Forty-second Annual Postgraduate Program

October 17, 2009 Atlanta, GA

# Infertility Counseling and Cross-Border Reproductive Care

# Course





Developed in Cooperation with the Mental Health Professional Group

Sponsored by the American Society for Reproductive Medicine



## Dear Postgraduate Course Participant:

In order to maintain and improve the quality of its educational programs, ASRM regularly conducts evaluations and content tests. We ask your cooperation in assessing the quality of your learning experience in this postgraduate course.

- Within 3 days after the Annual Meeting you will be sent an email asking you to complete an online evaluation of this postgraduate course. A personalized Web link to the evaluation will be provided in your email. Please do not share this unique link.
- 2. In late November you will be sent a second email with a personalized Web link asking you to complete the post-test on the content of the course. This test is identical to the pre-test and will enable ASRM to assess the effectiveness of this postgraduate course as a learning activity. For your convenience, the test questions are printed in the course syllabus.

After both steps have been completed, you will be able to print a Certificate of Attendance.

Results of both the course evaluation and the post-test are anonymous.

Both steps must be followed completely by **December 31, 2009**.

Please be aware that some email systems flag emails with Web links as junk mail, and you may need to check your junk-email folder for your notifications.

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\*\*\*\*\*Deadline = December 31, 2009\*\*\*\*\*

## AMERICAN SOCIETY FOR REPRODUCTIVE MEDICINE

Developed in Cooperation with the MENTAL HEALTH PROFESSIONAL GROUP ANNUAL MEETING POSTGRADUATE COURSE ATLANTA, GA
October 17, 2009

# "INFERTILITY COUNSELING AND CROSS-BORDER REPRODUCTIVE CARE"

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All speakers at the 2009 ASRM Annual Meeting and Postgraduate Courses were required to complete a disclosure form. These disclosures were reviewed and potential conflicts of interest resolved by the Subcommittee on Standards of Commercial Support of the Continuing Medical Education Committee. The faculty has revealed the following information as potential conflicts of interest:

Linda Hammer Burns, Ph.D.: Nothing to disclose

Jean Haase, M.S.W., R.S.W.: Nothing to disclose

Eric Blyth, C.Q.S.W., B.A., M.A., Ph.D.: Nothing to disclose

Elinor Wilson, Ph.D.: Nothing to disclose

This activity may include discussion of off-label or otherwise non-FDA approved uses of drugs or devices.

## **American Psychological Association**

The Mental Health Professional Group (MHPG) of the American Society for Reproductive Medicine is approved by the American Psychological Association to offer continuing education for psychologists.

Those attending course 2 will be offered 6.5 CE credits for psychologists. The MHPG maintains responsibility for the program and its content.

#### **National Association of Social Workers**

This program is approved by the National Association of Social Workers (NASW) (provider # 886496548) for 6.5 continuing education contact hours.

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Please turn off/mute cell phones and pagers during the postgraduate course and all Annual Meeting sessions.

Thank you.

## INFERTILITY COUNSELING AND CROSS-BORDER REPRODUCTIVE CARE

## **NEEDS ASSESSMENT AND COURSE DESCRIPTION**

Cross-border reproductive care has become increasingly challenging. Migration trends and reproductive tourism have increased the variety of patients who present for infertility treatment at facilities in the United States and elsewhere. Physicians, as well as mental health professionals, need to understand the cultural, religious, and ethnic perspectives about infertility, reproduction, and childbearing that impact patient decision-making about medical issues. Understanding of these issues will allow physicians to be more accepting of cultural practices that may be medically obstructive or faith based.

Little if any information is available in medical journals concerning infertility counseling dealing with transcultural psychosocial issues, religious beliefs, and reproduction. Articles aimed at physicians do not include psychosocial information, such as how a patient's religious beliefs may influence medical decision making, how recent immigrants who present for treatment in the US may have differing expectations of physicians than native born or assimilated patients, how culturally specific sexual practices influence medical treatment, or the request for gender selection through treatment. Conversely, sociology journals have articles about cultural beliefs and assimilation issues related to childbearing practices, but do not cover reproductive and infertility medical issues.

This postgraduate course will provide valuable information that both physicians and mental health professionals can use in their daily practice. Several aspects of reproductive tourism, or cross-border reproduction, will be addressed, including the development of government standards, the consumer perspective on reproductive tourism, the role of infertility counseling and counseling standards of practice.

#### ACGME COMPETENCY

Patient Care Interpersonal and Communication Skills

#### **LEARNING OBJECTIVES**

At the conclusion of this course, participants should be able to:

- 1. Compare and contrast the practices and roles of mental health professionals in different countries.
- 2. Assess the laws and regulations regarding the practice of infertility counseling worldwide, including psychological assessment and counseling for specific infertility treatments.
- 3. Critique qualifications for infertility counselors in various countries.
- 4. Identify patients' motivations to cross borders for reproductive treatments.

## AMERICAN SOCIETY FOR REPRODUCTIVE MEDICINE

Developed in Cooperation with the MENTAL HEALTH PROFESSIONAL GROUP ANNUAL MEETING POSTGRADUATE COURSE ATLANTA, GA
October 17, 2009

# "INFERTILITY COUNSELING AND CROSS-BORDER REPRODUCTIVE CARE "

Linda Hammer Burns, Ph.D., Chair, Jean Haase, M.S.W., R.S.W., Co-Chair

## Saturday, October 17, 2009

08:15 – 08:30	Welcome and Course Introduction Linda Hammer Burns, Ph.D. and Jean Haase, M.S.W., R.S.W.
08:30 – 09.05	Current Challenges in Cross-Border Reproductive Care: A Global Perspective Elinor Wilson, Ph.D.
09:05 - 09:15	Questions and Answers
09:15 – 09:50	Cross-Border Reproductive Care and Counseling Part 1: Issues and Challenges for Counselors Jean Haase, M.S.W., R.S.W.
09:50 - 10:00	Questions and Answers
10:00 – 10:30	Break
10:30 – 11:05	Patient Perspectives on Cross-Border Reproductive Care Eric Blyth, C.Q.S.W., B.A., M.A., Ph.D.
11:05 – 11:15	Questions and Answers
11:15 – 11:50	Cross-Border Reproductive Care and Counseling Part 2: A Survey of the Experiences and Perspectives of Counselors Jean Haase, M.S.W., R.S.W.
11:50 – 12:00	Questions and Answers
12:00 – 13:00	Lunch
13:00 – 13:50	Clinical Issues in Transcultural and International Infertility Counseling Linda Hammer Burns, Ph.D.
13:50 – 14:00	Questions and Answers

# Saturday, October 17, 2009 (continued)

14:00 – 14:50	Exploitation: What is its Role in Cross-Border Reproductive Care?  Eric Blyth, C.Q.S.W., B.A., M.A., Ph.D.
14:50 – 15:00	Questions and Answers
15:00 – 15:30	Break
15.30 – 16:45	Case Presentations and Panel Discussion All Faculty
16:45 – 17: 00	Summary and Closing Remarks Elinor Wilson, Ph.D.

# CURRENT CHALLENGES IN CROSS-BORDER REPRODUCTIVE CARE: A GLOBAL PERSPECTIVE

Elinor Wilson, Ph.D.
President, Assisted Human Reproduction Canada

## **LEARNING OBJECTIVES**

At the conclusion of this presentation, participants should be able to:

- 1. List the differences between medical tourism and cross-border reproductive care (CBRC), and the factors contributing to both.
- 2. Identify quality and safety issues pertaining to CBRC.
- 3. Discuss data challenges in assessing CBRC.
- 4. Demonstrate this knowledge in working with clients considering CBRC.

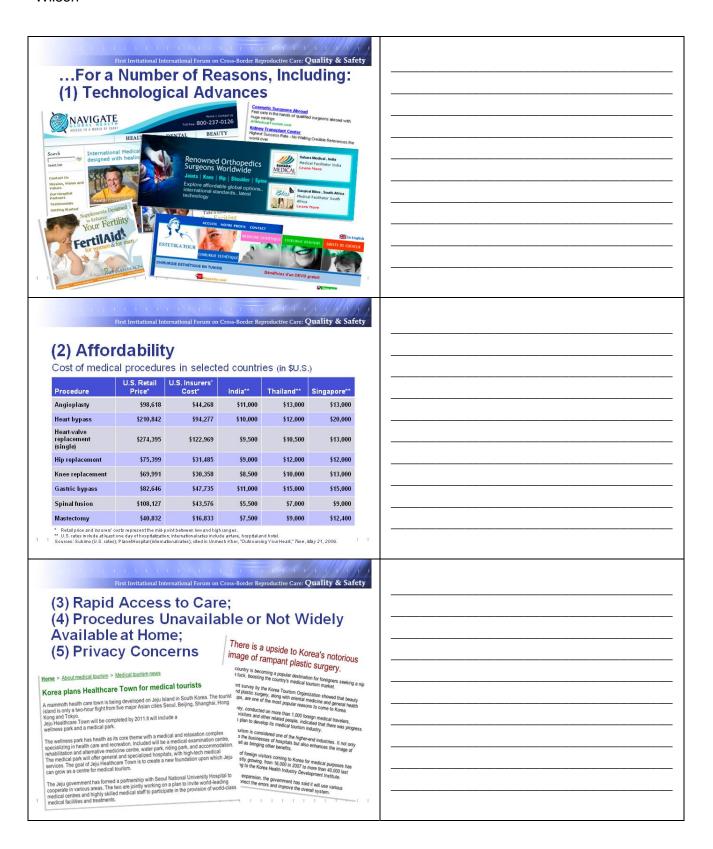
Current Cha	allenges in Cross-Border Reproductive
A Global Pe	rspective
	Dr. Elinor Wilson, Ph.D. President, Assisted Human Reproduction Canada
	International Forum on Cross-Border Reproductive Care: Quality & Safety
Learning Obj	ectives
should be able  1. List the diff and cross-l and the fac  2. Identify qua CBRC.  3. Discuss da  4. Demonstra	on of this presentation, participants to: erences between medical tourism porder reproductive care (CBRC), tors contributing to both. ality and safety issues pertaining to ta challenges in assessing CBRC. te this knowledge in working with sidering CBRC.
First Invitationa	I International Forum on Cross-Border Reproductive Care: Quality & Safety
Disclosure	
presentation First Invitat Cross-Bord and Safety of Assisted	ns contained in this n reflect the discussions at the ional International Forum on ler Reproductive Care: Quality n and are not necessarily those Human Reproduction Canada. has nothing to disclose

**Presentation Overview**  Medical tourism and CBRC The First Invitational International Forum on Cross-Border Reproductive Care (CBRC) · The physician survey (patient survey to be covered by Eric Blyth) · CBRC: The key quality and safety issues Patient and Physician "Prompters" **Medical Tourism and Cross-Border Reproductive Care** · "Medical tourism, a term that can also be used to describe medical outsourcing, is characterized by travel away from one's home region to procure treatment in another. It may take one of two forms: obligatory or elective." [Jones & Keith, 2006] It isn't new: the first recorded instance is over 2,500 years ago in ancient Greece. · But it is growing rapidly... First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety **Medical Tourism Estimates** U.S. outbound patient flow, 10-year projection (millions) 20 15 10 --- Upper limit - Base case 5

--- Lower limit

0

2007 08 09 10 11 12 13 14 15 16 17



First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	
(6) Improved Standards of Care  Joint Commission International  Trent Accreditation Scheme  International Organization for Standardization  The Society for International Healthcare Accreditation  HealthCare Tourism International  United Kingdom Accreditation Forum  TRENT  GCCCEditation SCHEME  Line Mon-Profit For Mean-Profit HealthCare Tourism International The Non-Profit For Mean-Profit HealthCare Tourism International The Non-Profit HealthCare Tourism International	
(7) Economic Imperative for Some Destination Countries  • "A number of countries, especially Asian states such as India and Thailand, are counting on this revenue as an important part of their gross domestic product. Health care abroad has become a multibillion dollar industry." [Pennings 2005]	
Cross-Border Reproductive Care Is Also a Growing Phenomenon  Experts say reproductive Care Is Also a Growing Phenomenon  Experts say reproductive tourism a growing worry  Mere porteuses, à quel prix?  Mere porteuses de prix application de la constant and prix application de prix application de la constant and prix applicat	

First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	
Although Reliable Data Are Hard to Come By	
Health warning to women over  Fertility four issues the second program of the second control of the second con	
First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	
Why CBRC and Not "Reproductive Tourism"?	
<ul> <li>The term CBRC was first proposed by Dr. Guido Pennings.</li> </ul>	
<ul> <li>The advantage of this term is that "it avoids the negative connotations of tourism; it is objective and descriptive; and it links with the more general term cross-border health care." [Inhorn &amp; Patrizio 2009]</li> </ul>	
First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety  Medical Tourism and CBRC: the Differences (1)	
<ul> <li>The consequences of successful cross- border reproductive care affect not just one individual, but also the child, or children, born of the process, as well as their own children and future generations.</li> </ul>	
<ul> <li>In cases where donor gametes or a surrogate are involved, the consequences spread even further.</li> </ul>	

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First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety
Medical Tourism and CBRC: the Differences (2)
"In poor resource areas, the need for infertility treatment in general, and IVF in particular, is great. The inability to have children can create enormous problems, particularly for the woman. She might be disinherited, ostracized, accused of witchcraft, abused by local healers, separated from her spouse, or abandoned to a second-class life in a polygamous marriage."
– Uluwole Akande, cited in ESHRE 2008
and the second of the second o
First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety
Medical Tourism and CBRC: the Differences (3)
<ul> <li>"These people are not ill in the usual sense What binds them together are three shared characteristics: the desire for a child, the inability to produce this child through natural means, and a willingness to do whatever is necessary to produce one." [Spar 2005]</li> <li>Some are not medically infertile, but rather "socially infertile."</li> <li>Some travel owing to limits imposed by domestic professional guidelines and law</li> </ul>
First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety
CBRC: Quality and Safety
<ul> <li>"The most important danger concerns control of quality and safety standards." [Pennings, 2005]</li> </ul>
<ul> <li>Quality: verified success rates; clinic respects professional and other standards.</li> </ul>
<ul> <li>Safety: donor screening; complication rates;</li> </ul>
multiple pregnancies; ovarian hyperstimulation; inappropriate use of unproven/experimental procedures.
Quality and safety failures can impact the home
health system, as well as patients, offspring, , , donors and surrogates, , , , , , , , , , , , , , , , , , ,
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First Invitational International	Forum on Cross-Border Reproductive Care: Quality & Safety	
The Forum: January 14-16, 2009		
behalf of a steering co  Steering committee be identifying key issues  Commissioned back physician and patient "prompters."  A working meeting invalues a series of lectures.  Focus on identifying tag for patients, offspring,		
First Invitational International	Forum on Cross-Border Reproductive Care: Quality & Safety	
Steering Committ	ee Members	
<b>Dr. Elinor Wilson</b> Canada	Ms. Beth Pieterson Canada	
Ms. Anna Pavlou European Commission	Professor Josiane Van der Elst Belgium	
Dr. Arne Sunde Norway Dr. Anna Veiga	Ms. Trish Davies United Kingdom	
Spain <b>Ms. Sandra Dill</b> Australia	<b>Dr. Petra Thorn</b> Germany (alternate)	
	Forum on Cross-Border Reproductive Care: Quality & Safety	
Forum Objectives		
	ation health professionals o cross-border reproductive	
<ul> <li>Explore the types of to make informed</li> </ul>	of information patients need choices	
	k of organizations and ed to safe, quality cross- e care	
<ul> <li>Provide a venue w organizations and another</li> </ul>	here individuals, countries can learn from one	

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First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	
Inclusive International Participation	
<ul> <li>Multilateral agencies</li> <li>Regulatory authorities</li> <li>Academics</li> <li>Medical researchers</li> <li>Patient advocates</li> <li>Professional associations</li> <li>Hospital-based providers</li> <li>Lawyers</li> <li>Ethicists</li> <li>Fertility clinics</li> <li>Government officials</li> <li>Policy makers</li> </ul>	
First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	
The Physician Survey: Introduction	
<ul> <li>Conducted by Ed Hughes, McMaster University</li> <li>Objectives: <ul> <li>To identify the scope of U.SCanada cross-border services</li> <li>To estimate the volume of cross-border fertility services in Canada and the U.S.</li> <li>To evaluate the three-way communication between patients and their two service providers</li> </ul> </li> <li>Results to inform development of physician "prompter"</li> <li>28 Canadian surveys and 125 U.S. surveys completed. [Hughes 2008]</li> </ul>	
First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	
The Physician Survey – Destinations and Procedures	
<ul> <li>Main procedure Canadians go abroad for is anonymous donor egg IVF         <ul> <li>Majority go to U.S.</li> </ul> </li> </ul>	
<ul> <li>Americans travel to the following destinations (in order of frequency): India/Asia, Europe, Latin America, Australasia, Canada</li> </ul>	

First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety

# The Physician Survey – Quality and Safety: Canadian Responses

- Strong regulatory control is considered very important by 40% of Canadian physicians. However, in their opinion, only 12% of patients would consider strong regulatory control as very important.
- 100% of Canadian physicians believe cost is somewhat or very important to patients in choosing a clinic.
- Most commonly, a recommendation is given for country destination, but not for clinic or specific provider. Three quarters noted that patients sometimes identify clinics for themselves.

First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety

# The Physician Survey – Quality and Safety: U.S. Responses

- Three leading reasons U.S. physicians feel non-U.S. patients come to them:
  - Confidence in effectiveness
  - Confidence in safety
  - Information from other patients
- The three pieces of information U.S. physicians most want to receive from the referring clinic are:
  - Recent laboratory results
  - Track sheets from previous treatment cycles
  - Copy of medical record

First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety

## The Big Issues...



First invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	
What Everybody Needs	
<ul> <li>"The lack of data on access, treatments and outcomes is central to current CBRC, for:</li> <li>Patients, to make informed decisions</li> <li>Doctors, to support outgoing and incoming patients pre-,</li> </ul>	
during and post-treatment  Solvernment agencies, to support patients, and especially,	
to guard safety ➤ Politicians, to react to suboptimal conditions on legal	
regulation and resource allocation	
➤ The public, for ethical discussion"  Karl Nygren, ICMART, presentation to Forum	
rannygren, romann, presentation to rotum	
First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	
The Data Challenge  Nygren found that:	
<ul> <li>There are few, if any, solid data, only rough estimates.</li> </ul>	
<ul> <li>Clinics do not usually distinguish between domestic and international patients when they report to national databases.</li> </ul>	
<ul> <li>Follow-up data on outcomes are often not gathered for international patients.</li> </ul>	
<ul> <li>Data on CBRC "are collected more easily in the country of treatment, but actually may be more important in the country of origin." [Nygren 2008]</li> </ul>	
<ul> <li>At the Forum, Dr. Nygren raised the possibility of adding country of origin and reason for travel to ICMART data</li> </ul>	
sets.	
First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	
What Patients Need	
√ Trusted sources of information	
<ul> <li>Information on treatment options, risks and costs</li> </ul>	
✓ Internationally accredited clinics, and an understanding of why this matters	
<ul> <li>✓ Counseling to understand psychosocial dimensions of choices</li> </ul>	

First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	
What Providers Need	
<ul> <li>✓ Timely and trusted information</li> <li>✓ Data on costs and outcomes</li> <li>✓ Standards of care</li> <li>✓ Protocols for advising patients on cross-border reproductive care</li> </ul>	
Perspectives from ESHRE and the ASRM	
<ul> <li>ESHRE has established a task force on CBRC, which will include ethics and law recommendations, and data collection project</li> <li>Results from a six-country pilot data collection project will be available in 2009</li> </ul>	
For the ASRM, Dr. Marc Fritz underlined the importance of clinical practice guidelines for safe, quality care	
First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	
What Health Authorities Need	
<ul> <li>✓ Awareness of current research</li> <li>✓ Monitoring of technological advances and their impacts/potential impacts on quality and safety</li> <li>✓ Research on the health of children conceived through assisted human reproduction (AHR).</li> <li>✓ International/multilateral collaboration on data and quality/safety basics</li> </ul>	

First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	
The Prompter Document	
<ul> <li>"Prompters are detailed reminder tools that can be customized to fit a range of situations. They are useful in organizing discussions and supporting information exchange and proactive decision-making in conversations between patients and physicians."</li> <li>No copyright – aim is wide distribution and customization.</li> <li>Contains: Patient Prompter; Physician Prompter; advice on getting quality, accurate information from the Internet.</li> </ul>	
First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	
Patient Prompter	
<ul> <li>Introduction</li> <li>Questions about your destination clinic</li> <li>Information about your proposed treatment</li> <li>Provision of counseling and emotional support</li> <li>If your proposed treatment involves surrogacy or a donor procedure</li> <li>Issues for offspring born as the result of surrogacy or a donor procedure</li> </ul>	
First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	
Physician Prompter	
<ul> <li>Checklist for clinic-to-clinic communication         <ul> <li>From the home to the out-of-country clinic</li> <li>From the out-of-country clinic to the home clinic</li> </ul> </li> <li>Medical issues</li> <li>Emotional and value issues</li> </ul>	

Key Challenges Identified by Forum **Participants**  To provide patients and stakeholders with the accurate and timely information they need to make informed choices. - Information should cover laws and guidelines. · To obtain reliable, relevant data on practice, efficacy and safety, and on all aspects of CBRC in all of the countries involved. To determine the broad range of approaches, from guidelines to legislation, that could be used for CBRC. **SUMMARY POINTS** · CBRC is a reality around the globe. · There are very few reliable data on the phenomenon. · Collective action from all parties is necessary to ensure quality and safety concerns are addressed. · In the interim, the Prompter Document is a useful tool for counselors, patients, physicians and others. First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety Moving Forward Together...

First Invitational International Forum on Cross-Border Reproductive Care: Quality & Safety	

#### **REFERENCES**

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# **NOTES**

# **NOTES**

# CROSS-BORDER REPRODUCTIVE CARE AND COUNSELING PART 1: ISSUES AND CHALLENGES FOR COUNSELORS

Jean Haase M.S.W., R.S.W.
Policy Analyst
Assisted Human Reproduction Canada

## **LEARNING OBJECTIVES**

At the conclusion of this presentation, participants should be able to:

- 1. Describe the relevance of cross-border reproductive care for counselors.
- 2. Identify clinical issues associated with cross-border reproductive care.
- 3. Explain the role of professional organizations.
- 4. Apply this knowledge in working with clients seeking or receiving cross- border reproductive care.

Cross-Border Reproductive Care and Counseling  Part 1: Issues and Challenges for Counselors  Jean Haase, M.S.W., R.S.W.  Assisted Human Reproduction Canada	
Learning Objectives	
At the conclusion of this presentation, participants should be able to:  1. Describe the relevance of cross-border reproductive care for counselors.  2. Identify clinical issues associated with cross-border reproductive care.  3. Explain the role of professional organizations.  4. Apply this knowledge in working with clients seeking or receiving cross-border reproductive care.	
Disclosure	
This presentation does not reflect the views of Assisted Human Reproduction Canada.  The author has nothing to disclose.	

Overview	
Counseling and Cross-Border Reproductive Care (CBRC):  The context The issues The implications For clinical practice For professional organizations For global standards	
Why Is CBRC Relevant for Counselors?	
<ul> <li>Part of overall globalization of health care</li> <li>Increasing options for patients</li> <li>Clinical issues before and after CBRC treatment</li> <li>Mental health professionals (MHPs) work with 'outgoing' and 'incoming' patients</li> <li>Few standards or guidelines about CBRC counseling</li> <li>CBRC challenges attitudes, assumptions, values</li> <li>Majority of CBRC patients do not receive counseling</li> </ul>	
'The Good Old Days'	
<ul> <li>When patients were referred by their physician to the nearest fertility clinic</li> <li>When the idea of being treated in another country—any country—would have seemed 'risky'</li> <li>When the information provided by medical professionals was considered more reliable than Websites</li> <li>When the main issue confronting recipients of third-party donation conception was to tell or not to tell their children</li> </ul> Merricks, 2008	



Marketing Strategies
"Our philosophy is BALANCE. We believe a balanced approach to everything in life is always the most successful approach."
"Providing this balance ensures patients get the best possible care while minimising their own stress levels. Infertility is a stressful time for couples and many studies reflect the negative impact this has on success."
www.barbadosivf.com
Support for Counseling in CBRC
<ul> <li>ESHRE task force on Ethics and Law         Refers to the importance of psychological counseling as 'compliance with ethical standards' Pennings et al, 2008</li> <li>AHRC International Forum on CBRC         "Make counselling an integral part of medical treatmentchange the perceptions of medical professionals so that they encourage counselling."         AHRC, 2009</li> </ul>
AHRC International Forum on CBRC
<ul> <li>"Counselling is critical, and yet many patients are resistant to it and view it as an additional burden."</li> <li>"The challenge is partly to change their perception, so that they see it as an effective means of emotional support"</li> <li>"Patients need information so they can make good decisions about where to go and how to improve their outcome and safety. Counselling should be emphasized as an important requirement for consideration in choosing a treatment clinic."</li> </ul>
AHRC, 2009

# **Support from Patient Organizations** • "Not all clinics provide counseling prior to treatment and very few are likely to provide counselling in your native language." • "It can be helpful to explore emotional issues with a counselor in your own country, even if he or she is not familiar with infertility treatment in the country where you are intending to undergo treatment." International Consumer Support for Infertility (iCSi), 2008 iCSi Guide Travelling abroad for assisted reproductive technology (ART) International Consumer Support for Infertility (iCSi) Patients - Will not reflect, but start treatment at all costs - Will not ask questions - Will feel intimidated, will not challenge lack of transparency in clinic abroad Counseling—becoming more established in Western countries—is often not available "We need to provide information, education and support." Thorn, 2009

Pre- Treatment Counseling	
<ul> <li>Education about options</li> <li>Preparation—questions to consider</li> <li>Managing expectations</li> <li>Connecting to information resources</li> <li>Referral</li> </ul>	
arouse isoriter reproductive care	
Post- Treatment Counseling	
<ul> <li>Unsatisfactory experiences</li> <li>Negative feelings</li> <li>Post-treatment access to information</li> <li>Managing privacy, disclosure</li> </ul>	
cross border reproductive care	
Long-term Implications of CBRC	
<ul> <li>Parents and families</li> <li>Offspring</li> <li>Donors and surrogates</li> <li>Clinics and professionals</li> <li>Regulators</li> </ul>	
press border reproductive care	

# **Challenges for Counselors** • Personal and professional values · Conflicts of interest • Awareness of exploitation Legal implications **CBRC:** A Role for Counseling Organizations? MHPG (USA) • GLASMI (Latin America) BICA (UK) JAPRCM (Japan) ANZICA (Aust/NZ) • Fertiforum(Switzerland) BKiD (Germany) • SEF (Spain) ESHRE (Europe) IICO (International) CSIG (Canada) • IFSW (International) **Global Counseling Standards** IIC Global Comparison of Standards/Guidelines

# Canada Counselling Special Interest Group (CSIG)

- Canadian counseling group affiliated with medical society [Canadian Fertility and Androgen Society (CFAS)]
- Significant growth in membership
- · Regulatory context for counseling
- Clinical practice guideline development
- Counselor training
- Annual award





#### USA

## Mental Health Professionals Group (MHPG)

- Guidelines and standards
- Training and professional development
- Networking and collaboration
- Research





cross worder reproductive Car

# United Kingdom British Infertility Counselling Association (BICA)

- Independent organization
- · Counseling must be "offered"
- Counselor training
- Counseling guidelines
- Counseling award





# Australia and New Zealand (ANZICA)

Australian and New Zealand Infertility Counsellors Association

- · Guidelines and standards
- Mandatory counseling for third party assisted human reproduction (AHR)
- Counselor training
- · Membership 'tiers'





### International Federation of Social Workers (IFSW)

#### Position on CBRC grounded in principles of:

- Human rights
- · Non-commercialization
- Protection from exploitation
- Self-determination
- Safety
- Ethics
- · Equality of access



IFFSW, 2008

# International Infertility Counseling Organization (IICO)

- Initial development between 2002 and 2003
- Officially launched at the International Federation of Fertility Societies (IFFS) meeting in 2004
- 8 founding member organizations
- Courses at ESHRE and ASRM
- Website





Other Relevant Guidelines	
<ul> <li>American Psychological Association (APA) guidelines on cross-cultural counseling</li> <li>APA International Psychology Division</li> <li>Guidelines for use of translators and cultural interpreters (various disciplines)</li> </ul>	
rorous border reproductive care	
Counselors Need:	
<ul> <li>Protocols and guidelines for CBRC</li> <li>Accurate sources of information and resources</li> <li>'Buy-in' from medical professionals, patient groups</li> <li>Opportunities for networking and outreach</li> <li>Research about impact and implications of CBRC</li> </ul>	
cross sucretor reproductive care	
Ongoing Challenges in CBRC	
<ul> <li>Keeping up with rapid developments in CBRC</li> <li>Expanding international networks</li> <li>Increasing patient access to, and uptake of, counseling</li> <li>Advocacy</li> <li>Cultural awareness</li> <li>Research and outcomes</li> </ul>	
coroses bearder reproductive bare	

## Haase

Final Thoughts	
"Traveling for reproductive care is far from a neutral experience. Instead, it may be challenging, time-consuming, frustrating, impoverishing, frightening, and even life-threatening. For most, it is a kind of forced travel from home, which may feel like a major yet underserved punishment. Such reproductive exile may add considerably to the despair and stigmatization of infertility, especially for couples coming from societies where physical reproduction is socially mandatory."  Inhorn, Patrizio, 2009	
'Cross- border issues require cross-border solutions'  Collins, 2009	
Questions	
oross sorder reproductive care	

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### PATIENT PERSPECTIVES ON CROSS-BORDER REPRODUCTIVE CARE

Eric Blyth, Ph.D.
Professor, School of Human and Health Sciences
University of Huddersfield, U.K.

#### **LEARNING OBJECTIVES**

At the conclusion of the presentation, participants should be able to:

- 1. Describe patient motivations for undertaking cross-border reproductive care.
- 2. Identify the services for which patients undertake cross-border reproductive care.
- 3. Discuss potential positive and negative implications of cross-border reproductive care.
- 4. Review clinical practice issues for counselors working with patients who access cross-border reproductive care.



# Patient Perspectives on Cross-Border Reproductive Care

Eric Blyth, Ph.D.
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#### **Disclosure**

The study on which this presentation is based was commissioned and funded by Assisted Human Reproduction Canada of the Canadian federal government and was conducted in cooperation with three support groups: ACCESS, Infertility Awareness Association of Canada and Infertility Network.

The author has no commercial and/or financial relationships with manufacturers of pharmaceuticals, laboratory supplies and/or medical devices.

Overview of the Online Survey		
Aim to seek views and experiences of people who had used cross-border reproductive services, had considered, or were considering doing so.		
Supported by 3 patient organizations: ACCESS, Infertility Awareness Association of Canada (IAAC) and Infertility Network.		
"Live" from July 1 until September 30, 2008, and accessed via the Websites of ACCESS, IAAC and Infertility Network.		
131 submissions made; 95 usable	responses	
Demographics and Treatment H	listory	
Geographical location: Canada (n = 55; 60%) Australia (n = 22; 24%) – rest from other countries (U.S.A. [n = 10], Israel [n = 3], UK [n = 2], Greece [n = 1])		
Age: <30 years (n = 6; 6%); 30-39 ye 52%); 40-49 years (n = 35; 38%); > 3; 3%)	ears (n = 47; 50 years (n =	
28 participants indicated they had undertaken cross-border reproductive care (CBRC).		
76 (86%) had received treatment in home country before seeking, or considering seeking, CBRC. 56% had previously undertaken treatment in home country for at least three years.		
Finding Out about Treatment in Countries	Other	
Internet	61 (64%)	
Patient support group	20 (21%)	
Media sources other than Internet	19 (20%)	
Another patient	14 (15%)	
Clinic treating individual in home country	13 (14%)	
Friend or family member	4 (4%)	

69 participants cited at least one country					
• 37 (54%) = USA					
24 countries: Argentina, Australia, Bangladesh, Barbados, Belgium, Canada, Cyprus, Czech Republic, Denmark, France, Greece, India, Israel,					
Italy, Mexico, Nether	rlands, Russia, Sc	outh Africa.		 	
Spain, Thailand, Tur Kingdom, USA, + ge	eneral regions in	Africa, Asia,		 	
Eastern Europe and South America (without naming a specific country)			 		
Mojerity openified of	ingle country cor	na liotad		 	
Majority specified si multiple potential de	estinations, e.g., "	'Ukraine,			
countries in Africa, I	Eastern Europe, (	Canada."			
			= $+$		
Treatment Sought					
11.721111111111111111111111111111111111				 	
F	40 (570/)			 	
Egg donation	16 (57%)			 	
IVF	7 (25%)				
ICSI	5 (19%)				
Sperm donation	5 (19%)			 	<del>-</del>
IUI	3 (11%)			 	
Embryo donation	2 (7%)			 	
Tubal surgery	2 (7%)			 	
Surrogacy	1 (4%)			 	
	•			 	
			=+	 	
Factors Taken into  Availability of donor eg		21 (75%)		 	
Success rates	<b>39</b> 0.0 <b>P</b> 0	18 (64%)		 	
Ouccess rates		17 (61%)		 	
Short waiting times		15 (54%)		 	
Short waiting times Cost of treatment				 	
	n home country	14 (50%)			
Cost of treatment		14 (50%) 8 (29%)		 	
Cost of treatment Services unavailable i	other patients				

# **Making Arrangements** Made own arrangements 19 (76%) Arrangements made by individual 5 (20%) or agency other than clinic in home country Arranged by clinic in home 0 country Combination of above 1 (4%) **Outcomes and Experiences of CBRC** 56% (14/25) of participants conceived a child as a result of treatment in another country; 44% (11/25) reported that it had not been successful. Reported positive experiences (117) outnumbered negative experiences (43). **Positive Aspects of CBRC** Availability of donor eggs/sperm 18 (72%) Short waiting list 15 (60%) Cost 12 (48%) Higher success rates 12 (48%) Facilities at clinic 12 (48%) Attitudes of staff at clinic 12 (48%) Atmosphere at clinic 10 (40%) Easier to keep treatment secret 8 (32%) Ability to take holiday at same time 6 (24%) Ability to put back more embryos 3 (12%)

### **Negative Aspects of CBRC** Difficulty finding clinic for bloods tests 8 (35%) and scans in own country **Travel difficulties** 8 (35%) Cost higher than expected 8 (35%) Language/communication problems 5 (22%) Lack of regulation 3 (13%) Communication problems between 3 (13%) clinic/agency and clinic where treatment provided Complications with treatment 2 (9%) Counseling 12 offered counseling (9 - clinic's own counselor; 3 arrangement with counselor in home country) 9 accepted counseling: 7 satisfied; 1 not satisfied; 1 no reply. Of 11 not offered counseling, only 3 thought it would have been useful. 1 had no opinion and 7 thought that it would not have been useful. None of the 3 participants who refused counseling thought it would have been useful. Factors To Be Taken into Account 63 (81%) Cost of treatment 61 (78%) Success rates Short waiting times 49 (63%) Positive reports from other patients 47 (60%) Availability of donor eggs/sperm 41 (53%) 39 (50%) Unavailability of services in home country Recommendation from clinic in home country 31 (40%) Implications for child of having treatment in a 14 (18%) country other than home country Ability to have more embryos replaced 10 (13%)

Limitations of Study	
Small numbers + just over a quarter had to be excluded.	
All participants self-selected.	
Since data were self-reported anonymously, it is not possible to guarantee accuracy of information.	
N.B. These problems not unique to this form of data-gathering.	
Conclusions	
Need for accessible/accurate/reliable information	
Providing advance information to patient known to be considering treatment in another country?	
Increased engagement by clinics in home country?	
Using feedback from other patients	
Heavy reliance on Internet/other media for information → make more sophisticated, systematic, effective use.	
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University of HUDDERSFIELD  Thank you  e.d.blyth@hud.ac.uk	
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### CROSS-BORDER REPRODUCTIVE CARE AND COUNSELING PART 2: A SURVEY OF THE EXPERIENCES AND PERSPECTIVES OF COUNSELORS

Jean Haase, M.S.W., R.S.W.
Policy Analyst
Assisted Human Reproduction Canada

#### **LEARNING OBJECTIVES**

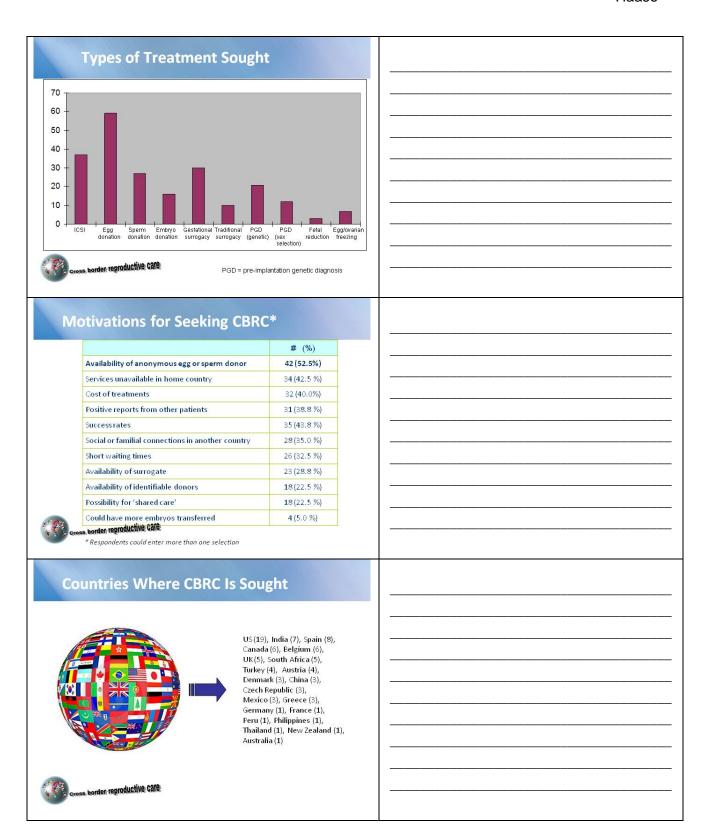
At the conclusion of this presentation, participants should be able to:

- 1. Identify the primary motivations for clients to seek cross-border reproductive care.
- 2. Summarize the role of the counselor in working with clients who access cross-border reproductive care.
- 3. Describe ethical challenges experienced by counselors working with cross-border reproductive care clients.
- 4. Consider ongoing professional learning needs with respect to cross-border reproduction issues.

Part 2: A Survey of the Experiences and Perspectives of Counselors  Jean Haase, M.S.W., R.S.W.  Assisted Human Reproduction Canada	
Learning Objectives	
At the conclusion of this presentation, participants should be able to:  1. Identify the primary motivations for clients to seek cross-border reproductive care.  2. Summarize the role of the counselor in working with clients who access cross-border reproductive care.  3. Describe ethical challenges experienced by counselors working with cross-border reproductive care clients.  4. Consider ongoing professional learning needs with respect to cross-border reproduction issues.	
Disclosure	
This survey was conducted independently and is not linked to any other surveys associated with Assisted Human Reproduction Canada.  The author has nothing to disclose.	
Green border reproductive CATE	

# **Overview of the Survey** Questionnaire 'pre-tested' with counselors from 5 countries. Online survey, 'live' for 6 weeks (February 6 to March 23, 2009) Prospective participants notified of study through International Infertility Counseling Organization (IICO) member organizations • Participation was voluntary, anonymous • 154 surveys collected (only 80 complete) · 20 countries represented order reproductive care **Countries Represented** US 13 Germany 11 UK 11 Australia Canada Others order reproductive care **Professional Disciplines** Psychology 16 (20.0%) Social work Counseling 13 (16.2%) Family/marital therapy 5 (6.4%) 5 (6.4%) RN 4 (5.0%) Other order reproductive care

# **Number of Clients Seeking Cross-Border** Reproductibe Care (CBRC) in Past 5 Years Clients seeking CBRC Clients receiving CBRC Country out of your country in your country 1345 U.S. 312 U.K. 149 81 Germany 221 Australia 62 **1**00 Canada 166 210 323 2979 Other order reproductive care **Clients Who Have Sought CBRC Out of Your Country** 1000 800 600 400 200 order reproductive care **Clients Who Have Received CBRC in Your Country** 2000 1500 1000 500 order reproductive care



# **Countries from Which Clients Have Traveled to Seek CBRC** U.K. (15), Canada (9), India (9), France (9), China (6), Australia (6), U.S.A. (6), Japan (5), Philippines (4), Mexico (3), Germany (3), Denmark (3), Netherlands (3), Norway (3), Ghana (3), Belgium (2), Spain (2), Sweden (2), Switzerland (2), New Zealand (2), Sri Lanka (2), Nigeria (2), Israel (2) Peru (1) ter reproductive care Patterns of CBRC in U.S.A. Israel, Canada, India, South Africa, Russia, Argentina, Latvia, Mexico, Bolivia, Hong Kong, Japan, China, Canada, India, Philippines, Ireland, England, Greece, France, France, Egypt, Italy, Mexico, Costa Rica, England, Lebanon, Africa, Central American, Middle East, Caribbean rder reproductive care **Patterns of CBRC in Canada** U.S.A., Mexico, India, Israel, Belgium, U.S.A., France, Australia, Argentina, Philippines, Cyprus, Czech Republic, China, Peru England order reproductive care

### **Patterns of CBRC in Germany** Saudi Arabia, Spain, Czech Palestine, Russia, Republic, Austria, Sweden, Norway, Denmark, Russia, Netherlands, Russia, Switzerland, U.K., Poland, Belgium, Latvia, U.S.A. Switzerland, Turkey rder reproductive care **Patterns of CBRC in UK** Ghana, Poland, Cyprus, Denmark, Hungary, France, Spain, Czech Republic Zimbabwe, India porder reproductive care **Pre- and Post-treatment Counseling** Pre-treatment Post-treatment counseling counseling I don't I don't know know With you 60 37 26 5 10 1 With you At the other 18 7 28 At the other 10 36 treatment treatment facility facility Elsewhere Elsewhere rder reproductive care

Vith clients seeking CBRC elsewhere			
Counseling about psychosocial implications	50%		
Providing psychological support	36.2%		
Counseling about legal implications	7.5%		
Advocacy in facilitating cross-border care	2.5%	<u> </u>	
Referral to other source (e.g., legal advice, counseling)	2.5%		
Vith clients who have received CBRC			
	47.50/		
Providing psychological support	47.5 %	<del>-</del>	
Counseling about psychosocial implications	35.0 %		
Counseling about legal implications	5.0 %		
Advocacy in facilitating cross-border care	2.5 %		
Referral to other source (e.g., legal advice, counseling)	2.5 %		
been made aware of by the medical facility treatmentparticularly with respect to d number of embryos to transfer." (U.S.A.)  Communication with team  "Trying to educate clinicians about what the to consider the issues for the welfare of the ack of recognition  "If treatment per se was not recommendated."	e implications are and e child." (U.K.)		
reasons, but clinics abroad do not consult v countries." (Germany)			
reasons, but clinics abroad do not consult v countries." (Germany)  see, border reproductive CATE  DSITIVE ASPECTS OF CBF	vith counselor in other		
reasons, but clinics abroad do not consult v countries." (Germany) sea. borden reproductive CATE	vith counselor in other		
reasons, but clinics abroad do not consult v countries." (Germany)  bask borden reproductive CATE  DSITIVE ASPECTS OF CBF  railability of donor eggs, sperm, surrogates	(number) %		
reasons, but clinics abroad do not consult v countries." (Germany)  see, border reproductive CATE  DSITIVE ASPECTS OF CBF	(number) %		
reasons, but clinics abroad do not consult vicountries." (Germany)  border reproductive CAR  District Aspects of CBR  railability of donor eggs, sperm, surrogates ort waiting list	(number) % (55) 68.8% (32) 40.0%		
reasons, but clinics abroad do not consult vicountries." (Germany)  beat border reproductive Care  Distrive Aspects of CBF  realability of donor eggs, sperm, surrogates ort waiting list st gh successrates	(number) % (55) 68.8% (32) 40.0% (30) 37.5%		
reasons, but clinics abroad do not consult vicountries." (Germany)  se border reproductive CARE  Distrive Aspects of CBR  ailability of donor eggs, sperm, surrogates ort waiting list st gh success rates sier to keep treatment secret from others	(number) % (55) 68.8% (32) 40.0% (30) 37.5% (27) 33.8% (22) 27.5%		
reasons, but clinics abroad do not consult vicountries." (Germany)  border reproductive Care  Distrive Aspects of CBF  callability of donor eggs, sperm, surrogates ort waiting list st gh success rates sier to keep treatment secret from others cilities at clinic	(number) % (55) 68.8% (32) 40.0% (30) 37.5% (27) 33.8% (22) 27.5% (20) 25.0%		
reasons, but clinics abroad do not consult vicountries." (Germany)  best border reproductive Care.  Distrive Aspects of CBF  railability of donor eggs, sperm, surrogates ort waiting list st gh success rates sler to keep treatment secret from others cilities at clinic titudes of staff at clinic	(number) % (55) 68.8% (32) 40.0% (30) 37.5% (27) 33.8% (22) 27.5% (20) 25.0% (18) 22.5%		
reasons, but clinics abroad do not consult vicountries." (Germany)  District Aspects of CBF  railability of donor eggs, sperm, surrogates ort waiting list st gh success rates siler to keep treatment secret from others cilities at clinic titudes of staff at clinic onor anonymity	(number) % (55) 68.8% (32) 40.0% (30) 37.5% (27) 33.8% (22) 27.5% (20) 25.0% (18) 22.5% (17) 21.2%		
reasons, but clinics abroad do not consult vicountries." (Germany)  se horder reproductive care.  Distrive Aspects of CBF  ailability of donor eggs, sperm, surrogates ort waiting list st gh success rates sier to keep treatment secret from others clitities at clinic itudes of staff at clinic	(number) % (55) 68.8% (32) 40.0% (30) 37.5% (27) 33.8% (22) 27.5% (20) 25.0% (18) 22.5%		

# **Comments on Positive Aspects** These related to access rather than treatment per se: • "Laws in one state don't allow single women access to fertility treatment." (Australia) • "Different laws in other countries, easier for single women, lesbian couples to seek treatment elsewhere." (Germany) der reproductive care **Negative Aspects of CBRC** Number (%) Travel difficulties 38 (47.5%) Language/communication problems 27 (33.8%) Cost was higher than expected 21 (26.2%) Lack of post-treatment care and follow-up 17 (21.2%) Difficulty in finding a clinic in home country 12 (15.0%) to provide "shared care" Complications with treatment 11 (13.5%) Lack of regulation 10 (12.5%) border reproductive care **Comments on Negative Aspects** 1. Lack of legal protection · "No complaint channel...what if things go wrong... what's their legal protection?" (Canada) · "Fear of doing illegal action" (Germany) 2. Isolation and lack of support · 'Away from family' (Australia) · 'No counseling before, during or after treatment-made them feel even more isolated' (U.S.A.) 3. Consent issues "Given treatment without consent, e.g., using sperm donor" (U.K.) • "More embryos put back than requested" (U.K.)

Have You Ever Felt Your Professional	
Ethics and Values Were Challenged?	
Yes 53.6% No 46.4%	
163 551070	
4 14 16 14 16 14 16 14 16 14 16 14	
1. Welfare of child/identity issues	
<ul> <li>"NO ONE is thinking about the welfare of these children." (U.K.)</li> <li>"Protection of children born from ART, especially in relation to</li> </ul>	
donor gametes and anonymity" (Australia)	
2. Donor anonymity	
<ul> <li>"Strong belief that all children have a right to identifiable donors"</li> </ul>	
<ul><li>(New Zealand)</li><li>"I do not agree with anonymous donation, especially when</li></ul>	
potential parents are not intending to share information with	
children." (U.S.A.)	
Gross, border, reproductive, Care	
Have You Ever Felt Your Professional	
Ethics and Values Were Challenged?	
3. Secrecy	
"Staying here for a year to be able to claim a surrogacy pregnancy     """	
as their own when they return home" (U.S.A.)  • "Secrecy was the prime motivator in seeking care in this country	
and I advocate disclosure when using donor gametes."(U.S.A.)	
4. Age of patients	
<ul> <li>"Age of intended patients being over 51" (Canada)</li> </ul>	
<ul> <li>"Recipient couples in 50s and 60s" (Canada)</li> </ul>	<del></del>
Austin A210	
Gross border reproductive Care	
Have You Ever Felt Your Professional	
Ethics and Values Were Challenged?	
5. Coercion of donors/surrogates	
"Felt some women in third world countries were being	
exploited" (Canada)	
Control of the Contro	
6. Disclosure	
<ul> <li>"Cannot stand it when clients do not support honesty</li> </ul>	
and openness when donating and receiving gametes"	
(Canada)	
Care	
Gress, border, reproductive, Care	

Have You Ever Felt Your Professional	
Ethics and Values Were Challenged?	
7. Health and safety standards  • "Compared to regulated National Health Service (NHS) clinics where there are set protocols and procedures, felt there was a missing link in level of care" (U.K.)  • "When multiple embryos are implanted with resulting multiple pregnancy, which is then reduced" (Australia)  8. Sex selection  • "Client willing to go anywhere and do anything to have access to this service." (Australia)  • "Sex selection requests based on cultural belief systems" (U.S.A.)	
Gross, border reproductive care	
Cross-Cultural Challenges	
<ul> <li>"Legal and ethical aspects are difficult to know from other countries."</li> </ul>	
<ul> <li>"Difficulty conducting counseling with language barriers and interpreters. Tight time restraints due to pre- arranged travel and treatment dates."</li> </ul>	
<ul> <li>"Country/clinic values and laws and those of other country may clash, especially regarding donor conception."</li> </ul>	
Gross, border reproductive care	
Ethical Conflicts for Counselors	
<ul> <li>"I don't know whether it is right or not to have a baby by reproductive treatment involving a third party." (Japan)</li> </ul>	
<ul> <li>"Treatment with both donated eggs and sperm is against my professional ethics and values." (Finland)</li> </ul>	
<ul> <li>'My personal ethical attitude was clear, but my professional standards of being neutral were challenging." (Germany)</li> </ul>	
Gross, border, reproductive care:	

# **Ethical Conflicts for Counselors** · Counselors seem divided on the issue of ethical challenges and CBRC. · Are they more like to feel conflicted about crossborder reproductive care if they live and work in countries where there are laws and regulations about the provision of fertility treatment? · How might this affect their clinical practice? border reproductive care Do You Feel You Have Adequate Yes 58.0% No 42.0% **Knowledge of CBRC?** • "Difficult to be aware of all the different state or national legislation and cultural issues that may be relevant to the patients' decisions." • "Language barriers and lack of good interpreter services can be a challenge and a hindrance." • "I think it would be a very good idea for IICO to present the global views of counseling regulations/practice in different countries, as well as regulations on donor anonymity and payment on third party reproduction." border reproductive care **Limitations of Study** · Survey only available in English • Overall study provides a 'snapshot' of CBRC • Number of countries participating likely only a fraction of overall number involved in CBRC • Small numbers (many excluded questionnaires) · Participants were self-selected • Self-reported data cannot be verified for accuracy, and are subject to personal bias · Study partly relied upon participants' recall of involvement with CBRC clients order reproductive care

#### Conclusions

- Study sheds some light on the overall experiences and perceptions of counselors about CBRC.
- Implications counseling and provision of support are central to counseling role.
- CBRC is creating new ethical issues for counselors.
- There is a need for education, information, CBRC counseling standards, and communication and collaboration between counselors at an international level.
- The need for further research—both quantitative and qualitative—is evident.



# **Acknowledgements**

Samantha Yee Petra Thorn Joi Ellis Janet Takefman Sheila Pike AHRC

IICO member organizations
All those who completed the survey



## Haase

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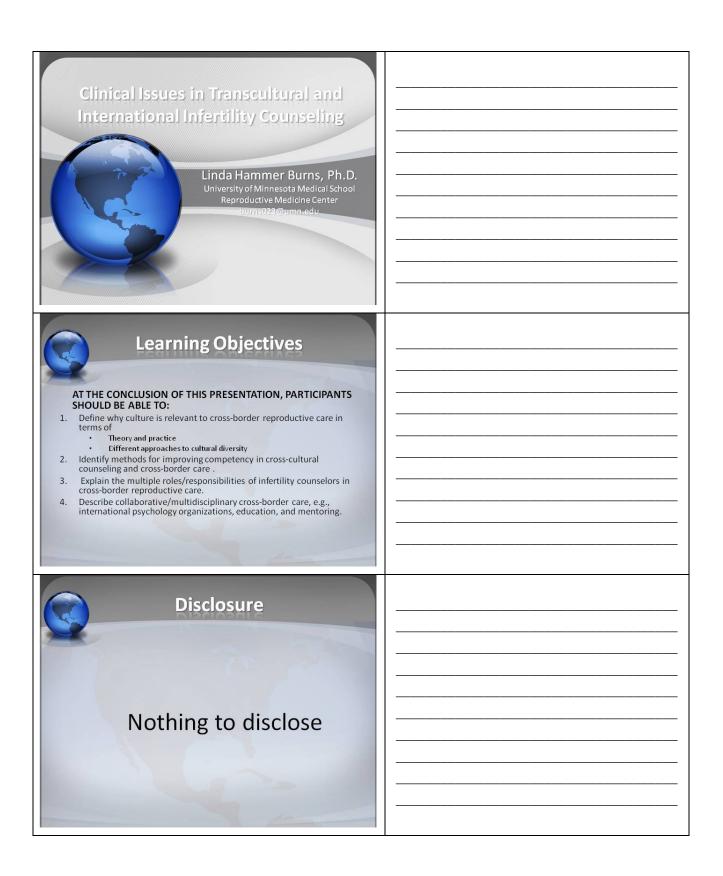
# CLINICAL ISSUES IN TRANSCULTURAL AND INTERNATIONAL INFERTILITY COUNSELING

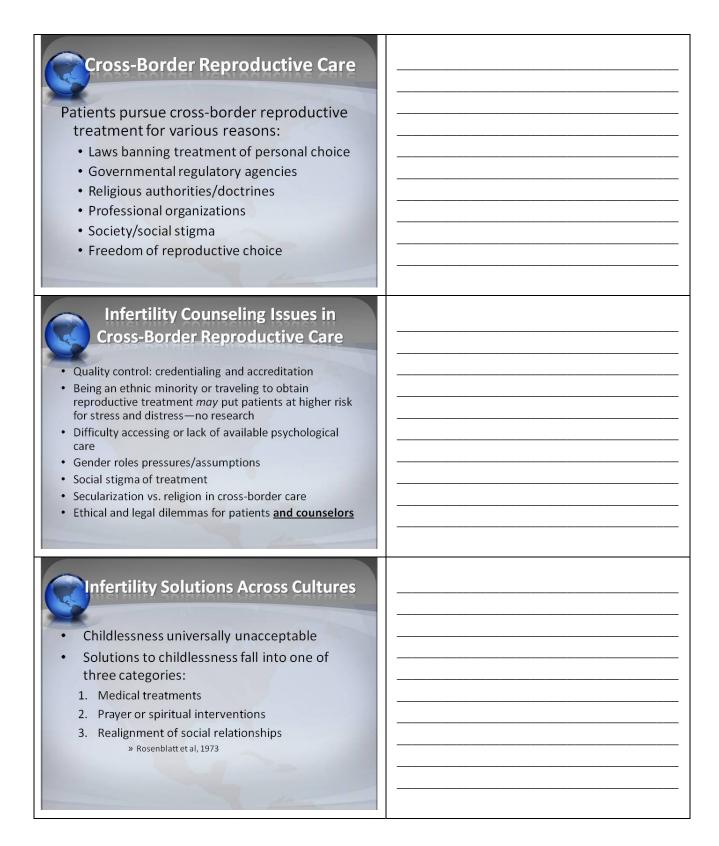
Linda Hammer Burns, Ph.D. University of Minnesota Medical School

#### **LEARNING OBJECTIVES**

At the conclusion of this presentation, participants should be able to:

- 1. Define why culture is relevant to cross-border reproductive care in terms of theory and practice, different approaches to cultural diversity, and impact on families and children.
- 2. Identify methods for improving competency in cross-cultural counseling and cross-border care.
- 3. Explain the multiple roles/responsibilities of infertility counselors in cross-border reproductive care.
- 4. Describe collaborative/multidisciplinary cross-border care, e.g., international psychology organizations, education, and mentoring.





Infortility Solutions Assocs Cultures	
Infertility Solutions Across Cultures	
Realignment of social relationships least	
acceptable solution	
• Divorce	
Polygamy/extramarital relationships	
Traditional adoption/fostering	
Prenatal adoption (i.e., gamete donation)	
Changes the social structure of the community	
World Religions	
NAUTH DENKIND	
Christianity: 2.1 billion     Chinese traditional religion:  394 million 394 million	
- Roman Catholicism: .1 billion 394 million - Protestantism: 50 million • Buddhism: 376 million	
Eastern Orthodoxy: 240 million     Mahayana: 185 million     Anglican: 84 million     Theravada: 124 million	
Oriental Orthodoxy, Assyrians,     Primal indigenous 300 million:	
and other Christians: 350 million     Islam: 1.3 billion     African traditional/	
- Sunnism: 940 million diasporic: 100 million;	
- Shi'ism: 170 million • Spiritism: 15 million • Secular/Irreligious/Agnostic/ • Sikhism: 23 million	
Secular/Irreligious/Agnostic/     Atheist:1.1 billion     Judaism: 14 million	
Hinduism: 900 million	
http://www.cia.gov/cia/publications/fa ctbook/geos/xx.html. 8.20.2005	
Infertility Solutions Across Cultures	
micrality solutions Across cultures	
Prayer, spiritual ceremonies, pilgrimages	
<ul><li>Source of comfort</li></ul>	
<ul><li>– Powerful intervention</li></ul>	
Also a stressor if religious doctrine opposes	
specific medical family-building treatment	
• Patients often practice both: prayer, herbal	
therapies, sy <mark>mbol</mark> s, ceremonies and ARTs—	
but may not tell caregiver	
	1

Infertility Solutions Across Cultures  Medical treatments  ART: altering interpersonal relationships, redefining meaning of "family," "kinship"  ART: provides the appearance that meanings and definitions remain unchanged  No medical solution universally acceptable across all cultures	
Infertility Solutions Across Cultures  Medical treatments  Today the most acceptable solution  Offer a variety of family-building alternatives  Treatments (and choices) come at a price:  Emotionally  Financially  Socially	
Infertility Solutions Across Cultures  • Infertility counselor's responsibility is to take into account not only culture, language, and tradition but also acceptable solutions to infertility to patients/intended parents.	



## **Ethnic Diversity Is a Reality**

Acquiring skills in multicultural counseling is critical for infertility counselors because:

- ➤ Most countries are ethnically heterogeneous, not homogeneous
  - · Differences in religion, customs, language
- Reproductive tourism is common (Fathalla, 2005)
- ➤ Immigration/emigration is widespread globally



## What Is Culture?

- Socially shared and transmitted:
  - · Beliefs and values
  - Norms and practices
  - Social institutions (APA, 2002)
- Ethnicity is a type of culture
  - Shared values and customs based on shared ancestry (Hays, 2008)

APA = American Psychological Association

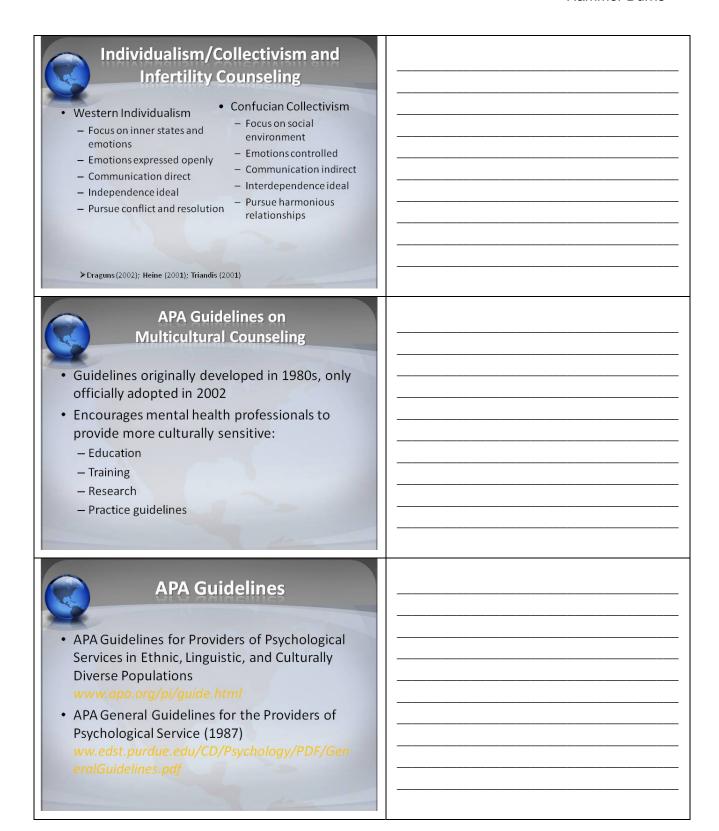


# How Culture Influences Beliefs and Behaviors

- Tend to see their own worldviews as natural and obviously true (Kim & Berry, 1993)
- Tend to see members of their own groups as varying, but other groups as all the same (Taylor, 1981)
- We make assumptions about others, even when we do not intend to (Hays, 2008)

A Cross-Cultural Model of Diversity  • Dimensions of difference (Hofstede, 1983)  — Individualism versus collectivism  — Power distance  — Masculinity versus femininity  — Uncertainty avoidance	
<ul> <li>Approaches to Cultural Diversity</li> <li>Emic approaches to culture         <ul> <li>Every culture is unique and has a unique psychology</li> <li>Etic approaches to culture</li> <li>Cultures hold different positions on universal psychological dimensions</li> </ul> </li> </ul>	
<ul> <li>Emic Ways of Thinking about Culture</li> <li>"Cultural psychology"</li> <li>Need to learn the norms and beliefs that are indigenous to each culture</li> <li>Concepts, treatments, measures developed in one culture do not transfer to others</li> <li>Multicultural Counseling Competencies is an emic model to diversity         ➤ Hynie and Burns, 2006     </li> </ul>	

## **Multicultural Counseling** Competencies Own cultural Client's Culturally values & worldview appropriate interventions biases Attitudes & beliefs Knowledge Skills >Arredondo et al., 1996; Sue et al., 1992 **Etic Ways of Thinking about Culture** Cross-cultural psychology · Need to learn how each culture solves similar problems · Concepts, treatments, measures developed in one culture may be modified for others • It is possible to compare cultures on a wide variety of factors: significant lack of comparison in cross-border reproductive care (CBRC) **Individualism and Collectivism** Individualism Collectivism - Highest in U.S.A., Canada, - Highest in India, China U.K., Australia, Northern - In-group goals ahead of Europe - Individual goals ahead of - Emphasize well-being of group, fulfillment of those of group social roles and - Emphasize personal goals, obligations fulfillment and control ➤ Markus & Kitayama (1998); Matsumoto et al., (1998)





## **Enhancing Cultural Awareness**

- Cultural Factors in Psychiatric Syndromes
   <u>www.mhsource.com/edu/psytimes/p950114.h</u>
   tml
- AMA Cultural Competence Compendium www.ama-assn.org/pub/category/4848.html

## **Multicultural Counseling Relationship**

- Awareness of how the counselor's cultural and racial attitudes impact counselor-client interactions
- Counselor typically a representative of the dominant group, which may impact therapeutic relationship
- Counselor's openness/warmth can be a critical factor in client's adjustment/overall reaction to counseling process

➤ Hynie and Burns, 2006



## How To Be a More Culturally Competent Counselor

- Understand racism/cultural difference and its impact on mental health.
- Understand stresses related to minority status, acculturation, low socioeconomic status (SES) and impact on mental health.
- Recognize how cultural differences may impede rapport/therapeutic alliance.
- Question/adapt psychology's concept of 'normal' behavior.



## Infertility-Specific Multicultural Questions:

- Do you discuss the fertility problem with others in your social circle?
  - Whom? Why?
- Do you feel pressure from relatives?
  - From whom? Your family or your spouse?
- In male sterility, is it accepted by your partner and/or his family?

➤ Gacinski, Yuksel, & Kentenich, 2002



# Infertility-Specific Multicultural Questions:

- Are there alternatives to a biologically-linked child for you?
  - Which are acceptable and why?
- Have you visited a doctor or caregiver in your home country?
  - Why seek treatment there/here?
- Have you considered treatments customary to your culture (e.g., herbs, ceremonies)?
  - Does your current caregiver know?
     ➤ Gacinski, Yuksel, & Kentenich, 2002



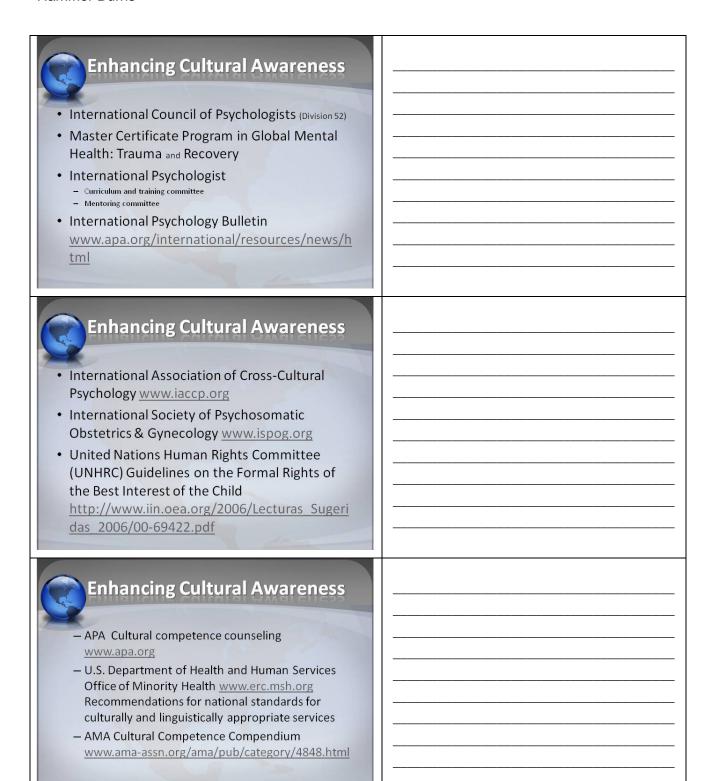
### **Practicing with Cultural Diversity**

- Communication
  - Employ professional translators—know how to use
  - Confirm and respect clients' goals
  - Be sensitive to differences in body language/clothing
- Ask about, and respect, other therapies and beliefs, including spiritual beliefs
  - About children, families, medicine, therapy, herbs
  - Consult with professionals from the relevant culture
- Recognize that counseling across cultures can be uncomfortable

## **Enhancing Cultural Awareness** Individuals vary greatly within cultures. •Cultures differ, even within the same region. •There is a gap between multicultural counseling theory and evidence-based practice. Worthington et al., 2007 **Cross-Border Reproductive** Counseling ven greater gap between cross-cultural counseling in cross-border infertility counseling · Complicated by multiple responsibilities and loyalties: - Lack of universal standards of practice Own culture/values and patients' culture/values - Profession-specific ethics/treatment goals - Legal/licensure requirements and patients' legal issues - Practice setting **Infertility Counselor Challenges in Cross-Border Care** Multiple responsibilities, roles, and loyalties too many? How to prioritize? • Lack of universal standards of practice in CBRC—medically and psychologically Infertility counselor's personal culture/values vs. patients' culture/values—at odds? • Profession-specific ethics/treatment goals

## **Infertility Counselor Challenges in Cross-Border Care** Infertility counselors' legal/licensure requirements vs. patients' legal issues · Practice setting: care-oriented medical clinic/private practice vs. profit-driven agency, clinic, private practice · Boundaries: personal, professional, legal vs. patients' willingness to cross personal boundaries to 'get treatment they want' What To Do as Infertility Counselor in Cross-Border Care · Become more culturally competent and aware. · Collaborate with other infertility counselors/ caregivers. KNOW WHAT THE GUIDELINES ARE AND FOLLOW THEM—ignorance is never a defense. • Do not be afraid to refer care of a patient to another professional or recommend treatment denial to care Help your clinic/practice become more culturally aware. **Enhancing Cultural Awareness** · Deaf/hearing impaired http://www.rid.org/UserFiles/File/pdfs/Stand ard Practice Papers/Mental Health SPP.pdf APA Guidelines for Providers of Psychological Services to Ethnic, Linguistic, and Culturally **Diverse Populations**

http://www.apa.org/pi/oema/guide.html





## **Guidelines on Multiple Roles**

- The Registry of Interpreters for the Deaf has a standard of practice paper on multiple roles <a href="http://www.rid.org/UserFiles/File/pdfs/Standard Practice Papers/Drafts June 2006/Multiple Roles SPP.pdf">http://www.rid.org/UserFiles/File/pdfs/Standard Practice Papers/Drafts June 2006/Multiple Roles SPP.pdf</a>
- Multiple roles has never been addressed in infertility counseling and/or cross border reproductive care.



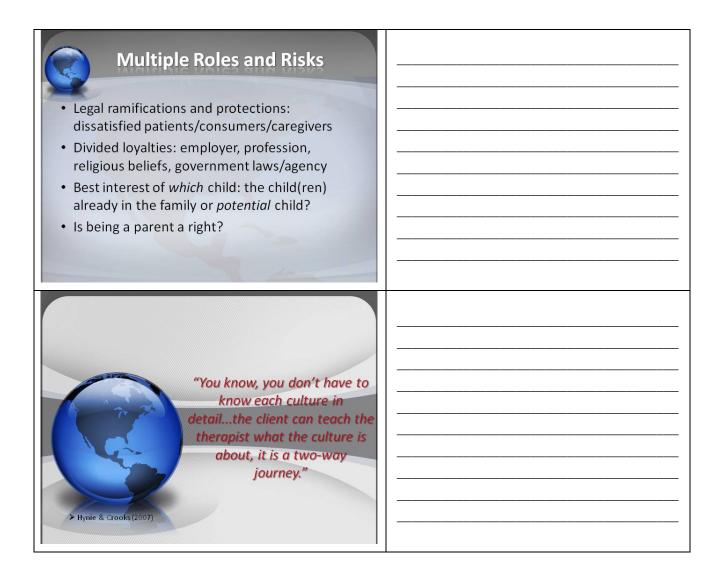
## **Multiple Roles and Risks**

- United Nations Human Rights Committee (UNHRC) Guidelines on the Formal Rights of the Best Interest of the Child <a href="http://www.iin.oea.org/2006/Lecturas Sugeri">http://www.iin.oea.org/2006/Lecturas Sugeri</a> das 2006/00-69422.pdf
- Best interest of which child: the child(ren) already in the family or potential child(ren)?
- · www.asrm.org



### **Multiple Roles and Risks**

- · Caregiver vs. gatekeeper
- · Consumer vs. professional caregiver
- Consumer advocate vs. professional caregiver
- Personal culture, laws, regulations, limitations vs. professional responsibility as caregiver/service provider
- Providing care where caregiver is licensed vs.
   where patient is treated



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### **NOTES**

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## EXPLOITATION: WHAT IS ITS ROLE IN CROSS-BORDER REPRODUCTIVE CARE?

Eric Blyth, Ph.D.
Professor, School of Human and Health Sciences
University of Huddersfield, U.K.

#### LEARNING OBJECTIVES

At the conclusion of the presentation, participants should be able to:

- 1. Identify potential sources of exploitation in cross-border reproductive care for patients/donors/surrogates/children.
- 2. Describe potential consequences of exploitation in cross-border reproductive care for patients/donors/surrogates/children.
- 3. Discuss potential demands on services in home country resulting from cross-border reproductive care.
- 4. Review clinical practice issues for counselors.



# Exploitation: What Is Its Role in Cross-Border Reproductive Care?

Eric Blyth, Ph.D.
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- 4. Review clinical practice issues for counselors.

#### **Disclosure**

The author has no commercial and/or financial relationships with manufacturers of pharmaceuticals, laboratory supplies and/or medical devices.

Exploitation and Cross-Border Reproductive Care (CBRC) 1	
No evidence apart from anecdotes/reports by investigative journalists $\rightarrow$ extent of problems unknown	
Nature of phenomenon $\rightarrow$ difficult to investigate ethically or systematically	
Reasons for seeking CBRC, sources of information about services (+ lack of protection in some destination countries) highlight scope of exploitation of patients, donors/surrogates and children – and additional demands on home health services	
Exploitation and CBRC 2	
Evidence of poor quality—possibly exploitative— treatment in home country and positive patient reports of CBRC	
The quality of care received in the clinic that I went to far surpassed what I received in the U.K., which was like being on a conveyer belt. The added bonus of being less expensive and no waiting times adds to the incentive. It is a real shame that U.K. residents receive a better service from other countries than they do in the U.K. (patient: IN UK, 2008)	
Major Reasons for Seeking CBRC	
1. Availability of donor eggs/sperm 2. Success rates 3. Short waiting times 4. Cost of treatment 5. Unavailability of services in home country 6. Temporary/permanent residence in another country 7. Privacy 8. Ability to take holiday at same time	

## Sources of Information about CBRC Internet 61(64%) 20 (21%) Patient support group Media sources other than Internet 19 (20%) **Another patient** 14 (15%) Clinic treating individual in home country 13 (14%) Friend or family member 4 (4%) NB since approximately 3/4 make their own arrangements, they are largely "on their own." (Blyth, 2008) Main Services Sought in CBRC **Egg donation Embryo donation** ICSI IUI **IVF** Sperm donation Surrogacy **Tubal surgery** (Blyth, 2008: IN UK, 2008) **Destination Countries** 2 patient/potential patient surveys conducted in 2008 alone revealed 29 destination countries (Blyth, 2008; IN UK, 2008) Argentina, Australia, Austria, Bangladesh, Barbados, Belgium, Canada, China, Cyprus, Czech Republic, Denmark, Egypt, France, Greece, Iceland, India, Israel, Italy, Mexico, Netherlands, Norway, Russia, South Africa, Spain, Thailand, Turkey, Ukraine, United Kingdom, U.S.A. + General regions in Africa, Asia, Eastern Europe and South America (without specifying a country)

Dicks for Potionts 4	
Risks for Patients 1	
We felt trapped and used by a very unethical team of otherwise highly respected doctors. We were given false hopes, wrong success rates, the quality of the work done was very low (much lower than what we had previously experienced at home), the price skyrocketed contrary to initial arrangements etc., etc., etc Somebody should stop these ruthless people. (Patient: Blyth, 2008)	
Risks for Patients 2	
latrogenic consequences of such things as multiple embryo replacement, ovarian stimulation, incompetent/experimental/unsafe treatment  Financial exploitation [NB 8 (35%) patients with experience of CBRC claimed actual cost was higher than expected] (Blyth, 2008)	
Risks for Donors/Surrogates 1	
I don't blame the donors in the slightest if they do it for the money: this enables them to pay for a roof over their heads and feed their own children. It's a hard world, but they have something I needed for my family life (eggs), and I had something (money) that they needed for their own family life. (patient: IN UK, 2008)	
Financial exploitation/inducement; donation/ surrogacy seen as solution to poverty for women	

Risks for Donors/Surrogates 2	
latrogenic consequences of such things as ovarian stimulation, incompetent/experimental/unsafe treatment	
Adequate aftercare?	
Donors/surrogates sufficiently well-educated to understand risks and provide informed consent?	
Conflict of interest if service providers responsible for providing care for donor/surrogate also stand to gain commercially from service.	
Risks for Children 1	
Commodification in respect to: commercial donation/surrogacy; gender selection	
latrogenic consequences of such things as multiple embryo replacement, incompetent/experimental treatment	
Legal status issues – especially in relation to citizenship; donor/ surrogate/intended parents	
Access to information about donor/other genetic relatives	
Risks for Children 2	
Female child was born in India in July 2008 following a surrogacy arrangement between a Japanese couple, an Indian egg donor and an Indian surrogate. However, the Japanese couple divorced one month before her birth. The commissioning mother no longer wanted her; neither did her birth mother or the egg donor. Her genetic/commissioning father, who wanted to keep her, was not allowed to take her out of the country because of Indian law banning single men from adopting girls and because the authorities refused to issue her with a birth certificate. The child's paternal grandmother was eventually permitted to take her to Japan.	

Demands on Health Services in Home Country	
McKelvey et al. (in press) - Demands placed on U.K.'s National Health Service following multiple births resulting from transfer of higher number of embryos in other countries than is permitted in U.K.	
Other potential demands not currently identified/ evaluated.	
Issues for Counselors  Counselors' ethical practice should help to	
insulate against exploitation  Problems associated with lack of access to counseling reported by approx ½ of CBRC participants and perceptions of its lack of relevance with ¾ of CBRC participants not offered counseling	
Need for counselors to demonstrate relevance/benefits to patients/service providers	
Responsibilities of counselor who has conscientious objection to service(s) sought?	
University of HUDDERSFIELD  Thank you	
e.d.blyth@hud.ac.uk	

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## **NOTES**

#### **Course #2 Test Questions**

- 1. Which one of the following is a key challenge to safety in cross-border reproductive care?
  - a. Patients may not know the identity of foreign donors.
  - b. Patients may not know how to access accurate information to make informed choices about their care.
  - c. Patients may not know the legal status of their offspring in their home country.
  - d. Lengthy travel time to point-of-care may make care more difficult.
  - e. There may be extra costs that only become apparent when the patient arrives at the foreign clinic.
- 2. Which one of the following statements most accurately reflects the primary perspective of Inhorn and Patrizio regarding cross-border reproductive care (CBRC)?
  - a. CBRC is a form of civil disobedience.
  - b. CBRC is morally and ethically repugnant.
  - c. CBRC involves exploitation of the poor by the affluent.
  - d. CBRC is a form of reproductive exile.
  - e. CBRC is a form of reproductive autonomy.
- 3. In the study 'A Survey of the Experiences and Perceptions of Counselors,' which one of the following did counselors perceive to be their primary role with clients who sought fertility treatment outside of their own country?
  - a. Providing psychological support
  - b. Counseling about legal implications
  - c. Referral to other source (e.g., legal advice, counseling)
  - d. Advocacy in facilitating cross-border care
  - e. Counseling about psychosocial implications
- 4. Which one of the following is the most common reason that patients give for undertaking or considering cross-border reproductive care?
  - a. They are prohibited from using services in their own country.
  - b. The treatment is cheaper.
  - c. The waiting times are shorter.
  - d. They can take a vacation at the same time.
  - e. There is greater availability of donor gametes.

(continued)

- 5. An American couple whose medical provider suggests that gestational carrier is their best treatment option have decided to use a gestational carrier in India after seeing a program on I and doing their 'homework' on the Internet. Although they have not discussed this with their medical doctor, they are seeking counseling with you on how to implement their reproductive plan. Which one of the following describes your counseling goals/responsibilities?
  - a. Provide psychosocial support to third-party collaborators.
  - b. Accompany intended parents to India to facilitate treatment and provide support during the pregnancy for them.
  - c. Ensure the couple is financially prepared for this family-building method.
  - d. Ascertain whether this is an option the medical clinic approves and proceed with your treatment plan on that basis (i.e., if clinic not involved, you should not be either).
  - e. Follow professional guidelines, standards of practice, and regulations with an awareness of multicultural perspectives of all parties involved in the reproductive plan.
- 6. Mr. and Mrs. A. are considering seeking fertility treatment in another country. Which one of the following information sources will they most likely use to make their decision?
  - a. Clinic in their home country
  - b. Patient support group
  - c. Internet
  - d. Media sources other than the Internet
  - e. Another patient