



Patient-centered fertility services

Special Interest Group Safety and Quality in ART

10

3 July 2011
Stockholm, Sweden



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**

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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

Scientific programme

09.00 - 09.30	Patient expectations - Clare Lewis-Jones (United Kingdom)
09.30 - 09.45	Discussion
09.45 - 10.15	Patient centered, patient-friendly or high quality ART? - Guido Pennings (Belgium)
10.15 - 10.30	Discussion
10.30 - 11.00	Coffee break
11.00 - 11.30	"shared decision making" in ART – Annick Delvigne (Belgium)
11.30 - 11.45	Discussion
11.45 - 12.15	How to measure patient centredness - Eline Dancet (Belgium) and Inge van Empel (The Netherlands)
12.15 - 12.30	Discussion
12.30 - 13.30	Lunch
13.30 - 14.00	Self-operated endovaginal telemonitoring - Jan Gerris (Belgium)
14.00 - 14.15	Discussion
14.15 - 14.45	The virtual fertility clinic - Jan Kremer (The Netherlands)
14.45 - 15.00	Discussion
15.00 - 15.30	Coffee break
15.30 - 16.00	tools for patient-centered care: Fertistat and Fertiqual - Jacky Boivin (United Kingdom)
16.00 - 16.15	Discussion
16.15 - 16.45	Fertility awareness and preconceptional counselling and care – Petra De Sutter (Belgium) and Ilse Delbaere (Belgium)
16.45 - 17.00	Discussion



ESHRE – European Society of Human Reproduction and Embryology

What is ESHRE?

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

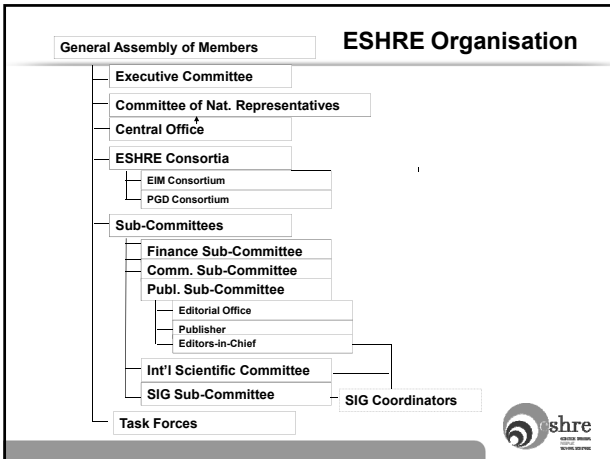
- promote interest in, and understanding of, reproductive science
- facilitate research and dissemination of research findings in human reproduction and embryology to the general public, scientists, clinicians and patient associations.
- inform policy makers in Europe
- promote improvements in clinical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



Executive Committee 2009/2011


Chairman	• Luca Gianaroli	Italy
Chairman Elect	• Anna Veiga	Spain
Past Chairman	• Joep Geraedts	Netherlands
	• Jean François Guérin	France
	• Timur Gürgan	Turkey
	• Ursula Eichenlaub-Ritter	Germany
	• Antonis Makrigiannakis	Greece
	• Miodrag Stojkovic	Serbia
	• Anne-Maria Suikkari	Finland
	• Carlos Plancha	Portugal
	• Françoise Shenfield	United Kingdom
	• Etienne Van den Abbeel	Belgium
	• Jolieneke Schoonenberg-Pomper	Netherlands
	• Veljko Vlasisavljevic	Slovenia
	• Søren Ziebe	Denmark






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 Clinical Embryologist Certification Exam Page 1 of 16
28 June 2009, Amsterdam

Clinical Embryology Certification Examination

1. Which of the following statements is true?
Numbers:

a. A centriole from the sperm forms the
b. The zygote loses the mitochondria
c. Polyploidic oocytes divide to form
d. Major activation of the human embryo

28 June 2009, Amsterdam
www.eshre.eu
www.eshre.org

ESHRE Pages

Revised guidelines for good practice in IVF laboratories

14. Cristina Magli, Elvira Tasci, Albert Sorrel, Lucio, Neeraj Kumar, Zeynep Yildirim, Luis Garcia for Committee of the Special Interest Group on ART/IVF

ESHRE
EUROPEAN SOCIETY FOR HUMAN 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)



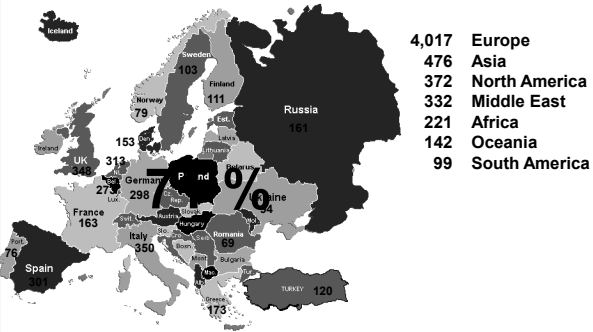
Retweets to MHR



Find a member



ESHRE Membership (1/3)



TOTAL MEMBERSHIP*: 5 659 members

* as of July 2010

ESHRE Membership (2/3)

	1 yr	3 yrs
Ordinary Member	€ 60	€ 180
Paramedical Member*	€ 30	€ 90
Student Member**	€ 30	N.A.

*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/Paramedicals	€ 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: 8,055 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 54651500
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)



Annual Meeting – Pre-congress courses

- 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
- 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



Contact



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info@eshre.eu / www.eshre.eu



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

“Care that is respectful of and responsive to individual patient preferences and needs and that is guided by patient values”

- Compassion, empathy and responsiveness to needs, values and expressed preferences
- 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?

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

DEPRESSION
Especially as the months & years go by

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".*

And at the end of all that???

TIRED!

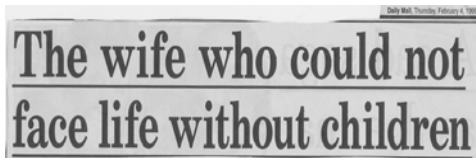
Loss of confidence

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 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

Dancet, E A F et al 2011

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.”

Dancet, E A F et al 2011

“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

L. Schmidt et al 2003

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 1) 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 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

W.S. Tuil et al 2006

- 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

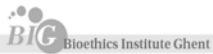
1. Kerr J, Brown C, Balen AH. The experiences of couples who have had infertility treatment in the United Kingdom; results of a survey performed in 1997" Hum Reprod 1999; 14:934-8
2. "Patients' attitudes to medical and psychosocial aspects of care in fertility clinics: findings from the Copenhagen Multi-centre Psychosocial Infertility (COMPI) Research Programme. Hum. Reprod. 2003 Mar; 18(3): 628-37.
3. "The patients' perspective on fertility care: a systematic review" Human Reproduction Update, Vol.00, No.0 pp 1-21, 2010
4. W.S. Tuij; A.J. ten Hoopen; D.D.M. Braat; P.F. De Vries Robbe; J.M. Kremer. "Patient-centred care: using online personal medical records in IVF practice. Hum Reprod 2006; 21 (11) 2955-2959

Thank you

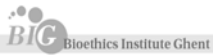
Patient-centred, patient-friendly or high-quality ART?

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

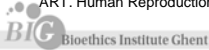
The future: high quality ART:

- | | |
|--------------------------------------|------------------------------|
| 1. cost-effectiveness | benevolence (doing good) |
| 2. equity of access | justice |
| 3. minimal risk for mother and child | non-maleficence (do no harm) |
| 4. treatment choice for patient | autonomy |

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.

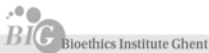
Pennings, G. & Ombelet, W. (2007) Coming soon to your clinic: patient-friendly ART. Human Reproduction 22 (8): 2075-2079.



1. Cost-effectiveness

NORMATIVE BASIS: BENEFICENCE

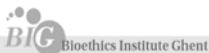
- The optimal use of scarce resources MAXIMISES WELL-BEING (utilitarianism)
- Three levels of distribution of scarce resources:
 - Between health care and other societal needs (education etc.)
 - Between infertility and other diseases (cancer etc.)
 - Between patients for infertility treatment.
- Money 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

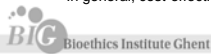


2. Equity of access

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.

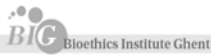
In general, cost-effective treatment will increase equity



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

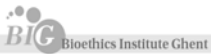
Breast cancer

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.



Treatment choice for the patient

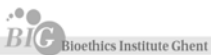
Infertility

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.



Treatment choice for the patient

Stress is to a large extent explained by

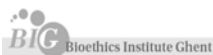
- fear of the unknown,
- anxiety about hormone injections and
- concerns about side effects of the drugs (Hammarberg, 2003; Pistorius et al., 2006)

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.



Treatment choice for the patient

- 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

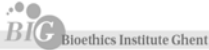
First example: parenthood

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 (Evenson & Simon, 2005)
- Parents of grown children have no higher well-being than adults who never had children (McLanahan & Adams, 1989)

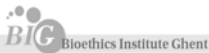
Why are we making all these people unhappy?



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

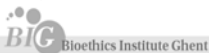


Patient-centred approach

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 proscribed 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



Patients' preference and multiple pregnancies

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
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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 (*in 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**

Robinson et al., 2008
AHRQ in USA

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.

Maumjid 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.

Charles et al., Soc Sci Med. 1999

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 a common agreement
 - Two actors share responsibility

→ **Confusion...**

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

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 et al.
 - Identification of different analytic stages of SDM
 - Definition of major characteristics of SDM

Dolan JG, Patient Educ Couns 2008; Charles et al., J Clin Oncol, 2003

From theory to practice

- Complex decision:



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

**Educations of students and physicians
Systematic progression in SDM**

Hall C, 2002; Dolan, JD 2008

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

Dolan JG, Patient Educ Couns 2008

AHP in practice...Dolan JD, 2008

Steps in a shared decision making process & the AHP

Shared decision making	Analytic Hierarchy Process
Definition of the problem & options available	Create a decision model that contains the decision goal, the options being considered, and the criteria used to determine how well the options are likely to meet the goal
Review of options' pros and cons	Pairwise comparisons regarding how well the options satisfy the criteria
Elicitation of patient values and preferences	Pairwise comparisons to prioritize factors affecting the decision (the decision criteria)
Clinician recommendations	Review results using the clinician's perspective
Review of patient's ability to implement plan	Include feasibility as a decision criterion
Check for clarity and understanding	Detailed review of model results, sensitivity analyses if indicated
Make a decision or defer until later	Use results to inform the decision making process

From: Patient Educ. Couns. Author manuscript, available in PMC 2009 December 1.
 Published in final edited form as:
 Patient Educ. Couns. 2008 December; 73(3): 418-425.
 Published online 2008 August 28; doi: 10.1016/j.pep.2008.07.032.

AHP in practice...Dolan JD, 2008

Steps in the Analytic Hierarchy Process

- Define the decision elements:
 - goal of the decision,
 - the options, and
 - the criteria for determining how well the options meet the goal.
- Construct decision model
- Decompose the decision into smaller parts
 - Compare importance of criteria in achieving goal
 - Compare alternatives' abilities to meet the criteria
- Synthesis: How well can alternatives be expected to meet goal?
- Sensitivity analysis
- Make decision or refine the analysis

Drug	Risk of side effects	Ease of administration	Effectiveness	Monthly price
A	1%	1 tablet twice a day	85%	\$5
B	5%	1 tablet daily	90%	\$50
C	0.5%	1 tablet daily	75%	\$25

From: Patient Educ. Couns. Author manuscript, available in PMC 2009 December 1.
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Conceptual framework

- Context of Life threatening disease
- 3 steps:
 - Information exchanges*: to ways exchange

physician	patient
Natural history of the disease	Health history
Side effects of treatment alternatives	Lifestyle
Descriptions of the procedures	Social context (work & family responsibilities)
Resources and information available for the patients	Beliefs & fears about the disease
	Knowledge of options (from network or other sources)

→ How each expects the decision making process to proceed?

- Deliberation* about treatment options
 - The process of expressing and discussing treatment preferences
 - Consensus or negotiation as equal partner (? An expert with a vulnerable patient)
 - Create a safe environment where the patient feels comfortable to discuss and question
- Deciding* on the treatment to implement

Charles et al., Soc Sci Med. 1999

Conceptual framework

Models of treatment decision making*

Analytical stages	Model	Paternalistic (in between approach)	Shared (in between approach)	Informed
Information exchange	Flow	One way (top to bottom)	Two way	One way (bottom to top)
Direction		Physician → patient	Physician & patient	Physician → patient
Type		Medical	Medical and personal	Medical
Assess ^b		Minimum legally required	All relevant for decision making	All relevant for decision making
Deliberation		Physician alone or with other physicians	Physician and patient/other personal others	Patient/physician/other
Decision on treatment to implement		Physician	Physician and patient	Patient

* Illustration for an encounter focusing on the case of a (treated) physician-patient dyad. For more complex cases see text.
^b Minimum required.

Description of the various analytical stages
 Description of behavioral expectations of both partners
 Switching or choose among 3 models during encounter is possible

Model used to teach and to test SDM

Charles et al., Soc Sci Med. 1999

Adhesion of patients and physicians

- Doctors survey in "oncology clinic"

%	surgeons	oncologists
paternalistic	5,3	4,1
Some sharing	28,2	33,7
Informed	26,8	21,4
SDM	93,8	86,7
others	0,5	3,1

- Patients:
 Breast cancer (202), Prostate disease (880), fractures (202), continence (46), orthopedic (111), rheumatology (56), multiple sclerosis (22), HIV/AIDS (431), infertility (454), cardiac disease (300)

autonomous	1.2%
SDM	77.8%
passive role	20.3%

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

- 3491 patient with cancer: preferred role
 - 26% active
 - 49% collaborative
 - 25% passive
- SDM requires trust in physician

Charles et al., 2003 *Deber et al., 2007; Singh et al., 2010; Kreatschmer et al., 2004*

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?

		Laparoscopic results		
		+	-	total
Vaginal	+	75	1	76
US	-	12	45	57
Total		87	46	133

Sensitivity:88,2% and specificity 97,8% //PPV:98,6% and NPV: 78,8%
(grade I endometriosis and adhesion)

- 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)

age	Trial 1	Trial 2	≥_Trial 3
≤ 35	1	1 top or 2	≤ 2
36-39	≤ 2	≤ 2	≤ 3
≥ 40	?	?	

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

Van Peperstraten et al., 2008
Gerris 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?
- Anonymous / non anonymous gamete donation?
- 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
But: is it really democracy (power relation)?
Ethical legitimacy of this process of decision-making?

Frith, J Med Ethics, 2011

SMD in ART: at what stage?

- During the treatment? Yes...

- Cancel the treatment in IVF in case of poor response?
 - Same PR in IVF/shift IUI/IUI + stimulation (Wood et al, 2003; Freour et al., 2010)
 - IUI but less risk and less expensive
 - IUI less informative...
- IUI and multifollicular ovarian response to stimulation?
 - Cancel the cycle
 - Accept the multiple pregnancy risk
 - Perform a 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
 - < patient and medical team
 - Cryopreservation for future use? "cryopreservation decision"
 - When do patients want to use it? "transfer decision"
 - Continuation? "storage decision"
 - o Yes: how long?
 - Country's law? ie: 5 years in Belgium (less/more according to couple choice)
 - o 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

Provoost et al., 2009 and 2011

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 asses:
 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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UMC  St Radboud 

How to measure patient-centredness

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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



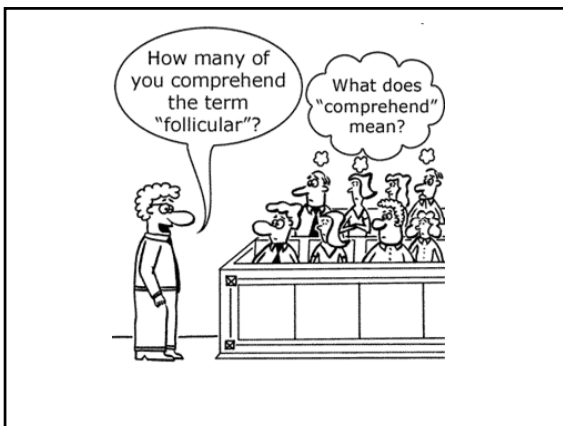
Bengoa (WHO), 2006 and Corrigan (IOM), 2001

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 ^{1,3,4,5}

1. Corrigan (IOM), 2001
2. Sima, 1998
3. Bengoa (WHO), 2006

4. Shaller, Commonwealth Fund, 2008
5. Frampton et al, 2008



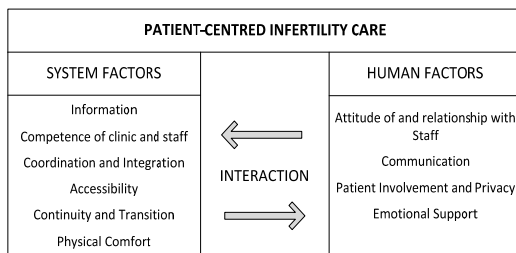
What is Patient-Centred Infertility Care (PCIC)?

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

An interaction model for PCIC



Dancet, van Empel et al, 2011.

9 reasons to pay attention to PCIC

1. Patients have negative experiences with current fertility care ¹
2. PCC is very important to fertility patients ²⁻⁶
3. Physicians underestimate the importance of patient-centredness²
4. Lack of PCC is a reason for changing clinics and for drop-out^{2,7}
5. Treatments represent high physical & emotional burden and high drop-out⁷⁻⁹
6. 30% of the infertile couples will never achieve live birth ¹⁰⁻¹¹
7. PCC contributed to better co-operation between patients and professionals¹²
8. Professionals cannot evaluate their performance regarding PCC adequately¹³
9. PCIC is positively associated with higher QoL and patient satisfaction ^{1,14}

- | | | |
|----------------------------------|---------------------------|-----------------------------|
| 1. Van Empel et al, 2010b | 6. Van Empel et al, 2010a | 11. Brandes et al, 2010 |
| 2. Van Empel, Dancet et al, 2011 | 7. Van Broeck et al, 2009 | 12. Patwarathan et al, 2009 |
| 3. Dancet et al, 2010b | 8. Verhaak et al, 2007 | 13. Aarts et al, 2011a |
| 4. Dancet et al, 2010a | 9. Damar et al, 2010 | 14. Aarts et al, 2011b |
| 5. Schmitt et al, 2003 | 10. Pinborg et al, 2009 | |

The measurement of patient-centredness

Measuring PCIC necessary for improving PCIC



Not the way: measuring patient satisfaction

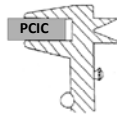


The way: measuring patients' concrete experiences with relevant aspects of care¹⁻²

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://humrep.oxfordjournals.org>
 - <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

- $QI = \text{Importance} \times (3 - \text{Experience})$

Discriminative power

- Multilevel analysis

Results: quality of the PCQ-Infertility

Response 75% (888 couples)

Item quality

- 7 items exit → 46 items in final PCQ

Reliability

- Total scale $\alpha = 0.92$
- 7 reliable subscales

Validity

- All hypotheses confirmed ($p < 0.01$)

Content PCQ-Infertility

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

* Range 0 – 3

Top 5 Quality Improvement scores

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

* Range 0 – 9

Discriminative power: large differences between clinics

Scale Range scores (scale 0 – 3)

Overall PCIC 1.66 – 2.53*

Accessibility 1.65 – 2.63*

Information 1.88 – 2.88*

Communication 1.74 – 2.82*

Respect for patient values 1.21 – 2.62*

Continuity & transition 1.44 – 2.63*

Patient Involvement 1.74 – 2.82*

Competence 1.97 – 2.74*

Scale 1 - 100
40 – 87

* Significant differences with and without case-mix correction ($P \geq 0.001$)

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 exilers¹
 - Fertility patients cross borders^{2,3}
 - European reimbursement is coming⁴ → 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&Patrizzo, 2009 3. Shenfield et al, 2010
2. Penning et al., 2009 4. www.europarfert.europa.eu

PCIC-Europe project partners



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 (3% 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	}	2/3
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

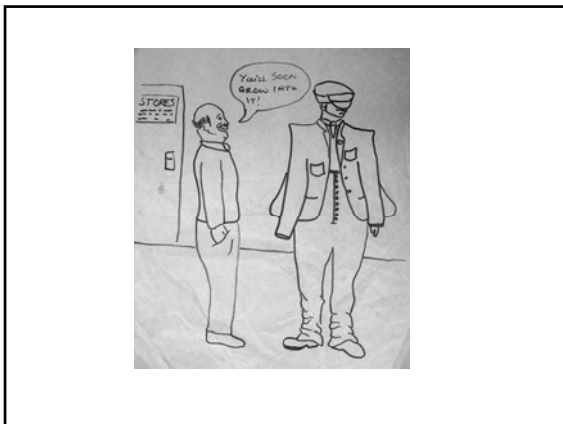
ENDOCARE: Patient-centred endometriosis care in Europe (1)

- 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 countries 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

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- www.europarl.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

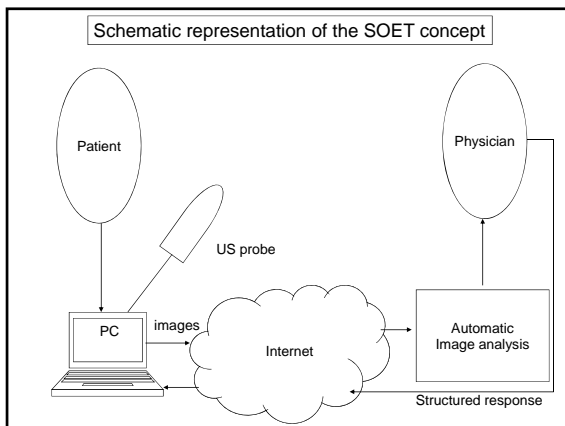
- Main advances in recent years:
 - Decrease in risks of complications of ART
 - Multiple pregnancies
 - Less OHSS
 - A more patient-friendly approach:
 - Friendly ovarian stimulation
 - Natural cycle IVF
 - Self-injection of rec-gonadotropins using the “pen”
 - OPU under conscious sedation
 - Recognition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

Patient-friendly = patient-centric ART

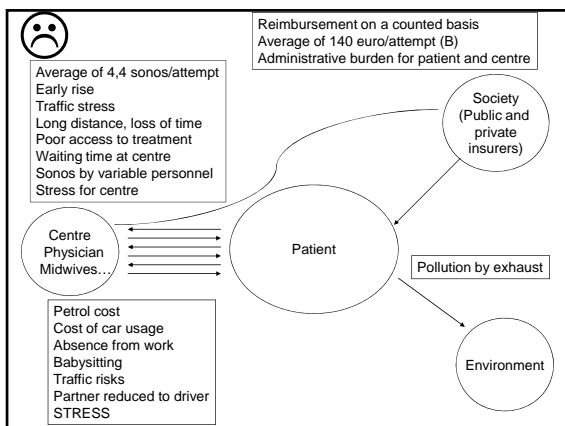
- Main remaining problem:
 - The need for frequent vaginal sonographic monitoring of follicular growth
 - For IVF/ICSI on average 4 to 5 sonograms
 - Many patients live at a distance from the centre:
 - Difficulty of access to treatment
 - Loss of time
 - Cost of petrol
 - Organizational stress reg.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

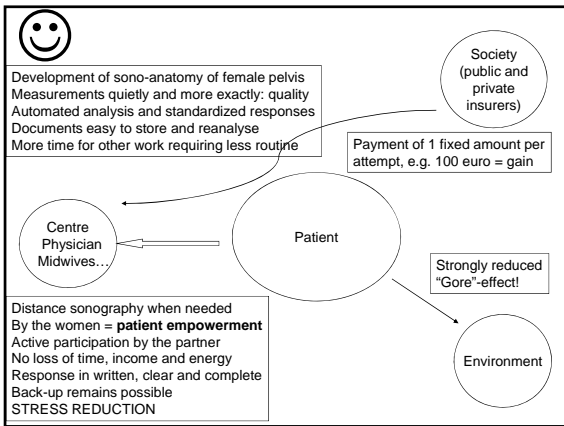
Idea: SOET = Self Operated Endovaginal Telemonitoring

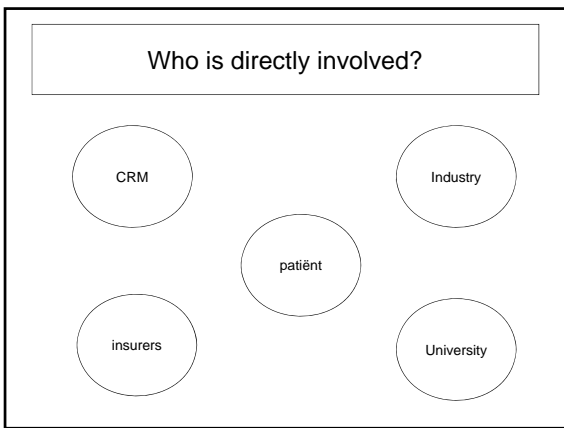
- Patient performs vaginal sonography herself (or partner)
- At convened moments of the stimulation protocol
- After a teaching session by a specialized nurse
- Using a set-up consisting of a vaginal probe linked to a PC
- After logging-in to a specific website
- Images are sent using widely available 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







- 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?

- Belgium
 - IVF/ICSI: stable number of ~15.000/year
 - 50% = candidate for SOET
 - Reduction of direct cost, e.g. $7.500 \times 100\text{€} = 750.000\text{€}$
 $7.500 \times 140\text{€} = 1.050.000\text{€}$
 - Indirect cost to be calculated (health economist)
- World
 - 1.000.000 attempts/year
 - Further growth likely
 - Especially if this complicated step is simplified in large countries (USA, India, China, ...)
 - Third world effect

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

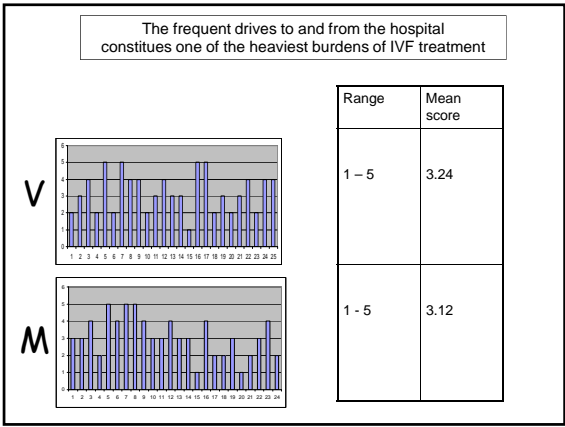
SOET 1

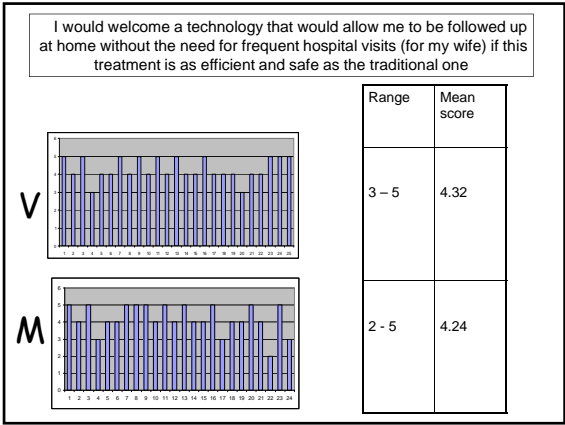
10 questions to patients and their partners

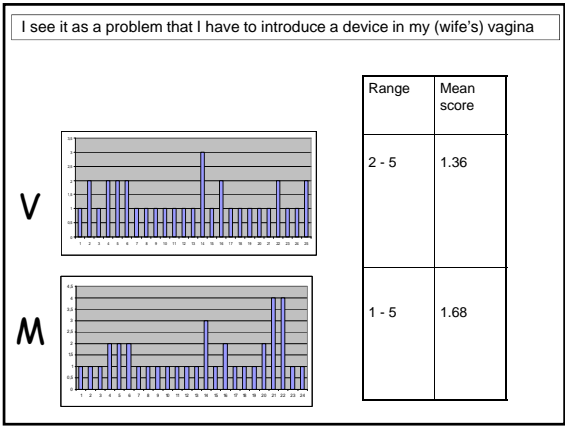
- Study approved by EC UZG nr. 2006/330
- Both answered independently from each other
- Ample time to respond
- Random distribution over 1st and subsequent attempts
- Couples living at a distance from CRM
 - In the far West-Flanders
 - Dutch and Germans

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

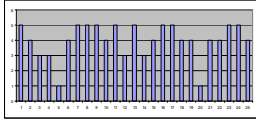




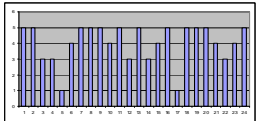


I am in favour of (my wife) making sonograms at home after a demo by a physician or a midwife, if that could avoid the frequent drives up and down

V



M



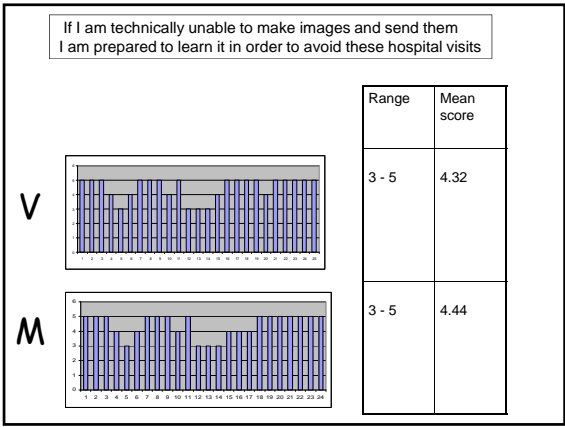
Range	Mean score
1 - 5	4.00
1 - 5	4.08

I have my own PC

	YES	NO
Patient	25	0
Partner	25	0

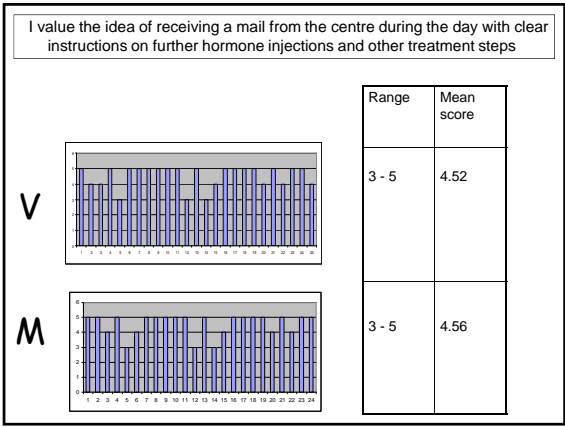
I am familiar with PC use and can mail images to the centre

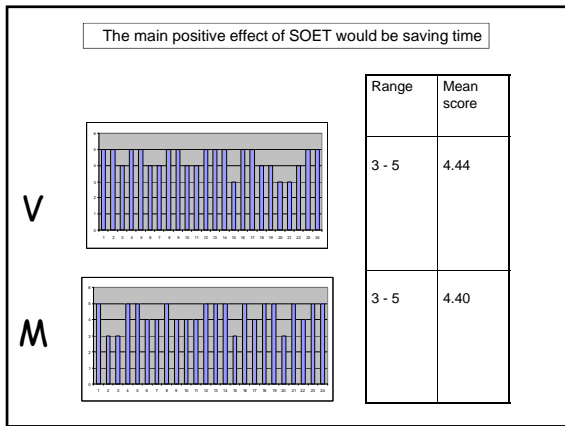
	YES	NO
Patient	24	1
Partner	24	1

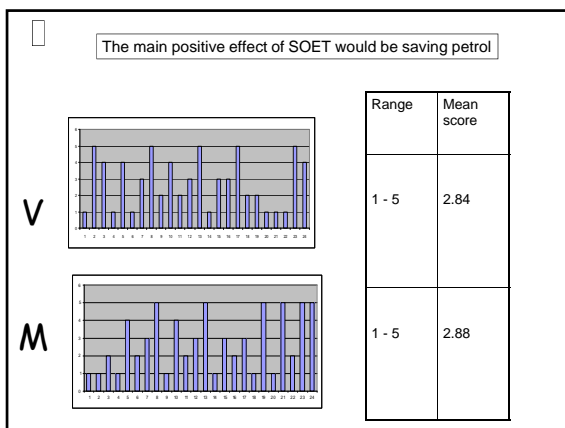


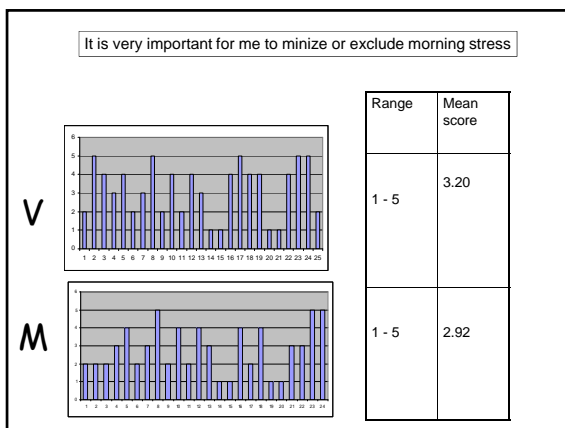
If needed I can do it every day including weekends

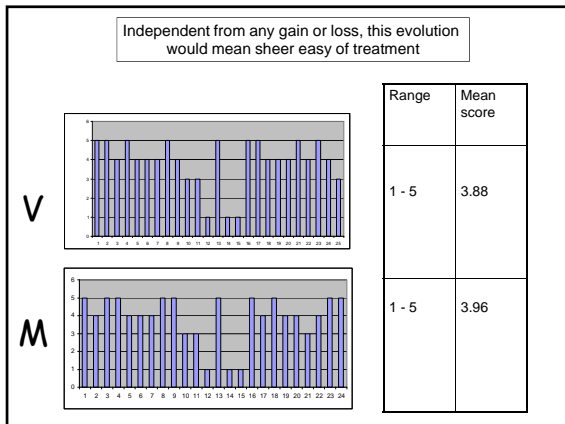
	YES	NO
Patient	24	1
Partner	25	0











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 treathening OHSS = coasting)
 - As many songraphies 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

PATIENT A

Clinical data	Op 1	Op 2	Op 3	Concordance
7d 200IU FSH	200IU on D8-9-10; repeat sono day 11	200IU for 3 days; then repeat sono	200IU on D8-9-10 Repeat sono day 11	excellent
10d 200IU FSH	5,000 IU HCG on day 12	5,000 IU HCG day 12 or one further sonogram	5,000 IU HCG day 12	excellent
Image quality	Perfect	Very good	Very good	Very good

PATIENT B

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

Image quality	Perfect	Very good	Very good	Very good
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PATIENT C

Clinical data	Op 1	Op 2	Op 3	Concordance
9 d 150IU FSH	5,000 IU HCG d11 or max 1 day later	5,000 IU HCG d 11	5,000 IU HCG today	excellent

Image quality	Perfect	Very good	Very good	Very good
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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

SOET 3

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

E. V. & V. in Obstet, 2009, 1 (3), 161-170 Original article

Patient acceptance of Self-Operated Endovaginal Telemonitoring (SOET): proof of concept

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Structured abstract

Introduction: Serial vaginal sonographies to monitor ovarian stimulation for assisted reproductive technologies (ART) remains a drawback for patients and health care providers.

Aim of the study: We asked patients make their own vaginal sonographies with a view to developing a home-applied vaginal probe and have them sent over the internet for analysis followed by same-day dosing advice and instructions. Twenty-five patients and their partners were questioned regarding the acceptability of this development. Reactions were unanimously positive. Using data from their attempts, we assessed concordance between clinical decisions taken on the basis of real-time sonography and those taken by a blinded assessor who interpreted the images later with nothing but standardized information regarding the patient. In all cases the same clinical decisions were taken. Twenty-one patients were taught by machines to record images themselves using an experimental set-up consisting of a small sonograph and a hospital intranet link to a stand-alone computer. Images were excellent and could be easily interpreted as if made in situ.

Results: Proof of concept was concluded from this initial experience. Specifications of the optimal instrument and operational algorithms fitting the needs of patients, health care providers and insurers, have to be developed. The advantages of such a patient-empowering and environment-friendly technology are explored in this paper.

Key words: Artificial reproductive technology, patient-empowerment, ovarian stimulation, self-operated vaginal sonography.

Describes

1. The idea and its theoretical advantages
2. The attitude of 25 couples: very positive
3. Experience with 20 IVF cycles: selected patients are perfectly able to make sonographic recordings themselves

↓

"In-house" proof of concept

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

Human Reproduction, Vol.25, No.3 pp. 563-568, 2010
Advanced Access publication on December 15, 2009 doi:10.1093/humrep/dqg440

human reproduction OPINION

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

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The need for serial vaginal sonographies to monitor ovarian stimulation for assisted reproductive technology (ART) treatments remains a major practical and organizational drawback both for patients and health-care providers. We explore the possibility of patients and/or their partners performing their own vaginal sonographies at home. To make this a reality, a portable, easy-to-use, home-applied vaginal probe for recording relevant images would have to be developed, as well as appropriate software to transfer images using modern communication technology to the centre, to analyse the recordings and to send a swift structured response, comprising dosing advice and next step instructions. A simplification of the encountered need to perform these sonographies, even if applicable to just a selected proportion of IVF patients, could fit in the general tendency to make IVF more patient-centred and friendly, to implement telemedicine and to increase patient empowerment by supervised active participation to their treatment. The advantages of such a technology are explored in this paper, aiming at opening up a debate on whether patients themselves would, could and should achieve a further substantial simplification of ART without loss of quality while strongly curbing costs.


Key words: artificial reproductive technology / patient empowerment / ovarian stimulation / self-operated endovaginal sonography



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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 j.kremer@obgyn.umcn.nl

Stockholm, 3-7-2011


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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

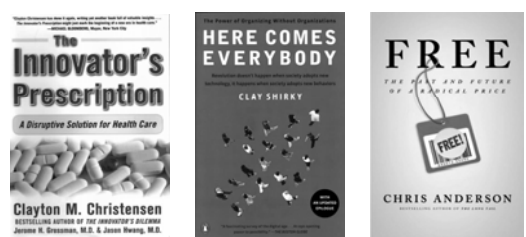
Health 2.0



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Inspiration



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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



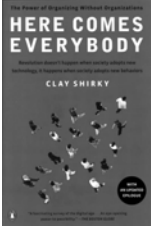
Clayton M. Christensen
BESTSELLING AUTHOR OF THE INNOVATOR'S DILEMMA
JOSHUA N. GROSSMAN, M.D. & JASON KWANG, M.B.A.

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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



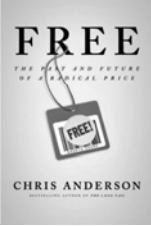
HERE COMES EVERYBODY
CLAY SHIRKY

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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




FREE
THE RISE AND FUTURE OF ZERO-COST THINGS
CHRIS ANDERSON
THE CHIEF ECONOMIST AT DISNEY

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How did I get involved in 2.0?



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Heyendaal Castle, 2001

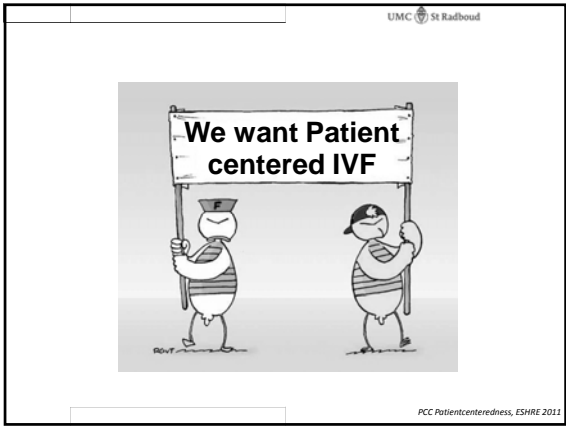


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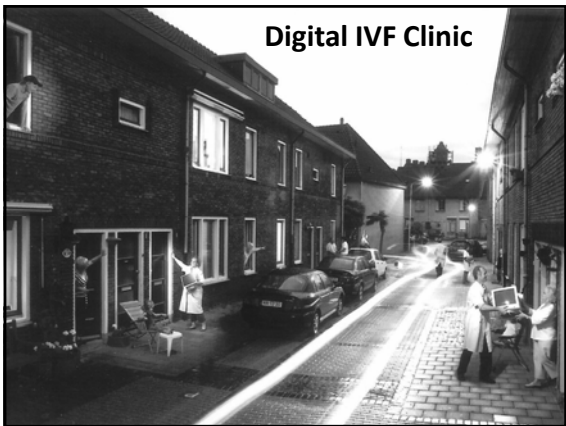
What do you think of our IVF care?

	POLICY	ORGANIZATION	PEOPLE
TECHNIQUE	Goals	Tasks	Expertness
	<i>More attention patients needs</i>	<i>Shorter lines</i>	<i>More social skills</i>
POLITICS	Influence	Decisions	Autonomy
	<i>Better tuning</i>	<i>More clearness</i>	<i>Empowerment patient</i>
CULTURE	Climate	Collaboration	Attitude
	<i>Safer atmosphere</i>	<i>Better collaboration</i>	<i>More compassion</i>

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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

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Digitale Fertendo Poli - Follikelpunctie - Microsoft Internet Explorer

De digitale IVF poli UMC St Radboud

Waarom? Voortentoonstelling - Stimulatie - Punctie - Lab. bewerking - Teruggelating - Uitkomst

Medisch Record

Dag planner

Follikelpunctie

In de vruchtblaasjes in de eierstok, de eiblaasjes, bevinden zich de eicellen. Het aanpakken van deze eiblaasjes wordt follicelpunctie of oocyte punctie genoemd en wordt gepland vlak voor de te verwachten eisprong. Deze punctie vindt plaats via de vagina. De rijpe follikels, waarin zich de eicellen bevinden, worden aangeprikt en leeggezogen.

Voorbereiding
gebruikt op de dag van de punctie 's ochtands een normaal ontbijt (minimaal een licht ontbijt). Het is belangrijk dat u tijdens de punctie een lege blaas heeft. Op uw vinger wordt een klemmetje aangebracht waarmee tijdens de punctie uw hartslag en ademhaling worden gecontroleerd. U krijgt een speciale doek over uw onderlichaam.

Met behulp van echoscopie worden de eiblaasjes in beeld gebracht. Via een naaldzonder wordt vervolgens een speciale naald ingebracht. De punt van de naald is zichtbaar op het beeldscherm van het echoscoopapparaat. De eiblaasjes worden één voor één met de naald aangeprikt en leeggezogen.

De punctie vindt plaats op de punctiekamer op de IVF-afdeling. Het is mogelijk uw eigen muziek op de punctiekamer op de IVF-afdeling te brengen bij de follicelpunctie.

Zaadvrije punctie
Voor de punctie moet zaad worden ingevroerd bij het IVF-laboratorium op de polikliniek. Het zaad wordt door

Uitkomst
Uitkomst

Uitkomst

Uitkomst

Digitale Fertendo Poli - Uitslag - Microsoft Internet Explorer

De digitale IVF poli UMC St Radboud

Waarom? Voortentoonstelling - Stimulatie - Punctie - Lab. bewerking - Teruggelating - Uitkomst

Medisch Record

Dag planner

Uitslag

Antal embryo's ontbond:	0	Uitslag
Antal embryo's getransfereerd:	2	Uitslag
Antal embryo's ingevroerd:	0	Uitslag
Kwaliteit 1e embryo:	4	Uitslag
Kwaliteit 2e embryo (naden van bevestiging):	4	Uitslag

Embryo foto's

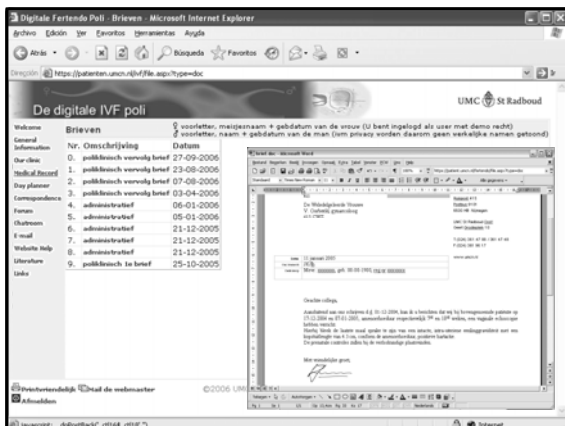
Complicaties: geen

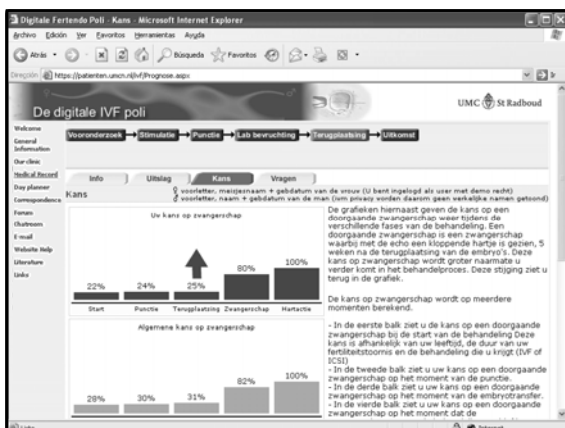
Complexiteit: geen

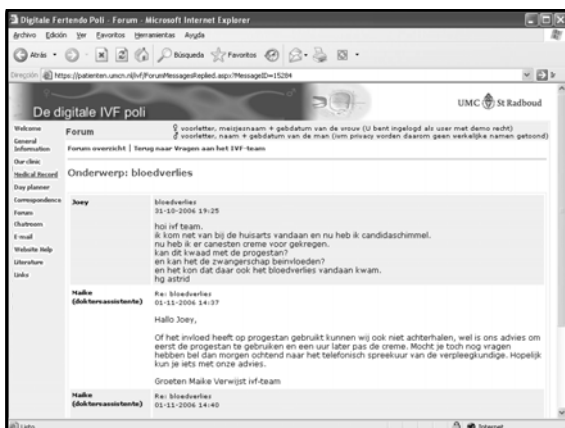
Gereed

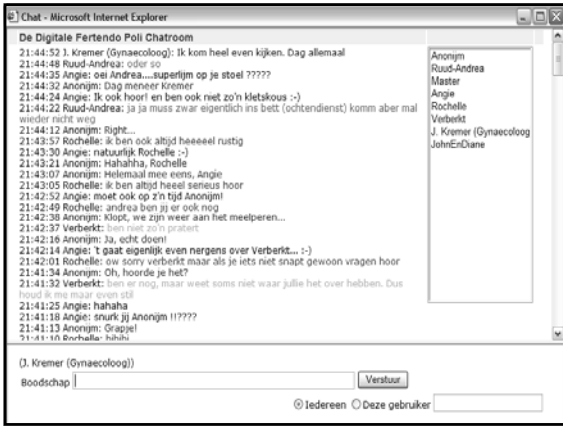
Uitkomst

Uitkomst










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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,

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Human Reproduction Vol.21, No.11 pp. 2055-2059, 2006. doi:10.1093/humrep/del214
Advance Access publication September 18, 2006.

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

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BACKGROUND: Generic patient-accessible medical records have shown promise in enhancing patient-centred care for patients with chronic diseases. We sought to design, implement and evaluate a patient-accessible medical record specifically for patients undergoing a course of assisted reproduction (IVF or ICSI). **METHODS:** The personal medical record (PMR) database was developed using three formative evaluation steps, and its user-experience was evaluated through a cross-sectional study. Fifty-four patient-couples receiving an IVF or ICSI treatment in our hospital were granted access to the PMR. Main outcome concerns the usage of the PMR, the perceived usefulness of its functions and user attitudes towards privacy and financial issues. **RESULTS:** The PMR consists of 15 major functions that can be classified into personal information, general information and communication functions. Fifty-three patient-couples accessed the website and 51 couples filled out the evaluation questionnaire. They rated most functions as useful and preferred personalized to general functions. The results also show that some functions require further development. Patients using the PMR have little concerns regarding privacy, and 76% are willing to pay for such a service in the future. **CONCLUSIONS:** The patients in this study frequently and intensively used the Internet-accessible PMR. This suggests that the PMR offers very useful functions from an IVF/ICSI patient's perspective.

Key words: consumer health informatics/electronic health record/Internet/IVF/patient education

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UMC St Radboud

Empowering patients undergoing in vitro fertilization by providing Internet access to medical data

Wouter S. Tull, M.Sc.,¹ Chris M. Verhaak, Ph.D.,² Didi D. M. Bruut, M.D.,³ Pieter F. de Vries Robbe, M.D.,⁴ and Jan A. M. Kremer, M.D.⁵
 Departments of ¹Gynaecology and ²Obstetrics, ³Medical Psychology and Pediatrics, and ⁴Medical Informatics, Radboud University Nijmegen Medical Center, Nijmegen, The Netherlands.

Objective: To study the effect of an Internet-based personal health record on the empowerment of patients undergoing IVF.
Design: Randomized clinical trial.
Setting: Patients undergoing IVF and intracytoplasmic sperm injection (ICSI) in an academic research environment.
Patients: We selected patients who were undergoing an IVF or ICSI treatment, have an Internet connection, and speak fluent Dutch.
Intervention(s): An Internet-based personal health record that provides patients with general and personal information concerning their given treatment and that also provides facilities for communication with fellow patients and physicians.
Main Outcome Measure(s): Patient empowerment (measured as a multidimensional concept consisting of self-efficacy, actual and perceived knowledge, and involvement in the decision process), patient satisfaction, meaning of infertility problems, social support, anxiety, and depression.
Results: A total of 51 female and 19 male participants were suitable for analysis. No significant differences were observed in per person change in patient empowerment. We did not find any significant differences regarding per person change in patient satisfaction, the meaning of infertility problems, social support, anxiety, and depression.
Conclusion(s): Usage of the personal health record did not have any effects on patient empowerment, but, at the same time, the study did not find that the personal health record had any significant adverse effects either. (Fertil Steril 2007;88:361-6. ©2007 by American Society for Reproductive Medicine.)

Key Words: Consumer health informatics, patient empowerment, Internet, IVF, electronic health record

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Human Reproduction Vol.23, No.3, pp. 2981-2986, 2008
 Abstract Article published on July 23, 2008

IVF patients show three types of online behaviour

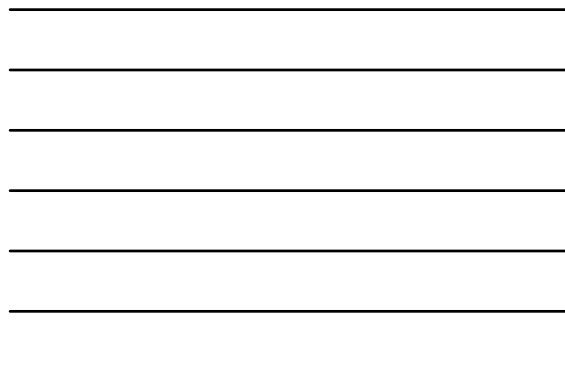
W.S. Tull^{1,4}, C.M. Verhaak², P.F. De Vries Robbe³ and J.A.M. Kremer⁵

¹Department of Obstetrics and Gynaecology, Radboud University Nijmegen Medical Centre, PO Box 9101, 6500 HB Nijmegen, The Netherlands; ²Department of Medical Psychology, Radboud University Nijmegen Medical Centre, PO Box 9101, 6500 HB Nijmegen, The Netherlands; ³Department of Medical Informatics, Radboud University Nijmegen Medical Centre, PO Box 9101, 6500 HB Nijmegen, The Netherlands; ⁴Correspondence address. E-mail: w.s.tull@isg.umcn.nl

BACKGROUND: The Internet introduces new ways to deal with stress. However, it is unclear how its resources are used in everyday life. Using a web-based personal health record (PIHR), we observed the patient's online behaviour and linked this to distress, theories on dealing with stress and demographics. **METHODS:** Between 2004 and 2007, all visited web-pages were logged and categorized into 14 content types. Behavioural styles were elicited using factor analysis. These behavioural styles were subsequently correlated to data on demographics, coping mechanisms and distress from the female partners of the first 51 patient couples that used the PIHR. **RESULTS:** One thousand and fifty patient couples viewed 588 887 web pages during their first treatment cycle. Factor analysis elicited three online behavioural styles explaining 66.9% of all variance in usage of the website: an 'individual information style', a 'generic information style' and a 'communication style'. The 'individual information style' correlated negatively to having paid employment (Spearman = -0.364, P = 0.007) and emotional coping mechanisms (Spearman = -0.305, P = 0.026). The 'communication style' correlated positively to having paid employment (Spearman = 0.318, P = 0.021) and anxiety (Spearman = 0.281, P = 0.005). **CONCLUSIONS:** IVF patients show three types of online behaviour. Only limited correlations exist between these styles and demographics, coping mechanisms or distress. When planning a website or portal for IVF patients, content should be adopted accordingly.

Keywords: IVF; coping; internet; consumer health informatics; factor analysis

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Dynamics of usages during a IVF cycle

Page views per visitor per treatment day, stratified by content type. Error bars, 95% confidence interval
 T1 – pretreatment stage, T2 – hormonal stimulation, T3 – laboratory stage, T4 – luteal stage, and T5 – posttreatment phase.

Content Type	T1	T2	T3	T4	T5
Generic Information	~1.5	~2.5	~10.5	~3.5	~2.5
Patient specific information	~1.5	~1.5	~8.5	~2.5	~1.5
Communication	~1.5	~2.5	~3.5	~6.5	~3.5

Fig. Dynamics of internet usage. Fertil Steril 2009.


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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



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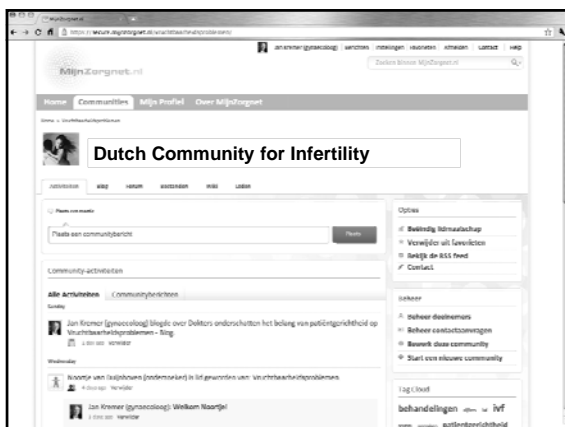
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Health communities

- 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



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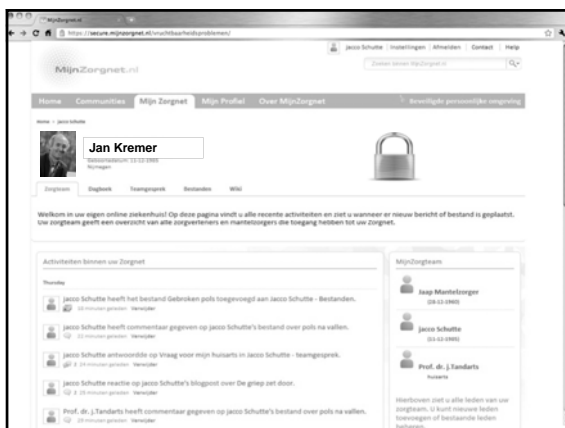
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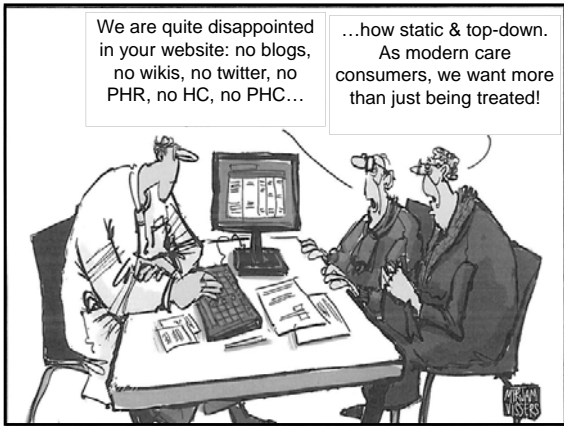
Next step: Personal Health Community


- 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)



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Tools for patient-centred care:
FertiQoL
FertiSTAT


Jacky Boivin, PhD, CPsychol

School of Psychology
Cardiff University

CARDIFF UNIVERSITY
 UNIVERSITY OF CARDIFF  ESHRE, Stockholm, 2011

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

Cardiff Fertility Studies 

Objectives

Describe development and validation of two tools to support initiatives in fertility care

- FertiQoL – Fertility Quality of Life
- FertiSTAT – Fertility Status Awareness Tool

Cardiff Fertility Studies 

Human Reproduction Update Advance Access published March 11, 2010
Human Reproduction Update, Volume 16, No. 2, pp. 1-21, 2010
doi:10.1093/hupd/erq016

human reproduction update

The patients' perspective on fertility care: a systematic review

E.A.F. Dancet^{1,2,3}, W.L.D.M. Nelen¹, W. Smeets¹, L. De Leeuw¹, J.A.M. Kremer¹, and T.M. D'Hooghe^{1,4}

¹Leuven University Hospital, Leuven University Fertility Centre, Herestraat 49, 3000 Leuven, Belgium; ²Department of Obstetrics and Gynecology, Radboud University Nijmegen Medical Centre, Geen Gewoosje Ziek 10, 6525 GA Nijmegen, The Netherlands; ³Catholic University Leuven, Center for Health Services & Nursing Research, Espermeirweg 36, 3000 Leuven, Belgium

*Correspondence address: E-mail: thomasdhooghe@uckh.uva.be

Submitted on September 21, 2009, modified on December 21, 2009, accepted on January 26, 2010

Cardiff Fertility Studies

Consensus important & problematic domains (Dancet 2010, Hum Reprod Update)

5

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

- ... 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)

Cardiff Fertility Studies

Measurement tools in fertility

Negative affect/Impact of infertility

1. Infertility Questionnaire Bernstein, 1985
2. Infertility Reaction Scale Collins 1992
3. Fertility Problem Inventory Newton, 1999
4. Infertility Cognitions Questionnaire Verhaak, 2005
5. Questionnaire of Emotional Maladjustment and Adaptive Resources in Infertility Moreno-Rosset, 2009
6. Cognitive Appraisal Scale for Infertility Saito, 2009.
7. SCREENIVF Verhaak, 2010
8. Fertility Problem Stress Inventory Abbey 1991
9. Infertility Feelings Questionnaire Stanton 1991
10. Infertility Distress Scale Peok, 1999
11. Polycystic Ovary Syndrome Quality-of-life Cronin 1998
12. Endometriosis Health Profile-30 Jones 2001
13. Quality-of-Life in infertile men Schanz 2005

Cognitions & coping

1. Wikman Reproduction Scale Wikman 1990
2. Child Project Questionnaire Stoleru 1993
3. Fertility Adjustment Scale Glover 1999
4. Irrational parenthood thoughts scale Fekkes 2003
5. Infertility Self-Efficacy Scale Cousineau 2006
6. Coping Scale for Infertile Couples Lee 2000.

Treatment

1. Daily Record-Keeping Sheet Bolvin 1995
2. Psychological evaluation test after ART Franco 2002
3. Concerns about reproductive technologies Klonoff-Cohen 2004
4. Difficulties with infertility and its treatment Benyamini 2005

Boivin, Evidence-Based Approaches to Infertility Counseling. In Covington & Burns, A comprehensive handbook for clinicians, 2008

Development process

- Literature review/expert consultation to generate items
 - Psychosocial/fertility experts in reproductive health (n=27): researchers, psychologists, social workers, counselors, 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=136 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

Boivin et al. 2011. HR. Supplemental Table 1

Cardiff Fertility Studies



Psychometric sample

Boivin et al. 2011. HR. Table 2

Variable	Online (N=1048)	Clinic (N=366)	(χ ² or t)
Demographics			
Age in years mean (SD)	32.9 (4.9)	35.2 (4.0)	7.9***
Women % (n)	96.8 (1014)	79.5 (291)	113.4***
Single % (n)	.2 (3)	4.0 (13)	49.4***
Mean years together (SD)	6.85 (3.9)	7.0 (3.9)	.6
University education (% , n)	57.1 (598)	66.2 (139)	9.5 [†]
Country % (n)			243.4***
Australia/NZ	14.5 (152)	25.1 (92)	
Canada	10.3 (108)	42.0 (154)	
UK	8.7 (91)	2.7 (10)	
USA	64.1 (672)	30.2 (111)	
Other	2.4 (25)	--	

Psychometric sample

Boivin et al. 2011. HR. Table 2

Variable	Online (N=1048)	Clinic (N=366)	(χ ² or t)
Health & Reproduction			
Other health problems % (n)	30.8 (309)	24.0 (260)	5.8 [†]
Parenthood % (n)	18.9 (197)	30.1 (108)	19.8***
Years infertile mean (SD)	3.4 (2.9)	2.9 (2.0)	2.4 [†]
Perceived diagnosis % (n)			82.4***
Unexplained	10.9 (86)	14.0 (38)	
Female factor	44.5 (351)	18.0 (49)	
Male factor	19.9 (157)	21.7 (59)	
Mixed	11.9 (94)	14.7 (40)	
Same-sex	1.6 (15)	3.3 (9)	
Age-related	4.1 (32)	8.8 (24)	
Other	7.1 (56)	19.5 (53)	
Years treated mean (SD)	2.03 (2.4)	2.43 (1.8)	1.6

Factor loadings (CORE)

Boivin et al. 2011. HR. Table 2

	Emotional	Relational	Mind/Body	Social
Angry	.752 (.800)			
Grief/loss	.763 (.792)			
Sad/depressed	.730 (.772)			
Fluctuate hope/despair	.643 (.759)			
Jealousy & resentment	.737 (.634)			
Unable to cope	.640 (.594)			
Affectionate		.749 (.732)		
Difficult to talk		.629 (.696)		
Negative impact on relationship		.707 (.633)		
Content relationship		.768 (.616)		
Strengthen relationship		.713 (.603)		
Satisfied sexual relationship		.575 (.600)		
Fatigue			.731 (.745)	
Pain/discomfort			.566 (.663)	
Feel worn out§			.620 (.627)	
Disrupt activities			.704 (.625)	
Concentration	(.634)*		.554 (.413)	
Life on hold§	(.577)*		.572 (.355)	
Family understand				.669 (.669)
Friend support				.751 (.649)
Society respect				.495 (.446)
Isolated	(.558)*			.509 (.531)
Handle/pregnant others§	.538* (.589)*			.306 (.350)
Shame, embarrassment§	.527* (.580)*			.319 (.440)

Note. Items reversed to avoid negative loadings. Clinic loadings in parenthesis. *Cross-loadings. §Wording has changed in final version.

Factor loadings Optional Treatment Module

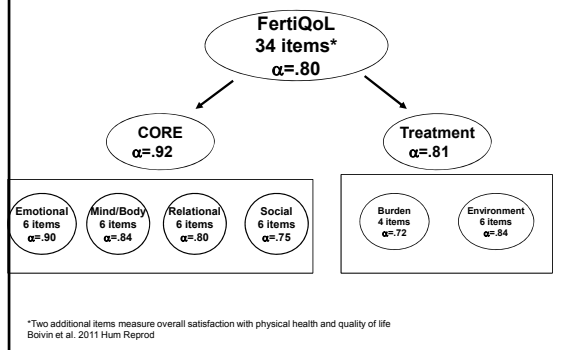
Boivin et al. 2011. HR. Table 3

	Treatment Environment	Treatment Tolerability
Interactions with staff	.813 (.784)	
Quality treatment information	.802 (.784)	
Quality surgery & medical treatment	.780 (.763)	
Fertility staff understand us	.728 (.750)	
Quality emotional services	.632 (.664)	
Medical services desired available	.576 (.585)	
Bothered/effect daily activities & work		.799 (.790)
Bothered/physical effects		.792 (.732)
Complicated medication & procedures		.645 (.715)
Treatment effects on mood		.645 (.681)

Note. Items reversed to avoid negative loadings. Clinic loadings in parenthesis. *Cross-loadings. §Wording has changed in final version.

Cardiff Fertility Studies

FertiQoL Structure & reliability



FertiQoL



The first internationally validated instrument to measure quality of life in individuals experiencing fertility problems

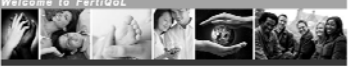
Professionals can download FertiQoL FREE OF CHARGE

www.fertiqol.org





Welcome to FertiQoL



- Home
- FertiQoL Team
- FertiQoL Description
- FertiQoL Tool
 - Download FertiQoL
 - Account
 - FAQs

Before downloading any FertiQoL PDFs please read the following terms and conditions.

1. You must use FertiQoL as it is without making any changes to the items, order of items, instructions or response scales. If you detect an error or a problem or you wish to give us some feedback then email us at ferti@fertiqol.org.

2. FertiQoL is free to use but you must acknowledge the sponsors in any publication. The acknowledgements should state: "FertiQoL was developed by Jacky Babin, Janet Talbot and Jackie Toews with sponsorship from the European Society of Human Reproduction & Embryology (ESHRE), Fertility Society of Australia (FSA) and Merck Serono S.A. FertiQoL is a registered trademark of FertiQoL."

3. Please email any comments or suggestions to ferti@fertiqol.org. We will be happy to receive your feedback and will use it to improve the instrument. We will also be happy to acknowledge your contribution in any publication.

4. If you are using FertiQoL for research purposes, please email us at ferti@fertiqol.org to discuss the use of the instrument in your study. We will be happy to provide you with the necessary information and will be happy to acknowledge your contribution in any publication.

5. Please email us at ferti@fertiqol.org if you have any questions or need any help. We will be happy to provide you with the necessary information and will be happy to acknowledge your contribution in any publication.

See www.fertiqol.org for update: Arabic, Greek, Croatian, Korean in progress

Cardiff Fertility Studies

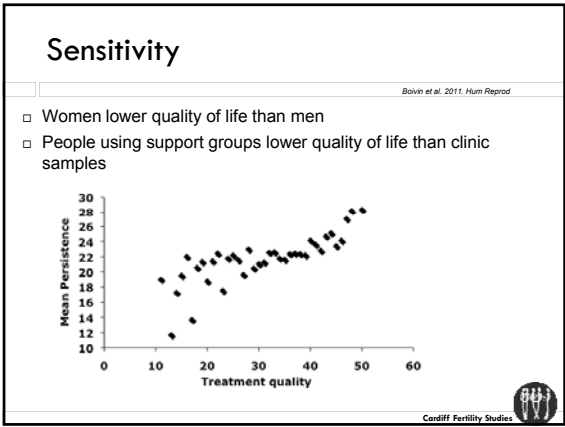
FertiQoL International
Optional Treatment Module

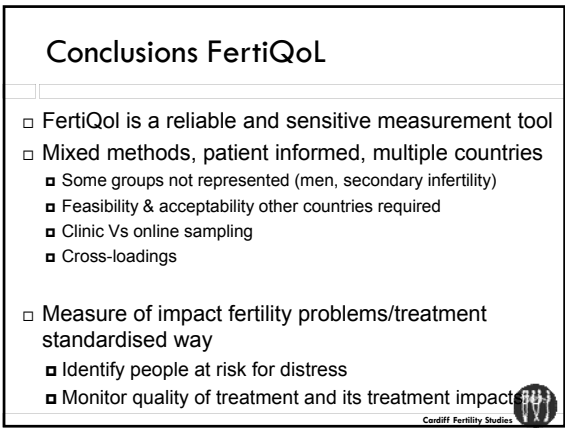
Please note: This module is only available to individuals who have started fertility treatment (this includes any medical consultation or intervention). If Yes, then please respond to the following questions. For each question, kindly check (tick the box) for the response that most closely reflects how you think and feel. Tick only one answer to your current thoughts and feelings. Some questions may relate to your personal life, but they are necessary to adequately measure all aspects of your life.

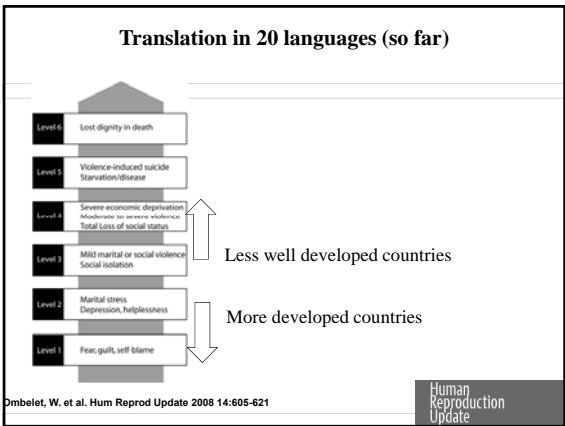
For each question, check the response that is closest to your current thoughts and feelings	Always	Very Often	Quite Often	Sometimes	Never
T1 Does fertility treatment negatively affect your mood?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T2 Are the fertility medical services you would like available to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

For each question, check the response that is closest to your current thoughts and feelings	For the lowest amount	Very Much	A Moderate Amount	A Little	Not At All
T3 I feel complicated in dealing with the procedures and/or administration of medication for your infertility treatments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T4 Are you bothered by the effect of treatment on your daily or work-related activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T5 Do you feel the fertility staff understand what you are going through?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T6 Are you bothered by the physical side-effects of fertility medications and treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

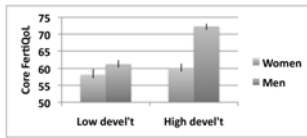
For each question, check the response that is closest to your current thoughts and feelings	Very Dissatisfied	Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
T7 Are you satisfied with the quality of services available to you to address your emotional needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T8 How would you rate the surgery/infertility medical treatment(s) you have received?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T9 How would you rate the quality of information you received about medication, surgery and/or medical treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T10 Are you satisfied with your interactions with fertility medical staff?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>





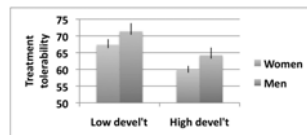


Cross-country sensitivity



Low development status:
BRA, BFA, IND, ARG

High development status:
AUS, BEL, USA, ITA



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Conclusions FertiQoL

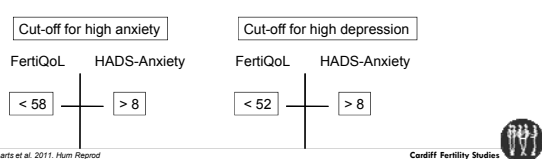
- FertiQoL is a reliable and sensitive measurement tool
- Mixed methods, patient informed, multiple countries
 - Some groups not represented (men, secondary infertility)
 - Feasibility & acceptability other countries required
 - Clinic Vs online sampling
 - Cross-loadings
- Measure of impact fertility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

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Reliability in Dutch sample

Table 1 Psychometric properties and Pearson's correlations of FertiQoL and HADS total and subscales in Dutch population^a.

Scale	Psychometric properties			Correlations HADS and FertiQoL scales ^b	
	Number of items	Mean score ^a	Cronbach's α^c	HADS-anxiety	HADS-depression
FertiQoL					
Total scale	34	70.8 (13.9)	0.91	-0.64*	-0.67*
Physical	8	70.8 (19.3)	0.80	-0.63*	-0.66*
Relational	6	78.2 (14.5)	0.72	-0.23*	-0.37*
Social	6	74.0 (16.6)	0.74	-0.49*	-0.54*
Emotional	6	59.6 (8.7)	0.81	-0.59*	-0.51*
HADS					
Anxiety	7	5.5 (3.7)	0.82	n.a.	n.a.
Depression	7	3.4 (3.2)	0.83	n.a.	n.a.



Aarts et al. 2011. Hum Reprod. Cardiff Fertility Studies

Fertility Awareness

- Lack of awareness of fertility risk indicators

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Consensus important & problematic domains

23

Donceel 2010, Hum Reprod Update

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

- ... on alternatives, helping themselves, plan for future, emotional aspects

Emotional support and alleviation of fear and anxiety

- Contact with prior patients

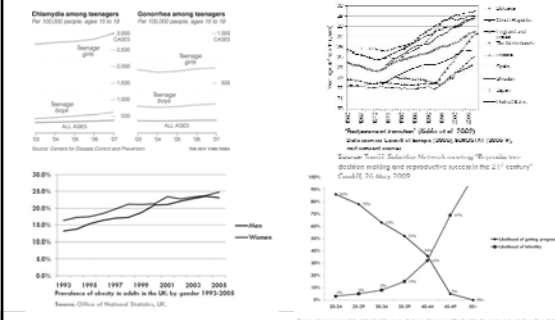
Physical comfort

- Accommodation of clinic, separate clinic (from pregnant groups)

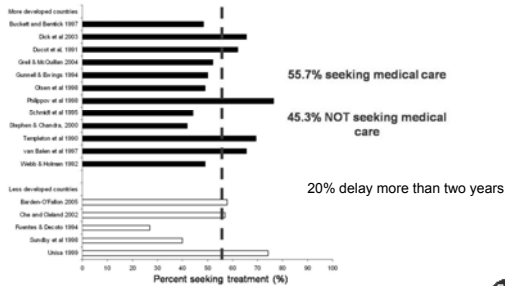
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Risk factors on the increase



Seeking timely medical advice



Boivin, Bunting, Collins & Nygren, Human Reproduction (2007)
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Lack of problem awareness

Normal Nipple	Inversion	Elevation	Characteristics
			when half of the milk ducts are blocked, the other half
			when the further judgment of the milk are regged or irregular
			when the color of the milk ducts throughout
			if the milk ducts are larger than a pencil's eraser

National Institutes of Health
National Cancer Institute
Cardiff Fertility Studies

Public health campaigns about fertility risk factors

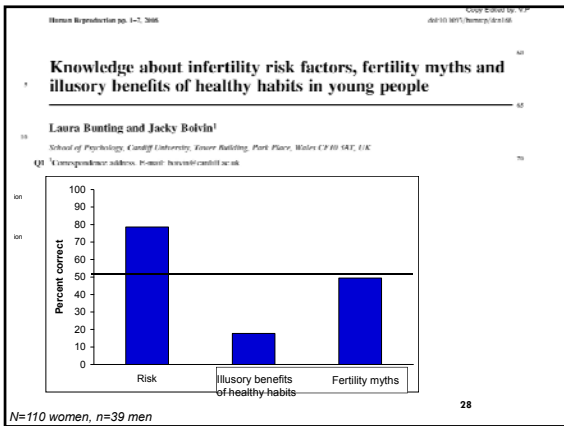
ADVANCING AGE DECREASES YOUR ABILITY TO HAVE CHILDREN.
 Women whose first children were born to them at older ages have a higher risk of having children who are born with Down Syndrome and other health problems.
 Your decisions now can impact your ability to conceive in the future.
www.ProspectFertility.org 1.800.228.0888 GET THE FACTS

PRACTICING SAFE SEX NOW PROTECTS YOUR ABILITY TO HAVE CHILDREN LATER.
 Having unprotected sex increases your risk of contracting HIV and other health problems.
 Your decisions now can impact your ability to conceive in the future.
www.ProspectFertility.org 1.800.228.0888 GET THE FACTS

IF YOU SMOKE THIS MIGHT BE YOUR ONLY USE FOR A BABY'S BOTTLE.
 Smoking may affect your ability to have children.
 Your decisions now can impact your ability to conceive in the future.
www.ProspectFertility.org 1.800.228.0888 GET THE FACTS

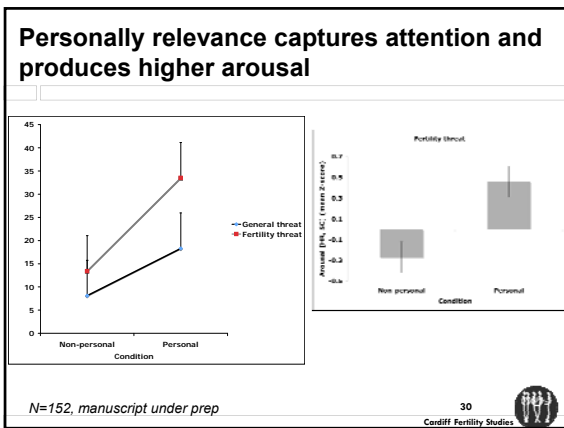
AN UNHEALTHY BODY WEIGHT MAY PREVENT YOU FROM HAVING CHILDREN.
 Low body weight and obesity can cause infertility.
 Your decisions now can impact your ability to conceive in the future.
www.ProspectFertility.org 1.800.228.0888 GET THE FACTS

American Society for Reproductive Medicine, 2006



Need to be personally relevant to be effective

Original advert: ASRM ≈2006



Steps in FertiSTAT development

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

Cardiff Fertility Studies 

Risk factors identified in review

- | | |
|--|--|
| <ul style="list-style-type: none"> □ Lifestyle <ul style="list-style-type: none"> • Alcohol use • Tobacco use • Class A drug use • Caffeine use • Excessive exercise • Steroid use • Unable to cope with current stress • Stress at work • Overweight • Underweight • Occupational exposures □ General medical history <ul style="list-style-type: none"> • Diabetes • Thyroid disease • Asthma • Heart disease • Kidney disease • SLE (lupus) • Epilepsy • Sickle cell anaemia • Cancer | <ul style="list-style-type: none"> • Reproductive history <ul style="list-style-type: none"> ▪ N° of sexual partners (unprotected) ▪ Menstrual cycle (<21 days, >35 days, irregular, severe pain, absence of period) ▪ STI (e.g., Chlamydia) ▪ Contraceptive use ▪ History of pelvic surgery ▪ Miscarriage/termination ▪ Pelvic inflammatory disease ▪ Endometriosis ▪ Polycystic ovaries ▪ Coeliac ▪ Undescended testicles ▪ Varicocele ▪ Mumps after puberty in males • Demographic <ul style="list-style-type: none"> ▪ Age ≥34 years ▪ Years trying to conceive ▪ Living standard ▪ Ethnicity |
|--|--|

Cardiff Fertility Studies 



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
 - Stress at work
 - Overweight
 - Underweight
 - Occupational exposures
- **General medical history**
 - Diabetes
 - Thyroid disease
 - Asthma
 - Heart disease
 - Kidney disease
 - SLE (lupus)
 - Epilepsy
 - Sickle cell anaemia
 - Cancer
- **Reproductive history**
 - N° of sexual partners (unprotected)
 - Menstrual cycle (<21 days, >35 days, irregular, severe pain, absence of period)
 - STI (e.g., Chlamydia)
 - Contraceptive use
 - History of pelvic surgery
 - Miscarriage/abortion
 - Pelvic inflammatory disease
 - Endometriosis
 - Polycystic ovaries
 - Celiac
 - Undescended testicles
 - Varicocele
 - Mumps after puberty in males
- **Demographic**
 - Age ≥34 years
 - Years trying to conceive
 - Living standard
 - Ethnicity



Cardiff Fertility Studies

Fertility STatus Awareness Tool

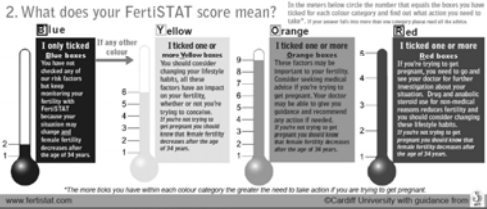
FertiSTAT is a free one-page questionnaire containing:

22 risks & indicators

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



Personalised guidance based on individual risk profile



Cardiff Fertility Studies

i. Preliminary cross-sectional validation

	Total (N=1073)	%
Country of Origin*		
United Kingdom	730	77.00
America	128	13.50
Canada	61	6.50
Australia	18	1.90
Other	27	3.00
Highest Educational Level*		
University	386	48.37
Post secondary certificate	285	35.21
Secondary	117	14.91
Primary	8	1.00
Age (SD)	29.6 (5.8)	-
Age range		
18 – 25	250	24.20
26 – 30	349	33.79
31 – 34	219	21.20
35 – 39	185	18.00
40 – 44	69	6.53
Recruitment Source		
Online (n = 602)		
Advertise	171	16.01
Referrals	115	10.72
Facebook	326	31.72
Media	26	2.45
University	132	12.30
Clinic (n = 470)		
Antenatal	326	30.38
Fertility	128	12.09
Termination	41	3.82

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

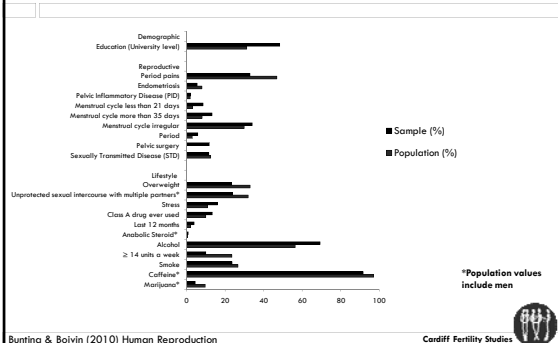
Pregnant = 532 (weeks pregnant range = 3 – 40 with 78.82% ≥ 12 weeks)

Not Pregnant actively trying = 202 (168 of these women were classified as *True Fertility Studies*)

Bunting & Bolvin (2010) Human Reproduction



Validation sample comparable risk pattern to general population

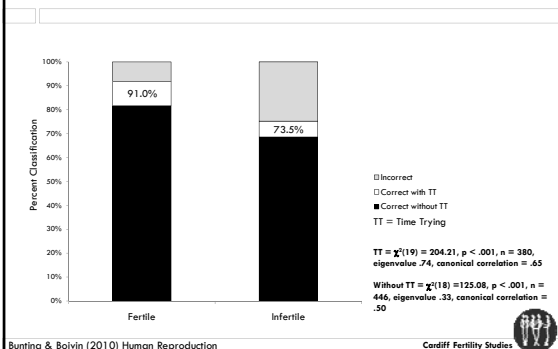


Bunting & Bolvin (2010) Human Reproduction

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Discrimination fertile versus infertile



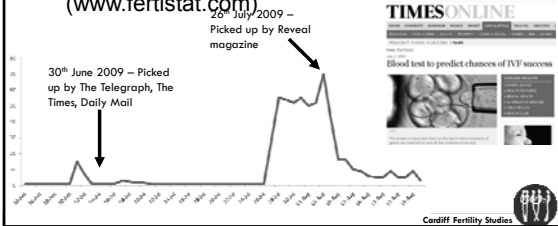
Bunting & Bolvin (2010) Human Reproduction

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Potential as public awareness tool

- ESHRE 30th June 2009 – released FertiSTAT (www.fertistat.com)



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

Cardiff Fertility Studies

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...” Shaalma & Kok, Psychol & Health, p. 6, 2009

- FertiQoL and FertiSTAT tools that demonstrate that science can be translated into valid ways of assisting in fertility care

Cardiff Fertility Studies

Need to develop support toolkit that can [really!] be integrated in the day-to-day

Needs assessment and intervention development techniques exist

- Intervention mapping^{Bartholomew et al. 1998}
- MRC complex intervention framework^{Campbell et al. BMJ, 2000}
- Taxonomy of behaviour change techniques^{Abraham & Michie, Health Psych, 2008}
- Evidence-based evaluation methods^{Sackett et al. EBM, 1996}
- etc



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 ➔ 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 => 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 → Increased fertility problems

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

Leridon 2004: 'Can assisted reproduction technology compensate for the natural decline in fertility with age? A model assessment.'

Table I. Success rates (pregnancies ending in live birth per 100 women of each age) for conception without assisted reproduction technology (ART): results of the model

	Woman's age when starting pregnancy attempt		
	30 years	35 years	40 years
Success:			
Conception (LB) within 12 months	75.4	66.0	44.3
Delay:			
Conception (LB) in 12-23 months	10.9	12.3	12.7
Conception (LB) in 24-35 months	3.0	3.9	4.7
Conception (LB) in 36-47 months	1.4	1.7	2.0
Total conceptions (LB) within 4 years	90.7	83.9	63.7
Total conceptions (LB) ever	93.9	85.9	65.1
At least one miscarriage before LB	14.4	15.7	16.3
Age Y when starting ART (in case of failure)	34 years	38 years	42 years
No conception at age Y	9.3	17.8	43.0

Leridon 2004: 'Can assisted reproduction technology compensate for the natural decline in fertility with age? A model assessment.'

Table II. Success rates (pregnancies ending in live birth (LB) per 100 women of each age) for conception with assisted reproduction technology (ART): results of the model

	Woman's age when starting pregnancy attempt		
	30 years	35 years	40 years
Age Y when starting ART (in case of failure)	34 years	38 years	42 years
(a) No conception at age Y (failure)	9.3	17.8	43.0
Total conceptions (LB) with ART			
Success: conception (LB) within 12 months	2.0	3.0	5.1
Delay: conception (LB) in 12-23 months	0.8	1.2	2.0
(b) Total conceptions (LB) within 2 years	2.8	4.2	7.1
(c) Apparent rate of success for ART (%) = 100*b/a	30.1	23.6	16.5
No conception at age Y = 2 (in case of failure)	6.5	13.6	35.9
Spontaneous conceptions (no treatment)			
(d) Within 2 years	1.4	2.5	6.7
(e) Net rate of success for ART (%) = 100*(b - d)/a	15.1	9.6	6.9
Hypotheses for ART			
Months without conception when starting treatment	48	36	24
Fecundability of non-sterile women multiplied by (MP)	3	2	1.2
Percentage of sterilities overcome (OS)	50	25	3

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.

Attitudes Toward Parenthood and Awareness of Fertility Among Postgraduate Students in Sweden

Agneta Skoog Svanberg, PhD¹; Claudia Lampic, PhD²; Per-Olov Karlström, MD, PhD¹; and Tanja Tydén, PhD^{1,2}

¹Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden; and ²Department of Public Health and Caring Sciences, Uppsala University, Uppsala, Sweden

- 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.

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- 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

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Agneta Skoog Svanberg, PhD¹; Claudia Lampic, PhD²; Per-Olov Karlström, MD, PhD¹; and Tanja Tydén, PhD^{1,2}

- Awareness of fertility issues

At what age is there a marked decrease in women's ability to become pregnant?	% Women	% Men
25-34 y	24	24
35-39 y	48	35
40-44 y	23	28
45-49 y	4	12

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- Awareness of fertility issues

For couples that undergo treatment with IVF, what is their chance, on average, of having a child?	% Women	% Men
0-19%	18	25
20-29%	23	22
30-39%	31	14
40-100%	28	35

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

Tanja Tydén¹, Agneta Skoog Svanberg^{2*}, Per-Olof Karlström^{2*}, Lisa Lihoff^{1*} and Claudia Lampic^{1*}

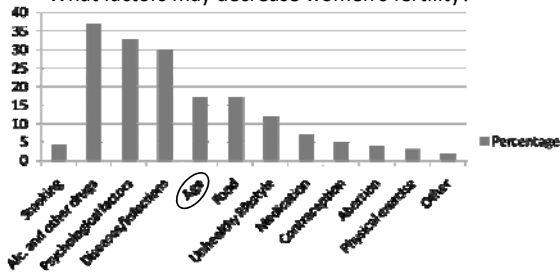
¹Department of Public Health and Caring Sciences, Döbelnsgatan 2, S 752 37 Uppsala, Sweden; ²Department of Women's and Children's Health, Academic Hospital, S 751 85 Uppsala, Sweden

- 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

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

Tanja Tydén¹, Agneta Skoog Svanberg^{2*}, Per-Olof Karlström^{2*}, Lisa Lihoff^{1*} and Claudia Lampic^{1*}

'What factors may decrease women's fertility?'



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

C. Lampic^{1,3}, A. Skoog Svanberg², P. Karlström² and T. Tydén^{1,2}

¹Department of Public Health and Caring Sciences, Uppsala University, Uppsala Science Park, S-751 83 Uppsala and ²Department of Women's and Children's Health, Academic Hospital, S-751 85 Uppsala, Sweden

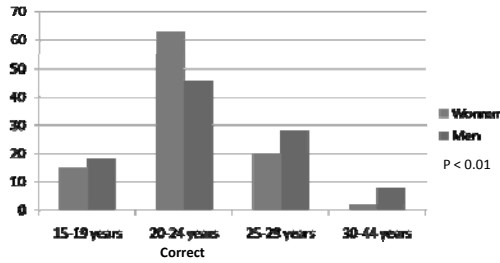
³To whom correspondence should be addressed at: Department of Public Health and Caring Sciences, Uppsala University, Dag Hammarskjölds väg 10B, 751 83 Uppsala, Sweden. E-mail: claudia.lampic@pubcare.uu.se

- 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

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

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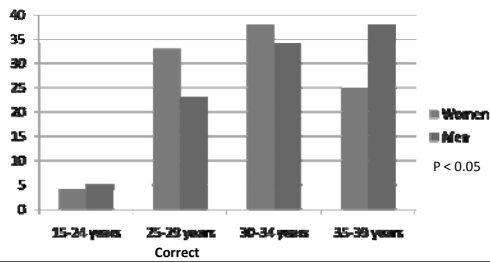
'At what age are women most fertile?'



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

C.Lampic^{1,3}, A.Skoog Svanberg², P.Karlström² and T.Tydén^{1,2}

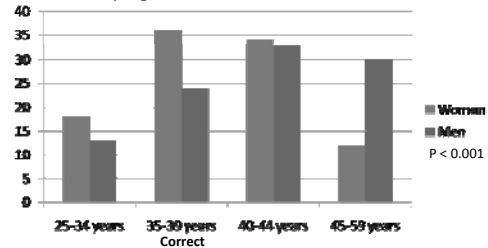
'At what age is there a *slight* decrease in women's ability to become pregnant?'



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

C.Lampic^{1,3}, A.Skoog Svanberg², P.Karlström² and T.Tydén^{1,2}

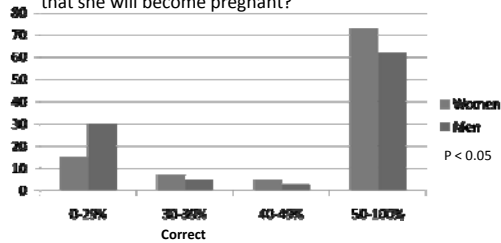
'At what age is there a *marked* decrease in women's ability to become pregnant?'



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

C. Lampic^{1,2}, A. Skoog Svanberg², P. Karlström² and T. Tydén^{1,2}

'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?

Karla L. Brethrick, Ph.D.,^{1,2} Nichole Fairbrother, Ph.D.,^{1,2} Luana Avila, B.Sc.,^{1,2} Sara H. A. Harbord, M.Sc.,^{1,2} and Wendy P. Robinson, Ph.D.³

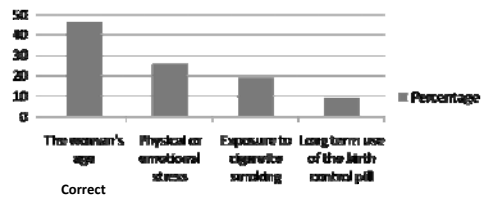
¹ Department of Medical Genetics, University of British Columbia, Vancouver; ² Interdisciplinary Women's Reproductive Health Research Training program, Child and Family Research Institute, Vancouver; and ³ Women's Health Research Institute, BC Women's Hospital and Health Centre, Vancouver, British Columbia, Canada

- 360 female undergraduate students (Vancouver, Canada)

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

Karla L. Brethrick, Ph.D.,^{1,2} Nichole Fairbrother, Ph.D.,^{1,2} Luana Avila, B.Sc.,^{1,2} Sara H. A. Harbord, M.Sc.,^{1,2} and Wendy P. Robinson, Ph.D.³

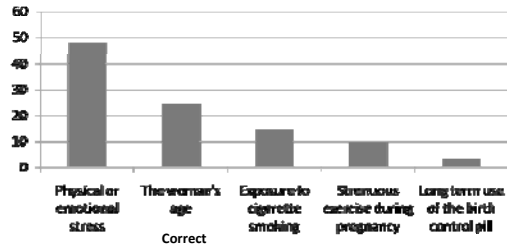
'Which of the following is the strongest risk factor for infertility?'



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

Karla L. Brethrick, Ph.D.,^{a,b} Nichole Fairbrother, Ph.D.,^{b,c} Luana Avila, B.Sc.,^{a,b} Sara H. A. Harbord, M.Sc.,^{a,b} and Wendy P. Robinson, Ph.D.^a

'Which is the strongest risk factor for miscarriage?'



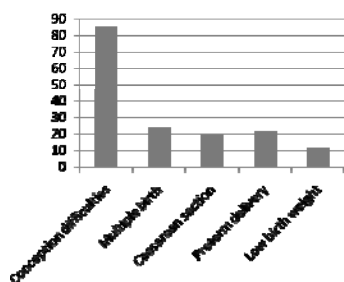
Conclusion: fertility awareness in students

- 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

What do women know about the risks of delayed childbearing?

Tough S, Benzie K, Newburn-Cook C, Tofflemire K, Fraser-Lee N, Faber A, Sauve R.

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



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

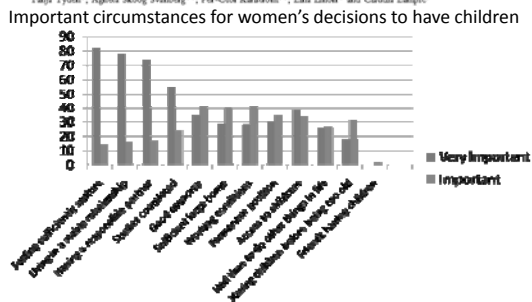
- Unplanned pregnancy (OR 1.48; 95% CI 1.03-2.14)
- Smoking (OR 1.83; 95% CI 1.29-2.60)
- Non – use of fertility treatment (OR 2.15; 95% CI 1.44-3.19)

Fertility awareness: two types of studies

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

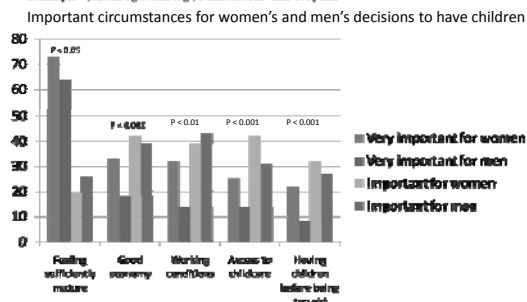
Female university students' attitudes to future motherhood and their understanding about fertility

Tanja Tydén¹, Agnes Skoog Svanberg^{2*}, Per-Olof Karlström^{2*}, Lisa Lihoff³ and Claudia Lampic⁴



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

C. Lampic^{1,2}, A. Skoog Svanberg², P. Karlström² and T. Tydén^{1,2}



Factors Influencing Childbearing Decisions and Knowledge of Perinatal Risks among Canadian Men and Women

Suzanne Tough · Karen Toffemire · Karen Benzie ·
Norie Fraser-Lee · Christine Newburn-Cook

- 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.



Original research article

Analysis why nulliparous women over age 33 wish to use contraception^{☆,☆,☆}

Sara Proudfoot[☆], Kaye Wellings[☆], Anna Glasier^{☆,☆,☆}

[☆]1992 Leishan Family Planning and IUD Women Service, Edinburgh EH4 1JG, Scotland, UK
[☆]Department of Public Health and Policy, University of London School of Hygiene and Tropical Medicine, London WC1E 7HT, UK
[☆]University of Edinburgh School of Clinical Science and Community Health, Edinburgh EH8 3AG, Scotland, UK

Received 11 August 2008; revised 27 August 2008; accepted 4 September 2008

- 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:
 - 74% gave reasons to do with their relationship
 - 34% 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

What do women know about the risks of delayed childbearing?

Tough S, Benzie K, Newburn-Cook C, Toffemire K, Fraser-Lee N, Faber A, Sauve R

Department of Medicine, University of Calgary, Calgary, AB. suzanne.tough@calgaryhealthregion.ca

- Qualitative study on 45 Canadian women aged 20 to 48 years

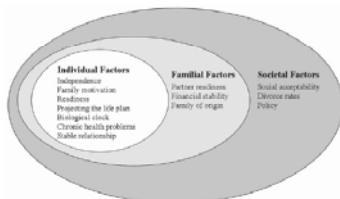


FIGURE 1
Factors that influence women's decisions about childbearing.

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 loose 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, paramedicals 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



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