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ASSESSING DISCLOSURE ELEMENTS OF IVF CONSENT DOCUMENTS: 1991, 2004, 2014

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INTRODUCTION

This study reviews the content of consent forms and accompanying information sheets used by Canadian IVF clinics (obtained in 1991, 2004 and 2014) with respect to documented inclusion of information that should be provided to patients in accordance with minimum ethical standards for disclosure.[1]

METHODS

Documents requested:

- in 1991 from all 17 clinics
- in 2004 from all 24 clinics
- in 2014 from all 35 clinics

Documents were reviewed for:

- The nature and objective(s) of IVF (Fig. 1)
- The potential benefits of treatment (Fig. 2)
- The potential harms & inconveniences of treatment (Fig. 3)
- Confirmation of voluntariness (Fig. 4)
- Assurances of confidentiality (Fig. 5)
- Disposition options for excess embryos & options for use and discard (Fig. 6)
- Disposition options for excess embryos in the event of donor's death (Fig. 7)

RESULTS

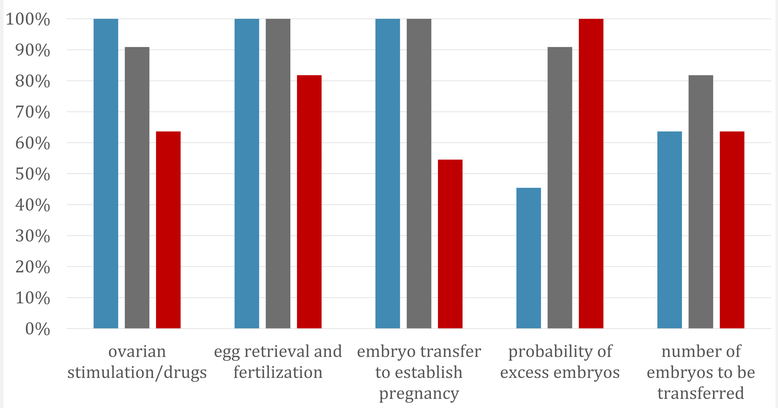
Response rates:

- in 1991 - 11/17 (65%)
- in 2004 - 14/24 (58%)
- in 2014 - 11/35 (31%)

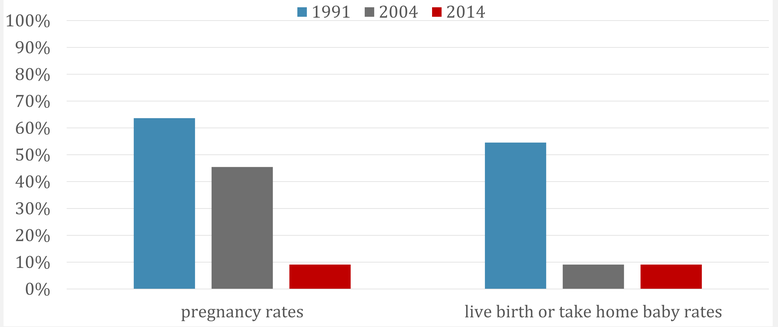
Impossible to make definitive conclusions due to variation in response rates but…

- In general, a decrease in documented disclosure of information that should be provided to patients in accordance with minimum ethical standards for disclosure.[1]
- Trend appears to be reversed in relation to documented disclosure of information about:
  - the probability of excess embryos
  - long term risks
  - the right to revoke consent
  - options for the disposition of excess embryos

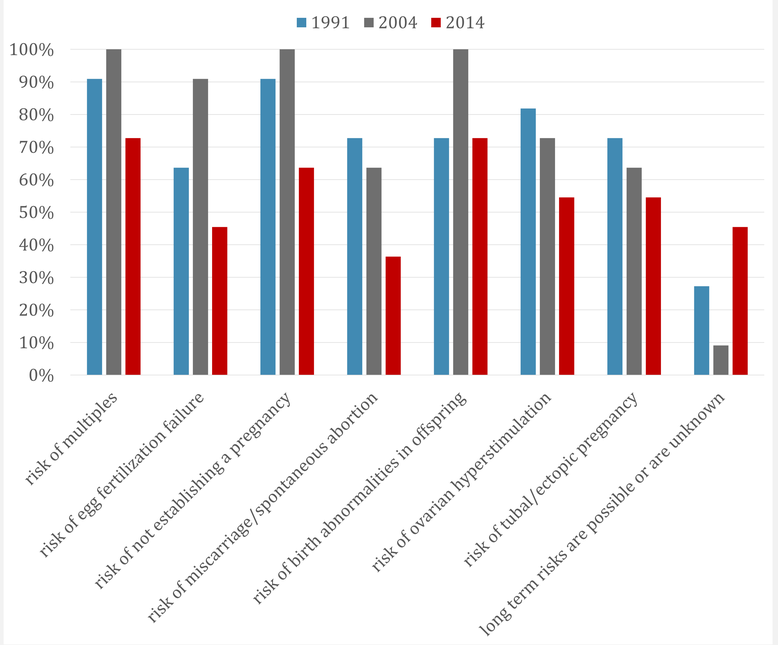
1. Disclosure of Information About the Nature & Objectives of IVF



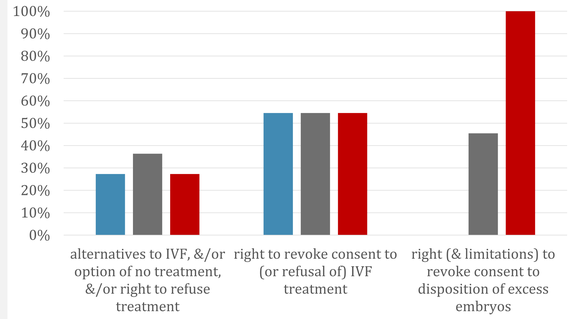
2. Disclosure of Information About Potential Benefits of IVF



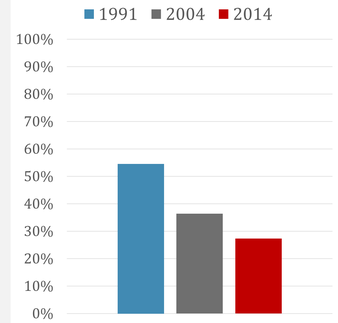
3. Disclosure of Information About Potential Harms or Inconveniences of IVF



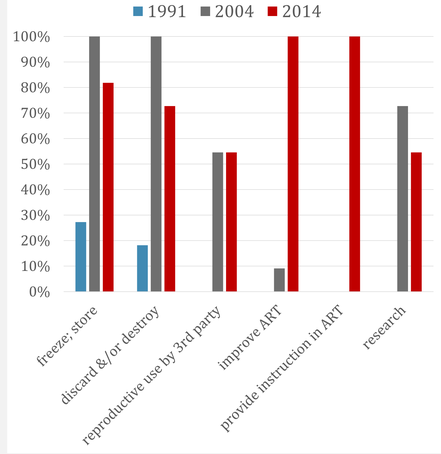
4. Confirmation of Voluntariness



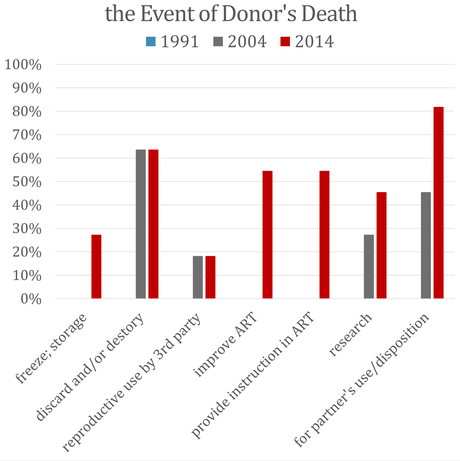
5. Assurances of Confidentiality



6. Disposition Options for Excess Embryos



7. Disposition Options for Excess Embryos in the Event of Donor's Death



CONCLUSION

The disclosure of information relevant to the interests of those who use IVF and those who are born of IVF appears to be on the decrease.

The information that is increasingly being disclosed appears to be distorting the orientation and content of the consent forms and information sheets away from the primary interests of women, couples and children.

As Robert Streiffer points out, a "satisfactory consent process requires more than a good consent form, but a bad consent form not only makes a satisfactory process unlikely, it makes documenting whether the process was satisfactory . . . extremely difficult."[2]

The failure to meet minimum ethical standards for disclosure across clinics' consent documents suggests the need for high quality model consent forms and information sheets. A challenge in Canada is how best to effectively promote and ensure compliance.

1. Baylis, F. (1993). Assisted reproductive technologies: informed choice. *Research studies of the Royal Commission on New Reproductive Technologies-Volume 1: New reproductive technologies: ethical aspects* (pp. 47-147). Ottawa, ON: Minister of Supply and Services Canada.
2. Streiffer, R. (2008). Reply to Robertson, Cohen and Hyun - Big bang theory: more reasons to scrap Bush's stem cell policy. *Hastings Center Report, 38,* 6.