PRE-CONGRESS COURSE 7

SIG Psychology & Counselling
The International Infertility Counsellors Organisation

"Psycho-social counselling in fertility treatment"

CONTENTS

PRE-CONGRESS COURSE 7 - PROGRAMME

SIG Psychology & Counselling
The International Infertility Counsellors Organisation

Psycho-social counseling in fertility treatment

Course co-ordinators: P. Baetens (B) and L. Hammer Burns (USA)

Course co-description: Many countries recognise (and in some cases legislate) infertility counselling. A growing need exists for a basic course counselling in the field of reproductive medicine. This pre-congress will be focused, therefore, entirely on the practice of counselling itself. What issues should be addressed during counselling? How should counsellors guide well-informed decision making?

Target audience: Counsellors involved in psychosocial guidance of couples having fertility treatments

Programme

09.00 - 09.30:	Initial counselling: processing information to patients and helping them to make well-informed decisions. -***J. Bitzer (CH)***
09.30 - 09.45:	*Discussion*
09.45 - 10.15:	Supportive counselling during treatment –***D. Greenfeld (USA)***
10.15 - 10.30:	*Discussion*
10.30 - 11.00:	***Coffee break***
11.00 - 11.30:	Counselling after successful treatment -***J. Darwich (CH)***
11.30 - 11.45:	*Discussion*
11.45 - 12.15:	Counselling after miscarriage, termination of pregnancy and issues in ending treatment -***U. Van den Broeck (B)***
12.15 - 12.30:	*Discussion*
12.30 - 13.30:	***Lunch***
13.30 - 14.00:	Specific counselling: issues to be addressed in donor insemination – ***P. Thorn (D)***
14.00 - 14.15:	*Discussion*
14.15 - 14.45:	Specific counselling: issues to be addressed in oocyte donation -***D. Guerra (E)***
14.45 - 15.00:	*Discussion*
15.00 - 15.30:	***Coffee break***
15.30 - 16.00:	Counselling lesbian couples -***A. Brewaeys (NL)***
16.00 - 16.15:	*Discussion*
16.15 - 16.45:	Intercultural counselling: addressing cultural differences -***M. Hynie (CND)***
16.45 - 17.00:	*Discussion*

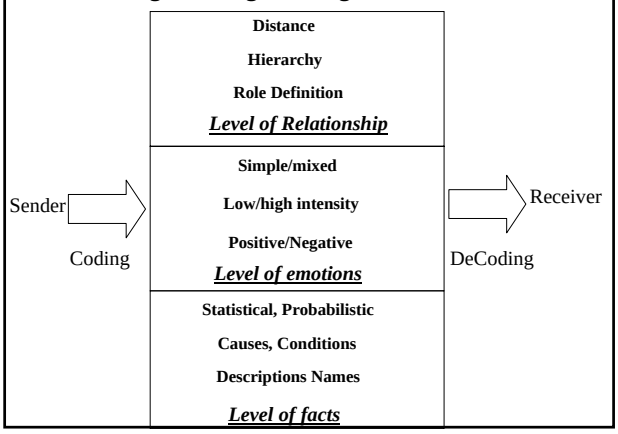
Initial Counseling: Processing information to patients and helping them to make well-informed decisions

Prof. J. Bitzer
UFK Basel

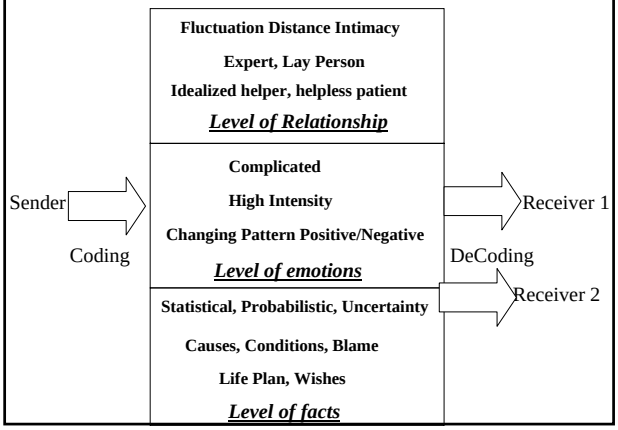
Objectives of Information Processing to patients

- Help patients to clarify their problems and/or their aims
  - Dialogue, Feed back, Verbalisation
- Empower patients
  - Increase knowledge about the problem
  - Help patients to cope with the information
- Help patients to come to a decision according to their interests and values
  - Anticipation, Benefits, Risks
- Help patients to solve a problem
  - Methods and techniques

Sending a message; Giving an information



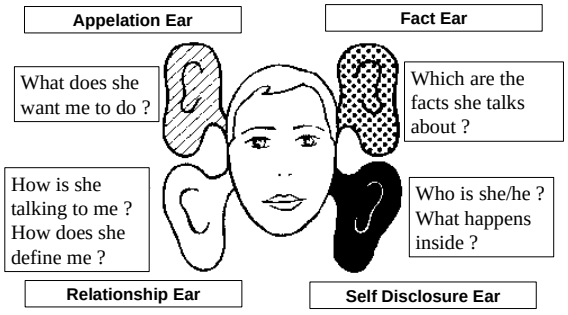
Special conditions of infertility counselling



The diagnostic phase
Information processing for patients

- Basics for professional listening and professional information exchange
- Information about diagnostic tests
  - Sperm Count, Postcoital Test
  - Ultrasound
  - Hormonal assays
  - Laparoscopy
- Information about diagnostic outcomes
  - No new information
  - Uncertainty
  - Bad news

Professional listening



Professional Information Giving (Exchange)

Assess the individual need for information: What and how much does the patient want to know ?

Structurizing: Structurize information, give importance and summarize

Announcing: Announce important messages. „ Now I want to tell you something very important, which I want you to understand ?“

Give small information units: Short sentences with repetitions if necessary.

Allow questions and check back: Encourage questions from the beginning and check back what has been understood by the patient.

Refer to patients‘ experiences and life: Use images and examples

Adress different sensory canals: Visualize what you have said. Write down in the presence of the patient. Give material

Information exchange

- Elicit the patient´s needs for information, her expectations and her pre-existing knowledge about the subject he/she would like to talk about.
- Provide a defined quantity of information. It is important that the information is given in small units, well structured, that important parts are announced and the patient is encouraged to interrupt this phase by direct questioning.
- Elicit the patient´s understanding and interpretation of the information by asking about the quantity, the speed, the clarity and the undertandability of the information given. In some situations it is equally important to ask the patient about the emotional meaning she gives to the information. “What does this information mean to you? Is it reassuring or worrying ? Are there new questions coming up?“

The diagnostic phase

- Information about diagnostic procedures
  - Sperm Count, Postcoital Test
  - Ultrasound of ovarian function
  - Hormone Samples

Problems

Idealization or devalorisation of the therapeut

Level of Relationship

Threat to intimacy, sexual life

Fear of getting hurt

Feeling devaluated , Body image impact

Level of emotions

Not understanding the language

No shared communication about genital organs and sexuality

Level of facts

The diagnostic phase

- Information about diagnostic procedures
  - Sperm Count, Postcoital Test
  - Ultrasound of ovarian function
  - Hormone Samples

Solutions

Address possible helper, couple relationship problems like intrusion, loss of distance etc

Level of Relationship

Adressing actively the issues of threat to intimacy, feelings of shame, insecurity, anxiety

Anticipating emotional reactions to outcomes, possible impact on body image etc.

Level of emotions

Finding a common language for genital organs and sexual activity

Helping to understand the meaning of the results in terms of probablities

Level of facts

The diagnostic phase

- Information about diagnostic results
  - No news
  - Uncertainty

Problems

Ambivalence, Mistrust

Level of Relationship

Insecurity, Frustration, Anger

Level of emotions

Misunderstanding the results

Positive or negative cognitive distortion

Level of facts

The diagnostic phase

- Information about diagnostic results
  - No news
  - Uncertainty

Solutions

Addressing actively the possiblity of mistrust and doubt

Reestablishing the relationship

Level of Relationship

Adressing actively the issues of uncertainty and possible disappointment

Sharing feelings about frustration and hope

Level of emotions

Finding a common language for the results. Using metaphors and pictures

Helping to understand the meaning of the results in terms of probablities Elicit, Provide, Elicit

Level of facts

The diagnostic phase

- Information about diagnostic results
  - Bad news

Problems

Change of the relationship from the positive idealized helper to the looser, the incompetent person

Level of Relationship

Frustration, Anger, Depression, Hopelessness, Envy, Aggression

Level of emotions

Not understanding, Denying, Distortion,

Level of facts

What are bad news ?

- „… results in a cognitive, behavioral or emotional deficit in the person receiving the news that persist for some time after the news is received“

Ptacek&Eberhard (1996), JAMA 14;276(6):496-502

What makes breaking bad news so difficult

- Concern how it will affect patient and family
- Need to individualize the manner of breaking bad news based on patient‘s needs and desires
- Unpleasant task, risk of change in physician-patient relationship
- Setting not ideal
- Physician uncertainty and discomfort, lack of communication skills
- Negative previous experience

Goals of breaking bad news

- to warrant that the patient receives the relevant information
- Assure that patient understands the information
- Provide opportunity to talk about the personal meaning of the information with the physician
- Understanding emotional reaction
- Enable processing to the information and prevent from additionally traumatizing the patient

Green et al., Health Technol Assess. 2004 Aug;8(33)

Steps in breaking bad news

1. Prepare setting
   - ASAP, but no bad news on answering machine
   - Sufficient time (30 min., privacy, no interruptions)
   - Who will participate?
2. Entrance to subject: „how do you see your situation after…“ „what went through your mind coming here“
3. Warning shot: „I am very sorry that I do not have good news for you“
4. Deliver news in simple, clear, understandable way with adequate speed

Baile et al. Oncologist, 2000; 5
Girgis&Sanson-Fisher, J Clin Oncol, 1995; 13
SCOPE, Dep. Of Health, 2003; 8
Rabow&McPhee, West J Med, 1999; 171

Steps in breaking bad news

5. pause and await reaction
6. handle emotions: NURS
   - Name: perceive and name the emotion
   - Understand: express understanding
   - Respect: express acceptance and respect for patient reaction
   - Support: provide support
7. Structure and discuss next steps
   - Enhance sense of control
   - Limit amount of information! Emotional activation hinders cognitive processing of information

Steps in breaking bad news

8. Assess understanding
9. Provide hope
10. Give time frame for next steps
    - If possible within 48 hours and inform about availability
11. Ask patient whom she wants to inform and offer help
12. Ask patient how she is going to get home

Relevant questions

- What preoccupies you most at the moment ?
- What was your concern before – after the diagnosis ?
- Can you briefly explain me what you have heard so far ?

Don‘ts

- Physicians often have tendency to talk without respite
- Falling silent is being interpreted as an invitation to talk against desperation
- Emotional reactions of the patient are being suppressed with therapies
- Conciliate: „Look, you already have a child!“
- Hide behind professional jargon
- Ambiguous statements: „As physicians we are not God“

Do‘s

- Pain can not be removed but has to be accepted as reality and be tolerated with the patient
- Express solicitousness openly
- Include partner if possible
- Encourage self-determination and involvement in decision making process
- Permit silence, respect required time
- Accept duration and form of bereavement and interindividual differences
- Know about risk factors for and presence of pathological/complicated bereavement

The therapeutic phase

- Information and decision making
  - Effective decisions versus Preference sensitive decisions
- Information about therapeutic options
  - Single option
  - Multiple options
- Information as help for therapeutic decision making.
  - Possible Bias
  - Shared decision making

Decision making Counselling

- Effective decisions
  - High level of evidence
  - Benefit outweighs by large risks or possible harm
  - In general all practictioners would make this decision
- Ex: Aspirin and Lipid lowering drugs after MY

- Preference sensitive decisions
  - Low or medium evidence and/or
  - Benefit does not clearly outweigh risk
  - Patients values and preferences contribute to the weighting of benefit and risk
- Ex.: Prenatal counselling, Menopause, Oncology

The therapeutic phase

- Information about therapeutic options
  - Single option
  - Multiple option

Problems

Imbalance of Power, Dependence on trust
Risk of Manipulation, Self criticism

Level of Relationship

Feelings of hope

Euphoria, Exitement

Fear

Level of emotions

Misunderstanding, Misinterpreation, Wishful thinking bias; Denial of negative information

Level of facts

The therapeutic phase

- Information about therapeutic options
  - Single option
  - Multiple option

Solutions

Define relationship

„Not ideal but good enough doctor“

Self reflection of the therapeut

Level of Relationship

Elicit emotional response and values related to the described options

Elicit expectations and fears

Level of emotions

Patient adapted language

Processing statistical information

Checking back about information processing

Level of facts

The therapeutic phase

- Information to help decision making
  - Decision making

Problems

Conflict between respect for autonomy and non maleficience-beneficience

Physicians‘ Preferences

Level of Relationship

Ambivalence

Disproportional Hope, Idealization,

Disproportional Fear

Level of emotions

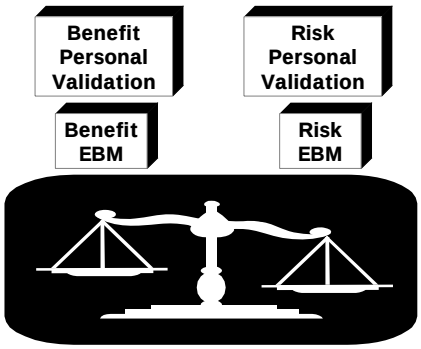
Bias with respect to balancing and comparing benefit/risk relations of different options

Level of facts

Decision making counselling

- Clarify the needs, values and objectives of the patient related to the specific issues of chances and risks and decisions to be made
- Elicit the need for information and the pre-existing knowledge
- Give a framework of chances and risks relating to everyday experiences
- Give absolute numbers, don't use relative rates and conditional probabilities
- Visualize chances and risks showing the relationship between risk and chances
- Encourage the patient to reflect about her values and the individual importance which she attributes to the benefits and risks shown.

Shared decision making



Supportive Counseling During Treatment

Dorothy A. Greenfeld, LCSW
Clinical Professor
Department of Obstetrics and Gynecology
Yale University School of Medicine

Learning Objectives

- At the end of this presentation, participants should:
  - Appreciate the importance of supportive counseling during treatment
  - Identify typical infertility treatment stressors
  - Be familiar with relevant research on supportive counseling

"Emotional distress is the *result*, not the *cause* of infertility".

Barbara Eck Menning, 1980

Provision of Psychological Support Services

- Recommended by:
  - Regulatory bodies in several countries
  - Professional organizations
  - Mental health professionals
  - Patients

Boivin, 2006

Guidelines for Counseling During Treatment

- International guidelines for counseling: ESHRE, HFEA, ASRM/MHPG, BICA, etc.
- Extensive body of literature on the psychological impact of infertility and its treatment
- Journals and textbooks dedicated to infertility counseling

Boivin et al, 2001; ASRM, 1996; Covington and Burns, 2006

Goals of Infertility Counseling

- Restore self-esteem
- Address narcissistic wounds
- Bereavement therapy
- Marital/sexual therapy
- Screening, guidance and preparation for treatment
- Advice, education and support
- Assist with decision making

Covington and Burns, 2006

Grief and Loss Specific to Infertility

- Loss of (potential) relationship
- Loss of health
- Loss of status or prestige
- Loss of self-esteem
- Loss of security
- Loss of someone of great symbolic value

Mahlstedt, 1985

Tasks of Counseling

- Information gathering and analysis
- Implications and decision-making counseling
- Support counseling
- Therapeutic counseling

ESHRE, 2001;HFEA, 2004

Information Gathering and Analysis

- Knowledge of medical diagnosis
- Knowledge of ever-changing treatment technologies
- Educated, well-informed counselor
- Educated, well-informed patient

Implications and Decision-making Counseling

- Patients entering treatment
- IVF/ARTs
- Third Party Reproduction - donor sperm, donor egg, surrogacy
- Special populations
- Patients ending treatment

Support Counseling

- Provide emotional support to patients experiencing distress
  - Emotional impact of infertility and the desire for a child
  - Emotional and physical impact of the treatment process
- Assess patient resources for coping with emotional and physical distress
- Provide strategies for coping

Therapeutic Counseling

- Progressively follows support counseling in symptomatic infertility patients
- Provides long-term solutions for coping with the psychological impact of infertility
- Individual, couples and group therapy
- Cognitive behavioral techniques, psychodynamic psychotherapy, solution-focused psychotherapy, and grief counseling.

Supportive Counseling During Treatment

- Gender differences: men and women respond differently to infertility
- Impact of infertility on couples: relationship issues
- Assessment of fertility related stress, anxiety,and depression
- Provide strategies for coping

Gender Differences: Women

- Receive the majority of treatment regardless of infertility diagnosis
- Childbearing more central to their identity
- Report infertility as most upsetting experience of their lives
- Experience greater social stigma
- More likely to seek information and access to support

Abbey et al, 1991; Wright et al, 1991

Gender Differences: Men

- Less apt to use social support
- Report less psychosocial distress
- Use more avoidant coping (denial, distancing and withdrawal)
- Adapt more easily to failed treatment and childlessness

Greil, 1997; Glover et al 1998; Wright et al, 1991

Gender Differences: Men

- Male factor diagnosis: higher levels of anxiety, self-blame, poor self-esteem
- Predictors of stress in infertile men:
  - Anxious disposition
  - Failure to seek social support
  - Avoidant coping style

Nachtigall et al, 1997

Gender Differences: Infertile Men and Women

- Compared to infertile men, infertile women report:
  - Lower levels of sexual and marital adjustment
  - More feelings of guilt, inferiority and isolation
  - Stronger negative effect of infertility on the quality of life
  - Significantly greater incidence of anxiety, depression, somatic complaints and diminished self-esteem

Boivin et al 1998; Collins et al 1992; Greil, 1997, Hjelmstedt et al, 1999

Impact of Infertility on Couples

- Ambivalence or unequal investment in desire for a child
- Women maintain high levels of distress throughout treatment
- Men may suffer silently in order to support their partners

Cousineau and Domar, 2007; Wright et al, 1991

Impact of Infertility on Couples

- Prolonged treatment increases marital conflict and distancing
- Rigors of treatment can disrupt sexual satisfaction

Cousineau and Domar, 2007; Wright et al, 1991

Impact of Infertility on Couples

- Infertility results in closer relationship with greater emotional intimacy
- Women report that spouse is greatest source of support during treatment

Leiblum et al, 1987; Seibel and Levin,1987; Boivin and Takefman,1996

Impact of Infertility on Couples

- Successful embryo transfer fosters feelings of closeness and intimacy between spouses
- Successful embryo transfer increases sense of optimism and reassurance about “biological compatibility”

Leiblum et al, 1987; Seibel and Levin,1987; Boivin and Takefman,1996

Impact of the Treatment

- IVF/ET considered to be most demanding treatment option

Leiblum et al, 1987; Callan et al, 1988

Impact of the Treatment

- Emotional and physical reactions vary according to stage of the treatment
  - Anxiety increases before oocyte retrieval and embryo transfer
  - Physical discomfort, breast tenderness, abdominal discomfort, and ovarian pain most pronounced at retrieval
  - Couples report surge of optimism after successful embryo transfer

Leiblum et al, 1987; Callan et al, 1988

Impact of the Treatment

- Anxiety reactions vary over the course of treatment
- Stress represents only one aspect of a woman's response to IVF
  - Hopefulness about becoming pregnant
  - Health
  - Relationship with spouse
  - Social network

Newton and Yuzpe, 1992; Boivin and Takefman, 1996

Impact of Treatment

- Compared to a menstrual cycle without treatment, women going through IVF reported
  - Fatigue throughout cycle
  - Fewer social contacts at time of retrieval/transfer
  - More social contacts during ovarian stimulation and the waiting period
  - Intimacy with spouse was greatest at time of ovulation

Boivin and Takefman, 1996

Counseling First Time IVF Patients

- Fatigue during cycle
- Emotional changes related to medication use
- Discomfort at time of retrieval-transfer
- Reduce activity at time of retrieval-transfer
- Help maintain realistic expectations at time of embryo transfer
- Model positive self-statements for women to use during all stages of treatment.

Boivin and Takefman, 1996

Counseling First Time IVF Patients

- Importance of social support at initial and final phases of treatment
- When social support is not available, important for program to fulfill that need
- Provide contact information for program support personnel
- Post treatment follow-up for those at risk for poor outcome after unsuccessful treatment.

Boivin and Takefman, 1996

Psychological Distress and Treatment

- If significant psychological distress is evident and prolonged, shift to therapeutic counseling
- If couple is coping well, continue to provide support as needed during course of treatment.

Summary

- Infertility and its treatment can result in psychological distress
- Supportive counseling plays an important role in providing couples with guidance, preparation and support during treatment
- Supportive counseling is flexible and client-based to strengthen coping skills during treatment

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Counselling after successful treatment

Psycho-social counselling in fertility treatment, 6 July 2008, Barcelona

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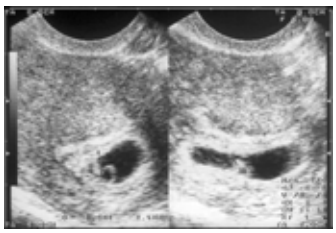
Learning objectives

- To gain knowledge on research results concerning transition to parenthood after ART
- To understand clinical implications for counselling: what important issues should be addressed
- To learn more about counselling interventions: how and when

Pregnancy after ART is considered as a success by the fertility team:

the goal has been reached !



But it is just a new beginning...

New questions arise

- Previously infertile couples' ongoing experience of the pregnancy ?
- Lingering effects from their struggle to conceive?

  If yes, do negative experiences associated with infertility affect psychological adjustment (pregnancy and early postnatal period)?

Transition to parenthood

- described as an adult's developmental stage
- contributes to maturation or causes instability
- is one of the most difficult family adjustments

Repercussions

On the woman and the man: reorganization both internal (identity) and external (social, financial, professional) – may be associated with emotional disturbances

Antonucci & Mikus, 1988

On the couple: decline in marital satisfaction related to increase of conflicts (chore-sharing, prenatal expectations, etc.)

Cowan & Cowan, 1992; Glade, Bean & Vira, 2005

Pregnancy after infertility: what risk factors ?

1. Difficulty to believe in the pregnancy's reality

   Delays psychological and material preparation to baby's arrival

Floyd, 1981; Olshansky, 1990

Example: 28-year-old female interviewed at 5th month of pregnancy

ICSI, 3 previous failures

« ... when they told me to take a pregnancy test, I refused ... and after the result, I was sure that the laboratory had made a mistake, I couldn't believe it, I took a second blood test ... a few days later, I had a hemorrhage, and I told myself this is my baby leaving »

Difficulty to believe in the pregnancy

Global measure of anxiety:

most studies showed no differences

Empirical studies: singleton pregnancies, matching for age and parity, measures during the pregnancy and/or the child's first year

Specific pregnancy-related anxieties

IVF more anxious about	
• announcing the pregnancy and material preparation of baby's arrival	McMahon et al., 1999
•loosing the pregnancy	Hjelmstedt et al., 2003
➢ one third stayed in bed (first month) vs 4% control mothers ➢ two thirds abstained from sex (whole pregnancy) vs 19.2% control mothers	Papaligoura et al., 2004

Specific pregnancy-related anxieties

IVF more anxious about	
• survival and normality of unborn baby	McMahon et al., 1997
• baby being injured during birth	Hjelmstedt et al., 2003
• separating from baby after birth	McMahon et al., 1997

2. <u>Depression and self-esteem associated with the infertility and its treatments</u> :

   Do they persist during pregnancy ?

   If yes, they could constitute a risk-factor (post-natal depression)

Depression and self-esteem

	No differences	IVF: more difficulties
Pre-post natal depression	McMahon et al., 1997 Gibson et al., 2000	
Self-esteem	Cox et al., 2006 Klock & Greenfeld, 2000 Bernstein et al., 1994	Cohen et al., 2000 McMahon et al., 1997 Gibson et al., 2000
Feeling of maternal competence	Gibson et al., 2000 McMahon et al., 1997	

3. Marital relationship under strain

- marital difficulties rarely dissolve at pregnancy's announcement; they add themselves to the usual decline in marital satisfaction
- making room for a third party (Hammer-Burns, 1996)
- sexuality changes (fear of endangering the fœtus)

Marital relationship

	No differences	IVF less satisfied	IVF more satisfied
Marital satisfaction	Hjelmstedt et al., 2004: decline Ulrich et al., 2004 McMahon et al., 1997	Cohen et al. ,2000 (couples, pregnancy) Gibson et al., 2000 (♂, postnatal)	Sydsjö et al., 2002) (IVF couples: no decline vs control group)

4. Idealization of the pregnancy and of the relationship to the baby

Experience of pregnancy: more stressful but also more exceptional

Hjelmstedt et al., 2003, Van Balen et al., 1996

Fœtal and postnatal attachment: no differences

Stanton & Golombok, 1993
Hjelmstedt et al., 2006
Cohen et al., 2000

	lower adjustment	higher adjustment
Perception of the baby	• difficult baby, less conversations (McMahon et al., 1999) • soothability difficulties (Punamäki et al., 2006) • difficult temperament (McMahon et al., 1997) • vulnerable and different baby (Gibson et al., 2000)	• more positive emotions (Harf-Kashdaei & Kaitz, 2007)

Data concerning the parent–child relationship: no more difficulties in ART families (Golombok et al., 1996 ; Colpin et al., 1995 ; Hahn & DiPietro, 2001)

5. Poorer obstetrical outcome after IVF:

IVF singleton pregnancies are associated with significantly higher odds of adverse perinatal outcomes (perinatal mortality, preterm delivery, low birth weight and small for gestational age)

IVF pregnancies are highly valued by patients and their doctors: labor induction and elective cesarean are more frequent

Jackson et al., 2004

Obstetrical complications might provoke or exacerbate emotional disturbances

Example (after birth): meeting the baby ...

« I had a shock when I saw him, he was all skinny, ha, he almost broke my heart, as if he had just escaped from starvation, he had no cheeks, no nothing, only bones, so yeah, I told myself I hadn't been able to feed him as I should have... »

« and the doctor came to tell me afterwards that he had a growth retardation so ah, it was hard… »

Research: Transition to parenthood after medically assisted procreation

Aim: to assess the influence of infertility diagnosis resolution on the transition to parenthood in IVF couples

FNSNF
Swiss National Science Foundation
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Prof. Guex, J. Darwiche, Prof. Germond, Prof. Favez

Research design

N = 80 couples, recruited before IVF/ICSI (no previous child)

Before the IVF/ICSI treatment

During pregnancy (5th month)

When the baby is 9 months old

1 year after first session (if no pregnancy)

Hypotheses

- Stress and marital adjustment should have an impact on infertility diagnosis acceptance
- Achieving pregnancy should improve diagnosis acceptance
- Diagnosis acceptance is supposed to help adaption to parenthood

Reaction to infertility diagnosis interview

(adaptation from Pianta & Marvin, 1992)

Objective: to investigate each person's reaction to the announcement of the infertility diagnosis

Coding:

- elements of resolution or non-resolution of the diagnosis
- narrative co-construction

Questionnaires

Marital relationship

Dyadic Adjustment Scale (Spanier, 1976)

Infertility-related stress

Fertility Problem Inventory (Newton, Sherrard & Glavac, 1999)

Assessment of the pregnancy

Antenatal and Postnatal Bonding Questionnaire (Condon, 1993)
Maternal Adjustment and Maternal Attitudes (Kumar, Robson & Smith, 1984)
Edinburgh Post Natal Depression Scale (Cox, Holden & Sagovsky, 1987)

Interactive situation

Pre- and postnatal Lausanne Trilogue Play (Fivaz-Depeursinge et Corboz-Warnery, 1999)

First results

- High infertility-related stress and low marital satisfaction have a negative impact on the diagnosis acceptance (N = 40 couples)
- No difference of diagnosis acceptance between pregnant (N = 20 couples) and non pregnant couples (N = 20 couples) at T2
- For the pregnant couples (N = 20 couples), a high diagnosis acceptance has a positive impact on fœtal attachment

Statistics: Hierarchical linear models (Bryk & Raudenbush, 2002)

Preliminary comments

1. Pregnancy itself does not positively influence diagnosis acceptance but other factors do (stress, marital adjustment)

   is contrary to the idea that pregnancy heals all wounds due to infertility

2. Importance of identifying sub-groups at risk

3. Another transition: from hyperspecialized medical follow-up to ordinary obstetrical follow-up

- Separation from the infertility team
- Medical dependance and overprotective obstetrician
- Rejection of their history of infertility and distancing from the infertility team

What clinical implications for counselling?

Purpose

To foster the development of preventive and tailored support for couples who need it and ask for it, without stigmatizing them nor limiting the development of their autonomy

Baetens, 2001; Shapiro, 1986; Allan & Finnerty, 2007

Tailored counselling - objectives

1. Tackling decisions or specific treatment-related questions

- Assisting the decision-making process: i.e. amniocentesis, multifœtal reduction, type of delivery, frozen embryos
- Informing about : multiple gestation, treatment's impact on the baby's health, obstetrical and perinatal risks
- Third-party reproduction: secrecy, ambiguous feelings toward the fœtus, future parent-child relationship, worries about the donor's health, the physical characteristics of the future baby

Tailored counselling - objectives

2. Identifying the couples' reactions to the pregnancy

Acknowledging the couples' efforts to separate their pregnancies from the special « high-tech » processes of conception

OR

their efforts to consider the pregnancy as a very special one

Sandelowski et al., 1992

Tailored counselling - objectives

3. Reducing anxiety levels, depressive feelings and fostering self-confidence

- Helping the couples to deal with the feeling of being in a « waiting to loose period » (Harris et al., 1991)
- Helping them to be more confident about the pregnancy's reality and the new life which is developing (cases of medical complications, previous miscarriage, ART multiple failures)

Tailored counselling - objectives

4. Touching upon feelings of ambivalence and idealization

- Allowing the couple to express ambivalence (upcoming changes and relinquishments)
- Helping the couple to anticipate the gap between pregnancy and parenthood idealization and reality

Tailored counselling - objectives

5. Identifying risk factors

- Previous or actual psychological and/or relational difficulties
- Sexual problems, actual or related to infertility
- Psychosocial situations
- Long medical infertility history and child-focused life
- Isolation from other parents
- Avoidance of the psychological and material preparation for the baby's arrival
- Inconspicuousness (personal uneasiness of the counsellor, Ulrich et al., 2004)

Tailored counselling - objectives

6. Identifying protective factors

- The couples are more prepared for a child's arrival
- Their coping strategies developed during the infertility period are additional resources; marital relationship reinforced by the infertility trials
- Both partners were involved right from the start
- Being older, their professional and socio-economic situation is often more stable

Tailored counselling - objectives

7. Preparing the child's arrival

- Discussing the anxiety reactivated by the approaching delivery
- If lack of trust and self-esteem: touching upon the attachment-relationship with the baby, helping to reinforce the parental competences in the early relationship

Tailored counselling

How and when to intervene?

- Counselling or any other type of intervention (psychotherapy, educational programs, group therapy, etc.)
- « Prenatal classes » which include the transition from infertility to parenthood
- Information sessions for pregnant couples
- Relaxation techniques
- Parent associations (i.e. parents of multiples)
- Liaison work

Tailored counselling – how and when to intervene ?

Liaison work

1. Quality of the transition between the fertility center and the obstetrical follow-up: what are the center's practices? what is the fertility specialists' ongoing experience of this transition? Awareness of the dependence which can take hold

Tailored counselling – how and when to intervene ?

2. Building up ties between the « world » of infertility and the « world » of obstetrics:

- A minimal collaboration is welcomed to ease the transition
- Making the obstetrical team (or private gynaecologists) aware that :
  - the couples have gone through stressful experiences which may have made them vulnerable OR given them additional resources
  - relationship with the fertility team is very involved

Future directions

- Defining and assessing the interventions during pregnancy (group, counselling) and their validity
- Better defining which are the risk groups
- Determining who is in charge of the interventions after a successful treatment (infertility team, obstetrical team – same or different persons ?)
- Specific studies of the pregnancy's development in third-party reproduction

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Counselling after miscarriage, termination of pregnancy and issues in ending treatment.

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No conflict of interest

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Learning objectives

- To understand the psychosocial implications of pregnancy loss (miscarriage and pregnancy termination).
- Have knowledge of possible helpful interventions for pregnancy loss.
- Have knowlegde of a university hospital based program for couples experiencing pregnancy termination
- Gain insight into counselling couples ending treatment.

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Overview

1. Psychology of pregnancy and pregnancy loss.
2. Loss, grief and mourning.
3. Degree of responsibility.
4. Psychosocial Pathway for Perinatal Loss.
5. Ending treatment.
6. Intervention: PLISSIT model.

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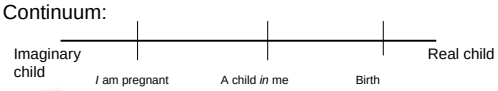
1. Psychology of pregnancy

- Continuum:



- confronting reality
- attachment

e.g. woman who became pregnant spontaneously versus woman who has been undergoing infertility treatment for 5 years before pregnancy

e.g. man who's not sure he wants to be a father versus man who has always dreamed about fathering a child and teaching his son football

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1. Psychology of pregnancy loss

Miscarriage and pregnancy termination
=
Ambiguous Loss
(Rosenblatt, 1987)

- 'What, if anything, has been lost.'
- Event or non-event?
- Between *something and nothing*. (Keirse, 2004)
- Diversity in understanding and experience of the loss
- Interpretation of the loss: 'unspeakable loss' >< 'no loss'

'No fit's all approach'

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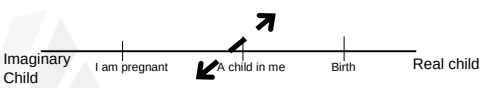
2. Loss, grief and mourning

- Grieving = normal, healthy, dynamic, universal and individual response to loss
- Mourning = healing process: surviving and continuing to live



Miscarriage and pregnancy termination create **boundary ambiguity.**
'Psychologically, the wished for child is present, but physically absent.'

Stages of grief
(Elizabeth Kübler-Ross, 1969)

The stages are:
- **Denial**: *"It can't be happening."*
- **Anger**: *"Why me? It's not fair."*
- **Bargaining**: *"If I did…, I would not have lost …."*
- **Depression**: *"I'm so sad, why bother with anything?"*
- **Acceptance**: *"It's going to be OK."*

Not normative; many other models (process)!
Steps not necessarily linear.
Diverse individual differences.
Normalize grief experience.

Miscarriage and termination of pregnancy

- Miscarriage
  - Spontaneous loss of the pregnancy in the first 20-24 weeks of pregnancy
  - Most common pregnancy loss
  - Estimated that 20-50% of pregnancies end in miscarriage
- Termination of pregnancy (TOP)
  - After diagnosis of severe fetal anomalies
  - Legally and morally accepted in many countries
  - First or second trimester of pregnancy

Unique aspects of grief with miscarriage and pregnancy termination

- Multidimensional loss:
  - ❑Loss of a baby
  - ❑Loss of self-esteem as a parent
  - ❑Feelings of failure as a women
  - ❑Loss of 'pregnant status'
  - ❑Fear of loss of reproductive capacity
  - ❑Fear of loss of health
  - ❑Fear of loss of control

Unique aspects of grief with miscarriage and pregnancy termination

- Grieving is difficult because
  - Little anticipatory grieving
  - 'invisible' loss
  - Few socially acceptable avenues for mourning
  - Often lack of social support
    - *intensifies shame and feelings of failure*
    - *'permission' to grieve*
  - Prospective nature of the loss:
    - *'pain of not ever knowing'*
    - *mourning for the hopes, wishes and fantasies of the future baby*

Unpredictable pattern of perinatal grief

- Tidal wave: growing and cresting, then reclining
  - recurrent grieving throughout life span
- Repetitive waves
- Shadow grief: reminders/triggers that rekindle the feelings of loss (Peppers & Knapp, 1980)
- Expressions of grief:
  - Emotions: shock, numbness, guilt, anger, anxiety, self-blame, depression, …
  - Physical symptoms: headache, shortness of breath, heartache, lack of appetite, sleeping problems,…
  - Cognitive symptoms: dreams, worrying, impaired decision making, intrusive thoughts about fetus, hallucinations of hearing baby cry
  - Social symptoms: isolation, withdrawal
- Eventually: loss integrated into a person's life; no longer consumes *all* energy

3. Degree of responsibility

Miscarriage >< Pregnancy termination

0 → 1

"It happens to me" — *"Maybe I caused this?"* — *'I choose* to terminate'

Element of choice: decision to 'choose' to end the pregnancy, especially if planned and desired is extremely difficult

- Ethical, moral, social, dilemma's
- Conflictual emotions
- Physical and emotional ambiguity (especially for women)
- 'taboo', social stigma, highly emotionally charged topic
  - Sense of isolation: shame, guilt
  - Fear of rejection or condemnation

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3. Degree of responsibility

- Irrational guilt and shame: fact or fantasy?
  - ❑ Helping to interpret fact or fantasy
  - ❑ Beware of criticism and judgement
- Searching for a cause: 'why?'
  - ❑ implications + reassurance
  - ❑ Inital information not always processed because of shock

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4. Psychosocial Pathway for Perinatal Loss

- Multidisciplinary support and counselling
  (doctors, nurses, psychosocial team, pastoral care)
  - ❑ Standard protocol if TOP after 15 weeks
- Special needs gynaecological unit: no postpartum confrontation
- Follow-up after discharge: medical + psychological

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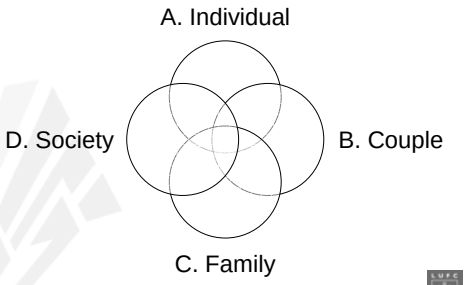
4. Psychosocial Pathway for Perinatal Loss



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A. Individual

- 'Psychological videotape' (Covington, 2006)
  - ❑'what does this experience mean to them?' → personal history and life-events
  - ❑Validates experience in its individual, unique way
  - ❑Repeatedly remembering creates distance
  - ❑Provides insight into functioning and cultural, social and personal norms

Attachment >< Gestation

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A. Individual

- Physical integrity: body becomes ambivalent object
- In infertility-context:
  - ❑ Succes and failure after repeated cycles of hope and sadness
  - ❑ Betrayed by medical technology: time- and emotionally consuming
  - ❑ 'Insult added to the injury'

→ *Being able to tolerate intense grief reactions versus socially more desirable 'scaling down'*

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Psychological Morbidity	***Prevalence of morbidity***	***Time span***
Depressive symptoms	20-55% elevated levels	Elevated for 6 months Decreased 1 year after miscarriage
Depressive disorder	Varied 10-50% diagnosed with DD following miscarriage	
Anxiety symptoms	20-40% of women shortly after miscarriage Centred on pregnancy related issues High levels of somatic complaints	Rates of anxiety dropped from week 1 (41%) to week 6 (18%) but rose again by week 12 (32%) Coincides with first menstrual cycle, anxieties about trying again?
Anxiety Disorder	Scarce evidence for Obsessive-Compulsive Disorder, Panic, Disorder, Phobic Disorder	
Post-traumatic Stress Disorder 1)re-experiencing of trauma 2)avoidance reaction to trauma 3)hyperarousal state	25% at 1 month FU 7% at 4 month FU Inconclusive	Traumatic nature of miscarriage → PTSD explains many of the symptoms experienced by women after pregnancy loss
Grief	40% of women immediatly after loss	Usually markable reduction of grief symptoms by one year

(Lok, I. & Neugebauer, R.,2007. Psychological morbidity following miscarriage)

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A. Individual

Trying again - mixed feelings and motivations:

- ***Trying Again Right Away***
  - The Need To Be Pregnant Again Right Away
  - The Desire To Get On With Life
  - The Desire To Have Something To Look Forward To Again
  - The Fear Of Never Being Able To Have Another Child
- ***Deciding To Wait***
  - The Need To Grieve
  - The Fear Of Having Another Baby Die
  - The Desire To Let Certain Milestones Pass Before Becoming Pregnant Again

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A. Individual

Trying again:

- Running out of time (~ infertility) verus grieving
- Communicating and compromise
- Focus on pregnancy increases: 'obsession'
- Careless pregnancy is gone
- Sexual relationship pressured
- Ritual and superstition: sense of control

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B. Couple

Women and men have equal but different needs

- Pre- and postnatal attachment is different
- Physical experience and pain
- Reality of the loss

→ psycho-education + validation

Re-setting of the relationship:
conflict
fusion

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B. Couple

- Gender differences:
  - ❑ Couples sometimes 'balance' grieving: different timing and emotions
  - ❑ "It's a journey, not a destination."
  - ❑ "Dance of closeness and distance" (Rosenblatt, 2006)
  - ❑ Fathers are often overlooked in the ob/gyn unit, feel ignored or excluded: have to deal with organisational tasks
  - ❑ Sexual relationship can be difficult for a while
    → physical reminder of the pregnancy

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B. Couple

Saying 'goodbye': reinforcing their unique needs
helping them to say goodbye

- Seeing, touching, spending time with the baby
- Naming the baby (or not)
- Planning for memorial service and disposition of the body

Creating mementos: 'giving credit to life and loss' - physical contact, photographs, footprints, cards etc.

REALITY REINFORCING INTERVENTIONS

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B. Couple

- Searching for an 'anchor'
- Reinforcing or installing coping behaviours
  - ❑Individual >< couple
  - ❑Time frame for mourning and differences
  - ❑Challenge social desirable cognitions and beliefs
    - 'I should be over this by now.'
    - 'I feel fine but everybody keeps treating me like I'll fall apart'
  - ❑Promoting self care activities at follow-up
    - Healing physically and emotionally
  - ❑Support groups: feeling connected and understood

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C. Family

- Often overlooked (especially in ob/gyn unit)
- Pregnancy loss = family loss

grandparents, parents, other children, siblings, other relatives

- Addressing the issues and dealing with 'taboo'
- Grief in the family
- Information and support
  - ❑ Provide a 'script' for children

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D. Society

Miscarriage and pregnancy termination
=
'invisible loss' + 'unrecognized loss'

- Preparing to go home
  - ❑ Hospital ~ safe cocoon, initial shock, supportive environment, …
  - ❑ Home ~ facing reality, letting it sink in, emptiness, questions and no answers, …
- Communication with the environment
  - ❑ Family, friends, co-workers, boss etc.: providing a script
  - ❑ Social stigma: 'right to mourn and grieve'
  - ❑ Facing the facts and reality

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Patient diary after miscarriage

'The hours, the days afterwards I had to decide if I wanted to see you, hold you. The biggest dilemma in my life. I felt so weak and sad, felt like I couldn't deal with it all.

I'm so terribly sorry I left you there, in the cold, with strangers, without keeping you safe and warm. I would give everything to keep you in my arms, keep you safe with me, talk to you, give you an everlasting and warming kiss…

So quickly you left me, no longer a part of my life, taken away and never returned. You and me, without one another. I let the chance slip away to cherish you for the first and last time, to see you, feel you, smell you …'

~ L.R., 29

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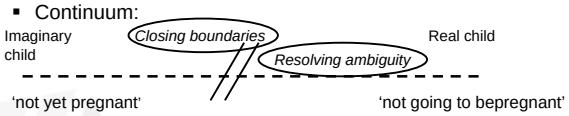
5. Ending treatment:

- Continuum:



long complex process
not a transitional moment
(Daniluk, 1996)

- Infertility = major loss, often unrecognized and socially 'unspeakable'
- Ambiguous and open-ended loss; hard to find closure
- Impact on identity → intrinsic to adult female and male identity

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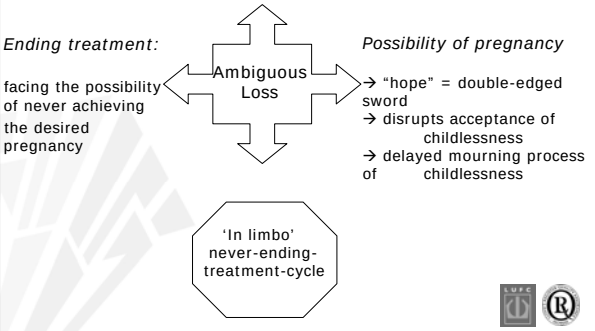
"When enough, is enough."



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"When enough, is enough."

- Starting IVF: anticipatory decision regret (Baetens,2005)
- *'If only'* : technology offers hope, but also an imperative to pursue treatment
- *'Maybe next time'* hope: impossible to know exactly where it ends.
- What is *'doing everything'?*
- Routes *into* IVF are clear, *out* of it more obscure.

No objectively identifiable end to IVF treatment
Subjective end point, determined by many factors

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Factors impacting the end of treatment (Takefman, 2006)

1. Sociodemographic factors
   - Parity
   - Age
   - Gender
   - Finances
2. Interpersonal factors
   - relationship beliefs and expectations: 'family life'
   - uncertainty about the future
   - congruence between couples

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3. Emotional factors
   - optimism
   - psychological distress
   - having done all you can: 'no regrets'
4. Fear Factors
   - not being able to cope with implications of ending treatment
   - life without children is deficient and unfulfilling
   - relationship will not survive childlessness

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Ending treatment sessions

- Routine session
- On demand ???
- Mandatory
  - Opportunity to talk about it normalizes experience
  - Couple-aspect underlined
  - Part of the infertility process and not giving up
  - Openness to discuss fears, doubts, etc.

Ending treatment sessions

1. *'How did they get here?'*

- Review infertility experience emotionally, cognitively,…
- Reflect on infertility process and help reduce blame
  - 'we've done all we can'
- Assumptions and expectations on entering treatment: 'fix things'
- Emotional and physical impact: disappointments become more difficult to deal with and 'bounce back', feelings of personal failure
- Repeated unsuccessful treatment: loss of control as well as the feeling that infertility takes over your life (invades most areas of life)
- Stance of the physian: hopeful or not?
  - 'carrot' dangling in front of you
  - Treatment = gamble, addiction

Ending treatment sessions

2. Value: 'what tips the scale?'

- Value can exceed the cost
- Motivation for and meaning of the wish for a child
- Normative, social value >< renewed life goals, future
- Recognizing limits, re-assessing
- Implicit or explicit assumptions
- Unknown or underlying agendas

Ending treatment sessions

3. Explore decision making:

- 'cost-benefit' analysis which includes both partners and incorporates different points of view (individual, couple, family, society,…)
- Importance of couple consensus: joined decision
- Re-evaluation probabilities of success and appraising patient perspective
- Let patients set the agenda and determine the speed: 'no time frame'
- Permission to express feelings – Dealing with intense emotional responses
- Pay attention to positive aspects: both in information giving and ending treatment
- Explore alternative options

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Ending treatment sessions

3. Explore decision making - Being 'stuck':

- 'all for nothing' if treatment ends without desired outcome
- Belief that persistence will pay off eventually:
  'If at first you don't succeed, try again – try harder.'
- Losing sight of yourself or the reasons for starting treatment:
  - desire turns to despair
    wish for a child becomes a need for a child (Demyttenaere, 1998)
    getting pregnant becomes a goal in itself
- Avoiding grief work by continuing treatment

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Ending treatment sessions

4. Ending ambiguity: 'yes or no'
   - Find control
   - Rearranging boundaries
   - Mourning the wished for child: mutual loss for couple
   - Mixed emotions: relief, anger, grief, hurt, loss,…
   - Turning toward the future: rewriting the script, reassessing parenthood and child wish, considering other roles

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6. Intervention: P L I S S I T model (Jack Annon, 1976)

P	L I	S S	I T
↓	↓	↓	↓
Permission	Limited Information	Specific Suggestions	Intensive Therapy

Differential model of treatment: not everyone needs the same things at the same time
→ sensitive and tailored interventions

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6. P L I S S I T model

- Risk factors for complicated grief
  (Covington, 2006; Athey et al., 2000)
  - ❑ History of poor psychological functioning or psychiatric history
  - ❑ History of reproductive loss
  - ❑ Medical history associated with the loss
  - ❑ Medical interventions to achieve or maintain pregnancy
  - ❑ Age
  - ❑ Marital instability (sometimes blaming the partner)
  - ❑ Social isolation/lack of social support
  - ❑ Recent crisis or loss
  - ❑ Parity - childless

⇨ **Screen for these factors in interview.**

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6. P L I S S I T model

- Counter-transference: being aware of your own feelings, ideas, morals, etc.

- Patient presentation:
  - ❑ Stripped of defences and vulnerable: deal with overwhelming feeling and integrate defences.
  - ❑ Wall of defences: explore the meaning and the purpose of the defences, don't crush them.

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UZ LEUVEN

Thank you for listening.

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Specific counselling: Issues to be addressed in donor insemination

Dr. phil. Petra Thorn
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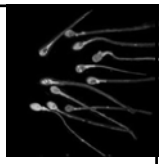
ESHRE SIG Psychology and Counselling
6. July 2008

Introduction



- Family building using DI involves managing diverse and often contradictory emotions
- Recipients run the risk of no or false information
- Especially with third party reproduction, cultural awareness and knowledge about legal implications are necessary
- How can recipients be motivated to take up pre-treatment counselling, to view it as an opportunity rather than an obligatory exercise?

Overview

1. Assessing readiness
2. Exploring disclosure
3. Supporting treatment
4. Sharing information with children
5. Sharing information with teenagers
6. Sharing information with adults
7. Counselling donors
8. Counselling recipients with personal donors
9. Current challenges (mandatory versus voluntary counselling, counselling settings)

1. Assessing readiness

- Agreeing about ending treatment with ICSI
- Facilitating grieving process of child biologically related to both parents
- Exploring meanings attached to DI
  (DI is only 2nd best, intuitive discomfort, illegal in some countries)
- Eliminating coercion by partner, by professional

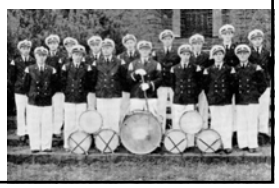
1. Assessing readiness

- Discussing pros and cons of adoption
- Determining financial and emotional resources
- Deciding type of donor (where possible):
  anonymous, known, personal, intrafamilial

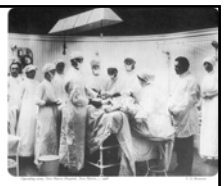
  and exploring implications (discussing and agreeing on meanings of donors, needs, boundaries, accounting for different needs of the child)

2. Exploring disclosure

- Support required by the couple/wife during treatment
- What reactions are feared if DI is disclosed with family members and friends?
- Helpful strategies for disclosure
- Typical reactions of others



3. Supporting treatment



- Typical emotional roller coaster
- Managing ambivalent feelings towards the semen of an anonymous donor inside the body
- Encouraging recipients to voice their needs with medical staff (i.e. breaks from treatment, information about donor)
- Facilitating grieving process if DI is unsuccessful, emotional or financial ressources are depleted, help to face life without children

3. Supporting treatment

In the case of pregancy:

- Validating and normalizing fantasies about the baby and the donor
- Fantasies typically subside as pregnacy advances
- Ask for non-identifiable information about the donor
- Helping the husband's anxiety not to be able to bond with the baby: research has indicated that the father-child relationship is quite secure

In the case of no pregnancy:

- Explore adoption, foster child, help to shift into a life without children

4. Sharing information with children

- Disclosure has been a controversial issue
- Secrecy protects the family, the child and the father from stigmatization, in some jurisdictions the donor from legal responsibilities
- Disclosure prevents a family secret, identity struggles, loss of trust within family, respects values such as openness and honesty in family,

  provides relevant medical information, fairness/similar possibilities in comparison to adopted children

Non-disclosure is often based on feelings such as fear and anxiety

4. Sharing information with children

- Easiest, both for parents and for child, when the child is 3 – 6 yrs old
- Parents may “practice” before this age
- Simple words, simple explanation, child’s developmental needs should determine parental disclosure process
- Disclosure is a process, children ask more complex questions as they get older
- Guidance material, workshops for parents, role models

4. Sharing information with children

- Increasingly, parents seek counselling for information sharing with older children
- Parents must prepare themselves for and work through any emotional reactions they themselves may have
- Needs of child must be the focus, there should be plenty of time for questions, discussions, reactions, time to reflect
- Use simple and plain language
- Avoid sharing in difficult times

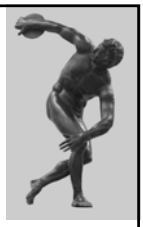
5. Sharing information with teenagers

- Parents to choose a time when child is emotionally settled
- Plain and simple language, short explanation why telling occurs now
- The older the child, the more complex the reaction. Older children’s identity is formed to a greater degree, this impacts on reactions
- Parents can follow up to indicate to child that this is a safe subject to discuss
- Typical fear: puberty, fear of rejection by the father

6. Sharing information with adults

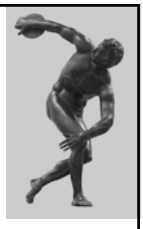
- Parents should explore their own emotions (typically not addressed when they underwent treatment)
- Parents can prepare a script, discuss with close friend, counsellor, prepare support for themselves afterwards
- Choose a time when child is settled, when there is sufficient and undisturbed time for telling, home is more suitable than public place
- Give basic information, acknowledge the child's feelings, provide follow-up

7. Counselling donors



- Typically, there is no/little counselling provision for semen donors
- With higher rates of disclosures and legislation providing access to offspring to records, in the future, more and more donors are likely to be contacted by offspring – implications counselling for donors is necessary
- Reflect motivation, exclude coercion (personal, intrafamilial donor), discuss potential needs of offspring for contact

7. Counselling donors



- Decide to donate for which group (heterosexual, lesbian, single women), limit no. of offspring
- Explore meanings of DI-offspring; this may change once donor has children of his own (half-siblings)
- Explore possibility of children being born with genetic disease inherited by donor – will he want information, will this influence his own family planning?
- Can clinics provide some information on no. of pregnancies/offspring born?

8. Counselling recipients with personal donors

- More often with lesbian and single women
- Exclude coercion for emotional reasons
- Roles, meanings and boundaries must be discussed and agreed upon by all involved
- Children may voice need for different boundaries
- Open communication channels are vital

9. Challenging issues

- Counselling in gamete donation involves additional skills, training helpful
- Mandatory or voluntary counselling?
- Clinics/doctors can impact on uptake of counselling, cooperation vital
- Couple counselling (individual and couple issues) educational groups (destigmatizing, normalizing, support network), educational workshops for parents who intend to tell their children (support network)

Questions

Discussion

Resources

BKID (2008) Leitlinien für die psychosoziale Beratung bei Gametespende. www.bkid.de (download).

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Specific counselling: issues to be addressed in oocyte donation

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IVI Barcelona

Learning Objectives

- Counselling donors

(anonymous and non-anonymous):

-Evaluation
-Implication counselling
-Offering support

Learning Objectives

- Counselling recipients :

-with anonymous donor
-with personal donor or egg-sharing

Assessing readiness
Exploring disclosure
Implications counselling
Supportive counselling
Disclosure

The role of mental health professionals appears to be of utmost importance because of the need to protect the emotional well-being of donors and recipients, and to help them understand as fully as possible the meaning and longer-term psychosocial implications of deciding to donate or receive genetic material.

Dra. Diana Guerra

Counselling donors

Anonymous:

-Evaluation:
Psychological
Motivation
Expectancy

- Implications counselling

- Offer support counselling

Dra. Diana Guerra

Counselling donors

Non-Anonymous:

-Evaluation (if mandatory):

Psychological
Motivation
Expectancy
Attachment

- Implications counselling

- Offer support counselling

Dra. Diana Guerra

The gendered assumptions behind the practice of gamete donation were demonstrated by Haimes (1993) in her analysis of the UK Warnock Report:

Egg donation is associated with altruism and takes for granted a family in which mother is central

Haimes E. 1993

Dra. Diana Guerra

Oocyte donor candidates were significantly more likely than controls to have experienced:

at least one emotional trauma related to reproduction or at least one family event such as death of a parent,

parental divorce

chemical dependency

psychiatric disorder in a relative,

or sexual abuse

Shover LR, et al., 1990;

Dra. Diana Guerra

The SEF Psychology Interest Group has suggested relative exclusion criteria for egg donors following ASRM criteria:

- significant psychopathology
- positive family history of heritable psychiatric disorders
- substance abuse,
- two or more first-degree relatives with substance abuse
- current use of psychoactive medications
- history of sexual or physical abuse with no professional treatment,
- excessive stress
- marital instability
- impaired cognitive functioning
- mental incompetence
- high risk sexual practices

Dra. Diana Guerra

Psychological Evaluation of Egg Donors at IVI Centers in Spain

- **INTRODUCTION.**
- After the Law 14/2006 1 came into force the psychological screening of ED has became an essential requirement for ART centers. Since January 2007 the IVI Psychological Team has carried out on a regular and protocolized basis a psychosocial evaluation to all donors following the Psychology Special Interest Group of the Fertility Spanish Society (SEF) Guidelines.
- **OBJECTIVES.**
- To study the profile of ED evaluated at 7 IVI Centers in Spain after the New Law came into
- To evaluate if the current protocol is suitable for this purpose.
- **MATERIAL AND METHOD**
- E D had to pass a semi structured interview and sometimes the Neo—FFI Inventory 3 as well which is more convenient than other psychopathological evaluation tools.
- The protocol has not specifically been designed to determine clinical diagnosis but it helps us to detect or discard them. The American Society for Reproductive Medicine (ASRM) has established some criteria for the ED selection. Despite the fact that these are temporary/ preliminary, the Psychological team has followed the proposed criteria .
- *Guerra et al, 2007*

Psychological Evaluation of Egg Donors at IVI Centers in Spain

	N (%)
Number of ED	816
Age	26,3 (18-35)
Nationality	Spanish 342 (67,9%) Other 32,1%
Academical bckg	Univ degree 128 (16,2%) Secondary 659 (%) Primary 29 (3,6%)
Employed	YES 683 (83,7%)
First contact	Press 346 (42,4%) Acquaintances 327 (40,1%)
Motivation	Economical 534 (65,4%) Altruism 272 (33,3%)
Marital status	Single 544 (66,7%) Married 154 (18,9%) Others 36 (4,4%)
Children	NO 388 (47,5%)
Abortion	NO 508 (62,3%) YES 212 (26%)

- *Guerra et al, 2007*

Psychological Evaluation of Egg Donors at IVI Centers in Spain

	N (%)
Alcohol	YES 616 (75,5%)
Smoker	NO 360 (63%)
Other drugs	NO 558 (68,4%) In the past
Psychological D.	NO 571 (73,2%) In the past 127 (16,2%)
Ψ Ds in family	NO 399 (85,3%) YES 68 (14,5%)

EXCLUDED 18 (2,4%)

Reason 5 Lack of commitment

- 3 Ψ Disorders in the family
- 2 Psychotic Disorder
- 2 Anxiety
- 2 Depression
- 1 Antisocial Disorder
- 1 Eating Disorder
- 1 Alcohol Abuse
- 1 Poor Cognitive Performance

- *Guerra et al, 2007*

Psychological Evaluation of Egg Donors at IVI Centers in Spain

- CONCLUSIONS.
- The profile of the IVI ED evaluated is a Spanish young woman that has finished secondary school and has a job. Almost half of them have already children and one out of three refers a previous abortion. More than fifty per cent of the interviewed ED mentioned the economical compensation as the main motivation to donate.
- The Semi structured Interview developed by the SEF Psychology Special Interest Group for the selection of ED has revealed reliable enough to meet the criteria suggested by the Mental Health Professional Group Ovum Donor Task Force of the ASRM
- *Guerra et al, 2007*

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Specific issues of donor's counselling

- Responsibility- Commitment
- Decission-making
- Motivation
- Implications
- Secrecy
- Attachment

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Based on the inherent separation between the biological parent and the child, "attachment born of separation" may be a rapidly emerging phenomenon in parent-child relationships originating in fertility technology.

Dunnington R N, et al. 1991

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Several factors have to be considered in potential attachments

DONOR-RECIPIENT/S

Personality factors + Psychological State +Setting

Belives | Attitudes | Expectation | Behavior

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Specific issues of recipient's counselling

- Genetic link- differences and similarities
- Attachment
- Implications
- Waiting period or drop-outs
- Disclosure
- Other children

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The egg donation mothers appeared to be more comfortable about parenting than were the donor insemination mothers in that they tended towards higher levels of joy/pleasure whereas the donor insemination mothers tended towards higher levels of over protectiveness towards the child

There were no differences in parent-child relationships between gamete donation families where the parents favored non-disclosure or were still undecided

Golombok, S.,et al, 2005

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Those conceived by egg donation were no more likely than their naturally conceived counterparts to show raised levels of psychological problems or cognitive impairment

There were no differences according whether the donor was previously known or unknown to the parents

Golombok, S. et al, 2005

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Based on Evidence

- Attachment studies
- Follow-up of families created by ART
- Adoptions

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Attachment theory is meant to describe and explain people's enduring patterns of relationships from birth to death

According to attachment theory, children develop attachments to those who respond to them as parents, rather than to those who are merely their biological relatives

Dra. Diana Guerra

According to attachment theory, children develop attachments to those who respond to them as parents, rather than to those who are merely their biological relatives

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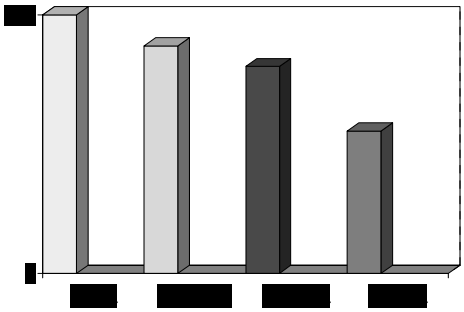
Disclosure: % parents who decided not to tell



Golombok et al, 1998

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Discussion

- Debate:
  - donor “payment”
  - receptors and donors ages
  - ethical issues
  - disclosure

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Oocyte Donation "Receipt"

Sometimes, Mummies do not have good eggs and need other women´s egg help to achieve a pregnancy

Ser Padres en el Siglo XXI- Sensibilización social

Dra. Diana Guerra

Golombok, S., Jadva, V., Lycett, E., Murray, C., MacCallum, F.: Families created by gamete donation: follow-up at age 2. Hum Reprod 2005 ; 20: 286-293

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- Golombok,S.,Brewaeys,A, Giavazzi MT, Guerra, D. MacCallum, F. and Rust, J. The European study of assisted reproduction families: the transition to adolescence Human Reproduction, Vol. 17, No. 3, 830-840, March 2002
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- Human Reproduction, Vol. 15, No. 2, 476-484, February 2000

Dra. Diana Guerra

Counselling Lesbian Couples
Anne Brewaeys, Ph.D. Psychologist
Free University Amsterdam

Content:

- Evolutions : growing body of empirical knowledge
  growing social acceptance
- Counselling candidate parents
- Donor linking counselling

Learning Objectives:

- Insight into the functioning of lesbian families
- Insight into counselling guidelines and protocols

A growing body of empirical knowledge during the past 30 years

1.Studies of *children* born in a heterosexual family and raised by post divorce (single) lesbian mothers, compared with single heterosexual mothers

a.o.

- Golombok et al.(1983) "children in lesbian and single parents households". J Child Psychol Psychiatr,38,783-791
- Green et al. (1986). "Lesbian mothers and their children: a comparison with solo heterosexual mothers and their children". Arch of Sex Behav ,&,175-181.

2. Studies of *children* born in lesbian Donor Insemination families and compared with heterosexual (DI) parents

a.o.

- Brewaeys et al. (1997). "DI, Child development and family functioning in lesbian mother families". Human Reprod, 12,1349-1359.
- Chan et al. (1998). "Psychological adjustment among children conceived via DI by lesbian and heterosexual mothers". Child Development,69,443-457.

A growing body of empirical knowledge during the past 30 years

3. Studies of *adolescents* and *adults* raised in lesbian families

a.o.

- Golombok & Tasker (1996). 'Do parents influence the sexual orientation of their children?" Findings from a longitudinal study of lesbian families." Dev Psychol, 32,3-11.
- Vanfraussen K., et.al. (2003)."What does it mean for youngsters to grow up in a lesbian family created by means of donor insemination?".J. Reproductive and Infant Psychology, 20, 4 , 237-252.

4. Studies investigating the *donor concept* of adolescents raised in lesbian DI families

a.o.

- Vanfraussen et. al.(2003). "Why do children want to know more about the donor? The experience of youngsters raised in lesbian families". J. Psychosom Obstet Gynecol 24, 31-38.
- Scheib J. et.al.(2003) *"Choosing identity release donors: the parents' perspective 13-18 years later."* Human Reprod. 18,5,1115-1127.

Main conclusions

Despite the diversity in methodology and sample characteristics, results are strikingly unanimous.

Family relationships

- Good Quality of overall parent-child interactions
- Quality of the relationship between child and co-mother better / equal to quality of the relationship between child and father
- Educational tasks more equally divided between mothers
- Grandparent equally involved with children

Main conclusions

Child development

- Good psychological adjustment
- Similar gender role behaviour compared with children from heterosexual families
- No elevated rates of homosexuality among adolescents and young adults
- Similar social development and quality of peer relationships
- During adolescence more secrecy about their lesbian family

Donor Concept

- Aware of their donor origin in an early developmental stage
- Curious about donor characteristics
- The majority wants to meet the donor in future

Growing social acceptance of lesbian parenthood in Western Society

- Increasing visibility of a diversity of lesbian families
- Lesbian and gay couples get married
- Development of legislation acknowledging the educational role of both mothers
- Growing acceptation of lesbian mothers as adoption and foster parents
- The emergence of gay fatherhood

Counselling candidate parents

Content:

- •Screening: in and exclusion criteria
- •Analysing motivations
- •Informing the couple
- •Decision making and informed consent

Counselling candidate parents

Screening: in and exclusion criteria

The welfare of the future child needs to be guaranteed. There is no basic difference between heterosexual and lesbian couples in defining the in and exclusion criteria.

1.Inclusion criteria

- Biological mother < 40 y
- Social mother <45 y.
- Good somatic and psychological health
- Adequate cognitive functioning
- Long-lasting and stable partner relationship
- An "accepting" social context with regard to their lesbian identity
- Self acceptance of lesbian identity and coming out

2. Exclusion criteria

Potential risk factors in their capacity of (1)coping with the challenges induced by DI and being lesbian mothers, (2) creating a safe educational environment for the child

-

Counselling candidate parents
analysing motivations

- •History of child wish in both women
- •Who gets pregnant and why?
- •Why DI?
  - Being a non genetic parent?
  - Dealing with the donor in the future family?
  - Meeting the donor in future?
- •Lesbian motherhood:
  - self acceptance of lesbian identity
  - coping with social prejudices
  - family concept: dealing with the absence of a father
    the role of both women in childrearing
  - legal arrangements with regard to shared parenthood

Counselling candidate parents

Informing the couple about the following issues

- The use of a donor:
  - legislation: anonymous vs. identity registered donors
  - donor selection and matching
  - practical arrangements during treatment
- Long term psychological effects of DI on family building:
  - results of follow up studies investigating child development and potential risk factors
- Information processes:
  - How and when to inform the child about DI and lesbian motherhood
  - How and when to inform significant others about the child project
  - How to deal with the child 's curiosity about the donor?

Donor linking counseling: practical conclusions from available follow up studies

- Children raised in lesbian mother families are informed about DI in an early developmental stage
- Most informed children wish identifying information about their donor and/or wish to meet him
- Their most important motive is information seeking:
  - Personal and physical donor characteristics
  - Other children from the same donor
  - Current life circumstances of the donor
- Some children have worries about meeting the donor
- Some children experience their wish to meet the donor as being disloyal to their parents
- Most donors are still prepared to meet the children but half of their current partners are not

Donor linking counseling: The Dutch protocol

- Professional counseling is compulsory when donor offspring and donor wish to meet
- The role of the counselor is to mediate between both parties, tune in to both parties' expectations, and prevent any personal harm to offspring and donor.
- This implicates:
  - One or more meetings with the offspring
  - Written contact with the donor
  - One or more meetings with the donor (and his partner)
  - Mediating when the donor refuses the meeting and offering additional counseling
  - Arranging the exchange of non identifying information
  - Preparing the meeting if the donor agrees
  - Evaluating the meeting with both parties
  - Offering follow up counseling

Donor linking counseling:
contents (1)

Donor and offspring:

- •current psychological functioning
- •Current familial and social circumstances
- •Motives and worries with regard to meeting
- •Are expectations realistic?
- •Analysing possible consequences of the meeting
- •Discussing how , when and where the meeting will take place
- •Discussing the content of the non identifying information forwarded before the meeting
- •List of personal informations (not) to be released during meeting

Donor linking counseling:
contents (2)

Offspring

- •List of questions to be asked to donor during the meeting
- •attitudes of parents with regard to donor information seeking

Donor

- •List of questions to be asked to offspring during meeting
- •Attitudes of partner and children towards meeting

Donor linking counseling:
case study

Martha wants to meet her donor:

- •17 years old
- •Daughter of separated lesbian mother
- •College student
- •Suffering from anxiety and depression
- •Angry because she has no father

This donor linking counselling will be illustrated and discussed with the public

Intercultural Counselling: Addressing cultural differences

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Learning Objectives

- Recognizing why and how culture matters
  - With respect to couples and families
  - In counseling theory and practice
  - In health care
- Recognizing different approaches to cultural diversity
- Developing cultural awareness

What is Culture?

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

What do you believe?

- Should relationships between couples be egalitarian or hierarchical?
- Should good communication between couples be direct or indirect?
- Should emotions be expressed openly or controlled?
- How much autonomy on the part of individual family members is healthy and appropriate?

Source: Gushee et al. (2005)

Culture influences beliefs and behaviours

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

Ethnic Diversity is a Reality

- Acquiring skills in multicultural counseling is critical for infertility counselors because:
  - Most countries are ethnically heterogenous
    - Differences in religion, customs, language
  - Reproductive tourism is common (Fathalla, 2005)
  - Immigration is widespread

Patterns of Immigration

Receiving countries	Percent population migrating in
Europe	8.8%
Asia	1.4%
North America	13.5%
Africa	1.9%
Latin America	1.2%
Oceania	15.2%

Source: International Organization of Migration (2008)

Patterns of Immigration

Sending countries	Percentage of migrants
China	35%
India	20%
The Philippines	7%

Source: International Organization of Migration (2008)

Why does this diversity matter?

- Ethnic minority clients may not be well-served by “mainstream” counseling and psychology
  - Ethnic minority clients less likely to seek help from counselors/therapists
  - Ethnic minority clients leave therapy sooner

Source: Worthington et al., 2007

Why is “mainstream” counseling failing minority clients?

- Derived from work by and on middle/upper-class Americans and Western-Europeans
- Culture-bound assumptions that:
  - Self is autonomous and behaviour determined by internal traits and attributes
  - Mind (psychological problems) is separate from body (organic problems)
  - Culture is arbitrary superimposition on a fixed and knowable biology

Sources: Lewis-Fernandez & Kleinman (1994); Pederson (2003)

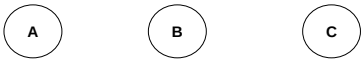
American Psychological Association Multicultural Guidelines

- As cultural beings, psychologists may hold attitudes and beliefs that can detrimentally influence their perceptions of and interactions with individuals who are ethnically and racially different from themselves
- Need to recognize importance of multicultural sensitivity/responsiveness to, knowledge of, and understanding about ethnically and racially different individuals
- Should apply culturally appropriate skills in clinical and other applied psychological practices

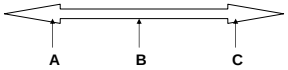
Source: APA (2002)

Approaches to cultural diversity

- *Emic* approaches to culture
  - Every culture is unique and has a unique psychology



- *Etic* approaches to culture
  - Cultures hold different positions on universal psychological dimensions



Emic ways of thinking about culture

- "Cultural psychology"
- Need to learn the norms and beliefs that are indigenous to each culture
- Concepts, treatments, measures developed in one culture do not transfer to others
- Multicultural Counseling Competencies is an emic model to diversity

Multicultural Counseling Competencies

	Own Cultural Values & Biases	Client's Worldview	Culturally Appropriate Interventions
Attitudes & Beliefs			
Knowledge			
Skills			

Sources: Arredondo et al., 1996; Sue et al., 1992

MCC example

- Attitudes and beliefs:
  - European Canadian counselor with recent Chinese immigrant couple
    - **Own:** Couples have children for emotional reasons
    - **Client's Worldview:** See having biological child as a link to ancestors
    - **Appropriate Skills:** Can establish empathic rapport with client

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

A cross-cultural model of diversity

- Dimensions of difference (Hofstede, 1983)
  - **Individualism versus collectivism**
  - Power distance
  - Masculinity versus femininity
  - Uncertainty avoidance

Individualism and Collectivism

- Individualism
  - Highest in USA, Canada, UK, Australia, Northern Europe
  - Individual goals ahead of those of group
  - Emphasize personal goals, fulfillment and control
- Collectivism
  - Highest in India, China
  - In-group goals ahead of own
  - Emphasize well-being of group, fulfillment of social roles and obligations

Sources: Markus & Kitayama (1998); Matsumoto et al., (1998)

I/C Example

- Western Individualism
  - Children desired for personal and emotional fulfillment
  - Childlessness is an individual choice
- Confucian Collectivism
  - Children desired to fulfill family needs and expectations
  - Childlessness may result in exclusion from social roles

Sources: Bos et al. (2005); Bos & van Rooij (2007); Hynie & Hammer Burns (2006)

I/C and Counseling

- Western Individualism
  - Focus on inner states and emotions
  - Emotions expressed openly
  - Communication direct
  - Independence ideal
  - Pursue conflict and resolution
- Confucian Collectivism
  - Focus on social environment
  - Emotions controlled
  - Communication indirect
  - Interdependence ideal
  - Pursue harmonious relationships

Sources: Draguns (2002); Heine (2001); Triandis (2001)

What does your client believe?

- Should relationships between couples be egalitarian or hierarchical?
- Should good communication between couples be direct or indirect?
- Should emotions be expressed openly or controlled?
- How much autonomy on the part of individual family members is healthy and appropriate?

Source: Gushee et al. (2005)

Danger!!!

- Risk of stereotyping
  - Individuals vary greatly within cultures!!
- Risk of overgeneralizing
  - Cultures differ greatly in terms of specific beliefs, values and norms, even if they are from the same region
- Risk of overconfidence or underconfidence
  - There is a gap between multicultural counseling theory and evidence based practice (Worthington et al., 2007)

Enhancing Cultural Awareness

- Learn more about other cultural worldviews
  - Literature, film, newspapers, community events
- Attend conferences and workshops on culture
- Enroll in ethnic studies courses
- Learn another language

Source: Arredondo et al. (1996)

Practicing with Cultural Diversity

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

- *"You know, you don't have to have a trained mental health therapist for each culture in detail...the client can teach the therapist what the culture is about, it is a two way journey." (Service Provider)*

Source: Hynie & Crooks (2007)

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