Patient Decision-Making About the Disposition of Surplus Cryopreserved Embryos in Canada

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Abstract

Objective: The objective of this study was to identify factors that contribute to patient decision-making for disposition of surplus cryopreserved embryos in Canada.

Methods: In 2013, interviews were conducted with 45 IVF patients from three clinic sites, representing a total of 33 households. Patients interviewed all had unused cryopreserved embryos in storage in 2010. Initial demographic data collection was followed by one in-depth semi-structured interview conducted in 2013. Data were managed and coded thematically.

Results: Most patients (21 patients, representing 16 households) renewed storage agreements to keep embryos in storage at the time of the interview. Among patients who did not renew their storage agreements at some point between 2010 and 2013, six patients (representing 5 households) had since used all their embryos, two patients (representing one household) had decided to keep their embryos in storage in perpetuity, three patients (representing 3 households) discarded their embryos outright, and 13 patients (representing 9 households) donated their embryos to research or clinical training. Among patients who donated to research or clinical training, three key themes emerged: a desire to "give back," to contribute to scientific progress, and to avoid "wasting" embryos. These patients were not always certain about whether they had chosen research or clinical training.

Conclusion: This study demonstrates the applicability of international findings about embryo disposition decision-making to the Canadian setting. Moreover, it identifies that while patients making disposition decisions often choose to donate embryos to research and/or clinical training, they are not always certain about what these options entail. Clinicians, counsellors, and others must ensure that patients are not only aware of their embryo disposition options, but that they understand the nature of these options as well.

Résumé

Objectif : Cette étude avait pour objectif d'identifier les facteurs qui contribuent au processus décisionnel chez les patientes en ce qui concerne la cession des embryons cryoconservés surnuméraires au Canada.

Méthodes : En 2013, des entrevues ont été menées auprès de 45 patients de FIV (représentant, au total, 33 ménages) au sein de trois cliniques. Les patients interviewés comptaient tous des embryons cryoconservés inutilisés en 2010. La collecte initiale de données démographiques a donné suite à la tenue, en 2013, d'une entrevue semi-structurée approfondie. Les données ont été gérées et codées de façon thématique.

Résultats : La plupart des patients (21 patients, représentant 16 ménages) avaient, au moment de l'entrevue, renouvelé leurs ententes d'entreposage de façon à conserver leurs embryons. Parmi les patients qui n'avaient pas renouvelé leurs ententes d'entreposage à un moment ou à un autre entre 2010 et 2013, six patients (représentant cinq ménages) avaient déjà utilisé tous leurs embryons, deux patients (représentant un ménage) avaient décidé d'entreposer leurs embryons à perpétuité, trois patients (représentant trois ménages) avaient détruit leurs embryons sur-le-champ et 13 patients (représentant neuf ménages) avaient fait don de leurs embryons à la recherche ou à des fins de formation clinique. Chez ces derniers, trois thèmes clés ont pu être dégagés : le souhait de « faire leur part », de contribuer à l'évolution de la science et d'éviter le « gaspillage » d'embryons. Ces patients ne se rappelaient pas toujours s'ils avaient choisi la recherche ou la formation clinique.

Conclusion : Cette étude démontre l'applicabilité des résultats internationaux en ce qui concerne le processus décisionnel quant à la cession des embryons dans le contexte canadien. De surcroît, elle indique que, bien que les patients devant prendre une telle décision choisissent souvent de faire don de leurs embryons à la recherche et/ou à des fins de formation clinique, ils ne sont pas toujours au fait des détails propres à chacune de ces options. Les cliniciens et les conseillers, entre autres, doivent non seulement s'assurer que les patients sont au courant des options qui leur sont offertes pour la cession de leurs embryons, mais également qu'ils comprennent la nature de ces options.

J Obstet Gynaecol Can 2016;38(1):60–66

Key words: cryopreservation, embryo disposition, embryo research, decision-making, qualitative research

Competing Interests: None declared.

Received on January 21, 2015

Accepted on March 11, 2015

http://dx.doi.org/10.1016/j.jogc.2015.11.007

INTRODUCTION

Up to one third of patients who undergo a cycle of controlled ovarian stimulation for IVF treatment will have more embryos created than will ever be transferred.[1] These unused embryos are routinely cryopreserved for patients' own use in a future reproductive cycle, though in

some cases patients will not seek future treatment or, even if they do, a number of cryopreserved embryos may remain.[2,3] Patients with surplus cryopreserved embryos in storage are then left to make decisions about embryo disposition that for many are difficult and rife with "ambivalence, discomfort, and uncertainty."[4]

When patients make these decisions about the use of their embryos in Canada, they are presented with a number of options, codified in the 2007 consent regulations of the *Assisted Human Reproduction Act*. Once embryos are created, patients can consent to their use for their own reproduction, the reproductive purposes of a third party, improving assisted reproduction procedures, providing instruction in assisted reproduction procedures, and/or for use in a specific research project (the goal of which must be stated in the consent).[5] Patients must consent to the use of their embryos for one or more of these purposes, although disposition in the event of unused embryos need not be specified at this time. For example, if a couple consents to the use of their embryos both for their own reproductive purposes and for improving assisted reproduction procedures, embryos no longer needed for reproduction may be used for improving assisted reproduction procedures, precluding the need for a further disposition decision. However, a couple could consent only to the use of their embryos for their own reproduction, and cryopreserve any embryos remaining thereafter with no directions for disposition, necessitating a further decision about how to proceed. Protocols and policies vary by clinic, and it is not always apparent how and when disposition decisions are made.

There is limited information about the disposition of cryopreserved embryos in this complex regulatory context. In a 2007 study, Newton et al. found that patient preferences may change from the time of treatment to the time that a disposition decision is made; however, this research took place prior to the establishment of the regulations outlining consent to use.[6] Further, Côté et al. found, in a 2013 study of signed consent forms, that of 458 individuals who had consented to the cryopreservation of surplus embryos, 68% agreed to the use of their embryos for the improvement of assisted reproduction techniques and training, while only 56% agreed to the use of the embryos in research.[7] In short, existing Canadian research provides some quantitative information on the disposition decisions patients make, but there is no qualitative information about the decision-making process informing how and why patients make certain disposition decisions rather than others.[7] The present study aimed to address the lack of qualitative research on embryo disposition decision-making in Canada by examining those factors that contribute to patient decision-making for disposition of surplus cryopreserved embryos in Canada, drawing on interviews with patients with from three clinic sites.

METHODS

Between March and May 2013, the three participating IVF clinics (in Halifax, Montreal, and Ottawa) sent consent forms to a total of 591 households that included patients who had cryopreserved embryos in storage in 2010 and who had been sent a storage renewal form that year. Study participants from the Montreal site were limited to those who had cryopreserved embryos in storage prior to August 2010, as the introduction of new public funding for IVF in Quebec at that time may have affected patients' disposition decision-making. Patients interested in participating returned signed consent forms and contact information directly to the principal investigator. As the terms of clinic participation included only one attempt to contact patients, no follow-up contact occurred.

Between April and July 2013, patients who returned consent forms were contacted by telephone, and completed a demographic questionnaire. Following this first stage of data collection, semi-structured interviews of one to two hours were conducted, comprised of approximately 70 open-ended questions about patients' views and understandings of the disposition of surplus cryopreserved embryos. Patients were interviewed either individually or as couples, either in English or in French (by native speakers) depending on preference.

Interviews were recorded and transcribed verbatim. To protect their privacy, patients were given pseudonyms used in transcripts and data analysis. The data were analyzed by examining the transcripts for mention of participants' decision-making, their views, and descriptions of how they felt about their embryos and making disposition decisions. After transcripts were examined, themes and subthemes were used to 'code' the data for ease of retrieving passages concerning similar themes across interviews. At regular team meetings, team members discussed analysis, coding and sub-coding segments of text, and compared responses across transcripts to ensure the patients' views were being adequately reflected in coding processes. Atlas.ti software (ATLAS.ti GmbH, Berlin, Germany) was used for coding and managing data.

Ethics approval for this study was obtained from IWK Health Centre Research Ethics Board (for Halifax and