



RETHINKIN EXPERT SEMINAR: COUNSELING INTENDED PARENTS WHO CONSIDER USING DONOR GAMETES

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CONTENT

- Patients in need of donor gametes and type of donation
- Counseling trajectory
- Egg and Sperm donation at UZ Brussel in numbers
- What is counseling?
- What do we offer during counseling?
 - Access to treatment?
 - Provision of information
 - Assess readiness
 - Guide decision making on (non-) disclosure and provide psycho-education
- Conclusions





PATIENTS IN NEED OF DONORGAMETES AND TYPES OF DONATION

Patients:







- Types of donation:
 - Anonymous
 - Known donation





COUNSELING TRAJECTORY



2 consultations with the psychologist → fertility doctor → fertility counsellor



only in case of egg donation within the couple

→ 1 consultation with the psychologist → fertility doctor → fertility counsellor



at least one consultation with the psychologist → fertility doctor → fertility counsellor





EGG AND SPERMDONATION AT UZ BRUSSEL IN NUMBERS

IUI with donor sperm: **432** patients (232 - (2)138 - (2)62







IVF with donor sperm: **267** patients

N° **patients** requesting for anonymous egg donation:

▶ 2019: **263** - 2020: **157** - 2021: **75**

No of thawing **cycles** for anonymous egg donation:

▶ 2019: **177** - 2020: **155**

N° oocyte pick-up's of anonymous egg donors:

▶ 2019: 86 - 2020: 84 - 2021: 37





WHAT IS COUNSELING?

- Information gathering and analysis
- Implications and decisionmaking counseling
- Support counseling
- Crisis counseling
- Therapeutic counseling

patient-centered care

→ NON-DIRECTIVE COUNSELLING with respect for PATIENT's AUTONOMY!

infertility counseling

psychotherapy

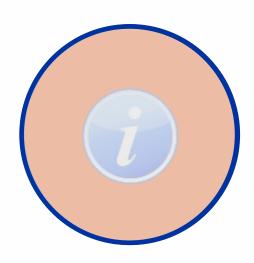
Counseling within infertility (Strauss, B., Boivin, J. 2002)





WHAT DO WE OFFER DURING COUNSELING?













ACCESS TO TREATMENT?

access free pass

- 2007: Law Medical Assisted Reproduction
- Art. 5: De fertiliteitscentra zorgen voor een grote transparantie van hun opties in verband met de toegankelijkheid van de behandeling: ze kunnen ten aanzien van de tot hen gerichte verzoeken een beroep doen op de gewetensclausule
- No treatment obligation (Oath of Hippocrates)
- Quality handbook
- Welfare of the child (Pennings 1999, 2007)
- The reasonable welfare principle: the future child has the possibility :
 - to develop normal human interests
 - to achieve life goals, which are generally considered to make human life worthwhile
- Ethical committee CRG/CMG







WHAT DO WE OFFER DURING COUNSELLING?













PROVIDE INFORMATION

- Type of donation? Anonymous vs known donation
- Implications of types of donation
- Medical information on use of donor gametes
- Legal information on use of donor gametes
- Donor assessment and selection?
- (Non-) Disclosure practices after use of donor gametes

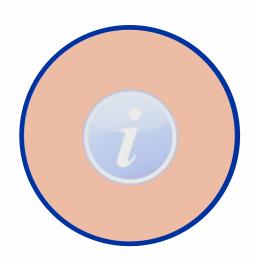






WHAT DO WE OFFER DURING COUNSELLING?







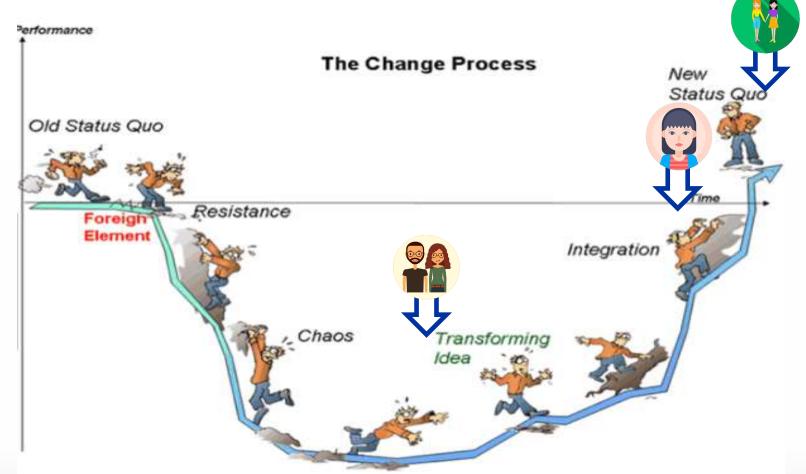






GUIDE THE TRANSITION TO PARENTHOOD WITH USE OF DG











GUIDE THE TRANSITION TO PARENTHOOD WITH USE OF DG

IN HETEROSEXUAL COUPLES



- Infertility history of the couple: experience and their motivation/reason to use donor gametes?
- Grieving process concerning infertility and the inability to have a child biologically related to both parents
- How and when did they decide to use donor gametes?
- Feelings and Comfort level with use of donor gametes (e.g. biological inequality and attachment concerns)
- Explore the meanings both partners attribute to the donor
- Explore disclosure intentions (towards significant others? towards the child?)

(Covington & Hammer Burns, 2017)





GUIDE THE TRANSITION TO PARENTHOOD WITH USE OF DG



"Making the child mine"

- Preconception strategies
 - Decisions about the type of donor
 - Minimization of the donor's contribution
 - Normalization of family diversity
- Importance of Pregnancy 'central role in the ownership of the child'
- Establishing a bond
- Child as wanted
- Mothers' influence beyond genetics
- Physical resemblance
- Managing reminders of egg donation
 - Comments about the child's appearance
 - Other reminders
- Finding a place for the donor

(Imrie et al., 2020)





ASSESS READINESS



Heterosexual couples

- Convinced that treatment option with own genetic material are exhausted
- Idea they tried everything with own material
- Time to adjust
- Switch from not ideal way but can give us our ideal family
- Focus on the desire to have a child ←→ focus on achieving a pregnancy
- Feeling at ease with their CHOICE to use donor material to conceive a child
 ←→ no choice
- Open attitude (to information, open for discussion)
- Awareness of a family building process = a continuous process





ASSES READINESS



Lesbian couples

- Stable relationship and who gets to go first?
- Openness towards network
- Usually enough time to accept the idea of use of donor gametes
- Reflection on the type of donation and donor as a person in the child's life
- Feeling confident on how to explain donor conception





ASSES READINESS



Single motherhood

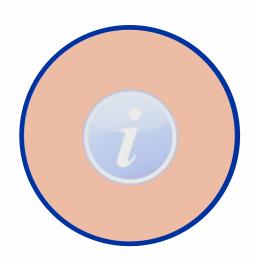
- Desire for a child > desire for a partner
- Significant others know and are supportive
- Emotional, professional and financial stability
- Experiences with partner relationships
- Not an impulsive decision!!
- Feeling at ease with use of donor material
- Feeling confident on how to explain donor conception





WHAT DO WE OFFER DURING COUNSELLING?













TO TELL OR NOT TO TELL?



	Openness	Secrecy
Single women	YES	NO GO
Lesbian couples	YES	NO GO
Heterosexual couples spermdonation	OPTIONAL	OPTIONAL
Heterosexual couples eggdonation	OPTIONAL	OPTIONAL

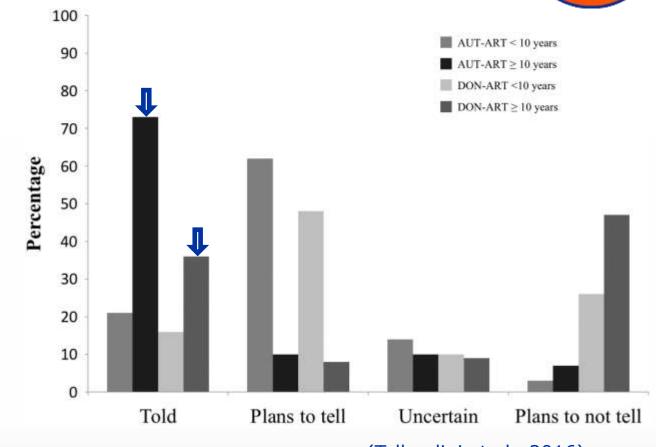




DISCLOSURE PRACTICES: PAST AND PRESENT



- Times have changed!
 - Before: Disclosure is harmful!!
 - Nowadays: Openness is still not a 'done deal' (Nordqvist et al, 2014)
- 61% revealed OD and 58% revealed SD (Sweden) (Lampic et al, 2020)



(Tallandini et al., 2016)





WHY OPT FOR SECRECY?



- No 'need' to tell because there is a pregnancy (<> adoption)
- No 'need' to tell because it will be "our child" / the child will reject me
- It will undermine my relationship with the child or disturb the child's development
- Religious, cultural beliefs make disclosure 'impossible'
- To protect the child (and oneself as a parent) from stigmatization
- It is considered a "private" matter e.g. infertility raises questions on masculinity/manhood
- Fear of stigmatization = justification for non-disclosure







ARE SECRETS HARMFUL?



- Secrecy = Often rooted in shame of broken rules, taboo subjects
- With the aim to prevent embarrassment, protect a family (member) from judgment or avoid punishment
- Negative impact on family dynamics!
 - Unequal division of power
 - Coalitions and therefor 'distance' between those aware and the unaware
- Internal trust issues, increased anxiety and shame
- Motivation to keep a secret?







IS NON-DISCLOSURE OF DC HARMFUL?



- Disclosed (too) late in life, in anger, by the inappropriate people
- Children feel betrayed by their parents rather then have problems with their donor conception!
- Genealogical bewilderment and identity problems or frustration when no information is available on the donor
- Hard to measure





WHY OPENNESS IN HETEROSEXUAL COUPLES?

- Alleviates the stress that secrets induce
- Avoids the (psychological) distance between those who know and those who may not know
- The child has the right to know his mode of conception
- Finding out late in life or by chance (<> via parents) causes trust issues between parents and children



Spit Kits, Sperm Donors, and the End of Family Secrets

At-home DNA testing is more accessible than ever. In The Lost Family, Libby Copeland learns how genetic revelations are upending lives.



The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business •

Joyce C. Harper ▼, Debbie Kennett, Dan Reisel

Human Reproduction, Volume 31, Issue 6, June 2016, Pages 1135–1140, https://doi.org/10.1093/humrep/dew065





WHY OPENNESS IN HETEROSEXUAL COUPLES?



- CHILDREN who are informed ARE DOING FINE!
- Children who know before age 7 show more psychosocial wellbeing at age 14 and have better family relationships (Ilioi et al., 2017)
- Early disclosure shows that (Jadva et al., 2009):
 - Children accept the information
 - Integrate it into their life story
 - Children have themselves positive reactions toward the disclosure decision of their parents



Nieuw informatiepunt zet zich in voor openheid pver donorconceptie

mrt 4, 2021

Op 12 maart 2021 wordt het Landelijk Informatiepunt Donorconceptie gelanceerd.





WHEN IS THE RIGHT TIME TO TELL?



- Lesbian Couples: strait away!
- Single mothers: strait away!
- Heterosexual couples: 4, 5, 6 years of age certainly < age 7!
 - <> "the right time strategy": When the child is old enough to understand
 - A joint decision made by both parents (Lampic et al, 2020)
 - Not a single occasion
 - Continuous process with several layers of information
- AVOID: anxiety-driven disclosure and move towards a conscientious choice for disclosure (Zadeh et al, 2016)







OPENNESS VS SECRECY?

What do patients need to take into account?



- Use of donor material = major life-event to be managed an entire life-time for the parents and the child!
- Environment focused on physical resemblance
- Environment will confront you with the use of donor material
- Openness is a continuous process!! <> tell it only once
- Hiding the truth = lying in the long run





BOOKS, STORIES, VIDEO'S

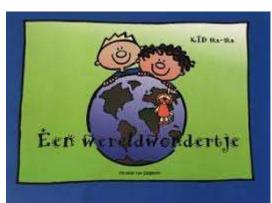
 For heterosexual couples, lesbian couples and single mothers





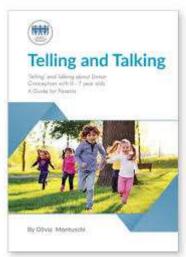
















CONCLUSIONS

Counseling intended parents who consider use of donor gametes:

- Times have changed!
- Counseling has evolved!
- Screening as well as providing information, preparation for DC, psychoeducation
- Initiating a family building process (<> a solution to one problem)
- Guide decision making regarding (non-)disclosure
- Providing a professional network and long term follow-up
- Challenging





THANK YOU





REFERENCES

- Sharon N Covington, Linda Hammer Burns. Infertility Counseling 2ed: A Comprehensive Handbook for Clinicians Paperback – Cambridge University Press; 2nd ed. editie (2 mei 2017) ISBN-10: 0521619491 ISBN-13: 978-0521619493
- Joyce C. Harper, Debbie Kennett, Dan Reisel (2016). The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business. *Human Reproduction*, Volume 31, Issue 6, June 2016, Pages 1135–1140, https://doi.org/10.1093/humrep/dew065
- Susan Imrie, Vasanti Jadva, Susan Golombok (2020). "Making the child mine": Mothers' thoughts and feelings about the mother-infant relationship in egg donation families. J Fam Psychol. 2020 Jun; 34(4):469-479. https://doi: 10.1037/fam0000619 Epub 2020 Jan 16.
- Petra Nordqvist (2014). The Drive for Openness in Donor Conception: Disclosure and The Trouble with Real Life. International Journal of Law, Policy and the Family, Volume 28, Issue 3, December 2014, Pages 321–338, https://doi.org/10.1093/lawfam/ebu010
- Raes, I., Ravelingien, A., & Pennings, G. (2015). Donor conception disclosure: directive or non-directive counselling? *Journal of Bioethical Inquiry*, 13(3), 369-379.





REFERENCES

- https://satir.web.unc.edu/about-virginia-satir/
- Bernhard Strauss and Jacky Boivin (2002). Fundamental issues in counselling:
 Counselling within infertility. ESHRE Monographs: Guidelines for Counselling in Infertility pp.4–6, 2002
- Maria Anna Tallandini, Liviana Zanchettin, Giorgio Gronchi and Valentina Morsan (2016).
 Parental disclosure of assisted reproductive technology (ART) conception to their children: a systematic and meta-analytic review.
 HumanReproduction, Vol. 31, No. 6pp. 1275–1287, https://doi:10.1093/humrep/dew068



