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Life on the Liminal Bridge Spanning Fertility and Infertility: A Time to Dream and a Time to Decide

"On a good day I dream of big family"

"The bridge right now that we have to cross is whether or not we want to have a third child...and if we do, is it through IVF?"

Introduction

Embryo cryopreservation (freezing) is frequently characterised as providing in vitro fertilisation

(IVF) patients with a reassuring fertility insurance benefit.¹ However, this description fails to

encompass the field of dreams that frozen embryo storage and retention creates for many infertile

couples and individuals. The transformative fertility bio-power that embryo cryopreservation

possesses can also produce an unanticipated conundrum: 'What to do with embryos no longer

needed for reproductive use?' A growing body of literature suggests that excess embryo

disposition decisions can be stressful and difficult.²

²CR Newton, F McDermid, F Tekpetey and I Tummon, "Embryo donation: Attitudes towards donation procedures and factors predicting willingness to donate" (2003) 18(4) HUM REPROD 878; CR Newton, V Fisher, F Feyles, F Teketey, L Hughes and D Issacson, "Changes in patient preferences in the disposal of cryopreserved embryos" (2007) 22(6) HUM REPROD 3124; G.Fuscaldo, S Russell and L Gillam, "How to facilitate decision about surplus embryos: Patients' views" (2007) 22(6) HUM REPROD 3129;.Lyerly et al. (2008), n 1; Nachtigall et al. n 1; S de Lacey, "Decision making about frozen supernumerary human embryos." (2013) 16(1) FERTIL STERIL 31. K Hug, "Motivation to donate or not donate surplus embryos for stem cell-research" (2008) 89(1) FERTIL STERIL 263.

¹ A Lyerly, K Steinhauser, C Voils, E Namey, C Alexander and B Bankowski, "Fertility patients' views about frozen embryo disposition: Results of a multi-institutional U.S. survey" (2008) 93(2) FERTIL STERIL 499; A Lyerly, S Nakagawa and M. Kupperman. "Decisional conflict and the disposition of frozen embryos: implications for informed consent." (2011), 26(3) HUM REPROD 646; RK Nachtigall, J MacDougall, J Harrington, J Duff, M Lee and G Becker, "How couples who have undergone in vitro fertilization decide what to do with surplus frozen embryos" (2009) 92(6) FERTIL STERIL 2094.

Much of the embryo disposition research has focussed on topics such as storage,

abandonment, donation and destruction trends,³ perceived barriers to decision making including patient indecision, dislike of disposition options, moral status/instrumentalism,⁴ and mandated retention limits.⁵ Regulatory regime studies have scrutinised consenting practices, clinic policies, and governance frameworks⁶. Other researchers including de Lacey,⁷ Chandler et al.⁸ and Machin⁹ have investigated patient counselling and identified gaps. Less well explored is the transformative space into which IVF patients enter when they consent to freeze their embryos.¹⁰

I argue that medicalization of fertility notably the cryopreservation of embryos does more than provide a fertility insurance: it suspends time. In so doing, a 'betwixt and between' liminal place is created where infertile individuals are rendered potentially fertile for as long as they

⁵ E Chandler, A Stuhmcke, J Millbank and I Karpin, "Rethinking consent, information-giving and counselling concerning stored embryos within IVF treatment" (2013) 20 JLM 759; I Karpin, J Millbank, A Stuhmcke and E Chandler, "Analysing IVF participant understanding of, involvement in and control over storage and destruction in Australia" (2013) 20 JLM 811; A Stuhmcke, "Tick Tock Goes the Clock: Rethinking Policy and Embryo Storage Limits" (2014) 22 FEM LEG STUD 285; S Takahasi et al., "Decision making process for the future of frozen embryos by Japanese infertile women: a qualitative study" (2012) 13 BMC 9. ⁶Provoost et al., n 4; Chandler et al., n 5; Karpin et al., n 5; Stuhmcke, n 5; L Machin, 2011. "A hierarchy of needs?: Embryo donation, in vitro fertilization and the provision of infertility

³ Newton et al., n 2; V Provoost, G Pennings, P De Sutter, A Van de Veld and M Dhont, "Trends in embryo disposition decisions: Patients' response to a 15 year mailing program." (2012) 27(2), HUM REPROD 506.

⁴ Nachtigall et al. (2009), n 2; Fuscaldo et al. n 2; de Lacey, n 2; V Provoost, G Pennings, P De Sutter and M Dhont, "Something of the two of us': The emotionally charged embryo decision making of patients who view their embryos as a symbol of their relationship." (2012) 33(1) J PSYCHOSOM OBST GYN 45.

counselling" (2011) 85(2) PATIENT EDUC COUNS 264.

⁷ de Lacey, n 2;

⁸ Chandler et al., n 5.

⁹ Machlin, n 6.

¹⁰ V Provoost, G Pennings, P De Sutter, J Gerris, A Van de Velde, E De Lissnyder and M Dhont, "Infertility patients' beliefs about their embryos and their disposition preferences" (2009) <u>24(5)</u> HUM REPROD 896.; Provoost et al. n 4; G_Becker, *Disrupted Lives: How People Create Meaning in a Chaotic World*. (1997) Los Angeles: University of California Press.

retain their embryos. Understanding the investments made by IVF patients in 'hope technology',¹¹ the cognitive dissonance¹² that fertility preservation generates, and the liminal places in which patients and their stored embryos dwell and experience time¹³ can assist counsellors to "prepare patients for the decisional journey that commences the day the decision to cryopreserve embryos is made."¹⁴

In recognising that the embryo disposition process is intimately tied to a liminal passage through a medicalised territory occupied by the IVF clinic and punctuated by embryo cryopreservation, I argue that regulators would more fully appreciate the psychosocial implications of imposing embryo storage time limits, an approach which Millbank et al.¹⁵ argue "fails to take into account the diversity of ways in which embryos have meaning for the women and men who created them." The implications of the rapidly extending fertility time horizon transformed by the promise of social egg freezing, the offers made by employers to fund egg freezing, and the increased supply of excess embryos generated as a consequence of the single embryo transfer policy puts renewed emphasis on the importance of understanding the investments made by patients in the transformative abilities of assisted reproduction technologies and the liminal space into which one enters once the decision to freeze eggs and embryos is made.

¹¹ S Franklin, *Embodied Progress: A Cultural Account of Assisted Conception*. (1997) London: Routledge

¹² S Festinger, *A Theory of Cognitive Dissonance*. (1957) Stanford CA. Stanford University Press: J Cooper, *Cognitive Dissonance: 50 years of a classic theory* (2007) Los Angeles/London: Sage.

¹³ V Turner, *The Ritual Process: Structure and Anti-Structure. (1969)* London: Routledge, Kegan Paul; B Thomassen, "The Uses and Meanings of Liminality" (2009) 2(1) IPAJ 5. ¹⁴ de Lacey, n 2, at 31.

¹⁵J Millbank, E Chandler, I Karpin and A Stuhmcke, "Embryo donation for reproductive use in Australia." (2013) 20 JLM 789 at 802.

The paper uses the spoken experiences of Canadian IVF patients who had completed or were in the process of undertaking their embryo decision journey to explore temporal and spatial facets of the liminal experience of medicalized fertility. The legal framework of Canada's embryo creation, donation and use regulations is explained at the beginning of the paper. The next section explores the multi-dimensional liminal spaces and temporal periods that IVF patients described and negotiated including their stories of infertility and the dreams, expectations, and personal investments that made up their fertility seeking projects. Lessons for law and policy are discussed in the final part of the paper.

Framing the Canadian legal context of embryo disposition

In Canada, consent to create, use and donate human embryos is federally regulated. The *Assisted Human Reproduction* (AHR) *Act*¹⁶ (*Section 8 Consent*) *Regulations*¹⁷ require patients to be informed prior to treatment that there could be a likelihood of excess embryos. Also, prior to treatment, patients must consent to the use of their embryos,¹⁸ including use in the case of death,¹⁹ donation to a third party, or to training or research of any excess embryos not needed for the patient(s') reproductive purposes²⁰.

In provincial jurisdictions other than Quebec, embryo cryopreservation storage agreements are contractual arrangements made between patients and the IVF clinic. Typically, contract renewal occurs annually with storage costs ranging from \$200-\$500 per year depending

¹⁶ Assisted Human Reproduction Act, S.C. 2004, c.2.

¹⁷ The Assisted Human Reproduction (AHR) Act (Section 8 Consent) Regulations SOR/2007-137 s.s 3(e).

¹⁸ SOR/2007-137, s.s.3(a)(i)).

¹⁹ SOR/2007-137, s.s.3(a)(ii); s.s.3(b).

²⁰ SOR/2007-137, s.s.3(a)(iii),(iv),(v).

on the clinic and the types of tissues stored (embryos, sperm and ovum). In Quebec, storage agreements are regulated by provincial legislation. At the time that the interview information was collected, the Quebec's medicare program covered storage costs for a period of three (3) years with the patient assuming storage fees for subsequent years. Quebec's publicly funded IVF treatment program requires patients to use all stored embryos before additional ones can be created.²¹

When Canadian IVF patients determine that they no longer need their stored embryos for their own fertility treatment and decide to no longer retain them, the *AHR Act (Section 8 Consent) Regulations* permit excess embryos to be donated with written consent to a third-party or to research (AHR training, AHR research and special research projects).²² The final consent decision to donate excess embryos replaces the advance consents made prior to IVF treatment. A decision to no longer retain frozen embryos will terminate the storage contract made with the clinic in the preceding year(s). IVF clinics offer patients the option to consent in writing to have their cryopreserved embryos destroyed.

The AHR Act *Section 8 Regulations* do not mandate a storage time limit. Unlike the UK²³ or Australia²⁴ no Canadian jurisdiction (federal or provincial) has imposed an embryo storage time limit. Embryos and gametes can be retained for as long as the terms of the storage contract are met. As part of the storage contract, individual clinics usually inform patients that embryos and gametes will be discarded in the event that patients fail to pay storage fees.

²¹ Quebec, An Act respecting clinical and research activities related to assisted procreation, CQLR.C-A-5.01; Quebec, Regulation respecting clinical activities related to assisted procreation, CQLR c A-5.01, r 1.

²² SOR/2007-137, Part 3: ss. 10-12

 ²³ Human Fertilization and Embryology Authority, 8th Code of Practice, Section 17: Storage of Gametes and Embryos. *Human Fertilisation and Embryology Act* as Amended 1990 s.s.4(2).
 ²⁴ Millbank et al., n 15; Stuhmcke, n 5.

Materials and Methods

The paper uses information obtained from "A comparative study of assisted human reproduction patients' views about the donation of eggs and embryos for scientific and clinical research" (Eggs and Embryos for Research Study project). The study purpose was to ascertain the beliefs, values, and commitments influencing the decision to donate or not donate embryos to research and was the first of its type to ask Canadian IVF patients about their use, storage and disposition of frozen embryos since Canada regulated consent for embryo donation in 2008. It significantly updates the Newton et al.²⁵ findings. The qualitative study interview questions were asked within the broader context of having to make a decision about the disposition of cryopreserved embryos no longer needed for personal reproductive use and it is this material which informs the discussion presented here.

Study participants

In April 2013, three (3) Canadian IVF clinics sent letters to a random sample of 591 patients, selected from the clinics' 2010 embryo storage mailing lists, inviting them to complete and mail a signed 'consent to be contacted' form to the Eggs and Embryos for Research Principal Investigator, Dalhousie University. A total of 45 individuals gave written consent to take part in 36 personal (face-to-face, telephone or Skype) semi-structured interviews held between May and December, 2013.²⁶ The level of participation compares favourably with similar studies, including the Haimes

 $^{^{25}}$ Newton et al., n 2.

²⁶ 78% were women; 12% were men; 91% were heterosexual; 9% were lesbian/bi-sexual. The author conducted about one-half of the interviews.

and Taylor²⁷ analysis of fresh embryo donation for research and a recent Australian examination of embryo storage and disposition²⁸.

Limitations

Certain population groups appear to be less likely to self-select to participate in studies of this type.²⁹ For example, persons who defaulted on their storage fees did not respond to the invitation letter; nor did those consenting to donate excess embryos for the reproductive use of an infertile third-party. Based on the information provided by the three participating clinics, about 2% of those sent interview-participation invitation letters had donated excess embryos for the reproductive use of others. Further information on study recruitment, interview questionnaires, respondent characteristics, and project publications is available from NovelTechEthics, Dalhousie University. ³⁰ Overall study findings pertaining to the donation of excess eggs and embryos to research have been reported.³¹

Analysis of Interview transcripts

Thirty-six semi-structured interview transcripts were coded using an identifying concepts

approach and further analysed using the qualitative information software analysis program.³²

Conceptual categories were organized in a framework to identify central phenomena and

²⁷ E Haimes and K Taylor, "Fresh embryo donation for human embryonic stem cell (hESC) research: The experiences and values of IVF couples asked to be embryo donors." (2009) 24(9) HUM REPROD 2142.

²⁸ Chandler et al., n 5.

²⁹ S de Lacey, "Parent identity and virtual children: Why patients discard rather than donate unused embryos" (2005) 20(6) HUM REPROD 1661;Nachtigall et al., n 1; Layerly et al. (2011) n 1; Takahashi et al., n 5.

³⁰ NovelTechEthics, Dalhousie University, www:noveltechethics.ca..

³¹ A Cattapan and A Doyle, "Patient Decision-Making About the Disposition of Surplus Cryopreserved Embryos in Canada" (2016) 38(1) J OBSTET GYNAECOL CAN 60.

³² ATLAS.ti 8

overarching topics.³³ This approach revealed the boundaries of the liminal space and its temporal dimensions that participants felt that they and their embryos occupied and it exposed a web of infertility and fertility life stories and IVF experiences. The paper presents findings for the entire study population. It reflects information obtained from participants who in 2013 continued to retain embryos as well as from those individuals who had made final embryo disposition decisions. In all but a few instances, individuals and couples had experienced at least one successful IVF conception, pregnancy, and birth. Pseudonyms replace participants' names.

Discussion: 'Betwixt and Between' temporal and spatial liminality of embryo cryopreservation

It has long been observed that assisted reproduction is a personal and culturally transformative experience.³⁴ Van Gennep's³⁵ concept of liminality is helpful to our understanding of the displacement of time and place and 'magical thinking' that embodies the transformative journey that individuals and couples undertake in their pursuit of fertility when using reproductive technologies. It is Turner's³⁶ elaboration of van Gennep's work – the focus on the transitional passage across a borderline separating social, cultural, economic or psychological spheres: a 'betwixt and between' state where relationships and agency are not easily resolved - which is

³³D Silverman, (2011). *Interpreting Qualitative Data*. 4th edition. London: Sage; S Timmermans and I. Tavory. "Theory Construction in Qualitative Research: From Grounded Theory to Abductive." (2012) 30(3) SOCIOL THEOR 167.

³⁴ S Franklin, "Origin stories revisited: IVF as an anthropological project" (2006) 30(4) CULT MED PSYCHIAT 547; M Strathern, "Introduction: A question of Context" (1999) in *Technologies of Procreation: Kinship in the Age of Assisted Conception.* J Edwards, S Franklin, E. Hirsch, F. Prices, and M. Strathern. (eds) (2nd edition) London: Routledge. 9-28; C Thompson, (2005) *Making Parents: The Ontological Choreography of Reproductive Technologies.* Cambridge: MIT Press; J Edwards and M Strathern, "Including our own" in J. Carsten (ed.) (1999) *Cultures of Relatedness.* Cambridge: Cambridge University Press, 149-166.

 ³⁵ A Van Gennep, (1960). *Rites of Passage*. Chicago: Chicago University Press.
 ³⁶ Turner, n 13, 94.

most useful to the understanding of the passage through time and space that IVF patients commence when they decide to cryopreserve their embryos. As Turner observes liminal transitions may manifest a lack of belonging and demark separation and marginalization. These aspects of liminality have been viewed as a negative, dangerous, or unstable state of being.³⁷ Yet, the process of transition and a rite-of-passage afford opportunity for agency though factors such as coercion undermine it³⁸ as does misplaced law, an argument that Stuhmcke³⁹ and Millbank et al.⁴⁰ have advanced with respect to the imposition of embryo retention limits.

In this paper, I draw on the work of Thomassen⁴¹ who expands on Turner's summation that "liminality refers to any 'betwixt and between' situation or object." Thomassen's critique permits the identification of spatial and temporal dimensions of liminality. It brings together the elements identified by Grimes who stated that the liminal rite-of-passage involves the crossing a threshold which can be spatial or temporal in nature: "If one attends to the boundary itself, the emphasis becomes spatial; but if one attends to the person making the crossing, the emphasis becomes temporal and processual."⁴²

Medicalisation⁴³ of the human body produces liminal boundaries of illness and health, fertility and infertility. The spatial and temporal modalities of the liminality invoked by the

³⁷ Turner, n 13, 95

³⁸ A Ashenden, "Problematising relations of agency and coercion: Surrogacy" in A. Madhok, A Phillips and K. Wilson (eds) (2013) Gender, Agency and Coercion, London: Palgrave Macmillan, 195-218; KB Jensen, "Space-time geography of female live-in child domestic workers in Dhaka, Bangladesh" (2014) 12(2), CHILD GEOG 154.

³⁹ Stuhmcke n 5.

⁴⁰ Millbank et al., n 15.

⁴¹ Thomassen, n 13, 16.

⁴² RL Grimes, (2006) *Rite Out of Place: Ritual, Media and the Arts*. Oxford: Oxford University Press, 113.

⁴³ P Conrad, (2007) *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders.* Baltimore: Johns Hopkins University Press.

cryopreservation of embryos is characterised by specific places, boundaries, and temporal modalities. For example, the IVF clinic provides a liminal space for patients to transition from infertility to fertility as signified by the experience of a successful pregnancy and childbirth.⁴⁴ The cryopreservation tank acts as a heterotopia, a secure, secluded space where time in so far as it pertains to the embryo is suspended.⁴⁵ From the perspective of the patient, the place where the embryos reside is a real-and-imagined safe space.⁴⁶ Moreover, it is a tightly controlled space as embryo entry and exit is managed by the IVF clinic in response to regulation, patient consent, and storage contractual agreements.

Thomassen⁴⁷ exposes the temporal dimensions of liminality which in the context of IVF can include a sudden or specific event such as the decision to cryopreserve embryos, or to extend or discontinue the storage contract. Liminality can involve extensive temporal periods, for example the multi-year duration of embryo storage or embryo use that could span the generations.⁴⁸ Finally, research on liminality occurring in specific health care instances reveals that in the case of some cancer patients the liminal threshold separating illness from health may never be crossed and could extend well beyond clinical tumour reoccurrence time limits.⁴⁹

⁴⁴ H Allen, "Experiences of infertility: Liminality and the role of the fertility clinic" (2007) 14(2) NURS INQ 132.

 ⁴⁵ M Foucault,(1998) "Different spaces" In Aesthetics, Method, and Epistemology: essential Works of Foucault. Edited by J.D. Faubion. Vol. 2, 175-185. New York: The New Press; P Johnson, "Unravelling Foucault's 'different spaces'" (2006) 19(4) HIST HUM SCI 75.
 ⁴⁶ E Soja, (1996). Thirdspace: Journeys to Los Angeles and Other Real-and-Imagined Places.

Oxford: Blackwell

⁴⁷ Thomassen, n 13, 17.

⁴⁸ J Carsten, (2004) *After Kinship*. Cambridge: Cambridge University Press; M Strathern,
"Regulation, substitution and possibility" (1999) in J Edwards, S Franklin, E Hirsch, F Price, and M Strathern. (2nd ed.) *Technologies of Procreation: Kinship in the Age of Assisted Conception*. London: Routledge, 171-202.

⁴⁹ E Blows, L Bird, J Seymour and K Cox, "Liminality as a framework for understanding the experience of cancer survivorship: A literature review." (2012) 68(10) J ADV NURS 2155; L

Using the Eggs and Embryos for Research interview material, I argue that the decision to cryopreserve embryos represents a specific temporal liminal point which in turn launches IVF patients into a reproductive decisional liminal space characterised by matter out of place and category mixing⁵⁰ during which they experience separation, difference and ambiguity, followed by the possibility for resolution once the decision is taken. The liminal space into which patients enter when they decide to freeze their embryos is one of unrealised fertility. In this liminal space, the infertile body becomes transformed by the potential of a technology⁵¹ that offers the promise of family, though to achieve fertility they must seek to fulfil the promise locked in the frozen timeless embryo. Yet for many the fertility dream cannot and will not be attained. As Caplan has noted: "freezing eggs and embryos is not like freezing chicken for dinner."⁵² Many factors figure in the realisation of the fertility promise of the embryo not the least of which is that IVF technology works in about 25% of the time.⁵³

Granek, and K Fergus, "Resistance, agency and liminality in women's accounts of symptom appraisal and help-seeking upon discovery of a breast irregularity" (2012) 75 SOC SCI MED 1753; S Tierney, C Deaton, A Jones, H Oxley, J Biesty and S Kirk, "Liminality and transfer to adult services: A qualitative investigation involving young people with cystic fibrosis" (2013) 50(3) INT J NURS STUD 738.

⁵⁰ M Douglas, (1975) *Implicit Meanings: Selected Essays in Anthropology*, London: Routledge, Kegan Paul.

⁵¹ C Waldby and K. Carroll, "Egg donation for stem cell research: ideas of surplus and deficit in Australian IVF patients' and reproductive donors' accounts" (2012) 34(4) SOCIOL HEALTH ILL 513; S Franklin, "The cyborg embryo: our path to transbiology",(2006) 23(7) THEOR CULT SOC 167.

⁵² Caplan quoted in Schmidt, M., February 3, 2016. "Pentagon to Offer Plan to Store Eggs and Sperm to Retain Young Troops'. *New York Times*.

http://www.nytimes.com/2016/02/04/us/politics/pentagon-to-offer-plan-to-store-eggs-and-spermto-retain-young-troops.html?_r=0 Assessed March 7, 2016.

⁵³ Human Fertilization and Embryology Authority, (2014) *Trends in Fertility Treatment 2013: Trends and Figures.*

In this 'betwixt and between' infertility/fertility liminal space, the materiality of reproductive technology is re-active.⁵⁴ The embryo signifies potential life opportunities. It interacts by shaping agency, influencing decision making, and creating boundaries. Both nature and knowledge become destabilized.⁵⁵ Vanessa a participant in the Eggs and Embryos for Research Study commented on technology's powerful ability to shape her views about her embryo: "*Most people don't think about embryos because they don't have to and they don't have to make those decisions. If you go through a regular pregnancy and if you end up losing your baby, then it is not like if you were to lose an embryo in five days, you wouldn't be aware of it. So you're not faced with the ethical issues that you have to think about life and where that begins because having the technology and having to make these decisions changes that perspective because it changes what you're able to do."*

The manner in which agency is constructed and fractured during the transition through the liminal space wherein the fertility story is held reveals the control exercised by clinics and reproductive technology which in turn thins and constrains agency. It exposes the separate components of a regulated embryo disposition process, the growing attachment to the metamorphosis from infertility to fertility represented by the embryo and the power of the IVF

⁵⁴ Barad, K. "Getting real: Technoscientific practices and the materialisation of reality." (1998) 10(2) DIFFERENCES 87. G Howie (2010) *Between Feminism and Materialism: A Question of Method.* New York, NY: Palgrave Macmillan; J Taylor, "Image of contradiction: Obstetrical Ultrasound in American Culture" (1998) in S Franklin and H Ragoné (eds) *Reproducing Reproduction: Kinship, Power and Technological Innovation.* Philadelphia, University of Pennsylvania Press, 15.

⁵⁵ M Strathern, "Introduction: A question of Context" in *Technologies of Procreaton: Kinship in the Age of Assisted Conception*. (1999) J Edwards, S Franklin, E Hirsch, F Prices, and M. Strathern. (2nd edition) London: Routledge. 9 at 10.

technology, and crystallises the importance of the 'gate point': "Will the embryos be used for additional attempts at conception?"⁵⁶

Given that none of the Eggs and Embryos for Research study participants donated their embryos to an infertile couple or individual for their reproductive treatments, the answer to the above noted question marked a critical threshold for both the couple and for the stored embryo. For the participants who had created a life story for their embryos, the act of giving personhood to the embryo transferred moral obligations which could be resolved only through its reproductive use: "*It is not just a frozen embryo but it is a person so we decided to put it back [to use it ourselves]*."

Yet such actions did not necessarily result in a successful fertility outcome. Catherine who had twins from her initial IVF treatment had two frozen embryos in storage said: "*As hard as it was to have a miscarriage [with one of the two remaining embryos]* ... *We don't have to have the discussion: 'Do we try for a family of four.*"

It is on the liminal bridge spanning infertility and fertility that couples and individuals make reproductive and embryo use decisions. How they got on the bridge and how long they remain there are as important as the passage across it. Indeed, some will never completely make the journey from one side to the other though this is not unknown as research has shown in other areas of health care where patients undertake a liminal journey. As no storage time limit is imposed by regulation, Canadian IVF patients can retain their frozen embryos for as long as they continue to pay the storage fees. As one couple explained, the embryos had a life force that co-existed with their lives. The clinic could inform them that their stored embryos had died in

⁵⁶ A Lyerly, K Steinhauser, E Namey, J Tulsky, R Cook-Deegan and J Sugarman. 2006. "Factors that affect infertility patients' decisions about disposition of frozen embryos." (2006) 85(6) FERTIL STERIL 1623 at 1625.

the cryopreservation tank, they said. But barring this situation: "we've talked about putting it in our will that upon our death...the embryos are to be buried with us...we'll just keep them in perpetuity."

To some this end of life wish may sound extreme. Yet, it denotes a quest for a *right-ofpassage*, a ritualized conclusion to the fertility story embodied by the embryo. The search for a suitable end point denotes agency and self-determination unencumbered by regulation though in this case enhanced by the financial means to continue storage for an extensive period.

The decision to cryopreserve: important temporal event

Coventry et al.⁵⁷ argues that the ability of patients to manipulate and modify their experience of time is critical to their subjective experience of agency and self-determination. The decision to cryopreserve embryos is a crucial point in liminal journey of imagined fertility initiated by assisted reproduction.

Most researchers have interpreted the decision to freeze and store embryos as a pragmatic and utilitarian outcome of IVF treatment. As Karpin et al.⁵⁸ noted about the comments made by the Australian IVF patients that they interviewed: "having excess embryos was viewed as a necessary part of treatment, a means to an end." Indeed, for most IVF patients having surplus, good quality embryos is a positive outcome, especially as cryopreservation enables future embryo transfers without incurring further medical risks (ovarian hyper-stimulation) or additional costs. As Charles remarked: "*I found that there is no cycle cost…it made common*

⁵⁷ P Coventry, A Dickens and C Todd, "How does mental-physical multimorbidity express itself in live time and space? A phenomenological analysis of encounters with depression and chronic physical illness" (2014) 118, SOC SCI MED 108.

⁵⁸ Karpin et al., n 5, 815.

sense to freeze the best." Others noted that it provided a reproductive insurance. Hailey observed: *"if it hadn't been a successful implantation then we had those backups."*

Yet for others, making the decision to seize the benefits of fertility insurance meant starting down a path marked by uncertainty. "I don't think there was mention of what happens after" Chloe told us. Jessica remarked: "I remember us leaving very distraught. I thought wow we have these frozen embryos. I hadn't thought about that and I don't know what to do with them. That was a factor that really weighed on me that I wasn't prepared for."

De Lacey⁵⁹ observes that from "the moment an embryo is frozen following IVF treatment, the patient commences a cognitive and emotional process." When patients decide to freeze their good quality embryos, they make a decision that separates them from other IVF patients as it secures a promise, though as yet unrealized, of future family creation. It is a decision that puts in play legal obligations as well as ethical ones. It launches the patient and the embryo into a liminal decisional space which serves to "detach the individual and set them apart from others."⁶⁰

Participants observed that retaining excess embryos and then finding themselves in a situation of being able to decide what to do with them created difference and separation from others who were trying to get pregnant. They said that they had left the group of infertile couples and individuals and entered a silent *communitas*⁶¹ populated by persons with extra embryos. Telling others about their unused embryos and what they had planned for them could be an isolating and socially dangerous activity. Olivia commented: *"I'm on a Facebook thing for*

⁵⁹de Lacey, n 2, 31

⁶⁰ Turner, n 13, 48.

⁶¹ V Turner, (1974). *Drama, Fields and Metaphors: Symbolic Action in Human Society*. Ithaca: Cornell University Press at 273-4.

infertility for people in our province, but there's never any talk about anything there [about embryos] because it's all for people who are trying to have kids... so you don't want to go yeah, I've got too many kids now so I don't want to use these anymore."

The lived experience of infertility shapes and inhabits the liminal space through which participants said they journeyed. The powerful legacy of infertility makes the frozen embryo's promise of fertility a cherished attribute. Women have told researchers that "infertility challenges their self-image"⁶² and "what it means to be a woman."⁶³ Infertility and the prospect of being childless have been described as being "a sad phase in their lives"⁶⁴ with some women indicating they felt "betrayed by their bodies."⁶⁵ The Eggs and Embryos for Research Project study participants said that the legacy of infertility underlay and influenced their embryo retention decisions. For example, Jennifer commented that being infertile made her life-story different: "Someone who has it all there, it's maybe nothing for them. But for someone who's going through it and thinking about their life without children, it's touchy."

The experience of infertility separates IVF patients from fertile women. The medicalization of fertility and promise offered by embryo cryopreservation enables infertile individuals to engage with a cultural and normative script of womanhood and mothering.⁶⁶ In so doing, it creates expectations of what to do with the embryos. For some participants, the thought that they might not use them for their own fertility treatments was unsettling. Some resolved the issued by using

⁶²J Jaffe and MO Diamond, (2011) *Reproductive Trauma: Psychotherapy with Infertility and Pregnancy Loss.* Washington: American Psychological Association Press, at 209.

⁶³ J Rehner, (1989) Infertility: Old myths, New Meanings. Toronto: Second Story Press at 23.

⁶⁴ N Pfeffer and A Wollett. (1983) *The Experience of Infertility*. London: Virago Press at 137.

⁶⁵ RD Klein, (1989) Infertility: Women Speak Out About Their Experiences of Reproductive Medicine. London: Pandora at 54.

⁶⁶M Sandelowski, D Holditch-Davis and BG Harris, "Living the life: Explanations of infertility." (1990) 12(2) SOCIOL HEALTH ILL 195.

the embryos while others said that they hoped to dodge the decision of what to do with embryos they might not use:⁶⁷ "We're not at the stage where we're done with our pregnancies and have embryos leftover. We're hoping not to be in that situation to be honest." The fertility dream embodied in the cryopreserved embryo co-exists with the cognitive dissonance that extended embryo retention creates. To delay in making an embryo disposition decision generates uncertainty and ambiguity at the same time as producing the "comfort feeling" that retaining embryos provides. Elaine observed: "It did take me that long to get over the feeling that I was going to use them for myself. So really that was a comfort feeling for me, that's why I kept delaying the decision...It just took me a few years to be certain I didn't want them for myself."

Knowing that embryos are in safe place also contributes to the "comfort" feeling: "*I* know that they 're [embryos] safe where they are, we know that..." Keeping embryos "safe" could be interpreted as symbolic of a parenting response. In this case, the patient is entrusting the clinic with the safe-keeping of a precious commodity. The location where the embryos dwelled provided a real-and-imagined place which in turn sustained the fertility dream. Ironically it was a space where time was suspended for the embryo. It was a safe place for as long as the storage time contract was in force. Reassurance about embryo wellbeing enabled participants to put their reproduction decisions on the "back burner" and to "put off" making an embryo disposition decision. In this cryopreserved heterotopia space, time is destabilised. Like Dutilleul, the character in Marcel Ayme's short-story *Le passe-muraille*⁶⁸, the cryopreserved embryos do not age though in their modified time and space existence they could run the risk of becoming

⁶⁷ S de Lacey, "Parent identity and virtual children: Why patients discard rather than donate unused embryos" (2005) 20(6) HUM REPROD 1661; Machlin, n 6; Millbank, n 15.
⁶⁸ M Aymé, (1943) *Le passe-muraille*. Paris: Gallimond (Edition: Folio, 1961).

permanently trapped, as would occur if patients discontinued the storage payments and clinics decided that they could not dispose of them.

Feelings of comfort and reassurance generated by retaining embryos contrasted with the unease that participants experienced when attempting to determine if their embryos were surplus to their reproductive needs. Among those who had not decided what to do with them apart from continuing to keep them in storage, there was an expression of the need to make the best decision, yet at the same time they feared a hasty conclusion. Chloe, who had not yet decided if they would have more children was troubled about reaching a certain age and encountering regret for not having using their stored embryos: "*I don't want to be, you know, 45 or 50 and go: Why did we mess that up?*"

Provoost et al.⁶⁹ observe that the fear of regret in making an ill-advised, hasty or rushed decision contributes to the anxiety and uncertainty experienced by those deliberating the decision to no longer retain their embryos. A hurried or poorly considered decision offers little protection against an ill-fated event such as miscarriage or child-loss. The undercurrent of infertility, the unrealised promise of fertility, and the reproductive timeline of the couple as contrasted to that of the frozen embryo punctuated their comments. The legacy of childlessness accentuated their fear of unfortunate events, separated them from those able to have children naturally, and reinforced their commitment to embryo retention. Zoey compared her situation to that of a fertile couple who might lose a child. In her view, such parents could easily recover and conceive again; whereas in her case no similar option existed should she relinquish her stored embryos: "If something happens to somebody else's baby they can just go have another one. Not to sound like

⁶⁹ Provoost et al., n 10.

at all cold about it. But you know what I mean! It's not as difficult to move on and get pregnant again and have another baby or whatever."

The reproductive safety net provided by embryo storage is a powerful incentive influencing couples to continue to retain embryos. Valerie, who had managed to conceive naturally, described their decision to retain their stored embryos: *"So I think last year when I got the [storage renewal] bill I was probably four months pregnant. I think at that point I was like: We got pregnant. Maybe we don't need to have these retained embryos anymore. But at the same time I was like what if I miscarry? What if there's a serious problem with the baby? That type of thing."*

Reproductive insurance provides a practical rational for retaining embryos. Concern about not using the stored embryos for family creation, the possibility of regret should a hasty decision be made, and the unpredictability of one's life outcome weighed heavily on some participants. These factors contribute to the phenomena noted by Provoost et al.⁷⁰ of keeping reproductive options open even when patients knew that they would not themselves use the retained embryos. Thus the pragmatic rationalization for retention became entangled with the belief in the saliency of the story that participants tell themselves about the dream of family that the embryos represent. Elaine, who had already donated her excess embryos to research, reflected on these factors and how they contributed to her indecision and served to delay her decision making:

"...because you just never know how your life is going to go, right? And there's always this degree of uncertainty about where we be in three years, four years. How will I feel in four years

⁷⁰V Provoost, G Pennings, P De Sutter, J Gerris, A Van de Velde and M Dhont, "To continue or discontinue storage of cryopreserved embryos?: Patients' decision in view of their child wish" (2011) 26(5) HUM REPROD 861.

or five years? Will I regret having given them up? Will I regret not having used them for myself? You have that feeling. So for me it was easier to just keep delaying the decision until I was really certain."

Some participants sought biological markers signalling an appropriate time for transiting the liminal space between fertility and fertility. Menopause, attaining the age 45-50, or just being 'too old to have more children' established points in time when the family reproductive story could have a 'natural' closure. Stiel et al.⁷¹ and Karpin et al.⁷² have commented on the role that a woman's age plays in family completion and its importance to patients' consideration of how long to store embryos. Zoey said her decision would have been different had she been younger: *"I would have had another one...but our age played a big factor in that"*.

Searching for a biological time-limit to wrap up the family story was noted by lesbian as well as heterosexual couples with menopause being viewed by some participants as a suitable point to relinquish the fertility dream offered by embryo retention. The following exchange provides a view of how strong a bio-marker age may be in signalling the time for crossing the bridge and passing from medicalised fertility into infertility:

Abigail: "Knowing myself I know I will probably keep them in storage probably..."

Claire: (chuckles) "Until you hit menopause."

Abigail: (chuckles) "Probably long enough until I was very sure with myself that I wouldn't necessarily take my immediate emotion of 'I'm done having kids'. I don't think I would trust that emotion, I would probably wait a long time until we can say 'yeah we're done'."

⁷¹ M Stiel, C McMahon, G Elwyn, and J Boivin, "Pre-birth characteristics and 5 year follow-up of women with cryopreserved embryos after successful in vitro treatment." (2010) 3(1) J PSYCHOSOM OBST GYN 32.

⁷²Karpin et al., n 5.

Being too old to have another child, reaching menopause, or attaining age 45 to 50 appears to denote a fertility limit that signals the end to embryo retention. It established a biological reproductive finality that these women could share with their fertile sisters. Surprisingly, no one expressed the view that they wished to extend their fertility beyond these years, though specification of the age range extending into the late 40s does seem to indicate that the window for childbearing has widened to encompass a point previously considered as being at its outer limits. Adoption of this end-point to fertility may be reflective of the boundary change occurring as a result of assisted reproduction, as it is not uncommon for those aged 45 to 50 to experience IVF births.⁷³ Reference by participants to menopause and the upward fertility boundary shift reveals the bio-power invested in the cyborg embryo which, through technology, reinvents nature to defy aging.⁷⁴ Normative notions of the closure of fertility and childbearing appear to be upwardly mobile and changeable given advances in reproductive technology. Persons retaining embryos may look to these boundaries for decisional assurance though given their fungible qualities they may not offer a definitive point of closure.

Van Gennep gave particular importance to ritual incorporation as closure of the rite-ofpassage liminal journey. Retention of embryos up to a normative reproductive age limit for women may provide a ritualized biological end point signalling that embryos need no longer be retained, though as noted reproductive age limits appear seemingly elastic and flexible. Other options also exist to extend fertility. However, few participants discussed surrogacy as a reason for continued embryo retention. Nor did they raise adoption as a parenting option.

⁷³ Human Fertilisation and Embryology Authority, n 53.

⁷⁴ DJ Haraway, (1991) *Simians, Cyborgs and Women*. London: Free Association Books; Franklin, n 51.

Crossing the bridge that the spans the liminal space of medicalised fertility

Participants' comments underscore that they were acutely aware that deciding that they no longer needed their embryos for their own reproductive project meant that they and their embryos would be crossing over a fertility threshold. As none of the participants decided to donate the embryos to another couple, crossing this boundary signified a return to infertility. To make the decision meant "*crossing the bridge*" and in its more negative contexts: "*shutting down*", "*closing the door*", and "*letting it go*". Carmen told us that as no more eggs were going to be obtained from her, the frozen embryos were "*their last shot*." It was "a *point of no return*".

Crossing the liminal fertility/infertility threshold ended participants' symbolic relationship with their embryos and finalised the family story they had created with them. Chantelle remarked: "It's like saying I'm not going to have another kid. To me it's very final, there's no turning back so that was the hard one, not so much what to do with them. It was really just the decision to say goodbye and let them go. Realize that's it: We're a family of three."

The decision to no longer keep embryos also means letting go of the safe space afforded by the clinic. Kelsey said: *"It's difficult because we were severing our ties with the clinic and you're eliminating the option of having another child. It's not something you do lightly. It wasn't about the research versus discarding. It's just signing whatever we were going to sign and send it off means that embryo is gone as an option for us. So that's the hardest."*

Embryo cryopreservation holds out a promise of fecundity to the infertile, enables normative views of 'womanhood', facilitated the hopes and dreams represented by notions of the 'idealised family', and reified motherhood. All of these aspects were challenged by infertility and returning to this state by crossing the bridge signified rejection of the dream of unending fertility. Chantelle, in recalling her decision said: *"It affects my womanhood. I can't have kids*

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the old fashioned way, so to me it was hard. I needed to make a decision and that means our family is done. It wasn't so much the [disposition] options that gave me trouble."

IVF and the retention of cryopreserved embryos challenge existing views of fertility and fecundity by enabling infertile persons to engage in the possibility of future family building, even though IVF offers a low probability of success. The clinic mediates and extends the liminal process of transition into fertility through medicalization, reproductive technology, embryo cryopreservation and provision of a safe embryo storage place. Within this 'betwixt and between' liminal state of medicalised fertility patients construct a reproductive narrative and develop a symbolic parenting relationship with their embryos.

Interview participants indicated that the liminal transition was marked by ambiguity, uncertainty, and emotional chaos during which they feared experiencing regret should a hasty decision be taken. To make the crossing across the bridge that spanned the hopes and dreams of family, participants needed to confront their infertility story, set aside the promise of fertility that cryopreservation holds, and diminish the bio-power invested in the frozen embryo.

One fundamental element of a liminal transition is ritual closure.⁷⁵ When embryos are used for reproductive purposes, a successful birth would be celebrated and marked by social, cultural and religious rituals denoting a successful transition from infertility and childlessness. However, no social ritual signals the decision to not use stored embryos and to no longer retain them. The medicalization of fertility, materialisation of the embryo through reproductive technology, and regulated altruism fractures agency and replaces, controls and limits ritual. Lisa and Harry who had donated embryos to research described their need to achieve a ritualised closure that also recognized their altruism. Lisa stated what she would have liked to have

⁷⁵ Van Gennep, n 35; Turner, n 13; Grimes, n 42.

experienced: "For me to get a letter and say ...your embryo has been used for great purposes. Thank you very much for your donation. Thank you for that piece of you that you gave away. And here's where it was for four, five years. I know it's crazy, and it's probably this tiny little thing, plastic tube. I just feel like if I could know that that's somewhere near me. It's in our backyard. It's under a plant that I've chosen."

Lessons for Law and Policy

I have argued in this paper that understanding the multiple discursive realities of liminal time and space through which patients journey when they make the decision to cryopreserve their embryos reveals the power invested in the dream of fertility that assisted reproduction embodies. As well, I suggest that liminality can provide a framework that could be used by counsellors to prepare patients for the journey on which they will embark on fertility preservation: a counselling goal advocated by de Lacey⁷⁶ and Chandler et al.⁷⁷ Liminality reveals the multiple realities that patients may experience, suggesting a need for flexibility in clinic procedures, notably renewal notices, follow-up procedures, and alternative disposition options. During the liminal journey, the ability of patients to modify time was important though specific temporal events could increase ambiguity and uncertainty. For example, participants' ability to alter and adapt their embryo storage duration was crucial to their experience of agency even though some recalled the negative implications of indecision: "*we just paid the 400\$ a year for years and years*" or "*I kept paying the money every year to keep them frozen* [...]against my husband's wishes".

⁷⁶ de Lacey, n 2.

⁷⁷ Chandler et al., n 5.

Clinic storage renewal procedures have the potential to destabilize agency. Valarie noted that she had worried about not receiving the renewal notice: "we were moving...and I was like do you have my address? Please don't destroy our embryos." Lisa said that it took her a long time to tell the clinic about their decision to no longer retain the embryos: I'm surprised they didn't charge us for more freezing, because from the time we got the letter, I read it, and I put it aside because I couldn't even think about answering it. I put it aside for probably three months, and then felt so bad that we hadn't responded so started making those calls and asking those questions, and then even after I had signed the papers and we had to sign what we were going to do, it took me another probably three months to put it into the mailbox. I did it, I went many times to the mailbox with it in my hand. I had it every day in my car, but I just couldn't put it in."

Liminality exposes power centres imbedded in the management of reproduction through medicalization, regulation, and the technological materialisation of the embryo. IVF clinics are embryo and fertility gate-keepers. Tasked by federal statute they administer the consent to use and donate embryo regulations and manage embryo storage renewal contracts. How Canadian IVF clinics negotiate their roles, deliver counselling, manage storage contracts, design and use consent forms, and inform patients warrants continued examination.

Another area meriting further investigation concerns the incorporation of ritual. As this study shows, there are multiple realities and participants can perceive the liminal journey in different ways. For some, the investments made in the dreams of family meant that cryopreserved embryos could occupy a powerful life-shaping force Seeking closure for the embryo disposition decision was an important objective that could not always be realised within accepted practices. As one of the participants succinctly noted, a ritual burial of the embryo is *"the taboo topic of IVF"*. Some participants found it necessary to validate the embryo by

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ensuring it did receive a dignified resting place of their making, often it was their flower garden; in effect replacing one heterotopia for another.⁷⁸ In so doing, these women and couples sought a closure that was in keeping with the socially constructed bonds of belonging that they had created with their embryos. Agency for these participants was enhanced and the socio-cultural boundaries of the sacred and profane and fertile and infertile bodies redrawn.

As more individuals decide to preserve their fertility, ethicists, counsellors and regulators will need to grapple with issues of continued retention, donation, and destruction along with the aims of patients seeking to achieve a ritual marking of the journey that they and the embryo have undertaken. Some patients may seek to give the embryo a ritualised burial while others may ask for recognition of a donation. However, the liminal space of continued embryo retention presents for some a regulatory challenge the solution for which necessitates the imposition of storage time limits. Canada imposes no storage time limits and IVF patients make decisions within the limits of the temporal boundaries they construct. I argue that patient agency can be thickened when policy and law accommodate to the socially constructed bonds of belonging that have developed during the liminal passage. I suggest that a way forward is to develop mechanisms to enhance autonomous decision-making not inhibit it.

This study reveals that the journey through liminal time and space of medicalised fertility involves indecision, uncertainty, and disequilibrium. The dream of undiminished fertility is a potent force though its realisation is difficult and the letting go of the fertility stories are complicated. In jurisdictions where storage time limits are imposed, patients find decision making to be very difficult undertakings.⁷⁹ As the Canadian study shows, crossing the

⁷⁸ Johnson, n 45, 79.

⁷⁹ Mason J.K. and G.T. Laurie. (2013). *Law and Medical Ethics*. (9th edition) Oxford: Oxford University Press at 296-301.Karpin et al., n 5; Stuhmcke, n 5.

liminal bridge is complex yet none of the participants felt that they had been forced by regulation to make a decision though the annual contract renewal notice acted as a temporal reminder.

The imposition of a storage limit holds pragmatic attraction to law makers, yet as Stuhmcke⁸⁰ and Millbank et al.⁸¹ have discussed forced embryo disposition does not necessarily prevent the ethical conundrum created by embryo abandonment and regulated disposal as evidenced by an annual destruction in 2014 of over 10,000 embryos by the HFEA.⁸² As noted, no Canadian jurisdiction has imposed embryo storage time limits. Unlike other jurisdictions Canada has not attempted to link an idealised reproductive time horizon to a legalised embryo storage limit. As this study demonstrates, participants did make decisions about the use, donation, and destruction of their embryos thereby putting into question the view that limitless storage presents a social and reproductive danger.⁸³ Nor were patients prevented from removing their embryos from the clinic and arranging a personalised ritual marking of the transition from fertility to infertility that they and the embryo have taken.

Given that most of the participants interviewed determined what they would do with their frozen embryos, I argue that the imposition of time limits is not needed. To do so would create further ambiguity and liminality and confuse notions of the passage of time with that of reproductive purpose. By giving women and men the autonomy to determine storage timelines, reproductive agency is enabled. As well, by finding ways for individuals and families to make

⁸⁰ Stuhmke, n 5.

⁸¹ Milbank et al., n 15.

⁸² Human Fertilisation and Embryology Agency, Freedom of Information Notice, F-2014-00104
Embryos allowed to perish after coming to the end of the storage period.
http://www.hfea.gov.uk/8941.html

⁸³ See Stuhmcke, n 5 for a discussion of this issue.

a transition that validates the investments they have made in the potential of the embryo should be a fertility counselling goal. Formalised recognition of the importance of agency and ritual is important as both could serve to shore up donation as well as bring closure to the liminal journey of embryo retention. It is essential that legislators do not close off opportunities for patients to customise and control their determination of embryo storage time and the assisted reproductive journey they take across the bridge that spans fertility and infertility.

Ethics review

Research Ethics Board approval for the Eggs and embryos for Research Project was obtained from the IWK Research Ethics Board for the Halifax and Ottawa sites and from the Montreal Hospital Research Ethics Board for the Montreal site.

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