



# Male Factor Infertility: Meeting men's unmet emotional and informational needs

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# What do we know?

- MFI is extremely common
- 8–12% of reproductive-aged couples worldwide suffer from infertility
- Males contribute to 50% of infertility cases<sup>1</sup>.

# Psychosocial Impact

- Signs of depression/anxiety can be major predictors of QOL during the investigation of infertility<sup>2</sup>
- Men with MFI responded more negatively to infertility, than men without a male factor problem<sup>3</sup>
- Profound grief and loss for those who had not biologically fathered a child and had been diagnosed as the sole cause of the couple's infertility problems<sup>4</sup>

# Psychosocial Continued

- Inability to conceive is seen by men as a social stigma, a reflection of impaired masculinity, or as a disability
- Experience self-blame and lower self-esteem, compared to men in couples with female infertility diagnoses
- Lower quality of life after diagnosis
- Men living without children after unsuccessful IVF treatment had a lower quality of life years after treatment discontinuation compared to those with children<sup>6, 8-9</sup>

# The Fertility Experience

- Infertility has negative impacts on psychosocial functioning
- Feelings like grief & loss can continue beyond treatment, esp. unsuccessful<sup>5-7</sup>
- Like clinics themselves, support services (e.g. counselling) are female facing and may not be well utilized by men
- Is this because men 'don't need them' or is it because for some men, they 'aren't what is wanted'?

# 2013 Collaboration

- Kevin McEleny and I meet and share mutual work interests
- His experience working with men with MFI and my experience working with stress during IVF...
- How can we help meet men's needs during this period: a collaboration begins

Stevenson, Cheng, Chang, & McEleny (in press). **Male public perception of male-factor infertility in the United Kingdom**, British Journal of Nursing

- Sought to assess the UK public's understanding and awareness of male fertility issues compared to female fertility issues
- Survey across the UK

- N= 2006 men responded to the survey
- Over half: > 30 years old.
- 28.17% of the participants already had children
- Of the total sample 30.2% (n=605) had male fertility problems



# Summary of findings

- The public feel male infertility is not discussed as much as female infertility
- Men are not talking about their infertility with providers and spouses, younger men open to online support
- Public lacks a solid understanding of pertinent lifestyle issues

# What about their emotional and informational needs?



*Report of Empirical Study*

## **Applying the Adaptive Leadership Framework for Chronic Illness to understand how American and British men navigate the infertility process**

**Eleanor L Stevenson<sup>1</sup>, Kevin R McEleny<sup>2</sup>, Eilis Moody<sup>2</sup> and Donald E Bailey<sup>1</sup>**

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- We asked: What are the challenges men recently diagnosed with Male Factor Infertility (MFI) face?
- Prospective qualitative study
- American and British men and their partners with MFI
- Sample size of 13 couples (saturation was reached)

# Male Results: challenges

- Three themes men faced during fertility treatment (**challenges**)
  - Avoidance (of social network, friends with children),
  - Uncertainty (about ability to have a biological child fertility related information, and MFI status/cause/fertility goals)
  - Affective symptoms (sadness, shock, disbelief, denial, about not achieving fatherhood and poor outcomes)

# Male Results: coping

- Three themes related to **coping** men used during fertility treatment
  - Goals (Having clear, actionable steps, focusing on parenthood, exhausting all options)
  - Learning (Getting knowledge from urologist, actively acquiring information/understanding issue)
  - Relationship & Support from partner (Support from health care team. Provision of emotional support, Increased comfort with staff over time)

# Female Results

- Three Themes

- Men's negative emotional response to diagnosis: shock, disappointment, internalization/non- disclosure to social network)
- Women employed intentional strategies to help their partner cope with the diagnosis and treatment, such as the use of prayer/humor, by offering reassurance, support, love, and by active management to reduce negative male feelings
- Fertility assessment/treatment had an impact on their relationship quality:
  - For those who offered reassurance to partners of their love/support, women perceived their relationship as stronger.
  - For those who worked to reduce men's negative impact on their feelings/ego, women perceived their relationship as strained.
  - Women who perceived infertility as a shared experience reported improved relationship quality

- Men are dealing with a lot, so how do we address this?

# Hot off the presses...

- What do men with MFI desire in order to address their psychosocial and educational needs during the fertility process?
- Prospective qualitative study
- Men seeking a MFI consultation with a urologist
- Nineteen participants were recruited from a fertility urology clinic in a large academic medical center; thematic analysis



# Psychosocial and Education Study results

- Mean age: 35.3 yrs
- Participants prefer technology based communication to receive health information (i.e. 'mychart') because of the ease, access, and efficiency
- Participants were not amenable to alternative medical structures (i.e. group sessions for emotional support), but were interested in anonymous digital platforms to meet psychosocial needs

# What have we learned?

- Public has a poor perception
- Men felt the stigma of MFI
- Men have significant information needs
- Men have significant emotional needs
- Women actively manage the IF process
- Men want support but more open to alternative ways to receive it



# How can we help?

- Given this information, something substantive was needed to help men during and after fertility assessment and treatment.

# Peer Support

- Established model for many health care issues
- Fits well with modern busy lives
- Traditional peer support (group therapy)- not what our research participants wanted
  - Most men do not want to meet in person to talk about their fertility issues with their peers
- Modern technology allows us other ways to approach peer support--remotely from a mobile phone and anonymity can be maintained

# Peer Support Platform; needed a partnership

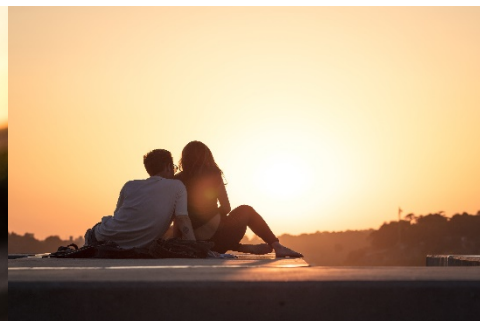
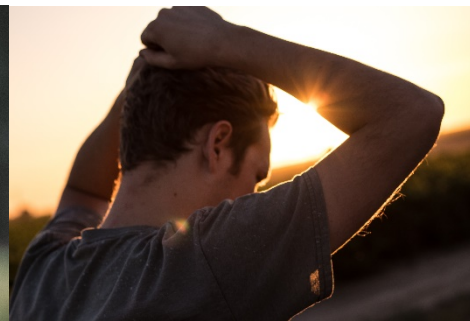


- We approached Cryos International
- Understood /respected our rules on non-commerciality
- Team of IT and Marketing experts complemented our expertise





- From ESHRE 2019 onwards ES & KM worked to prepare original articles, to support the information-seeking adaptive work undertaken by male patients
- Articles are written by leading experts, based on our knowledge of their specialties (50-60)
- Broad variety of themes: Scientific, Medical, Psychosocial
- Male orientated, but articles of interest to women also
- Have developed a Peer Support Platform



# Affiliations established with others

- Widen awareness of AAF in the Fertility Community
- Offer HCPs another tool in their patient support armamentarium
- Encourage users to visit other sites







## WHEN MEDICAL TREATMENT AFFECTS YOUR FERTILITY – WHAT CAN BE DONE?

I often meet individuals whose fertility has been compromised by a medical problem or treatment. Unfortunately the ovaries and testes cannot always be protected from damage caused in treating another, ...



## FROM HER OWN PERSPECTIVE: LIFE AS A CHILD OF SPERM DONATION

My name is Emma Groenbaek, and I am 23 years old. I am studying to be a nurse in Aarhus, Denmark where I was also born and raised. My parents ...



## THINKING ABOUT TRAVELLING ABROAD FOR FERTILITY TREATMENT? THINGS TO CONSIDER

Every year thousands of people make the decision to pack their bags and travel abroad for fertility treatment. Whilst for some this represents the first step toward potential parenthood (perhaps ...



## PARENTING AS AN OLDER FATHER

Later-life parenting is on the rise, and many more babies than ever before are welcomed into their families by older fathers. In 1972, the average age of fathers of newborns ...



## USING DONOR SPERM

If you are reading this, let's start by acknowledging that using donor sperm probably wasn't in your original plans. Babies have been conceived with donor sperm since 1884; until recently, ...



## HAVING YOUR SPERM QUALITY TESTED – HOW DOES IT WORK?

For most men, sperm cells are constantly produced in the testicles, however, it usually takes around two days to generate a new portion of sperm cells after an ejaculation, hence ...





Danielle Kaplan

24. January 2020

[Articles Female](#)[Articles Male](#)

# USING DONOR SPERM

If you are reading this, let's start by acknowledging that using donor sperm probably wasn't in your original plans. Babies have been conceived with donor sperm since 1884; until recently, however, most people using donor sperm were encouraged not to talk about it with their children or communities. In fact, we even lack good estimates of how many children are conceived each year using donor sperm. Over the last few decades we have come to understand the use of donor sperm for what it is – one of many options for building a family.



## Who needs donor sperm to achieve a pregnancy?

Men who use sperm donors do so for two main reasons. One is that either they or their partners do not have sufficient sperm available with which to fertilize an egg, either because of the number of sperm they produce or because of the quality of their sperm. With advances in assisted reproductive technology (ART), it has become increasingly possible for men to use their own sperm for conception. However, some men are azoospermic, meaning that they do not produce any sperm. In that case, donor sperm is needed. Transgender men also do not produce sperm. If their partners also do not currently produce sperm or have their own sperm available, a sperm donor is needed to achieve a pregnancy. At times, men may also use donor sperm if it is discovered that their sperm carry a hereditary genetic mutation that would interfere with creating a viable pregnancy or a healthy child.

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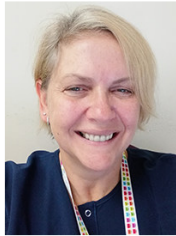
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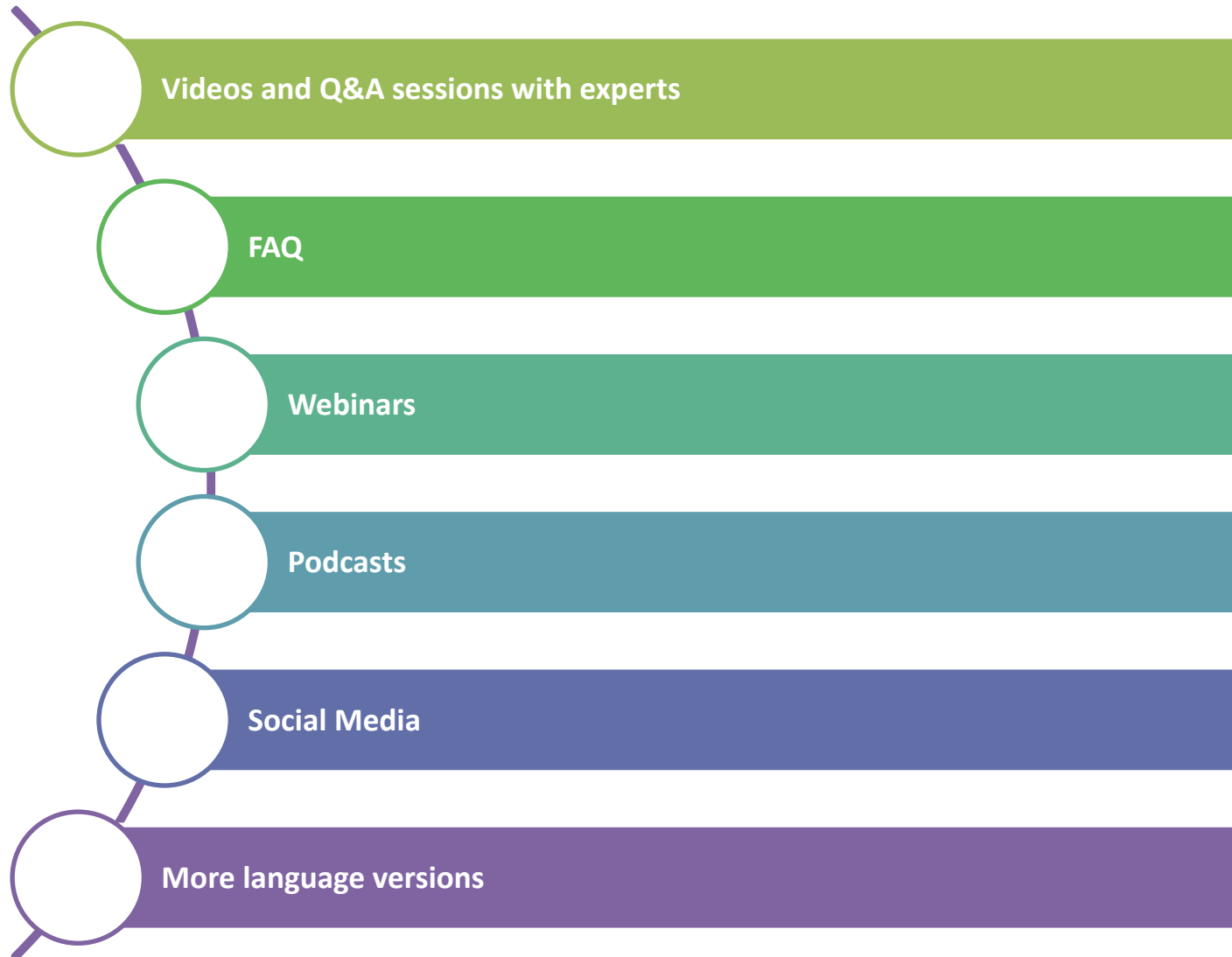
# Support forum

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## Support Forum

This support forum is for all men, who have questions about or experienced infertility and would like to have anonymous discussions with other men in the same situation. Here you have a safe environment where you can talk about your situation, share your concerns and help other men struggling with the same issues. You can only add a topic or reply if you are signed up for the forum. Remember to read the forum rules before posting.

# Future plans



# Conclusions for making an impact

- Click on the logo to go to the website  
or go to <https://all-about-fertility.com/>



*Thank  
you!*

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