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An Environmental Scan of Patient Resources: Supporting Women's Fertility Preservation Decisions Before Cancer Treatment

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Background & Study Aims

There is a need for the development of a resource for cancer services and women, to support decision-making about fertility preservation. [1-2]

The *Cancer, Fertility and Me* project aims to develop a patient decision aid (ptDA) to support women with cancer making fertility preservation decisions. [3]

This environmental scan is part of the identifying evidence to inform the development of the ptDA. [4]

The environmental scan aims to:

Assess the quality of patient information and clinical guidelines for women being treated for cancer offered fertility preservation, by:

- Scanning open-access resources for women and professionals
- Synthesising and evaluating resources for 'active' decision making components
- Identifying evidence to inform content ptDA

Methods

Design: survey employing systematic review methods

Sample: open-access patient information or clinical guidelines

Searches: (November-December 2015)
1. Google (Chrome) – first 15 pages of hits from 10 unique search strategies, using combination of terms [cancer] [women] [treatment] [fertility preservation] [decision-making] [decision aid] [booklet] [information]

2. Repositories – The Decision Aids Library Inventory, Trip, NHS Evidence, The National Guidelines Clearinghouse, Clinical Trials; terms [cancer] [breast] [leukaemia] [lymphoma] [gynaecological] [fertility preservation]

3. Decision Aid Experts – SHARED-L distribution list; steering group expertise (resources/ prior research)

Inclusion Criteria:

Resources: a) woman treated for cancer; b) implications of cancer treatment(s) on fertility; c) describe fertility prevention options and consequences; d) provide explicit decision making statements and/or guidance.

Guidelines: a) raise awareness about fertility preservation; b) what to discuss about fertility preservation options; c) when to discuss fertility preservation options; d) how to support the patient in shared decision making.

Data Extraction Sheet:
- Demographics
- Understand health problem (illness representation theory)
- Supporting active thinking (components)
- International Patient Decision Aid Standards (IPDAS 12 criteria)

Conclusion

The content and quality of resources varied. Only one resource met literacy standards. Most patient resources were not designed to support decision making explicitly. Fertility preservation was largely explained within the infertility treatment pathway. Limited structures used to support active, unbiased reasoning between options in the context of treatment for cancer.

Future directions:

There is a need for the development and evaluation of a ptDA that:
- Helps women to understand fertility preservation as part of reducing impact of cancer treatment on fertility, in the long term.
- Includes structure to enable active reasoning about own values, risk perceptions cancer treatment, and trade-offs.

References
1. Jones GL, Hughes J, Mahmoodi N, et al. What factors influence the decision-making process for women with cancer contemplating fertility preservation? A narrative review. RCOG World Congress, Abstract, July 2016, Birmingham: UK.

2. Jones GL, Hughes J, Greenfield D, et al. What factors influence the fertility preservation treatment decision-making process in women with cancer? the qualitative findings of the PreFer study. European Shared Medical Decision Making conferences, Abstract, July 2016, London: UK.

3. Jones GL, Hughes J, Mahmoodi N, et al. Observational study of the development and evaluation of a fertility preservation patient decision aid for women diagnosed with cancer: The Cancer, Fertility and Me research protocol (Manuscript in preparation for BMJ Open)

4. Mahmoodi N, Jones GL, Hughes J, et al. Decision aids' efficacy to support women's fertility preservation choices before cancer treatment: an environmental scan. European Shared Medical Decision Making conferences, Abstract, July 2016, London: UK.

Results

Search results:
From screening a total of 2751 potential records, 443 were identified. Once duplicates were removed, 158 records were assessed for eligibility. From these, 24 patient resources and 0 guidelines were included for data extraction.

Demographic information:

Category	%	n	Description
Country	46%	(n = 11)	USA
	25%	(n = 6)	Australia/ New Zealand
	17%	(n = 4)	UK
	12%	(n = 3)	Other Europe
Media	79%	(n = 19)	booklet (paper/ PDF)
	29%	(n = 7)	web-pages
	8%	(n = 2)	interactive website (app)
Readability (23 English, 1 Dutch)	4%	(n = 1)	standard/ easy
	29%	(n = 7)	difficult
	67%	(n = 16)	very difficult/ complex
Purpose	13%	(n = 3)	make decisions
	25%	(n = 6)	communicate with clinical team
	29%	(n = 7)	inform/ cope
	33%	(n = 8)	no stated purpose
Cancer Type	67%	(n = 16)	any cancer type
	25%	(n = 6)	breast cancer
	4%	(n = 1)	gynaecological cancer
	8%	(n = 2)	other single cancer (leukaemia/ lymphoma)

Understanding health problem:
Incomplete information about cancer and infertility problems. Causal links between cancer and infertility not explicit.

	Cancer Type (%)	Fertility (%)	Infertility (%)
Label/symptom	13	29	17
Timeline	8	25	21
Cause	4	46	8
Consequence	63	13	21
Cure/control	21	4	29

Descriptions:
Most described the treatment options (n= 18, 75%) about infertility, but not the decision about fertility preservation.

Describe infertility:
"Infertility is a term which describes the situation when a couple are having difficulty getting pregnant (conceiving)". (infertility centre)

Describe causal links cancer and infertility:
"The main treatment for cancer are chemotherapy, radiotherapy, surgery, hormonal therapy and targeted therapy. These treatments affect fertility by damaging the eggs, ovaries or womb; and affecting hormone production" (cancer charity)

Describe fertility after cancer:
" It is difficult to predict exactly how your fertility will be affected by cancer treatment. Many specialist advise women to wait at least two years before becoming pregnant, as the possibility of cancer coming back can lessen over time" (cancer charity)

Component ptDA's
Only 7 (41%) had 50% or more of the IPDAS quality components for a decision aid.

IPDAS items	Patient Resource Number 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24	%
1. Describes health condition	x x x x x x x x x x x x x x x x x x x x x x x x	100
2. States explicit decision	x x x x x x	25
3. Describes options	x x x x x x x x x x x x x x x x x x x x x x x	96
4. Describes positive features	x x x x	13
5. Describes negative features	x x x x x x x	33
6. Describes the experience of the consequence of options		0
7. Balanced and equal detail for all options	x x	8
8. Citation to evidence	x x x x x x x x x x	42
9. Publication date provided	x x x x x x x x x x x x x	58
10. Update policy provided	x x x x x x x x x	42
11. Information about levels of uncertainty around event		0
12. Funding source	x x x x x x x x	29
Total IPDAS score	5 6 5 6 6 3 4 4 3 4 3 4 2 6 3 2 7 4 4 3 2 8 5 8	