When treatment fails: Psychological aspects of unsuccessful treatment

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Overview

A) General psychological framework
1. Infertility treatment: *against the odds*
2. Psychology of pregnancy and loss: *between something and nothing*
3. Treatment failure: *the winding road and how to walk it*
4. Trying again: *the roller coaster ride*
5. Intervention Model: *reading between the lines*

B) Nurses in the (in)fertility unit
1. Role of the nurse in the unit: *'building bridges'*
2. Referrals: *'how, when and why'*
3. Dealing with the emotional impact: *'holding it together'*

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B) Nurses in the (in)fertility unit

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To understand any living thing,
you must creep within
and feel the beating of its heart.

W. Macneile Dixon

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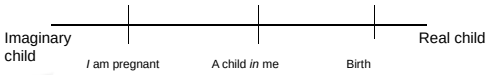
1) Infertility treatment: *against the odds*

- Success rates IVF: 30%
- Unsuccessful treatment : 70%
- Fertility unit mostly deals with 'failure and trying again'
- Feeling of 'against the odds' often unanticipated

2) Psychology of pregnancy and pregnancy loss

Unfulfilled wish for a child

Continuum:



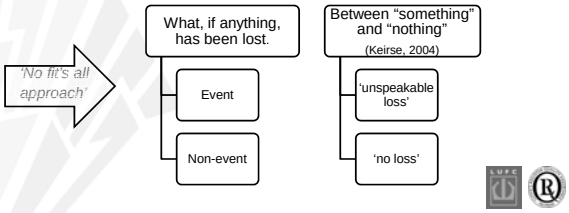
- wish for a child: process of attachment and growing towards an 'imaginary' baby and confronting reality
  - *e.g. the 'wished' for child versus the 'actual child'*
- attachment and interpretation of the child wish can differ:
  - *e.g. woman who became pregnant spontaneously versus woman who has been in 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*

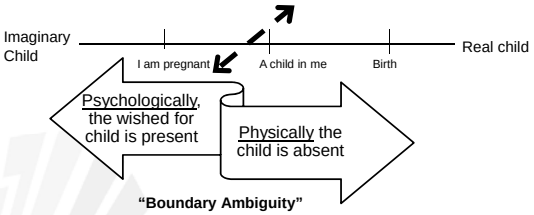
'Unsuccessful treatment and pregnancy loss'

=

"Ambiguous Loss"

(Rosenblatt, 1987)





"Boundary Ambiguity"

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

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3) Treatment failure: *the winding road?*

- Options if treatment fails:
  1) **No Hcg:**
     - try again >< stop treatment
  2) **Grey area: Biochemical pregnancy**
     - Pregnancy
     - Miscarriage
  3) **The end of the biological line:**
     - 3rd party reproduction
     - Adoption
  4) **Ending infertility treatment: challenges**

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3) Treatment failure: *the winding road?*

3a) Grieving in the context of pregnancy/pregnancy loss/infertility/unsuccessful treatment

3b) Ending infertility treatment: challenges

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3a) Treatment failure: the winding road and how to walk it…

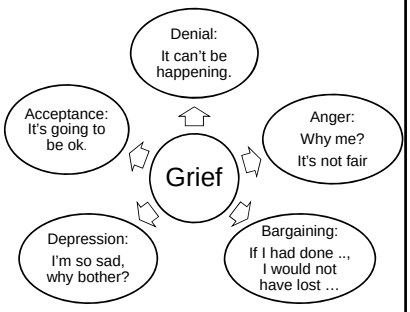
- Treatment failure can evoke a number of emotional and physical reactions:
  - Sadness, disappointment, anger, numbness,crying, ….
  - Headache, muscle tension, stomach problems, …
- Grieving occurs often, but not always

→Individual differences in coping
→Gender differences

3a) Stages of grief

(Elizabeth Kübler-Ross, 1969)

- Steps not necessarily linear.
- Diverse individual differences.
- Normalize grief experience + easy to recognize
- Newer grief theories: process models
- From severing bonds to maintaining bonds
- Focus on cognition and meaning making in addition to emotion
- Challenges concept of endpoint



3) Treatment failure:
the winding road and how to walk it.

3a) Unique aspects of grief

(in infertility, biochemical pregnancy, miscarriage,…)

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

3) Treatment failure:
the winding road and how to walk it.

3a) Unique aspects of grief in infertility, pregnancy loss…

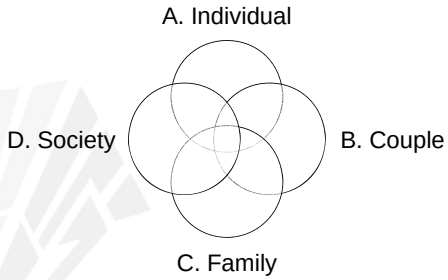
- Grieving is difficult because
  - Prospective nature of the loss:
    - o *'pain of not ever knowing'*
    - o *mourning for the hopes, wishes and fantasies of the future baby*
  - 'Invisible' loss
  - Few socially acceptable avenues for mourning
  - Often lack of social support
    - o *intensifies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

3a) Unpredictable pattern of perinatal grief

- Tidal wave: growing and cresting, then reclining + repetitive waves
  - recurrent grieving throughout life span
- 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, memory problems, impaired decision making, intrusive thoughts about fetus, hallucinations of hearing baby cry
  - **Social symptoms**: isolation, withdrawal

3a) Grief … in the eyes of the beholder….
A systemic approach



3a) Grief … in the eyes of the beholder….
A systemic approach

- Fertility unit: working with ‘patients’
- Outside of the fertility unit:
  not a vacuum for our patients
  → larger system
- We don’t work with the system,
  but we do have to deal with it.

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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Grief … in the eyes of the beholder….
A systemic approach

A. Individual

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

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Grief … in the eyes of the beholder….
A systemic approach

B. Couple

Women and men have equal but different needs

- Meaning of the child wish
- Physical experience and pain
- Reality of the loss of the 'wished for child'
- Etiology of fertility problems
- Decision making strategies

→ psycho-education + validation

Relationship under pressure:
- conflict
- fusion

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)
  - Sexual relationship can be difficult and strained
    → physical reminder of the pregnancy/loss/infertility/etc.

Grief … in the eyes of the beholder….
A systemic approach

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'm falling apart'
  - Promoting self care activities at follow-up
    Healing physically and emotionally
  - Support groups: feeling connected and understood

Grief … in the eyes of the beholder….
A systemic approach

C. Family

- Often overlooked
- Unfulfilled wish for a child = family loss

parents, grandparents, siblings, other relatives

- 'We inform our patients. They inform their family.'
- Dealing with social expectations, social desirability and taboo
- Grief in the family/ child wish in the family
- Social support:
  - For patients
  - For themselves

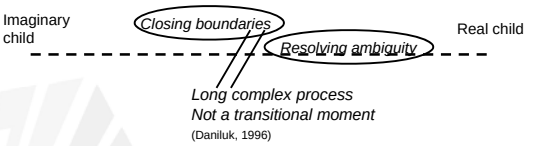
D. Society

‘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: ‘life goes on’

3b) Ending infertility treatment

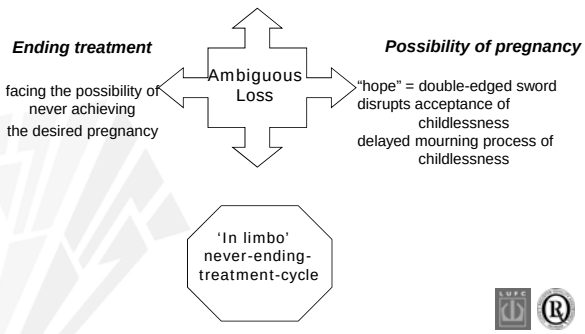
‘not yet pregnant’ **‘not going to be pregnant’**



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

“When enough, is enough.”



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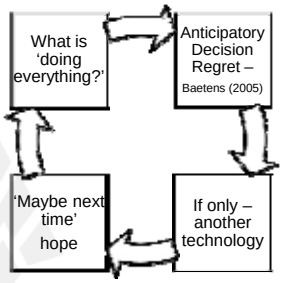

- Routes into IVF are clear, out of it more obscure.
- Subjective end point, determined by many factors

Factors impacting the end of treatment (Takefman, 2006)

Sociodemographic Factors
- Parity
- Age
- Gender
- finances

Interpersonal Factors
- Relationship beliefs
- Expectations about 'family life'
- Uncertainty about future
- Couple congruence

Emotional factors
- Optimism
- Psychological distress
- Having done all you can – 'no regrets'

Fear Factors
- Not being able to cope
- Childless life is unfulfilling
- Relational anxiety

3b) Ending infertility 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

'The winding road…'

- Review and reflect on infertility experience emotionally, cognitively,… to 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 and invades most areas of your life
- Stance of the doctor: hopeful or not?
  - 'carrot' dangling in front of you
  - treatment = gamble, addiction

Ending treatment sessions

'Getting lost and stuck – along the way'

- '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

4) Trying again: *the roller coaster ride.*

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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4) Trying again: *the roller coaster ride.*

- It takes time to process information
- It takes time to process emotions

→Anxiety and wish to fix the problem >< careful consider of short term and long term implications of treatment decisions

→Factors influencing decision making

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4) Trying again: *the roller coaster ride.*

- Treatment decision making:
  - **Situational factors**: physical invasiveness, financial costs, commitment, short- and long term consequences of interventions and drugs used, probability of successful outcome
  - **Personal factors**: beliefs and values about importance of parenthood, morality and ethics involving treatment option, religious beliefs, ethnic and cultural values
  - **Other factors**: age, gender role identity, emotional well-being, self-esteem, locus of control, …

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4) Trying again: *the roller coaster ride.*

"Health care professionals appear to exert significant influence in the determination of couples' treatment decision" (Frank, 1989)

- Ranked 3rd after personal and partner's beliefs
- Ranked higher than degree of emotional stress, probability of success, opinions of family and friends, legal ramifications, religious beliefs

→ Important to recognize our own bias in acceptability and viability of treatment options

→ Non-verbal communication!

→ Need to empower patient to make decision within the context of their lives

5. Intervention model (Jack Annon, 1976):
reading between the lines

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

5) Intervention model : caveat

- Every couple is unique !
- Be sensitive !
- Keep your eyes open !
- Listen, don't judge !
- Remember yourself !
- Remember your place !

B) Nurses in the (in)fertility unit

1. Role of the nurse in the unit: *'building bridges'*
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1) Role of the nurse in the unit:
'building bridges'

- 'Bridge function' ~ mediators
  - Patient care: spokesperson/sounding board
  - Bridge to doctors
  - Bridge to lab personnel
  - Bridge to other disciplines
  - Bridge to paramedical staff
- General training + specific setting and skills

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1) Role of the nurse in the unit:
'building bridges'

- Nurse/midwife : unique position
  - Maintaining constant contact with patients
  - Specific technical skills
  - Caring for patients
  - Emotional and physical needs
  - Observation and support

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2) Referrals: 'how, when and why'?

'Every man (woman) to his trade.'

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2) Referrals: 'how, when and why'?

- Referring to counsellors/ mental health professionals/ psychologists:
  - **HOW**: what to tell the patients
  - **WHEN**: indications for infertility counselling and/or psychotherapy
  - **WHY**: benefit for patients (and fertility units)

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3) Dealing with the emotional impact: 'holding it together'

- Qualitative study – (Payne & Goedeke, 2007)
  - To investigate roles and experiences of nurses in art
  - New Zealand: interviews 15 nurses
  - Interpretive description

Main findings:

*role of the nurse to 'hold together' multiple components of the art-experience

*role of the nurse may positively contribute to patients' experience

*nurses need to be educated in both emotional and medical aspects of art

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3) Dealing with the emotional impact: 'holding it together'

- 'Holding it together'
  1) Supporting
  2) Informing
  3) Interpreting
  4) Advocacy

→day-to-day close contact

→constant presence (intervention + telephone communication)

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3) Dealing with the emotional impact: 'holding it together'

- **Potential role of the nurse/midwife**:
  - Holding together clients' emotional and physical experiences of art
    = patient-oriented
  - Holding together roles of different specialist team members
    = team-oriented
  - Holding together own emotions
    = organization-oriented

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Take home message

…

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Thank you for your attention!

Any questions?

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Thank you for your attention.
Questions?

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