of addressing challenges needs to be identified

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- E.A.F. Dancet, W.L.D.M. Nelen, W. Sermeus, L. De Leeuw, J.A.M. Kremer and T.M. D'Hooghe. The patients' perspective on fertility care: a systematic review. Human Reproduction Update. 2010;16 (5):467-8

Cardiff Fertility Studies 



Tackling the burden of ART: A practical guide for clinical staff


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Guidelines and then: how to implement psychosocial care in daily practice


Dr. Nathalie Vermeulen
(ESHRE - Belgium)

Learning objectives: Key question?

- What are clinical guidelines?
- How does ESHRE develop guidelines?
- What is implementation?
- An implementation strategy
- Implementation strategy: an example
- Implementation strategy: first experience
- Implementation of the guideline on psychosocial care: challenges and tailored approach



No conflicts of interest to disclose.



What are clinical guidelines?

Systematically developed statements to assist care providers and patient in making decisions about appropriate health care for specific clinical circumstances



Field & Lohr 1990



What are clinical guidelines?

- Statements including recommendations
- Intended to optimize patient care
- Informed by a systematic review of evidence
- Assessment of benefits and harms of alternative care options

RKM, 2011 Clinical practice guidelines we can trust (report).



What are clinical guidelines?

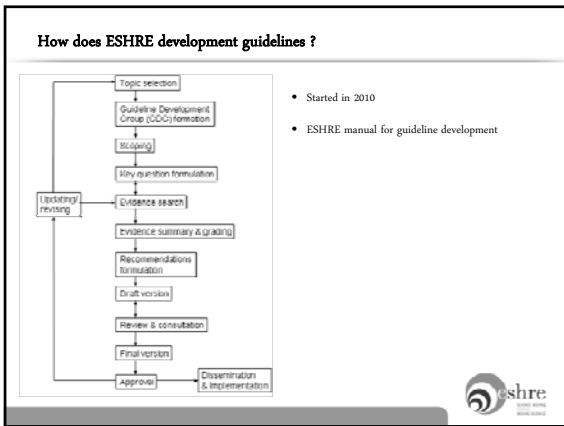


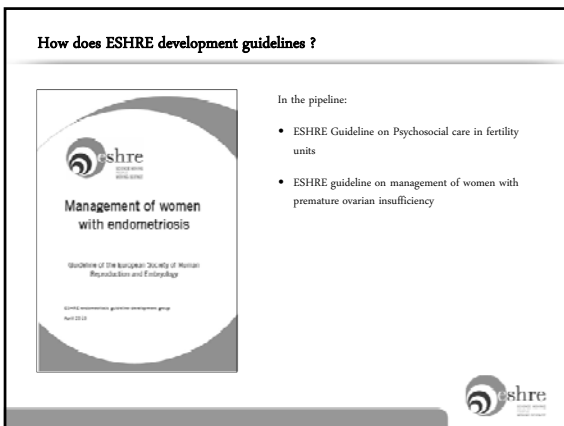
Decrease variation in care + Increase efficiency of care



Improvement quality of care







What is implementation?


Implementation: the act of implementing or putting into effect

Guidelines are not self implementing

OR

It was not enough to produce satisfactory soap, it was also necessary to induce people to wash.


How do you get people to use the guideline?



Joseph Schampeter, 2009 | Sholekh et al. Implementation Science 2012

Implementation?


- 30–40% of patients do not receive care based on available scientific evidence
- 20–25% of provided health care is unnecessary



McGlynn et al. 2003 N Engl J Med *Gen. 2001 Med Care*


Implementation?

We need a...



There is not 1 implementation strategy or 1 implementation tool with a guarantee for success

Implementation requires a tailored approach




An implementation strategy

- *Relatively little research evidence about how guideline developers should improve implementability*
- *If guideline developers wish to enhance the implementability of their guidelines then current best practice suggests that developers use strategies to support guideline uptake*

Strategies to support guideline uptake


- *Widespread identification of potential barriers to recommendations, and a priori generation of solutions to address them by the guideline development group. At a minimum the guideline group should be aware of the potential barriers*
- *Use of behaviorally specific language in the guideline*
- *Use of multiple formats and channels for guideline dissemination based on preferences of the target group of health care practitioners*
- *Development of educational resources adapted in content, and vehicle to each target group of health care practitioners*
- *Identification of the resource implications of recommendations, ensuring their availability before starting*
- *Use of data collection tools (for example, simple audit templates)*



Shadish et al. Implementation Science 2012 7:62

An implementation strategy

1. Pre-emptive identification of potential barriers of recommendations and a priori generation of solutions to address them by the guideline development group.
2. Use of behaviorally specific language in the guideline
3. Use of multiple formats and channels for guideline dissemination based on preferences of the target group of health care practitioners
4. Development of educational resources adapted in content, and vehicle to each target group of health care practitioners
5. Identification of the resource implications of recommendations, ensuring their availability before starting
6. Use of data collection tools (for example, simple audit templates)

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Coghlan et al. Implementation Science 2011, 7:26


An implementation strategy

1. Pre-emptive identification of potential barriers of recommendations and a priori generation of solutions to address them by the guideline development group.

HOW ?

Questionnaire for the guideline development group:

- Which are potential barriers of each recommendation?
- Which are potential facilitators?

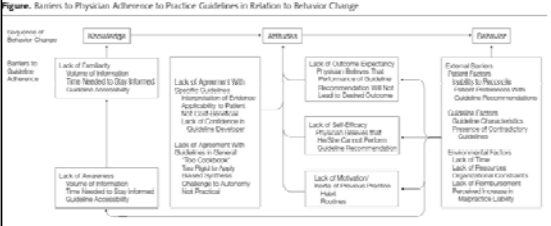
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Coghlan et al. Implementation Science 2011, 7:26

An implementation strategy


Which are potential barriers of each recommendation?

Figure. Barriers to Physician Adherence to Practice Guidelines in Relation to Behavior Change



The diagram illustrates the following components:

- Barriers to Behavior Change:**
 - Knowledge:**
 - Lack of Familiarity: Source of information, Time Needed to Stay Informed, Guidance Accessibility
 - Lack of Awareness: Source of information, Time Needed to Stay Informed, Guidance Accessibility
 - Attitudes:**
 - Lack of Agreement with Specific Guidance: Applicability of Patient, Not Used/Ineffective, Lack of Confidence in Guideline Developer
 - Lack of Agreement with Guidelines in General: Backlash to Overall "Too Confusing", Inherent Systems, Challenge to Authority, Not Practical
- Attitudes (continued):**
 - Lack of Outcome Expectancy: Physician Believes That Performance of Outcome Recommendation will Not Lead to Desired Outcome
 - Lack of Self-Efficacy: Physical/Intuitive Input, Has/Has Not Pretest, Guideline Recommendation
 - Lack of Motivation: Inertia, Involvement, Positive, Routine
- Facilitator:**
 - External Barriers: Support Factors, Feasibility to Practice, Patient Performance over Guideline Recommendations
 - Guideline Factors: Guideline Translatability, Presence of Contradictory Guidance
 - Environmental Factors: Lack of Time, Lack of Resources, Organizational constraints, Lack of Reinforcement, Personnel Increase in Response Liability

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SOUTH AFRICAN HEALTH SERVICES RESEARCH

Chikwe MD, et al. JAMA. 2009 Oct 22;302(15):1458-65.

An implementation strategy

Which are potential barriers of each recommendation?


Types of barriers – 4 categories:

Barriers related to the "professional"

- Attitudes/ believes of the clinician
- Skills/knowledge of the clinician
- Lack of agreement with the guideline
- Inertia of previous practice
- Lack of Outcome Expectancy, disbelieve in significant outcome change

Barriers related to the "guideline"

- Guideline is difficult to use,
- Recommendations not identifiable
- Recommendations don't contain a specific and unambiguous action
- Recommendations are not concise,
- Recommendations don't contain sufficient information as which patients and in which conditions they should be applied



Cabana MD, et al. JAMA. 1999 Oct 20;282(15):1458-65.

An implementation strategy

Which are potential barriers of each recommendation?


Types of barriers – 4 categories:

Barriers related to the "patient"

- Recommendation does not reconcile with the patient preferences
- Patients may be resistant or perceive no need for guideline recommendations
- Patient may perceive the recommendation as offensive or embarrassing

Barriers related to the "environment"

- External factors related to the system
- Acquisition of new resources or facilities
- lack of a reminder system, lack of counseling materials
- insufficient staff or consultant support
- poor reimbursement
- increased practice costs, and increased liability
- lack of time



Cabana MD, et al. JAMA. 1999 Oct 20;282(15):1458-65.

An implementation strategy

1. Pre-emptive identification of potential barriers of recommendations and a priori generation of solutions to address them by the guideline development group.

Which are potential facilitators?

Barriers related to the "professional"


Barriers related to the "guideline"

Barriers related to the "patient"

Barriers related to the "environment"

Facilitators, depending on the barriers

- a patient version of the guideline
- option grid to ease decision-making
- addition of pictures, video-material
- educational material
- meeting, courses
- clinical audit and feedback
- ...



Cabana MD, et al. JAMA. 1999 Oct 20;282(15):1458-65.

An implementation strategy

2. Use of behaviourally specific language in the guideline

Summary points

Psychological research shows that the more precisely behaviours are specified, the more they are likely to be carried out

Rewriting guidelines to increase behavioural specificity may be the simplest, most effective method of increasing implementation

Specifying what, who, when, where, and how will assist implementation

Behavioural analysis of the controlling antecedents and consequences of implementation may help develop effective interventions

Michie S, Lester K. *BMJ* 2004; 287(633): 345-345

An implementation strategy

2. Use of behaviourally specific language in the guideline

- To determine whether writing clinical guideline recommendations in behaviourally specified "plain English" language increases the likelihood of their implementation by service users (patients)

Table 1 Examples of text taken from original NICE guidelines in comparison with behaviourally specific "plain English" text

Original text	Behaviourally specific text
...if you are psychologically unwell, you will need support. If you do not have psychological support, this may lead to further health problems. You should discuss which medicine is best for you with the help of your doctor.	...if you are psychologically unwell, you will need to have psychological support. You should discuss which medicine is best for you with the help of your doctor.
It is also particularly useful if you have been prescribed that much and you are finding it difficult to take. You should discuss with your doctor which medicine is best for you with the help of your doctor.	It is also particularly useful if you have been prescribed that much and you are finding it difficult to take. You should discuss with your doctor which medicine is best for you with the help of your doctor.
...if you are psychologically unwell, you will need support. If you do not have psychological support, this may lead to further health problems. You should discuss which medicine is best for you with the help of your doctor.	...if you are psychologically unwell, you will need to have psychological support. You should discuss which medicine is best for you with the help of your doctor.

Table 2 Means (SD) when test text statistics for negative predictors in 11 function of test version (n=42)

Scale and points	intervention text	original text	difference (SD)	P (test)	OR (95% CI)
Number of words in text	124 (21.1)	122 (20.8)	2.0 (0.19)	0.02	0.32**
Words per sentence	6.26 (1.75)	6.41 (1.85)	-0.15 (0.21)	0.75	0.20**
Number of words per sentence	1.81 (0.45)	1.82 (0.56)	-0.01 (0.27)	0.98	0.98**

OR, odds ratio; CI, confidence interval; SD, standard deviation; P, probability of implementation.

Michie S, Lester K. *Qual Saf Health Care* 2005; 14:367-370.

An implementation strategy

3. Use of multiple formats and channels for guideline dissemination based on preferences of the target group of health care practitioners

Standard publications

- full-length version are posted on the ESHRE Website
- publication in Human Reproduction
- inclusion on the National Guidelines Clearinghouse's Website.

Additional publications

- patient version
- online version of the guideline

An implementation strategy

3. Use of multiple formats and channels for guideline dissemination based on preferences of the target group of health care practitioners

Announcements

- announcement in "Focus on Reproduction"
- a newflash on the ESHRE website's homepage
- a news item in the monthly digital ESHRE newsletter
- specific guideline session at the annual ESHRE meeting
- all related National Societies are separately informed about the guideline release
- all appropriate remaining stakeholders - for instance, European policy makers, patients societies and industry representatives - will be separately informed.



An implementation strategy

4. Development of educational resources adapted in content, and vehicle to each target group of health care practitioners

- Informational or educational resources for patients/caregivers
- Tools / Questions for clinicians to facilitate discussion
- Decision aids to support patient involvement:



An implementation strategy

4. Development of educational resources adapted in content, and vehicle to each target group of health care practitioners

Option Grids

- Options more visible and
 - Clinicians found it easier to undertake shared decision making
- ⇒ enhance patients' confidence and voice, increasing their involvement in collaborative dialog.

Treatment option	Benefits/risks	Side-effects
Mastectomy	There is no difference between mastectomy and lumpectomy in terms of survival.	There is no difference between mastectomy and lumpectomy in terms of survival.
Lumpectomy	There is no difference between mastectomy and lumpectomy in terms of survival.	There is no difference between mastectomy and lumpectomy in terms of survival.

Case 2 A 50 years old woman with breast cancer.
This patient used an Option Grid to compare mastectomy to lumpectomy (conservation surgery with radiotherapy). She noticed the difference in the local cancer recurrence rate, observing that it was double in lumpectomy. She was also alerted to the side-effects of radiotherapy, such as breast tenderness and shrinkage. These issues were important to her decision.




Byrne, G., et al. Patient Educ Couns 2015; 91(2): 207-212


An implementation strategy

5. Identification of the resource implications of recommendations, ensuring their availability before starting

Anticipated changes, resources and competencies required to adapt and accommodate guideline utilization

- Technical
- Regulatory
- Human resources
- Professional
- Workflow
- Costs


Environmental barriers




An implementation strategy

6. Use of data collection tools (for example, simple audit templates)

- Development of quality indicators
 - *The first quality indicator: there should be evidence in the medical record that the patient's current emotional well-being was assessed within 1 month of the patient's first visit with a medical oncologist.*
 - *The second quality indicator stipulates that, if a problem with emotional well-being was identified, there is evidence in the patient's medical record that action was taken to address the problem or an explanation is provided for why no action was taken.*
- Performance of the indicators
 - 1st indicator: ranged from 12% to 86% across sites (median, 47%). (13% of patients)
 - 2nd indicator: 13% to 100% (median, 57%).
- Providing feedback about the quality of psychosocial care (QOPI)

	T0	12 months later	
1st indicator	64%	73%	P .001
2nd indicator	74%	76%	P .41





Jacobson and Wagner. Journal of clinical oncology. 2012;30(11):1244-8.

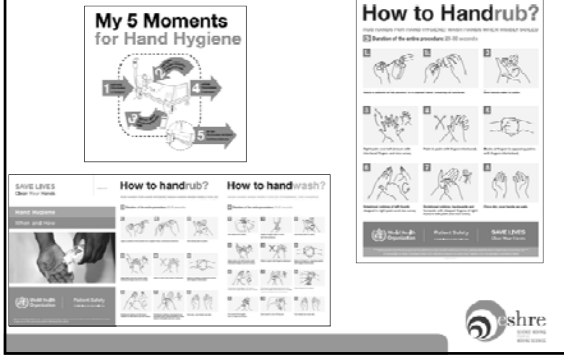
Implementation strategy: Example

WHO hand hygiene guidelines

- Full guideline and summary document
- Action plan for implementation
- Tools for system change:
 - Guide to implementation
 - Material for reproducing, adapting and translating WHO hand hygiene illustrations
- Tools for education
 - Slides for education
 - Training films
- Tools for evaluation and feedback
 - Soap/Handrub Consumption Survey
 - Questionnaire on knowledge of hand hygiene
- Tools as reminders at the workplace

Implementation strategy: Example
WHO hand hygiene guidelines



Implementation strategy: First experience
ESHRE endometriosis guideline

- Results of a questionnaire on barriers and facilitators
- Different versions of the guideline:
 - Text version
 - Online tool
 - Patient version
 - Option grid / decision-aid
 - ...



Implementation of the guideline on psychosocial care: challenges and tailored approach



Implementation of the guideline on psychosocial care: challenges and tailored approach

IMPLEMENTATION STRATEGY

1. **Pre-emptive identification of potential barriers of recommendations and a priori generation of solutions to address them by the guideline development group.**
2. **Use of behaviorally specific language in the guideline**
3. **Use of multiple formats and channels for guideline dissemination based on preferences of the target group of health care practitioners**
4. **Development of educational resources adapted in content, and vehicle to each target group of health care practitioners**
5. **Identification of the resource implications of recommendations, ensuring their availability before starting**
6. **Use of data collection tools (for example, simple audit templates)**



Coghlan et al. Implementation Science 2011, 7:26

Implementation of the guideline on psychosocial care: challenges and tailored approach

2. Use of behaviorally specific language in the guideline

- Who, what, when, where and how
- Scientific language, scientific evidence reporting

3. Use of multiple formats and channels for guideline dissemination based on preferences of the target group of health care practitioners

- full length version are posted on the ESHRE Website
- publication in Human Reproduction
- inclusion on the National Guidelines Clearinghouse's Website.

- patient version
- online version of the guideline

- Different announcements



Implementation of the guideline on psychosocial care: challenges and tailored approach

4. Development of educational resources adapted in content, and vehicle to each target group of health care practitioners

- Decision aids to support patient involvement
 - Presentation/ leaflet to aid in raising awareness of the guideline
- ⇒ Depends on barrier analysis

5. Identification of the resource implications of recommendations, ensuring their availability before starting

- 6. Use of data collection tools (for example, simple audit templates)**
- ⇒ Study implementation




Implementation of the guideline on psychosocial care: challenges and tailored approach

1. Pre-emptive identification of potential barriers of recommendations and a priori generation of solutions to address them by the guideline development group.

Literature search for barriers / facilitators

- ⇒ Some evidence exists on:
 - ⇒ Guidelines on psychosocial care for cancer patients
 - ⇒ Guideline on psychosocial care after disasters, terrorism and shocking events
 - ⇒ Guideline on dementia
 - ⇒ Could this be extrapolated to psychosocial care in fertility units?

Survey for guideline group members



Implementation of the guideline on psychosocial care: challenges and tailored approach

Barriers related to the "professional"


- Knowledge
- Attitude
- Values
- Self-efficacy
- Communication skills
- Time

⇒

Facilitators could be...

- Training of clinicians (basic psychosocial care, communication skills)
- Integration of psychosocial care in student education
- Provide leaflet with key information, for instance results of a survey among patients expectations, needs
- Feedback system, system of rewards
- Reminders

Schofield P, et al. *Psycho-oncology* 2006; 15(10):863-872



Implementation of the guideline on psychosocial care: challenges and tailored approach

Barriers related to the "guideline"

- Language
- psychology – clinicians barrier
- Dissemination
- Confidence
- Lack of high quality evidence


Additional barriers from analysis using the GLIA tool

⇒

Facilitators could be...

- Include clinicians in GDG and review
- Rigorous methodology
- Organize meeting, courses

Schofield P, et al. *Psycho-oncology* 2006; 15(10):863-872



Implementation of the guideline on psychosocial care: challenges and tailored approach

Barriers related to the "patient"

- Attitudes
- Patients resistant to diagnosis and treatment
- perceiving testing as unethical for undocumented patients,
- questionable relevance of pre-test counseling,
- lack of expertise in discussing sexuality,
- language barriers,
- lack of time
- 'in denial'
- Stigma and resistance

Facilitators could be...

- Patient version of the guideline
- Tools for increasing awareness among patients
- Combining visits for medical and psychosocial care

Southern Health Research Ethics

Schiefel P, et al. 2006. *Maitland L, et al. AIDS Educ Prev* 2012

Implementation of the guideline on psychosocial care: challenges and tailored approach

How do patient feel about the guideline and recommendations ?

Psychosocial items	Patients'		HC (V, nurses)		Association between items: Pearson's chi-square (2x2 test)
	Rank (No. of respondents)	Rank (No. of respondents)	% of respondents	Rank (No. of respondents)	
The doctor leads a normal life with all his responsibilities and concerns regarding work and treatment	1,176 (200/346)	4,275 (42/118)	96.12 (70)	4,466 (71)	2.046
A woman has enough time to discuss everything that is important for her with her doctor	2,245 (224/346)	4,277 (42/118)	25.16 (70)	4,467 (71)	2.046
There are opportunities for women to discuss questions about their diagnosis or treatment	1,475 (172/346)	4,278 (42/118)	45.16 (70)	4,468 (71)	1.046
A doctor takes a woman and offers her a gentle introduction on all the challenges and difficulties of different types of treatment	4,466 (207/346)	4,279 (42/118)	25.16 (70)	4,469 (71)	2.046
Doctors collaborate or communicate a doctor with a woman about any side effects she is experiencing	2,246 (208/346)	4,280 (42/118)	35.16 (70)	4,470 (71)	3.046
A doctor offers to a woman about any concerns she may have about the chances of the cancer coming back	4,467 (209/346)	4,281 (42/118)	35.16 (70)	4,471 (71)	3.046
Doctors have clear to discuss the way a woman might impact on her life, and how they might feel and respond to side effect treatments	1,177 (190/346)	4,282 (42/118)	75.16 (70)	4,472 (71)	4.046
A woman is asked about her sexual history and how she might feel - her thoughts and feelings about sex	4,468 (191/346)	4,283 (42/118)	15.16 (70)	4,473 (71)	5.046
A doctor asks about any concerns women have about how to prevent lymphedema (swelling in the arm)	4,469 (192/346)	4,284 (42/118)	15.16 (70)	4,474 (71)	6.046

Southern Health Research Ethics

Lam WW, et al. *Supportive care in cancer* 2006; 17(3):219-228

Implementation of the guideline on psychosocial care: challenges and tailored approach

Barriers related to the "environment"

- Time
- Role definition
- Lack of assessment systems
- Lack of private interruption-free consultation spaces
- Lack of appropriate allied health professionals for referral
- Lack of quality information resources

Facilitators could be...

- Information for clinicians
- Easy, quick, rapidly available tools
- Proposal for psychosocial care should be sustainable and cost-effective

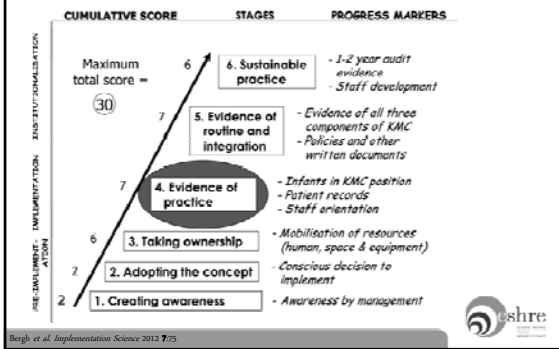
Southern Health Research Ethics

Schiefel P, et al. *Psychosomatics* 2006; 15(4):563-572

Implementation of the guideline on psychosocial care: challenges and tailored approach



Model for progress monitoring



Implementation of the guideline on psychosocial care: challenges and tailored approach



Take home message



Knowing is not enough; we must apply.
Willing is not enough; we must do.

Johann Wolfgang Von Goethe (1749 – 1832)



Do you have any remarks or input on the implementation of the guideline on psychosocial care in fertility units ?

Do you want to be invited as reviewer of the guideline ?

Please contact me:

Dr. Nathalie Vermeulen
Research specialist

Telephone (ESHRE central office): + 32 (0)2 269 09 69
E-mail: nathalie@eshre.eu



Patients' and professionals' barriers and facilitators of tailored expectant management

N.M. van den Boogaard, M.D.

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Conflict of interest

- None

Learning objectives

- Tailored expectant management (TEM) in reproductive medicine: Who, how and why?
- Risk factors for non-adherence to TEM
- Qualitative study on patients' and professionals' barriers and facilitators of TEM
- Nationwide survey of impact of the barriers and facilitators on:
 - Patients' appreciation of TEM
 - Professional' adherence to TEM
- RCT to test implementation strategy: Improvement Study

Tailored Expectant Management

Expectant management for 6-12 months in subfertile couples with unexplained or male subfertility and a chance of natural conception of >30% per year

ESHRE, NICE fertility guidelines:

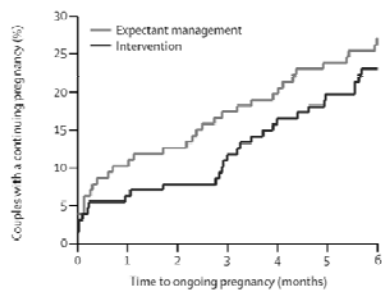
- Each couples should receive information about their chances on a spontaneous conception
- Patients should not be exposed to ineffective treatment

Dutch Fertility guidelines:

Couples with unexplained or male subfertility and a chance of natural conception of >30% \implies Expectant management 6-12 months

Tailored expectant management, who?

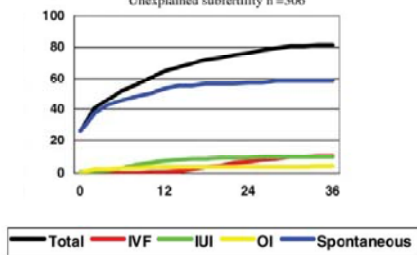
Couples with unexplained or male subfertility and an intermediate chance of natural conception



Steures Lancet 2006

Tailored expectant management, who?

Unexplained subfertility n=306



Brandes et al. HR, 2010

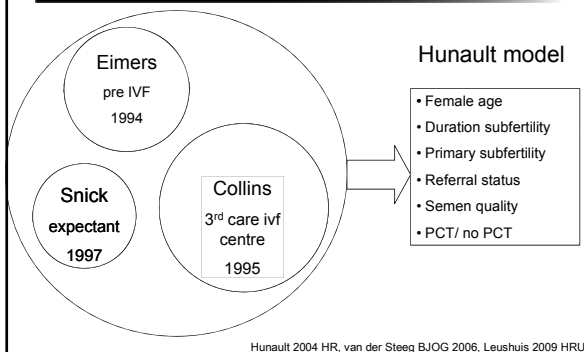
Tailored expectant management, how?

Prediction models can help to differentiate between couples who need treatment from couples who are likely to conceive spontaneously ^{1 2 3 4}

After the fertility work up, 30-40% of the couples is eligible for TEM for 6-12 months ⁵

1: Hunault 2004 Human Reproduction, 2: Steures 2004 Fertil Steril, 3: Templeton 2000 Ann N Y Acad Sci
4: Leushuis 2009 Human Reproduction Update 5: van der Steeg 2007 Human Reproduction

Prediction natural conception



Tailored expectant management, why?

- Prevention unnecessary treatment and its' complications
- Cost effective



Poor implementation

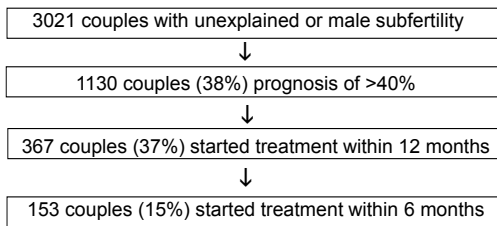
Implementation TEM is poor, estimated overtreatment 35'

- Implementation study on the barriers and facilitators of TEM to gain insight and improve implementation

1: van den Boogaard 2011 Human Reproduction

Risk factors for non-adherence to TEM

Multi centre prospective cohort study
Study protocol advised TEM if prognosis >40%



van den Boogaard et al. 2011 Human Reproduction

Risk factors for non-adherence to TEM

PATIENT CHARACTERISTICS	Treatment within 6 months n=153 (15%)	
	OR	95% CI
Mean maternal age (per year older)	1.06	1.01 to 1.1
Mean duration of subfertility (per year longer)	1.37	1.1 to 1.8
History ≥1 live birth	0.99	0.65 to 1.5
History ≥1 miscarriage	1.54	0.93 to 2.6
Socio Economic Status (%)		
High	0.88	0.53 to 1.5
Low	0.99	0.59 to 1.6
CLINICAL CHARACTERISTICS		
Fertility meeting (yes)	0.84	0.52 to 1.36
Fertility doctor (yes)	0.62	0.39 to 0.99
Clinic with IVF-ICSI license (yes)	0.89	0.47 to 1.7
Clinic with Satellite IVF (yes)	1.43	0.89 to 2.3

van den Boogaard et al. 2011 Human Reproduction

Qualitative study

- Semi structured in depth interviews with 21 subfertile patients counselled for TEM
- Focus-group interviews with 21 professionals in the field of reproductive medicine

Interviews:

- Patients could choose the location (hospital or home)
- Preferred to interview the couples separate
- Topic list based on literature, adapted after each interview
- Until data saturation
- Audio taped and fully transcribed

van den Boogaard et al. 2011 Human Reproduction

Qualitative study

Analyses

- 2 researches
- Open coding > axial coding > selective coding
- Codes compared and discrepancies discussed
- Maxqda

Results qualitative study – patients (1)

Barrier: Lack of confidence in the natural conception

“At that moment, that they sent us home to try it again ourselves I really thought: but we are already trying for such a long time, why would we succeed now? We did not come to the hospital to be sent home!”

Results qualitative study – patients (2)

Barrier:

Not informing the couple about the option of TEM during the first consultation

“If we would have known from the beginning that expectant management could be an option I could have changed my expectations and I would not have been so disappointed and sad.”

Results qualitative study – patients

Domain 1 Characteristics of the intervention	Domain 2 Characteristics of the professional	Domain 3 Characteristics of the patient	Domain 4 Characteristics of the context
Lack of confidence in the natural conception (b)	Not informing the couple about the option of TEM during the first consultation (b)	Inappropriate expectations prior to the first consult (b)	The length of time taken for the whole process (b)
Patient information material about prognosis and TEM (f)	Unclear way of counselling and communicating chances (b)	Misunderstandings the reason for TEM (b)	Practice in other clinics (b)
A perception that TEM is considered as a waste of time (b)	Not explicitly mentioning TEM, but conceal TEM in waiting period for treatment (f)	Overestimation of the success rates of treatment (b)	
Complexity of the prognostic model (b)		Inability to comprehend and retain information given during the consult (b)	
		Irrational interpretation of pregnancy chances (b)	
		Progressing female age (b)	
		Twin is a welcome complication (b)	

Results qualitative study – patients

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Results qualitative study – professionals (1)

Barrier:

Expectations of immediate treatment after the fertility work up

"If you take your time for the first consultation and explain the steps of the fertility work-up and all the options after the work up, including expectant management, you will save a lot of time, incomprehension, discussions and dissatisfied patients"

Results qualitative study – professionals (2)

Facilitator:

A regular Fertility meeting, a local protocol and local consensus

"When I have to decide on my own this couple needs an expectant management, I think the consult will end differently than when it was decided during a central fertility meeting. It feels more comfortable when it is discussed with the whole team"

Results qualitative study – professionals

Domain 1 Characteristics of the intervention	Domain 2 Characteristics of the professional	Domain 3 Characteristics of the patient	Domain 4 Characteristics of the context
Existing prognostic models do not include all the relevant predictors (b)	Limited knowledge about the prognostic models and subsequent TEM (b)	High expectations of success with treatment (b)	A regular Fertility meeting (f)
Lack of adequate patient information materials (b)	Difficulties convincing couples who have their minds made up (b)	Urgency for action in the couple (b)	Local protocol (f)
Not convinced about the usefulness of the prognostic models and TEM (b)	Difficulties in counselling and communicating chances (b)	Expectations of immediate treatment after the fertility work up (b)	Local consensus (f)
Explaining TEM takes time (b)	Comparison of treatment chances versus spontaneous pregnancy chances (f)	Couples' misinterpretation of chances (b)	Centralisation of fertility care (f)
	Close relationship with couple (b)	Progressing female age (b)	Regional organisation (f)
		Miscarriage population (b)	

Results qualitative study – professionals

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Conclusion qualitative study

Patients: 14 barriers and 2 facilitators were identified
Professionals: 14 barriers and 6 facilitators were identified

What is the impact of the barriers and facilitators on:
 - Patients' appreciation of TEM
 - Professional' adherence to TEM

⇒ Nationwide survey among patients and professionals

van den Boogaard et al. 2011 Human Reproduction

Nationwide survey

Methods:

- Two questionnaires were developed:
 1. Paper questionnaire for patients
 2. Online questionnaire for professionals

Questionnaires:

- Baseline characteristics
- Barriers and facilitators translated into statements
- Level of agreement per statement on 5 point likert scale
- Professionals: adherence to TEM on 10 point likert scale
- Patients: appreciation of TEM on 10 point likert scale
- Two reminders within 7 weeks



Methods (II)

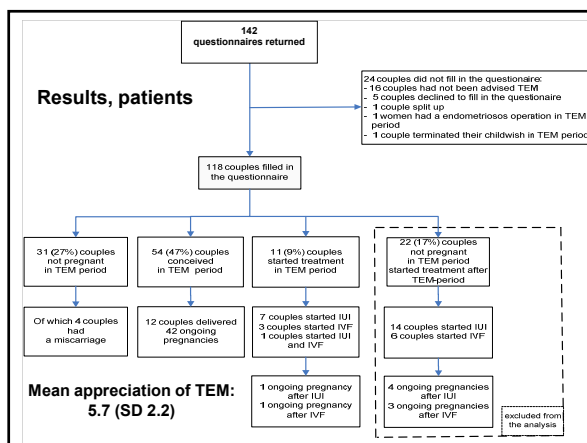
Invited population:

167 registered Dutch fertility physicians
195 subfertile couples who had been counselled for TEM

Analyses

- Per domain sumscore was tested for internal consistency
- Logistic regression analyses to identify association between baseline characteristics, the barriers & facilitators and patients' appreciation of TEM and professionals' adherence to TEM
- Backward selection method, $P < 0.15$

Results, patients



Percentage of couples that perceive this as a barrier (b) or facilitator (f)	Couples n= 96
Lack of confidence in the natural conception (b)	85 (89%)
Knowledge of the factors used in the prognostic model (b)	75 (78%)
A need for more instructions about TEM period (b)	45 (47%)
A need for more information material about prognosis and TEM (b)	39 (41%)
Characteristics of the professional	
Preference for being informed about the option of TEM during the first consultation (f)	42 (44%)
Comparing spontaneous pregnancy chance with treatment (f)	29 (30%)
Unclear way of counselling and communicating chances (b)	9 (9%)
Characteristics of the patient	
Expected to get a cause for the subfertility (b)	84 (87%)
Expected to get treatment (b)	27 (28%)
Expected to get a cause for the subfertility and treatment (b)	19 (20%)
First reaction to prognosis and subsequent TEM: positive**	43 (45%)
negative**	28 (29%)
mixed feelings: happy and disappointed	66 (69%)
Understanding that with good prognosis, treatment was not indicated (f)	85 (88%)
Twin is a welcome complication despite the risks (b)	76 (79%)
Knowledge that good prognosis was reason for TEM (f)	74 (77%)
Inability to remember prognosis (b)	52 (54%)
Progressing female age (b)	52 (54%)
Longer duration of subfertility (b)	63 (66%)
Expected that with treatment >50% of all couples conceive (b)	43 (45%)
Expected to have a good spontaneous prognosis and not needing treatment (f)	36 (37%)

Association with reported appreciation of TEM

Multivariable association between the patients' appreciation of TEM and patient characteristics, barriers and facilitators	P- value
Domain of the intervention	
Need for patient information about prognosis and TEM, sum score	0.047
Domain of the professional	
Not informing the couple about the option of TEM during the first consultation	0.955
Comparing natural conception chance with treatment	0.124
Domain the patient	
Understanding that with good prognosis, treatment was not indicated	0.810
Domain of the clinic	
Practice in other clinics	0.463

Results, professionals

70% (117/167) professionals responded

Baseline characteristics	Professionals n = 117
Male (%)	39 (33%)
Age (mean, SD)	45 (9.7)
Years of experience (median, range)	11 (8.5)
Fertility doctors (%)	45 (39%)
University hospital	37 (32%)
Teaching hospital	55 (47%)
Non-teaching hospital	23 (20%)
Private clinic	2 (17%)
Self reported adherence to TEM (% , median)	63% (75)

Barriers & facilitators of Tailored Expectant Management	Percentage of Professionals that perceive this as a barrier
Domain of the intervention	
Missing factors in the prognostic models	40%
Not convinced about the prognostic models & TEM	29%
Use of the model takes time	16%
Domain of professional	
Forget to use the model	36%
Difficulties in counselling and communicating chances	18%
Limited knowledge about the prognostic models & TEM	17%
Close relation with the couple	16%
Not (always) have access to the model	13%
Treatment will generate income	0%
Domain of the patient	
Progressing female age	80%
Urgency for action in the couple	74%
Expectations' of immediate treatment after the fertility work up	59%
Miscarriage population	37%
Couples misinterpretation of chances	22%
Domain of the Context	
Regular fertility meeting	89%
Local protocol & consensus	89%
Centralisation of fertility care (clinic level / professional level)	72%
Electronic Patient File	58%

Barriers & facilitators of Tailored Expectant Management	Percentage of Professionals that perceive this as a barrier
Domain of the intervention	
Missing factors in the prognostic models	40%
Not convinced about the prognostic models & TEM	29%
Use of the model takes time	16%
Domain of professional	
Forget to use the model	36%
Difficulties in counselling and communicating chances	18%
Limited knowledge about the prognostic models & TEM	17%
Close relation with the couple	16%
Not (always) have access to the model	13%
Treatment will generate income	0%
Domain of the patient	
Progressing female age	80%
Urgency for action in the couple	74%
Expectations' of immediate treatment after the fertility work up	59%
Miscarriage population	37%
Couples misinterpretation of chances	22%
Domain of the Context	
Regular fertility meeting	89%
Local protocol & consensus	89%
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Association with reported adherence to TEM

Per domain sumscore showed internal consistency (Cronbach $\alpha > 0.7$)

Multivariable association between the professionals' reported adherence to TEM and the professional' characteristics, barriers and facilitators	P value
Professional and Clinical characteristics	
Type physician: fertility doctor	0.041
Regular seeing fertility patients	0.195
Local protocol	0.981
Local consensus	0.380
Fertility meeting	0.667
Sum score** barriers in the domain of the professional	0.008
Sum score** facilitators in the domain of the clinic	0.091
Interaction term fertility meeting * sumscore clinic	0.374

Conclusions nation-wide survey



- Patients' mean appreciation of TEM 5.7 (1-10 scale)
- Professional' self reported adherence to TEM was 63%

- A lower appreciation of TEM was associated with a need for patient information materials

- Professional being a fertility doctor increases the adherence to TEM
- Professionals experience most barriers in the patient domain
- The barriers in the professional domain are associated with a lower adherence to TEM


van den Boogaard et al. 2011 Human Reproduction

Implementation strategy

Implementation strategy addresses three levels:


- (1) Patient level: education materials: information leaflet & website
- (2) Professional level: audit & feedback, educational outreach visit, communication training, access to a digital version of prognostic model
- (3) Organizational level: local protocol

Primary outcome: percentage guideline adherence on TEM.



Improvement study  IMPROVEMENT

- Ongoing study
- Cluster randomised controlled trial
- 25 hospitals in the Netherlands
- Randomisation between implementation strategy and care as usual

- Primary outcome: will be the percentage guideline adherence on TEM.
- Cost effectiveness analysis

 **ZonMw** van den Boogaard et al. 2013 Implementation Science

Take home message

- Implementation of TEM is poor > 
- Implementation of TEM:
 - higher female age & longer duration of subfertility
 - if counselled by fertility-doctor instead of gynaecologist
- Low patient satisfaction of TEM is associated with need for more information about TEM
- Professional adherence to TEM is associated with type of doctor and with barriers in professional domain (knowledge, counselling skills)
- A clustered RCT is testing a implementation strategy  IMPROVEMENT



HOW CAN MENTAL HEALTH PROFESSIONALS WORK WITH OTHER CLINIC STAFF TO IMPLEMENT PSYCHOSOCIAL SUPPORT?

SOFIA GAMEIRO, PHD

ESHRE Pre-Congress Course 6
London, 7th July 2013



Cardiff Fertility Studies
Research Centre for Reproductive Health

Conflict of interest (past three years)

- Honorarium and/or research funding from Merck-Serono S.A.

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Learning objectives

- Understand the rationale and goals of the New ESHRE Psychology & Counselling Guidelines
- Acknowledge the implications of the Guidelines in the provision of psychosocial support at fertility clinics
- Discuss ways of
 - Supporting other clinic staff in the deliverance of psychosocial support
 - Developing feasible interventions that can be integrated in routine care
 - Enhancing quality of care for everyone (patients, staff, clinic)

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New ESHRE Guidelines for Psychology and Counselling in Infertility

- Best practice advice on how to **incorporate psychosocial care in routine infertility care** to the **benefit of patients and health care providers** in the field of infertility and Medically Assisted Reproduction
- **Key-moments across the patients' treatment pathway** at which psychosocial care can/should be provided



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Recommendations focus on

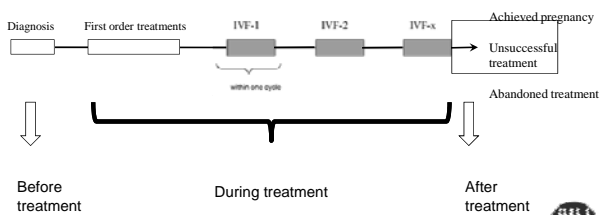
- Which **characteristics of the fertility staff and clinic** are associated with patients' satisfaction with care provided?
- Which characteristics of fertility staff and clinic are associated with patients' adjustment /wellbeing?
- Which **psychosocial care components (methods, techniques) are valued** by infertility patients?
- What are the **specific psychosocial needs of patients** before/during/after the treatment period?
- **How can fertility staff detect the needs** of patients before/during/after the treatment?
- **How should staff address the psychosocial needs** of patients before/during/after fertility treatment?

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Horizontal time-line

- Supporting the infertile patient (individual, couple) along ALL treatment stages



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Vertical approach

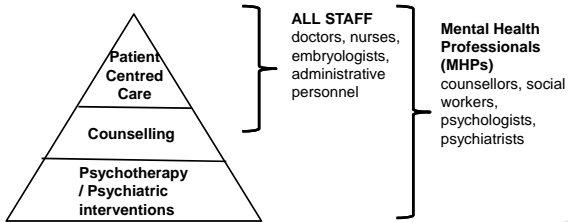
- Tailoring support to patient characteristics & needs
 - Adjustment
 - mental health, partnership, social relationships and work;
 - Awareness/knowledge about infertility & treatment
 - Concerns/worries about infertility & treatment
 - Behaviour related to infertility & treatment
 - e.g., compliance to treatment, smoking.



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Vertical approach

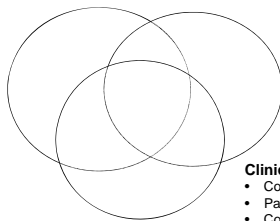
- Tailoring support to patient characteristics



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Enhancing care for everyone

- Patient**
- Pregnancy
 - Distress
 - Quality of life
 - Satisfaction with care
 - ...



- Staff**
- Quality of life
 - Job satisfaction
 - Burnout
 - ...

- Clinic**
- Cost-efficiency
 - Patient satisfaction
 - Compliance
 - ...



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(More) Team work within clinics

- Patients want to receive emotional support
 - From doctors and nurses during daily care
 - From specialized staff at emotional emergencies

Dancet et al., 2011. Human Reproduction, 26, 827-833.

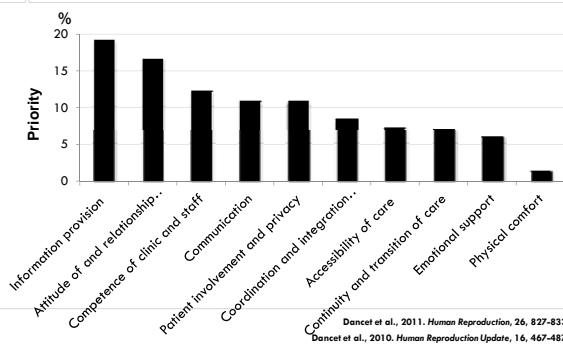


1. Educate about psychosocial issues
2. Develop information & educational materials
3. Offer training and provide feedback
4. Define responsibility limits of non MHP staff

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Increase awareness about patients preferences



Dancet et al., 2011. Human Reproduction, 26, 827-833;
Dancet et al., 2010. Human Reproduction Update, 16, 467-487.

Increase awareness about psychosocial issues

- Distressful aspects of treatment
 - e.g., disclosing intimate info
- Emotional reactions during treatment
 - e.g., the two week waiting period
- Patient reasons for discontinuing treatment
- How and when should treatment feedback be provided to patients and the potential impact of negative feedback
- Challenges of dealing with specific patient populations

Benyamini et al., 2005. Fertility & sterility, 83, 275-283

Boivin et al., 1998. Human Reproduction, 13, 3262-3267.

Gameiro et al., 2012. Human Reproduction Update, 18, 652-669.

Boivin, 2000. Proceedings of Social Science Research on Childlessness in a Global Perspective.

Nachtigall et al., 2009. Fertility & Sterility, 92, 116-123.

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Develop information & educational materials

- Only 48% of patients receive information about emotional support that is stipulated in national guidelines

Mourad et al., 2009. *Human Reproduction*, 24, 1420-1426.

- Information aspects identified by patients as important and problematic

- Written information
- Information on treatment alternatives
- Information on helping themselves
- Known plan for the future
- Information on emotional aspects of treatment

Dancec et al., 2010. *Human Reproduction Update*, 16, 467-487.



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Offer training in communication & interaction skills

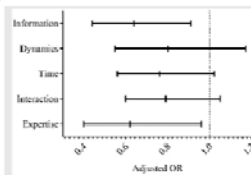
Training in empathic skills improves the patient-physician relationship during the first consultation in a fertility clinic

Dolores Garcia, B.S., Olga Baubista, B.S., Laura Vivero, B.S., David Gil, M.D., Ph.D., Rita Vazquez, D.V.M., Ph.D., and Valeria Vercano, M.D., Ph.D.
*Fertility Unit and Department of Clinical Psychology and Assisted Reproduction Clinic IVIR, Barcelona, Spain

- 13 physicians evaluated by 2146 patients

Training:

- 2 days = 14 hours
- Theoretic classes, audio visual materials & practical workshops
- Empathy, emotional intelligence, verbal and nonverbal communication, active listening, and behavioural styles



Likelihood of low scoring after the empathic training for all items, also adjusted odds ratio (OR) for low scoring physicians in the questionnaire. OR: 0.95%, CI: Information: 0.64 (0.44-0.94) Dynamics: 0.8 (0.55-1.17) Time: 0.78 (0.56-1.17) Interaction: 0.79 (0.5-1.05) Expertise: 0.62 (0.4-0.98)

Garcia et al., 2013. *Fertility & Sterility*.

Implement feedback procedures

- Visual feedback: tables, graphics, pictures
- As specific as possible: to the clinic, to the individual
'I would prefer to receive real and concrete examples. For instance, patients state that they want to have an overview of all their treatments . . . then you [researcher] can provide us with a good overview that we can use immediately.'
- Support with practical translation: improvement plan and execution
'They should visit the clinics after they've received the feedback report and provide them with the most efficient ways of improving the level of patient-centeredness. I would even pay for that service.'
- Remarks from patients are useful

Huppelchoten et al., in press. *Fertility & Sterility*.

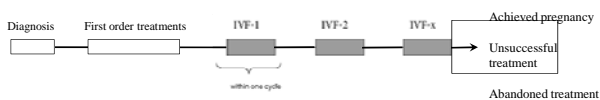
Define responsibility limits of non MHP staff

- Implement screening & referral criteria
 - Educate staff on how to use screening tools
 - Provide staff with a list of criteria for referral
- Facilitate access to MHPs
 - Provide clear instructions easily accessible for all patients
 - e.g., brochures/posters within the clinic or on website.
 - Assure the simplicity and privacy of the referral procedure
 - e.g., eliminate intermediaries
 - Establish early contact with patients
 - e.g., include meeting with MHP on first consultation

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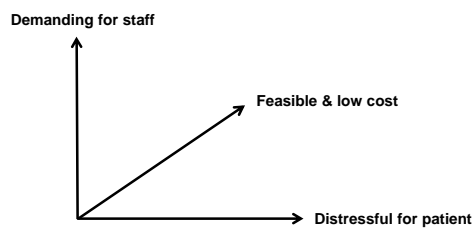


Develop new forms of intervention



1. Promote consensus about priorities for intervention
2. Develop feasible interventions tailored to patient & treatment stage
3. Investigate barriers to implementation of psychosocial support

Promote consensus about priorities for intervention



- E.g., communicating/receiving negative treatment results


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Develop **feasible** interventions tailored to patient & treatment stage

- Expert & patient consultancy
 - ▣ Multimedia psychosocial support program
 - *What is the viability of a CD-ROM at your setting?*
 - *What psychological issues are the most relevant and can be addressed by a CD-ROM?*
- Cousineau et al., 2004. *Fertility & Sterility*, 81, 532-538.
- Compare with other 'appropriate alternative' interventions
 - ▣ PRCI – A Positive Reappraisal Coping Intervention for the pregnancy waiting period

Lancastle & Boivin, 2008. *Human Reproduction*, 23, 2299-2307.
 - Usability & acceptance testing
 - ▣ SCREEN-IVF

Van Dongen et al., 2012. *Human Reproduction*, 27, 3493-3501.
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Investigate staff needs (speaker Boivin)

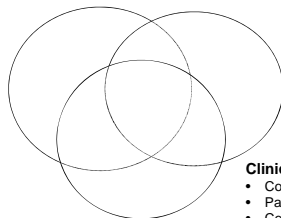
- Staff underestimate the importance patients attribute to Patient Centre Care
- Van Empel et al., 2011. *Human Reproduction*, 26, 584-593.
- Staff & patients evaluations of care differ
- Aarts et al., 2011. *Human Reproduction*, 26, 1119-1127.
- Staff perceive many constraints to the implementation of psychosocial support
 - ▣ Barriers: lack of time, pressure, change of regime, financial support...
 - ▣ Facilitators: committed team, own efforts lead to more PCC

Huppelschoten et al., 2013. *Fertility & Sterility*.

Enhancing care for everyone

Patient

- Pregnancy
- Distress
- Quality of life
- Satisfaction with care
- ...



Staff

- Quality of life
- Job satisfaction
- Burnout
- ...

Clinic

- Cost-efficiency
- Patient satisfaction
- Compliance
- ...



1. Evaluate costs and benefits of change

Evaluate costs and benefits of change


- Higher focus on staff outcomes
 - ▣ Quality of life, job satisfaction, burnout, time
- Investigate associations between patient, staff & clinic outcomes
- Benchmarking

'Transparency about clinics' performance is important . . . How is a clinic certificated? What are their results? We have to develop a quality label and put that on a clinic when it meets the criteria.'

Huppelschoten et al., in press. *Fertility & Sterility*
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Conclusion

- The new Guidelines aim to provide best advice on how to incorporate psychosocial care in routine infertility care
- MHPs can support other clinic staff in the provision of psychosocial care
 - ▣ Provide training & consultancy on how to implement care
 - ▣ Develop feasible interventions to be delivered by any member of staff
 - ▣ Address barriers to the implementation of psychosocial care
 - ▣ Consider how changes in the deliverance of care may affect everyone (patients, staff and clinic)

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Additional information

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How could doctors implement psychosocial care?

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Disclosure of potential conflicts of interest

- Honoraria and travel grants from Merck Serono S.A.
- Honoraria and consultation fees from IPSEN
- Travel grants from Merck, Sharp & Dome, Ferring S.A.

Learning objectives

- Understand the relationship between doctors and psychosocial care in modern practice
- Discuss the importance of psychosocial care in IVF
- Depict the problems of current practice in terms of delivering psychosocial care
- Explore the ways that doctors could provide psychosocial care to patients
- Describe the potential problems of implementing psychosocial care from a doctor's perspective

Doctors vs. Psychosocial care



Doctors vs. Psychosocial care

Common "misconceptions"...

Doctor = Physician → "A person licensed to practice medicine; a medical doctor"



Physical → "Of or relating to the body as distinguished from the mind or spirit"

www.thefreedictionary.com

Treat the organ/disease/condition



VS.

Treat the actual person



Doctors vs. Psychosocial care

...& other reasons

- Training in psychosocial care has been introduced in Medical School curricula relatively recently – Limited experience in this field

Novack et al.,

1993

- Many doctors do not have a good understanding of the term "psychosocial care" and what it entails

- Psychosocial care vs. Psychological care - provided upon request by others or (psychologists, psychiatrists, social workers)



ould be
doctors

What is “psychosocial care”?

The care that aims to cover the psychosocial needs of the patients:

- Emotional (stress, anxiety, depression)
- Social (spouse-partner, friends & family, work)
- Awareness/Knowledge (disease, treatment)
- Concerns/ worries (disease, treatment)
- Patient behaviour (lifestyle, exercise, nutrition etc.)

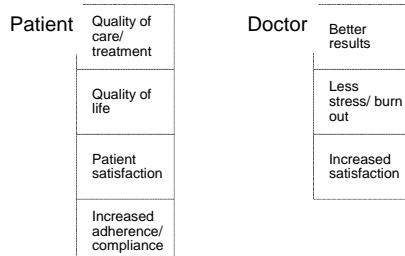
Is “psychosocial care” an integral part of medical care?

Quality of care

- **effective**, delivering health care that is adherent to an evidence base and results in improved health outcomes for individuals and communities, based on need;
- **efficient**, delivering health care in a manner which maximizes resource use and avoids waste;
- **accessible**, delivering health care that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need;
- **acceptable/patient-centered**, delivering health care which takes into account the preferences and aspirations of individual service users and the cultures of their communities;
- **equitable**, delivering health care which does not vary in quality because of personal characteristics such as gender, race, ethnicity, geographical location, or socioeconomic status;
- **safe**, delivering health care which minimizes risks and harm to service users.

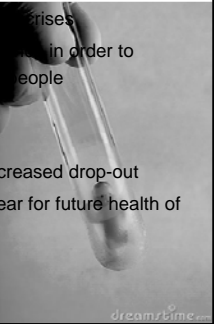
WHO, 2013

How important is “psychosocial care”?



“Psychosocial care” in IVF: challenges

- Infertility: one of the most traumatic life crises
- The notion of needing medical assistance in order to achieve what is only natural for most people
- Not one patient, but two !
- Costly, lengthy treatments
- High probability of cycle failure → increased drop-out
- High-tech treatment: Intimidating – fear for future health of self and offspring
- Ethical/ spiritual issues



Is there a deficit of psychosocial care in modern IVF practice?

Ask the experts

Patients

Subspecialists

Is psychosocial care in modern IVF practice important for patients?

- Systematic review of 51 studies in ART

Patients' satisfaction, experience and preference is also largely dependent on other aspects of treatment

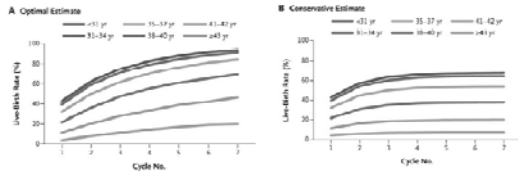
- 1) Access to care
- 2) Respect for patient's values, preferences, needs
- 3) Coordination and organization of care/ Continuity
- 4) Information, communication and education
- 5) Emotional support
- 6) Partner involvement
- 7) Physical comfort
- 8) Attitude of fertility clinic staff

These aspects were considered important and often problematic

Dancet et al., 2010

Is psychosocial care in modern IVF practice important for patients?

2004-2009: 471,028 ART cycles

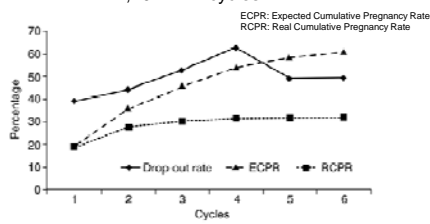


Adherence to the treatment plan maximizes live birth potential

Luke et al., 2012

Is psychosocial care in modern IVF practice important for patients?

4,102 ART cycles

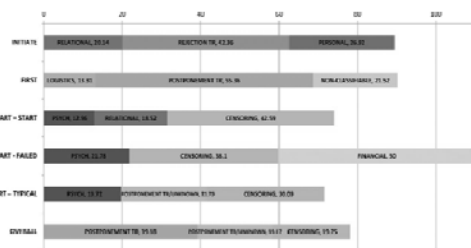


Dropping out has a substantial cost in terms of CPR

Schröder et al., 2004



Is psychosocial care in modern IVF practice important for patients?

Solving the riddle of drop-outs



Gameiro et al., 2012

Emotional needs of couples undergoing ART treatment

Not all patients have the same emotional needs

These emotional needs are different in the various stages of treatment

Emotional needs of couples undergoing ART treatment

Not all patients have the same emotional needs

- Most women seem to be able to deal effectively the burden of successive cycles
- Most women seem to adjust well, even to unsuccessful treatment, but still a considerable number develops **clinical relevant emotional problems** as a result of ineffective IVF

Emotional needs are different in the various stages of treatment

- Usually there is a lack of enhanced anxiety or depression before treatment
- The use of fertility drugs (injections) is a stressful period for women
- The 2-week period of waiting before the pregnancy test is probably the most stressful period for the patients
- The stress of the treatment is predominantly determined by the threat of failure
- IVF that results in pregnancy → negative emotions disappear

Verhaak et al., 2007

How can doctors offer psychosocial care to their patients?

Addressing emotional needs

- Communication skills are important !
- Listen to your patients! Encourage them to express their feelings!
- Empathy (*Garcia et al., 2013*)
- Actively screen for emotional maladjustment
- Use validated tools (SCREENIVF) and refer patients at high risk to specialists (*Verhaak et al., 2010*)

How can doctors offer psychosocial care to their patients?

Tips for good communication

- Greet the patient
- Introduce yourself
- Ask patient's name/ use patient's name
- Show approval or agreement
- Elicit feelings
- Do not interrupt/ encourage the woman to speak/ to keep talking
- Use good eye contact
- Used open posture



Leite et al., 2005

How can doctors offer psychosocial care to their patients?

Reducing stress/ anxiety

- **Use patient-friendly treatment regimens**
- 1) *Facilitate and/or reduce number of injections*
 - Pre-filled pen
 - GnRH-antagonist protocols (Devroey et al., 2009a)
 - Corifollitropin-alfa (Devroey et al., 2009b)
 - Non-injectable luteal phase support (van der Linder et al., 2011)
 - 2) *Use less drugs*
 - Mild stimulation protocols (Fauser et al., 2010)



How can doctors offer psychosocial care to their patients?

Reducing stress



Tailor the treatment protocol to each specific patient

How can doctors offer psychosocial care to their patients?

Relational strain/ Social consequences

- Build a monitoring/ treatment plan with minimal disruption of everyday activities
- Try to involve the partner as much as possible !
- Screen and treat the partner – Not only in male factor infertility !
- Offer counseling/ peer group support



How can doctors offer psychosocial care to their patients?

Addressing information needs

Type of information

- General information
- Information on diagnosis
- Information on treatment alternatives
- Treatment plan (including plan B in case of failure)
- Information on risks/ adverse events
- Information on helping themselves
- Information on emotional aspects of treatment (know what to expect)

Provision of information

- Written information (leaflets etc)/ Other media (video, animation etc)
- Avoid scientific jargon/ use layman's terms
- The right information for the right patient
- Sufficient time for discussion

Dancet et al., 2010

How can doctors offer psychosocial care to their patients?

Addressing concerns/worries

Allow patients to "digest" all the information provided

Give time

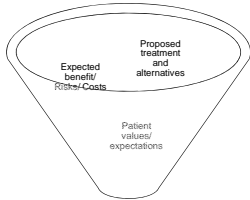
Ask patients

Ask them to bring forward any concerns/ worries regarding any aspect of the treatment

Provide answers

Address their concerns/worries in a sensitive manner and provide information/ offer contact with peers that could help

How can doctors offer psychosocial care to their patients?



Informed-Decision Making

Stewart et al., 2001

How can doctors offer psychosocial care to their patients?

Behavioural changes

Describe the importance of:

- Having a normal body-weight
- Not smoking
- Reducing alcohol consumption
- Exercising regularly
- Periconceptual folic acid uptake
- Complementary therapy/ Alternative treatments

NICE, 2004

Offer interventions/ programs that will help patients achieve their goals

How can doctors improve the psychosocial care offered to their patients?

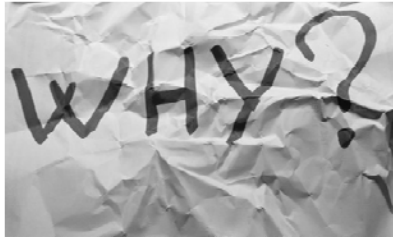
Review

Audit

Request for feedback/ Questionnaires



So, why doctors do not offer the level of psychosocial care their patients expect them to?



A doctor's perspective

- Not all doctors have been trained to incorporate psychosocial care in their practice
- Most doctors do not acknowledge a deficit in psychosocial care
- Not all doctors have the same interest in providing psychosocial care to their patients
- Not all doctors have the same communication skills
- Not enough time/ Workload
- The structure/ organization of the clinic does not ensure continuity of care and does not facilitate the provision of proper psychosocial care
- The view that "the patients ask too much/ are never happy"



Summary

- Many doctors do not quite understand what is psychosocial care
- Psychosocial support is a fundamental aspect of quality of care
- Infertility and IVF are characterized by specific challenges when it comes to implementing psychosocial care
- Most IVF doctors tend to underestimate their patients' psychosocial needs

Summary

- Doctors should try to address the emotional needs of their patients and facilitate their adjustment to infertility and IVF
- Actively screening emotional maladjustment and having a good communication with the patient is crucial
- Offering patient-tailored and patient friendly treatment regimens and allow the patient to make informed decisions
- Involve the couple – Not just the woman

Summary

- Address the patients' information needs by providing information regarding treatment, complications etc.
- Written information/ or use of other media in order to enhance understanding is advised
- Always ask patients to express their worries/ concerns and try to address them
- Ensure that the patient is making informed decisions
- Try to assist the patients in making behavioral changes that will help them achieve their goals

Summary

- Each and every practice should be evaluated for effectiveness and acceptability in regular intervals
 - Review
 - Audit
 - Patient feedback
- Proper training of physicians might allow them to detect their patients' psychosocial needs and facilitate provision of psychosocial care

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How could doctors implement psychosocial care?

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How to support patients in the waiting period?

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Registered Psychologist

Acknowledgment: Professor Jacky Boivin

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Conflict of interest

- I have no commercial relationships or other associations that could be perceived as a conflict of interest

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Learning Objectives

1. To learn about the psychology of waiting and its impact on psychological well-being
2. To understand the necessity to tailor interventions to the specific practical and psychological requirements of the situation
3. To explain the principles of coping theory, and illustrate how coping interventions may best serve the specific needs of patients during the waiting period

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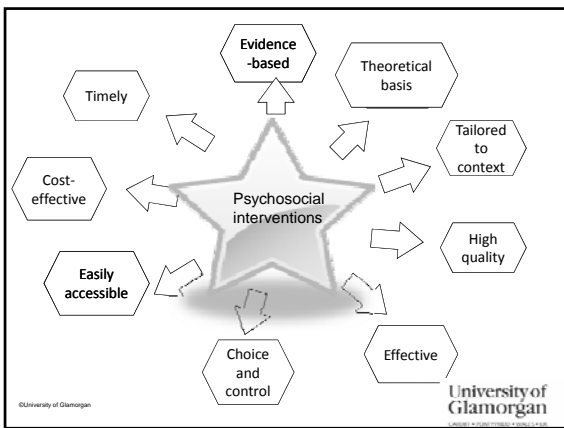
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Gold Standards for Psychosocial Intervention



Guideline on the implementation of psychosocial care by healthcare professionals in infertility and medically assisted reproduction

Framework for the design and evaluation of complex interventions (Campbell et al., 2005)



Important questions

- Why are medical waiting periods difficult?
- What are the psychological effects of waiting?
- What do we know about how people naturally manage during stressful events?
- Are some ways of coping likely to be more helpful than others?
- Can we promote or support ways of coping during medical waiting periods?

- *Should we be proactive rather than reactive when we know an experience will be difficult?*
- *Should a selection of early, self-help interventions be routinely available for all?*
- *Should people be introduced to new ways of coping during a difficult experience?*

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Medical waiting periods

- Waiting is a typical requirement of many medical encounters!
 - Waiting lists
 - Waiting to be put on a waiting list!
 - Waiting in a clinic waiting room for a consultation
 - ‘Watchful waiting’
 - Waiting for a period of time before a test to see if a condition has been cured/is in remission
 - Waiting for the results of a diagnostic test



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Waiting and Stress

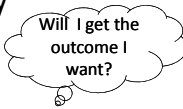
- Lazarus & Folkman (1984) propose a number of situation properties which can influence the experience of stress during *any* experience
- 3 apply particularly to medical waiting periods
 1. Uncertainty
 - Outcome, temporal
 2. Uncontrollability
 - Can the outcome be changed or controlled?
 3. Meaningfulness
 - The personal significance of the experience

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1. Uncertainty

- Waiting is characterised by uncertainty
- Uncertainty has an outcome dimension with anticipated emotional consequences
 - Positive outcome: Relief, joy, happiness, satisfaction
 - Negative outcome: Grief, bitterness, disappointment, anger, depression
- Uncertainty has a temporal dimension with associated emotional consequences
 - Until you know: Worry, anxiety, pessimism, optimism, eagerness, excitement
- Even within the context of infertility there are different temporal dimensions of waiting:



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Chronic uncertainty

- Uncertainty for infertile individuals can continue for a considerable period of time (e.g., will I ever conceive?)
- At some point they'll know the answer to this question
- For infertile women the final answer to the question is provided by the menopause
- An ongoing and unresolved stressor lasting perhaps 30 years

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Acute uncertainty

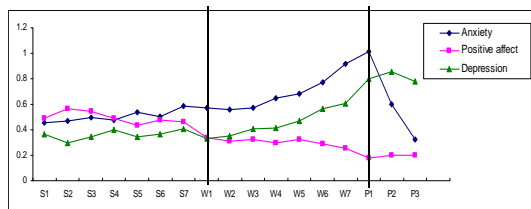
- Uncertainty can be discrete and time-limited (e.g., waiting for a pregnancy test after fertility treatment)
- You know the date when you will find out the outcome of a test or procedure
 - The waiting period is a 'countdown' to that day
- An expectable trajectory of emotional reactions as the day of the pregnancy test approaches:

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Psychological effects of uncertainty

Boivin & Lancastle (2010)



Stimulation phase Waiting period Pregnancy test +



9 of 61 women had a positive pregnancy test at P1 (14.75%)

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Psychological effects of uncertainty

- 'Bracing' for the possibility of a negative result
 - One strategy is to alter expectations downwards (e.g., Shepperd et al. 2006).
- Rumination over possibilities
 - Experience of actual and anticipated emotions associated with those possibilities
- Anticipating an imminent test result increased cognitive distraction and reduced recall of information about a medical test (Portnoy, 2010)
- Uncertainty is demanding, confusing and anxiety provoking
 - Can interfere with the cognitive processing needed to evaluate and employ effective ways of coping (Lazarus & Folkman, 1984).

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2. Uncontrollability

- The extent to which one can control an outcome in medical waiting periods depends on the relationship between the onset of the wait and the relevant biological processes
 - When waiting for surgery for coronary heart disease, action can be taken to improve the future outcome
 - After a breast biopsy for suspected breast cancer nothing can be done to change the test result as the disease is (not) already present in the sample
 - Embryo transfer is followed hopefully by implantation but the woman cannot control this. Should she
 - Rest?
 - Carry on as usual?

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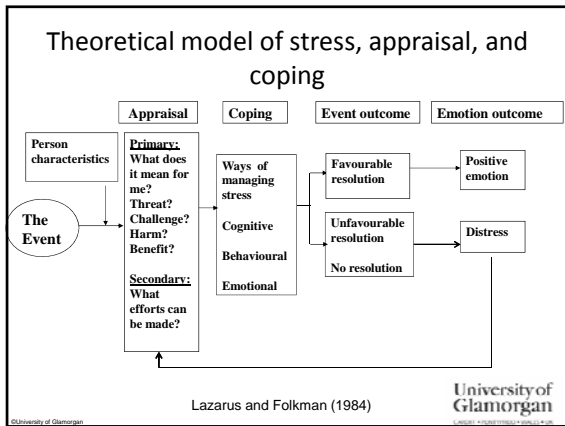
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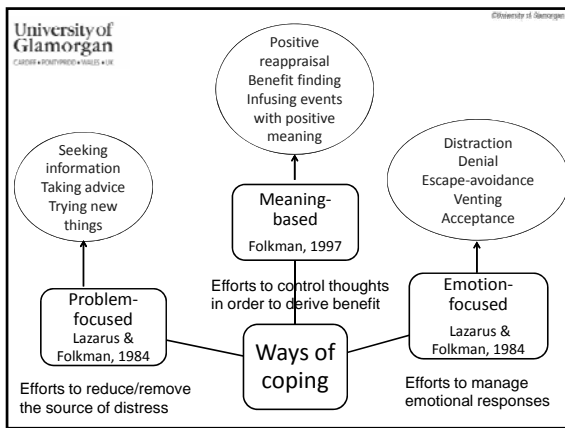
3. Meaningfulness

- The majority of medical waiting periods relate to a condition and/or outcome that is important to the individual
- Fertility treatment demands considerable investment
 - Physical
 - Financial
 - Time
 - Emotional
 - Relationship
- The costs are definite and can be considerable
- A poor outcome is distressing because of the personal significance
 - Repeated attempts are undertaken with prior knowledge of emotions associated with failed attempts

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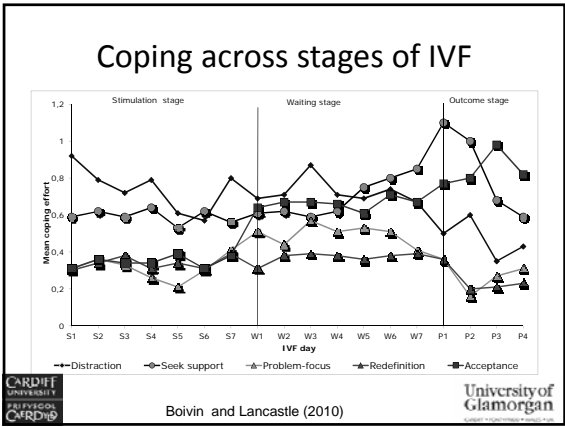


Coping effectiveness

Problem-Focused, Emotion-Focused, Meaning-Based: Which is best?

- Depends on the nature of the stressful event, whether constructive action is actually possible
 - The effectiveness is constrained by the situation (Goodness of Fit).
 - You cannot change or control every situation!
- The strategies can work together
 - Emotion-focused coping can relieve negative emotions in the short term, freeing up the resources needed to act
 - Problem-focused strategies can reduce negative emotions by removing the source of distress
 - Meaning-based strategies can reduce the emotional consequences of ruminating about negative possibilities

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Daily coping strategies occurring naturally during the IVF waiting period

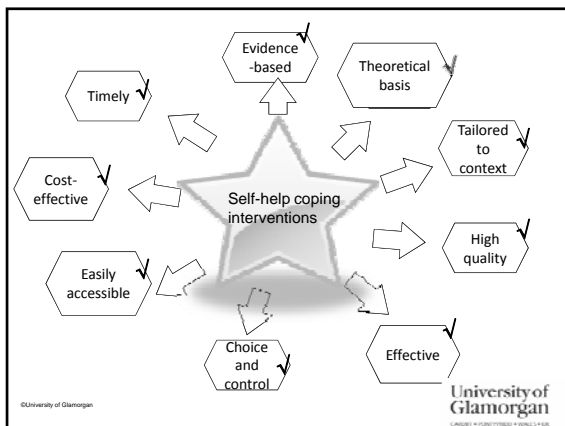
- **Distraction** – used the most until around the time of the pregnancy test
- **Social support** – increased towards the end of the waiting period and peaked on pregnancy test day
- **Positive reappraisal** – consistently low, despite evidence suggesting that it is beneficial
- Can we intervene to support/alter coping to make the waiting period more tolerable?

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Interventions

- Interventions for infertility have some benefits (Boivin, 2003)
 - Counselling (e.g., psychotherapy, infertility counselling)
 - Educational programmes focusing on individual or combined skills training (e.g., coping training, sex therapy, information provision)
- But the practicalities must be considered
 - Some are time intensive (e.g., 4-12 sessions of 45 minutes +)
 - Some take place in clinics (time off work and a special trip to clinic)
 - Administered by a trained professional (costly for NHS or patient)
 - Only 10-15% of infertile patients used the counselling provided by fertility clinics (Boivin et al., 1999)

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The PRCI (Positive Reappraisal Coping Intervention) (Lancastle & Boivin, 2008)

- Ten statements on a card
- Small, cheap to produce, and easily accessible
- Not prescriptive
- Focus on any positive aspects of a situation to minimise dwelling on possibilities
- Theoretically based; Items from validated coping instruments
- Well received by women (Lancastle & Boivin, 2008)

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

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Distraction-based coping intervention (Phelps, Bennett et al., 2006)

- Self-help distraction-based coping leaflet for waiting periods in cancer genetic risk assessment
- Think of your own techniques too and allow specific times to think about worries
- Cost-effective, easy to provide, simple to use, validated using MRC framework
- Effects moderated by distress; the highly distressed on referral reported significantly lower distress a month later (Bennett et al. 2007)

	Distraction techniques included in the coping leaflet
	Things you can think
	Counting to 50, while imaging the numbers in your head
	Thinking of a calm or favourite place
	Thinking of a holiday or other enjoyable times or plans
	Things you can do
	Talk to someone about anything other than the worry in your mind
	Absorb yourself in something interesting or fun to do

Online infertility support groups



<http://www.infertilitynetworkuk.com/acebabes>



<http://www.fertilethoughts.com/>



Valuable social support from people living through similar experiences (see Malik & Coulson, 2008, 2010)

Social support via online facilities

- Support from others 'in the same boat' is the philosophy behind group interventions
- Online support is easily accessible and cheaply available to many
- Benefits: better relationship with partner, reduced isolation, greater knowledge and sense of control
 - Some negatives if very happy or sad news was shared (Malik & Coulson, 2008)

Self-help mechanisms in the 2-week wait	
Empathy	35.6%
Sharing personal experiences	48.4%
Sharing information and advice	19.8%
Gratitude	11%
Friendship	10.6%
Chatting	4.4%
Seeking information and advice	12.6%
"Universality": Not being alone	1.6%
Negative statements	0.3%
Creative expression	0%

Malik & Coulson (2010)

Discussion questions

- Should we be proactive rather than reactive when we know an experience will be difficult?
- Should a selection of early, self-help interventions be routinely available for all people during fertility treatment?
- Should people be introduced to new ways of coping during a difficult experience?

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Screening on distress in ART patients; theoretical background and practical implications


Angelique J.C.M. van Dongen, MD
Radboud University Medical Centre, the Netherlands
7 July 2013

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- Angelique van Dongen
 - Gynecologist, fertility specialist
 - PhD project: psychosocial care in IVF
- No conflict of interest



2

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Learning objectives

Participants will learn:

- **Why** we should screen on emotional maladjustment
- **How** we could screen on emotional maladjustment
- What patients think about psychosocial screening
- Other implications of psychosocial screening
- The next step after screening for emotional maladjustment

3

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Content

- Screening on distress in ART
- SCREENIVF
- Practical implications
- Future research
- Learning objectives

4

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Screening on distress in ART

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Screening on distress in ART

- Involuntary childlessness
 - Worldwide 72-80 million people
 - 1 out of 6 couples
- IVF
 - In vitro fertilization
 - The Netherlands: 16.000 IVF cycles
 - 1 out of 38 children



6

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Screening on distress in ART

- IVF
Complex, time consuming, stressful¹
- 30% drop out because of psychological burden²
- 6 months after last unsuccessful IVF: ~20% of the women suffer from anxiety/depression³

1. Brandes et al. 2009; Boivin et al. 2011
2. Olivius et al. 2004; Rajkhowa et al. 2006; Brandes et al. 2009; Domar et al. 2010; Bovin et al. 2011
3. Verhaak et al. 2005

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Screening on distress in ART

- Screening
 - Emotional problems
 - In time
- Goal¹
 - Offering additional psychosocial care
 - Anticipate to emotional vulnerability in consultation
 - Prevention of problems
 - Asset to standard care

1. Schmidt 2006; Verhaak et al. 2010

8

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SCREENIVF

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SCREENIVF

- SCREENIVF¹
- Introduced in September 2009
- Five risk factors:
 - Pre-treatment anxiety
 - Pre-treatment depression
 - Helplessness regarding fertility problems
 - Less acceptance regarding fertility problems
 - Lack of social support

1. Verhaak et al. 2010

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SCREENIVF

Risk factors	Questionnaire	Cut-off
Anxiety	HADS: 7 items	>8
Depression	HADS: 7 items	>8
Helplessness	ICQ: 6 items	>12
Acceptance	ICQ: 6 items	<10
Social support	ISI: 5 items	<15

11

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SCREENIVF

- Identify **women** at risk for emotional maladjustment before starting IVF
- Sensitivity: 69%¹
- Specificity: 77%¹
- Response rate: 78-80%²
- 1/3 at risk^{1,2}
- 48% clinical relevant psychosocial problems¹

1. Verhaak et al. 2010
2. Van Dongen et al. 2012

12

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Process analysis - Aim

- Process analysis
 - Uptake rate
 - Experiences of the people exposed
 - Action following the results
 - Non responders
- Optimise the use of SCREENIVF

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Process analysis - Aim

- Process analysis¹:
 - To assess the level of adherence to a new intervention
 - Optimise the implementation of a new intervention
- Process analysis²:
 - Key processes
 - Outcome
 - Mechanisms that will lead to improved outcome
 - Identify barriers

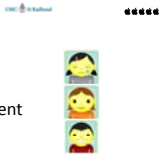
1. Hulscher et al. 2003
2. Campbell et al. 2007

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Process analysis - Methods

- All patients that started IVF between December 2009 and February 2010
- Tertiary IVF clinic
- 304 patients
- Additional process analysis questionnaire
- Telephone survey: non responder assessment



Screening Stress en IVF:
Wat vindt de patiënt?

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Process analysis - Results

- Uptake rate
 - 78%
 - 1/3 at risk
 - 43% completed process analysis questionnaire (n=91)

```

graph TD
    A((304)) --> B((236))
    B --- C["(response SCREENIVF)"]
    B --> D((210))
    B --> E((26))
    E --- F["(returned SCREENIVF too late)"]
    D --> G((91))
    G --- H["(response process analysis)"]
    G --> I((24))
    I --- J["at risk"]
    G --> K((67))
    K --- L["not at risk"]
  
```

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Process analysis - Results

- Non responders
 - 41% 'no actual need for psychological help'
 - 19% forgot to complete the screening

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Process analysis - Results

- Experiences of patients

Experiences	percentage
Screening useful	91%
Completing SCREENIVF not unpleasant	95%
Satisfied with explanation SCREENIVF	97%
Instructions understandable	91%
Neutral or positive about length of SCREENIVF	89%
Recognition in risk profile	98%

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Process analysis - Results

- **Action of patients**
 - 29% (women at risk) planned to seek professional help

Actions	At risk (n=24)		Not at risk (n=67)	
	agree	disagree	agree	disagree
Generally speaking, psychosocial help is useful.	67%	33%	78%	22%
I would benefit from psychosocial help.	62%	38%	57%	43%
My family would support me if I would seek help.	100%	0%	100%	0%
My friends would support me if I would seek help.	100%	0%	100%	0%
My job is an obstacle when seeking help.	0%	100%	9%	91%
Travelling distance is an obstacle.	46%	54%	48%	52%
I don't know if my insurance covers psychosocial help.	79%	21%	61%	39%

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Process analysis - Conclusion

- Screening for emotional risk factors is feasible
 - High uptake rate
 - Improvement via reminders, other language
 - High acceptance, and high acceptability of the risk profile
 - Low percentage in help seeking behaviour
 - Barrier: travelling distance
 - Psychosocial care offered by Internet

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Practical Implications - Screening for dropout

- Aim
- Methods
- Results
- Conclusion

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Dropout - Aim

- Dropout often due to psychosocial reasons:
 - 34% due to emotional distress after start IVF¹
 - Main reason in standardized interview: psychological burden (Likert scale: x=5.96)²
 - Prospective cohortstudy: 28%: physical or psychological burden³
 - Unsuccessful treatment and psychological distress most important in decision to stop treatment⁴

1. Brandes et al. 2009
 2. Van den Broeck et al. 2009
 3. Verberg et al. 2008
 4. Rajkhowa et al. 2006

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Dropout - Aim

- Gameiro (2012)¹:
 “Psychological burden of treatment was a main reason for discontinuing treatment at all stages, especially during ART”
- Boivin (2012)²:
 “Identify the highly distressed patient entering treatment”
- Prevent burden of treatment and its related dropout
- Can SCREENIVF predict dropout?

1. Gameiro et al. 2012
 2. Boivin et al. 2012

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Dropout - Methods

- Retrospective cohort study
- Couples placed on IVF-waiting list between November 2009 and November 2010
- One year later: follow-up
 - Local IVF registry
 - Medical chart
 - Telephonic survey
- Assess:
 - Results SCREENIVF men and women
 - Dropout due to personal reasons
 - Pregnancy rate

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Dropout - Results

- 679 couples, 12 (1.8%) exclusion
- Analysis with 667 couples
- 86 (12.9%) discontinued
 - 9 (10.4%) clinic factors
 - 37 (43.0%) stop on medical advise (passive censoring)
 - 40 (46.5%) dropout due to personal reasons

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Dropout - Results

Patient characteristics

Patient characteristics	Continued treatment	Dropout	p-value
Age of woman <i>years, mean (SD)</i>	33.12 (4.17)	31.98 (4.73)	0.64
Duration of infertility <i>months, mean (SD)</i>	28.70 (25.09)	38.53 (23.51)	0.74
Diagnosis <i>number (%)</i>			
-male factor	211 (63.7)	24 (60.0)	0.89
-female factor	50 (15.2)	4 (10.0)	0.44
-both male and female factor	8 (2.4)	1 (2.5)	0.94
-unknown	59 (18.0)	9 (16.1)	0.39
-missing	3 (0.9)	2 (5.0)	0.03

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Dropout - Results

- SCREENIVF:
 - Uptake rate: 76.6%
 - At risk: 38.0% women; 30.7% men
- Pregnancy rate:
 - 68.6% pregnant after one or more IVF cycles
 - 82.1% continuous pregnancy
 - 12.0% multiple pregnancy
 - 17.1% miscarriage
 - 0.8% extra uterine gravidity

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Dropout - Results

Relation between SCREENIVF and patients who discontinued before or after one treatment cycle

	Odds ratio	95% CI
Women at risk		
Overall at risk score	1.44	0.65 – 3.18
Depression	0.96	0.80 – 1.14
Anxiety	1.06	0.94 – 1.20
Helplessness	0.92	0.81 – 1.05
Acceptance	1.13	1.03 – 1.24
Social support	0.83	0.72 – 0.95
Men at risk		
Overall at risk score	0.54	0.20 – 1.46
Depression	1.02	0.84 – 1.24
Anxiety	0.95	0.80 – 1.12
Helplessness	1.01	0.90 – 1.13
Acceptance	1.25	1.10 – 1.42
Social support	1.04	0.92 – 1.16

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Dropout - Conclusion

SCREENIVF with its current cut-off values cannot predict dropout due to personal reasons

- Lower social support in women pretreatment is related with dropout
- Higher acceptance of the infertility in men and women is related with dropout

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Dropout - Conclusion

- Developing modified tools or combination of tools
 - FertiQol
 - Relational questionnaire
- Information about reasons for dropout
 - Exit interview
- Tailored psychosocial care
- Adjust for dropout we should prevent:
 - "Positive choice to dropout" in couples with higher acceptance?

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Future research

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Future research

- Digital coaching
- Predicting of dropout
- Validation

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Future research – digital coaching

- Digital coaching: psychosocial care offered by Internet
- 60% of patients in Western Europe use Internet for health-related questions¹
- E-health:
 - Efficiency and costs
 - Accessibility
 - Free communication
 - Effective in e.g. Post Traumatic Stress Disorder, headache

1. Atkinson et al. 2009

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Future research – digital coaching

- Digital coaching: psychosocial care offered by Internet
- Internet and IVF
 - Search for information
 - Support groups
- Psycho-education and cognitive behavioural therapy seems most successful in IVF patients with emotional problems¹

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Opdrachten - Windows Internet Explorer

Naam: scootijl; een situatie waarin u geconfronteerd wordt met een situatie waarin u niet wilt handelen. Vul kolom 3, 4, 5 en 6 van tabel 11.4

Nr. Situatie	Gevoel (D-10)	Gedachten	Gedrag	Waarom? Wat ga ik doen? A. Situatie B. Gedachte C. Gedachten D. Gedrag E. Gedrag F. Gedrag G. Gedrag	Wat kan ik doen? A. Gedrag B. Gedrag C. Gedrag D. Gedrag E. Gedrag F. Gedrag G. Gedrag
1	Mijn moeder doet het voor mij. Dit doe ik ook. Het is mijn taak.	Ik wil dat de dokter mijn moeder voor mij doet. Het is mijn taak.	Ik doe het. Het is mijn taak.	A en B	het kan ook anders. Het is mijn taak.
2	Mijn moeder doet het voor mij. Dit doe ik ook. Het is mijn taak.	Ik ben blij dat de dokter mijn moeder voor mij doet. Het is mijn taak.	Ik doe het. Het is mijn taak.	A en B	het kan ook anders. Het is mijn taak.
3	Mijn moeder doet het voor mij. Dit doe ik ook. Het is mijn taak.	Ik ben blij dat de dokter mijn moeder voor mij doet. Het is mijn taak.	Ik doe het. Het is mijn taak.	A en B	het kan ook anders. Het is mijn taak.

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Future research – digital coaching

- 2006 pilot:
 - 5 women:
 - “user friendly”
 - “reduction anxiety scores”
 - “less rise in depression scores”
- Next step:
 - Randomized controlled trial
 - Women with coaching vs. women with regular treatment
 - Outcome: scores on anxiety and depression

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Future research – dropout

- Modify SCREENIVF to predict dropout
 - Combination of tools (FertiQoI, relational questionnaire)
 - Other cut-off values specific for dropout

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Future research – validation

- Validation SCREENIVF for men and couples
- Tailor psychosocial care

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Learning objectives

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Learning objectives

- SCREENIVF is a validated screening instrument to identify women at risk for emotional maladjustment before starting IVF
- Screening patients is feasible, and can be implemented in your clinic
- SCREENIVF can be helpful in tailoring psychosocial care

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Learning objectives

- Digital coaching can be helpful in overcoming barriers for helpseeking behaviour
- SCREENIVF can be helpful in predicting dropout due to personal reasons
- Future research should focus on validation of SCREENIVF for men, and on validation of SCREENIVF for dropout

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Supporting patients in changing lifestyle

Rotterdam Lifestyle interventions

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PhD-student

Dept. Reproductive Medicine

&

Section Medical Psychology and Psychotherapy

Erasmus MC

Commercial Relations:

Mirace Grand Erasmus MC & MSD

Learning objectives

Participants will:

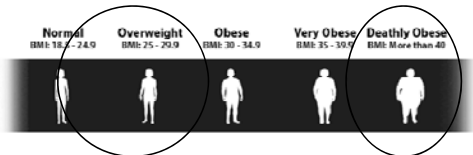
- Be aware of the impact of obesity on reproductive outcomes
- Understand what the problems are when implementing a guideline for overweight and obese women
- Know what we can do as a fertility clinic for obese patients

*Fatness and flabbiness are to blame.
The womb is unable to receive the semen and
they menstruate infrequently...*

Hippocrates

Essay to Scythians 4th century B.C.

When we think of obesity...



We forget:

Subfertility is elevated above 23.9 kg/m²

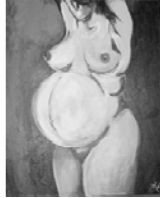
(Nurses Health Study) Rich-ardwards, et al 1994

- Obese women are more prone to anovulation

(Pasquali et al., 2007)

- Complications during pregnancy
- Higher maternal and neonatal morbidity and mortality
- Increased costs

(Sebire et al., 2001; Cedergren, 2004; Linne, 2004; Weiss et al., 2004; Usha Kiran et al., 2005).



Impact of overweight/obesity on ART

In 2007:

Women with a BMI >25 kg/m² have:

- lower chance of pregnancy following IVF
- require higher dose of hormones
- increased miscarriage rate

→ Insufficient evidence of impact BMI on live birth, cycle cancellation, oocyte recovery and ovarian hyperstimulation syndrome.

(Maheshwari et al., 2007)

Doctors couldn't believe...

In 2012:

- No evidence of overweight or obesity increasing the risk of complications following ART
- Obesity marginally reduces the success rates
- But inform women health and obstetric risks and slightly lower success rates of ART
- Overweight and obesity itself should not be a reason to withhold ART

(Koning, et al 2012)

ESHRE Task Force on Ethics and Law (2010)

If there is a high risk of serious harm for the future child is anticipated, fertility treatment should be denied

Note:

- Although this risk is obvious for alcohol consumption and smoking, it is unclear whether this recommendation can be applied in daily clinical practice with respect to adipose subfertile women.

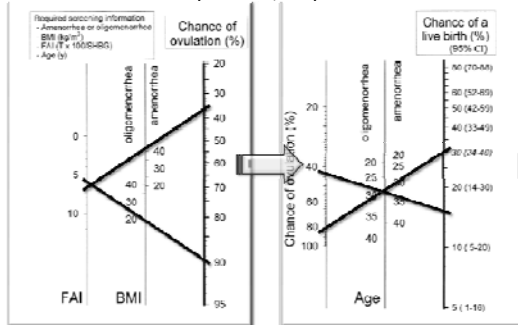
But...

Modest weight loss improves reproductive outcome for many obese women

(Clark et al., 1995, 1998; Glazer et al., 2004).

Ovulation & Live Birth Rate in PCOS

(Imani et al., 2002)



Knowledge among infertile women

Obesity increases the risk of:

- infertility (82.7%)
- irregular periods (70.0%)
- miscarriage (60.7%)
- cesarean section (48.7%)
- birth defects (29.3%)
- stillbirth (22.7%)

Conclusion:

Limited knowledge of reproductive outcomes affected by obesity

(Cordova, et al 2012)

Do we agree?

Women undergoing fertility treatment are **motivated** for reproductive success and may be **uniquely receptive** to obesity education and weight loss intervention.

(Cordova, Et al 2012)

Or do we think...

“Subfertility was not
the gleaming teachable moment
to change lifestyle as I had hoped”

‘ ‘Is this supposed to be my job?’

(Calhoun, 2013)

Need for national recommendations:
hesitant to develop BMI restrictions for fear
that they will be considered discriminatory

(Harris, et al 2011)

Something strange...

Providers avoid this topic in fear
of causing emotional harm,
making the patient angry,
or stigmatizing the patient
with a diagnosis of obesity

(Phelan, 2010)

What if we ask the patient...

Counsel patients about:

- The positive effects on their chance of pregnancy of the elimination of a harmful lifestyle

And provide:

- Information on the negative consequences for achieving a pregnancy in case of a high BMI

(Den breejen., Et al 2013)

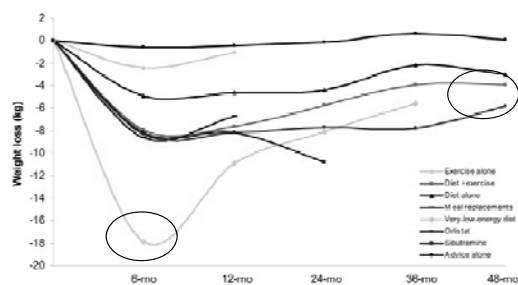
It helps....

“Patients who are counseled to lose weight are nearly three times more likely to try, underscoring the role of the healthcare provider as the impetus for change”

(Galuska., Et al 1999)

How to lose weight?

Franz., et al 2007



How can we help...

Cognitive-behavioural interventions appear to be the most effective interventions especially when combined with dieting and exercise

(Shaw, 2005)

But...

“A major problem with my free group was attendance. I naïvely believed that improved fertility would be sufficient motivation”

(Calhoun, 2013)

That's true!

- Poor rates of compliance (Moran et al., 2003)
- Lifestyle programs are perceived to be too slow for women who are competing against their biological clocks (Palomba et al., 2008).
- Maybe E-Health can help (Appel, 2011)
- Drop-out is a big problem

Drop-out

- Dropout rates have been reported up to 77% (Davis and Addis, 1999; Honas et al., 2003; Inelmen et al., 2005; Finley et al., 2007).
- Drop out is an important limiting factor in the success it is related to little weight change (Finley et al., 2007).

Special lifestyle programs

- 24% drop out rate in lifestyle programs for overweight and obese infertile women
- Women who dropout lose less weight and have lower spontaneous pregnancy chances
- Intervention- or patient-related factors associated with dropout not found yet. (Mutsaerts., et al 2013)

New Zealand, 2000

- New Zealand: clinical priority access criteria (CPAC)
- Treatment for women with a BMI 18-32 kg/m²
- For couples who where most in need but balanced by those who would benefit most from treatment (Gillett., et al 1997)

England, 2004

- National institute for clinical excellence (NICE)
- Providers are encouraged to provide patients with lifestyle advice
- Women with a BMI above 29 kg/m² should be informed about their lower pregnancy chances

USA, 2011

Do you have a cutoff?

- 42,9% for ovarian stimulation or IUI
- 54,8% for IVF

Should there be a BMI cutoff?

- 73,2% for ovarian stimulation or IUI
- 82,9% for IVF

What is your cutoff right now?

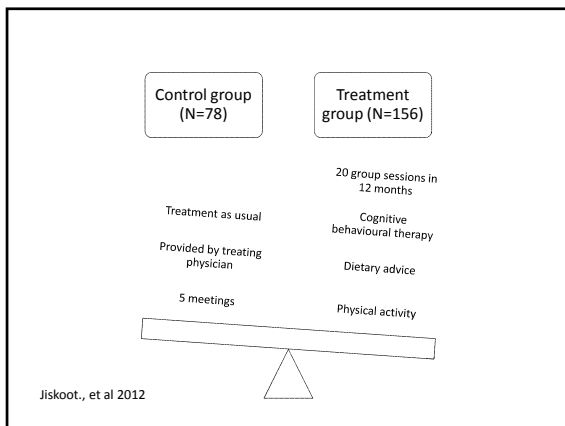
30-55 kg/m² (mean 40 kg/m²)

(Harris., et al 2011)

Rotterdam lifestyle intervention(s)

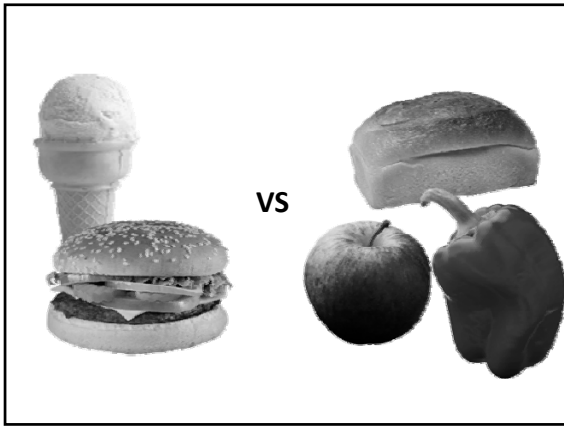
- Started in 2009
- Especially for PCOS women
- All women with a BMI > 25 kg/m² have to participate

- In 2012 the same program started for obese women, men and children (Centre for healthy weight)



- ### The intervention
- Multidisciplinary team
 - Intensive 1 year program
 - 20 group sessions
 - 3 partner meetings
 - 5 individual sessions
 - Combined with a maintenance program via Short Message Service (SMS)

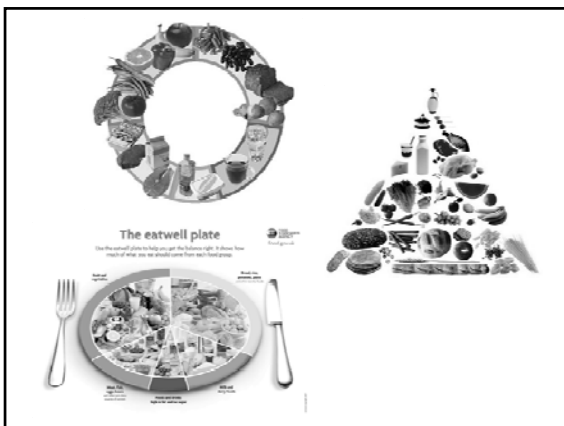
- ### Psychology
- Cognitive behavior therapy
 - *"I can't live without chocolate"*
 - Problem solving therapy
 - *My partner bought a lot of candy*
 - Pro active coping
 - *I'll eat healthy this week*



Diet

- “Carbohydrates are bad for you”
- “I should be able to eat chips now and then”
- I don’t eat that much!
- First food diary: 900-1300 kcal

→ NO (crash) DIET



Physical activity

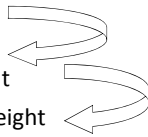
- The gym is not a favorite place
- How to exercise if your overweight or obese
- “I didn’t know I could do this”
- Feeling confident

→ Making exercise possible and fun

Goals

- BMI > 30 kg/m² Obesity
- BMI 25 - 29.9 kg/m² Overweight
- BMI 24.9 - 18.5 kg/m² Healthy weight

- BMI > 35 kg/m² - 5 / 10 %

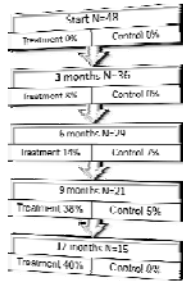


What happend?

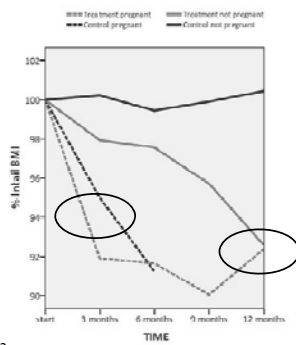
Dutch internet forum

“I would go to the Maxima Medical Centre or the Catharina Hospital because they don’t have that weird BMI cutoff”

(Ir)regular cycle



Jiskoot, et al 2012



Jiskoot, et al 2012

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- Female genital tract congenital malformations: new insights in an old problem
27-28 September 2013 - Thessaloniki, Greece
- Introducing new techniques into the lab
4-5 October 2013 - Barcelona, Spain
- Polycystic ovary syndrome: A new look at an old subject
25-26 October 2013 - Rome, Italy
- Infections from conception to birth: role of ART
7-8 November 2013 - Berlin, Germany
- Endoscopy in reproductive medicine
20-22 November 2013 - Leuven, Belgium
- From early implantation to later in life
28-29 November 2013 - Brussels, Belgium

Mark your calendar for:

- Premature ovarian insufficiency
6-7 December 2013 - Utrecht, The Netherlands

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(see "Calendar")

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