Resource Allocation of Publicly-Funded Fertility Treatments: A Grounded Theory Focus Group Study of Patients' Perspectives

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List of Abbreviations

Abbreviation	Definition
ART	Assisted Reproductive Technology
BMI	Body Mass Index
CARTR	Canadian Assisted Reproductive Technologies Register
CPAC	Clinical Priority Assessment Criteria
FSH	Follicle-Stimulating Hormone
ICSI	Intracytoplasmic Sperm Injection
IUI	Intrauterine Insemination
IVF	In Vitro Fertilization
MOHLTC	Ministry of Health and Long-Term Care
MSH	Mount Sinai Hospital
OFP	Ontario Fertility Program
OHIP	Ontario Health Insurance Plan
REB	Research Ethics Board

Abstract

Background: In December 2015, the Ontario Fertility Program (OFP) introduced public funding for 5000 in vitro fertilization (IVF) cycles annually in Ontario. However, apart from the age limit of 43, fertility clinics were not instructed on how to distribute their allotted publicly funded IVF cycles. This qualitative study aimed to answer: (1) What do the people who require IVF think are important factors to consider when distributing public funding for fertility treatments? (2) What are the barriers to accessing publicly funded IVF?

Methods: This study was approached with a social constructivist interpretative framework with grounded theory methodology with focus groups. Two researchers conducted all interviews and independently reviewed the transcriptions and analyzed the data for open coding, followed by axial coding then selective coding to determine themes.

Results: A total of thirteen subjects participated in four focus groups. Themes emerged of procedural justice regarding transparency and consistency amongst clinics, and gatekeeping of the funding waitlist. Themes of substantive and distributive justice were raised with respect to how to prioritize the funds. There was a consistent call for providing a fair chance and equal access to IVF funds. Lack of communication, costs and stress of experiencing infertility were cited as barriers to accessing publicly funded IVF.

Conclusions: Our goal was to make the distribution of publicly funded IVF fairer, and based on factors that people who require IVF think are important. At the very least, transparency and better communication should be implemented to increase substantive rights for patients and reduce emotional stress.

Introduction

Background Information

In Ontario, 1-2% of live births are achieved with assisted reproductive technology (ART) (1). In addition to the cost of medications, the in vitro fertilization (IVF) procedure costs about $10-15 000 CDN, and thus, finances can be a barrier to access.

The Ministry of Health and Long-Term Care (MOHLTC) introduced the Ontario Fertility Program (OFP) on December 21, 2015 (2). Through the OFP, each Ontario woman under the age of 43 is eligible for one publicly funded IVF cycle in her lifetime (2). However, the program is limited to 5000 IVF cycles per year, with capped annual cycles allocated to each fertility clinic based on their historical demand. After the introduction of funding, there was significant demand and waitlists were reported up to 1.5 years (3). Clinics were required to develop their own strategies for resource allocation. No principles of prioritization were suggested by the MOHLTC and there is no standardization.

In addition to the OFP, patients can still access privately funded IVF and undergo IVF within weeks.

Literature Review

A survey of fertility clinics in Ontario demonstrated that 38% of clinics distributed public IVF funding based on a first-come, first-serve basis, 10% used a lottery system, and 52% used multiple factors to determine allocation (4). Factors considered, and prioritization varied amongst clinics. Not one clinic consulted patients when developing their allocation methods (4).

Gotz et al., 2017, surveyed 271 patients about their opinions regarding the OFP and its current implementation (5). Most respondents (84.5%) thought that all clinics should use the same policy. While the majority (70.8%) thought the method of distribution should be based on a scoring system, rather than lottery (1.5%) or first-come, first-serve (18.5%), there was disagreement about which factors to prioritize in the scoring system (5). To further explore and clarify the survey results, this qualitative study was developed to provide a deeper understanding of patient perspectives. The study objectives are to

determine: 1) What factors do the people who require IVF think are important to consider when distributing public funding for fertility treatments? 2) What barriers to accessing publicly funded IVF exist?

Methods

Grounded theory methodology, with a social constructivist interpretative framework, was chosen to generate a theory that is grounded from the data from subjects who have experienced the process of waiting for IVF. Purposeful, extreme sampling was used to capture patients waiting for OFP-funded IVF and who have received OFP-funded IVF. Approval for the research was granted by the institution's Research Ethics Board (REB # 17-081-E). Women who are 43 years or older were excluded, as they are ineligible for OFP-funded IVF. Participants were recruited with poster advertisements in the waiting room at the institution's fertility clinic. The current method of allocating OFP-funded IVF at this clinic is via a first-come, first-served, approach. Four focus groups with two to five individuals were the minimum plan with further focus groups intended until data saturation was reached. Participants were split into groups based on those who have received a funded IVF cycle and those who are still waiting. Focus groups were chosen to allow for interaction among members of the group and a deliberative process to try and clarify and explore a range of beliefs related to the proposed questions.

All participants provided written consent prior to participating in the focus group. Prior to starting the focus group, a questionnaire was distributed to participants collecting baseline demographic data and fertility history. One hour, in-person focus groups were conducted by researchers A.A. and N.C. They were audio recorded within permission and later transcribed verbatim. A topic guide based on results of the patient survey, literature review, and collaborator discussion, was used **(Appendix 1).** Novel topic points discussed during focus groups were brought up in subsequent focus groups. After the focus group, subjects were asked to write a free-text rank list of five factors that should be prioritized for allocation of OFP-funded IVF cycles.

The focus group and rank list transcriptions were analyzed using thematic analysis. Data analysis began with reviewing the transcription for open coding, followed by axial coding then selective coding to determine themes (6). A.A. and N.C. independently conducted the data analysis then met to compare coding. Discrepancies were discussed with K.B and C.J. The original transcriptions were reviewed again to ensure the final themes capture the essence of the data and that saturation was reached. The themes were then interpreted to answer the study questions. All members of the research team agreed on final themes and interpretations. Demographic data from the questionnaire was analyzed with descriptive statistics and presented in table format.

Results

We conducted four focus groups with a total of thirteen participants, ten females, with an average age of 36.4 years (range 28-40.7). The average duration of infertility was 1.9 years (range 0.4-3); see **Table 1** for demographics**.** Here we present a summary of the themes developed from the participants' discussion and written rank list exercise. With respect to our first study question, we found two main categories of discussion: issues of procedural justice and substantive and distributive justice.

Procedural Justice

See **Table 2.1** for procedural justice themes and corresponding quotes.

Transparency from clinics

There is a current lack of transparency about the process of funding allocation, and in general when dealing with the fertility clinics. Participants cited issues regarding a scarcity of data about clinic success rates, allocation procedures, and the number of available funded cycles at each clinic. Misinformation is also being presented and circulated, for example thinking the waitlist was controlled by a centralized provincial body. Ultimately, whatever method is chosen, participants felt that increased transparency is key to a fair process.

Consistency amongst clinics

Most participants assumed the OFP funding allocation was a centralized process or at least standardized

between clinics and argued inconsistency is contradictory to our Canadian healthcare system. There was also discussion about inconsistent practices between private clinics in the community compared with fertility clinics associated with a hospital. They questioned motives of the clinic when structuring allocation strategies—for example, trying to maximize profits or charge extra fees to make up for lost revenue. Without a centralized, standardized process, participants identified that they would be motivated to shop around fertility clinics to increase their chances at obtaining publicly funded IVF.

Gatekeeping of the funding waitlist

Participants described inconsistencies between clinics with respect to when an individual is registered on the clinic's IVF waitlist. Participants expressed that entering the waitlist should either be standardized and transparent, for example at everyone's first visit or based on objective clinical criteria. With respect to management of the waitlist they shared concerns about a lack of correspondence with the clinic about their spot on the waitlist, describing poor communication about whether they were on the waitlist, and when their turn for funding came, it was not clearly confirmed. This inhibited their ability to plan and coordinate other aspects of their lives. To achieve procedural justice, there needs to be transparency and consistency amongst how funds are allocated and who is offered a funded IVF cycle. Patients need more information and communication with clinics.

Substantive and Distributive Justice

See **Table 2.2** for substantive and distributive justice themes and quotes.

Provide a fair chance and equal access to IVF

There were numerous debates over the prioritization of equal access versus optimizing outcomes. The participants recognized the inherent difficulties with this question. Most participants believed the goal of the program should be to increase access to IVF for all women; obtaining a fair chance at having a child was the most important outcome. This was even at the sacrifice of achieving live births, as they felt older women should be prioritized so they would get their chance, at the risk of lower success rates since

success of IVF declines with age (7). This was on the caveat that a physician would only recommend IVF if there was a 'reasonable' chance of pregnancy.

A few individuals felt outcome should be primarily considered from a cost-effective and health perspective. They suggested prioritizing younger women, recognizing that they have a higher chance of a live birth, and less likely to have complications associated with advanced maternal age. A few participants also thought that older individuals would be more likely to afford IVF on their own.

The right to procreation was also discussed and how barriers, such as cost, should be eradicated to allow citizens to exercise that right.

Methods of Distribution

A lottery system was consistently felt to be unfair by participants due to its basis on luck or random chance and not on any logic or reason. The subjects preferred an element of bias is introduced to allow for consideration of important factors rather than pure chance. They also felt that with a lottery you may never get picked, whereas on a waitlist your turn would eventually be reached. First-come, first-serve was seen by some as an acceptable method to distribute the funds, but with a fair and standardized gate-keeper of the list.

A scoring system based on objective factors seemed to be the most appealing of the allocation options to the participants because they felt there was more structure and reasoning behind the allocation decisions. When deliberating upon factors for scoring, there was disagreement and they realized the challenges of putting this together. Most agreed that older age should be the top factor prioritized since they were 'running out of time'. Another consistent factor discussed was previous children; even women with children agreed that this factor should deprioritize someone on the wait list. Participants did recognize that defining previous children can be challenging with blended families or previous adoption.

Subjects discussed that the duration of infertility should be factored as time spent waiting is stressful. However, one participant did note that this could be subjective and should not be considered. There were

inconsistent opinions on income. Some took the stance that income level should have no bearing, arguing that IVF is so expensive that even those with 'good incomes' need loans to afford it, also because they feel they shouldn't be penalized for their hard work. Others felt the public funding should be prioritized to those who could not otherwise afford it. It was agreeable that if you have private insurance that covers the IVF procedure, this should be utilized first (although they acknowledged that this was rare). Other factors inconsistently mentioned were: fitness to be a parent, medical need or dependence on IVF, medical urgency for IVF (ex. A cancer treatment window).

We also discussed some of the pitfalls of a scoring system. For example, how to handle individuals with equal scores and what would happen to those considered who have low priority. Participants suggested that those with equal scores should then be entered on a first-come, first-serve waitlist. Secondly, the scoring system should be reassessed every few months and time waiting should be factored into the score. This allows those with lower priority to eventually get their chance at a funded IVF cycle but wait longer than those considered high priority. Some participants suggested that individuals should be able to assess their own score with an online tool (on a government website) to assess their priority status based on their own factors. This would allow for increased transparency, ensure consistency and allow for personal planning.

This data demonstrates that success is defined by individuals who require ART, as being given a chance at trying to conceive. They recognize the difficulty of making the decision and recommend an objective scoring system be implemented.

Barriers and Challenges

See **Table 2.3** for themes and quotes regarding barriers and challenges.

Lack of information and communication

Subjects felt a lack of communication and support with respect to managing their fertility medications. They felt information in writing and a patient navigator would help facilitate the IVF process.

Cost of fertility treatments

Costs associated with IVF are a major barrier. Participants shared that to receive previous private IVF cycles they needed to take out loans, and others acknowledged that without the OFP it would not even be an option. Even with a funded cycle, the extra costs for medications, storage and ancillary fees, pose as a barrier.

Stress of experiencing infertility

Participants cited significant emotional stress in dealing with infertility. Contributing factors were the length of time waiting and hearing about friends and family members who became pregnant easily. The frequency of appointments and personally invasive examinations was tolling. Participants advocated for more psychosocial supports.

Alternative Options

See **Table 2.4** for themes and quotes regarding alternative options.

Adoption as an option

Participants discussed that for many of them the end goal is to be a parent and have a child, and adoption is an option that was not discussed enough at the fertility clinic. They felt there should be more integration with the adoption process and more information provided by the fertility clinic.

Alternative funding options

Some mentioned a family planning grant could be offered to families, and they could choose to use this grant to fund fertility treatments or adoption. A tax deduction model was discussed where higher income families would receive a tax deduction and lower income families could receive a reimbursement.

Discussion

This study provides patient perspectives for a fair allocation system of publicly funded IVF. A diagram depicting themes and their interrelationships is illustrated in **Figure 1.** Important procedural elements include transparency and consistency amongst clinics regarding how funds are distributed and when publicly funded IVF is recommended. Information sharing and communication between patients and

clinics is essential. The ministry should publicize how many cycles are distributed to each clinic and the method of distribution.

Participants strongly advocated for equal access, regardless of outcomes, highlighting the importance of providing the chance to try for a pregnancy. With respect to how funds should be allocated, a lottery system was consistently seen as unfair, first-come, first-serve was deemed acceptable, but a scoring system was preferred by patients so that relevant factors could be considered. There was disagreement about all factors to consider, however, there was a consistent theme that older women, since they were running out of time, should be prioritized, and couples with children should be deprioritized. Participants recognized the difficulty in these decisions.

Our qualitative findings confirm the patient survey results which also showed that most subjects believed there should be a standardized policy, a scoring system should be used, and access rather than outcome should be prioritized (4). Our study helps to clarify which factors should be considered on the scoring system.

Based on these findings, patients believe that a standardized protocol should be used by fertility clinics. This protocol should be a scoring system that focuses on increasing access to IVF, with some consideration of time waiting. When patients are otherwise equal on the scoring system, they should be entered on a first-come, first-serve waitlist. The scoring system should be updated every few months, and time-waiting should be a factor that will allow those with a low-priority score to eventually become high-priority. Ways to address this could be similar to a clinic triaging system. There can be urgent IVF spots kept available reserved for the highest priority patients, if not filled they can be reallocated to the medium and low priority patients. Additionally, there are routine spots available for lower priority patients and the determining factor would be length of time waiting. An alternative method would be a score multiplied by time waiting in months. The point at which the patient is considered for IVF should also be standardized across clinics. This process, as well as the scoring system, should be transparent and readily available to patients. Ideally, this scoring system would be uniform among fertility clinics and managed centrally to

ensure a standardized approach. However, this would be administratively challenging to do, as patients were able to identify during the focus groups.

In addressing our second research question, participants discussed the lack of information, the extra costs and the stress of infertility as challenges in their journey. A strong focus on communication, orally and in writing, should be partaken by clinics. Information about the fertility process, the OFP and the extra costs should be clearly provided. Psychosocial supports should be offered more often to patients at fertility clinics to ease their process. Facilitating the adoption process should be considered more often by fertility clinics. The government could also consider a tax deduction or family planning grant as an alternative funding option.

Limitations of our study include: a small sample size and single institution recruitment. The perspectives of patients may be biased by the communication strategies employed at this single fertility clinic which may be different at other clinics across Ontario. Potential participants who lived further away were less likely to enroll in the study due to distance and time requirements. As a result, all our participants were from Toronto or the Greater Toronto Area. Furthermore, since this is group was selected from a fertility clinic, we missed the population that has not attended at a fertility clinic. Thus, we may be missing upfront barriers to accessing fertility treatment.

Conclusion

IVF is now a publicly funded option for patients who require ART in Ontario with a finite limit. Currently, there are no standardized strategies amongst participating clinics deciding how this fertility option should be distributed. We hope the results of this study will be considered by relevant stakeholders including the MOHLTC and fertility clinic directors in Ontario, and any other jurisdictions with a similar funding program. Our goal was to make the distribution of publicly funded IVF fairer and based on factors that people who require IVF think are important. At the very least, transparency and better

communication should be implemented to increase substantive rights for patients and reduce emotional stress.

"I was going to say thank you for doing this as your project because I didn't even fully realize the depth of all of this and it's obviously something that's really important to a lot of people so thank you for investigating it."

Tables and Figures

Table 1: Patient Demographics

Patient Characteristic	n (%)
Gender	
Female	10 (77)
Male	3 (23)
Region of Residence	
Toronto	6 (46)
GTA	6 (46)
No Answer	1 (8)
Relationship Status	
Married	12 (92)
Partnered	1 (8)
Number of Children at home	
None	9 (69)
One	4 (31)
Annual Income	
<$25, 000	0
$25, 000-34, 999	1 (8)
$35, 000-49, 999	0
$50, 000-74, 999	2 (15)
$75, 000-99, 999	2 (15)
$100, 000-149, 999	2 (15)
$150, 000-199,999	4 (31)
≥ $200, 000	2 (15)
Funded IVF Status	
Received IVF	6 (46)
Waiting for IVF	7 (54)

Table 2.1 Procedural Justice themes and corresponding quotes

Procedural Justice	
Sub-theme	Quote
Transparency from clinics	*I wasn't made aware of any sort of transparent process, I was just told I'm on a waitlist with no like contact information or where am I on the waitlist is it a lottery-wait list is it a time-based wait list I have no idea and I also didn't know it's the clinic themselves that are doing it.*
	At the least I mean, if the clinics are doing different things, I think they need to be extremely transparent about what they're doing, at least you're going in with your eyes open you know, understanding the difference from clinic to clinic…that way you can make an informed decision.
Consistency amongst clinics	*It just doesn't make sense if I walk down the street and go to another clinic I'm going to get a different you know different care this is completely contrary to you know what the Ontario Health Care System, Canadian Healthcare System is about.*
	There has to be same criteria. It kind of made me mad to be honest, that now I have to shop around? To see which clinic I would have better options with?
Gatekeeping of funding waitlist	*I was on the list at Mount Sinai just 'cause they threw me on first time I met with them. But at another place they wouldn't, they said to wait, but I don't know if it's because they had a different system that wasn't first-come, first-serve.*
	They need to have some kind of standardized protocol, like this person comes into clinic… first assessment whole bunch of different tests then we're going to do try IUI if that's an option. We do at least 3 or 4 if you don't get pregnant by 3 then it's no chance vs. you know somebody who comes into the clinic IUI is not an option, could be low sperm count or whatever it is, and then they go to IVF right away. But again transparency –needs to be a clear process and if you don't get placed on the list right away you need to know why.
	I received the email by the end of last year, that oh we have an opening, so I replied to the email right away, and then I didn't hear anything and I thought oh I probably didn't make it, so next time when I saw the doctor to do the timed intercourse, then they told me oh we have an opening, do you want to be on the list? I said sure!

Table 2.2 Substantive and Distributive Justice themes and corresponding quotes

Substantive and Distributive Justice	
Sub-theme	Quote
Provide a fair chance and equal access to IVF	*I think when you define success, to the ministry is live births. I know that's the end goal, but success I think as a society… is the access. That is giving everybody a chance. Even for me if I had multiple cycles and it didn't work yes…the end result wasn't live birth, but I emotionally and whatever would feel like I gave it all my all and I tried. And that would have gave me peace of mind no matter the age.*
Methods of Distribution	*Age is another important factor, so it's up to 43 years and the people who are closest should be able to get on this list as soon as possible so they have as many chances as they can to get it.*
	I actually have a kid and I don't think I should be I should have priority over someone who doesn't have a kid

Table 2.3 Barriers and Challenges themes and corresponding quotes

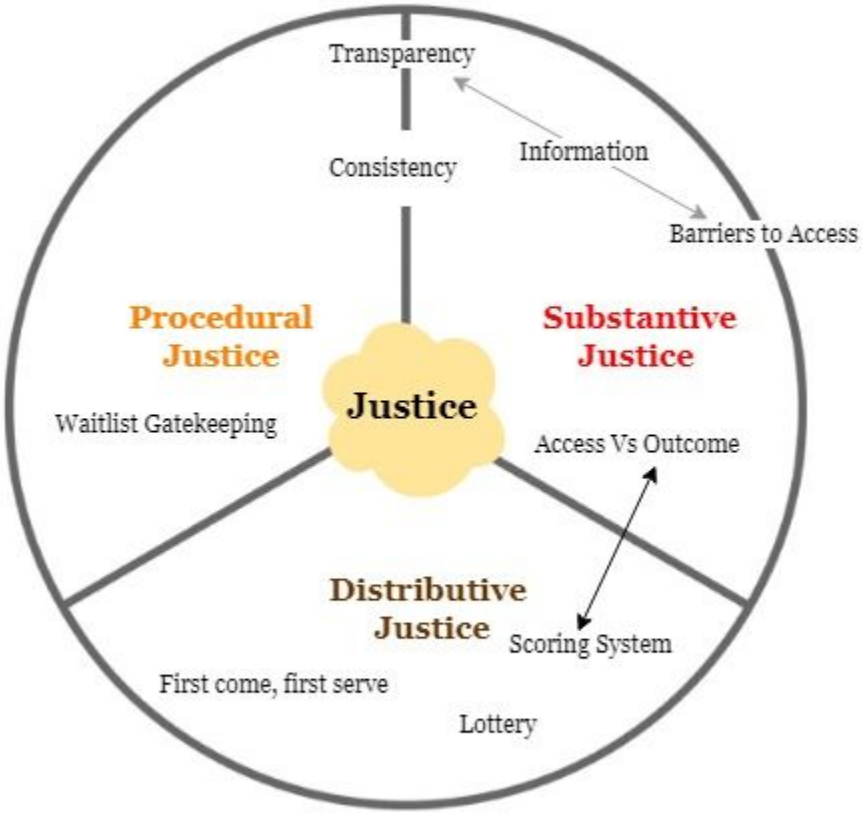
Barriers and Challenges	
Sub-theme	Quote
Lack of information and communication	*It's already like you're trying to remember how to take the medication and everything else there's a huge list [of extra fees] and strain out what's actually relevant to you, it's just a little overwhelming.*
	I literally got a new phone because I need my phone to always be charged and available because that one day it's not available and I can't get a hold of them, and I miss a call, and they leave a message and if I have a question about the message, [it's hard] getting a hold of them.
Cost of fertility treatments	*Even just the medication, aside from the procedure, even just the medication is enough to like, even this month, me and my husband are very tight on our finances, this month we had to struggle more because we had to pay for the freezing of the embryos, the medication, he almost fell over and passed out seeing what we're paying for.*
Stress of experiencing infertility	*It's an emotional time when you're going to a fertility clinic and you're being told what your options are and are not and I feel like for me to be able to make a good decision, a right decision, there should be social worker involvement or even a psychologist to put things into perspective would have been helpful, it almost feels like a factory at times, when you're just*

	another patient.

Table 2.4 Alternative Options and corresponding quotes

Alternative Options	
Sub-theme	Quote
Adoption as an option	*This is just how our entire healthcare system is, but they are just so separated and disconnected. You know if I were to decide right now I wanted to adopt I have to go to a completely different journey, figure out how does this system work in Ontario. What do I do, how much does it cost, does it cost anything, what other criteria?...We'll try this mountain first. And then maybe we'll do the other mountain.*
Alternative funding options	*If we're looking at making a better society then, and now I might get a little emotionally here sorry, but to see your partner go through the ups and downs and yes this is a good cycle and this could work and then it doesn't work and then now think is it all worth it what if you just told us we could have this much funding to adopt a kid I mean in our situation I'd be like yes thank you please end this cycle.*

Figure 1: Thematic Analysis



Appendix 1: Focus Group Topic Guide

1. What are your thoughts on how the current system, the OFP, is currently functioning?
2. How do you think the funding should be distributed across the province?
3. If a scoring system is used, what factors should be prioritized?
4. What are barriers to accessing IVF?

References

1. Greenblatt E. Advisory Process for Infertility Services Key Recommendations Report. Ontario, Canada. 2015 Jun 23. [cited 2018 Sept 19] Available from http://health.gov.on.ca/en/public/programs/ivf/docs/ivf_report.pdf
2. Ontario Ministry of Health and Long-Term Care. Ontario Announces 50 Clinics Offering Government-Funded Fertility Treatments: Helping Ontarians Grow their Families. 2015 Dec 21 [accessed 06 Feb 2018]. Available from: https://news.ontario.ca/mohltc/en/2015/12/ontario-announces-50-clinics-offering-government-funded-fertility-treatments.html
3. Blackwell T. Waitlists for IVF Stretch to 2018. National Post. 2016 May 26 [cited 2018 Sept 19] Available from https://www.pressreader.com/canada/national-post-latest-edition/20160526/281505045461992
4. Gotz T, Jones C. Prioritization of patients for publicly funded IVF in Ontario: a survey of fertility centres. Journal of Obstetrics and Gynaecology Canada. 2017 Mar 1;39(3):138-44.
5. Gotz T, Goldstein S, Chauhan N, Jones C. Distribution of Funded IVF in Ontario: A Patient Perspective. Paper presented at: 63rd Annual Meeting of the Canadian Fertility and Andrology Society Conference ; 2017 Sept 14-16; Vancouver, BC
6. Strauss A, Corbin J. Basics of qualitative research: Grounded theory procedures and techniques. Newbury Park, CA: Sage, c1990.
7. Canadian Assisted Reproductive Technologies Registry (CARTR) Plus. Final treatment cycle and pregnancy outcome data for 2015. Better Outcomes Registry & Network Ontario. Ottawa ON, 2017 Sept

Procedural Justice	
Sub-theme	Quote
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Substantive and Distributive Justice	
Sub-theme	Quote
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Alternative Options	
Sub-theme	Quote
Adoption as an option	*This is just how our entire healthcare system is, but they are just so separated and disconnected. You know if I were to decide right now I wanted to adopt I have to go to a completely different journey, figure out how does this system work in Ontario. What do I do, how much does it cost, does it cost anything, what other criteria?...We'll try this mountain first. And then maybe we'll do the other mountain.*
Alternative funding options	*If we're looking at making a better society then, and now I might get a little emotionally here sorry, but to see your partner go through the ups and downs and yes this is a good cycle and this could work and then it doesn't work and then now think is it all worth it what if you just told us we could have this much funding to adopt a kid I mean in our situation I'd be like yes thank you please end this cycle.*

Standards for Reporting Qualitative Research (SRQR)*

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	Page/line no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1/8-9
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	3/1-24
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	4/1-24
Purpose or research question - Purpose of the study and specific objectives or questions	5/1-3
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	5/5-6
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	5/19
Context - Setting/site and salient contextual factors; rationale**	5/10-11
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	5/7-8, 9-10, 12-13. & 6/4-5
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	5/8-9
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	5/17-24

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	5/19-20
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	6/10-12
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	6/1-8
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	6/1-8
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	5/5-8 6/3-7

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pages 6 - 12
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Pages 15-17

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	12/ 17-23, 13/1-2
Limitations - Trustworthiness and limitations of findings	12/10-16

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	6/3-7
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	1/30-36

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388