FACULTY OF ARTS AND PHILOSOPHY

AN ETHICAL PERSPECTIVE ON THE PUBLICATION OF THE SUCCESS RATE OF FERTILITY CLINICS

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Public reporting

What is the purpose of making the data public?

1. Informing patients

2. Evaluating and/or sanctioning fertility clinics

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Informed consent

Important ethical argument: informed consent of the patients.

What information should be provided so that patients are adequately informed?
Highly complex issue and it is very difficult to obtain consensus.

Example: you need surgery (heart, knee, brain). What is the success rate of the surgeon who will operate on you?
This is highly relevant information for any patient and is never provided although the information is frequently available to the clinic.

Should the fertility centre inform the patients which embryologist will be handling their embryos? This information is valuable since research has shown that for instance assessment of embryo quality differs between clinics and between embryologists (Storr et al., 2017).
Which gynaecologist will perform the transfer?
Which nurse will perform the insemination?

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Informed consent

Interesting ethical problem: if patients have a right to this information, what would happen when all patients are informed of the success rate of the surgeon? They will all want to be operated on by the best surgeon, leaving the others out of a job.

As a general policy, this reaction is unworkable and counterproductive (but still a smart choice by the patient). When the high performing surgeon is unavailable, the surgery can only be performed by inexperienced surgeons.

Solution: every surgeon should perform around the mean and those who perform below the mean should be assisted to improve. Then every patient will have reasonably good health care.
The same is true for fertility clinics.

Patient-friendly ART

Coming soon to your clinic: patient-friendly ART

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The current practice in medically assisted reproduction is still too exclusively focused on effectiveness and success rates. This has a number of considerable, and more importantly, avoidable drawbacks. Single embryo transfer was an important move away from this model to include safety and welfare of mother and child. Patient-friendly ART goes one big step further. It is composed of a mix of four criteria: cost-effectiveness, equity of access, minimal risk for mother and child and minimal burden for patients. All four components have a strong normative ethical basis: cost-effectiveness relies on the optimal use of community resources to maximise well-being; equity of access is based on justice, minimal risk is founded on the fundamental non-maleficence rule and minimal burden is largely based on the autonomy principle. The inclusion of the four criteria in decision-making about treatment would express these values in clinical practice.

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Patient-centered care

Table 2 Dimensions of patient-centered treatment

	Definition	Includes
Effectiveness	The likelihood that a treatment will result in a desired outcome, which may be broadly understood as achieving parenthood or more narrowly construed as achieving pregnancy and live birth within a particular time-frame	Estimated pregnancy success rates for treatment; Estimated live birth rates for treatment; Estimated number of treatment cycles to achieve pregnancy
Burden	The physical and emotional workload and responsibility that a treatment requires of patients and their partners as well as "the impact of treatment on patient functioning and well-being"	Pain/discomfort of treatment; Strain on relationships; Stress and anxiety associated with treatment
Time	The amount of time involved in treatment; time to achieving parenthood	Time involved in treatments (e.g. appointments); Estimated time to parenthood for treatment; Effect of additional elapsed time on future options
Financial Costs	The out-of-pocket cost of a treatment	Price tag of treatment options; Payment plans/options; Effect of cost on future options
Potential Risks	The negative outcomes associated with treatment that may or may not actually occur	Maternal risks (e.g. OHSS); Fetal/infant/child risks (e.g. prematurity); Multiple gestation/birth
Genetic Parentage	Genetic/biological connection to child	Whether a treatment involves the use of a patient's and partner's own gametes, or involves donated genetic material, such as sperm, egg, or embryo

Duthie et al., 2017

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Patient-centered care

Table III Overall priorities of patie

Dimensions of PCIC	Overall European patients' priorities	
	Overall Euro-pean numeral ranking	Description of the similarities in priorities across countries
Provision information	1	Always top-4
Attitude of and relationship with staff	2	Never bottom-3
Competence of clinic and staff	3	Never bottom-3
Communication	4	Never bottom-3
Patient involvement and privacy	5	Both in top-3 and bottom-3
Emotional support	6	Both in top-3 and bottom-3
Coordination and integration	7	Never top-3
Continuity and transition	8	Never top-3
Physical comfort	9	Never top-3
Accessibility	10	Always bottom-4

Dancet et al., 2012: Additionally, themes that should definitely be covered across all countries include a clear plan of the complete treatment route, information on administering medication, treatments' success rates, differences between clinics (with respect to treatment possibilities, success rates and patients' experiences/satisfaction), and patients' own test results.

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Selective data

Key issue: is the success rate a deciding factor for patients when choosing a clinic? Patients choose a clinic based on multiple criteria and the success rate is only one of them. Of course, when two clinics are comparable on other criteria, the success rate may tip the balance.

Biggest danger of the current data: the exclusive focus on success rate can result in a biased end balance that can be detrimental to patients.

Reporting in an official report avoids more biased presentation of results (that can be found now on several clinic websites) which can be even more misleading. Many Australian clinics still use clinical pregnancy as their main standard.

Patients' reasons for choosing clinics

Table 2 Patients' reasons for choosing clinics: the HFEA responses

	IVF patients	NHS funding
Count	815	646
Six most important reasons you used a particular clinic or clinics?	Location/distance from home/work: 55% Information about success rates: 45% Referred there by GP: 37% Good first impression of the clinic and clinic staff: 33% Treatment options offered: 31% Referred there by a specialist consultant: 23% Cost: 18% Clinic websites: 19% Recommendation from family or friends: 18% Convenient opening hours/flexible appointment times: 17% The HFEA Choose a Fertility Clinic website: 17% Inspection ratings/reports: 14% Events such as open evenings: 11% Feedback on social networks, blogs or forums: 10% Other: 8% Can't remember: 0%	Location/distance from home/work: 48% Information about success rates: 39% Referred there by GP: 47% Good first impression of the clinic and clinic staff: 30% Treatment options offered: 27% Referred there by a specialist consultant: 25% Cost: 17% Clinic websites: 16% Recommendation from family or friends: 15% Convenient opening hours/flexible appointment times: 15% The HFEA Choose a Fertility Clinic website: 14% Inspection ratings/reports: 15% Events such as open evenings: 9% Feedback on social networks, blogs or forums: 11% Other: 6% Can't remember: 0%

Source: HFEA [28]

HFEA Human Fertilisation and Embryology Authority, *IVF* in vitro fertilisation, *GP* General Practitioner

Zhu et al., 2021

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Balancing criteria

The general idea is that the total picture should be taken into account. Patients should balance the different criteria, be it within certain limits.

Example: patients may want to increase the chance of a pregnancy by having three embryos replaced.

The first step would be to find out how patients experience certain things and what they find important.

Example: how many clinics offer patients routinely the option of mild stimulation?

Studies indicate that patients are willing to trade off success in live birth against fewer side effects, less discomfort, shorter duration of stimulation and simplicity (Braat and Kremer, 2004; Pistorius et al., 2006; Hojgaard et al., 2001).

Task for the future: perform surveys on patient satisfaction in all clinics and for the most important criteria.

Clinic success rate

Two problems with clinic success rates:

1. Differences in success may not be caused by differences in quality of treatment but by different patient populations.

Johnson et al., 2007: The two groups differed in their ethnicity, cause of infertility, prevalence of uterine fibroids and smoking and alcohol consumption habits. Group A had a significantly lower live birth rate (OR = 0.45, 95% CI 0.21–0.95, P = 0.02) compared with group B. This study confirms the impact of the non-IVF-related patient characteristics on treatment outcome and the poor validity of comparing IVF clinics' success rates based on the sparse data published by national IVF registries. (UK study)

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Clinic success rate

Two problems with clinic success rates:

2. General information on success rate per clinic tells patients very little on how high their chances are. Patients may believe that the general success rate applies to them.

Collins et al., 2024: Augmented predictors BMI, FSH, and AMH proved to be significant predictors with coefficients of 0.95, 0.76, and 0.88. A 35-year-old woman with three previous cycles has a 38% chance of having a live birth from the next complete cycle of IVF. With a BMI of 30kg/m2 and AMH of 0.80ng/mL her chances change to 14%. (UK study)

The question is whether providing the success rate per clinic does indeed increase the possibility of patients to make an informed decision.

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Public reporting

Public reporting can lead to improved clinical outcomes in a commercial setting (Campanella et al., 2016). This is based on several assumptions such as ‘patients select providers based on success rate’ and ‘providers are motivated to improve quality to attract more patients’.

Gunderson et al., 2020: ‘Public reporting of ART clinical outcomes is intended to drive improvement, promote trust between patients and providers, and inform consumers and payers. However, providers reported that they modified their practices, felt others denied care to poor-prognosis patients, and limited participation of trainees in procedures in response to public reporting of ART outcomes.’ (US study)

The importance of success rate depends on the context: in a commercial setting, this information may be more important than in other settings.

What is the effect in the Belgian context?

Has anyone seen a difference since the publication in May 2024?

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Public reporting and justice

There is evidence that public reporting leads to the exclusion of poor prognosis patients.

Clinics may also introduce stricter criteria (on age, BMI) to boost their numbers.

That reaction goes against accessibility and justice of the system.

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Data collection and quality assurance

The task to verify the quality of the Belgian fertility centres has been assigned to the College of Medics in Reproductive Medicine. This College should organize the external evaluation of all aspects of the application of ART (Royal Decree of 15 Feb. 1999).

It appears that an independent audit of the clinics that perform significantly worse than the mean should be conducted, followed by the implementation of corrective measures to improve their success rate.
When this is done properly, there is no need to make the success rate of the clinics public.
In fact, this task is completely independent of the broadcast.

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Conclusions

Making the success rates of clinics publicly available increases transparency and can increase informed decision making. However, because no information is available on other criteria for the clinics, success may get disproportionate weight and thus reduce informed decision making. To avoid this problem, information on the other criteria (such as patient satisfaction) should also be collected and made public.

The ministry of health (through the College) should guarantee the quality of care provided to patients. Success rate is one important measure to measure the quality of care.

When a centre performs significantly lower than the mean, measures should be taken to improve its performance.

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