#ESHREjc report: Discrete choice experiments and patient decision-making in ART

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PEER PERSPECTIVES

#ESHREjc report: Discrete choice experiments and patient decision-making in ART

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The November ESHRE Journal Club was dedicated to discussing an often-forgotten aspect in ART—patient awareness, attitudes and experiences. The discussion was based on a paper published by Abdulrahim *et al.* (2021)—'Assessing couples' preferences for fresh or frozen embryo transfer: a discrete choice experiment' (Abdulrahim *et al.*, 2021).

In recent years, there has been a shift towards freeze all followed by frozen embryo transfer owing to improved cryopreservation technology (Maheshwari *et al.*, 2018). The aim of this Journal Club was to discuss the limited evidence available in the literature about the value couples place on embryo transfer approaches and their outcomes through the use of a discrete choice experiment (DCE) as in Abdulrahim *et al.* (2021).

A DCE in a clinical setting is a survey-based, quantitative research method to understand patient preferences using hypothetical scenarios. Responses are used to infer the value that patients assign to different attributes in hypothetical treatments and their influence on personal preferences (Mangham *et al.*, 2009). Abdulrahim *et al.* (2021) undertook a DCE to analyse the motivators that patients undergoing their first round of IVF had when asked to choose between two hypothetical treatment options: fresh embryo transfer vs freeze all embryos followed by thawed embryo transfer differing in several attributes. Abdulrahim *et al.* (2021) initially considered seven attributes for inclusion in the DCE, but eventually excluded two (ovarian hyperstimulation syndrome (OHSS) and time to embryo transfer) because they were considered to be linked to the transfer approach itself (fresh vs frozen embryo transfer). A third attribute, pregnancy complication rate, was also dropped after a pilot interviewing phase. Therefore, the number of attributes included in the final DCE was four: live birth rate, miscarriage rate, neonatal complication rate and cost (allowing calculation of patients' willingness to pay); OHSS and time to embryo transfer were incorporated into the description of treatments.

When debating on the question whether the most impactful attributes were chosen by Abdulrahim *et al.* the Journal Club participants discussed the difficulty of finding a balance between including too many or too few attributes. The former that would increase cognitive burden and discourage patients from participating, or too few attributes that would not accurately reflect their patients' decision-making process in clinical practice. Journal Club participants concluded that it is important to consider pilot phases that can help the researchers decide objectively which attributes are necessary, whether different levels should be considered for each attribute, and which attributes can be dropped to improve the design of the DCE. Journal Club participants agreed that the most important thing to keep in mind is that DCE attributes should be quantifiable and help reflect the patients' preferences for treatments.

Abdulrahim *et al.* (2021) showed that when looking at the attributes associated with the question of fresh vs frozen embryo transfer, a higher chance of a live birth was valued by all questionnaire takers but not at a cost of neonatal complications. However, when a subgroup of older patients was asked, it was evident that they did not prioritise against elimination of a neonatal complication risk and that live birth was of prime importance. The nature of this considerable result was discussed by Journal Club participants who justified these observations on societal and medical grounds. Specifically, Journal Club participants argued that the combination of a long duration of infertility and advanced age qualifies these patients as poor prognosis patients and, thus, puts them into an emotionally strenuous situation. These patients probably have a different perception and are willing to sacrifice safety for efficacy, as previously shown in a study comparing single vs multiple embryo transfer preference (Newton *et al.*, 2007). However, Journal Club participants felt that interpretation of this result—older patients placing higher value on the success outcome—should be taken with caution since the decision-making process is complex and the design of a DCE (i.e. based on hypothetical scenarios) might not fully reflect the decision. Moreover, it is not *de facto* that couples would make the same choices in real life. Abdulrahim *et al.* (2021) did not take gender differences into consideration, nor report them, in questionnaire results, although Journal Club participants argued these results would have been intriguing since the decision is never left to one partner. Rather, it is the result of compromise between the two and heavily impacted by counselling received and information obtained, including information obtained outside the clinic setting.

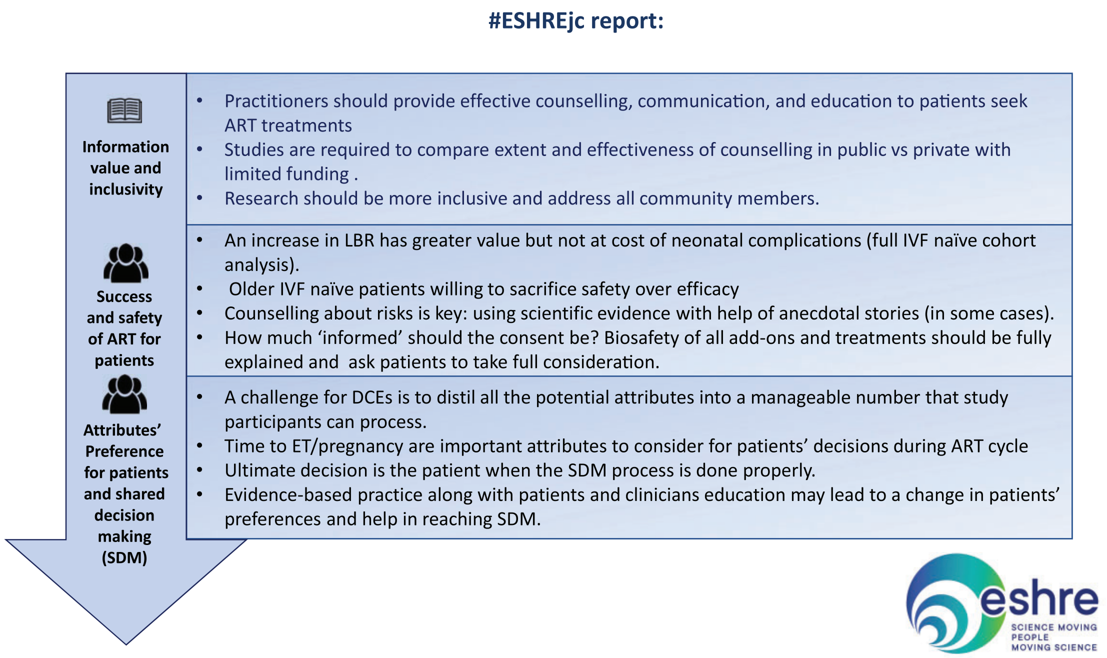
Thorough patient counselling by fertility specialists is paramount for a truly informed decision-making process, but more evidence is required to understand how patients wish to be counselled and what they require to hear. Journal Club participants pondered the value that information about fertility treatments and causes of infertility has for patients. The questionnaire employed by Abdulrahim *et al.* (2021) showed that a striking 40% (87 out of 208) of patients were not informed about the aetiology of their infertility. Journal Club participants concluded that this observation could imply that aetiology is not so important for patients when they are already in the process of ART treatment, or that more effective counselling and communication should be in place. Journal Club participants agreed that improved information resources from ART Centres and professional reproductive medicine societies about ART treatments and infertility aetiology should be available for patients.

From a clinician perspective, convening benefits and risks of multiple treatment options is a complex task. It is not always easy to gain feedback on patients' preferences to build an effective shared decision-making process. A Twitter poll asking Journal Club participants how research should investigate patients' preferences—apart from the ultimate goal, which is a healthy baby—underlined the importance of informed consent as a preferred tool (52%); 29% would like more DCEs and only 19% chose asking patients for feedback at various treatment stages. Journal Club participants discussed that the poll results represented a choice between investigating the individual patient's preferences (discussion during visits) or preferences from a population of patients (DCEs conducted in studies). For example, the 'birth plan', which should be written by patient and doctor together and based on evidence (Mirghafourvand *et al.*, 2019), is gaining popularity in obstetrics. However, in another Twitter poll about a hypothetical 'IVF plan', 43% of Journal Club participants said that the informed consent already has that function. During the visit dedicated to giving an informed consent, in addition to the discussion of general benefits and risks of the various techniques (including obstetrics and neonatal risks), the indication and biosafety of add-ons should be explored. In a private clinic setting, discussion about funding is also a relevant step.

Public funding itself might have an impact on patients' preferences and decisions. Journal Club participants speculated that patients' willingness to make some choices regarding ART treatment and accepting treatment-associated risks would be affected by their economic circumstances, available governmental funding schemes and whether ART treatment is conducted in public or private practices (Smith *et al.*, 2011). Journal Club participants agreed that clinics with different funding schemes should be included in multi-centre DCE studies to find out whether different financial situations would lead to outcomes different to those reported by Abdulrahim *et al.* (2021). Combining factors such as public and private economic resources and time for patients to attain the age for public funding could prove helpful in understanding patient attitudes and needs and, potentially, inform counselling to account for those factors.

Journal Club participants also expressed the urgent need to have clear and inclusive legislations for ART for LGBTQ+ (Lesbian, Gay, Bisexual, Transgender, Questioning, and other sexual identities) communities. Eligibility criteria for receiving government funding and/or ART treatment for LGBTQ+ families differ substantially across countries (Calhaz-Jorge *et al.*, 2020). LGBTQ+ couples undergoing ART, where there usually is gamete donation involved, frequently have segmented cycles with thawed embryo transfer. Despite this, only 3 out of 104 couples included in Abdulrahim *et al.* (2021) were from the LGBTQ+ community. There was a consensus among Journal Club participants that patient-centred research should be more inclusive and representative of all communities. As such, comparison studies between heterosexual and LGBTQ+ families are essential to determine factors that influence decision-making in IVF cycles.

While informed consent with each individual patient or couple is paramount, Journal Club participants discussed whether shared decision-making is always possible and ethical in the field of ART. A clinician's oath is to do no harm and patients may make risky decisions for their treatment plan when they are convinced it will be key in bringing home a baby. For example, a possible risk of OHSS may contraindicate a fresh transfer but patients may insist on a shorter time to pregnancy regardless. In other scenarios, the analysis of risk-benefit carried out by clinicians often shows an even larger discrepancy to that perceived by patients. In other scenarios, such as when choosing how many embryos to transfer or whether to begin a 'futile' cycle with less than 1% estimated success rate, the benefit-risk analysis carried out by clinicians often shows an even larger discrepancy to that perceived by patients (Copp *et al.*, 2020). Journal Club participants agreed that to ensure bodily autonomy, the ultimate decision must lie with the patient as long as the performance of the treatment is ethically acceptable to the physician. However, ideally, shared decision-making will involve thorough and evidence-based discussions before informed consent is given. In this way, patients and clinicians can come to a clear agreement about the best course of treatment—one that retains a high chance of success while not risking the health of patient or child. The Journal Club concluded with participants highlighting the importance of not only factual in-depth discussions but also psychological counselling for patients and support for doctors. For an overall summary, see Fig. 1.



#ESHREjc report:

Information value and inclusivity

- Practitioners should provide effective counselling, communication, and education to patients seek ART treatments
- Studies are required to compare extent and effectiveness of counselling in public vs private with limited funding .
- Research should be more inclusive and address all community members.

Success and safety of ART for patients

- An increase in LBR has greater value but not at cost of neonatal complications (full IVF naïve cohort analysis).
- Older IVF naïve patients willing to sacrifice safety over efficacy
- Counselling about risks is key: using scientific evidence with help of anecdotal stories (in some cases).
- How much 'informed' the consent be? Biosafety of all add-ons and treatments should be fully explained and ask patients to take full consideration.

Attributes' Preference for patients and shared decision making (SDM)

- A challenge for DCEs is to distil all the potential attributes into a manageable number that study participants can process.
- Time to ET/pregnancy are important attributes to consider for patients' decisions during ART cycle
- Ultimate decision is the patient when the SDM process is done properly.
- Evidence-based practice along with patients and clinicians education may lead to a change in patients' preferences and help in reaching SDM.

Figure 1. **#ESHREjc November edition report: overall summary of Journal Club discussion.**

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Conflict of interest

J.L. declares receiving consulting fees from Ferring Pharmaceuticals, Merck KGaA as well as Gedeon-Richter. He also declares having received payment or honoraria for lectures, presentations, speakers bureaus, manuscript writing or educational events from Ferring Pharmaceuticals, Merck KGaA, Gedeon-Richter, MSD, Theramex and IBSA. Finally, he declares having received support for attending meetings and/or travel from Gedeon-Richter.

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