Oncofertility decision support resources for women of reproductive age: a systematic review

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Abstract

Background: Cancer treatments have the potential to cause infertility among women of reproductive age. Many cancer patients do not receive sufficient oncofertility information or referrals to reproductive specialists prior to beginning cancer treatment. While health care providers cite lack of awareness on the available oncofertility resources, the majority of cancer patients utilize the Internet as a resource to find additional information to supplement discussions with their providers.

Objective: To identify and characterize existing oncofertility decision support resources for women of reproductive age with a diagnosis of any cancer.

Methods: Five databases and the grey literature were searched from 1994 to 2018. The developer and content information for identified resources was extracted. Each resource underwent a quality assessment.

Results: Thirty-one open access resources including four decision aids and 27 health educational materials were identified. The most common fertility preservation options listed in the resources included embryo (100%), egg (100%), and ovarian tissue (97%) freezing. Notably, approximately one-third (35%) contained references and five (16%) had a reading level of grade 8 or below. Resources were of varying quality; two decision aids from Australia and the Netherlands, two booklets from Australia and the United Kingdom, and three websites from Canada and the United States rated as the highest quality.

Conclusions: This comprehensive review characterizes numerous resources available to support patients and providers with oncofertility information, counseling, and decision-making. More focus is required to improve the awareness and the access of existing resources among patients and providers. Providers can address patient information needs by leveraging or adapting existing resources to support clinical discussions and their specific patient population.

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Introduction

Many life-saving cancer treatments, including chemotherapy, radiation, and surgery, have the potential to impair reproductive function in women [1-3]. Even if treatment does not directly impact fertility, some cancer treatments are recommended for up to 10 years after diagnosis, delaying pregnancy attempts and resulting in natural fertility declines as patients' age [4, 5]. As such, women of reproductive age who are diagnosed with cancer are faced with having to make a fertility preservation (FP) decision before they begin treatment [3].

The decision to pursue or not to pursue FP is preference-sensitive; there is no 'best' option for everyone, rather the weighting of the risks and benefits of each FP option are dependent upon personal values [6, 7]. For optimal decision-making, patients need to work in partnership with their healthcare team to receive fertility information and (when necessary) referrals to reproductive specialists or psychosocial support in a manner that is timely, and promotes understanding of the possible outcomes for different options with consideration of the personal value they place on the risks and benefits [8]. This process of shared decision-making [9] is particularly important for preference-sensitive decisions, including FP decisions, as it helps ensure that clinical care aligns with patients' values and preferences [10]. While women of reproductive age want fertility-related information prior to treatment [11, 12], in reality many women start cancer treatment without receiving adequate information on the treatment-related risks to fertility, potential FP options or referrals to reproductive specialists [13-15]. The implementation of oncofertility decision support resources (such as decision aids) early in the clinical pathway is therefore recommended to supplement fertility discussions and assist patients and health care providers in collaborative decision-making [8, 11, 13, 16-20].

Resources could be of great use to women diagnosed with cancer and a valuable tool for providers; however, many providers cite lack of awareness on the available resources as a barrier to information provision and fertility discussions with patients [21-23]. One recently published study by

de Man *et al*. [24] cataloged and assessed the quality of online fertility health information for females. However, gaps remain in the categorization of available resources and creation of an inventory of high quality resources accessible online for providers to utilize and refer to their patients. Other studies have listed a selection of resources but were limited to resources in the United States [19, 25] and those with a published evaluation [19, 26]. As many patients' access web-based health information as an alternative source of medical information [27], and up to 96% of patients use the Internet as a resource for more information [28], there is a need to systematically identify and evaluate existing resources that are accessible to women and providers. Accordingly, the aim of this narrative review was to identify and characterize oncofertility decision support resources for women of reproductive age with a diagnosis of any cancer.

Methods

Search Strategy

Information specialists conducted a search of MEDLINE, PsycINFO, CINAHL, Cochrane Central and Database of Systematic Reviews, and EMBASE from January 1, 1994 through to April 4, 2018. Key words and their synonyms were used in the search strategy (Multimedia Appendix 1). Manual screening of the included articles reference lists occurred to further identify any relevant publications. The database search was limited to studies on human subjects and publications in English.

Consultation with experts in the field of oncology and a grey literature search (Multimedia Appendix 2) allowed for the identification of additional relevant resources not captured in our database search. We searched the grey literature using the search engine Google (Mountain View, CA) [29] as it is the most popular search engine accounting for approximately 75% of online searches [30] and the ClinicalTrials.gov [31] database entering the key phrase 'resources for cancer patient's fertility'. The Google search was run in Canada (Toronto, Ontario) on July 15, 2014, August 17, 2016, and March 13, 2018. We recorded the total number of results and screened the first five

pages (approximately 50 website links) as evidence shows most users will not continue their search past the first few pages of search results [32].

Eligibility and Selection

We use the overarching term ‘resources’ to encompass decision aids and health education materials. Decision aids are defined as “*evidence-based tools designed to help patients make specific and deliberate choices among healthcare options*” [33]. They provide evidence-based information and a personalized focus on treatment options and outcomes for the purpose of supporting people in clarifying their values on the benefits and risks of the available health options to allow for a more informed decision [33, 34]. Health education materials are defined as resources that “*help people understand their diagnosis, treatment and management in general terms, but given their broader perspective, these materials are not focused on decision points…*”[33]. Inclusion of both types of resources in this review ensured identification of the diverse resources available through a patient- or provider-initiated web search.

Two reviewers independently screened the publication and website titles, abstracts, and full-texts. Criteria for inclusion included: (1) publication/website is in English and describes or is a resource on oncofertility or describes the development and/or evaluation of such a resource; (2) full resource is accessible online at the time of the search; (3) websites contains printable oncofertility information defined by The Patient Education Materials Assessment Tool (PEMAT) as “printed booklets, brochures, and materials that can be printed from Web sites (e.g., PDFs or html text)” [35] or are websites dedicated to oncofertility; and (4) target audience includes women of reproductive age with a diagnosis of cancer facing a FP decision. We excluded articles that only detailed the development of resource components (e.g., values clarification methods), survey articles, resources intended solely for male patients, resources without open access online, as well as blogs, YouTube videos, forums, and websites from fertility programs/clinics.

Data Extraction and Analysis

Two reviewers independently extracted descriptive information into a data extraction table created in Microsoft Excel 2010. Information included author, publication date and date of last update, type of resource, target population, length of resource, country where resource was developed, sections of resource, the fertility options before treatment and parenthood options after treatment, and the specific content pertaining to fertility (e.g., cancer treatments impact on fertility). Analysis of the resources involved synthesizing descriptive characteristics and tabulating the results.

Quality Assessment

Since no single quality assessment tool was appropriate for the evaluation of the different resources identified, we used three separate quality assessment tools based on the type of resource. The International Patient Decision Aid Standards Collaboration (IPDAS) checklist (V.4.0) is internationally approved and recognized as the most credible measure to evaluate the quality of decision aids [36, 37]. The modified version includes 44 items separated into three categories: (1) qualifying as a decision aid criteria (6 items); (2) certification criteria (10 items); and (3) quality criteria (28 items), each rated as present or absent [38]. The PEMAT is the main tool used to assess any printable health educational material (e.g., brochures, booklets, sections of websites that are printable) [35]. The PEMAT uses a systematic method to evaluate and compare the understandability and actionability of educational materials. An inventory of 17 characteristics produced an understandability score and an inventory of 7 items produced an actionability score. Eysenbach *et al.* [39] created the “Seven Quality Domains” for websites that includes 58 quality items most relevant for online health information rated as present or absent, of which 49 items from six domains were applicable to the non-printable websites dedicated to oncofertility identified in this review. Finally, the Flesch-Kincaid readability test was used to determine the grade level of each resource using an online readability calculator [40]. For the non-printable websites dedicated to oncofertility, an overall grade level was calculated based on the average readability level of each web page.

Two reviewers (SM and CD) independently assessed the quality of each decision aid and two

reviewers (BS and TL) independently assessed the quality of each health educational material. The Cohen's kappa score was obtained to determine the level of inter-reviewer agreement [41].

Results

Description of resources identified

Figure 1 describes the systematic database and grey literature search resulting in a total of 31 resources included in this review (Figure 2). The database search yielded 2,620 unique articles following removal of duplicates. After title and abstract review, 46 articles underwent a full-text review. Two studies met the selection criteria and were included; no additional articles were identified from the reference list review.

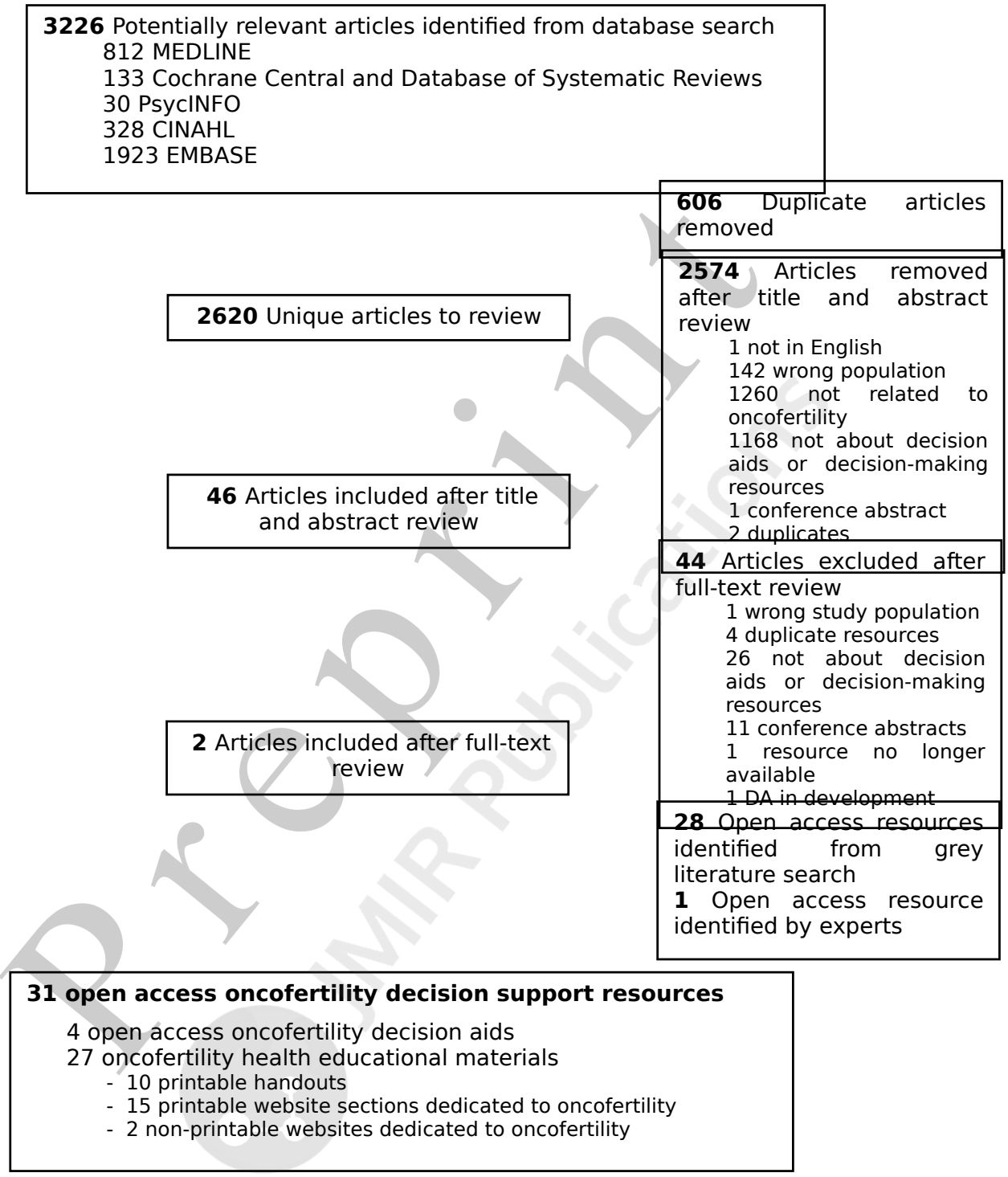

Figure 1. Description of systematic database and grey literature search

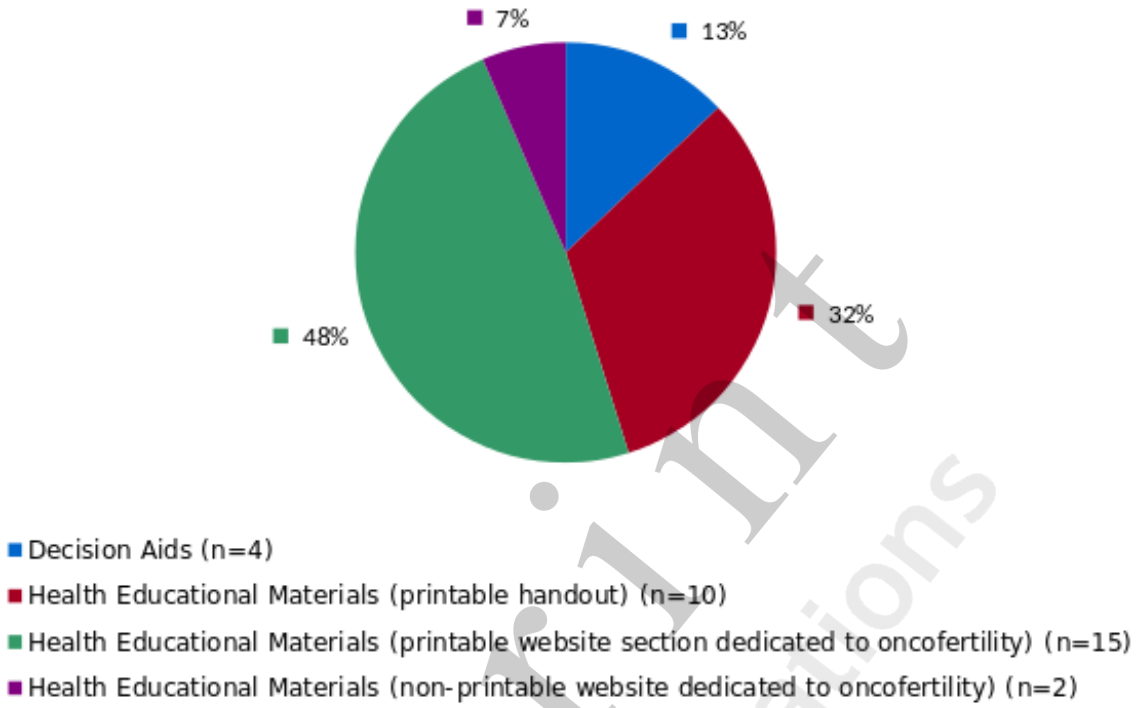

Figure 2. Oncofertility decision support resources identified

The grey literature search in 2014 yielded ~11,000,000 results and this increased over twofold in four years to ~26,600,000 results in the 2018 search. From the grey literature search and consultation with experts in the field of oncology, an additional 29 resources were identified. We also identified four decision aids in development, including one in Switzerland by Tschudin *et al*. [42], one in the United Kingdom by the Cancer, Fertility and Me study group and Jones *et al*. [43], one in the United States by Woodard *et al.* [44, 45], and one in Germany by Ehrbar *et al*. [46]. These decision aids were not accessible online at time of this review and therefore were not included.

This review identified four decision aids categorized as two traditional decision aids (6.5%) and two option grids (6.5%). In 2011, Peate *et al*. developed a decision aid in the form of a booklet for women with early-stage breast cancer in Australia [47]. The Australian decision aid was updated in 2016 and is also being developed into an easily accessible website [48]. In 2013, Garvelink *et al*. developed a web-based decision aid for women with breast cancer in the Netherlands [49]. In Canada, a shared decision-making fertility option grid was created in 2015 as part of a large pan-Canadian study focusing on young breast cancer patients [50]. Finally, a personalizable tool from LIVESTRONG [51] was created that allows patients to input their age, treatment, and cancer type to identify and compare the available options in an option grid format.

An additional 27 health educational materials were identified and categorized as 10 printable handouts (e.g., brochures and booklets) (32%), 15 printable website sections dedicated to oncofertility (e.g., the Canadian Cancer Society contains a section of oncofertility information on their website that is printable) (48%), and two non-printable websites dedicated to oncofertility (7%). The 10 printable handouts included a brochure and booklets from Fertile Future [52], Breast Cancer Care [43], Cancer Council Australia [53], and LIVESTRONG [51]; factsheets

from Cancer.net [54], Leukemia and Lymphoma Society [55], American Society for Reproductive Medicine [56], and CancerCare [57]; pamphlet from Princess Margaret Hospital (PMH) [58]; and pocket guides from the Oncofertility Consortium [59]. The printable handouts were created between 2013 and 2017 and ranged in length from one to 84 pages. The 15 websites that contain printable oncofertility information for patients included the American Cancer Society [60], BreastCancer.org [61], CancerPoints [62], Canadian Cancer Society [63], Cleveland Clinic [64], Johns Hopkins Medicine [65], Mayo Clinic [66], MD Anderson Cancer Center [67], Memorial Sloan Kettering Cancer Center (MSKCC) [68], National Comprehensive Cancer Network [69], National Cancer Institute [70], National Health Service [71], OncoLink [40], WebMD [72], and the Young Survival Coalition [73]. These websites were created/updated between 2004 and 2018 and ranged in length from one webpage to 21 webpages of general cancer and oncofertility-related information for women of reproductive age with a cancer diagnosis. Finally, the search identified two non-printable websites dedicated to oncofertility including the Alliance for Fertility Preservation [74] and Fertile Action [75]. These webpages were created in 2015 and 2008 respectively and contain 42 and 52 pages. Table 1 outlines the characteristics of all resources.

Table 1. Oncofertility decision support resource description

Resource Name	Author	Development Group	Year Created/ Updated	Type	Length	Language	Sex	Cancer Type
Decision Aids								
Australian Decision Aid	Peate *et al.*	Academic Teaching Institution	2011/ 2016	DA Booklet	37 pages	English	Females	Breast Cance
Dutch Decision Aid	Garvelink *et al.*	Academic Teaching Institution	2013	DA Website	26 web pages	Dutch	Females	Breast Cance
SPOKE Option Grid	Warner *et al.*	Academic Hospital	2015	Online PDF Grid	1 page	English	Females	Breast Cance
LIVESTRONG FB Option Tool	LIVE-STRONG	Non- Profit Organization	–	Online Tool	2 web pages	English	All	All Cancer Typ
Health Educational Materials (printable handouts)								
ASRM Fact Sheet	ASRM	Non- Profit Organization	Revised 2014	Fact Sheet	1 page	English	Females	"Female Canc
Breast Cancer Care Booklet	Breast Cancer Care	Breast Cancer Charity	2017	Booklet	36 pages	English	Females	Breast Cance
CCA Booklet	Cancer Council Australia	Non-Government Organization	2014/ 2016	Booklet	84 pages	English	All	All Cancer Typ
Cancer.net	ASCO	Non- Profit Organization	2013	Fact Sheet	1 page	English	All	All Cancer Typ
Cancer Care Fact Sheet	Editor, Lewis, S	National Organization	Updated 2017	Fact Sheet	2 pages	English	All	All Cancer Typ
Fertile Future Brochure	Fertile Future	Non- Profit Organization	–	Brochure	6 pages	English/ French	All	All Cancer Typ
LIVESTRONG Booklet	LIVE-STRONG	Non- Profit Organization	2013	Booklet	11 pages	English	All	All Cancer Typ
LLSC Fertility Facts	LLSC	Voluntary Health Agency	Revised 2014	Fact Sheet	7 pages	English	All	Leukemia/ Lymphoma
Save My Fertility	Onco-fertility Consor-tium®	Private Research University	2016	Pocket Guide	2 pages	English	All	All Cancer Typ
UHN – PMH Pamphlet	PMH	Teaching Hospital	–	Pamphlet	2 pages	English	Females	All Cancer Typ
Health Educational Materials (printable website sections dedicated to oncofertility)								
American Cancer Society	ACS	Voluntary Health Organization	2017	Educa-tional Website	2 web pages/ 16 pages printed	English/ Spanish	Females	All Cancer Typ
BreastCancer .org	Breast Cancer. org	Non-Profit Organization	2018	Educa-tional Website	21 web pages	English/ Spanish	Females	Breast Cance
CancerPoints	Kant-rowitz, M	Cancer Information Website		Educa-tional Website	1 web page/ 7 pages printed	English	All	All Cancer Typ
Canadian Cancer Society (CCS)	CCS (ON)	National Organization		Educa-tional Website	1 web page/1 0 pages printed	English/ French	All	All Cancer Ty

Table 1. Oncofertility decision support resource description (continued)

Resource Name	Author	Develop-ment Group	Year Created/ Updated	Type	Length	Language	Sex	Cancer Type
Health Educational Materials (printable website sections dedicated to oncofertility)								
Cleveland Clinic	Clevelan d Clinic	Academic Hospital	2013	Educa-tional Website	1 web page/ 3 pages printed	English	Females	Breast Cance
Johns Hopkins Medicine (JHM)	Kolp, L	Private Research Hospital		Educa-tional Website	5 web pages/ 12 pages printed	English	All	All Cancer Typ
Mayo Clinic	Mayo Clinic	Non-Profit Medical Practice/ Research Group	2016	Educa-tional Website	2 web pages / 10 pages printed	English/ Spanish/ Portugues e/ Chinese	All	All Cancer Typ
MD Anderson Cancer Center	MD Anderso n Cancer Center	Comprehensi ve Cancer Center	-	Educa-tional Website	1 web page / 2 pages printed	English/ Spanish/ Arabic/ Chinese/ Turkish	All	All Cancer Typ
Memorial Sloan Kettering Cancer Center (MSKCC)	MSKCC	Private Cancer Center	2017	Educa-tional Website	5 web pages/ 14 pages printed	English	Females	All Cancer Typ
National Comprehensi ve Cancer Network (NCCN)	NCCN	National Organization	-	Educa-tional Website	1 web page/ 4 printed pages	English	All	All Cancer Typ
National Cancer Institute (NCI)	NCI	Government Health Agency	2017	Educa-tional Website	1 web page/ 5 pages printed	English/ Spanish	Females	All Cancer Typ
National Health Service (NHS)	NHS UK	Government Health Agency	2015	Educa-tional Website	1 web page/ 5 pages printed	English/ Google Translate	All	All Cancer Typ
OncoLink	Vachani, C	Cancer Information Website	2016	Educa-tional Website	1 web page/ 5 pages printed	English/ Spanish	Females	All Cancer Typ
WebMD	WebMD	Online Health Publisher	2004	Educa-tional Website	4 web pages/ 4 pages printed	English	Females	Breast Cance
Young Survival Coalition (YSC)	YSC	Non-Profit Global Organization	-	Educa-tional Website	5 web pages/ 12 pages printed	English	Females	Breast Cance
Alliance for FP	Alliance for FP	Charitable Organization	2015	Educa-tional Website	42 web pages	English	All	All Cancer Typ
Fertile Action	Alice Crisci	Cancer Charity	2008	Educa-tional Website	54 web pages	English	Females	All Cancer Typ

Abbreviations: ACS, American Cancer Society; ASCO, American Society of Clinical Oncology; ASRM, American Society for Reproductive Medicine; AU, Australia; CCA, Cancer Council Australia; CCS, Canadian Cancer Society; CDN, Canada; DA, decision aid; FB, family-building; FP, fertility preservation; JHM, John Hopkins Medicine; LLSC, The Leukemia & Lymphoma Society of Canada; MSKCC, Memorial Sloan Kettering Cancer Center; NCCN, National Comprehensive Cancer Network; NHI, National Cancer Institute; NHS, National Health Service; NL, Netherlands; ON, Ontario; PMH, Princess Margaret Hospital; SPOKE, Surgeon and Patient Oncofertility Knowledge Enhancement; USA, United States of America; UHN, University Health Network; YSC, Young Survival Coalition

Fertility and parenthood options presented in resources

All resources provided information on embryo and egg freezing. Most resources provided information on ovarian tissue freezing (30/31) and many provided information on ovarian suppression (23/31). Less than 50% of resources provided information on other FP options including ovarian transposition (13/31), fertility-sparing surgery (12/31), ovarian shielding (6/31), and *in vitro* maturation (5/31). The Australian and Dutch decision aids as well as the PMH pamphlet, MSKCC website, Breast Cancer Care booklet, and Cancer Council Australia booklet (6/31) were the only resources to included information on the option of not pursuing FP or 'wait and see'. Nine resources (29%) provided no additional information on parenthood options after cancer treatment. The most commonly described parenthood options after treatment included egg donation (17/31), surrogacy (17/31), adoption (15/31), natural conception/having fertility testing completed (14/31), and embryo donation (13/31). Few resources listed no more children (6/31) or foster parenting (2/31) as parenthood options after cancer treatment. Multimedia Appendix 3 presents all fertility options listed in each resource.

Content and sections in resources

The Australian decision aid and Cancer Council Australia booklet were the most comprehensive resources covering a range of topics and included sections. These resources also contained the most pages, with 37 and 84 pages of content respectively. Only the decision aids from Australia and the Netherlands contained explicit values clarification methods. The values clarification method in the Australian decision aid is a personal worksheet with questions and a pros and cons list to identify the drawbacks and advantages for each fertility option [47]. The Dutch decision aid includes a 5-point leaning scale where patients indicate their preference towards a fertility option by sliding the scale from very negative to very positive [49].

Few resources contained information on fertility in women (10/31), with more focusing on infertility in women (13/31). Most resources included information on cancer treatments (22/31), an explanation on how the treatment impacts fertility (25/31) and fertility outcomes after treatment (e.g., reduced fertility, early menopause or immediate menopause) (21/31). Many resources also listed sources for patients to access more information (23/31). Finally, 11 resources (35%) contained references detailing the sources of evidence and seven resources (23%) had a glossary of medical terms. Multimedia Appendix 4 lists the content for each decision support resource identified.

Quality assessment of resources

Each resource underwent a quality assessment (Multimedia Appendix 5). The Cohen's kappa score indicated substantial inter-rater agreement for all reviewers (0.75 kappa score) [41]. Table 2 outlines the highest rated resources based on the specific quality assessment used.

The decision aid quality assessment revealed that the Australian and Dutch decision aids met all the qualifying criteria, while the two option grids met most qualifying criteria (83%). The Dutch decision aid met all certification criteria, while the Australian decision aid and Canadian option grid met most certification criteria, 83% and 67% respectively, and the LIVESTRONG option grid met only one certification criteria (17%). All decision aids met at minimum three of the applicable quality criteria, including the ability to compare features of available options, inclusion of outcome probabilities, and the event rates for the outcome probabilities. The Australian and Dutch decision aids met the most quality criteria, 83% and 87% respectively, when compared to the option grids.

Table 2. High quality oncofertility decision support resources based on the International Patient Decision Aid Standards (IPDAS), Patient Education Materials Assessment Tool (PEMAT), and Seven Quality Domains

Resource Name	Quality Assessment Tool	Quality Assessment Rating
Decision Aid		
Australian Decision Aid	IPDAS	Qualifying criteria: 100% Certification criteria: 83% Quality criteria: 83%
Dutch Decision Aid	IPDAS	Qualifying criteria: 100% Certification criteria: 100% Quality criteria: 87%
Health Educational Materials (printable handouts)		
Breast Cancer Care Booklet	PEMAT	Understandability score: 87% Actionability score: 80%
Cancer Council Australia Booklet	PEMAT	Understandability score: 94% Actionability score: 80%
Health Educational Materials (printable website sections dedicated to oncofertility)		
Canadian Cancer Society	PEMAT	Understandability score: 83% Actionability score: 80%
Memorial Sloan Kettering Cancer Center (MSKCC)	PEMAT	Understandability score: 80% Actionability score: 80%
Health Educational Materials (non-printable websites dedicated to oncofertility)		
Alliance for Fertility Preservation	Seven Quality Domains	38 out of a possible 49 quality characteristics (76%)

Using PEMAT, five of the printable handouts and printable website sections dedicated to oncofertility shared the greatest actionability score (80%) (i.e. material was the most actionable for patients), including the Cancer Council Australia booklet, the Leukemia and Lymphoma Society factsheet, the Breast Cancer Care booklet, and the Breastcancer.org, Canadian Cancer Society, MD Anderson Cancer Center, and MSKCC websites. Six resources rated 80% or above on understandability (i.e. material was more understandable for patients), including the Cancer Council Australia booklet (94%), American Cancer Society (87%), Breast Cancer Care booklet (87%), Canadian Cancer Society website (83%), the MSKCC website (80%), the National Cancer Institute website (80%). More than half (64%) of the printable handouts and printable website sections dedicated to oncofertility scored 50% or below on the actionability and 52% of these resources scored below a 70% on the understandability. However, all resources used the active voice for most sentences, did not expect users to complete any calculations, did not contain material that distracted from the resources purpose, and presented the information in a logical sequence.

The oncofertility dedicated websites had variable quality, meeting between 23 (47%) and 38 (76%) of the 49 possible criteria. Both websites contained technical elements such as information on the ownership of the site, clear statement about their objectives and target audience, transparency on funding, compliance with advertising rules, and geographic location of the site. Additionally, each website contained design elements such as scroll bars, sub-headings and grouping of information, a menu with listings, proper layout and typography, and correct presentation of content when viewed in a partial web page window. For readability and usability, the websites had appropriate sentence construction, use of active voice for most sentences, and road signs to indicate next/previous topics, minimal downloading time, appropriate functionality

to support content, and ease of navigation in finding the desired content. However, some aspects that neither website displayed included the date of creation/last update/technical maintenance, message alert when leaving the secure site, clear statement about the editorial review process, hierarchy of evidence clearly displayed, and interactive learning tools (e.g., online quiz).

Only five resources were assessed at a reading level of grade 8 or below. All other resources ranged from a grade 8 to grade 12 and above readability level (Multimedia Appendix 6).

Discussion

This review identified and characterized 31 open access resources of varying quality for use by women of reproductive age diagnosed with cancer and their providers. Of the identified resources, two decision aids from Australia [47] and the Netherlands [49], two printable handouts from the United Kingdom [76] and Australia [53], and two websites from Canada [63] and the United States [68, 74] rated as the highest quality. This review adds multiple new resources for women of reproductive age with cancer to the three online resources from the United States identified by Kelvin *et al.* in 2012 [25], and the one decision aid for early stage breast cancer patients (Australian decision aid [47]) identified in a 2016 review by Zdenkowski *et al*. [26] Zdenkowski *et al.,* described a gap in oncofertility decision aids for young breast cancer patients and this review revealed that decision aids are now available or under development for cancer patients in Canada, the Netherlands, Germany, Switzerland, the United States, and the United Kingdom. This review also expands on a recent review by de Man *et al.* [24], and further characterized the oncofertility resources available for women of reproductive age diagnosed with cancer, extended the categorization and quality analysis by type of resource, and includes a quick reference list that practitioners can use to identify high quality resources to supplement fertility discussions and recommend to their patients. The creation and use of

resources as an adjunct to fertility discussions with providers is strongly supported in the literature [8, 19]. Additionally, this review highlighted the increased attention surrounding the topic of oncofertility in cancer patients as the search engine results more than doubled from 2014 to 2018.

While the number of resources has increased, this review found the quality of these resources could be enhanced. While more resources is of benefit to patients and providers, developers should adhere to best practices, such as the IPDAS [34], to ensure resources are high quality and usable by the target population. Additionally, only the IPDAS checklist evaluated if the decision aids underwent field testing with patients and providers. As the health educational materials were identified through the grey literature search, it was unclear if there had been any field testing of these materials with target users. Field testing is recommended by the IPDAS to ensure the information in the resource resonates with and is understood by the population of interest and does not cause any bias in decision-making [77].

The Australian decision aid by Peate *et al.* [47] and booklet by Cancer Council Australia [53] were the most comprehensive and detailed resources identified in our search. However, both resources were long, highlighting the tradeoff between comprehensiveness and ease of use in clinic for patients and providers. Longer resources may be more useful as a take home tool since limited clinic time may result in the inability for patients and providers to fully review the resource and have in depth fertility discussions. Yet, a challenge with comprehensive resources used by patients independently outside of clinic is the inability to guarantee that shared decision-making occurs in follow-up consultations [78]. In comparison, resources such as the Canadian option grid were specifically designed to be used as a concise in-clinic shared decision-making tool with patients and providers. However, effective use of these in-clinic resources requires the

active involvement and engagement of providers [79]. To ensure continued and proper use of in-clinic resources, providers must agree on need for the resource, use the resource in clinic regularly, and administer the resource effectively to promote shared decision-making with patients [79-81].

Women of reproductive age want fertility information and desire participation in discussions around FP prior to starting fertility-risking cancer treatment [82]. The risk of infertility from cancer treatment is of such importance to women that it can impact treatment decision-making [83]. As such, patients' information needs are also important for providers to consider when deciding on the appropriate resource to provide as an adjunct to discussions. Some patients may benefit from shorter resources (e.g., option grid or fact sheet) and more in-clinic shared decision-making, whereas others may prefer more comprehensive resources that provide information on fertility, exposure to all available FP and parenthood options, and assistance in decision-making. Additionally, some patients may benefit from both types of resources in clinic and to review independently or with their support person(s). This review identified a wide range of easily accessible resources, alleviating the barrier of lack of awareness on the available resources cited by providers [21-23]. Providers should promote the high quality and applicable resources to interested patients based on their identified information needs. Resource developers can also modify existing resources to improve their quality and meet the needs of their patient population. To enable use of the resources, developers should create a dissemination and education plan that is aligned with patients' needs and providers' practices to ensure accessibility and continued use. [84]

Through the exploration of grey literature, the review was strengthened by the discovery of decision aids in development and resources not identified in previous reviews [19, 26, 85]. This

review also included various resources created by academic centers, non-profit organizations, and charities for cancer patients accessible through a search engine query. While this review excluded resources designed solely for men, it is important to highlight that male-specific resources are also necessary to identify and evaluate. However, due to the differences in infertility risks and FP options between men and women [86], male resources should be characterized and evaluated in a separate review [87]. Only open access and English language resources were included – as such, resources not identified using the key search terms and phrase at the time of the search, resources in another language, or resources only accessible when logged on to an organizations network server may have been missed in this review. The characteristics of the resources including the content and the fertility options presented in this review may change as developers update them to reflect advances in the field of oncofertility.

We also conducted the grey literature search using one search engine (Google) in one location (Toronto, Ontario). Although different results may have been obtained with other search engines and in other geographic locations, the search was conducted at three different time points capturing search engine index changes. Additionally, the review of approximately 50 websites during each search ensured a broad range of potentially eligible websites and aimed to replicate the searching strategy of a patient recently diagnosed with cancer.

Conclusion

Fertility preservation prior to cancer treatment is an important topic of discussion for women of reproductive age, and resources can help to facilitate patient-provider discussions prior to fertility-risking treatment. This review identified 31 oncofertility decision support resources that are publically available. The quality assessments revealed the resources are of varying quality, which indicates that there is room for improvement for many of these resources. As further

resources are developed to fill an information gap, developers should adhere to patient education best practices during resource development to ensure a high quality tool. Field testing should also be completed by stakeholders of the resource prior to publication of the content online.

Practical Implications

This review allowed for the comparison and quality assessment of resources potentially accessed by women of reproductive age with a diagnosis of cancer and/or used by providers as an adjunct to clinical discussions. Applicable resources that align with the clinical population, local context, and patient information needs can be identified from this review. As such, we need to focus on enhancing the awareness and the access of these resources to ensure use and promotion of high quality resources to patients who desire more information before fertility decision-making and cancer treatment. The identified resources can also be modified to enhance the quality and meet the local needs of a clinic and patient population.

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%22group%22%3A%22searchEngine%22%2C%22sort%22%3A%7B%22share%22%3A-1%7D%2C%22id%22%3A%22searchEnginesDesktop%22%2C%22dateInterval%22%3A%22Monthly%22%2C%22dateStart%22%3A%222017-10%22%2C%22dateEnd%22%3A%222018-09%22%2C%22segments%22%3A%22-1000%22%7D. (Archived by WebCite® at http://www.webcitation.org/73O6kPkhP).

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Supplementary Files

Multimedia Appendixes

Multimedia Appendix 2. Grey literature searched.
URL: https://assetapi.jmir.pub/assets/a2330d529bb1f0679837d131b86bbee5.docx

Multimedia Appendix 3. Fertility and parenthood options in oncofertility decision support resources.
URL: https://assetapi.jmir.pub/assets/c61f5f93c5656aaba9117a9ffcbc5ca7.docx

Multimedia Appendix 4. Content and sections in the oncofertility decision support resources.
URL: https://assetapi.jmir.pub/assets/a9839524f477db617a5cbf75d19ecc34.docx

Multimedia Appendix 5. Quality assessments of the oncofertility decision support.
URL: https://assetapi.jmir.pub/assets/4d1663ff40bef62ccf3c6a244e9d8c07.docx

Multimedia Appendix 6. Readability level of the oncofertility decision support resources using the Flesch Kincaid Grade Level.
URL: https://assetapi.jmir.pub/assets/a346dc1b16115690cbec6de9f443c713.docx