Patient-centered fertility services

Stockholm, Sweden
3 July 2011

Organised by
Special Interest Group Safety and Quality in ART and the Task Force Developing Countries and Infertility
Contents

Course coordinators, course description and target audience  Page 5

Programme  Page 7

Introduction to ESHRE  Page 9

Speakers’ contributions

Patient expectations - Clare Lewis-Jones (United Kingdom)  Page 17

Patient centered, patient-friendly or high quality ART? - Guido Pennings (Belgium)  Page 32

"shared decision making" in ART – Annick Delvigne (Belgium)  Page 40

How to measure patient centredness - Eline Dancet (Belgium) and Inge van Empel (The Netherlands)  Page 52

Self-operated endovaginal telemonitoring - Jan Gerris (Belgium)  Page 64

The virtual fertility clinic - Jan Kremer (The Netherlands)  Page 79

Tools for patient-centered care: Fertistat and Fertiquol - Jacky Boivin (United Kingdom)  Page 90

Fertility awareness and preconceptional counselling and care – Petra De Sutter (Belgium) and Ilse Delbaere (Belgium)  Page 105

Upcoming ESHRE Campus Courses  Page 120

Notes  Page 121
Course coordinators

Petra De Sutter (Belgium) / Jan Kremer (The Netherlands)

Course description

The aims of this course are to discuss different aspects of patient-centeredness in its relation to assisted reproduction. The attendee should gain insight into the principles of patient-centered medicine, and understand some of its ethical aspects. The view point of the patient will be discussed and also some tools to measure patient-centredness and quality-of-life aspects of infertility and its treatment. Some examples of current projects and concepts in this field will be discussed. Finally fertility awareness will be addressed and its relationship with preconceptional counseling and care.

Target audience

Reproductive physicians, paramedicals, psychologists, counsellors
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<tr>
<th>Time</th>
<th>Event</th>
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<tbody>
<tr>
<td>09.00-09.30</td>
<td>Patient expectations - Clare Lewis-Jones (United Kingdom)</td>
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<td>09.30-09.45</td>
<td>Discussion</td>
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<td>09.45-10.15</td>
<td>Patient centered, patient-friendly or high quality ART? - Guido Pennings (Belgium)</td>
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<td>11.00-11.30</td>
<td>&quot;shared decision making&quot; in ART – Annick Delvigne (Belgium)</td>
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<td>11.30-11.45</td>
<td>Discussion</td>
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<td>11.45-12.15</td>
<td>How to measure patient centredness - Eline Dancet (Belgium) and Inge van Empel (The Netherlands)</td>
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<td>12.30-13.30</td>
<td>Lunch</td>
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<td>15.30-16.00</td>
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<td>16.45-17.00</td>
<td>Discussion</td>
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What is ESHRE?

ESHRE was founded in 1985 and its Mission Statement is to:

- promote interest in, and understanding of, reproductive science
- facilitate research and dissemination of research findings in human reproduction and embryology to the general public, scientists, clinicians and patient associations.
- inform policy makers in Europe
- promote improvements in clinical practice through educational activities
- develop and maintain data registries
- implement methods to improve safety and quality assurance

Executive Committee 2009/2011

<table>
<thead>
<tr>
<th>Position</th>
<th>Name</th>
<th>Country</th>
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<tr>
<td>Chairman</td>
<td>Luca Gianaroli</td>
<td>Italy</td>
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<tr>
<td>Chairman Elect</td>
<td>Anna Veiga</td>
<td>Spain</td>
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<tr>
<td>Past Chairman</td>
<td>Joep Geraedts</td>
<td>Netherlands</td>
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<td>Jean François Guérin</td>
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<td>Timur Gürgan</td>
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<td>Ursula Eichenlaub-Ritter</td>
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<td>Antonis Matrigiannakis</td>
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<td>Miodrag Stojkovic</td>
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<td>Anne-Marie Sulkari</td>
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<td>Carlos Plancha</td>
<td>Portugal</td>
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<td>Françoise Shenfield</td>
<td>United Kingdom</td>
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<td>Etienne Van den Abbeel</td>
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<td>Jolienwe Schoonenberg-Pomper</td>
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<td></td>
<td>Veljko Vaisarjevic</td>
<td>Slovenia</td>
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<td></td>
<td>Søren Ziebe</td>
<td>Denmark</td>
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General Assembly of Members

ESHRE Organisation

- Executive Committee
- Committee of Nat. Representatives
- Central Office
- ESHRE Consortia
  - ESHRE Consortium
  - PGD Consortium
- Sub-Committees
  - Finance Sub-Committee
  - Comm. Sub-Committee
  - Publ. Sub-Committee
  - Editorial Office
  - Publisher
  - Editors-in-Chief
- SIG Sub-Committee
- SIG Coordinators
- Task Forces

ESHRE Journals

- Human Reproduction with impact factor 3.859
- Human Reproduction Update with impact factor 7.042
- Molecular Human Reproduction with impact factor 3.005

Campus Activities and Data Collection

- Campus / Workshops
  - Meetings are organised across Europe by Special Interest Groups and Task Forces
  - Visit www.eshre.eu under CALENDAR
- Data collection and monitoring
  - European IVF Monitoring Group data collection
  - PGD Consortium data collection
ESHRE Activities

- Embryology Certification
- Guidelines
- Position papers
- News magazine “Focus on Reproduction”

ESHRE COMMUNITY

RSS feeds for news in reproductive medicine

Since launch 12/2009: 1,360 Fans

Since launch 12/2009: 190 followers
(journalists, scientific organisations, patient societies, governmental bodies)

Retweets to MHR

ESHRE Membership (1/3)

TOTAL MEMBERSHIP*: 5 659 members

* as of July 2010
**ESHRE Membership (2/3)**

<table>
<thead>
<tr>
<th></th>
<th>1 yr</th>
<th>3 yrs</th>
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<tr>
<td>Ordinary Member</td>
<td>€ 60</td>
<td>€ 180</td>
</tr>
<tr>
<td>Paramedical Member*</td>
<td>€ 30</td>
<td>€ 90</td>
</tr>
<tr>
<td>Student Member**</td>
<td>€ 30</td>
<td>N.A.</td>
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*Paramedical membership applies to support personnel working in a routine environment such as nurses and lab technicians.

**Student membership applies to undergraduate, graduate and medical students, residents and post-doctoral research trainees.

**ESHRE Membership – Benefits (3/3)**

1) Reduced registration fees for all ESHRE activities:
   - Annual Meeting
     - Ordinary: € 480 (€ 720)
     - Students/Paramedics: € 240 (€ 360)
   - Workshops*
     - All members: €150 (€ 250)

2) Reduced subscription fees to all ESHRE journals – e.g. for Human Reproduction €191 (€ 573)

3) ESHRE monthly e-newsletter

4) News Magazine “Focus on Reproduction” (3 issues p.a.)

5) Active participation in the Society’s policy-making

*Workshop fees may vary

**Special Interest Groups (SIGs)**

The SIGs reflect the scientific interests of the Society’s membership and bring together members of the Society in sub-fields of common interest.

- Andrology
- Psychology & Counselling
- Early Pregnancy
- Reproductive Genetics
- Embryology
- Reproductive Surgery
- Endometriosis / Endometrium
- Stem Cells
- Ethics & Law
- Reproductive Endocrinology
- Safety & Quality in ART
Task Forces

A task force is a unit established to work on a single defined task / activity

- Fertility Preservation in Severe Diseases
- Developing Countries and Infertility
- Cross Border Reproductive Care
- Reproduction and Society
- Basic Reproductive Science
- Fertility and Viral Diseases
- Management of Infertility Units
- PGS
- EU Tissues and Cells Directive

ESHRE – Annual Meeting

- One of the most important events in reproductive science
- Steady increase in terms of attendance and of scientific recognition

Track record:
ESHRE 2010 – Rome: 9,204 participants
ESHRE 2009 – Amsterdam: 8,095 participants
ESHRE 2008 – Barcelona: 7,559 participants

Future meetings:
ESHRE 2011 – Stockholm, 3-6 July 2011
ESHRE 2012 – Istanbul, 1-4 July 2012

ESHRE 2011, Stockholm, Sweden

When: 3 - 6 July 2011
Where: Stockholmsmässan, Mässvägen 1, Älvsjö, Sweden
www.stockholmsmassan.se

Chair of conference: Kersti Lundin

Hotel and Travel:
MCI - Stockholm Office
Phone: +46 (0)8 54561500
E-mail: eshre@mci-group.com

For updates visit www.eshre.eu
ESHRE 2011, Stockholm

Keynote Lectures
Aneuploidy in humans: what we know and we wish we knew – Terry Hassold (USA)

Historical Lecture
A brave new world with a brave old humankind; quo vadimus – E. Diczfalusy (SE)

MHR Symposium – The paternal genome
Sperm chromatin packaging – B. Robaire (CDN)
The human sperm epigenome – B. Cairns (USA)

ESHRE 2011, Stockholm: Debates

This house believes that obese women should not receive treatment until they have lost weight
• Yes: Mark Hamilton (UK)
• No: Guido de Wert (NL) - TBC

Paramedical invited session: Should we pay donors?
• Yes: Herman Tournaye (BE)
• No: Laura Witjens (UK)

Annual Meeting – Pre-Congress Courses

• PCC 1: The challenges of embryo transfer (Paramedical Group)
• PCC 2: The blastocyst: perpetuating life (SIG Embryology and SIG Stem Cells)
• PCC 3: From genes to gestation (SIG Early Pregnancy and SIG Reproductive Genetics)
• PCC 4: Lifestyle and male reproduction (SIG Andrology)
• PCC 5: Ovarian ageing (SIG Reproductive Endocrinology)
• PCC 6: The impact of the reproductive tract environment on implantation success (SIG Endometriosis/Endometrium)
• PCC 7: Adhesion prevention in reproductive surgery (SIG Reproductive Surgery)
### Annual Meeting – Pre-congress Courses

- **PCC 8**: Theory and practice update in third party reproduction  
  (SIG Psychology and Counselling)
- **PCC 9**: Ethical aspects of non-invasive prenatal diagnosis  
  (SIG Ethics & Law)
- **PCC 10**: Patient-centered fertility services  
  (SIG SQUART)
- **PCC 11**: Clinical management planning for fertility preservation in female cancer patients  
  (TF Basic Science and TF Preservation in Severe Disease in collaboration with the US OncoFertility Consortium)
- **PCC 12**: Opportunities for research in female germ cell biology  
  (TF Basic Science)
- **PCC 13**: Assisted reproduction in couples with HIV  
  (TF Fertility and Viral Diseases)
- **PCC 14**: Prevention of infertility – from preconception to post-menopause  
  (TF Reproduction and Society)
- **PCC 15**: Hot topics in male and female reproduction  
  (ASRM exchange course)
- **PCC 16**: Academic Authorship programme  
  (Associate Editors ESHRE journals)
- **PCC 17**: Science and the media, an introduction to effective communication with the media  
  (Communications SubCommittee ESHRE)

### Certificate of attendance

1. Please fill out the evaluation form during the campus
2. After the campus you can retrieve your certificate of attendance at [www.eshre.eu](http://www.eshre.eu)
3. You need to enter the results of the evaluation form online
4. Once the results are entered, you can print the certificate of attendance from the ESHRE website
5. After the campus you will receive an email from ESHRE with the instructions
6. You will have TWO WEEKS to print your certificate of attendance
Commercial Relationships / Potential Conflict of Interest

- Infertility Network UK operate a corporate partnership scheme which offers different levels of partnership and allows companies to sponsor the charity’s activities enabling the charity and corporate organisations to make an active and visible commitment to the development of high quality patient support and care. In the UK the Assn. of British Pharmaceutical Industries do not permit such companies to advertise their products to patients directly nor would I N UK agree to as we must remain independent.
- Accordingly both I N UK and our current corporate partners, Ferring Pharmaceuticals, Merck Serono, and Casmed do not publicise their product to our members/beneficiaries.

Patient-Centred Fertility Care

Patient Perspective

Clare Lewis-Jones MBE
Chair – Fertility Europe
And
Chief Executive
Infertility Network UK

Learning Objectives

- An understanding of the need for information, support, empathy, and honesty from clinics
- What clinics can do to help patients and provide patient-centered care
- The role of the Internet
- The role and importance of patient organizations’ as a partner with clinics in improving the patient journey and experience
- The importance of emotional support and counselling for couples going through fertility treatment
Topics to be covered

• What do we mean by “patient centred”?
• Emotional impact of infertility
• Do different patients interpret “patient-centred” in different ways? Perhaps “Patient Friendly”?
• The safety and efficacy of treatment in relation to patients autonomy.
• Just what is the “bottom line” for patients in relation to patient-centred care?
• How ART clinics might address patients concerns.
• The role of the Internet
• How patient organisations can help

Definition of “Patient Centred Care”
The Institute of Medicine

| Definition of “Patient Centred Care” | Compassion, empathy and responsiveness to needs, values and expressed preferences
| Care that is respectful of and responsive to individual patient preferences and needs and that is guided by patient values | Co-ordination and integration |
| Information, communication and education |
| Physical comfort |
| Emotional support, relieving fear and anxiety |
| Involvement of family and friends |

Results of a survey performed by the National infertility Awareness Campaign in 1997 on the emotional and financial impact of infertility

Kerr J et al 1997

• Tearfulness 97%
• Depression 94%
• Anger 84%
• Loss of sex drive 80%
• Inadequacy 72%
• Guilt / Shame 62%
• Envy/jealousy of pregnant women 2%
• Sadness 2%
• Helplessness 1%
• Despair 1%
Suggestions as to why patients feel these emotions

ANGER -
With themselves.
With Society.
With the NHS.
With the clinic.

SHAME -
Why me?
Why us?
I’m letting my partner down.
I’m letting my doctors down.

FRUSTRATION
Everything seems to take so long
Why aren’t I pregnant yet?
Why did the treatment fail -
again?

DENIAL
But there has never been
a history of this in my family
What the hell am I/are we
doing here?

FEAR
What will happen?
Who will I see and why?
What questions will we be asked?
Will we know the answers?

DEPRESSION
Especially as the months &
years go by

ISOLATION
Nobody understands
My brothers/sisters/friends
all have children
Too private/personal to
talk to people about

Fears of remaining childless

- The following were fears described by a member of More to Life on one of our forums:
  - Getting old and having no one.
  - Getting ill and having no one to care.
  - Never moving on from this and living life to the full!
  - Having lots of regrets for not trying harder to have a child one way or another.
  - Having no one phone me - i.e. a daughter or a son - to say “hi mum”.

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Page 19 of 128
And at the end of all that???

TIRED!

Loss of confidence
Lack of self-esteem
All of the emotions discussed are exhausting

The emotional impact cannot be under-estimated

One in five respondents to the Kerr et al survey indicated they had experienced suicidal thoughts whilst going through infertility

The wife who could not face life without children

The funding of fertility treatment affects patients views in relation to patient autonomy and patient friendly treatment

• In the UK it is estimated that approx. 70-80% of IVF takes place in the private sector
• Poor NHS funding leading to "Treatment by Postcode" or "Treatment by bank balance"
• Feel they need to take these risks – particularly if they can only afford to pay for one cycle of treatment
• If a patient is paying for their treatment should they have more say in that treatment?
The patients’ perspective on fertility care: a systematic review
E.A.F. Dancet et al 2010

- Results:
  - “Overall, fertility patients want to be treated like human beings with a need for: medical skills, respect, coordination, accessibility, information, comfort, support, partner involvement and a good attitude of and relationship with fertility clinic staff”

Patient-centred infertility care: a qualitative study to listen to the patient’s voice
Dancet, E A F et al 2011

- Method: 14 focus group discussions were organised with patients (n = 103) from 2 European countries to find out about patients’ positive and negative experiences with infertility care
- Results: The patient-centredness of infertility care depends on 10 detailed dimensions, which can be divided into system and human factors, and there is two-way interaction between both kinds of factors

System factors
(In order of patients priority)

1. Provision of information
2. Competence of clinic and staff
3. Coordination & integration
4. Accessibility
5. Continuity and transition and physical comfort

Dancet, E A F et al 2011
Human factors
(In order of patients priority)
1. Attitude of and relationship with staff
2. Communication
3. Patient involvement and Privacy
4. Emotional support

Conclusions

• “This study provides a details patient’s perspective of the concept “patient-centred infertility care” and an interaction model that aids understanding of the concept.”
• “Fertility clinics are encouraged to improve the patient-centredness of their care by taking in to account the detailed description of the dimensions of patient-centred infertility care, and by paying attention to both system and human factors and their interaction when setting up “patient-centred improvement projects.”

“Patients’ attitudes to medical and psychosocial aspects of care in fertility clinics: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme”
L. Schmidt et al 2003

• 2250 patients responded – 80% response rate
  – Vast majority considered a high level of medical information and patient-centred care as important
  – Fewer felt that professional psychosocial services were important and/or had the intention to use these services
  – Main predictor of perceived importance in patient-centred care and professional psychosocial services was high infertility related stress in the marital, personal and social domain
Conclusions

- A supportive attitude from medical staff and the provision of both medical and psychosocial information and support should be integral aspects of medical care in fertility clinics.
- Although only a minority of the participants perceived professional psychosocial services as important, they should be available for patients whose infertility causes them much strain, especially for patients whose marital relationship suffered much because of infertility.

With apologies to UK clinics...

- Results of complaints received by the Human Fertilisation & Embryology Authority 2007/08
  - Attitude (Human factor – Priority 1) 1
  - Response (Human factor – Priority 2) 1
  - Incident (System factor – Priority 2) 2
  - Consent (Human factor – Priority 2) 3
  - Finance & Administration (System factor – Priority 1) 7
  - Information (System factor – Priority 1) 8
  - Other 8
  - Consultation Inc. clinical treatment (Human factor – Priorities 1 & 2; System factor – Priority 2) 30

Information
(System factor: Priority 1)

- Conflicting information regarding sperm donation
- Overwhelming quantity of information
- Insufficient information regarding failed/abandoned cycles
- Lack of information and lack of staff concern
- Incorrect and lack of information
Consultation and Clinical treatment
(Human factor – Priorities 1 & 2)

- Concern about type of treatment offered
- Insufficient information regarding donor anonymity
- Donor details requested 5 months late
- Poor treatment
- Centre did not act in best interests of patients
- After care following treatment
- Doctor didn’t know patient and provided incorrect information

Recurrent theme

- Matches closely the issues raised by patients in general feedback to the HFEA
- In particular the quality and timeliness of information and emotional support received

Discussion

- Complaints remain low in relation to number of treatments per year – are patients nervous of complaining?
- Rushed consultation and a lack of understanding or empathy and failing to listen to patients is a common complaint about consultation with clinicians
- Complaints also arise because of differences in diagnosis when patients change to another clinic
- Lack of clarity and information for patients about costs – hidden extras e.g. scans/blood tests
Information via the Internet

- A fantastic thing! But a dangerous thing!
- ANYONE can set up a web site!
- Practically impossible to police!
- Too much information?
- Much of it inaccurate.
- Huge potential for conflicting information.
- Trying to compare clinics success rates from their web sites is impossible.
- Great for anonymity but stops patients meeting face to face.

Social Networking

- Facebook
  - “Facebook is a social utility that connects people with friends and others who work, study and live around them. People use Facebook to keep up with friends...”
  - 600 million users as of 5.1.11
  - In March 2011 it was it was reported that Facebook removes approximately 20,000 profiles from the site every day for various infractions
  - HARD TO CONTROL CONTENT!

Social Networking

- Twitter
  - “Twitter is without doubt the best way to share and discover what is happening right now”
  - Twitter was created in March 2006. Since then Twitter has gained popularity worldwide and is estimated to have 200 million users, generating 65 million tweets a day and handling over 800,000 search queries per day. It is sometimes described as the "SMS of the Internet."
  - NO CONTROL!
Blogs

- Most blogs are interactive, allowing visitors to leave comments and even message each other via widgets on the blogs and it is this interactivity that distinguishes them from other static websites.
- Many blogs provide commentary or news on a particular subject; others function as more personal online diaries. A typical blog combines text, images, and links to other blogs, Web pages, and other media related to its topic. The ability of readers to leave comments in an interactive format is an important part of many blogs. Most blogs are primarily textual, although some focus on art, photographs, videos, music, and audio.
- As of 16 February 2011 (2011-02-16), there were over 156 million public blogs in existence.
- NO CONTROL!

Potential for good uses of the Internet!

Patient-centred care: using online personal medical records in IVF practice

- The study aimed to specify and implement a patient-centred and process-directed Personal Medical Record (PMR) for IVF patients and assess the patient-perceived usefulness of the embedded components.
- Researchers designed, implemented and evaluated a patient-accessible medical record specifically for patients undergoing a course of assisted reproduction (IVF or ICSI)
Some points made in Discussion section in published paper

• Patient-centred internet tools that are tightly integrated into clinical practice, such as the PMR in this study, are feasible and offer useful information and functions that are not yet available to IVF patients.
• More evidence needed on the clinical benefits
• Assessments of outcomes such as a PMR's influence on patient participation, patient empowerment, psychosocial variables and even pregnancy rates are much needed.

Given the fact that people are increasingly using the Internet to communicate and receive communications, I believe this is an exciting step forward in contributing to improvements in patient-centred care.

Patient Organisation websites

• Full of information
• Relevant to their country
• Chat rooms
• Forums
• Need to be carefully managed/transparent/impartial
• Fertility Europe website
  www.fertilityeurope.eu

Some ideas
How Can Clinics Help “Get It Right” for the Patients?

- Information
  - Give patients written information on all aspects of their investigations/treatment right the way through their time at the clinic in a range of languages/formats
  - Responsible use of the Internet
  - Costed treatment plans
  - Information evenings

How Can Clinics Help “Get It Right” for the Patients?

- Communication
  - Ensure patients know who to contact if they have questions/concerns
  - Responsible use of the Internet
  - Access to a counsellor - within the clinic and externally

How Can Clinics Help “Get It Right” for the Patients?

- Awareness
  - Think about how you give the patients their results - especially if negative obviously
  - Does the patient appear to be being impatient? Be aware that this might be the one and only IVF attempt they could afford
  - Remember - patients are trying to achieve possibly the most important thing in a couples lives
Environment

- Allocate area / space where patients can go for privacy
- Avoid using same waiting room as ante-natal clinic
- If not possible, then remove posters / literature which may upset or offend

Counselling

- Should be available at ALL clinics
- Should be available at all stages of treatment - i.e. Before, during and after
- Basic training in counselling for ALL clinic staff
- Leaflet explaining benefits of counselling and how to access it given to all patients

Time

- The most expensive thing of all, but almost the most important
How Can Patient Organisations Help?

- Access to personal experiences
- Access to good and impartial information
- Websites with interactive chat rooms and forums – must be managed efficiently
- Self-help
- Mutual help
- Removes the feelings of isolation

What information do patients need?

- Clinics must remember that their patients are people – and not numbers
- Clinics to be consistent
- Clinics to have standardised information
- Clinics to be honest
- Clinics to be strong
- Clinics to be supportive
- Clinics not be to divisive or blaming others

Idea!

Leaflet about the "Patient-centred care, Patient-friendly" fertility treatment and Patient Autonomy? ESHRE?
References

1. Kerr J, Brown C, Balen AH. "The experiences of couples who have had infertility treatment in the United Kingdom; results of a survey performed in 1997". Hum Reprod 1999; 14:934-8


Thank you
Patient-centred, patient-friendly or high-quality ART?

Guido Pennings

Pre-congress course Safety and Quality in ART, 27th annual meeting ESHRE, Stockholm, 3-6 July 2011

I have no conflict of interest

Definition

Patient-friendliness corresponds with 1 dimension of the total picture and cannot serve as the general label without creating confusion.

Different institutes and authors give a different content to the major dimensions. My only concern are the morally relevant elements and aspects covered in the analysis?

The main contribution of the discussion on patient-friendliness is that it brought to the front the importance of other dimensions beside safety and effectiveness.

For sake of a better label: high quality ART.
High quality ART

The future: high quality ART:
1. cost-effectiveness
2. equity of access
3. minimal risk for mother and child
4. treatment choice for patient

The 4 main principles in bioethics (Beauchamp & Childress)

One should simultaneously try to maximise all 4 criteria. There is no fixed ranking between the principles. The different values should be balanced depending on the specific circumstances.


1. Cost-effectiveness

NORMATIVE BASIS: BENEFICENCE

• The optimal use of scarce resources MAXIMISES WELL-BEING (utilitarianism)

• Three levels of distribution of scarce resources:
  – Between health care and other societal needs (education etc.)
  – Between infertility and other diseases (cancer etc.)
  – Between patients for infertility treatment.

• Money spend on cost-ineffective treatment deprives other patients of the treatment they need.

Cost-effectiveness

• A health care system that offers equitable access to basic health care services is only viable when the interests of the individual patient and the social system are balanced. Patients have a right to the most cost-effective treatment but not to the most effective treatment (regardless of costs).

• There are numerous instances in which ART can be performed in a less costly way
  – Use of clomiphene citrate for ovarian stimulation in IUI cycles
  – Offer 6 IUI cycles in case of mild male factor infertility, unexplained infertility and mild endometriosis

Finding: less than half of the practitioners in the Netherlands follow the recommendations on IUI of the professional organisations
2. Equity of access

NORMATIVE BASIS: JUSTICE

• If the wish for a child is a basic need, then it is a duty of society to ensure equity of access. The 'ability to pay' should not be a criterion to obtain treatment.
• The allocation of public funds generates an obligation for practitioners to work cost-effectively and to minimise the costs.
• Balancing different criteria simultaneously: access (reimbursement) and cost-effectiveness. Reimbursement policy should avoid unwanted effects:
  – E.g., IVF being offered as first option
  – E.g., a patient opts for a treatment that costs her the least while it is the most expensive for society.
In general, cost-effective treatment will increase equity.

3. Risk minimisation

NORMATIVE BASIS: DO NO HARM (non-maleficence)

• The main current risks are connected to the stimulation:
  – OHSS
  – multiple pregnancies (detrimental for both mother and children)
• New movement away from standard 'aggressive' stimulation towards 'soft', 'mild', 'minimal stimulation', 'natural' ... IVF. This indicates again a major change in the value hierarchy.
• Again, guidelines (about monitoring, embryo transfer etc.) are not followed by many clinics in practice. Coercive legislation is a necessity in many countries.

4. Treatment choice for the patient

NORMATIVE BASIS: AUTONOMY

• The essence of patients rights: when there are different possible treatments, all options must be discussed with the patients in order to allow them to choose.
• Psychological, physical and social stress of IVF is high.
  – Psychological distress is the main reason why patients drop out (Olivius, 2004)
  – Mild stimulation has fewer side-effects and causes less stress (Verberg et al., 2008)
Treatment choice for the patient

Breast cancer
Radical mastectomy: value: survival / life extension
Conservative surgery with radiotherapy: value: self image

The doctor cannot evaluate / has no expertise on the last value.
The doctor focuses mainly on medical interests.

There are important values beside survival.

Conclusion: the doctor is neither the best, nor the only person to decide what is in the patient’s best interest.

Infertility
IVF / ICSI: value: success rate / child
Conservative or non-IVF treatment: value: peace of mind

The doctor cannot evaluate / has no expertise on the last value.
The doctor focuses mainly on medical interests.

There are important values beside success rate.

Conclusion: the doctor is not the best, nor the only person to decide what is in the patient’s best interest.

Stress is to a large extent explained by
- fear of the unknown,
- anxiety about hormone injections and
- concerns about side effects of the drugs (Hammarberg, 2003; Pistorius et al., 2006)

Relevant aspects on which treatment may differ include not only success rate, but also stress, psychological burden and financial aspects. The patient should have a major say in weighing all these factors. She (they) should be able to choose for a less effective but considerably less burdensome treatment.
Treatment choice for the patient

- Patients preferences were rarely studied or considered in reproductive medicine: they were (and still are) often assumed.
- When patients are offered a choice between different treatments, they do not automatically opt for the most effective one.
  - Van Empel et al. 2011: patients were willing to trade off a higher pregnancy rate for patient-centredness than physicians recommended them to (discrete choice experiment).
  - Hojgaard et al., 2001: patients preferred low stimulation cycle.

More studies on the emotional, psychological and physical advantages and disadvantages of alternative stimulation protocols are needed.
- Eijkemans et al., 2006: compares the effectiveness, health economics (costs) and patient discomfort (quality of life or psychological burden) of 2 treatment strategies that differ in ovarian stimulation protocol and embryo transfer policy.

The comparison of treatment procedures requires a new measure of success which must be a cumulative success rate within a certain time period.

Patient-centred approach

Depends on how one defines well-being

1. Desire satisfaction: a treatment is good for the person / couple because it realises the desire they have.
   - subjective standard
2. Value realisation: a treatment is good for the person / couple because it realises / creates certain states (regardless of the person’s desire)
   - objective standard

Does a patient-centred / patient-friendly approach refer to the subjective or objective well-being of the patient?
Desire vs. value

First example: parenthood

Desire-satisfaction: fertility treatment is good for a couple because it realises their wish for a child

Value-realisation: fertility treatment is good for a couple when it creates a situation which increases the well-being of the person, i.e., it is in the best interests of people to have a child.

- Parents raising children are significantly more depressed and emotionally distressed than childless adults (Umberson & Gove, 1989)
- Parents with young children report far more depression, emotional distress, and other negative emotions than non-parents (Everson & Simon, 2005)
- Parents of grown children have no higher well-being than adults who never had children (McLanahan & Adams, 1989)

Why are we making all these people unhappy?

Patient-centred approach

Example: patients with spontaneous pregnancy prospects close to 40% want to have treatment immediately

1. Desire satisfaction: immediate treatment is in the patients' interests.
   - feelings of frustration and uncertainty

2. Value realisation: postponing treatment is best for the person / couple
   - prevents unnecessary medical, financial and psychological costs

Patient-centred approach

Example: patients want a treatment that does not have a higher cost-effectiveness than no treatment (expected management of "wait and see")

RCTs have shown that no treatment is as effective as current first-line treatments for unexplained infertility (Wordsworth et al., 2011)

1. Desire satisfaction: treatment is in the patients' best interests.
   - perception by couples of their own state (infertile)
   - their desire to receive tangible treatment
   - low acceptability of waiting without treatment (Bhattacharya et al., 2008)

2. Value realisation: postponing treatment is best for the person / couple
   - prevents unnecessary medical, financial and psychological costs

Is it acceptable to spend money purely for the psychological benefit of the patient?
Patients' preference and multiple pregnancies

Example: Patients want to transfer a higher number of embryos back than prescribed by the good practice guidelines. In many countries (EIM data), the multiple pregnancy rate is around 20%.

1. Desire satisfaction:
   - love twins
   - ready-made family
   - better twins with a handicap than no child

2. Value realisation: SET has
   - highest cost-effectiveness (taking into account all indirect costs)
   - lowest risks for mother and children
   - prevents unnecessary medical, financial and psychological costs

Very hard case: patients keep insisting replacement of multiple embryos even after confrontation with scientific facts. Apparently, the value scale of the patients differs from those of the doctors regarding:

- acceptability of risks
- desirability of twins

Question: does more autonomy of the patient imply that the doctor should (within reasonable limits) replace the number of embryos that the patient wants?

Answer: no, since the approach demands the balancing of all 4 ethical principles simultaneously.

Shared decision-making

General issues raised here:
- deviations from the good practice guidelines because the patient demands or prefers it.
- risks of overtreatment because the patient demands or prefers it.

Proposed solution: shared decision-making

This is the logical solution to include the people involved from their different perspectives:
- the doctor as an expert in health and medicine, and
- the patient as an expert on her values and preferences, social circumstances, attitudes towards illness and risks etc.

The third party involved is the society through legislation and reimbursement policies.
Conclusions

High quality ART should include at least four components: cost-effectiveness (maximising well-being), equity of access (justice), minimal risk for mother and child (non-maleficence) and treatment choice for the patient (autonomy).

The introduction of high quality IVF demands major changes in the general way of looking at ART. It demands a relatively complex balancing of multiple criteria that should be introduced step by step.

Much more effort should be invested to find out what the non-medical effects of different protocols and procedures are and the patients should be offered the choice among these. Simultaneously, patient autonomy should be restricted on the basis of the other ethical principles.
« Shared decision making » in ART

Annick Delvigne, MD, PhD
Head of ART center
Saint-Vincent Clinic - CHC
Liège- Belgium

Disclosure:

• Nothing to disclose

Plan : Learning Objective

• Definition of « shared decision making » (SDM)
• From theory to practice
• Medical application of « shared decision making »
• « shared decision making » in ART?
  – is it already applied in ART?
  – Which fields of ART should be concerned?
  – Survey in 2 ART centers: results and perspectives
Introduction

• First description:
  – "philosophy of medicine" by Szasz and Hollender in 1956 (Arch Intern Med)
  – "physician-patient relationship", by Emanuel et al., in 1992 (JAMA)

• Increasing papers from mid-1990

• Paradigm shift: "SDM" instead of the old notion "doctor knows best"

• 1998: "health expectation" journal

"Informed shared decision making, partnership, patient involvement, patient-centred care, evidence-based patient choice..."

Why to share decisions?

• SDM is part of Patient Centered Care (PCC) which is recognized as a measure of quality of healthcare (AHRQ in USA):
  – Improves communication
  – Promotes patient involvement in care
  – Creates a positive relationship with the physician
  – Improves the adherence to treatment

• Is there a real implementation of PCC?
  – "always" in 45-62% of patient encounters
  – 6 to 18% of patients have "never" experimented PCC

• Why is it so difficult?
  – It changes the traditional patterns of interaction
  – Time and cost consuming
  – Vagueness about the concept

Definition: why?

"Both patients and physicians participate"

But...

• Different types and levels of patient and physician participations
• It is so evident that no definition is required
• Own interpretation varies between individuals

→ Confusion and ambiguity
→ Interpretation of the studies?
→ ? Dissatisfaction for patients and doctors
Definition

• Do we talk about the same thing?
  – Review of 76 papers: Clear and consensual definition?
    • Several authors clearly define SDM
    • 1/3 cite these authors but 30% are inconsistent
    • 28% don’t use any definition
  ➔ Several clear definitions of SDM have been proposed but only a minority of the authors use it adequately.

Moumjid et al., 2007

Definition

• Information exchange in two ways
  – Available options
  – Best evidence in risk and benefits
  – Patient specific characteristics and values

• Deliberation and Interaction
  • Work of both parties to reach an agreement
  • Both parties have an investment in the ultimate decision
  • Both actors assume their responsibilities
  ➔ Share of * all steps of the decision process
  * ownership of the decision making

Coulter et al. 1999; Charles et al., 2006; Towle et al., 1999

Definition

• This process
  – Means that communication is crucial among all those involved
  – Depends of the commitment of both parties
  – Implies that the doctor acknowledges the legitimacy of the patient’s preference
  – Implies that the patients accept also to share the responsibility for the treatment decision
  – May be influenced by cultural affiliations, educational levels and trust between parties
  – May be extend to the family or close friends

Coulter et al. 1999; Charles et al., 2006; Towle et al., 1999
Definition

• 3 interaction models
  – Paternalistic
  – Informed
  – Shared decision-making
4th model: “Physician-as-agent for the patients”
  • Patient communicates her preferences
  • Physicians has the technical expertise
  • Physician “resolves the dilemma” and is sole decision-maker and assumes responsibility for directing the health care utilization for the patients.

Definition: not synonymous !

• “Informed Decision Making”
  – Physician transfers the knowledge to the patient
  – Patient is sole decision maker

• SDM
  – Patient and physician mutually inform each other
  – Together they reach an common agreement
  – Two actors share responsibility

  → Confusion...

US Preventive Services Task force’s definition of SDM

“SDM is a particular process of decision-making by the patient and clinician in which the patient:
1) understands the risk or seriousness of the disease or condition to be prevented;
2) understands the preventive service, including the risks, benefits, alternatives, and uncertainties;
3) has weighed his or her values regarding the potential benefits and harms associated with the service;
4) has engaged in decision making at a level at which he or she desires and feels comfortable.”

Kaplan et al., 2004
From theory to practice: “good tools for good work”

- Analytic Hierarchy Process (AHP)
  - Method to create a framework that improve patient-provider communication, clinical decision making and quality of patient care

- Conceptual framework by Charles at al.
  - Identification of different analytic stages of SDM
  - Definition of major characteristics of SDM

From theory to practice

- Complex decision:

  - Intuition and uncertainty are inescapable
  - Bias and heuristics may distort the SDM

AHP: theoretical model

- Multicriteria method
  - Theoretical underpinnings
  - Practical applications in wide variety of complex circumstances

- Hierarchy and organizational framework
  - Inputs: comparison between 2 decision elements
  - Output: simple scales derived of pairwise comparison
  - finally: built-in measure of the consistency of the judgments
AHP in practice... Dolan, J.D., 2008

Steps in the Analytic Hierarchy Process (AHP)

1. Define the decision elements:
   - goal of the decision
   - the alternatives
   - the criteria for selecting the best alternative

2. Construct the decision model:
   - Use of pairwise comparisons to evaluate the importance of each criterion
   - Use of pairwise comparisons to evaluate the attractiveness of each alternative

3. Determine the decision strategy:
   - Use of a mathematical model to calculate the relative importance of each alternative
   - Use of a mathematical model to calculate the overall attractiveness of each alternative

4. Synthesize the results of the pairwise comparisons:
   - Use of a mathematical model to calculate the overall attractiveness of each alternative

5. Decision analysis:
   - Use of a mathematical model to calculate the overall attractiveness of each alternative
   - Use of a mathematical model to calculate the overall attractiveness of each alternative

Conceptual framework

- Context of life threatening disease

- 3 steps:
  - Information exchange: to ways exchange
  - Deliberation about treatment options:
    - The process of expressing and discussing treatment preferences
    - Consensus or negotiation as equal partners (An expert with a vulnerable patient)
    - Create a safe environment where the patient feels comfortable to discuss and question
  - Creating the treatment to implement

**Conceptual framework**

<table>
<thead>
<tr>
<th>Model of shared decision making*</th>
<th>Model</th>
<th>Passive</th>
<th>Autonomous</th>
<th>Collaborative</th>
<th>diced model</th>
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<tr>
<td>Subjective bias</td>
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<td>collaborative</td>
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<td>Power and control</td>
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<tr>
<td>Degree of control</td>
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<td>High</td>
<td>High</td>
<td>High</td>
<td>High</td>
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<td>Patient's role</td>
<td>Passive</td>
<td>Autonomous</td>
<td>Collaborative</td>
<td>Passive</td>
<td>Passive</td>
</tr>
</tbody>
</table>

Description of the various analytical stages
Switching or choose among 3 models during encounter is possible
Model used to teach and to test SDM


**Adhesion of patients and physicians**

- **Doctors survey in "oncology clinic"**

<table>
<thead>
<tr>
<th>% surgeons</th>
<th>oncologists</th>
</tr>
</thead>
<tbody>
<tr>
<td>autonomously</td>
<td>1.2%</td>
</tr>
<tr>
<td>informed</td>
<td>24.2%</td>
</tr>
<tr>
<td>SDM</td>
<td>31.2%</td>
</tr>
<tr>
<td>others</td>
<td>43.5%</td>
</tr>
</tbody>
</table>

Doctors survey in "oncology clinic"

- **Patients:**

Breast cancer (200), Prostate disease (80), Fracture (50), Chronic and painful disease (120), Gynecology (50), Multiple sclerosis (90), HIV/AIDS (30), Infertility (30), Cardiac disease (30)

- **Older and less educated individuals: most likely to prefer passive roles.**

- 3491 patients: cancer: 26%, active: 49%, collaborative: 25%

- SDM requires trust in physician

Charles et al., 2003

**Medical applications**

- Oncology: life threatening situations +++
- Chronic and painful disease +
- Gynecology: postmenopausal treatment +

- Few studies in infertility field!
  - Is it really SDM?
  - When it is informed DM or simple informed consent?
  - Different steps of the treatment
  - Different specific situations
SMD in ART: at what stage?

• Assessment of infertility? Yes...

  – Is laparoscopy and or HSG mandatory before treatment?

<table>
<thead>
<tr>
<th>Laparoscopic results</th>
<th>4</th>
<th>1</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td>Vaginal</td>
<td>75</td>
<td>1</td>
<td>76</td>
</tr>
<tr>
<td>laparoscopy</td>
<td>32</td>
<td>15</td>
<td>47</td>
</tr>
<tr>
<td>Total</td>
<td>107</td>
<td>16</td>
<td>123</td>
</tr>
</tbody>
</table>

Sensitivity: 88.2% and specificity 97.8% // PPV: 98.6% and NPV: 78.8%

→ Young patients with normal HSG - delayed laparoscopy
→ ICSI for male infertility: avoid laparoscopy

Ubaldi et al., 1998

SMD in ART: at what stage?

• To chose the treatment? Yes...

  o Adaptation of lifestyle: weight, smoking, drinking...

  o First line treatment:
    • IVF/surgery: vasectomy, tubal sterilization
    • IUI/IVF
    • Ovarian stimulation in IUI
    • Classical fecundation/ICSI
    • ICSI/ donor insemination
    • Number of embryo to transfer

Number of embryo to transfer?

• Multiple pregnancy rate in Europe: 23%
• Multiple pregnancy in a program of eSET: 12%
• Law in Belgium (Sweden)

<table>
<thead>
<tr>
<th>age</th>
<th>Trial 1</th>
<th>Trial 2</th>
<th>Trial 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>≤ 35</td>
<td>≤ 36–39</td>
<td>≥ 40</td>
</tr>
<tr>
<td>Trial 1</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Trial 2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Trial 3</td>
<td>0</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

• Discussion on EBM but...
• Perform eSET remains a difficult decision according to numerous factors influencing both professionals and patients

Van Peperstraten et al., 2008
Gerra et al., 2007
### SMD in ART: at what stage?

#### To chose the treatment?  
Yes...

**Specific situations:** “to approach and resolve ethical issues”

- HIV infected patient: washed sperm or donor sperm?
- Old patient: try with own oocytes or go to oocyte donation?
- Surrogate mother or adoption?
- Use IVF with PGD for “saviour sibling” etc...

Ethical decision: consensus reached by members of staff + clinical ethics committee
Ethical legitimacy of this process of decision-making?  

---

#### SMD in ART: at what stage?

#### During the treatment?  
Yes...

- Cancel the treatment in IVF in case of poor response?
  - Same PR in IVF/MII IUI/IVF stimulation (Wood et al, 2003; Freour et al, 2010)
  - No but less risk and less expensive

- IUI and multifollicular ovarian response to stimulation?
  - Cancel the cycle
  - Accept the multiple pregnancy risk
  - Perform follicular reduction
  - Shift in rescue IVF

- In case of OHSS risk?
  - Chose one of the preventive attitude (Delvigne et al, 2002)
  - Cancel the cycle and avoid hCG

- In case of doubt of integrity of the embryo, replace the embryo or not?

---

#### SMD in ART: at what stage?

#### After the treatment?  
Yes....

- Multifetal pregnancy reduction

- Postmortem insemination in case of cryopreserved gametes

- Outcome of supernumerary embryos
  - Duration of conservation
  - Which use after the cryopreservation period
Supernumerary embryos

- Informed consent at the beginning of treatment
  - Cryopreservation for future use? "cryopreservation decision"
  - When do patients want to use it? "transfer decision"
  - Continuation? "storage decision"
    - Yes, how long?
      - Country's law or 5 years in Belgium (flexible according to couple choice)
    - No or no more: "Embryo disposition decision"
      - Donation to another couple
      - Donation for research/science
      - Discarding

Inconsistent decision regarding the child wish
Role of patient conceptualization of their embryos

SDM in ART

- Information: "decision aids"
  - Face to face
  - Informative brochures*
  - Collective information meetings*

*But often after that the type of treatment was decided...

→ Sequencing of involvement?

SDM in ART: limitations

- Cost effectiveness
  - Vaso-vasostomy
  - IUI in idiopathic infertility

- Law limits SDM
  - PGD in general or for elective indication (sex selection)
  - Use of non ejaculated sperm
  - Number of embryos to transfer, or choose the best embryo for eSET...
  - Continue IVF (own oocytes or oocytes donation) beyond a certain age
Pilot multicentric study in ART centers

• **Aim of the study:**
  - Evaluation of the Shared treatment decision in ART
    - From the patient's point of view
    - From the physician's point of view
    - Correlation between patient/physician perception
  - Information provided before and during treatment
    - Correlation between what the physician explains and what the patient perceives and understands
    - Type of decision aids proposed by physician and used by patients
  - Sharing decision for treatment modalities
    - Correlation between what the physician intends to share and what the patient feels to have chosen

Pilot multicentric study in ART centers

• **Material and methods:**
  - Questionnaire to the physicians:
    1. General
      - Level of patient's participation in treatment choice
      - Level of shared treatment decision preferred by physician
    2. Specific information provided to the couple about
      - Lifestyle and ART treatment
      - Side effects of treatment
      - Type of decision aids which were proposed
      - Pregnancy rate
    3. Which level of agreement was proposed to the patient for choosing the modalities of treatment

Pilot multicentric study in ART centers

• **Material and methods:**
  - Questionnaire to the patients to assess:
    1. General
      - Level of patient's participation in treatment choice
      - Level of patient's satisfaction in the process of choosing the treatment
      - Role and involvement wished by patient for treatment choice
    2. Specific information provided to the couple about
      - Lifestyle and ART treatment
      - Side effects of treatment
      - Which type of decision aids were proposed and used
      - Pregnancy rate
    3. Which level of agreement was proposed to the patient for choosing the modalities of treatment
Pilot multicentric study in ART centers

• Results and discussion will be presented in July at the pre-congress course ESHRE 2011

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How to measure patient-centredness

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Eline A.F. Dancet, RM, MSc, PhD-fellow
Leuven University, Belgium
Radboud University Nijmegen Medical Centre, The Netherlands

PhD promotors: Prof. J. Kremer, Prof. T. D’Hooghe, Dr. W. Nelen

Nothing to disclose

Learning objectives

To understand:

• The general concept Patient-Centred Care (PCC)
• The specific concept Patient-Centered Infertility Care (PCIC)
• The importance of providing PCIC to fertility patients
• The available and future instruments to measure PCC
• The usefulness of measuring patient-centredness
What is Patient-Centred Care (PCC)? (1)

Patient-centredness: an essential element of high-quality care

What is PCC? (2)

- PCC is care respectful of and responsive to individual patients’ needs and values, and ensuring that patient values guide all clinical decisions ¹
- PCC is quality of care through the patients’ eyes ²
- PCC increasingly receives attention from policymakers and healthcare organizations ³, ⁴, ⁵

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1. Corrigan (IOM), 2001
2. Sixma, 1998
3. Bengoa (WHO), 2006
5. Frampton et al., 2008
What is Patient-Centred Infertility Care (PCIC)?

Ten dimensions of PCIC:
1. Information provision
2. Attitude of and relationship with staff
3. Competence of clinic and staff
4. Communication
5. Patient involvement and privacy
6. Coordination and integration
7. Accessibility
8. Continuity and transition
9. Emotional support
10. Physical comfort

Dancet al, 2010; Dancet, van Empel et al, 2011

An interaction model for PCIC

9 reasons to pay attention to PCIC
1. Patients have negative experiences with current fertility care.
2. PCIC is very important to fertility patients.
3. Physicians underestimate the importance of patient-centredness.
4. Lack of PCIC is a reason for changing clinics and for drop-out.
5. Treatments represent high physical & emotional burden and high drop-out.
6. 30% of the infertile couples will never achieve live birth.
7. PCIC contributed to better co-operation between patients and professionals.
8. Professionals cannot evaluate their performance regarding PCIC adequately.
9. PCIC is positively associated with higher QoL and patient satisfaction.

Dancet et al, 2010; Dancet, van Empel et al, 2011
The measurement of patient-centredness

Measuring PCIC necessary for improving PCIC

- Not the way: measuring patient satisfaction
- The way: measuring patients’ concrete experiences with relevant aspects of care 1,2

1. Patwardhan and Patwardhan et al., 2009
2. Wensing and Elwyn et al., 2003

Instruments to assess PCIC

- Actually: PCQ-infertility
- In the near future: PCIC-Europe
- For endometriosis care: ENDOCARE

1. Patwardhan and Patwardhan, 2009
2. Wensing and Elwyn, 2003

The PCQ-infertility

Patient-Centredness Questionnaire Infertility

- A country-specific measurement instrument for PCIC
- Validation study: Van Empel et al., Hum Reprod. 2010
- Available in Dutch and English
- Online available:
  - http://www.umcn.nl/PCQInfertility
Development & validation

1. Conceptualizing PCIC
   - 7 focus group discussions with 54 infertile patients
   - Analysis: 729 relevant quotes → 53 care aspects

2. Development of the questionnaire
   - Per care aspect (n=53) → 1 importance item (I)
   → 1 experience item (E)
   - Background questions

3. Validation study
   - 29 Dutch fertility clinics: 3061 patient codes
   → random sample of 1189 patient couples

PCQ-Infertility was examined on:

- Item quality
  - Missings, skeweness, importance
- Reliability
  - Cronbach’s alpha
- Validity
  - 8 hypotheses
- Quality improvement potential
  - QI = Importance x (3 – Experience)
- Discriminative power
  - Multilevel analysis

Results: quality of the PCQ-Infertility

<table>
<thead>
<tr>
<th>Response</th>
<th>75% (888 couples)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item quality</td>
<td>7 items exit → 46 items in final PCQ</td>
</tr>
</tbody>
</table>
| Reliability | Total scale α = 0.92
  - 7 reliable subscales |
| Validity | All hypotheses confirmed (p<0.01) |
## Content PCQ-Infertility

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Item example</th>
<th>Items</th>
<th>Score*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessibility</td>
<td>Access by phone of staff for questions</td>
<td>2</td>
<td>2.13</td>
</tr>
<tr>
<td>Information</td>
<td>Explanation on possible side-effects medication</td>
<td>11</td>
<td>2.03</td>
</tr>
<tr>
<td>Communication</td>
<td>Did the physician take the time</td>
<td>7</td>
<td>2.53</td>
</tr>
<tr>
<td>Respect</td>
<td>Attention paid to emotional impact of infertility</td>
<td>7</td>
<td>1.98</td>
</tr>
<tr>
<td>Continuity</td>
<td>A lead physician for evaluations and decisions</td>
<td>7</td>
<td>1.95</td>
</tr>
<tr>
<td>Involvement</td>
<td>Shared decision-making if preferred</td>
<td>3</td>
<td>2.38</td>
</tr>
<tr>
<td>Competence</td>
<td>Physician was well prepared for appointments</td>
<td>6</td>
<td>2.45</td>
</tr>
<tr>
<td>Care organization</td>
<td>Need to wait &gt;3 weeks for having a first appointment with the physician</td>
<td>3</td>
<td>-</td>
</tr>
</tbody>
</table>

* Range 0 – 2

## Top 5 Quality Improvement scores

<table>
<thead>
<tr>
<th>Care aspect</th>
<th>I</th>
<th>-E</th>
<th>Q/I*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assign each couple one staff member for questions/problems</td>
<td>2.1</td>
<td>2.0</td>
<td>4.1</td>
</tr>
<tr>
<td>Supply an overview of the treatment and time schedule</td>
<td>2.3</td>
<td>1.5</td>
<td>3.5</td>
</tr>
<tr>
<td>Make each patient get access to own medical records</td>
<td>1.8</td>
<td>1.9</td>
<td>3.4</td>
</tr>
<tr>
<td>Provide information on possible side effects of medication</td>
<td>2.3</td>
<td>1.4</td>
<td>3.2</td>
</tr>
<tr>
<td>Ensure a maximum of 4 physicians in a couple’s treatment</td>
<td>2.0</td>
<td>1.5</td>
<td>3.0</td>
</tr>
</tbody>
</table>

* Range 0 – 9

## Discriminative power: large differences between clinics

<table>
<thead>
<tr>
<th>Scale</th>
<th>Range scores (scale 0 – 3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall PCIC</td>
<td>1.66 – 2.53*</td>
</tr>
<tr>
<td>Accessibility</td>
<td>1.65 – 2.63*</td>
</tr>
<tr>
<td>Information</td>
<td>1.88 – 2.88*</td>
</tr>
<tr>
<td>Communication</td>
<td>1.74 – 2.82*</td>
</tr>
<tr>
<td>Respect</td>
<td>1.21 – 2.62*</td>
</tr>
<tr>
<td>Continuity &amp; transition</td>
<td>1.44 – 2.63*</td>
</tr>
<tr>
<td>Patient involvement</td>
<td>1.74 – 2.82*</td>
</tr>
<tr>
<td>Competence</td>
<td>1.97 – 2.74*</td>
</tr>
</tbody>
</table>

Scale 1 - 100 = 40 – 87

* Significant differences with and without case-mix correction (P ≤ 0.001)
The PCQ-Infertility...

- ...is valid and reliable
- ...can identify weaknesses from patient perspective
  → allows internal quality improvement
- ...can discriminate between fertility clinics
  → allows benchmarking on PCIC

Patient Centredness Infertility Care (PCIC)-Europe

- Care all over Europe needs to be patient-centered for countries’ residents and reproductive exiles
  - Fertility patients cross borders
  - European reimbursement is coming → patients’ mobility
- Need for European benchmarking for patient-centeredness

PCIC Europe’s aim: To develop and validate a reliable instrument for the patient-centeredness of infertility care across Europe

1. Inhorn & Patrizio, 2009
2. Pennings et al., 2009
3. Shenfield et al., 2010
4. www.europarl.europa.eu
The European concept PCIC

- International multi-lingual qualitative research
  - 6 European regions; 5 languages
- The 10 dimensions of patient-centered infertility care are universal across Europe (Dancet et al 2011; in preparation)
  - 375 codes (9% new codes besides Dancet, van Empel et al, 2011)
  - Most codes (55%) discussed >3/6 regions
  - rarely detailed codes (16%) discussed in one region only
- Deep infertility care desires are universal across Europe

The PCIC-Europe Questionnaire (1)

- Development
  - Part I: 24 demographic and medical questions
  - Part II: 103 care aspects,
    - Selected from 386 codes through:
      - Experts
      - Analysis of patients’ priority lists
      - Patient representatives
    - Rated on two 4-point scales for ‘Importance’ and ‘Performance’
    - Two computed outcomes: ‘Patient-Centeredness Scores (PCS)’ and ‘Quality Improvement Indices (QII)’
  - Part III: 2 open questions
The PCIC-Europe Questionnaire (2)

- Pilot test in Flanders
- Reciprocal translation from Dutch to 4 additional languages

- Dissemination
  - Six European regions
  - At clinic level
  - Three phase strategy
  - Online Questionnaire
  - Goal: 1800 patients (300/region; ♂ & ♂)

The PCIC-Europe Questionnaire (3)

- First results: validation and reliability tests
- Adaptation → Final PCIC-Europe Questionnaire

ENDOCARE: Patient-centred endometriosis care in Europe (1)

ENDOCARE I (Dancet et al, 2011; submitted)
- Ten dimensions of patient-centred endometriosis care (PCEC)
- Valid and reliable questionnaire for Europe

ENDOCARE II (Dancet et al, 2011; in preparation)
- 13 counties at country level via patient organizations
- Determinants of patient-centredness; case-mix adjustments
- Cultural comparison of importance ratings
- European patient-centeredness benchmarking at country level
- Identification of country specific patient-centered improvement targets
ENDOCARE: Patient-centered endometriosis care in Europe (2)

ENDOCARE III (Dancet et al., 2011; in preparation)
- Postal dissemination in 2 countries at clinic level
- European patient-centeredness benchmarking at clinic level
- Identification of clinic specific PC improvement targets
- Relation between patient-centeredness of care and quality of life

Take home messages
- PCIC will bring benefit to patient and professional
- PCIC is a universal 10-dimensional concept
- Patient-centredness is an assessable quality dimension now
- Comparison specific PCQ-Infertility – universal PCIC-Europe
- European benchmarking instruments are coming to your countries and clinics
- Targets to improve patient-centredness can be set
Future research

- To identify barriers and facilitators for providing PCC
- To evaluate whether patient-centredness data influences reproductive exile
- To prospectively investigate the effect of PCIC on:
  - Patients' quality of life
  - Passive drop-out from treatment
  - Patients' decision to change clinics
- To investigate the most (cost-)effective strategy to improve PCIC
- To develop instruments to measure PCC in other patient groups
- To benchmark European countries and clinics on PCIC

Thank you

Eline.dancet@uz.kuleuven.be
I.vanEmpel@obgyn.umcn.nl

References (1)

References (2)


References (3)


- www.maripol.europa.eu
Self-operated endovaginal telemonitoring.  
A more economic and more patient friendly approach of IVF treatment

Pre-Congress Course ESHRE - Stockholm 030711
Jan Gerris, MD PhD  
Centre for Reproductive Medicine  
University Hospital  
Ghent

Introductory slide

• I will present only original material  
• The work presented is experimental work in progress  
• I have no vested commercial interests

Learning objectives

• Identify areas for improvement of ART treatment from the patient’s perspective  
• Introduce a challenging idea (SOET)  
• Explore relevant aspects of this approach  
• Describe patients’ willingness and ability to apply this approach  
• Describe initial experience  
• Describe the challenges of future work
Patient-oriented ART

• Main advances in recent years:
  – Decrease in risks of complications of ART
    • Multiple pregnancies
    • Less OHSS
  – A more patient-friendly approach:
    • Friendly ovarian stimulation
    • Natural cycle IVF
    • Self-injection of rec-gonadotropins using the “pen”
    • OPU under conscious sedation
    • Recognition of psychological stress

Patient-friendly = patient-centric ART

• Main remaining problem:
  – The need for frequent vaginal sonographic monitoring of follicular growth
  – For IVF/ICSI on average 4 to 5 sonograms
  – Many patients live at a distance from the centre:
    • Difficulty of access to treatment
    • Loss of time
    • Cost of petrol
    • Organizational stress reg. job and other kids
    • Waiting times at the centre
    • Sonograms made made by different operators

Idea: SOET
  = Self Operated Endovaginal Telemonitoring

• Patient performs vaginal sonography herself (or partner)
• At convened moments of the stimulation protocol
• After a teaching session by a specialized nurse
• Using a set-up consisting of a vaginal probe linked to a PC
• After logging-in to a specific website
• Images are sent using widely available software
• To the centre at convenient hours
• Where they are analyzed
• A reply is given by mail:
  – Dose, interval and further instructions
  – Invitation for in situ sonogram if necessary
Potential advantages of SOET

- Patients from far distances can be treated (access to treatment) (important in large countries)
- They can be treated directly, without intermediaries
- No need for an average of 5 x loss of time/energy/money
- Ecological advantage (less petrol)
- Patient and her partner can participate actively in an essential part of the treatment
- Storage of all images is possible allowing later controls
- Active participation of reproductive nurses
- Financial gain if well understood and applied by government

Reimbursement on a counted basis
Average of 140 euros/attempt (B)
Administrative burden for patient and centre

Environment

Centre

Patient

Pollution by exhaust

Petrol cost

Cost of car usage

Absence from work

Babysitting

Traffic risks

Partner reduced to driver

STRESS

Centre

Physician

Midwives...

Patient

Society (Public and private insurers)

Petrol cost

Cost of car usage

Absence from work

Babysitting

Traffic risks

Partner reduced to driver

STRESS

Average of 4.4 sonos/attempt

Early rise

Traffic stress

Long distance, loss of time

Poor access to treatment

Waiting time at centre

Sonos by variable personnel

Stress for centre

Reimbursement on a counted basis
Average of 140 euros/attempt (B)
Administrative burden for patient and centre
Who is directly involved?

- CRM
- Insurers
- Industry
- University
- Patient

For whom is SOET intended?

- 1. First phase: intended for some IVF/ICSI patients, i.e. without contra-indications
- 2. If given proper instruction by midwife + demomaterial + possibility to exercise
- 3. Back-up using traditional on site sonography
- 4. Only if informed consent
- 5. Later extension possible for other fertility treatments, early pregnancy?
Is there a “market” for SOET?

<table>
<thead>
<tr>
<th>Belgium</th>
<th>World</th>
</tr>
</thead>
<tbody>
<tr>
<td>- IVF/ICSI: stable number of ~15,000/year</td>
<td>- 1,000,000 attempts/year</td>
</tr>
<tr>
<td>- 50% = candidate for SOET</td>
<td>- Further growth likely</td>
</tr>
<tr>
<td>- Reduction of direct cost, e.g. 7,500 x 100€ = 750,000€</td>
<td>- Especially if this complicated step is simplified in large countries (USA, India, China, ...)</td>
</tr>
<tr>
<td>- Indirect cost to be calculated (health economist)</td>
<td>- Third world effect</td>
</tr>
</tbody>
</table>

What is needed?

- 1. Recruitment of patients
- 2. Instruction by midwife well-versed in sonography
- 2. Development of “sono-anatomy” of pelvis minor
- 3. Development teaching material for patients
- 4. ICT connection between centre and patient’s home (login)
- 5. Specialist in RM to analyse, interpret, decide and answer
- 6. Portable, easy-to-use, low-end SOET-device:
  - Small, light, handy, easy to use, cheap
  - For rent, lease or sale (depending on business model)

What more is needed?

- 1. Willingness to use from patients and their partners: does the patient want to make her own sonograms?
- 2. Can a woman make her own sonograms?
- 3. Can the images be sent over the internet, be analysed ex tempore, and be correctly interpreted and responded to?
- 4. Can anyone make such a device for a commercial price?
SOET project: clinical research steps

• (1) Formulating the idea
• (2) What do patients think about it? = SOET 1
• (3) Is it feasible to interpret recorded images? = SOET 2
• (4) Can a patient make reliable images after instruction by a nurse? = SOET 3
• (5) Can patients produce reliable images alone at home after a teaching session? = SOET 4
• (6) The health-economic analysis = SOET 5

SOET 1

10 questions to patients and their partners

• Study approved by EC UZG nr. 2006/330
• Both answered independently from each other
• Ample time to respond
• Random distribution over 1st and subsequent attempts
• Couples living at a distance from CRM
  – In the far West-Flanders
  – Dutch and Germans

Scoring system

• 1 = absolutely unimportant or incorrect
• 2 = of secondary importance or largely incorrect
• 3 = of some importance or there is some truth in it
• 4 = very important or very correct
• 5 = essential or completely true
The frequent drives to and from the hospital constitutes one of the heaviest burdens of IVF treatment.

<table>
<thead>
<tr>
<th>Range</th>
<th>Mean score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 – 5</td>
<td>3.24</td>
</tr>
<tr>
<td>1 - 5</td>
<td>3.12</td>
</tr>
</tbody>
</table>

I would welcome a technology that would allow me to be followed up at home without the need for frequent hospital visits (for my wife) if this treatment is as efficient and safe as the traditional one.

<table>
<thead>
<tr>
<th>Range</th>
<th>Mean score</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 – 5</td>
<td>4.32</td>
</tr>
<tr>
<td>2 - 5</td>
<td>4.24</td>
</tr>
</tbody>
</table>

I see it as a problem that I have to introduce a device in my (wife's) vagina.

<table>
<thead>
<tr>
<th>Range</th>
<th>Mean score</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 - 5</td>
<td>1.36</td>
</tr>
<tr>
<td>1 - 5</td>
<td>1.68</td>
</tr>
</tbody>
</table>
I am in favour of (my wife) making sonograms at home after a demo by a physician or a midwife, if that could avoid the frequent drives up and down.

<table>
<thead>
<tr>
<th>Range</th>
<th>Mean score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-5</td>
<td>4.00</td>
</tr>
<tr>
<td></td>
<td>4.08</td>
</tr>
</tbody>
</table>

I have my own PC

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>25</td>
<td>0</td>
</tr>
<tr>
<td>Partner</td>
<td>25</td>
<td>0</td>
</tr>
</tbody>
</table>

I am familiar with PC use and can mail images to the centre

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>24</td>
<td>1</td>
</tr>
<tr>
<td>Partner</td>
<td>24</td>
<td>1</td>
</tr>
</tbody>
</table>
If I am technically unable to make images and send them, I am prepared to learn it in order to avoid these hospital visits.

<table>
<thead>
<tr>
<th>Range</th>
<th>Mean score</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 - 5</td>
<td>4.32</td>
</tr>
</tbody>
</table>

If needed I can do it every day including weekends.

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>24</td>
<td>1</td>
</tr>
<tr>
<td>Partner</td>
<td>25</td>
<td>0</td>
</tr>
</tbody>
</table>

I value the idea of receiving a mail from the centre during the day with clear instructions on further hormone injections and other treatment steps.

<table>
<thead>
<tr>
<th>Range</th>
<th>Mean score</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 - 5</td>
<td>4.52</td>
</tr>
<tr>
<td>3 - 5</td>
<td>4.56</td>
</tr>
</tbody>
</table>
The main positive effect of SOET would be saving time:

<table>
<thead>
<tr>
<th>Range</th>
<th>Mean score</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 - 5</td>
<td>4.44</td>
</tr>
</tbody>
</table>

The main positive effect of SOET would be saving petrol:

<table>
<thead>
<tr>
<th>Range</th>
<th>Mean score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - 5</td>
<td>2.84</td>
</tr>
</tbody>
</table>

It is very important for me to minimize or exclude morning stress:

<table>
<thead>
<tr>
<th>Range</th>
<th>Mean score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - 5</td>
<td>3.20</td>
</tr>
</tbody>
</table>
Independent from any gain or loss, this evolution would mean sheer ease of treatment.

<table>
<thead>
<tr>
<th>Range</th>
<th>Mean score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-5</td>
<td>3.88</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Range</th>
<th>Mean score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-5</td>
<td>3.96</td>
</tr>
</tbody>
</table>

**SOET 2**

- Pilot (n=5) feasibility study:
  - Recording vaginal sonographies in IVF patients undergoing ovarian stimulation by one operator and interpreting them by another operator
  - Assessing the degree of concordance in clinical decision-taking when comparing “real” images with recorded images
- EC University Hospital Ghent approval nr 2006/229

**QUESTIONS**

1. Is it possible to obtain and record images by performing blind vaginal sonographies for ulterior interpretation by another operator?
2. What is the concordance between decisions taken using the “real” images versus the recorded ones?
MATERIALS

- 5 IVF patients agreed to participate to the study
- Regular IVF stimulation in all 5:
  - Short agonist scheme
  - Stimulation with either Menopur, Gonal-F or Puregon
  - According to generally accepted rules (no dosage increase if sustained follicular growth, increase by 75IU or smaller increments if no growth, withholding FSH in case of threatening OHSS = coasting)
  - As many sonographies as needed but no more (return frequency)
  - 5,000 IU HCG if at least one follicle exceeds 20x20 mm in diameter

METHODS

- First sonogram planned after at least 7 days of starting dose
- Sonogram performed by a single operator (Op 1)
- Clinical decision taken immediately after:
  - Increase/decrease or maintain dose and mark day for next visit
  - Decide for HCG to be given
  - Decide to cancel the cycle
- Second sonogram, blind (no screen control), by same operator, recorded while being performed
- Interpretation months later by two second operators (OP 2 and Op 3) with sonographic experience
- Analysis of concordance of clinical decisions taken

<table>
<thead>
<tr>
<th>PATIENT A</th>
<th>Clinical data</th>
<th>Op 1</th>
<th>Op 2</th>
<th>Op 3</th>
<th>Concordance</th>
</tr>
</thead>
<tbody>
<tr>
<td>FSH 200IU</td>
<td>7d 200IU on D8-9; repeat sono day 11</td>
<td>200IU on D8-9; repeat sono day 11</td>
<td>200IU on D8-9; repeat sono day 11</td>
<td>excellent</td>
<td></td>
</tr>
<tr>
<td></td>
<td>10d 200IU FSH</td>
<td>5,000 IU HCG on day 12 or one further sono</td>
<td>5,000 IU HCG day 12</td>
<td>5,000 IU HCG day 12</td>
<td>excellent</td>
</tr>
<tr>
<td>Image quality</td>
<td>Perfect</td>
<td>Very good</td>
<td>Very good</td>
<td>Very good</td>
<td></td>
</tr>
</tbody>
</table>

Page 75 of 128
PATIENT B

<table>
<thead>
<tr>
<th>Clinical data</th>
<th>Op 1</th>
<th>Op 2</th>
<th>Op 3</th>
<th>Concordance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pill stop echo</td>
<td>Basal status Start 7d 112.5 IU FSH</td>
<td>Basal OK start low dose</td>
<td>Basal status; Start low dose</td>
<td>Excellent</td>
</tr>
<tr>
<td>7d 112.5 IU FSH</td>
<td>112.5 IU next 3 days; then sono</td>
<td>Same dose 3 days; then sono</td>
<td>Maintain dose 3 days</td>
<td>Excellent</td>
</tr>
<tr>
<td>10 d 112.5 IU FSH</td>
<td>112.5 IU FSH today; 5,000 IU HCG tomorrow</td>
<td>5,000 IU HCG after one more day</td>
<td>5,000 IU HCG today or tomorrow</td>
<td>Excellent</td>
</tr>
</tbody>
</table>

Image quality | Perfect | Very good | Very good | Very good |

PATIENT C

<table>
<thead>
<tr>
<th>Clinical data</th>
<th>Op 1</th>
<th>Op 2</th>
<th>Op 3</th>
<th>Concordance</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 d 1500 IU FSH</td>
<td>5,000 IU HCG d 11 or max 1 day later</td>
<td>5,000 IU HCG d 11</td>
<td>5,000 IU HCG today</td>
<td>excellent</td>
</tr>
</tbody>
</table>

Image quality | Perfect | Very good | Very good | Very good |

CONCLUSIONS

• The person who performed the sonograms and the person who took clinical decision, always took the same clinical decision
• The two later operators found image quality excellent or very good
Are patients able to make sonographic recordings themselves?

- 20 cycles followed in UH Ghent
- First classical sonogram, then SOET, images recorded
- Images clear and useful
- Images sent through intra-net link to stand-alone PC
- Patients and partners enthusiastic
- Need for demonstration
- PROOF OF CONCEPT GIVEN

Opinion article exploring the diverse aspects of SOET and reporting initial experience

Self-operated endovaginal telemonitoring (SOET): a step towards more patient-centred ART?

Joh. Gervis and Patricia De Beul

The need for patient-centred care is currently driven by new advances in medical technology and practice. This has led to a greater focus on the patient experience and the role of technology in enhancing the patient’s understanding of their conditions. The introduction of new technologies can help in making the patient-centred approach more effective by providing them with more control and involvement in their care. SOET (Self-operated Endovaginal Telemonitoring) may offer a new approach to patient-centred ART (Assisted Reproductive Technology) by empowering the patient to take a more active role in monitoring their own reproductive health. This approach can potentially improve patient satisfaction, reduce anxiety and increase adherence to treatment regimens. However, further research is needed to evaluate the effectiveness and impact of SOET on patient outcomes and experiences.
The Digital IVF Clinic
as an example of Health 2.0

Jan A.M. Kremer, gynaecologist
Head of the Radboud IVF center
Director of MijnZorgnet
@JKNL_jkremer@obgyn.umcn.nl
Stockholm, 3-7-2011

Learning objectives

• To know the essentials of Health 2.0
• To know the meaning of PHR, HC and PHC
• To know some examples of IVF 2.0
• To develop the motivation to start 2.0 initiatives

Inspiration
Disruptive innovation

• Healthcare is not complex, we have made it complex
• Sustaining innovations make good things better
• Disruptive innovations make things more affordable and simple
• Disruptive innovations are not good for current organizations, but are good for mankind

Internet 2.0

• The power of organizing without organizations
• Spectacular developments of internet 2.0 and its social consequences
• Web 2.0 is a platform of virtual communication & participation
• Consumers are the new producers in these agile and fluent networks

The radical price of Free

• Memory capacity, CPU speed and connection speed double each year while prizes halve
• Everything in bits and bytes tends to free
• Innovations should necessarily be cheap
• We need innovative business-models in healthcare
How did I get involved in 2.0?

Heyendael Castle, 2001

What do you think of our IVF care?

<table>
<thead>
<tr>
<th>POLICY</th>
<th>ORGANIZATION</th>
<th>PEOPLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>TECHNIQUE</td>
<td>Goals</td>
<td>Tasks</td>
</tr>
<tr>
<td>More attention</td>
<td>Shorter</td>
<td>More</td>
</tr>
<tr>
<td>POLITICS</td>
<td>Influence</td>
<td>Decisions</td>
</tr>
<tr>
<td>Better</td>
<td>More</td>
<td>Empowerment</td>
</tr>
<tr>
<td>CULTURE</td>
<td>Climate</td>
<td>Collaboration</td>
</tr>
<tr>
<td>Safer</td>
<td>Better</td>
<td>More</td>
</tr>
</tbody>
</table>
We want Patient centered IVF

From paradigm shift to dream

Digital IVF Clinic
Components of the Digital IVF Clinic

- General information 1.0
  - Patient interviews, education leaflets, practical information, video’s

- Personal information: Personal Health Record (PHR)
  - Test results (semen analysis, hormones), pictures, letters, reports, lab processes, prognosis

- Communication
  - Chat, forum discussions, Q&A, email
Evaluation

- Eight years online, without any problem
- Almost 4000 patients online, >100,000 forum items
- Patients are the motor of this innovation
- More trust, less complaints, better culture
- Less consultations, marketing benefits, prizes,
Empowering patients undergoing in vitro fertilization by providing internet access to medical data

Mary J. Sadik, M.D.*; Chua M. Wee, Ph.D.*; Ihsan M. Quraishi, M.D.*

*Department of Obstetrics, Gynecology and Reproductive Sciences, Mount Sinai School of Medicine, New York, NY, USA

Objective: To study the effect of the internet-based patient/health record on the empowerment of patients undergoing IVF treatment.

Methods: IVF patients undergoing treatment were allocated at random to either an intervention group provided with internet access to their patient/health record or a control group receiving standard care. The intervention group was able to access their health record and receive clinical consultations through a secure internet portal. The control group was assessed through questionnaires and interviews. Results: The intervention group demonstrated a significant improvement in psychological well-being, as compared to the control group. The intervention group also reported a higher level of satisfaction with the care received. Conclusions: The internet-based patient/health record is a valuable tool for improving the quality of care in IVF treatment.

IVF patients show three types of online behavior

W.G. Zulfi1, C.M. Verbaan1, P.J. De Vries Rohal1, and A.A.M. Koens1

1Department of Obstetrics and Gynecology, Academic Medical Center, Amsterdam, The Netherlands

Objective: To study the online behavior of patients undergoing IVF treatment.

Methods: A survey was conducted among patients undergoing IVF treatment at a university hospital. The survey included questions about internet use, online shopping, and online information sources. Results: The majority of patients (80%) reported using the internet for health-related information. The most popular online information sources were websites of medical institutions and government health websites. Conclusions: Patients undergoing IVF treatment rely heavily on the internet for health-related information. Providers should be aware of this trend and ensure that the information provided is accurate and up-to-date.

Dynamics of usages during a IVF cycle

Page 86 of 128
Next step: Health communities

- Digital IVF Clinic is a combination of a Personal Health Record (PHR) and a Health Community (HC) for patients of our own IVF center.

- We just started a provider for Health Communities: MijnZorgNet (MyCareNet)

- Make a profile as a person and become member of one or more Health Communities

Health communities

- Public or private communities:
  - Between professionals with a joined interest
  - Between patients with a joined interest
  - Between professionals and patients with a joined interest
  - Between professionals and patients from one IVF center

- Functionalities of a community
  - Blogs and forum
  - Library and wikis
  - Messages and chat
Next step: Personal Health Community

- You are as a patient the owner of a very special community: your PHC
- You are the boss, and you can give any person (doctors, family members and friends) access to your PHC
- Your PHC contains:
  - your medical data (files, wikis & diaries)
  - your communication (forum & e-consults)
We are quite disappointed in your website: no blogs, no wikis, no twitter, no PHR, no HC, no PHC…

…how static & top-down.

As modern care consumers, we want more than just being treated!
Tools for patient-centred care:
FertiQoL
FertiSTAT

Jacky Boivin, PhD, CPsychol
School of Psychology
Cardiff University

Conflict of interest (past three years)

- Speaker fees, honorarium and/or research funding from Merck-Serono S.A., Merck & Co (then Schering Plough), EMD Serono Inc

Objectives

- Describe development and validation of two tools to support initiatives in fertility care
  - FertiQoL – Fertility Quality of Life
  - FertiSTAT – Fertility Status Awareness Tool
Consensus important & problematic domains

Access to care
- Waiting (referral, treatment, waiting room), freq of appointments, cost, distance
Technical skills
- Comprehensive treatment & testing, quality of information
Coordination and integration of care
- Continuity of care with fertility staff, attitude office staff
Information, communication and education
- ... on alternatives, helping themselves, plan for future, emotional aspects
Emotional support and alleviation of fear and anxiety
- Contact with prior patients
Physical comfort
- Accommodation of clinic, separate clinic (from pregnant groups)

Measurement tools in fertility

Negative affect/impact of infertility
1. Infertility Questionnaire Berlin (1989)
3. Fertility Problem Inventory New (1999)
4. Infertility Expectations Questionnaire Verhaak, 2006
5. Questionnaire of Functional Maladjustment and Adaptation Resources in Infertility Men
7. MINI-MENT Verhaak, 2006
8. Fertility Problem Motive Inventory Abbey 1991
9. Infertility Motives Scale Park 1999
10. Polysyndic Stress Syndrome Quality of Life Cronin 1999
11. Polysyndic Stress Syndrome Quality of Life Cronin 1999
12. Quality of life in infertile men's lives 2005

Cognitions & coping
1. Willems Reproductive Scale Willems 1990
2. Child Project Questionnaire Dumas 1994
3. Personal and relational thoughts scale Halbes 2005
4. Infertility Self-Efficacy Scale Coudouera 2004
5. Coping Scale for Infertile Couples Lee 2000

Treatment
1. Daily Record-Keeping Sheet Basic 1995
2. Psychological evaluation test after ART France 2002
3. Concerns about reproductive technologies Kinscliff-Cuban 2004
4. Difficulties with infertility and its treatment designee 2005
Development process

- Literature review/expert consultation to generate items
  - Psychosocial/fertility experts in reproductive health (n=27): researchers, psychologists, social workers, counsellors, patients, gynecologists, nurses, and clinicians in 11 countries: AUS, CAN, DNK, AUS, FRA, DEU, ITA, NZL, SWE, CHE, NZL, SWE, CHE, GBR, USA

- Conceptual classification of item pool to core dimensions
  - FertiQoL technical working group & expert panel

- Patient focus groups to validate item pool/dimensions
  - 17 focus groups (n=138 men & women) from CAN, DEU, MEX, USA, ITA
  - < or > 35, duration of infertility < or > 2 years, with/without children

- Survey to assess acceptability and feasibility of FertiQoL items in different languages
  - n = 525 men and women in 10 countries: ARG, BRA, CAN, FRA, DEU, GRC, ITA, MEX, NZL, ESP, GBR, USA

Psychometric sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>Online (n=1049)</th>
<th>Clinic (n=388)</th>
<th>χ² or t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age in years mean (SD)</td>
<td>32.9 (4.9)</td>
<td>35.2 (4.8)</td>
<td>7.9**</td>
</tr>
<tr>
<td>Women % (n)</td>
<td>90.8 (1614)</td>
<td>78.5 (291)</td>
<td>113.4**</td>
</tr>
<tr>
<td>Single % (n)</td>
<td>.7 (3)</td>
<td>4.9 (13)</td>
<td>49.4**</td>
</tr>
<tr>
<td>Mean years together (SD)</td>
<td>6.05 (5.9)</td>
<td>7.9 (3.9)</td>
<td>.6</td>
</tr>
<tr>
<td>University education (%; n)</td>
<td>57.1 (609)</td>
<td>66.2 (129)</td>
<td>9.5</td>
</tr>
<tr>
<td>Country % (n)</td>
<td></td>
<td></td>
<td>240.4**</td>
</tr>
<tr>
<td>Australia/ZN</td>
<td>14.5 (152)</td>
<td>25.1 (62)</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>10.3 (105)</td>
<td>42.9 (154)</td>
<td></td>
</tr>
<tr>
<td>UK</td>
<td>8.7 (91)</td>
<td>2.7 (13)</td>
<td></td>
</tr>
<tr>
<td>USA</td>
<td>56.1 (623)</td>
<td>30.2 (111)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2.4 (26)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Psychometric sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>Online (n=1049)</th>
<th>Clinic (n=388)</th>
<th>χ² or t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health &amp; Reproduction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other health problems % (n)</td>
<td>30.8 (399)</td>
<td>24.6 (260)</td>
<td>5.8</td>
</tr>
<tr>
<td>Parenthood % (n)</td>
<td>10.9 (197)</td>
<td>39.1 (190)</td>
<td>19.8**</td>
</tr>
<tr>
<td>Years infertile mean (SD)</td>
<td>3.4 (2.5)</td>
<td>3.8 (2.6)</td>
<td>2.4</td>
</tr>
<tr>
<td>Perceived diagnosis % (n)</td>
<td></td>
<td></td>
<td>82.4**</td>
</tr>
<tr>
<td>Unexplained</td>
<td>10.9 (16)</td>
<td>14.0 (39)</td>
<td></td>
</tr>
<tr>
<td>Female factor</td>
<td>46.6 (351)</td>
<td>18.0 (69)</td>
<td></td>
</tr>
<tr>
<td>Male factor</td>
<td>19.9 (157)</td>
<td>21.7 (99)</td>
<td></td>
</tr>
<tr>
<td>Mixed</td>
<td>11.9 (94)</td>
<td>14.7 (50)</td>
<td></td>
</tr>
<tr>
<td>Same-sex</td>
<td>1.6 (13)</td>
<td>3.2 (26)</td>
<td></td>
</tr>
<tr>
<td>Age-related</td>
<td>4.1 (32)</td>
<td>8.8 (34)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>7.1 (59)</td>
<td>13.6 (53)</td>
<td></td>
</tr>
<tr>
<td>Years treated mean (SD)</td>
<td>2.03 (2.4)</td>
<td>2.43 (1.8)</td>
<td>5.8</td>
</tr>
</tbody>
</table>
Factor loadings (CORE)

<table>
<thead>
<tr>
<th>Emotional</th>
<th>Physical</th>
<th>Mind/Body</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.72</td>
<td>0.72</td>
<td>0.81</td>
<td>0.81</td>
</tr>
<tr>
<td>0.72</td>
<td>0.72</td>
<td>0.81</td>
<td>0.81</td>
</tr>
<tr>
<td>0.81</td>
<td>0.81</td>
<td>0.78</td>
<td>0.78</td>
</tr>
</tbody>
</table>

Boivin et al. 2011. HR. Table 2
Cardiff Fertility Studies

Factor loadings Optional Treatment Module

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Environment</th>
<th>Variability</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.81</td>
<td>0.81</td>
<td>0.78</td>
</tr>
<tr>
<td>0.81</td>
<td>0.81</td>
<td>0.78</td>
</tr>
<tr>
<td>0.81</td>
<td>0.81</td>
<td>0.78</td>
</tr>
</tbody>
</table>

Boivin et al. 2011. HR. Table 3
Cardiff Fertility Studies

FertiQoL Structure & reliability

FertiQoL
34 items*
α=0.92

Treatment
α=0.81

Emotions
8 items
α=0.84

Activities
8 items
α=0.75

Sleep
8 items
α=0.80

*Two additional items measure overall satisfaction with physical health and quality of life
Boivin et al. 2011 Hum Reprod
### FertiQoL International

#### Option Treatment Module

<table>
<thead>
<tr>
<th>Item</th>
<th>Math</th>
<th>Emotional</th>
<th>Physical</th>
<th>Social</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>40</td>
</tr>
<tr>
<td>2</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>40</td>
</tr>
<tr>
<td>3</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>40</td>
</tr>
<tr>
<td>4</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>40</td>
</tr>
<tr>
<td>5</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>40</td>
</tr>
<tr>
<td>6</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>40</td>
</tr>
<tr>
<td>7</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>40</td>
</tr>
<tr>
<td>8</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>40</td>
</tr>
<tr>
<td>9</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>40</td>
</tr>
</tbody>
</table>

**Note:**
- Math: Math ability, Emotional: Emotional ability, Physical: Physical ability, Social: Social ability, Total: Total score
- Each item is scored on a scale of 1-10, with 10 being the highest score.
- The total score is calculated by summing the scores for each category.
Sensitivity

- Women lower quality of life than men
- People using support groups lower quality of life than clinic samples

Conclusions FertiQoL

- FertiQoL is a reliable and sensitive measurement tool
- Mixed methods, patient informed, multiple countries
  - Some groups not represented (men, secondary infertility)
  - Feasibility & acceptability other countries required
  - Clinic Vs online sampling
  - Cross-loadings
- Measure of impact fertility problems/treatment standardised way
  - Identify people at risk for distress
  - Monitor quality of treatment and its treatment impacts

Translation in 20 languages (so far)
Cross-country sensitivity

Low development status: BRA, BFA, IND, ARG
High development status: AUS, BEL, USA, ITA

Conclusions FertiQoL

- FertiQoL is a reliable and sensitive measurement tool
- Mixed methods, patient informed, multiple countries
  - Some groups not represented (men, secondary infertility)
  - Feasibility & acceptability other countries required
  - Clinic vs online sampling
- Cross-loadings
- Measure of impact fertility problems/treatment standardised way
  - Identify people at risk for distress
  - Monitor quality of treatment and its treatment impacts

Reliability in Dutch sample

<table>
<thead>
<tr>
<th>Cut-off for high anxiety</th>
<th>Cut-off for high depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>FertiQoL</td>
<td>HADS-Anxiety</td>
</tr>
<tr>
<td>&lt; 58</td>
<td>&gt; 8</td>
</tr>
</tbody>
</table>
Fertility Awareness

- Lack of awareness of fertility risk indicators

Consensus important & problematic domains

Access to care
- Waiting (referral, treatment, waiting room), freq of appointments, cost, distance

Technical skills
- Comprehensive treatment & testing, quality of information

Coordination and integration of care
- Organizational aspects

Continuity and transition
- Continuity of care with fertility staff, attitude office staff

Information, communication and education
- Contact with prior patients

Emotional support and alleviation of fear and anxiety
- Physical comfort
- Accommodation of clinic, separate clinic (from pregnant groups)

Risk factors on the increase
Seeking timely medical advice

Lack of problem awareness

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

Laura Bunting and Jackie Berlin
School of Psychology, Cardiff University, Ffwrheision, Park Place, Wales CF10 3XT
E-mail: l.bunting@cardiff.ac.uk

Risk Illusory benefits
Percent correct

Need to be personally relevant to be effective

Original advert: ASRM <2006

Personally relevance captures attention and produces higher arousal

N=152, manuscript under prep
Steps in FertiSTAT development

1. Comprehensive review of the literature
   - 58 studies reviewed
   - 31 risk factors identified (demographic, reproductive, medical, lifestyle)

2. Mini-delphi round with 20 reproductive experts
   - Selection of risk factors and consensus of critical thresholds
   - 20 factors confirmed as independent risks for reduced female fertility as per clinical practice
   - 2 risk factors associated with reduced male fertility included

3. Consultation and pilot testing for guidance development

Risk factors identified in review

- **Lifestyle**
  - Alcohol use
  - Tobacco use
  - Chemical use
  - Obesity
  - Stress
  - Vascular disorders
  - Steroid use
  - Unprotected sex
  - Stress at work
  - Underweight
  - Occupational exposures

- **Reproductive history**
  - Infertility (primary or secondary)
  - Menopause (natural or induced)
  - Medication (e.g., Cushing, 50-year-old women, history of miscarriage)
  - Moxiphetin use
  - History of pelvic surgery
  - Pre-existing fertility issues
  - Polyzygotic anevent
  - Carcinoma
  - Undescended testicles
  - Varicocele
  - Hormones
  - Mumps after puberty in males

- **General medical history**
  - Diabetes
  - Thyroid disease
  - Asthma
  - Heart disease
  - Kidney disease
  - SLE (lupus)
  - Epilepsy
  - Sickle cell anaemia
  - Cancer

- **Demographics**
  - Age ≥ 34 years
  - Years trying to conceive
  - Living standard
  - Ethnicity

Assisted Conception Task Force:
**Independent risk factors (key to health campaigns)**

- **Lifestyle**
  - Alcohol use
  - Tobacco use
  - Class A drug use
  - Caffeine use
  - Excessive exercise
  - Steroid use
  - Unable to cope with current stress
- **Reproductive history**
  - Number of sexual partners (unprotected)
  - Multiple miscarriages (<25 years)
  - Pelvic inflammatory disease
  - STI (e.g., Chlamydia)
  - History of pelvic surgery
  - HSV, inflammatory disease
  - Endometriosis
  - Polycystic ovaries
  - Undescended testicles
  - Hormones after puberty in males
- **General medical history**
  - Diabetes
  - Thyroid disease
  - Asthma
  - Heart disease
  - Kidney disease
  - SLE (lupus)
  - Epilepsy
  - Sickle cell anaemia
  - Cancer
  - Pelvic inflammatory disease
  - Endometriosis
  - Polycystic ovaries
  - Coeliac disease
  - Undescended testicles
  - Varicocele
  - Mumps after puberty in males
- **Demographic**
  - Age ≥ 34 years
  - Years trying to conceive
  - Living standard
  - Ethnicity

---

**Fertility STatus Awareness Tool**

FertiSTAT is a free one-page questionnaire containing:

- **22 risks & indicators**

Guidance about how to take action to safeguard fertility and when to get help.

---

**Personalised guidance based on individual risk profile**

2. What does your FertiSTAT score mean?
i. Preliminary cross-sectional validation

- Eight month collection period
  - 1073 women completed the Fertility Risk Factors Survey

- Pregnant = 532 (weeks pregnant range = 3 – 40 with 78.62% ≥ 12 weeks)

- Not Pregnant actively trying = 202
  - 76.6% of these women were classified as fertile

Validation sample comparable risk pattern to general population

Discrimination fertile versus infertile

<table>
<thead>
<tr>
<th>Fertile</th>
<th>Infertile</th>
</tr>
</thead>
<tbody>
<tr>
<td>91.2%</td>
<td>72.9%</td>
</tr>
<tr>
<td>81.0%</td>
<td>61.4%</td>
</tr>
</tbody>
</table>
Potential as public awareness tool

- ESHRE 30th June 2009 – released FertiSTAT (www.fertistat.com)
  - Picked up by The Telegraph, The Times, Daily Mail

Conclusions FertiSTAT

- FertiSTAT self-administered, multi-factorial tool that can enable women to get fertility guidance based on their own lifestyle and reproductive profile
- Preliminary validation is promising but predictive utility needs to be examined in prospective research
- Ethics and value of 'nudging in the right direction' (Thaler & Sunstein, 2003) and pre-symptomatic fertility monitoring needs to be deliberated

General Conclusions

- "...need to find a balance between employing [interventions] that should be effective in an ideal world, and intervention activities and materials that match the reality of priority populations and intervention contexts..." Shaarshon & Hatt, Psychol & Health, p. 6, 2009
- FertiQoL and FertiSTAT tools that demonstrate that science can be translated into valid ways of assisting in fertility care
Need to develop support toolkit that can [really!] be integrated in the day-to-day

<table>
<thead>
<tr>
<th>Needs assessment and intervention development techniques exist</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Intervention mapping</td>
</tr>
<tr>
<td>□ MRC complex intervention framework</td>
</tr>
<tr>
<td>□ Taxonomy of behaviour change techniques</td>
</tr>
<tr>
<td>□ Evidence-based evaluation methods</td>
</tr>
<tr>
<td>□ etc</td>
</tr>
</tbody>
</table>
Fertility awareness and preconception counselling and care

Prof. dr. Petra De Sutter, PhD, MD
dr. Ilse Delbaere, PhD
Department of Obstetrics & Gynaecology, University Hospital, Ghent

Learning objectives

• To understand the impact of maternal age on fertility
• To get a picture of knowledge on fertility and attitudes towards parenthood in students and people of reproductive age
• To understand current reasons for delaying childbearing in people of reproductive age
• To perceive the necessity of sensibilisation actions in increasing fertility awareness
• To consider the relevance of preconception counselling and the introduction of a Reproductive Life Plan within increasing fertility awareness

Fertility awareness: Background

• Delayed motherhood
  – Reproductive trend since 1990, as a consequence of two other reproductive trends:
    • Large scale use of contraception (1960)
    • Success of assisted reproductive technologies (1980)

  – Impression that female fertility can be manipulated at any stage of life
Fertility awareness: Background

- Delayed motherhood \( \rightarrow \) increased fertility problems
  - Becoming pregnant may take twice as long for women aged > 35 years compared with women aged < 25 years.
  - Increased risk for involuntary childlessness
    - Regular cycle ≠ unhindered fertility
    - Due to reduction in quantity and quality of oocytes \( \Rightarrow \) also decreased success in achieving pregnancy by IVF, more miscarriages
    - Increased risk of pregnancy complications

Do people want children?

- Sweden:
  - 95% of childless women and men aged 23-25 years want children
  - 80% of people already having a child, want a second child
- Belgium:
  - 91% of women aged 20 – 40 years want children
- Canada:
  - 89% of women aged 20-45 years indicated a child-wish
- US:
  - 33% of professional women are childless at age 40, yet only 14% of these women planned lives without children

Delayed motherhood \( \rightarrow \) Increased fertility problems

- Growing number of patients in fertility centers
- Can assisted reproduction technology compensate for the natural decline in fertility with age? \( \rightarrow \) Model assessment by Leridon 2004.

<table>
<thead>
<tr>
<th>Women’s age when starting pregnancy attempt</th>
<th>35 years</th>
<th>37 years</th>
<th>40 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conception (L) within 1 month</td>
<td>74.4</td>
<td>70.2</td>
<td>54.7</td>
</tr>
<tr>
<td>Delay</td>
<td>65.4</td>
<td>70.0</td>
<td>72.7</td>
</tr>
<tr>
<td>Conception (L) in 12-23 months</td>
<td>8.9</td>
<td>10.3</td>
<td>12.7</td>
</tr>
<tr>
<td>Conception (L) in 24-35 months</td>
<td>1.2</td>
<td>1.3</td>
<td>1.3</td>
</tr>
<tr>
<td>Conception (L) in 36-45 months</td>
<td>0.2</td>
<td>0.2</td>
<td>0.2</td>
</tr>
<tr>
<td>Total conception (L) within 4 years</td>
<td>9.2</td>
<td>9.0</td>
<td>7.0</td>
</tr>
<tr>
<td>Total conception (L) 5 years</td>
<td>5.2</td>
<td>4.8</td>
<td>4.2</td>
</tr>
<tr>
<td>Age 4 years starting ART</td>
<td>14.0</td>
<td>16.0</td>
<td>19.0</td>
</tr>
<tr>
<td>(No case of failure)</td>
<td>3.5</td>
<td>3.7</td>
<td>4.1</td>
</tr>
</tbody>
</table>

Fertility awareness

- Why do couples postpone parenthood?
  - Traditional assumptions:
    - Longer education of women
    - Job demands/financial considerations
  - Recent studies indicate:
    - Lack of knowledge on the impact of age on fertility
    - Women are choosy for the future father of their child
Fertility awareness: two types of studies

- Knowledge of fertility and attitudes towards parenthood
- Pregnancy intention: reasons for delaying childbearing

Knowledge of fertility and attitudes towards parenthood

- Few studies: 3 Swedish, 2 Canadian
- Particularly assessment of knowledge in university and postgraduate students
  - Likely to delay childbearing in their quest for professional, academic and career training.

Random selection of 200 female and 200 male postgraduate students at Uppsala University
- Pilot – tested self-developed questionnaire

- 141 women (71%) and 116 men (58%) responded
  - 91% of women and 90% of men wanted to have children
  - Preferred mean age for having the first child was 31 years for women and 32 years for men.
  - 13% of women wanted their first child after the age of 35.
  - The desired mean age for having the last child was 36 years for both women and men. Sixty – six percent of women wanted their last child after the age of 35.
• Perceived obstacles towards parenthood for this group of students:
  - Completing research project
  - Employment conditions
  - Supervisors expectations
  - Financial support during parental leave
  These obstacles were perceived more by women than by men
• Considerations in the decision to become a parent
  - Having a stable relationship
  - Having access to child care
  - Having children before a certain age

At what age is there a marked decrease in women's ability to become pregnant?

<table>
<thead>
<tr>
<th>Age Group</th>
<th>% Women</th>
<th>% Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>25-34 y</td>
<td>24</td>
<td>24</td>
</tr>
<tr>
<td>35-39 y</td>
<td>48</td>
<td>35</td>
</tr>
<tr>
<td>40-44 y</td>
<td>23</td>
<td>28</td>
</tr>
<tr>
<td>45-49 y</td>
<td>4</td>
<td>12</td>
</tr>
</tbody>
</table>

For couples that undergo treatment with IVF, what is their chance, on average, of having a child?

<table>
<thead>
<tr>
<th>Success Rate</th>
<th>% Women</th>
<th>% Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-19%</td>
<td>18</td>
<td>25</td>
</tr>
<tr>
<td>20-29%</td>
<td>23</td>
<td>22</td>
</tr>
<tr>
<td>30-39%</td>
<td>31</td>
<td>14</td>
</tr>
<tr>
<td>40-100%</td>
<td>28</td>
<td>35</td>
</tr>
</tbody>
</table>
Female university students’ attitudes to future motherhood and their understanding about fertility

Tina Tyénö1, Agnes Mjong Fossum2**, Lina Mikkelsen3**, Lone Lind4** and Christer Largh5**
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5Department of Women’s and Children’s Health, East Hospital, S 19, 155 Upsala, Sweden

• Distribution of questionnaire university students:
  – Waiting room survey to female university students (Student Health Centre) (N=300)
    • Mean age: 23 (range 19-37)
    • 70% had a stable relationship
    • 95% of women planned to have children (2 to 3)
    • Women wanted to be on average 29 (range 20-40) years old for the first child and 35 (range 29-43) for the last child

• 222 female and 179 male students in degree programmes ≥ 4 years
• Mean age: 24.4 years in women, 23.8 years in men
• Stable relationship: 60% of women, 51% of men
At what age are women most fertile?

At what age is there a slight decrease in women's ability to become pregnant?

At what age is there a marked decrease in women's ability to become pregnant?
A young woman (< 25 years) and a man have unprotected intercourse at the time of ovulation – how large is the chance that she will become pregnant?

Fertility and aging: do reproductive-aged Canadian women know what they need to know?

Kamal B, Bherer L, Ph.D., 13 Nicola Korsten and Ph.D., 13 Lorna Arick, R.C.L., 13 Sarah A. Herford, M.K., 13 and Wendy F. Beaton, Ph.D.

13 Department of Psychology, University of British Columbia, Vancouver; 13 Reproductive Health and Methods Research Unit, University of British Columbia, Vancouver.

- 360 female undergraduate students (Vancouver, Canada)

Which of the following is the strongest risk factor for infertility?

The woman’s age

Correct

Physical exercise

Exposure to smoking

Percentage
‘Which is the strongest risk factor for miscarriage?’

Fertility and aging: do reproductive-aged Canadian women know what they need to know?

Correct Conclusion:

• Swedish students understand the association between age and fertility, but overestimate the probability of achieving pregnancy at the time of ovulation and underestimate age as a factor in infertility

• Canadian undergraduate women underestimate the influence of female age on childbearing success and success of in vitro fertilization

Conclusion: fertility awareness in students

What do women know about the risks of delayed childbearing?

Women’s perceptions of childbearing risks associated with advanced maternal age.

Limited knowledge of maternal age—related pregnancy risks were associated with:

• Unplanned pregnancy (OR 1.48; 95% CI 1.03-2.14)
• Smoking (OR 1.83; 95% CI 1.29-2.60)
• Non-use of fertility treatment (OR 2.15; 95% CI 1.44-3.19)
Fertility awareness: two types of studies

- Knowledge of fertility and attitudes towards parenthood
- Pregnancy intention: reasons for delaying childbearing

Female university students' attitudes to future motherhood and their understanding about fertility

Important circumstances for women's decisions to have children

Fertility awareness, intentions concerning childbearing, and attitudes towards parenthood among female and male academics

Important circumstances for women's and men's decisions to have children
Factors Influencing Childbearing Decisions and Knowledge of Perinatal Risk among Canadian Men and Women

- **Age-stratified random sample of individuals, aged 20-45 years, without children (N=1066 women, 500 men).**
- **Top four factors that influenced timing of childbearing:**
  - Financial security
  - Partner suitability to parent
  - Own interest/desire for having children
  - Partner's interest/desire for having children
  - Other factors that were particularly important for women: health status, leave at employment, and feeling of a 'biological clock' ticking
- **Only 2% of responders believed the ideal age to begin parenting was over 35 years, although 10.5% of first-time births in Canada are in women over the age of 35 years.**

Questionnaire survey of 234 nulliparous women aged 34 and over attending a family planning clinic in Scotland

- 116 (49.6%) of these women wanted children
  - 71% were (very) concerned about their future fertility
  - Reasons for delay:
    - 54% gave reasons to do with their relationship
    - 14% gave work/training issues
  - 118 (50.4%) did not
  - These women had sufficient knowledge on the association age – fertility, but showed a 'it will not happen to me' mentality

Qualitative study on 45 Canadian women aged 20 to 48 years

- **Factors that influence women's decisions about childbearing:**
  - Individual Factors
    - Education
    - Employment
    - Marital Status
  - Financial Factors
    - Income
    - Housing Stability
  - Partner Factors
    - Partner's Support
    - Partner's Age
  - Related Factors
    - Family History
    - Social Support
  - Other Factors
    - Health Status
    - Leave at Employment
    - Feeling of 'Biological Clock' ticking
Conclusions of studies on fertility awareness

- Educational aspirations and financial reasons are traditionally enumerated as common reasons for delayed motherhood
- Reality is more complex, decisions about the timing of motherhood are influenced by multiple and complex interrelated factors:
  - Societal expectations for financial independence (concerns about increasing divorce rates) underlie the pressure to achieve education and career goals

Sensibilisation on fertility awareness

- Preventive campaigns in order to inform the public
  - Compensation for media bias
  - www.testjevruchtbaarheid.be
- Preconception counseling
- Reproductive Life Plan

Media bias in fertility awareness

- Success stories of births in women after age 40
- Lack of discussion about the reproductive technology measures often required
Preconception counseling and care

- January 2010: start preconception consultations at University Hospital Ghent
- Part of research – profile FREA
  - Fertility and Reproductive Awareness
  - Assessing models for improving preconception care
- General objectives preconception care
  - Preventive lifestyle measures before organogenesis
  - New impulse for improvement perinatal care
- Specific objective:
  - Gatekeeper for infertility centre

Preconception consultation as gatekeeper for the infertility centre

- Transfer to infertility centre:
  - Not too early:
    - TTP is often underestimated (see research) and young couples can be reassured if pregnancy does not occur within the first 6 months
    - Information on the impact of lifestyle on fertility (recommendation to lose weight, to stop smoking, etc.)
  - Not too late:
    - E.g. couple of 37 years old, after one year unprotected intercourse
    - E.g. woman of 27 years old with amenorrhoea
    - E.g. woman of 24 with child wish for more than 2 years
**Preconception care and fertility awareness**

- Patients currently visiting our consultation have a good knowledge of their menstrual cycle
  - Bias: high-educated, involved group, particularly employed in health-care and education
- Extra information is appreciated:
  - On optimal coitus frequency and timing
  - Parameters for fertile period in women with irregular cycle
  - Knowledge of lifestyle impact on fertility is limited
  - Reassurance is often needed when TTP > 6 months

**Reproductive Life Plan (RLP)**

- In the US, the use of a Reproductive Life Plan (RLP) in primary care is encouraged.
- When patients at reproductive age visit their general practitioner for any purpose, the issue of reproduction is addressed and patients are encouraged to reflect on and to discuss their desire for children with their partner and their GP.
- Objectives:
  - To identify inefficient use of contraception
  - To identify intention to delay parenthood
- Feasibility of introduction to RLP – webtool by GP?

**Feasibility of RLP – webtool?**

- Visitors are asked for their profile:
  - Aged 28 years without immediate desire for children/any age with completed child wish or no desire for children
    - Assessment of contraception use
    - Tailored information on effective contraception use if necessary
  - Aged 28 years or older, with desire for children in the future
    - Information on the impact of age and lifestyle on fertility
    - Desire for children in the immediate future
    - Information on the impact of health and lifestyle on the conception and young embryo (incl. folic acid advise)
Towards different paths in the labor market?

- Hewlett 2004:
  - Male path through young adult life doesn’t work so well for women: if women focus exclusively on career until age 35 they are apt to get in trouble.
  - The marriage market is difficult
  - Fertility may decline as soon as one’s late 20s
  - Different paths in the labor market?
  - Aim for personal goals in the late 20s – mid 30s?
  - To climb the career ladder in one’s 40s - 50s?
- Is this realistic?
  - Can ambitious women temper their enthusiasm?
  - Will women still have the same chances at older age?
  - Striving for independence of a partner is one of the reasons for women to build a career nowadays.

Recommendations

- Women and men need to be well informed about the declining rates of conception for women in their 30s and the limitations of success using assisted reproduction
- Sensibilisation actions are needed in order to inform the public. A Reproductive Life Plan – webtool will be pilot-tested.
- If reality is understood, informed decisions can be made
- Realistic media stories are needed
- More studies needed in this area:
  - Literature ‘Knowledge on fertility’ is dominated by Swedish and Canadian research
  - E.g. social acceptance: does pregnancy intention depend on situation of friends and peers?

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Mark your calendar for the upcoming ESHRE campus workshops!

- Early pregnancy disorders: integrating clinical, immunological and epidemiological aspects
  23-26 August 2011 - Copenhagen, Denmark
- The management of infertility – training workshop for junior doctors, paramedics and embryologists
  7-8 September 2011 - St. Petersburg, Russia
- Basic genetics for ART practitioners
  9 September 2011 - Bucharest, Romania
- The whole man
  22-23 September 2011 - Sevilla, Spain
- Accreditation of a Preimplantation Genetic Diagnosis Laboratory
  3-4 October 2011 - Athens, Greece
- Human reproductive tissues, gametes and embryos: Innovations by science-driven culture and preservation systems
  9 October 2011 - Cairns, Australia
- Comprehensive preimplantation screening: dynamics and ethics
  13-14 October 2011 - Maastricht, The Netherlands
- Endometriosis and IVF
  28-29 October 2011 - Rome, Italy
- Endoscopy in reproductive medicine
  23-25 November 2011 - Leuven, Belgium
- What you always wanted to know about polycystic ovary syndrome
  8-10 December 2011 - Sofia, Bulgaria

www.eshre.eu
(see “Calendar”)

Contact us at info@eshre.eu