





New generation patients

Munich, Germany 29 June 2014

Organised by
The ESHRE Task Force Management of Fertility Units, the ESHRE Special
Interest Group Psychology and Counselling & Fertility Europe

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Course coordinators

Luca Gianaroli (Italy) and Chris Verhaak (The Netherlands)

Course description

Social and demographic changes occurred in the last few years had an impact also on the demand for ART treatments.

Alongside traditional patients, new categories of patients with peculiar needs emerged. At the same time, the role of new technologies in the interaction between clinicians and patients is becoming preponderant.

This course aims to provide medical and paramedical staff of IVF units with useful information regarding emerging populations of patients and with tools to face their specific needs. Moreover, the course will analyze the role of new forms of communication in ART with the aim to provide participants with advice on how to manage them in an effective and safe way, thus maximizing their usefulness

Target audience

Clinicians, psychologists, paramedical staff

Course type

Advanced

Scientific programme

08:45 - 09:00	Introduction Veljko Vlaisavljevic - Slovenia			
Session 1: New	generation patients: Social aspects			
Chairmen: Lieve	e Decaluwe – Belgium and Alina David - Romania			
09:00 - 09:30	Evolution of socio-demographic situation and reproductive behaviour: do we see the same patient as before? Tomas Kucera - Czech Republic			
09:30 - 09:45 09:45 - 10:15	Discussion Social freezing Juan Garcia Velasco - Spain			
10:15 - 10:30	Discussion			
10:30 - 11:00	Coffee break			
Session 2: ART f	or medical reasons			
Chairmen: Denis	sa Priadkova – Slovakia and Timur Gürgan - Turkey			
11:00 - 11:30	New applications of PGD Luca Gianaroli - Italy			
11:30 - 11:45	Discussion			
11:45 - 12:15	Gametes storage for fertility preservation			
12.15 12.22	Ana Cristina Cobo Cabal - Spain			
12:15 - 12:30	Discussion			
12:30 - 13:30	Lunch break			
Session 3: ART f	or legal and social reasons			
Chairmen: Paul Devroey – Belgium and Elin Einarsdottir - Iceland				
13:30 - 14:00	Travelling patients: the business of cross-border Tonko Mardesic - Czech Republic			
14:00 - 14:15	Discussion			
14:15 - 14:45	Different models of family thus different types of ART patient			
4445 45 00	Amparo Ruiz Jorro - Spain			
14:45 - 15:00	Discussion			
15:00 - 15:30	Coffee break			
Session 4: New technologies and communication				
Chairmen: Sofia	a Gameiro – Portugal and Clare Lewis-Jones - United Kingdom			
15:30 - 16:00	E-patients: from Dr. Google to Telemedicine Karoline Steckley - Italy			
16:00 - 16:15	Discussion			

16:15 - 16:45	How to communicate with new generation patients <i>Sofia Gameiro - Portugal</i>
16:45 - 17:00	Discussion
17:00 - 17:15	Closing remarks Paul Devroey - Belgium

ESHRE GUIDELINE:

// PSYCHOSOCIAL CARE IN INFERTILITY AND MEDICALLY ASSISTED REPRODUCTION



The draft of the guideline will be presented at the ESHRE Annual Meeting 2014 by Dr. Sofia Gameiro

Be there! Monday 30 June at 15:15, Room 5



GIVE YOUR OPNION!

The guideline will be open for external review after the annual meeting.

Take this opportunity to review the guideline and submit your comments!

For more information check www.eshre.eu/guidelines or email nathalie@eshre.eu

GUIDELINE GROUP

Sofia Gameiro (Chair), Jacky Boivin, Eline Dancet, Cora de Klerk, Marysa Emery, Clare Lewis-Jones, Petra Thorn, Uschi Van den Broeck, Christos Venetis, Chris Verhaak and Tewes Wischmann

New generation patients	
Introduction Veljko Vlaisavljević	
Professor in Obstetrics and Gynaecology at the University of Ljubijana Department of Reproductive Medicine	
University Medical Centre Maribor	
Conflicts of interest	
Nothing to declare	
Lagrania a phiastica a of the suddebus	
Learning objectives of the syllabus	
New generation of patients: social aspects MAR for medical reasons	
MAR for legal and social reasons New technologies and communication	

Timetable of MAR

80's
IVF laboratory



• 90's Lab technology





• 2000's Drugs & therapy



• 2010's Patients & patient's rights



New P@tients

- Social aspects of MAR
- New applications of MAR for medical reasons
 Special families
- ePatients



Reproductive medicine today

Participatory model

Drastic change in the nature of patients **due to internet** as an alternative source of information.

Reproductive medicine today

Quality assessment

Quality control becomes a key feature!

- Guidelines
- International QM standards
- Legislation (national level, EU level)



Patient centerdness

Being respectful of individual preferences, needs and values; and ensuring that patient values guide all clinical decisions.

Institute of Medicine 2001



PubMed patients
New methods, drugs, treatments

www.IVF Centres

Veh pages mobile application

Social media

How to ensure the right information and protection of the patient against low quality practice?

				Norman 2011
	Low	Moderate	High	The elite
Fresh PR	Moderate	High per ET	High per cycle	High single live term birth (SLTB)*
Frozen PR	Low	Moderate	High	High SLTB*
Cumulative fresh&cryo	Low	Moderate	High	High SLTB*
Multiple PR	High	Low	Low (< 10%)	Low (<5%)
Patient side effect	Moderate	Moderate	Low	Very low
Patient satisfaction	Moderate	Moderate	High	Excellent
Treatment options	Low	Moderate	Customisation	Personalized
Emphasis of quality	None	Moderate	High TQM	Exceptional TQN

The per	fect	clinic
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PREGNANCY RATES	Transparent, honest, audited
EDUCATION OF STAFF	Training, skills, technology, ethics
RESEARCH & INOVATION	Implementation, outputs
FOCUS ON PATIENT CARE	Feedback, options, finances
EMOTIONAL ENGAGEMENT	Communication, consultation
CONTROLLED SYSTEMS	Total quality management, ISO
TRUTH	Results, unexpected events, treatments, literature
	Norman 2011



EBCOG
The European Board and College of
Obstetrics and Gynaecology
FINAL DRAFT



Standards of Care for Women's Health in Europe

Report of a Working Party
EUROPEAN BOARD AND COLLEGE OF OBSTETRICS & GYNAECOLOGY
(EBCOG)
(www.ebcog.eu)
15/11/2013
Gynaecology Services (Volume 2)

Infertility and Assisted Conception

Standards of Care for Women's Health in Europe,2013

Staffing and competence

- 6.1 A quality manager should be employed in each specialised centre.
- 6.2 All staff should be certified by the appropriate national body.
- 6.3 Specialised centres should have regular meetings to discuss and manage cases in a multi-disciplinary environment



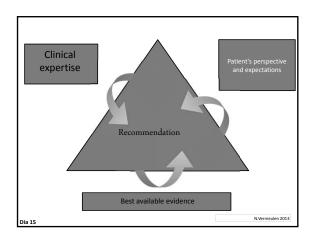
Running an IVF Centre

- 10% clinical skills
- 30% scientific skills
- 60% sheer organisation

TQM= the scientific way of doing business

From: Mortimer D& Mortimer S.T.: Quality and risk management in the IVF laboratory.

Cambridge University Press, 2005



" In God we trust, all others must bring data."	
W. Edwards Deming,Ph.D	
IVF Centre Database!	
Paperless office & online registration	
General Control Contro	
THE COLUMN TWO IS NOT	
Science starts when centre begins to operate with quantitative measurements and numbers.	
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	-
Quality of treatment	
Madical and laboratory associate	
 Medical and laboratory aspects Psychological and ethical aspects Organisational aspects 	
Fulfilment of quality expectations from the patient's perspective	

ePatients • Expect a better understanding of the treatment process. • Need help to make the right decision. Why are social media popular? Almost anyone can participate • Little or no censorship • Engaging patients in multiple channels Mobile friendly sites in Patient communication Creating communication f Video content Twitting QUALITY OF ORGANISATION = QUALITY OF CARE (Patient satisfaction + better outcome) Today, patients expect to be treated like a customer. They require services characterised by: Responsiveness Quality Respect

Patient satisfaction

Patient satisfaction is becoming a vital factor.

 IVF centres need to develop a higher level of personalised service and satisfaction, otherwise they will risk losing patients.

ESHRE'S GOOD PRACTICE GUIDE Cross border reproductive care



- High quality and safe MAR treatment
- Patients / children / third party collaborators
- equal treatment of domestic and cross border patients
- avoid "disproportionate stimulation"
- avoid "deviation from the rules of embryo transfer"

Shenfield et al., HR, 2011

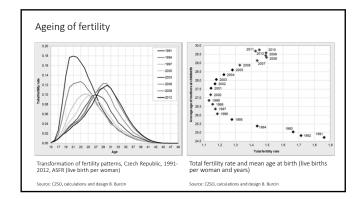
Conclusion

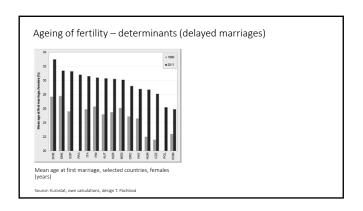
- Internet has enhanced the process of transforming Europe into a borderless area for patients seeking fertility treatment.
- ePatients are able to seek help for their specific fertility treatment needs outside their native country.
- Restrictive national regulations have become less important in the era of globalisation and cross border medicine.
- Restrictive national regulations in MAR generate inequality among the nationts

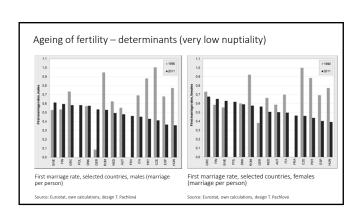
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Evolution of the socio-demographic situation and reproductive behaviour: are we seeing the same	
patient as before?	
Dr. Tomáš Kučera, Charles University in Prague, Department of Demography and Geodemography	
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Disclosures	
The author of this presentation is not in a commercial and/or financial relationships with manufacturers of pharmaceuticals, laboratory supplies	
and/or medical devices.	
Objective	
Objectives To trace the most profound changes in reproductive behaviour	
of European populations expressed through changing levels	
and patterns of fertility To overview and comment basic socio-economic factors determining low	
and aged fertility in most of European countries	
 To estimate changes of the ART patients contingent size and structure 	

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Historical changes in fertility and its driving forces	
During the past two centuries the overall level of fertility in Europe has decreased from about 5-6 to 1-2 live births per woman.	
The observed decrease in fertility was the result of a transition from a highly extensive to an intensive mode of population reproduction labelled	
as (the first) demographic transition. Major intensification of human population reproduction was a part	
of the universal process of modernization represented namely by the process of industrialization and accompanying changes (urbanization, secularization and ceding some traditional roles of the family to the social	
state) experienced by most European societies during the 19 th and the first half of the 20 th century.	
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Historical changes in fertility and its driving forces	
Ongoing changes of values, norms and attitudes during the second half of the 20 th century, which has led to the individualization of modern societies, resulted in new patterns of family and reproductive behavior,	
called the second demographic transition. As a result of this second transition, the total fertility rate further declined	
significantly below the replacement level. In some European countries this process was speeded up and deepened by	
an economic recession accompanying the transition from a centrally planned to a market economy during the 1990s.	
Recent development of fertility	
However the recent development of fertility is not only about the increase	
or decrease of total fertility rate values. Fertility has also been intensively ageing - overall fertility distribution	
according to the mother's age has been transformed and its central values have moved to higher ages.	







Ageing of fertility – other determinants

Growing proportion of couples is living in a consensual union.

Between one third and one half of newly born children in EU countries are born out of wedlock, to single mothers or unmarried couples.

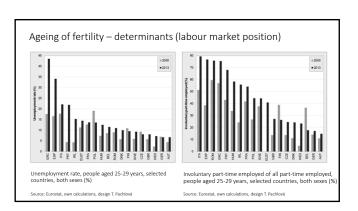
Described phenomena reflect modern times opportunities as well as limitations:

- ability to very effectively regulate reproduction
- existence of a wide range of self-fulfilment opportunities
- necessity and possibility to study
- increasing emancipation and gender equality but also worsening position of young people on the labour market

Ageing of fertility — determinants (tertiary education)

**Topology of the series of the series (%)

**Proportion of people at age 30.34 with attained tertiary education, selected countries, both seves (%)

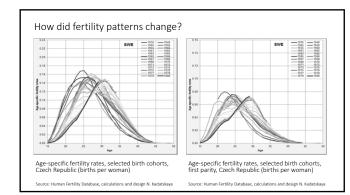


Ageing of fertility – determinants (risk of poverty) People at risk of poverty, aged 25-29 years (%) Is it the same patient or not? The same patient in the demographic sense of the word, is a patient of the same sex and age. Statistically the same patient would mean an approximately stable structure of health problems as well as a very similar volume and structure of medical procedures required and many other similar parameters of the medical care system. This is not a medical problem even though it draws the interest of all people responsible or interested in the effective functioning of the healthcare system or of part of it. Is it the same patient or not? Our further considerations are based on the assumption that the patient's age is a very important parameter influencing parameters of the provided care as well as its results. Therefore we are eager to know what will basic characteristics likely be, as to the size and age structure of the female source population.

Is it the same patient or not? The volume of services depends on the size and age structure of the source population as well as on the age specific exposure rates, i.e. intensities of attempts to conceive. Assuming that to a particular age, a corresponding number of attempts is needed to get a unit outcome and since the other number of attempts lead to a unit failure, one can suppose that the number of failures and thus the specific demand for ART, is in relation with the number of outcomes. Therefore a change in the age specific fertility rate can represent a relatively robust estimator of change of an analogical intensity of the demand for ART. Together with the change of size and age structure of the source population, it determines changes in the size and structure of the demand Is it the same patient or not? Of course, there are numerous assumptions out of our control and therefore any sufficiently reliable estimate is practically impossible. Nevertheless we can try to see what is going to happen with the main factors - size and structure of the exposed population and with one of the main estimators of the demand - age specific fertility rates. How did fertility patterns change?

Age-specific fertility rates, selected birth cohorts, first parity, Czech Republic (births per woman)

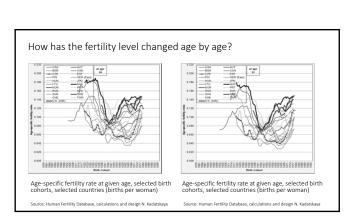
Age-specific fertility rates, selected birth cohorts, Czech Republic (births per woman)

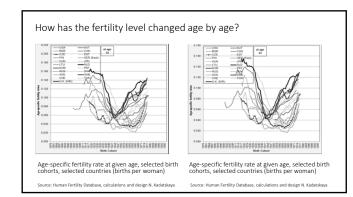


How has the fertility level changed age by age?

Age-specific fertility rate at given age, selected birth cohorts, selected countries (births per woman)

Age-specific fertility rate at given age, selected birth cohorts, selected countries (births per woman)

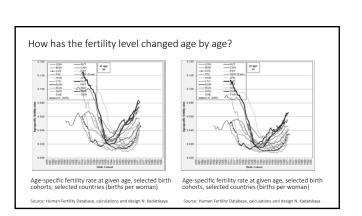


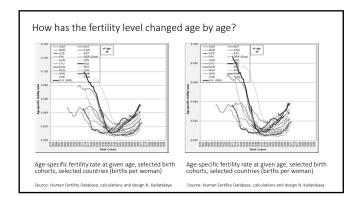


How has the fertility level changed age by age?

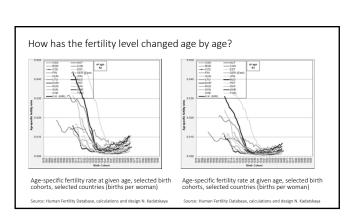
Age-specific fertility rate at given age, selected birth cohorts, selected countries (births per woman)

Source: Human Fertility Database, calculations and design N. Kadatskaya





How has the fertility level changed age by age? | The content of the content of



Is it the same patient or not? Is it the same patient or not? Referring to the distribution of cycles by age groups, we limited the main contingent of potential patients by the exact ages 28 and 43 years. At the beginning of 2013, there were almost 52,2 million females in this age interval (28-42). Their number is going to decrease by more than 15 % (8.3 million) by 2035 and consequently after a small oscillation around the middle of the century it should relatively stabilize at the level of about 43 million females. Regardless of all these intensive changes, the relative age structure of this contingent is going to be highly stable since the average age should only vary in the very narrow interval between 35,4 and 35,7 years. The assumed decrease of its size without a principal ageing of the contingent itself would significantly reduce the demand for ART. The expected reduction is going to be partially compensated by further ageing of fertility. However ageing of fertility ran out of its potential in most Europe as it was seen also in the previous graphs. Is it the same patient or not? To sum up, the relative age structure of patients, and consequently also their demand **should not change** significantly in the EU27 during the next However there will very likely be fewer patients, of course, if the sex and age specific prevalence of diseases treatable by ART is not going to change This conclusion primarily refers to the "average" population of the EU27. However national as well as regional populations and fertility development can principally differ from our observations and estimates. Therefore it is only a general but not a universal conclusion



IVI) Why "social"

- Medical/onco indicatins vs non-medical
- If it is technically feasable, why not do it?
 - risk?
 - costs?
 - expectations?

We are less fertile

- o less children <35y
 - 27% in Australia
- o sperm is loosing quality (WHO 2011)
 - 20% pure male factor
- o demand for ART keeps increasing
 - 9% from 2003 to 2009
 - 41% in women >40 y

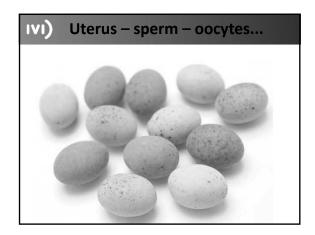


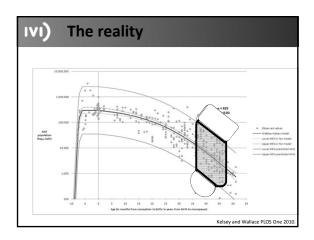
ASRM 2012

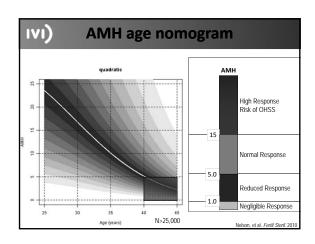
We are less fertile

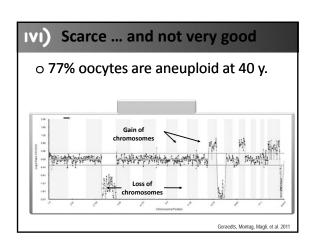
- 1/25-100 children born after ART
- 1/7 children in >37 y
- risk of being childless

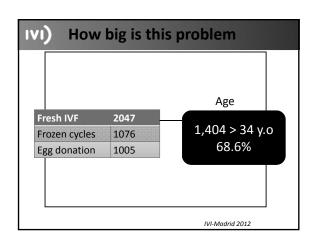
<30 y	6%
<35 y	14%
40 v	35%

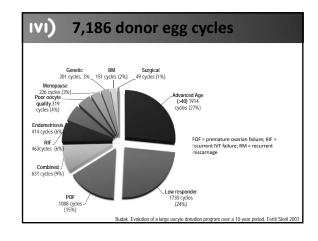


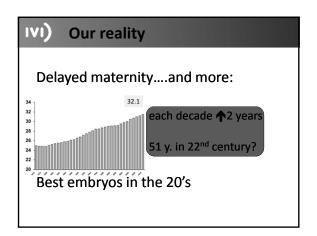












No, causes diseases

- brain damage (dementia)
- a great percentage of IVF cycles done today are because of women age
- use of medicine for "social/life style diseases"? (obesity)



O 20-25% opt not to have kids Education level? DINKS double income no kids SSS single, sexy, successful

IVI) Safe Current protocol - rFSH / Antag/ GnRHa 0.41% (17) Complications Intraabdominal bleeding 0.34% (14) Severe pain 0.05% (2) 0.02% (1) Ovarian torsion Bodri et al. 2008 • Practically no OHSS risk - as no hCG is used - and no embryo transfer performed

IVI) Safe

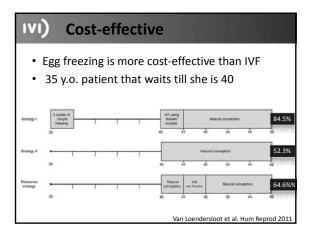
- And the child?
 - Low birth weight, preterm... NOT related to freezing
 - Similar chromosomal abnormalities by FISH



Cobo et al. 2001

- 900 new borns similar to general population
- 200 new borns similar to IVF patients Noyes et al. 2009

Chian et al. 2008



o survival after thawing 90-97% o fertilization 71-79% o implantation 17-41% o pregnancy 36-61% O Pregnancy/ thawed oocyte 4.5-12% Most are young women <35 y ASRM Practice Committee 2012

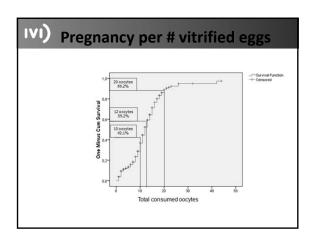
	ole III Clinical outcom ytes received	e according to t	he type of
		Egg-bank	Fresh
Nun	nber of embryos transferred	267 (90.5)	259 (89.6)
Mea	n number of embryos	513 (1.74 ± 0.7)	498 (1.72 ± 0.7)
	nber of cycles with embryo itrification*/cryopreservation	196 (66.7)	216 (74.7)*
	n number of re-vitrified or preserved embryos	592 (2.0 ± 2.1)	743 (2.5 ± 2.3)*
Impl	antation rate	205 (39.9)	204 (40.9)
Posi	tive hCG test/cycle	165 (55.9)	159 (55.0)
Clini	cal pregnancy rate/cycle	148 (50.2)	144 (49.8)
Posit	tive hCG test/transfer	165 (61.8)	159 (61.4)
Clini	cal pregnancy rate/transfer	148 (55.4)	144 (55.6)
Twir	pregnancy rate	48 (32.4)	54 (37.5)

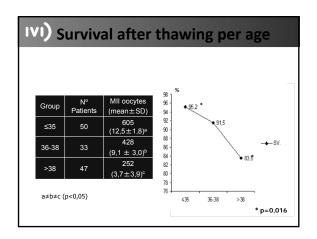
	ARTICLE IN PRESS
ASRM PAGES	
Mature a guidel	oocyte cryopreservation: ine
The Practice Committees Reproductive Technology	of the American Society for Reproductive Medicine and the Society for Assisted
Society for Reproductive Me	licine and Society for Assisted Reproductive Technology, Birmingham, Alabama
are used as part of IVF/ICSI is developmental deficits has be ventional IVF/ICSI and the gent experimental. This document	irillization and programcy aries are similar to IVF/ICSI with fresh oncytes when virifined/manned oncyte iry young women. Although data are limited, so increase in chromosomal abnormalities, brith effects, an one reported in the obligating hore from copyreserved oncytes when compared to programatics from comment population. Evidence indicates that coop're virification and warming doubt no longer be considere replaces the document last published in 2000 titled, "Ovarian Tis- tion," Fertil Steril 2008;50:5241-6. [Fertil Steril® 2012;18:18 - 8.
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Cobo 2008 (24) Cobo 2010 (25) Rienzi 2010 (25) Parmegian	immary of randomized cont	rolled trials comparing fresh ver	sus vitrified occutes		
No. patients 30 vitrification 295 vitrification 40 vitrificati	minuty or randomized conc			Rienzi 2010 (25)	Parmegiani 2011 (19)
No patients 30 virification 295 virification 40 virification 31 virification 30 fresh 30 fresh 30 fresh 30 fresh 40 fresh 31 fresh 30 fresh 40 fresh 31 fres	tient population C	Oocyte donors	Oocyte donors	of age requiring ICSI	Infertile patients <42 years of age requiring ICSI with >5 mature occytes
No. ooyfes 231 vtrification 3286 vtrification 144 vtrification 168 vtrification 169 vtrification				40 vitrification	31 vitrification
No. coortes per retrieval 219 fresh 318.5 fresh 120 fresh NA fresh Survival 96.9% 92.5% 98.9% Perfilization rate 76.3 virtification 92.6 fresh 83.3% fresh 73.9% fresh 83.3% fresh 72.6% fresh No. transferred virtification 3.8 virtification 1.7 fresh 2.5 fresh 2.5 fresh 2.6 fresh 2.9 virtification 2.7 fresh 2.5 fresh 2.6 fresh 2.8 virtification 3.8 virtification 3.9 fresh 3.8 virtification 3.9 fresh 3.9 fresh 3.9 fresh 3.9 virtification 3.9 fresh 3.9 virtification 3.9 vir	ean age at retrieval	26	26	35	35
Survial 96.9% 92.5% 98.8% Perlikation rate 22.7 kept 74.8 km/stackon 24.8 km/stackon 24.8 km/stackon 27.9 km/stackon 27.9 km/stackon 27.9 km/stackon 27.6 km/stackon					168 vitrification NA fresh
Fertilization rate 7.6.3 strification 24% withfication 79.2% virification 71% withfication 79.2% virification 7.1% withfication 8.2.5 fresh 72.6% feet 8.3.3% fresh 72.6% feet 9.3.3% fresh 72.6% feet					
No. transferred vtrification 3.8 v trification 2.5 v trification					89.9%
No. transferred vitrification 3.8 vitrification 1.7 vitrification 2.3 vitrification 2.5 vitrification 3.9 fresh 1.7 fresh 2.5 fresh 2.6 fresh 2.6 fresh 3.9					
vs. fresh 3.9 fresh 1.7 fresh 2.5 fresh 2.6 fresh Day of transfer 3 3 2 2					
Day of transfer 3 3 2 2					
		L9 tresh	1.7 tresn	2.5 tresn	2.6 tresh 2–3
		n col visification	20 00 visitiestion	20 40/ vitrification	17.1% vitrification
100% fresh 40.9% fresh 21.7% fresh NA fresh					
	PR/transfer vitrification 6	0.8% (23 vitrification transfers)			35.5% vitrification
			4.5%	12%	6.5%
Note: All used vitrification with Cryotop, 15% EG - Association - Section -	te: All used vitrification with Country	15% FG -		1	

IVI) But......

- 50% live birth rate in women <35 years and 12 oocytes in the OPU
- oand "Mr Right" needs 450 IU rFSH to obtain 2 oocytes





IVI) Ethically acceptable

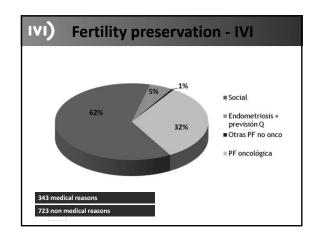
- o would reduce the need for donor eggs o would allow to have children with their own gametes at advanced maternal age o would reduce the number of failed cycles
- at AME o would provide women with reproductive autonomy

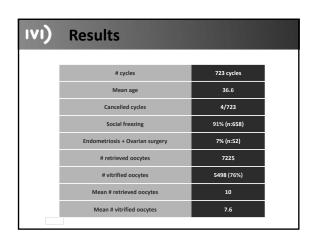
Gorthi 2001, Loockwood 2011, Pennings 2011)

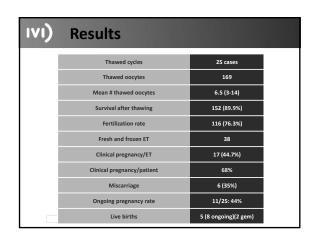
IVI) But...why?

- o delay in stablished partner "Mr Right" is late to appear...or doesn't exist
- o increased divorce rate
- o "lack of compromise"
- o lack of partner
- o huge pressure to find 'ideal' partner in a specific time frame

Occyte vitrification—Women's emancipation set in stone Fertility and Sterility® Vol. 91, No. 4, Supplement, April 2009 Roy Homburg, F.R.C.O.G.** Fulco van der Veen, M.D.* Sherman J. Silber, M.D.* reproduction vs age 1960's 21st century







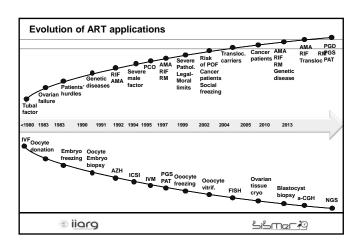
IVI) Conclusions

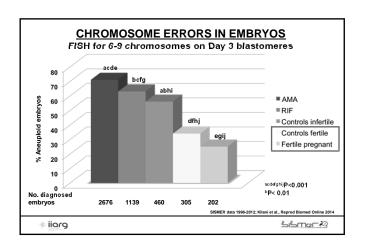
INFORM

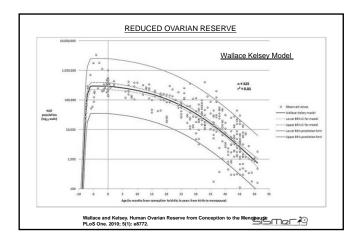
- Medically speaking, best moment to have a child naturally is before 35y
- We freeze GAMETES, not fertility
- Spread the possibilities of the technique
- Avoid unrealistic expectations by information based on general data too late
- It is our responsibility to inform society about the big impact that age has on fertility

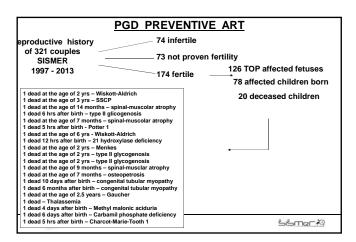
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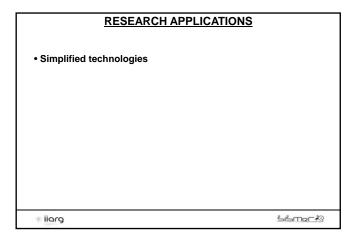


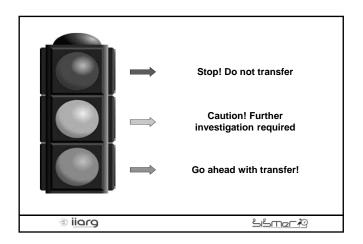


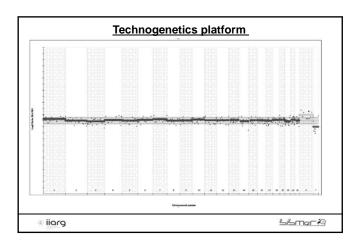


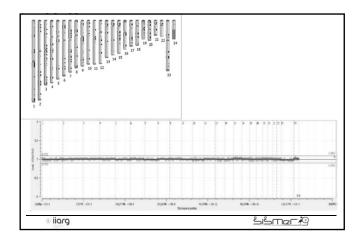


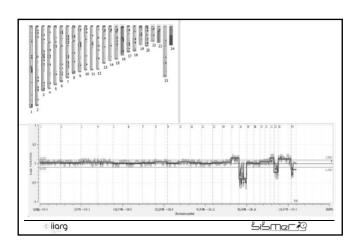
CLINICAL APPLICATIONS • Oocyte donation • Social freezing • Mitochondrial disorders

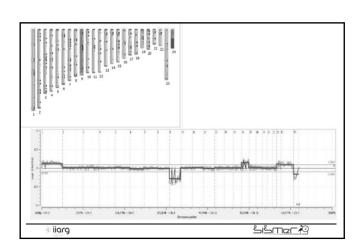








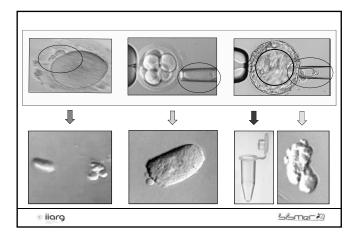


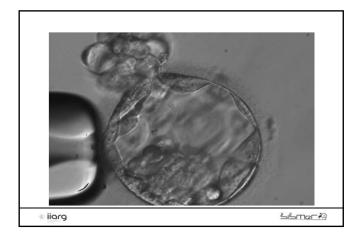


RESEARCH APPLICATIONS

- Simplified technologies
- New sources of embryonic DNA

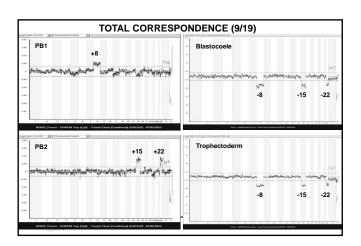
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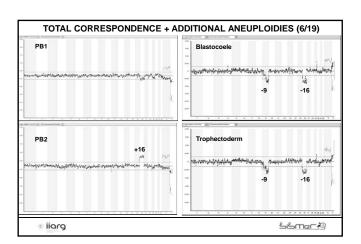


Blastocoelic fl	luids
No. blastocoelic fluids	28
With no DNA (%)	9 (32)
With result (%)	19 (68)
to the second second second second	Ctrl+ C
	Failed amplification

TOTAL CORRESPONDENCE (9/19)								
Sample	PB1	PB2	Blastomere	Blastocoele	Trophectoderm			
3	euploid	loss 2	-	gain 2	gain 2			
5	gain 8	gain 15, 22	-	loss 8,15,22	loss 8,15,22			
7	-		loss 14	loss 14	loss 14			
9	-		euploid	euploid	euploid			
13	gain 4,5,6,7,9,11,12,15,19,20,X loss 1,2,3,8,10,13,14,16,18	gain 1,2,3,8,10,13,14,16,18 loss 4,5,6,7,9,11,12,15,19,20,X	-	euploid	euploid			
19	euploid	euploid	-	euploid	euploid			
21	-	-	euploid	euploid	euploid			
22	-	-	euploid	euploid	euploid			
29	euploid	euploid	-	euploid	euploid			
*	iarg	⇒ ilarg S5mer#9						



Т	TOTAL CORRESPONDENCE + ADDITIONAL ANEUPLOIDIES (6/19)							
Sample	PB1	PB2	Blastomere	Blastocoele	Trophectoderm			
1	loss 16	loss 12	-	gain 12,16 loss 15	gain 12,16 loss 15			
4	euploid	gain 22	-	loss 17,22	loss 17,22			
11	euploid	gain 16	-	loss 9, 16	loss 9, 16			
24	-	-	loss 16	loss 14,16,17 ←	→ loss 16			
28	euploid	loss 21	-	gain 21 ←	gain 21, loss 1			
33	euploid	gain 15	-	loss 1,15 ←	→ loss 15			
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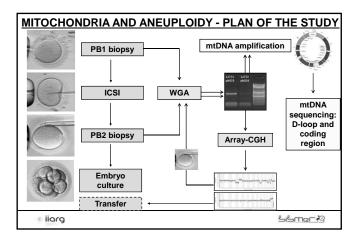
No. blastocoelic fluids	28
With no DNA (%)	9 (32)
With result (%)	19 (68)
total correspondence	9 45
correspondence + other aneuploidies	6 15
partial correspondence	3
no correspondence	1

RESEARCH APPLICATIONS

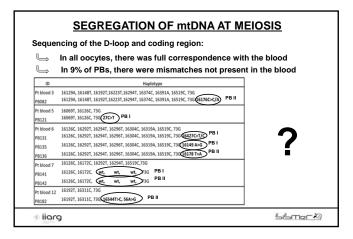
- Simplified technologies
- New sources of embryonic DNA
- · Mitochondria and aneuploidy

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MITOCHONDRIA AND ANEUPLOIDY Number of patients 13 40.2 ± 1.5 Mean age ± SD (years) Total number of PBs 89 aneuploid (%) 68 (76) Total number of oocytes aneuploid (%) 27 (67.5) - Segregation of mtDNA at meiosis - Correlation between aneuploidy and haplogroup » iiarg څاڅπα۲₹9



SEGREGATION OF mtDNA AT MEIOSIS

Sequencing of the D-loop and coding region:

 $\begin{tabular}{ll} \end{tabular}$ In all oocytes, there was full correspondence with the blood

 $\;\; \mathrel{\bigsqcup} \;\;$ In 9% of PBs, there were mismatches not present in the blood

Technical issue:

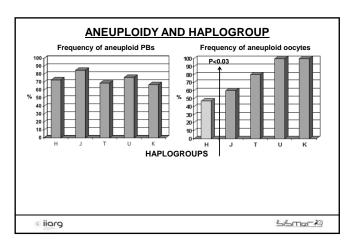
in the ooplasm these changes were under the detectable threshold level, but not in PBs.

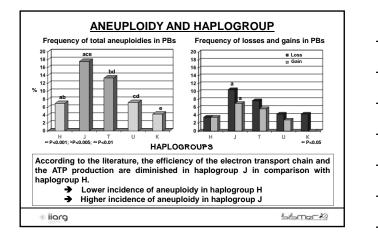
Biological issue: the oocyte could have an active mechanism to preserve a condition of 'normality by guiding the extrusion of mtDNA variants in the PBs. This would prevent the transmission of severe mutations that cause an altered mitochondrial energy metabolism.

At the same time, the controlled accumulation of mtDNA variants in the

germline might allow to produce a bioenergetic diversity that could be advantageous in new environments.

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MITOCHONDRIA

In PBs, there are mtDNA polymorphisms that are not detected in corresponding oocytes and blood.

Different haplogroups may affect the meiotic process:

- Oocytes from haplogroup H had the lower incidence of aneuploidy.
- The sister haplogroups J/T presented a significantly higher incidence of chromosome errors when compared with haplogroup H and U/K.

 The haplogroup J losses occurred more frequently than gains, whereas the two figures were similar in haplogroup H.

This may occur through a diverse level of ATP production.

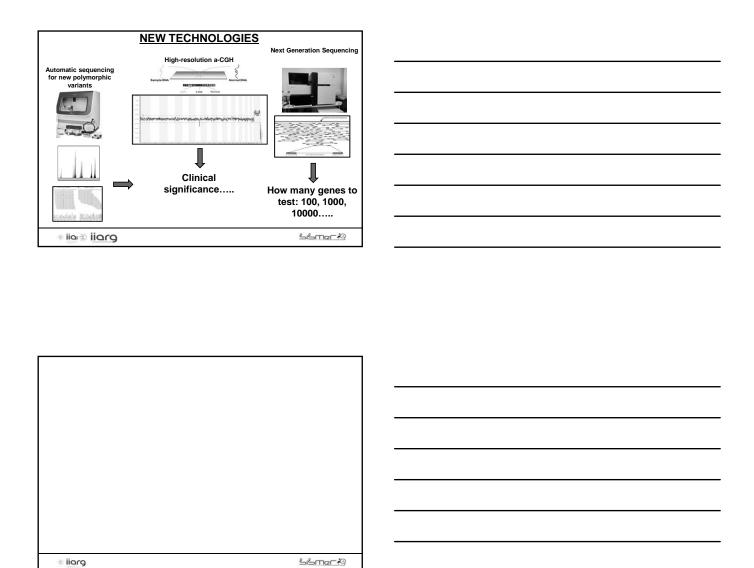
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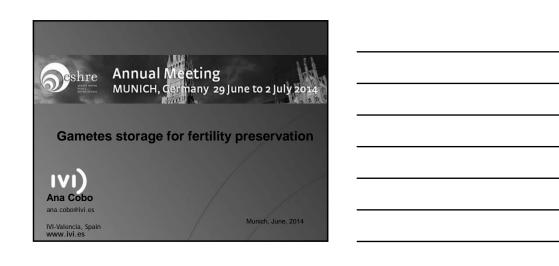
RESEARCH APPLICATIONS

- Simplified technologies
- New sources of embryonic DNA
- Mitochondria and aneuploidy
- Gene expression

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GENE EXPRESSION Study of transcriptome of - Normal karyotype Monozygotic twins fetal fibroblasts - Trisomy 21 To assess the perturbations of The differential expression gene expression in between the twins is organized in trisomy 21 domains along all chromosomes To eliminate the that are either upregulated or noise of genomic downregulated. variability) iiarg SiSmar ₹9 **GENE EXPRESSION** - Normal karyotype Monozygotic twins - Trisomy 21 The nuclear compartments of trisomic cells undergo modifications of the chromatin environment influencing the overall transcriptome. Gene expression dysregulation domains may contribute to some trisomy 21 phenotypes. iiarg SiSmar∤9 **RESEARCH APPLICATIONS** • Simplified technologies • New sources of embryonic DNA • Mitochondria and aneuploidy Gene expression New technologies » iiarg SiSmar∤9





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l declare no d	conflict of interest
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* Objective

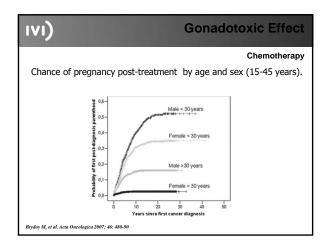
To review the cryopreservation of male and female gametes as an alternative for fertility preservation

IVI) Contents I. Introduction II. Male FP III.Female FP IVI) Who can benefit from FP? Medical reasons Cancer Iatrogenic reasons Vasectomy Medical reasons Cancer Other (endometriosis, Turner S., Fragile X etc.) Social Freezing IVI) **Fertility Preservation** Oncological patients Gonadotoxicity • Age. • Initial condition of the gonad. • Type of cancer (lymphoma, breast). • Agent used.

- Association with other chemotherapy.

- Combinations CHT-RT.

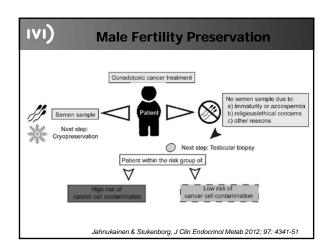
• Dose and cycles applied.

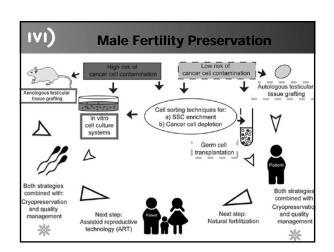


Breast cancer: The most common malignancy in women at reproductive age 6.4% <40 yrs at diagnosis Supervivencia Cáncer de Mama (%) 100 90 80 70 60 11970s 11990s

FP IN MALES Sperm cryopreservation Testicular tissue cryopreservation FP IN FEMALES Medical protection of the gonads Orthotopic ovarian grafting Oocyte/embryo vitrification

Months	Chemotherapy		Radiotherapy	
	Total patients	Azoospermic patients [n (%)]	Total patients	Azoospermic patients [n (%)]
3	40	15 (37)	44	2 (4)
6	32	11 (34)	43	11 (26)
9	42	5 (12)	46	9 (19)
12	46	3 (6)	69	6 (9)
24	33	1(3)	57	3 (6)
atment	semen ch	ılar function in aracteristics do in cryopreserving	not predict	recovery

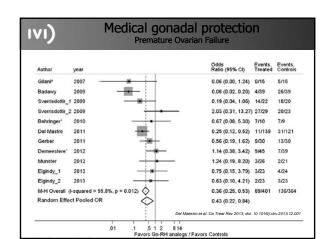


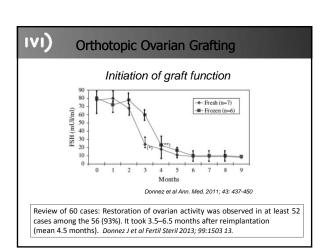


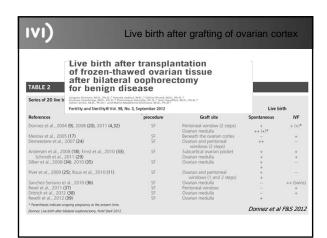
IVI)

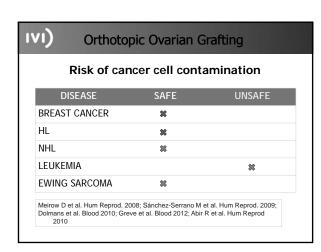
Fertility preservation in cancer patients

- FP IN MALES
 - · Sperm cryopreservation
 - · Testicular tissue cryopreservation
- FP IN FEMALES
 - · Medical protection of the gonads
 - · Orthotopic ovarian grafting
 - · Oocyte/embryo vitrification

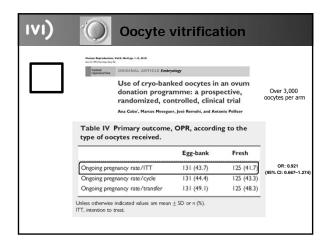


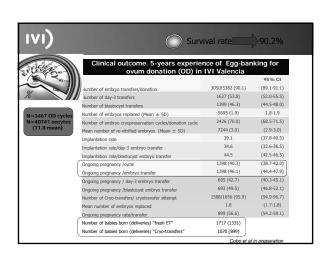




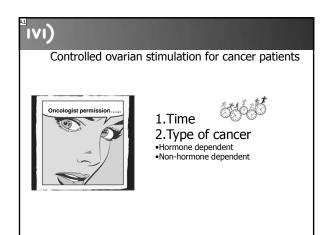


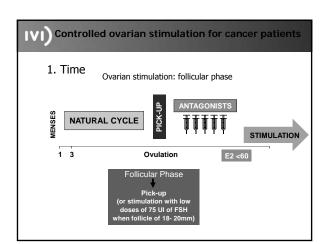


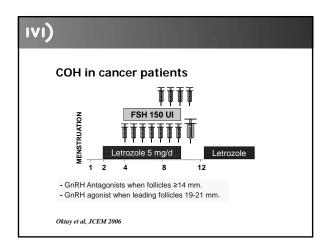




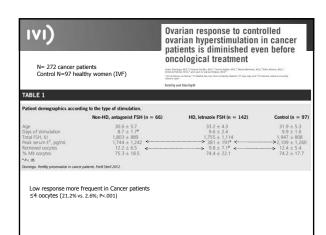
			Peri	natal outcon	ne
עועו		Fresh oocytes N=1224	Vitrified oocytes N=1027	OR(95%CI)	p value
	Gestational age	38.2 (38.0-38.4)	38.2 (38.0-38.4)		ns
-	Weight	2871 (2834-2908)			
	LBW < 2500gr	29.6% (27.0-32.2)	29.9% (27.1-32.7)	1.01 (0.85-1.21)	ns
-20	LBW <1500gr	3.7% (2.4-5.0)			
7753	Height	48.8 (48.7-49.0)	48.9 (46.6-49.1)		ns
	Cranial perimeter	33.6 (33.5-33.8)	33.5 (33.4-33.7)		ns
- Sp	Apgar 1	8.9 (8.88.9)	8.8 (8.7-8.9)		ns
	Apgar 5	9.6 (9.5-9.6)	9.6 (9.5-9.6)		ns
	Apgar 10	9.6 (9.5-9.7)	9.6 (9.5-9.7)		ns
	Malformation	1.4% (0.9-2.2)	1.7% (1.0-2.1)	1.20 (0.61-2.32)	ns
	Major malformation	0.8% (0.4-1.5)	0.7% (0.3-1.4)	0.83 (0.32-2.20)	ns
	Minor malformation	0.6% (0.3-1.2)			
	Intensive care adm.	14.2% (12.3-16.3)	13.8 (11.8-16.0)	0.97 (0.76-1.23)	ns
	ICU stay (days)	12.6 (10.5-14.7)	12.3 (10.0-14.5)		
	Perinatal Mortality	0.1% (0.04-0.6)	0.09% (0.01-0.5)	0.59 (0.05-6.66)	ns
	Healthy infant	99.9% (98.9-100)			
 ;	Female	47.5% (44.7-50.3)	53.8% (50.7-56.8)	1.29 (1.10-1.51)	0.04
Cobo et al	Male	52.5%	46.2%		

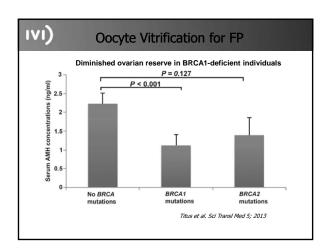


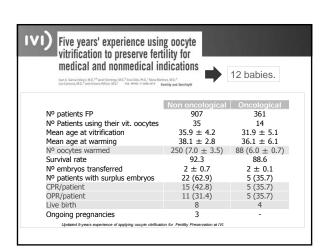


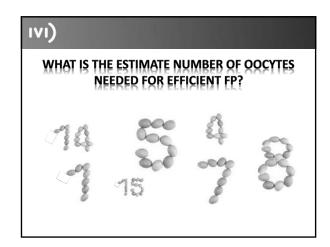


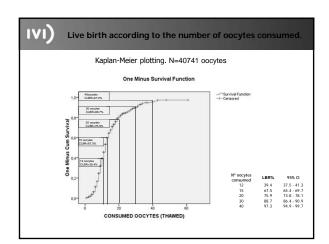
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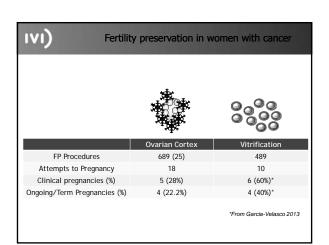












IVI)

Take home messages

FP in Males

- Sperm cryopreservation prior to antitumoral treatment is the strategy of choice.
- Prepubertal: Testicular tissue cryopreservation offers good expectations.

FP in Females

- Oocyte vitrification is an efficient an standardized option whose expectations of success are similar to those of ART.
- If time and oncologyts allows COH.
- 15 oocytes stored provide around 65% chance of LBR.
- Also useful for social reasons.
- Orthotopic ovarian grafting: Ovarian function recovers in >90% after 4 months. Pregnancy rates around 30% (natural+IVF)



IVI)

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Travelling patients: the business of cross-border T.Mardesic Sanatorium Pronatal, Prague Disclosure I declare that I have no commercial and /or financial relationships with manufacturers of pharmaceuticals, laboratory supplies and/or medical devices Learning objectives • Introduction • CBRC- a growing phenomenon • Reasons for cross-border reproductive care • Risks of cross-border reproductive care • Ethical problems regarding CBRC • Economic consequences od CBRC • ESHRE's good practice guide for CBRC • Recommendations

- Despite international calls for the prevention and appropriate treatment of infertility, this condition is becoming more and more common in the developed world (United Nations 1994)
- EU parliament ackowledged that infertility is one of the causes of demographic decline throughout the Europe (European Parliament 2008)
- These health and social considerations mean that the number of infertility cases is growing resulting in progressive increase in the need for assisted reproductive technology

Europe- the continent with the lowest fertility

Indications and possibilities of ART for infertile patients and couples

- Tubal infertility
- Male infertility (ICSI, MESA-TESE in azoospermia)
- Endometriosis, imunologic infertility, infertility of unknown origine (transfer of blastocysts, freezing of embryos)
- Sperm donation, oocyte donation, embryo donation
- Social freezing
- Preimplantation genetic screening and diagnosis (PGS, PGD)
- Surrogate motherhood

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Accessibility of ART for infertile couples

- Due to different reasons the access to fertility treatment is not equal in Europe
- Apparent increase in people travelling outside their home country to obtain ART
- Cross-border reproductive care (CBRC)

Cross-border reproductiva care (definition)

 Cross-border reproductive care (CBRC) refers to a widespread phenomenon where infertile patients or collaborators (such as egg donors or potential surrogates) cross international borders in order to obtain or provide reproductive treatment outside their home country

Cross border medical care is a growing phenomenon

- The number of persons seeking CBRC abroad is difficult to estimate even inside Europe
- According to ESHRE data, there is a minimum estimate of 24.000- 30.000 cycles / year (Shenfield 2010)

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Main causes of cross-border reproductive care

- Required type of treatment is forbidden by law (egg
- Required type of treatment is forbidden by law (egg donation, sex selection)
 Certain patients and couples are not eligible for ART (lesbian couples, single women, reproductive age)
 Waiting lists are too long in home country (egg donation)
 Out-of-pocket costs are too high (absence of insurance)
 Required type of treatment is not available because of lack of expertise (PGD, PGS)

- Expecting a higher quality of provided healthcare (several treatment failures)
- Personal whishes (privacy considerations)

Main causes of cross-border reproductive care

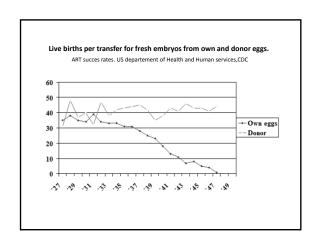
• Legal restrictions

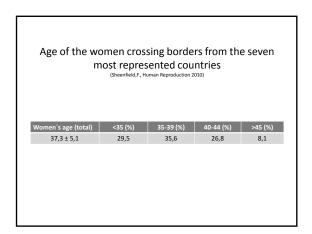
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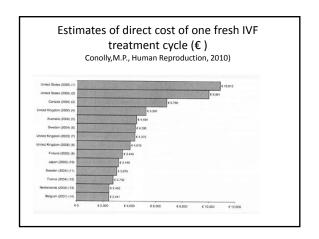
Availability

Mean age of women at the birth of the first child, 2009 rces: Eurostat, 2012, and United Nations Statistical Division, 2011, and National Statistical Offices, 2011

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General reasons for travelling (%) (Shenfield, F., Human Reproduction 2010)	
Legal reasons Access difficulty Better quality Previous failure 54,8 7,0 43,2 29,1	
There is a clear correlation between certain legal prohibitions in the patient's country of origin and the number of patients who travel abroad (Pennings,G., Human Reproduction 2009)	
Seeking cross-border reproductive care	
local limitation of rights to access reproduction care	
(All citizens have a right to access to decent health care, including reproductive health care in affluent societies: ESHRE Task Force on Ethics nad Law 14,2008)	
CBRC is a solution that enhances patient's autonomy	
 Since countries in democratic world committed to the free movement of persons can do little to restrict such movements, 	
restrictive legislation appears meaningless, except in a very powerful symbolic sense.	

	1
Risks of CBRC	
Cross border reproductive treatment has	
provoked extensive commentary, ethical	
debate and media speculation, often presenting spectacular cases	
presenting spectacular cases	
	_
Dialog of CDDC	
Risks of CBRC	
 There is evidence showing that couples who have obtained reproductive services abroad 	
requiring extensive pre- and post-natal care upon their return can place a strain on national health	
services	
(McKelvey at al.,BCOG 2009)	
 91,4% of all patients obtained informations in their language and considered satisfactory and 93,7% received information on cost 	
93,7% received information on cost (Shenfield,F., Human Reproduction 2010)	
Ethical considerations	
Resource poor countries:	
·	
CBRC may have undesirable implications for the the health care system in these countries.	
the the health care system in these countries and for the local patients	
Danger of exploitation (oocyte donation and	
surrogacy)	

Ethical considerations Physician: • Ina case of permissive law, it is morally allowed (taking into account the reproductive autonomy) to refer to a center abroad (However, required treatment must be supported from national and international professional societies) • Proffesional responsibility of reffering physician is to make sure that patients are treated well by the clinic to which she/he referrs CBRC - effect on legislation? • Growing numbers of patients going abroad for ART can be seen as a form of civil disobedience intending to change the existing legislation • Politicians may accept these movements as a "safety valve" decreasing the pressure for law reform internally What do we know about socio-demographic characteristics of CBRC patients? Received little attention in the literature so far: • Probably only wealthy patients are able to access CBRS (Hudson et al., Reprod Biomed Online 2011) • CBRC could allow less wealthy patients to have access to cheaper treatments that they cannot afford at home (Pennings,G., Human Reproduction 2004)

Broader economic consequences of ART-conceived children

Few studies tried to to quantify the economic impact of IVF children to the society

 IVF children (like any other individual) will engage in economic activities that influence financial transfers between the state and the citizen in the form of education, healthcare and future tax payments

Broader economic consequences of ART-conceived children

- Discounted net tax revenue paid over the lifitime of a singleton IVF child born in 2005 are rougly £ 110.000
- Costs to achieve an IVF child are approximately £ 13.000



8-fold return of investment for government

(Conolly,M.P. et all, Hum Reprod Update 2010, Svensson,A. et al., Scand J Public Health, 2008)

Broader economic consequences of ART-conceived children

Even more important:

Age structure of population, whereby the proportion of working-aged cohort relative to economically inactive cohorts is more relevant for economic growth

human reproduction ESHRE PAGES	
ESHRE's good practice guide	
for cross-border reproductive care for centers and practitioners [†]	
F. Shenfield ¹ , G. Pennings ² , J. De Mouzon ³ , A.P. Ferraretti ⁴ ,	
and V. Goossens ⁵ , on behalf of the ESHRE Task Force 'Cross Border Reproductive Care' (CBRC)	
*University College London Hospitals Trust. Reproductive Medicine Unit, London, UK *Organismes of Philosophy, Societica Institute Chare (BRC) Clear University; Clears, Belgem *Cochn-Sian Vereice De Pala Service de Gyldcope Chooletope al et de Mellocine de la Reproduction; Paris, France *SIATER, 8.1.1. Reproductive Peladre Wilde Siates, but \$55.945 (Central Orifox, Contralegram, Belgium)	
Submitted on February 23, 2011; resubmitted on February 23, 2011; accepted on March 2, 2011	
The ideal is fair access to fertility treatment at	
home for all patients.	
•	
	-
	1
ESHRE's good practice guide for cross-border	
reproductive care for centers and practitioners	
Polovant principles for nationts, denors, future	
Relevant principles for patients, donors, future	
children, surrogates and professionals:	
• Equity	
• Safety	
• Efficiency	
• Effectiveness	
• Timeliness	
Patient centeredness	-
]
ESHRE's good practice guide for cross-border	
reproductive care for centers and practitioners	
• Equity: similar protocols, fees, information and counseling	
for foreign as for national patients	
 Quality, safety and evidence-based care 	
provision: minimal risks with maximum chance of	
pregnancy. For gamete donation it is essential to follow the recommendations of EU tissue directive	
• For donors: stimulation that minimizes the health risks for	
the oocyte donors	
	I and the second

ESHRE's good practice guide for cross-border reproductive care for centers and practitioners Surrogacy: single embryo transfer is the only acceptable option Children: restrictive embryo transfer policy for egg donation embryo transfer must be limited to two embryos Professionals: collaboration between the home practitioner and the receiving center	
Summary and recommendations • While all European countries have reached the final stage of demographic transition characterized by low (or even lowest-low) fertility and high life expectancy, there are large groups of patients with no access to required infertility treatments at home who are forced to seek the medical help abroad.	
	1
 Summary and recommendation As a result of clear inequality of access to fertility treatments in Europe leading to growing number of cross-border patients and couples, broad social, ethical, medical and political problems may arise. Solution can be found only through coordinate efforts from various stakeholders like patient's organizations, professional societies and policy makers both on national and international levels. 	

Recommendation

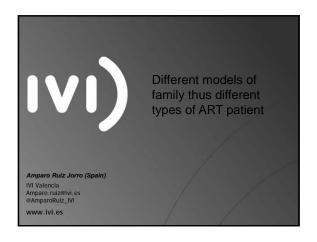
Professional society should gather information and:

- Inform the law makers, media and public of the benefits of ART for infertile people and couples
- Explain the negative consequences of restrictive laws
- Explain the responsibility of referring professionals
- Defend respect for different opinions

Recommendation

Legislation:

- Provide at least partial reimbursement for treatment to ensure equitable access for all citizens
- Adopt a less restrictive laws not to force large groups of patients to travel abroad
- Systems of control and verification should be installed



IVI)

Different models of family thus different types of ART patient

I declare no commercial or financial conflict of interest

IVI)

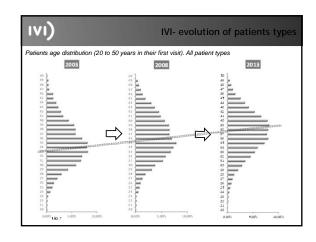
Different models of family thus different types of ART patient

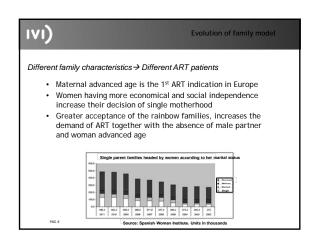
Learning objectives

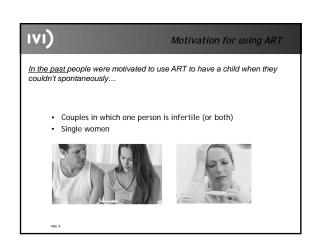
This is an overview of the different types of ART patients that are currently in fertility units, as a consequence of the social changes in the family models and the necessity to be updated and prepared for these situations:

- Evolution of family models in the society
- Progress of motivation for using ART
- Evolution of types of ART patients
 Evolution of ART procedures

IVI) What is a family?	
Family: A group of people who are related to each other, such as a mother a father and their children (Cambridge dictionary)	
PMG 4	
	İ
Evolution of family model	
But the structure of the traditional family has changed along the time	
Consequently, the motivation for using ART has also changed	
PMG.5	
	1
Evolution of family model	
The extension of stay in the parents' household, postpones the transition to adulthood and thus the	
creation of one's own family	
This change in the type of intended parents	
directly influences the activity of infertility units	
PMG.6	





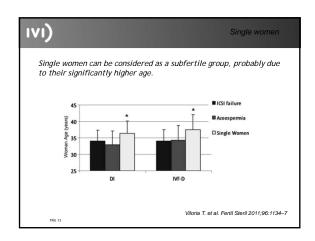


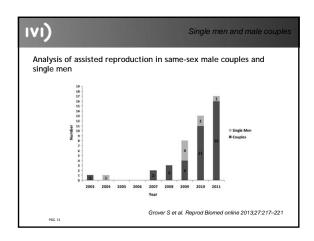
IVI) Motivation for using ART <u>Currently</u> people are motivated to use ART to have a child, genetically related if possible, in a variety of circumstances: · Couples in which one person is infertile (or both) Couples/women with repeated abortion · Lesbian couples · Homosexual male couples Couple in which one or both partners are transgender Single man/woman Homosexual or transgender man/woman Women undergoing chemotherapy Women who want to delay childbearing Couples who need/want to use pre-implantation genetic diagnosis (PGD) Moreover, as genetic screening becomes more popular, affordable, and able to test for a greater number of characteristics, it is possible that more people who are not infertile will use ART and PGD in order to minimize the risk of transmitting genetic diseases. Ombelet, W. Gampo R. Reprod Blomed Online 2007;15:257-65. IVI) It is necessary to be updated about the reproductive wishes of different types of patient to be prepared and avoid looking confused Knowledge of legal frame in each country

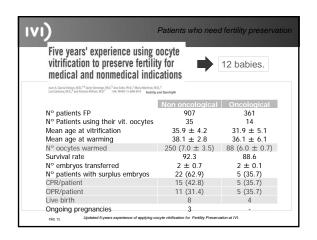
- To offer appropriate ART alternatives
- For filiation of the new born
- Adapted informed consents and informative documents
- Adapted database
- Special paperwork for certain cases
- Ethical and legal consultation organ
- Psychological specialized support

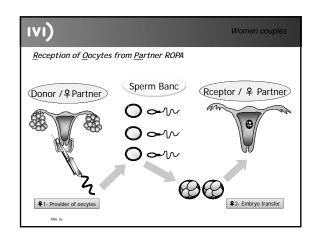
Amato P, Jacob MC. Sex Reprod Menopause 2004; 2:83-7.

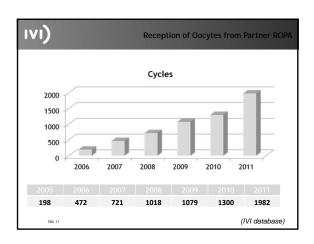
IVI) It is also necessary to analyze the characteristics of these specific groups of patients in order to optimize their success chances...

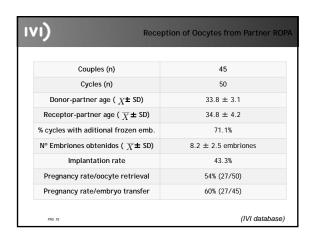


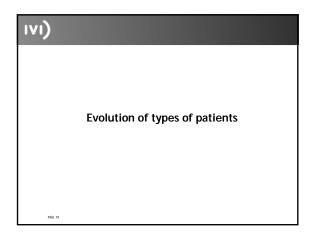


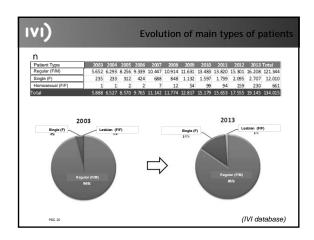


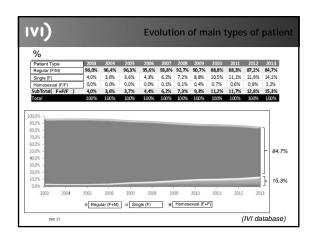


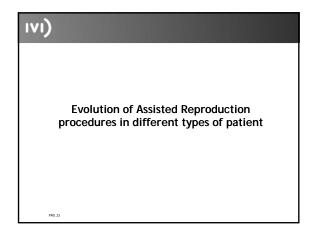


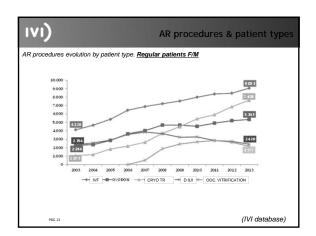


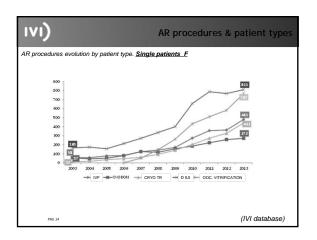


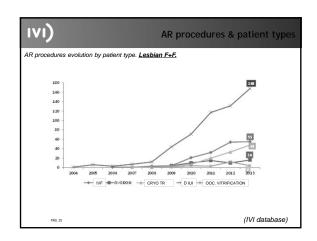


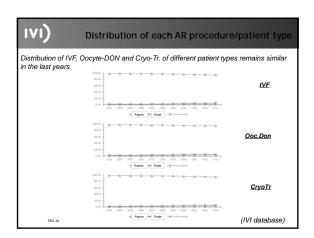


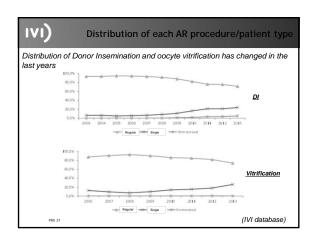


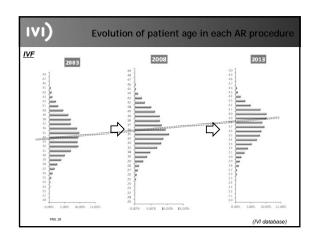


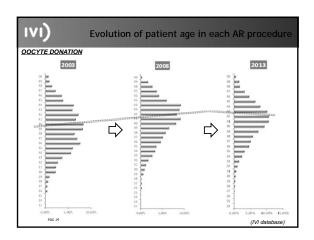


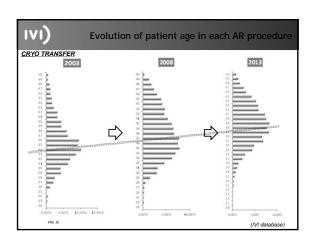


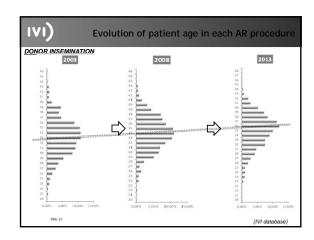


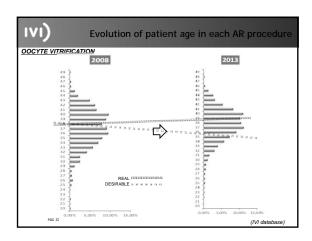


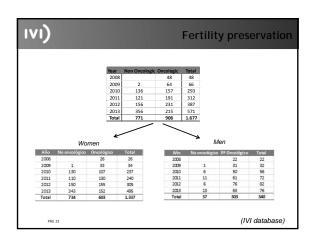


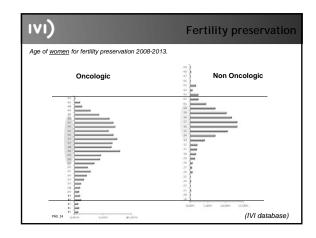


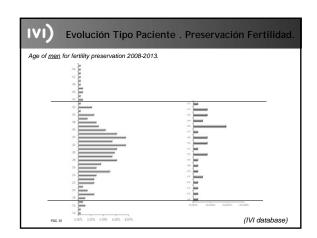












Conclusion It is a fact that there are a variety of patients types who require appropriate reproductive solutions, mainly: Single woman Treatment with sperm donation Single men and same-sex men couples Subrogation Lesbian couples Sperm donation / ROPA Patients who need/want to postpone motherhood Fertility preservation An adequate medical care, technical development and legal coverage is necessary to serve present and future needs of all patients

IVI) Take home messajes Know the social evolution of your environment. Take into account the possible types of patients in your clinic. Know the legal conditions in the place you perform fertility treatments. Study your dates for each group of patients and inform properly about the success probabilities. Adapt all documents and database. Go one step forward developing solutions for future possible situations.

IVI)

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- Ana Cobo. Director of Cryo preservation. IVI Valencia
- Antonio Requena. General Medical Director. Equipo IVI

IVI)

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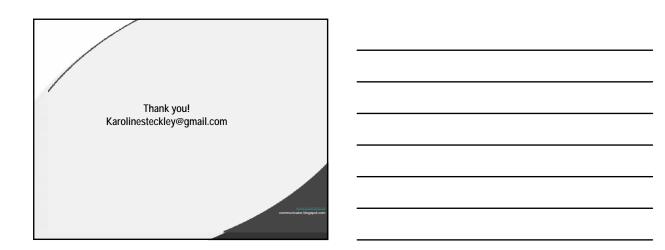




Realistic Feedback is impossible Where can doctors get this information? Can a fertility doctor REALLY ask a fertility patient for Feedback? Sure, you could, but what would you get? Scenario 1: Patient got pregnant under your care: You are a genius. You did a GREAT JOB! 5 stars! Scenario 2: Patient didn't get pregnant: You are a jerk, and a lousy doctor. 1/2 star! Scenario 3: No results. Clock is ticking. Patient changes doctors and is never to be heard from again. 0 stars. Disclaimer 2: I am a real life Case Study. Disclaimer 3: I work in communications. Disclaimer 4: I had a good outcome But... I still have my horror stories that I tell about my experience. The cell phone my doctor answered during my visit. The witch doctor counting her money. Don't pay now... I will get you later. How doctors talk about each other. Here is what else I noticed: Every visit was like starting from scratch. The patient is a science experiment. We are bombarded with false information outside the clinic. There is a lack of information for patients within the clinic. The problem of patient loyalty and incongruency Patients change doctors on average about three times during treatment. Every patient is a "free agent". Patients are well informed by the time they arrive at the clinic. Patients do not look at a Dr.'s results because they know they are manipulated by refusing patients who have a low risk of pregnancy. A patient's idea of "expert" may be different than the doctor's. The patient has "nothing to lose". Choice is based on word of mouth and results of friends. Fertility doctors have a terrible reputation for being cold, money-hungr forgetful and focused on research.

	1
Making the Process Bearable takes courage	
The fertility treatment process is a lough one psycologically and physically	
Many of us try new things as a result of the mental stress. We all have different ways of dealing with our situation.	
dealing with our Situation.	
Spend a lot of time on the internet	
Talk to other people in the same situation	
Run a marathon	
Get a drastic haircut	
Start a blog	
Destination IVF	
	•
"If you want to be in the top 5% you have to do what the other 95%	
do not want to do."	
Robin Sharma	
To be the Best of the Best , Aim to be a DESTINATION and a resource for what patients	
are really looking for:	
A doctor/team who is human.	
The doctor who listens to and understands and respects the modern patient can make a real difference.	
Transparency on information, pricing, expectations.	
Exercise empathy.	
	•
You, too, can become "Dr. Google"	
Pay attention to your online reputation.	
What are they saying about you?	
Spend at least as much time doing something about it as you do reading abou it.	
Define your values and practice them every day and online	
If they are sincere and your decisions are firmly rooted in these values, you will create a solid and positive reputation in spite of 'results'.	
Listen.	
Understand where your patients are getting their information. Stay updated on the latest online trends. Keep an eye on the most popular sites and blogs.	
Do not be defensive or intimidated by technology.	
Embrace the real opportunity to be heard through social media.	
Share your thoughts and ideas with your patients.	

Changing the Culture from top to bottom Going back to our learning objectives: Understanding the modern e-patient. Embracing new technology. Advice on becoming 'Dr. Google,' but BETTER! 'Friending' social media. Creating a value-based approach to fertility treatment and and online reputation. Conclusion: Considerations Pros Cons Ouestions.



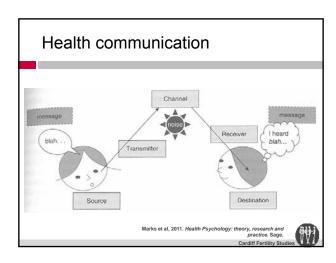


Conflict of interest (past three years) Nothing to declare

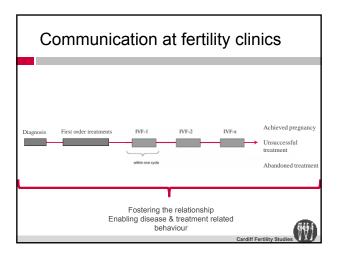
Learning objectives

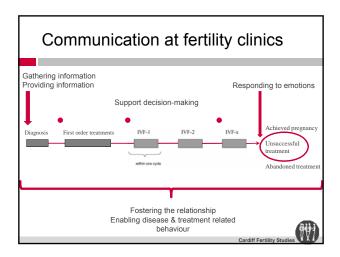
- 1. Understand the functions of health communication in fertility care
- 2. Profile new generation patients and their communication needs
- 3. Discuss how to ensure the effectiveness of health communication in fertility care

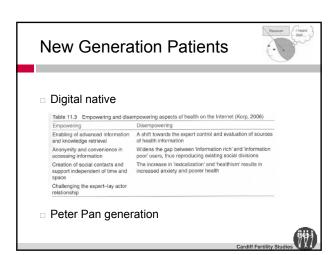




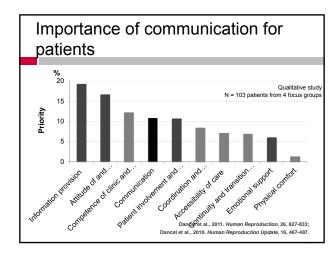
	Fund	ctions of	health co	ommunica	tion
	Six function model of medical communication	Goals	Immediate endpoints	Intermediate (and/or surrogate) endpoints	Long term endpoint
1	Fostering the relationship(s)	Good and effective relationship	e.g., + eye contact + patient participation - physiological stress measure	e.g., + trust + sense of rapport + satisfaction with consultation	patient satisfaction patient health physician stress and burn out
2	Gathering information	Adequate diagnosis and/or interpretation of symptoms	e.g., + explorative behavior + expression of patient concerns	e.g., adequate diagnosis / treatment plan diagnostic test ordering medical errors	+ patient health + physician satisfaction
3	Providing information	Good information provision	e.g., + check understanding / explore prior knowledge - used of jargon	e.g., + recall + understanding	e.g., - patient uncertainty + patient autonomy
4	Decision making	Decision based on information and preferences	e.g., check decision making preference / patient values + provide information	e.g., - decisional conflict + satisfaction with decision	+ satisfaction with decision + health
5	Enabling disease & treatment related behavior	Adequate and feasible disease and treatment related behavior	e.g., address patient motivation and efficacy	e.g., + iliness related behavior + treatment adherence + life style ? costs	+ patient health
6	Responding to emotions	Supporting the patient, enhancing the communication and referral where needed	e.g., + clinician explorative skills / silence + patient expression of emotions ? time constraints	e.g., + patient sense of support + treatment of psychopathology	+ patient emotional adjustment - psychological distres ? costs

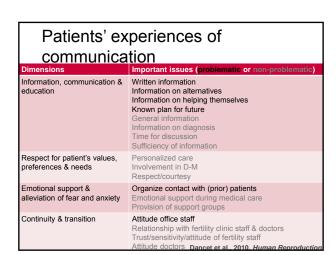


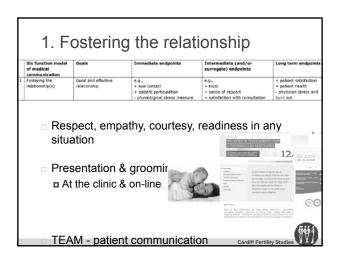




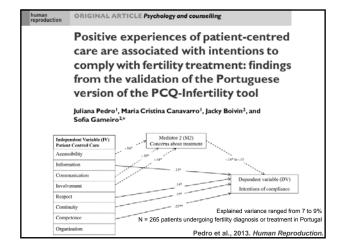
Use of internet & email for health care 4764 individuals with internet access & 5 chronic conditions (70%RR) 40% information or advice 6% communicate with doctor or health provider 26% communicate with family/friends about health 11% communicate with other people with health concerns 67% improved understanding of disease & treatment 30% improves ability to manage disease 16% affected treatment used 30% improved ability to manage other health needs 7% led to seek another health provider

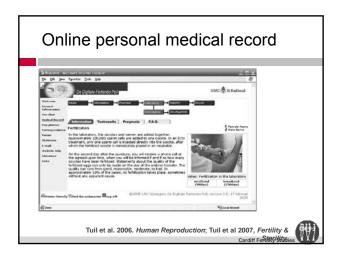


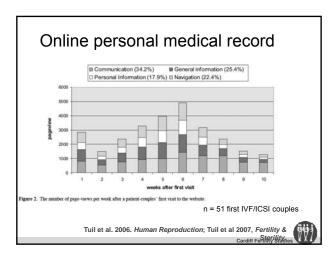


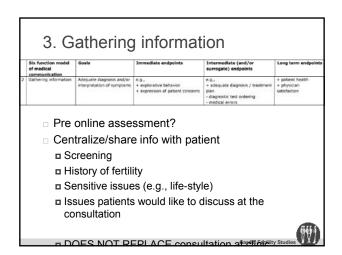


Training in empathic skills improves the patient-physician relationship during the first consultation in a fertility clinic | Description | A. | Construction | A. |









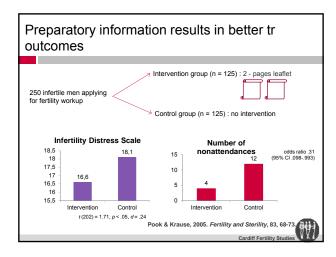
4. Providing information Addressing concerns and misconceptions □ Clear and thorough knowledge/understanding about ■ Health status ■ Different options and related outcomes ■ Practical procedures (daily plan) Information provision in fertility care Only 57% of patients receive information according to fertility guidelines □ Main determinants of receiving information Use of checklists ■ Presence of obstetrics/gynaecology residents ■ Presence of specialized nursing personnel ■ Higher patient anxiety scores

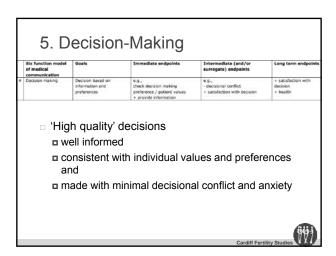
How do patients want to receive information?

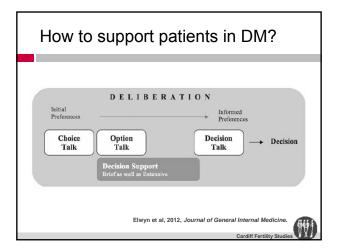
- □ Treatment related information, not clear which
- Customized is better than general
- □ Men and women want info about treatment options & results
- □ Women value more than men information about psychosocial support
- Preferences about how information is presented can be known & staff could try to provide in preferred formælencet et al 2010. Human Reproduction Update; Hope 2010. Fertility & Sterility; Mourad et al 2011, Human Reproduction; Schmidt et al 2003, Human Reproduction.

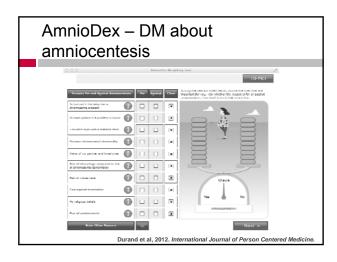
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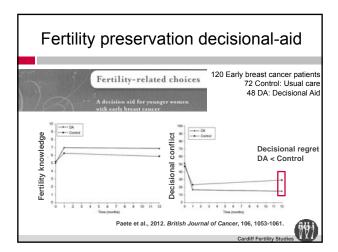


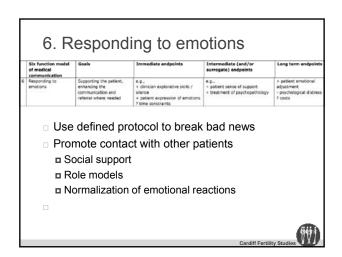












Identifying distressed patients

- Active listening: look for verbal, physical cues and somatization
 - u 'I guess a lot of people feel down when they get cancer'
- □ Avoid distancing techniques
- □ Prompt patients for information
 - Do not assume patients will express all their needs
- Use words with emotional content
- □ Use screening/ quality of life tools
 Ryan et al, 2005. European Journal of Cancer Care.



Supporting distressed patients

Independent variable (IV)
Patient Centred Care (PCC)

PCC - Interpersonal

Respect
Involvement
Competence
Information
Accessibility
Organizations

Explained variance ranged from 6 to 20%

N = 265 patients undergoing fertility diagnosis or treatment in Portugal

Gameiro et al., 2013. Patient Education and

Conclusions

- 1. Communicate to meet ≠ goals at ≠ tr stages
- 2. New Generation Patients
 - Use technologies to complement their communication with health professionals
 - Value information provision & other communication functions
- ≠ responsibility & techniques → ≠ goal(s) of communication

ALL STAFF should

- Undergo communication & empathy skills training
- □ Facilitate patient access to information materials & communication tools



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