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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)

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:

<table>
<thead>
<tr>
<th>Country</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>46% (n = 11)</td>
</tr>
<tr>
<td>Australia/ New Zealand</td>
<td>25% (n = 6)</td>
</tr>
<tr>
<td>UK</td>
<td>17% (n = 4)</td>
</tr>
<tr>
<td>Other Europe</td>
<td>12% (n = 3)</td>
</tr>
</tbody>
</table>

Understanding health problem:

Incomplete information about cancer and infertility problems. Causal links between cancer and infertility not explicit.

<table>
<thead>
<tr>
<th>Label/symptom</th>
<th>Cancer Type (%)</th>
<th>Fertility (%)</th>
<th>Infertility (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>13</td>
<td>29</td>
<td>17</td>
</tr>
<tr>
<td>8</td>
<td>25</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>48</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>63</td>
<td>13</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>4</td>
<td>29</td>
<td></td>
</tr>
</tbody>
</table>

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.

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.

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.

References