Article details: 2018-0182

Perspectives on resource allocation of publicly-funded fertility treatments in Ontario: a focus group study

Authors: Angela Assal MD MHSc, Nipa Chauhan MHSc, Eyun-Jung Shin MSc, Kerry Bowman PhD, Claire Jones MD

Jones MD		
Reviewer 1	Hazar Haidar	
Institution	McGill University and Université de Montréal, Institute for Health and Social Policy and Centre de recherche en éthique	
Reviewer comments	Author response	
Abstract:	•	
p.4 lines 35-37: The statement in the conclusion is very optimistic and it should be more realistic. The sentence should be reformulated to clarify that the goal of your study is to pinpoint factors that participants think are crucial in order to make the distribution of publicly funded IVF fair or maybe fairer than it currently is rather than "our goal was to make the distribution of publicly funded IVF fairer". Also, with the results of one qualitative study it is hard to respond to such an important goal.	Thank you for the suggestion, the abstract conclusion was edited based on your suggestions and in keeping with the appropriate CMAJ open format requirements	abstract, page 2
p.4 line 39: Patients have so many substantive rights. I suggest specifying what substantive rights are you pointing to.	Thank you for the suggestion. This has been clarified within the appendix.	Page 22
Introduction		
Background information		
p.5 lines 8-12: I suggest reorganizing this section. Moving the sentence 'In addition access' to the end of this section will allow a better flow of information because you start with live births in Ontario while mentioning the IVF procedure cost and then you go on by describing the OFP and get back to privately funded IVF. So, the cost of the procedure should be mentioned along with patients seeking privately funded IVF in order to show that the cost constitutes a barrier to access.	Thank you for your suggestion; the manuscript was edited to integrate your suggestion.	Intro page 3
You state as a well that in addition to the cost of medications, the IVF procedure costs about 10-15000 CAD. However, it should be specified that those medications are IVF drugs that are not funded by the province under the OFP and are paid out-of-pocket. I would also suggest adding the approximative cost of those drugs to emphasize the overall expense of the IVF.	Thank you for your suggestion; the manuscript was edited to integrate your suggestion.	Intro page 3
p.5 lines 17-20: It would be interesting to mention that in Ontario, IVF procedure is covered as well for same sex couples and single people.	Thank you for this suggestion; we wish to have included this in our manuscript but were limited due to the word count. We found this fact to not be directly relevant to the aims of our study.	NA
Literature review	The and the second an	Intra no con O
A literature review is generally based on many studies and papers. However, you only made reference to two studies (references 4 and 5). So, I don't think that the title of this section fits its content. Also, if it's a literature review why, among others, you did choose ONLY those two studies? I suggest adding this section to the previous one and under the same title; background information or too simply introduction.	Thank you for your suggestion; the manuscript was edited to integrate your suggestion.	Intro page 3
p.5 lines 38-43: 52% used multiple factors. Could you please offer examples of these factors?	Thank you for your suggestion; the manuscript was edited to integrate your suggestion.	Intro page 3
p.5 lines 47-48: should use the same policy in regard to what? To resource allocation or to methods of allocation (scoring system,	Thank you for your suggestion; the manuscript was edited to	Intro page 3

first-come first-serve, lottery).	integrate your suggestion.	
Finally, a short sentence explaining shortly the three methods of	Thank you for your suggestion;	Introduction,
allocation that are employed (scoring system, first-come first-	the manuscript was edited to	page 3
serve, lottery) could be helpful to the reader.	integrate your suggestion.	' '
Methods		
p.6 lines 14-18: You mention Grounded theory methodology	Thank you for bringing this to our	Methods page
without any reference. Please add a reference.	attention. References added.	4
- You mention thata theory that is grounded from the data from the subjects who have experienced the process of waiting for IVF. Then, in the next lines (18-20) you state that the purposeful sampling included both patients waiting for OFP-funded IVF and those who have received OFP-funded IVF. Between both sentences there is a contradiction because while you recruited both, those who are waiting and those who received funded IVF, you are generating a theory from the data of patients who have experienced the process of waiting for IVF. Do you mean that all those participants from your sample (N=6) who received funded IVF have experienced the process of waiting because maybe	Thank you for your comment. Those who eventually received a funded cycle still went through the process of waiting for it, and thus we were still interested in their perspective; we edited the text to clarify this.	methods page 4
some of them haven't? Please clarify.  - Usually, in research ethics the term participants is used instead of subjects.	thank you, edited throughout the manuscript	Throughout
p.6 lines 18-25: you state that you used purposeful sampling to capture patients waiting for OFP-funded IVF and who have received OFP-funded IVF. Than you mention that the study is approved by the REB and you go on to say that women who are 43 years or older were excluded. There are many questions to be addressed:	,	
1- Since the sampling is a purposeful one, the characteristics of your sample were ONLY age (43 yo or older) and IVF funding (whether received or waiting for it)? Are there any others? If yes, please specify.	Anyone eligible for IVF and their partners were included. Women seeking IVF 43yo or older were excluded as they are ineligible for OFP. We did only include English-speaking persons capable of consent. we updated the manuctip to reflect this	methods section, page 4
2- Mentioning the approval of the study by a REB comes at a wrong place. It cuts the sentence related to the characteristics of your sample and it does not mention the name of the institution from where you got the approval to conduct the study. Unless the journal requires it to be anonym for reviewing purposes, it is crucial to mention the institution name.	Thank you for suggestion, Moved to the end and added institution name	methods section, page 5
p.6 lines 48-50: the first question in your focus group topic guide (appendix 1, p.21): 'what are your thoughts on how the current system, the OFP, is currently functioning" implies that participants were aware about how the current system is functioning. Was it the case? If not did you provide any information about it or did you facilitate a guided deliberation about the OFP? Because if this is the case, this might bias the participants' responses and should be noted in the limitations. Please in both cases, clarify.	Since participants were recruited from the fertility clinic waiting room and the requirement for study participation was that they were either waiting for or received publicly funded IVF, we assumed most participants already had some idea about the OFP. We did include a generic intro about the OFP, which we have added to the appendix with the topic guide, we read the same intro for each session but realize this could bias participant responses and noted this in the limitations. Thank you for the feedback.	methods page 4, limitations page 11, and appendix 1, page 20
p.7 lines 3-7: Did you use any software to facilitate your coding?	No, manuscript updated	Methods page
-		4
Results		•

p.7 lines 32-36: how did you group some themes under procedural justice and others under substantive and distributive justice? Was there any standard definition that you followed for each of the terms in order to facilitate the organization of your coding and data? Maybe if you provide a definition of each of the terms (procedural vs. distributive vs. substantive) the way of	Thank you for pointing this out, we have added our definitions of these philosophical concepts in an appendix 3.	Appendix 3
organizing your results would become clearer to the reader.  My general comment regarding the results' section: one of the main characteristics of a qualitative study is the narrative it includes reflected and expressed by the quotes from participants. Unfortunately, this narrative is missing from your results. In other terms, grouping all the quotes into tables weakens the story of the qualitative study and makes it hard to follow. Therefore, I suggest inserting quotes into the text to make it richer and to strengthen your analysis. In addition, for your quotes, can you give them a participant or a focus group number or pseudonym.	Thank you for your comments, we added quotes throughout the results to add to the narrative aspect of our study.	Results sectionResults page 5-10
p.3 lines 53-55: please specify what do you mean by method. Is it the approach that the clinic is using to distribute IVF funding?	Yes, that is what we meant, edited the text for clarity	Page 8
p.8 lines 35-40: when presenting your data analysis, you should avoid interpreting your data or jumping into recommendations as is the case here. I suggest removing the sentence 'To achieve procedural justicewith clinics" and add it where you think it fits, whether in the interpretation or the conclusion section.	Thank you, we've moved this to the interpretation section	Interpretation 11
p.8 lines 48-50: It is unclear what do you mean by optimizing outcomes. What outcomes? With regard to pregnancy? Having a child? IVF success?	We meant successful live birth from IVF, we've edited the text for clarity	Results page 10
Further, you state that 'the participants recognized the inherent difficulties with this question". Which question? I don't think it is a question included in the topic guide (appendix 1), so how did it come up?	Question refers to the debate of optimizing live births vs. equal access to IVF for everyone regardless of their chances of a successful pregnancy. Questions and comments evolved throughout the focus group, the topic guide questions were used to initiated discussion amongst participants	results page 10
Rank list: it would be interesting to know if, in the rank list, some factors were more cited than others.	Thank you for your comment, when coding the data and determining the themes, we did consider the frequency of rank list factors. We considered adding a quantitative table showing frequency of themes based your suggestion, however we opted against this as we did not set up appropriate methodology for a quantitative data analyss	Not available
p.9 lines 19-22: a more detailed analysis is needed with regard to the right to procreation. From which angle was it discussed? For example, did participants state that they believe that procreation or having a child is a right and thus they have a right to access IVF?	Thank you for your comment, there was not a deep enough discussion amongst participants to elaborate, and thus we removed this point as it wasn't a major theme.	Not available
p.9 line 24: Methods of distribution: considered alone, it is unclear what this subtheme refers to. Is it methods of IVF funding distribution?	Yes, this is what we mean, added clarification in the section header	Results page 10
p.10 lines 42-47: Again, I suggest removing this section since it belongs to the interpretation section. Also, replace they by participants.	Thank you, we've moved this to the interpretation section	interpretation page 10
p.10 line 50: Barriers and challenges to accessing IVF would be clearer.	Thank you, edited	Results p 9

p.11 line 30: Alternative options: Although interesting, but what does this theme (and the consequent subthemes) have to do with your two study objectives? How is it linked to them?  Discussion	Thank you for your comments, these were suggestions brought up by participants without us prompting. However, given that it's not related to our study question and that we are over word count, we eliminate this section	not available
The discussion reflects a repetition and a summary of the findings rather than an interpretation of the data and sometimes I am not clear as to how aspects of the discussion reflect on the findings from the paper. I think this section needs refining and a more profound analysis of the collected data.	Thank you for the feedback, the interpration section was edited	Interpretation page 10-11
<ul> <li>p.12 lines 5-6 and p.20 (diagram):it is very hard to follow your diagram and to understand the interrelationships created for the following reasons:</li> <li>There is a mismatch between the themes and the diagram.</li> </ul>	Thank you for your assessment, since the relationship isn't clear we've removed the diagram	removed
Does the diagram represent all your themes and sub-themes? For instance, while in the text you grouped distributive and substantive justice under one theme, the diagram shows that they are separated. Further, how did access vs. outcome sub-theme came up? The sub-theme you noted is fair and equal access. Similarly, while you grouped transparency and consistency under the procedural justice theme, the diagram shows that they are separated from it and are at the limit between procedural and substantive justice.		
- The text mentions interrelationships without any explanation of how they were created and what makes them linked to each other and what is the logic behind these interrelationships. And where did the big theme of justice in figure 1 (p.20) come from since it is mentioned nowhere throughout the paper? Further, it is hard to understand the concept mapping process. For instance, how is the scoring system related to access vs. outcome as shown by the arrow? What links both?  In sum, the diagram needs explanation and a better match with		
your data analysis and interpretation.  - If the main big theme of your data analysis is justice then it could be considered as the lens of your data interpretation. For instance, p.12 lines 5-14: how does the lack of transparency and consistency amongst clinics affects procedural justice and therefore patients' rights to be informed? What does the lack of transparency and consistency mean in light of procedural justice?	Thank you for the feedback, the interpration section was edited	interpretation page 10-11
This could be also applied to the other sections (p.12 lines 16 -57 and p.13 lines 3-30) of your interpretation. Again, you should avoid repeating your analysis.	Thank you for the feedback, the interpration section was edited	interpretation page 10-11
Limitations		
p.13 lines 32-45:  Did your participants include same sex couples or single woman and man who would like to resort to IVF? If no, why they were excluded? If yes, did they cite barriers; other than those reported in the current paper to accessing IVF?  Was there any difference in perspectives between women who	We did not exclude any participants on the basis of sexual orientation or relationship status. No single individuals chose to participate in our study. We did not collect demographic information on sexual orientation. We did not exclude single or same-sex male couples, however, the only males who chose to participate in this study were present with their female partners. No we did not note any	

have received a funded IVF cycle and those who are still waiting?	differences	
		Limitations
You mention many different characteristics of your participants	Thank you for the suggestion, we	
(ethnicity, income, region of residence, etc.) but how might these	edited the limitation section to	section, page
characteristics have coloured the findings? Could you give an	reflect this	11
example because this should be discussed in the limitations.		
Conclusions		
p.14 lines 5-12: please see my same comment in the abstract	Thank you for your comments,	conclusions, p
regarding p.4 lines 35-37.	conclusion edited	12
References		
p.22		
In general, I can see that there is a lack of references for a	Thank you for this observation, we	Throughout
qualitative study.	have added more references	3.3
4	interspersed through out the paper	
Further, in the discussion, you just had one reference and it is the	Thank you for your suggestion, we	Interpretations
same one used in the introduction. Maybe you can validate and	have compared our findings with	page 10-11
compare your findings with studies and research made in other	another similar study.	page 10-11
countries on the same topic.	another similar study.	
Reference number 6 is not inserted into the text.	The plane of the patient this this was	Mathada
Reference number 6 is not inserted into the text.	Thank you for noting this, this was	Methods
	a reference used for methodology	pages 4
	and added where appropriate	
p.5 line 56: patients' perspectives instead of patient perspectives.	Thank you, edited	
p.8 line 48: Remove the from the participants.	Thank you, edited	
p.12 line 6: patients' perspectives instead of patient perspectives	Thank you, edited	
Reviewer 2:	Cathy Popadiuk	
Institution	Memorial University, Dept of Wome	n's Health
Reviewer comments	Author response	
	Cost can still be a barrier as even	Results
It is not clear how cost and stress are barriers to access public		
funds. Poor communication of application process or otherwise	if IVF procedure is paid for, the	section page
can be a barrier and there is the inherent unfairness of those who	medications can cost up to \$5000	9-10
can afford privately funded IVF where public funding would not	out of pocket. We've added this	
be important to them.	clarifier to the cost section. Stress	
	made it harder for participants to	
	navigate the public funding	
	system, this was also added	
The authors could have also asked the IVF clinic staff physicians	Thank you, will consider for future	
and administrators to participate in focus groups to compare their	studies. The goal here was to	
thoughts as to how best to allocate these public funds, what	obtain patient perspectives.	
factors are considered in determining priority of which patients		
should receive them, and what barriers they see to allocating		
these funds. It would be interesting to view this perspective as		
well.		
The figures and tables of participant comments are rich with		
interesting information although not particularly novel and not		
necessarily related to the public funding dilemma itself.		
Nonetheless the feelings and contributions of the participants are		
important to understand. Admittedly there could have been		
selection bias as outlined by the authors as a limitation in		
addition to the single clinic in urban Toronto.	Thonk you this suggestion has	Intorresetations
There was no discussion as to how these results and this	Thank you, this suggestion has	Interpretations
population can be applied outside the province of Ontario.	been integrated within our	pages 10-11
Quebec had publicly funded IVF and it would have been	interpretation section. We have	
informative and interesting to review how their program is similar	chosen to compare and contrast	
or different from Ontario. There may also be similarities or	our study to a similar study from	
differences among other provinces and countries.	New Zealand.	
IVF and infertility affects only 1 to 2% of the population, but the	Thank you for this suggestion, we	Interpretations
allocation of scarce public funds applies to other disease	hoped to have acknowledged this	pages 10-11
processes, some more common and thus the findings could be	in our manuscript with depth, but	-
compared and contrasted to other similar or different programs	our word count was limited. We	
(cancer treatments, chronic disease management tools).	have chosen to compare and	
- realiser from the former of the fill discussion in a fault and the fill belief.	i have checon to compare and	Ĭ

There is vast research and literature outlining the stress and emotional burden on couples going through the fertility process. At times, the paper loses focus and spends much time concentrating on this aspect of the fertility journey. How much public funding adds to the unfairness of the journey increasing the emotional distress, could have been emphasized.	contrast our study to a similar study from New Zealand.  Thank you for your comment.  Overall, the availability of public funding is very much appreciated by individuals, the added stress is the way in which it is being distributed.	Throughout
As well, the reference list seems limited to Ontario and has only one peer reviewed source (JOGC) relevant to the topic excluding Strauss for Grounded Theory. A few more peer review academic sources may add to the credibility of the findings sound as they are.	Thank you for this observation, we have integrated a few more peer reviewed academic sources.	Throughout