when hello becomes goodbye – grief in art

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thank you and

acknowledgement



about me

- Graduated UWA 1997 BSc (Honours)
- Trainee Embryologist 1998 aged 21
- Small cog, enormous machine that is ART



what is infertility? The inability to conceive after one year of unprotected intercourse, or after 6 months in those aged ≥35, OR The inability to carry a pregnancy to term (live birth).

prevalence

- Infertility affects at least 1 in 6 people
- 186 million people worldwide or 17.5% of adult population
- Major health challenge globally
- Significant inequity in access to treatment persists

https://www.who.int/publications/i/item/978920068315





impact

- Infertility = reproductive trauma
- High incidence of anxiety & depression
- Invisible condition
 - invisible loss
 - repeated mourning
- Deprivation of basic reproductive right



recognition

- WHO acknowledge impact of infertility not well recognized (industry or society)
- Focus on:
 - STD
 - Unwanted pregnancy
- Little to no acknowledgement of:
 - Fertility
 - Preconception health epigenetic effects



- Physical pain & discomfort associated with treatment and/or cause of infertility. Eg — Endo
 - Post-operative pain & discomfort
 - Risk of illness secondary to treatment
 - Hormonal side-effects of treatment. Eg bloating,
 constipation

mental impact

- Sense of uselessness
- Identity & purpose in life undermined
- Hopelessness
- Feelings of inadequacy
 - o All my fault
 - o Not enough of a man / woman





sexual impact

- Diagnosis & treatment can lead to sexual dysfunction.
- Sex becomes perfunctory
- Spontaneity is lost to mechanics
- And then the mechanics fail!
- Guilt + inadequacy

emotional impact

- Roller-coaster of hope and grief through seeking help, diagnosis, treatment and unsuccessful treatment
- Grief
 - o Involuntary childlessness
 - o Loss of an embryo at any stage
- Uncertainty
 - o No guarantee of success
 - o Lack of control over treatment OR outcomes





financial impact

- Bulk-billing / public fertility treatment
 very limited treatment not accessible to all
- High cost of treatment
 - o Medicare Funding significant OOP
 - o Private Health Insurance limited coverage
- Missing out
- Accessing superannuation





loss & grief

- Loss within loss:
 - o Loss of reproductive choice
 - o Loss due to diagnosis
 - o Loss when treatments fail
- Lack of control & privacy
- Despair, fear & anxiety surrounding treatment & outcomes
- Mourning & grief akin to loss of a loved one

industry role

- >40 years in grief & support still not done well!
- Multifaceted approach to treatment, but approach to support remains less cohesive
- Clinical and detached









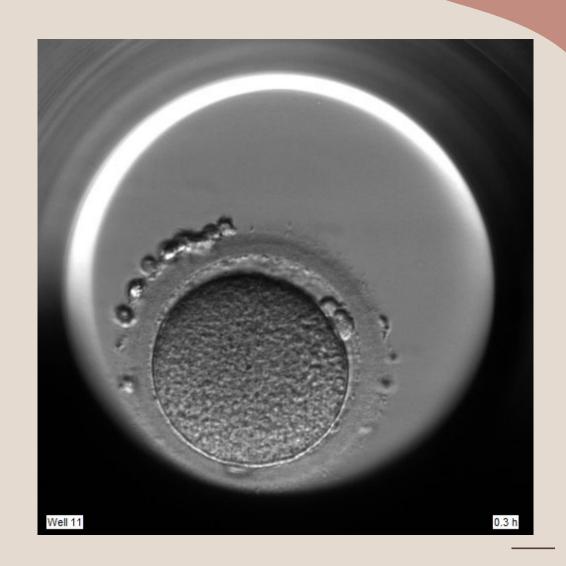
egg collection

- Meet patients in theatre
 - o Sometimes for the first time!
 - o Bright lights + stainless steel
 - o Scary, embarrassing
- Anaesthetic + legs in stirrups
- Cast of many!
- Risk of failure, risk of complications
 - o Fewer eggs / no eggs
 - o Anaesthetic risk
 - o TVOA risk



embryo culture

- 1 to 6 days
- Variable can be awful!
- Looking for milestones and significant events
 - o Cell numbers
 - o Cleavage pattern
 - o Abnormalities







embryo freezing

- Embryos in storage for ≤10 years
- Survival not guaranteed
 - o Grief over lost 'baby'
 - o Grief over lost chance at conception
- What to do with surplus embryos?
- Donate or discard?

breaking bad news

- Career started 1998
 - 021
 - o Green!
 - o Delivering life-changing results to patients
- No training in BBN until 2008
- Nothing further since then!

Bad News a

OW CAN YOU TRY AN

Who should tell them

- How should it be don
- When to do it?
- Who should be with t
 What does / should tl
 - hat to say and who

loss beyond the laboratory

- Failed cycles
- Biochemical & failed pregnancy
- Second and third trimester pregnancy loss
- Foetal abnormalities
- Stillbirth & NND



compassion fatigue

- Repeated delivery of bad news
 - Managing patient emotions
- Acknowledging distress and upset
- Maintaining professional approach
 - Negative feedback

making a difference





















thank you