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
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 Vandenbroeck (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 Lancastle - 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

Disclosure (past three years)

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

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
History and evolution

Psyche → Infertility
Infertility → Psyche
Assessment → Monitoring → Evaluation
Compliance
Systematic
reviews

1940
1977
1979
2009

Barbara Eck Menning
Nurse led, Patient Advocacy

Mahlstedt 195
“Working through” & grief & loss therapies

Year %
unexplained
range

< 1960 34.0 (Sandler, 1955)
1960 - 1969 21.84 11.2 - 58.0
1970 - 1979 16.13 10.0 - 27.0
1980 - 1982 12.1 5.8 - 19.4

Templeton et al. 1982
Evidence-based Medicine

Hammerli, 2009
Gameiro, 2013

Integrated Approach to Fertility Care

Patient individual causes

Treatment
compliance

Quality of life

Incomes

Clinical environment

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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)
Practical guide for staff

- Needs assessment
- Intervention development
- Impact assessment

Recognise issues for fertility teams

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

% agree/strongly agree: “Work environment is stressful”
- Physician: 48.9
- Administrator: 73.7
- Staff: 83.9

N=112 ART centres in USA

Gerson et al. 2004 Fertil Steril

Staff perspectives

- “Holding it together” (Payne & Goedeke, 2007)
- Emotional/physical experiences of patient AND roles/care experiences of specialist teams
- Change in primary responsibilities (Merris, 2006)
- Patient centered care Vs medically-orientated responsibilities
- Dealing with disappointed patients (Elipes et al. 2005)
- Insufficient time to support distressed patients
- Quality of care perceived differently than patients (Merris et al. 2011)
- How care should be delivered perceived differently than patients (Moline, 2002)
- Difficulty making changes toward patient centered care (Noponen et al. 2013)
**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/midwife, 3.4% academic, 2.3% mental Health

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**Sources of workplace stress in fertility staff**

- Time & workload
- Organisation, team & management
- Job content & environment

---

**Other workplace stressors**

- Frequency higher order stress categories
- Time & workload
- Organisation, team & management
- Job content & environment
- Clinical Treatment
- Patient needs
- Quality Control
- Finance
- Legal aspects
- Other
- Communication & counselling
Sources of difficulty working with patients

- Patient characteristics 
  - High or low anxiety
  - Uncooperative patients
  - Patients with difficult personalities
  - Sensitive, emotional patients
- Communicating
  - Patients who demand repeated, detailed information
  - Patients who are difficult to talk to
- Clinical treatment
  - Patients who demand unrealistic expectations
  - Patients who are impatient

Other difficulties working with patients

- Patient information & lack of knowledge
- Time pressure
- Financial issues
- Staff teaching/training
- Legal issues
- Management issues
- Teamwork issues
- Job content & responsibility
- Health education
- Workplace issues
- Clinical topics
- Other

Workshops willing to attend

- Patient characteristics & issues
- Clinical topics
- Communication & counseling
- Organizational & management
- Teamwork issues
- 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

TABLE A.1

<table>
<thead>
<tr>
<th>Item</th>
<th>Marketable</th>
<th>Customer-Driven</th>
<th>Production-Driven</th>
</tr>
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<tbody>
<tr>
<td>Item 1</td>
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<tr>
<td>Item 2</td>
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<td>Item 3</td>
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<tr>
<td>Item 4</td>
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</tbody>
</table>

TABLE A.2

<table>
<thead>
<tr>
<th>Item</th>
<th>Market</th>
<th>Customer-Driven</th>
<th>Production-Driven</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 1</td>
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<td>Item 2</td>
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<td>Item 3</td>
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<tr>
<td>Item 4</td>
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</tr>
</tbody>
</table>

Aarts et al. 2011 Hum Rep
N=875 patients

FertiQol International

FertiQol validation sample, n = 1027
Persistence = intention to persist with treatment
Boivin et al. 2011 Hum Reprod

Treatment quality of life and compliance

www.fertiqol.com -- 26 languages
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

Selected Bibliography


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

Jacky Boivin, PhD, Cpsychol
boivin@cardiff.ac.uk

School of Psychology
Cardiff
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

IOM. 2011 Clinical practice guidelines we can trust (report).

What are clinical guidelines?

Decrease variation in care + Increase efficiency of care

Improvement quality of care
How does ESHRE development guidelines?

- Started in 2010
- ESHRE manual for guideline development

In the pipeline:
- ESHRE Guideline on Psychosocial care in fertility units
- ESHRE guideline on management of women with premature ovarian insufficiency

What is implementation?

Implementation: the act of implementing or putting into effect

Guidelines are not self-implementing

Joseph Schumpeter, 1939

Shekelle et al. Implementation Science 2012

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

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

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.
An implementation strategy

1. Pre-emptive identification of potential barriers of recommendations and a priori generation of solutions to address these 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).

Gagliardi et al. Implementation Science 2011, 7:26
An implementation strategy

Which are potential barriers of each recommendation?

Types of barriers - 4 categories:

Barriers related to the "professional"
- Attitudes/beliefs of the clinician
- Skills/knowledge of the clinician
- Lack of consensus among clinicians in significant outcome change

Barriers related to the "guideline"
- Guidelines difficult to use
- Recommendations not identifiable
- Recommendations do not contain a specific and unambiguous action
- Recommendations are not concise

Barriers related to the "patient"
- Recommendation does not reconcile with patient preferences

Barriers related to the "environment"
- External factors related to the system
- Acquisition of new resources or facilities
- Patients may be resistant or perceive no need for guideline recommendations
- Patients may perceive the recommendation as offensive or embarrassing
- Lack of a reminder system, lack of counseling materials
- Inadequate staff or consultant support
- Poor reimbursement
- Increased practice costs, and increased liability
- Lack of time


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"
- Patient version of the guideline
- Critical path related to the guideline

Barriers related to the "guideline"
- Recommendations not identifiable

Barriers related to the "patient"
- Recommendations do not contain a specific and unambiguous action

Barriers related to the "environment"
- Lack of a reminder system, lack of counseling materials
- Inadequate staff or consultant support
- Poor reimbursement
- Increased practice costs, and increased liability
- Lack of time

Facilitators, depending on the barrier:
- Critical path of the guideline
- Options for new decision-making
- Addition of pictures, video material
- Educational material
- Meeting, course
- Clinical audit and feedback

2. Use of behaviorally specified language in the guideline

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

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 versions are posted on the ESHRE Website
- Publication in Human Reproduction
- Inclusion on the National Guidelines Clearinghouse’s Website

Additional publications
- Patient versions
- Online version of the guideline
An implementation strategy

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

Announcements
- Announcement in “Focus on Reproduction”
- a newsflash on the ESHRE website’s homepage
- a news item in the monthly digital ESHRE newsletter
- specific guidelines session at the annual ESHRE meeting
- all related National Societies are separately informed about the guidelines 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

Option Grids
- Options more visible and
- Clinicians found it easier to undertake shared decision making
- Enhances patients’ confidence and ease, increasing their involvement in collaborative decision-making.

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

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.
     - 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)
     - 1st indicator: 64% to 73% P .001
     - 2nd indicator: 74% to 76% P .41

WHO hand hygiene guidelines

<table>
<thead>
<tr>
<th>Implementation strategy: Example</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>WHO hand hygiene guidelines</strong></td>
</tr>
</tbody>
</table>

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

### Table

<table>
<thead>
<tr>
<th></th>
<th>To</th>
<th>12 months later</th>
</tr>
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<tbody>
<tr>
<td>1st indicator</td>
<td>64%</td>
<td>72%</td>
</tr>
<tr>
<td>2nd indicator</td>
<td>74%</td>
<td>78%</td>
</tr>
<tr>
<td>P</td>
<td>.001</td>
<td>.41</td>
</tr>
</tbody>
</table>
Implementation strategy: Example
WHO hand hygiene guideline

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
  - Online piloted/evaluated

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 guidelines

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 to context 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)
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
  - Guidelines on psychosocial care for chronic diseases, cancer and chronic care
  - Guidelines on dementia
  - Guidelines on palliative care in elderly

Survey for guideline group members

- Barriers related to the "professional"
  - Knowledge
  - Attitude
  - Values
  - Self-efficacy
  - Communication skills
  - Time

- Facilitators could be...
  - Training of clinicians (core psychosocial care, communication skills)
  - Integration of psychosocial care in medical education
  - Patient guide with key information, for instance:
    - Personal values
    - Self-efficacy
    - Communication
    - Time
  - Feedback system, system of rewards
  - Reminders


- Barriers related to the "guideline"
  - Language
  - Psychology - belief in better characterization
  - Confidence
  - Lack of high-quality evidence

- Facilitators could be...
  - Include clinician in GDG and review
  - Lack of evidence in GEC and sharing
  - Rigorous methodology
  - Organize meeting, review

Additional barriers from analysis using the GLI tool
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
- Language barriers
- "In denial"
- "No denial"- seeks treatment

Facilitators could be...

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

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

How do patients feel about the guideline and recommendations?

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

Facilitators could be...

- Information for clinicians
- Easy, quick, rapidly available tools
- "In denial" - seeks treatment
- "No denial" - seeks treatment


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

Guideline Institutionalisation Implementation

Model for progress monitoring

Cumulative score Stages Progress markers

1. Creating awareness
- Awareness by management

2. Adapting the concept
- Agreement decision to implement
- Resources and equipment
- Staff awareness
- Adoption of referral (policies, protocols, algorithms)

3. Taking ownership
- Staff empowerment
- Adaptation of referral (policies, protocols, algorithms)

4. Evidence of practice
- Evidence of all three components of EBP within documents
- Feedback in MRC's forum
- Staff involvement
- Adaption of referral (policies, protocols, algorithms)

5. Evidence of routine and integration
- Evidence of all three components of EBP within documents
- Feedback in MRC's forum
- Staff involvement
- Adaption of referral (policies, protocols, algorithms)

6. Evidence of routine
- Evidence of all three components of EBP within documents
- Feedback in MRC's forum
- Staff involvement
- Adaption of referral (policies, protocols, algorithms)

Maximun total score = 24

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

Change doesn't happen telepathically
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

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

N.M. van den Boogaard, M.D.
VU medical centre and Academic Medical centre Amsterdam

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 couple 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% 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=396

Brendes et al. FERL 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


Prediction natural conception

Collins 3rd care ivf centre 1995

Hunault model
- Female age
- Duration subfertility
- Primary subfertility
- Referral status
- Semen quality
- PCT/ no PCT

Tailored expectant management, why?

- Prevention unnecessary treatment and its´ complications
- Cost effective
Poor implementation

Implementation TEM is poor, estimated overtreatment 35¹

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

Risk factors for non-adherence to TEM

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

3021 couples with unexplained or male subfertility

1130 couples (38%) prognosis of >40%

367 couples (37%) started treatment within 12 months

153 couples (15%) started treatment within 6 months

Risk factors for non-adherence to TEM

<table>
<thead>
<tr>
<th>Treatment within 6 months</th>
<th>n=153 (15%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PATIENT CHARACTERISTICS</td>
<td>OR</td>
</tr>
<tr>
<td>Mean maternal age (per year older)</td>
<td>1.06</td>
</tr>
<tr>
<td>Mean duration of subfertility (per year longer)</td>
<td>1.37</td>
</tr>
<tr>
<td>History ≥1 live birth</td>
<td>0.99</td>
</tr>
<tr>
<td>History ≥1 miscarriage</td>
<td>1.54</td>
</tr>
<tr>
<td>Socio Economic Status (%)</td>
<td>0.88</td>
</tr>
<tr>
<td>High</td>
<td>0.99</td>
</tr>
<tr>
<td>Low</td>
<td>0.88</td>
</tr>
</tbody>
</table>

CLINICAL CHARACTERISTICS

| Fertility meeting (yes) | 0.84 | 0.52 to 1.36 |
| Fertility doctor (yes)  | 0.62 | 0.39 to 0.99 |
| Clinic with TIVF-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

<table>
<thead>
<tr>
<th>Domain 1</th>
<th>Characteristics of the intervention</th>
<th>Domain 2</th>
<th>Characteristics of the professional</th>
<th>Domain 3</th>
<th>Characteristics of the patient</th>
<th>Domain 4</th>
<th>Characteristics of the context</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of confidence in natural conception (b)</td>
<td>Not informing the couple about the option of TEM during the first consultation (b)</td>
<td>Inappropriate expectations prior to the first consult (b)</td>
<td>The length of time taken for the whole process (b)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient information material about prognosis and TEM (f)</td>
<td>Unclear way of counselling and communicating chances (b)</td>
<td>Misunderstanding the success rates of treatment (b)</td>
<td>Practice in other clinic (b)</td>
<td></td>
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<td></td>
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<td></td>
<td>Twin is a welcome complication (b)</td>
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</tbody>
</table>
### Results qualitative study – patients

<table>
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</tr>
<tr>
<td>Patient information material about prognosis and TEM (f)</td>
<td>Unclear way of counselling and communicating chances (f)</td>
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</table>

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### Results qualitative study – patients

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</table>
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

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<td>Not convinced about the usefulness of the prognostic models and TEM (b)</td>
<td>Difficulties in explaining the involved factors to the couple (b)</td>
<td>Expectations of immediate treatment after the fertility work up (b)</td>
<td>Local consensus (f)</td>
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<tr>
<td>Comparing TEM risks and advantages (b)</td>
<td>Couple’s misunderstanding of chances (b)</td>
<td>Computational of fertility care (f)</td>
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<td>Miscarriage population (b)</td>
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<tr>
<td>Lack of relevant patient information materials (b)</td>
<td>Difficulties communicating images also base line and follow up (b)</td>
<td>Urgency for results in the couple (b)</td>
<td>Local protocol (f)</td>
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<tr>
<td>Not convinced about the effectiveness of the prog nostic models (b)</td>
<td>Difficulties in communicating and understanding chances (b)</td>
<td>Expectations of immediate treatment after fertility work up (b)</td>
<td>Local consensus (f)</td>
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<td>Comparison of treatment chances versus spontaneous pregnancy chances (b)</td>
<td>Complex understanding of chances (b)</td>
<td>Centralisation of fertility care (f)</td>
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<td>Poor relationship with couple (b)</td>
<td>Progression based on age (b)</td>
<td>Misconceptions of chances (b)</td>
<td>Regional organisation (f)</td>
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<td>Misconceptions of patient population (b)</td>
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</table>

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
142 questionnaires returned
Mean appreciation of TEM: 5.7 (SD 2.2)

<table>
<thead>
<tr>
<th>Percentage of couples that perceive this as a barrier (b) or facilitator (f)</th>
<th>Couples or %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of confidence in the natural conception (b)</td>
<td>95 (98%)</td>
</tr>
<tr>
<td>Knowledge of the factors used in the prognostic model (b)</td>
<td>75 (78%)</td>
</tr>
<tr>
<td>A need for more instructions related to programs and TEM (b)</td>
<td>76 (80%)</td>
</tr>
<tr>
<td>Preference for being informed about the option of TEM during the first consultation (f)</td>
<td>42 (44%)</td>
</tr>
<tr>
<td>Comparing spontaneous pregnancy chance with treatment (f)</td>
<td>29 (30%)</td>
</tr>
<tr>
<td>Unclear way of counselling and communicating chances (b)</td>
<td>9 (9%)</td>
</tr>
<tr>
<td>Characteristics of the patient</td>
<td></td>
</tr>
<tr>
<td>Expected to get a cause for the subfertility (b)</td>
<td>84 (95%)</td>
</tr>
<tr>
<td>Expected to get treatment (b)</td>
<td>16 (18%)</td>
</tr>
<tr>
<td>Expected to get a cause for the subfertility and treatment (b)</td>
<td>70 (73%)</td>
</tr>
<tr>
<td>First reaction to prognosis and subsequent TEM period</td>
<td></td>
</tr>
<tr>
<td>Pessimal</td>
<td>42 (45%)</td>
</tr>
<tr>
<td>Mixed feelings: happy and disappointed</td>
<td>38 (41%)</td>
</tr>
<tr>
<td>Inability to remember prognosis (b)</td>
<td>52 (54%)</td>
</tr>
<tr>
<td>Progressing female age (b)</td>
<td>52 (54%)</td>
</tr>
<tr>
<td>Longer duration of subfertility (b)</td>
<td>63 (66%)</td>
</tr>
<tr>
<td>Expected that with treatment &gt;50% of all couples conceive (b)</td>
<td>43 (45%)</td>
</tr>
<tr>
<td>Expected to have a good spontaneous prognosis and not needing treatment (f)</td>
<td>36 (37%)</td>
</tr>
</tbody>
</table>
Association with reported appreciation of TEM

<table>
<thead>
<tr>
<th>Multivariable association between the patients’ appreciation of TEM and patient characteristics, barriers and facilitators</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domain of the intervention: Need for patient information about prognosis and TEM, sum score</td>
<td>0.047</td>
</tr>
<tr>
<td>Domain of the professional: Not informing the couple about the option of TEM during the first consultation</td>
<td>0.895</td>
</tr>
<tr>
<td>Domain of the clinic: Comparing natural conception chances with treatment</td>
<td>0.124</td>
</tr>
<tr>
<td>Domain of the patient: Understanding that with good prognosis, treatment was not indicated</td>
<td>0.810</td>
</tr>
<tr>
<td>Domain of the professional: Practice in other clinics</td>
<td>0.863</td>
</tr>
</tbody>
</table>

Results, professionals

70% (117/167) professionals responded

<table>
<thead>
<tr>
<th>Baseline characteristics</th>
<th>Professionals n = 117</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male (%)</td>
<td>39 (33%)</td>
</tr>
<tr>
<td>Age (mean, SD)</td>
<td>45 (9.7)</td>
</tr>
<tr>
<td>Years of experience (median, range)</td>
<td>11 (3-5)</td>
</tr>
<tr>
<td>Family doctors (%)</td>
<td>49 (42%)</td>
</tr>
<tr>
<td>University hospital</td>
<td>37 (32%)</td>
</tr>
<tr>
<td>Teaching hospital</td>
<td>55 (47%)</td>
</tr>
<tr>
<td>Non-teaching hospital</td>
<td>23 (20%)</td>
</tr>
<tr>
<td>Private clinic</td>
<td>2 (17%)</td>
</tr>
<tr>
<td>Self reported adherence to TEM (%) median</td>
<td>62% (75)</td>
</tr>
</tbody>
</table>

Barriers & facilitators of Tailored Expectant Management

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<tr>
<th>Percentage of Professionals that perceive this as a barrier</th>
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<tbody>
<tr>
<td>Domain of the intervention: Need for patient information about prognosis and TEM, sum score</td>
</tr>
<tr>
<td>Not convinced about the prognostic models &amp; TEM</td>
</tr>
<tr>
<td>Role of the model taken too small</td>
</tr>
<tr>
<td>Domain of professional: Forget to use model</td>
</tr>
<tr>
<td>Difficulties in discussing and communicating chances</td>
</tr>
<tr>
<td>Limited knowledge about the prognostic models &amp; TEM</td>
</tr>
<tr>
<td>Reluctance with the couple</td>
</tr>
<tr>
<td>Not always have access to the model</td>
</tr>
<tr>
<td>Treatment will generate income</td>
</tr>
<tr>
<td>Domain of the patient: Progressing female age</td>
</tr>
<tr>
<td>Progression of the disease</td>
</tr>
<tr>
<td>Expectations of immediate treatment after the fertility work up</td>
</tr>
<tr>
<td>Couple's interpretation of chances</td>
</tr>
<tr>
<td>Couple's comprehension of chances</td>
</tr>
<tr>
<td>Domain of the clinic: Regular fertility meetings</td>
</tr>
<tr>
<td>Local protocol &amp; consensus</td>
</tr>
<tr>
<td>Coordination of fertility care clinic, level 1 professional level</td>
</tr>
<tr>
<td>Electronic Patient File</td>
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</table>
### Barriers & facilitators of Tailored Expectant Management

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<tr>
<th>Domain of the Intervention</th>
<th>Percentage of Professionals that perceive this as a barrier</th>
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<tr>
<td>Missing factors in the prognostic models</td>
<td>40%</td>
</tr>
<tr>
<td>Not convinced about the prognostic models &amp; TEM</td>
<td>29%</td>
</tr>
<tr>
<td>Use of the model takes time</td>
<td>16%</td>
</tr>
<tr>
<td>Domain of professional</td>
<td></td>
</tr>
<tr>
<td>Forget to use the model</td>
<td>29%</td>
</tr>
<tr>
<td>Difficulties in counseling and communicating chances</td>
<td>16%</td>
</tr>
<tr>
<td>Limited knowledge about the prognostic models &amp; TEM</td>
<td>13%</td>
</tr>
<tr>
<td>Close relation with the couple</td>
<td>13%</td>
</tr>
<tr>
<td>Not always have access to the model</td>
<td>13%</td>
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<tr>
<td>Treatment will generate income</td>
<td>13%</td>
</tr>
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<td>Domain of the patient</td>
<td></td>
</tr>
<tr>
<td>Progressing female age</td>
<td>89%</td>
</tr>
<tr>
<td>Urgency for action in the couple</td>
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</tr>
<tr>
<td>Expectations of immediate treatment after the fertility work up</td>
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</tr>
<tr>
<td>Miscarriage population</td>
<td>89%</td>
</tr>
<tr>
<td>Domain of the Context</td>
<td></td>
</tr>
<tr>
<td>Regular fertility meeting</td>
<td>89%</td>
</tr>
<tr>
<td>Local protocol &amp; consensus</td>
<td>89%</td>
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<tr>
<td>Centralisation of fertility care (clinic level / professional level)</td>
<td>72%</td>
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Association with reported adherence to TEM

Per domain sumscore showed internal consistency (Cronbach’s α >0.7)

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<tr>
<th>Multivariable association between the professionals’ reported adherence to TEM and the professional characteristics, barriers and facilitators</th>
<th>P value</th>
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<tbody>
<tr>
<td>Professional and Clinical characteristics</td>
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<tr>
<td>Type physician: fertility doctor</td>
<td>0.041</td>
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<tr>
<td>Regular seeing fertility patients</td>
<td>0.195</td>
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<tr>
<td>Local protocol</td>
<td>0.981</td>
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<tr>
<td>Local consensus</td>
<td>0.360</td>
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<tr>
<td>Fertility meeting</td>
<td>0.667</td>
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<tr>
<td>Sum score** barriers in the domain of the professional</td>
<td>0.008</td>
</tr>
<tr>
<td>Sum score** facilitators in the domain of the clinic</td>
<td>0.091</td>
</tr>
<tr>
<td>Interaction term fertility meeting * sumscore clinic</td>
<td>0.374</td>
</tr>
</tbody>
</table>

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

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

• 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

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 an implementation strategy
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

Conflict of interest (past three years)

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

Learning objectives

☐ Understand the rational 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 than can be integrated in routine care
  ☐ Enhancing quality of care for everyone (patients, staff, clinic)
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

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?

Horizontal time-line

- Supporting the infertile patient (individual, couple) along ALL treatment stages
- Before treatment
- During treatment
- After treatment
- Achieved pregnancy
- Unsuccessful treatment
- Abandoned treatment
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.

Vertical approach

☐ Tailoring support to patient characteristics

ALL STAFF
doctors, nurses, embryologists, administrative personnel

Mental Health Professionals (MHPs)
counsellors, social workers, psychologists, psychiatrists

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
- ...

Cardiff Fertility Studies

Patient-Centred Care
Counselling
Psychotherapy / Psychiatric interventions
(More) Team work within clinics

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

  - Educate about psychosocial issues
  - Develop information & educational materials
  - Offer training and provide feedback
  - Define responsibility limits of non MHP staff

Increase awareness about patients preferences

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
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, 1430-1436.

- Information aspects identified by patients as important and problematic:
  - Written information
  - Information on treatment alternatives
  - Information on helping themselves
  - Known plan for the future

Offer training in communication & interaction skills

- 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. 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. Huppelschoten 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

Facilitate access to MHPs

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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

Feasible & low cost

Distressful for patient

E.g., communicating/receiving negative treatment results
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?
  - Cardiff Fertility Studies
  - 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

- Usability & acceptance testing
  - SCREEN-IVF

Investigate staff needs (speaker Boivin)

- Staff underestimate the importance patients attribute to Patient Centre Care

- Staff & patients evaluations of care differ

- 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 certified? 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

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)

Additional information

Please email Sofia Gameiro

gameiros@cardiff.ac.uk
References 1/2


References 2/2
How could doctors implement psychosocial care?

Christos A. Venetis, MD, MSc

Unit for Human Reproduction, 1st Dept. of OB/Gyn
Medical School, Aristotle University of Thessaloniki, Greece

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

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

& 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 – care that should be provided upon request by others and not the doctors (psychologists, psychiatrists, social workers...
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”?

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<th>Quality of care/treatment</th>
<th>Doctor</th>
<th>Better results</th>
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<td></td>
<td>Quality of life</td>
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<td>Less stress/burn out</td>
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<tr>
<td></td>
<td>Patient satisfaction</td>
<td></td>
<td>Increased satisfaction</td>
</tr>
<tr>
<td></td>
<td>Increased adherence/compliance</td>
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“Psychosocial care” in IVF: challenges

- Intensity: 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

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*
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
Is psychosocial care in modern IVF practice important for patients?

Solving the riddle of drop-outs

Boivin et al., 2012

Are fertility specialists aware of their patients’ psychosocial needs?

Physicians underestimate the importance of patient-centredness to patients: a discrete choice experiment in fertility care

Inge W.H. van Empel\textsuperscript{1,2}, Elza A.P. Denker\textsuperscript{1,3}, Xander H.E. Koekkoek\textsuperscript{1}, Willem E.D.M. Nelen\textsuperscript{1}, Elly A. Stolk\textsuperscript{1}, Wouter Brincker\textsuperscript{4}, Thomas P.L. D’Hooghe\textsuperscript{1}, and Jan A.P. Kremer\textsuperscript{1}

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Are fertility specialists aware of their patients’ psychosocial needs?

Doctor vs. patients

N=1189 couples

N=194 physicians

Aarts et al., 2011

How can doctors offer psychosocial care to their patients?

By addressing their psychosocial needs

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

- Most women seem to be able to deal effectively with 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

1) Facilitate and/or reduce number of injections
   - Pre-filled pen
   - GnRH-antagonist protocols (Devroey et al., 2003a)
   - Corifollitropin-alfa (Devroey et al., 2003b)
   - 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 them 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?

Describe the importance of:
• Having a normal body-weight
• Not smoking
• Reducing alcohol consumption
• Exercising regularly
• Periconceptual folic acid uptake
• Complementary therapy/Alternative treatments

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/questionnaire
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.
References


How could doctors implement psychosocial care?

Christos A. Venetis, MD, MSc

Unit for Human Reproduction, 1st Dept. of OB/Gyn
Medical School, Aristotle University of Thessaloniki, Greece
How to support patients in the waiting period?

Deborah Lancastle, PhD CPsychol
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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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?
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

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
    2. Uncontrollability
    3. Meaningfulness

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:
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

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:

Psychological effects of uncertainty

Boivin & Lancastle (2010)

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

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?

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
Theoretical model of stress, appraisal, and coping

Lazarus and Folkman (1984)

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Coping effectiveness

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

1. 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!

2. 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
Coping across stages of IVF

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?

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)
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)

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

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)

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

<table>
<thead>
<tr>
<th>Self-help mechanisms in the 2-week wait</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empathy</td>
<td>35.6%</td>
</tr>
<tr>
<td>Sharing personal experiences</td>
<td>48.4%</td>
</tr>
<tr>
<td>Sharing information and advice</td>
<td>19.8%</td>
</tr>
<tr>
<td>Gratitude</td>
<td>11%</td>
</tr>
<tr>
<td>Friendship</td>
<td>10.6%</td>
</tr>
<tr>
<td>Chatting</td>
<td>8.4%</td>
</tr>
<tr>
<td>Seeking information and advice</td>
<td>22.6%</td>
</tr>
<tr>
<td>“Universality”: Not being alone</td>
<td>1.6%</td>
</tr>
<tr>
<td>Negative statements</td>
<td>0.3%</td>
</tr>
<tr>
<td>Creative expression</td>
<td>0%</td>
</tr>
</tbody>
</table>

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?
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

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

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
Content

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

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
Screening on distress in ART

• IVF
  Complex, time consuming, stressful\(^1\)

• 30% drop out because of psychological burden\(^2\)
• 6 months after last unsuccessful IVF: “20% of the women suffer from anxiety/depression”\(^3\)

2. Olkusz et al. 2004; Rajkhowa et al. 2006; Brandes et al. 2009; Borrar et al. 2010; Boivin et al. 2010
3. Verhaak et al. 2005

Screening on distress in ART

• Screening
  • Emotional problems
  • In time

• Goal\(^1\)
  • Offering additional psychosocial care
  • Anticipate to emotional vulnerability in consultation
  • Prevention of problems
  • Asset to standard care

1. Schmidt 2006; Verhaak et al. 2010
SCREENIVF

- SCREENIVF\(^1\)
- 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

SCREENIVF

<table>
<thead>
<tr>
<th>Risk factors</th>
<th>Questionnaire</th>
<th>Cut-off</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>HADS: 7 items</td>
<td>&gt;8</td>
</tr>
<tr>
<td>Depression</td>
<td>HADS: 7 items</td>
<td>&gt;8</td>
</tr>
<tr>
<td>Helplessness</td>
<td>ICQ: 6 items</td>
<td>&gt;12</td>
</tr>
<tr>
<td>Acceptance</td>
<td>ICQ: 6 items</td>
<td>&lt;10</td>
</tr>
<tr>
<td>Social support</td>
<td>ISI: 5 items</td>
<td>&lt;15</td>
</tr>
</tbody>
</table>

SCREENIVF

- Identify **women** at risk for emotional maladjustment before starting IVF

- Sensitivity: 69%\(^1\)
- Specificity: 77%\(^2\)
- Response rate: 78-80%\(^2\)
- 1/3 at risk\(^1,2\)
- 48% clinical relevant psychosocial problems\(^3\)

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

- Process analysis
- Screening for dropout

Practical Implications - Process analysis

- Aim
- Methods
- Results
- Conclusion
Process analysis - Aim

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

Process analysis - Aim

- Process analysis 1:
  - To assess the level of adherence to a new intervention
  - Optimise the implementation of a new intervention
- Process analysis 2:
  - Key processes
  - Outcome
  - Mechanisms that will lead to improved outcome
  - Identify barriers

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

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
Process analysis - Results

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

Process analysis - Results

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

Process analysis - Results

• Experiences of patients

<table>
<thead>
<tr>
<th>Experiences</th>
<th>percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screening useful</td>
<td>91%</td>
</tr>
<tr>
<td>Completing SCREENIVF not unpleasant</td>
<td>95%</td>
</tr>
<tr>
<td>Satisfied with explanation SCREENIVF</td>
<td>97%</td>
</tr>
<tr>
<td>Instructions understandable</td>
<td>91%</td>
</tr>
<tr>
<td>Neutral or positive about length of SCREENIVF</td>
<td>89%</td>
</tr>
<tr>
<td>Recognition in risk profile</td>
<td>98%</td>
</tr>
</tbody>
</table>
Process analysis - Results

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

<table>
<thead>
<tr>
<th>Actions</th>
<th>At risk (n=24)</th>
<th>Not at risk (n=67)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agree</td>
<td>Agree</td>
<td>Agree</td>
</tr>
<tr>
<td>Generally speaking, psychosocial help is useful</td>
<td>67%</td>
<td>98%</td>
</tr>
<tr>
<td>Would benefit from psychosocial help</td>
<td>86%</td>
<td>94%</td>
</tr>
<tr>
<td>My family would support me if I would seek help</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>My friends would support me if I would seek help</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>My job is an obstacle when seeking help</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Travelling distance is an obstacle</td>
<td>46%</td>
<td>48%</td>
</tr>
<tr>
<td>Don’t know if my insurance covers psychosocial help</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

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

Practical Implications - Screening for dropout

- Aim
- Methods
- Results
- Conclusion
Dropout - Aim

- Dropout often due to psychosocial reasons:
  - 34% due to emotional distress after start IVF \(^1\)
  - Main reason in standardized interview: psychological burden (Likert scale: \(x=5.96\)) \(^2\)
  - Prospective cohort study: 28% physical or psychological burden \(^3\)
  - Unsuccessful treatment and psychological distress most important in decision to stop treatment \(^4\)

3. Verberg et al. 2008
4. Rajkhowa et al. 2006

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?


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
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

Patient characteristics

<table>
<thead>
<tr>
<th>Diagnosis number (%)</th>
<th>Continued treatment</th>
<th>Dropout</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male factor</td>
<td>211 (63.7)</td>
<td>24 (6.0)</td>
<td>0.89</td>
</tr>
<tr>
<td>Female factor</td>
<td>50 (15.2)</td>
<td>4 (1.0)</td>
<td>0.44</td>
</tr>
<tr>
<td>Both male and female factor</td>
<td>8 (2.4)</td>
<td>1 (0.2)</td>
<td>0.94</td>
</tr>
<tr>
<td>Unspecified</td>
<td>59 (18.0)</td>
<td>9 (16.1)</td>
<td>0.39</td>
</tr>
<tr>
<td>Missing</td>
<td>3 (0.9)</td>
<td>2 (5.0)</td>
<td>0.03</td>
</tr>
</tbody>
</table>

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
Dropout - Results

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

<table>
<thead>
<tr>
<th>Women at risk</th>
<th>Odds ratio</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall at risk score</td>
<td>1.44</td>
<td>0.65 – 3.38</td>
</tr>
<tr>
<td>Depression</td>
<td>0.96</td>
<td>0.85 – 1.34</td>
</tr>
<tr>
<td>Anxiety</td>
<td>1.06</td>
<td>0.94 – 1.20</td>
</tr>
<tr>
<td>Helplessness</td>
<td>0.97</td>
<td>0.81 – 1.15</td>
</tr>
<tr>
<td>Acceptance</td>
<td>1.13</td>
<td>1.03 – 1.24</td>
</tr>
<tr>
<td>Social support</td>
<td>0.83</td>
<td>0.72 – 0.95</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Men at risk</th>
<th>Odds ratio</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall at risk score</td>
<td>0.54</td>
<td>0.20 – 1.46</td>
</tr>
<tr>
<td>Depression</td>
<td>1.02</td>
<td>0.84 – 1.24</td>
</tr>
<tr>
<td>Anxiety</td>
<td>1.05</td>
<td>0.90 – 1.21</td>
</tr>
<tr>
<td>Helplessness</td>
<td>1.01</td>
<td>0.90 – 1.13</td>
</tr>
<tr>
<td>Acceptance</td>
<td>0.92</td>
<td>0.81 – 1.05</td>
</tr>
<tr>
<td>Social support</td>
<td>1.04</td>
<td>0.92 – 1.16</td>
</tr>
</tbody>
</table>

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

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?
Future research

- Digital coaching
- Predicting of dropout
- Validation

Future research – digital coaching

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

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
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

Future research – dropout

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

Future research – validation

- Validation SCREENIVF for men and couples
- Tailor psychosocial care
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

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
References

References


- Verhaak CM, Litten, AM, Evers AM, Ernst DD. Who is at risk of emotional problems and how do you know? Screening of women going for IVF treatment. Hum Reprod 2010; 25(5): 1234-1240
Supporting patients in changing lifestyle
Rotterdam Lifestyle interventions

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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 Scynthians 4th century B.C.
When we think of obesity...

We forget:
Subfertility is elevated above 23.9 kg/m²

- 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; Lines', 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., 1999, 1999; 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
(Condesso, 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.
(Condesso, 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

(De bruin, et al 2012)

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 naively 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).
- Dropout 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 (Gilbert., 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 happened?

Dutch internet forum

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


You can now register for these upcoming ESHRE Campus events:

- Application and challenges of emerging technologies in preimplantation and prenatal diagnosis
  12-13 September 2013 - Prague, Czech Republic

- 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

www.eshre.eu
(see “Calendar”)

Contact us at info@eshre.eu