

Regret surrounding fertility preservation decisions in the paediatric cancer population

Jayasuriya S¹, Kemertzis M², Peate M³, Allingham C⁴, Li N⁵, Gillam L⁶, Zacharin M⁶, Downie P⁷, Moore P⁸, Super L⁹, Orme L⁹, Agresta F, Stern C¹⁰, Jayasinghe Y¹⁰ on behalf of the Paediatric & Adolescent Fertility Preservation Taskforce, Melbourne, Australia

¹Monash University, Victoria; ²Department of Gynaecology, Royal Children's Hospital, Victoria; ³Department of Obstetrics & Gynaecology, Royal Women's Hospital, University of Melbourne, Victoria; ⁴Department of Paediatrics, University of Melbourne, Victoria; ⁵School of Population and Global Health, University of Melbourne, Victoria; ⁶Children's Bioethics Centre, Royal Children's Hospital, Victoria; ⁷Department of Endocrinology, Royal Children's Hospital, Victoria; ⁸Murdoch Children's Research Institute, Victoria; ⁹Monash Children's Cancer Centre, Monash Hospital, Victoria; ¹⁰Department of Paediatrics, Monash University, Victoria; ¹¹Children's Cancer Centre, The Royal Children's Hospital, Victoria; ¹²Melbourne IV, Victoria; ¹³Reproductive Services, Royal Women's Hospital, Victoria;



Background & Aim

- Decision regret (DR) has negative impacts on quality of life and wellbeing.
- Decision-making regarding fertility preservation (FP) may result in high levels of DR, due to the limited time available for discussion and distress at the time of a cancer diagnosis.
- In the paediatric & adolescent sector this is further complicated by the experimental nature of available techniques and ethical complexities surrounding surrogate decision-making.
- Creating the potential for regret in both patients as survivors and their parents.
- This is a growing issue as >80% of cancer patients aged 0-19 are surviving to adulthood¹
- No studies are yet to evaluate DR over FP decisions in the paediatric & adolescent cancer setting.

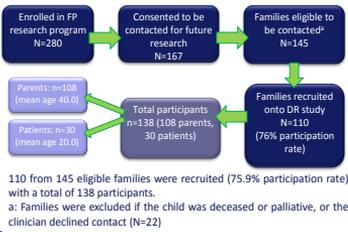
We aimed to determine the risk of DR in patients and parents involved in making a FP decision at the Royal Children's Hospital (RCH) Melbourne where an established oncofertility program was introduced in 2013.

Methods

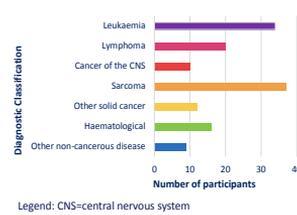
- Single site cross-sectional study
- Participants: Parents & patients (≥15 years)
 - Had a fertility discussion between Jan 1987- Nov 2016 at the RCH
 - Consented to be contacted for future research
- Materials
 - 10-Item survey containing: Decision Regret Scale²; Two Likert-type questions assessing impressions regarding the success of FP; free-text response items to provide reasons for satisfaction or regret over the decision. DR scores were calculated as per DR scale manual². Scores >30 indicate low/no regret³
 - Oncofertility data from FP research database
- Mixed methods approach

Results

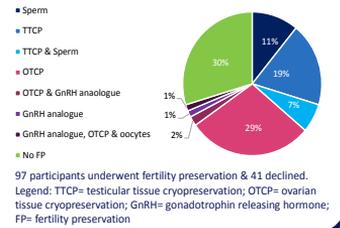
Recruitment process:



Diagnostic classification of participants:



FP measures undertaken:



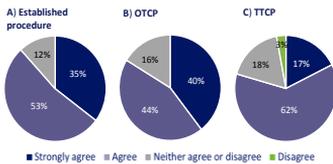
Clinical characteristics of participants:

Risk of infertility – n (%)	
High (>80%)	79 (57.2%)
Medium (20-80%)	40 (29.0%)
Low (<20%)	16 (11.6%)
Unknown	3 (2.2%)
Fertility consultation – n (%)	
Oncologist	32 (23.2%)
Oncologist & oncofertility specialist ^a	106 (76.8%)
Timing of discussion – n (%)	
Prior to high-risk gonadotoxic therapy	113 (81.9%)
Post high-risk gonadotoxic therapy	9 (6.5%)
Unknown	16 (11.6%)
Fertility procedure complications – n (%)^b	
Yes	4 (5.0%)
No	76 (95.0%)
Treatment status at time of survey – n (%)	
Active treatment	33 (23.9%)
On maintenance therapy	16 (11.6%)
Off treatment	84 (60.9%)
Other	5 (3.6%)

a: oncofertility specialist= paediatric endocrinologist or gynaecologist
b: Assessed out of those who had ovarian or testicular tissue preserved (n=80)

Expectations of FP

Participant impressions regarding how strongly they feel that FP procedures will be successful in this lifetime:



~80% of those that had an experimental procedure (ovarian or testicular tissue) also believe it will be successful in the lifetime of the next generation.

The experience of DR

High DR (score ≥30) was reported by 18.6% (n=24).

Factors that influence regret

Multivariate analysis (adjusted for confounders):

- Believing that FP will not be successful in one's lifetime (p<0.005, OR=2.962, CI=1.388–6.319),
- Not having a FP procedure (p<0.009, OR=214, CI=0.67–684),
- Having a fertility discussion only after high-risk therapy (p<0.014, OR=9.089, CI=1.566–52.759).

Qualitative analysis:

Reasons for satisfaction with FP decision

Those that proceeded with FP:

- Had hopes regarding the future "options", "choices" and "chances" that FP may provide (n=92), focusing on hopes for the patient to have children (n=27)

"It gives my son the option to reproduce when he hopefully is of a suitable age if he requires/desires"

Those that did not have FP:

- Referred to its experimental nature and the patient's age or health (n=11)

"[She is] too young for it to be viable with unnecessary risks to [her] health now..."

Reasons for regret over FP decision

- Related to the process of discussion, information provision & follow-up (n=5)

"I do not regret the decision... [but the discussion] was extremely rushed, and we perhaps did not get all the information on what follow up appointments etc. would be required..."

- Related to FP not being offered (n=6)

"...at the time we had to ask what was available... [FP] was not offered, which I was a bit disappointed with [as] so much was happening ...it could have been missed..."

Regret over time

DR was assessed longitudinally in 22 participants over 18 months:

- 8 had no change in score
 - 8 decreased / 6 increased in score: 3 (14%) had an increase/decrease sufficient enough to change categories.
- Free-text responses indicate need for accurate information about realistic chances of success to be provided at the time of discussion and ongoing fertility consultation well into survivorship.

Future indications

More research regarding DR over time is required in all clinical contexts due to a general paucity of data and for generalisability reasons.

Conclusion

- Overall levels of regret were low.
- Predictors of low regret: factors associated with quality, timely discussion and belief that technology would lead to parenthood in their lifetime.
- Participant expectations & hopes for the success of FP may be protective against regret, and should be clarified during fertility discussions to minimise false hope and subsequent regret.
- Amendments to the decision-making process are required to meet information needs and maximise satisfaction in all families.

References

- Australian Institute of Health and Welfare. Cancer in adolescents and young adults in Australia. Canberra: AIHW, 2011.
- Brahaat JC, O'Connor AM, Wood TJ, Hack TF, Siminoff L, Gordon E, et al. Validation of a decision regret scale. Medical decision making: an international journal of the Society for Medical Decision Making. 2003;23(4):281-92.
- Becerra Perez MM, Mosen M, Brahaat JC, Lagare F. Extent and Predictors of Decision Regret about Health Care Decisions: A Systematic Review. Medical decision making: an international journal of the Society for Medical Decision Making. 2016.

Acknowledgements & Correspondence
Funding for this research was provided by the Victorian Cancer Agency.
Contact: Dr Yasmin Jayasinghe, yasmin.jayasinghe@unimelb.edu.au