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Title: What factors hinder the decision-making process for women with cancer and contemplating fertility preservation treatment?

Running Title: Decision-making process and fertility preservation

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Abstract

Background: Although fertility preservation (FP) treatment options have increased, the existing evidence suggests that many women with cancer do not feel well supported in making these decisions, but find them stressful and complex and fail to take up fertility care at this crucial time. Whilst existing reviews have all made important contributions to our understanding of the FP decision-making process, none of them examine solely and specifically these processes for women of reproductive age with a diagnosis of any cancer, leaving a gap in the knowledge base. Given the expectation that care is patient-centred, our review aims to address this gap which may be of help to those managing patients struggling to make difficult decisions in the often brief period before potentially sterilising cancer treatment is started.

Objective and rationale: Underpinning this narrative review was the question "What factors hinder the decision-making process for women with any cancer and contemplating FP treatment?" Our objectives were to i) assess and summarise this existing literature, ii) identify the factors that hinder this decision-making process, iii) explore to what extent these factors may differ for women choosing different methods of FP, and iv) make recommendations for service delivery and future research.

Search methods: A systematic search of the medical and social science literature from the 1st January 2005 up to the end of January 2016 was carried out using three electronic databases (Web of Science (PubMed), Ovid SP Medline and CINAHL via Ebsco). Included in the review were quantitative, qualitative and mixed-method studies. Reference lists of relevant papers were also hand searched. From the 983 papers identified, 46 papers were included. Quality assessment was undertaken using the Mixed Methods Appraisal Tool and thematic analysis was used to analyse the data.

Outcomes: From the analysis, six key themes with 15 sub-themes emerged: 1) fertility information provision (lack of information, timing of the information, patient-provider communication); 2) fear concerning the perceived risks associated with pursuing FP (delaying cancer treatment, aggravating a hormone positive cancer, consequences of a future pregnancy); 3) non-referral from oncology (personal situation, having a hormone positive cancer, not a priority, transition between service issues); 4) the dilemma (in survival mode, whether to prioritise one treatment over another); 5) personal situation (parity, relationship status); and 6) costs (financial concerns).

Wider implications: This review has found that a wide range of internal and external factors impact the FP decision-making process. Key external issues related to current service delivery such as the provision and timing of FP information, and lack of referral from oncology to the fertility clinic. However, internal issues such as women's fears concerning the perceived risks associated with pursuing FP also hindered decision-making but these 'risks' were typically overestimated and non-evidence based. These findings suggest that the implementation of a range of decision support interventions may be of benefit within the clinical care pathway of FP and cancer. Women would benefit from the provision of more evidence-based FP information, ideally received at cancer diagnosis, in advance of seeing a fertility specialist, for example through the implementation of patient decision aids. Health care professionals in both oncology and fertility services may also benefit from the implementation of training programs and educational tools targeted at improving the communication skills needed to improve collaborative decision-making and deliver care that is patient-centred. Exploration of the current barriers, both intellectual and practical, that prevent some patients from accepting FP will help care providers to do better for their patients in the future. Finally, the extent to which a poor prognosis and moral, ethical and religious beliefs influence the FP decision-making process also warrant further research.

Key words: females, cancer, fertility preservation, decision-making, oncofertility, narrative review.

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Introduction

Treatments for cancer including chemotherapy, radiotherapy, hormonal, medical and surgical interventions may all affect female fertility. Loss of fertility is considered one of the most significant late-effects of cancer treatment (Mancini et al, 2008) and female cancer survivors often report it as one of the most distressing outcomes of their cancer treatment (Peate et al, 2009).

In the initial stages of treatment for cancer, the American Society of Clinical Oncology and the American Society of Reproductive Medicine recommends that options to preserve fertility are discussed with each woman (Lee et al, 2006; The Ethics Committee of the American Society of Reproductive Medicine, 2005). Similar guidelines have been published in the UK (NICE, 2004; 2013). Of the fertility preservation (FP) options that are available for women, the most well-established is embryo cryopreservation. However, in order to create embryos it is necessary to unite an oocyte and sperm. Many young women facing cancer treatment are not at a point in their lives at which this is feasible, as they are not in a long-term relationship (Ajala et al, 2010). In addition, for religious and or ethical reasons, some women have objections to embryo cryopreservation (Lee et al, 2006).

Another option is oocyte cryopreservation. Historically, this has not been successful due to inefficient methods for oocyte cryopreservation (Tao et al, 2008). However, use of vitrification has greatly improved survival of oocytes after freeze-thawing, giving women a better opportunity for FP without the need for fertilisation of the oocyte at time of collection.

Ovarian tissue cryopreservation and subsequent regrafting has also now emerged as a realistic option for FP for women and girls who are not able to undergo ovarian stimulation for oocyte or embryo cryostorage. There are also a number of cancer-specific fertility-sparing procedures including trachelectomy, ovarian transposition and ovarian shielding, but these are only suitable for women with specific cancer types or those undergoing pelvic radiotherapy.

The past 40 years has seen changes in the ideology and practice of medical decision making. Models of doctor-patient decision-making have shifted from a ‘paternalistic’ approach, which sees health professionals as the gatekeepers of medical information and sole decision-makers and patients as passive spectators of care. With the growing recognition that patients (including cancer patients) expect to participate and be involved in their treatment decisions (Breitsameter, 2010; Siminoff et al, 2010), attention has therefore turned to the significance of patient-centred care and a shared model of decision-making, as a quality benchmark for the delivery of dignified care (Coulter and Collins, 2011; Department of Health, 2010; NICE, 2014).

However, despite the evolving health care climate and growing FP options available to women, the existing evidence suggests that women do not feel well supported in making these decisions, with many patients missing out on fertility care at this crucial time (Breast Cancer Care, 2014). These decisions are time-pressured and stressful, as women are having to trade-off the immediate consequences of starting cancer treatment with the longer-term chances of having a biological child in the future, post cancer treatment. The choice made will have a life-long impact (Kirkman et al, 2014). Typically, women also have to make decisions regarding FP with specialist fertility services alongside planning care for their treatment of cancer with oncology/haematology services. This necessitates transitioning between very different medical services during the course of their cancer and fertility treatment and management (Lee et al, 2006).

There are a range of studies and reviews that examine the barriers and facilitators that influence engagement in FP care from the perspective of the patient/ family and healthcare professional. These have made valuable contributions to our understanding of patients experiences of FP and the factors that may hinder decision–making generally (Kissil and Davey, 2011; McDowell and Murray, 2013; Nachtigill et al, 2006; The Ethics Committee for American Society of Reproductive Medicine, 2015). Specifically, fifteen published reviews have explored FP and decision-making for women with cancer (Dow et al, 2004; Goossens et al, 2014; Goncalves et al, 2014; Holton et al, 2014; Howard-Anderson et al, 2012; Jensen et al, 2011; Loren et al, 2013; Peate et al, 2009; Quinn et al, 2011; Schmidt et al, 2016; Sobota and Ozakinci, 2014; Penrose et al, 2012; Tschudin and Bitzer 2009; Zdenkowski et al, 2016; Lee et al, 2010). Although they have all made important contributions to the literature at the time they were produced, none of them examine solely and specifically the decision-making process around FP for women with a diagnosis of any cancer, leaving a gap in the knowledge base.

Of the above reviews, six reported only on data from breast cancer patients (Dow et al, 2004; Goncalves et al, 2014; Howard-Anderson et al, 2012; Lee et al, 2010; Peate et al, 2009; Zdenkowski et al, 2016), thereby excluding information on women with many other different types of cancer contemplating FP. In addition, the review by Zdenkowski et al (2016) particularly focused on patient decision aids (PtDAs) for women with early stage breast cancer with only two PtDAs on FP included. Six reviews (Goossens et al, 2014; Jensen et al, 2011; Loren et al, 2013; Quinn et al, 2011; Tschudin and Bitzer 2009; Schmidt et al, 2014) included studies with mixed male and female participants or male-only studies. The review by Quinn (2011) was mainly focused on adolescents, including papers with participants aged between 12 – 18 years. One review (Penrose et al, 2012) compared the psycho-social impact of treatment-related potential infertility on women with a cancer diagnosis, compared to women without cancer but facing infertility. A review by Sobota and Ozakinci (2014) excluded qualitative studies. The final review (Holton et al, 2014) included studies examining the child-bearing and related information needs of women with cancer as well as a range of other chronic, non-communicable health conditions. More detail on the existing reviews and their contribution to knowledge in this field is provided in Table 1.

Defining the narrative review question

The aim of this paper was to build upon the existing knowledge and evidence base and undertake a narrative review to examine solely women with any type of cancer, of reproductive age, and facing fertility-impacting treatment, for their associated decision-making processes. Therefore, the question underpinning the narrative review was defined as "What factors hinder the decision-making process for women with any cancer and contemplating FP treatment?". Our objectives were to i) assess and summarise this existing literature, ii) identify the factors that hinder this decision-making process, iii) explore to what extent these factors may differ for women choosing different methods of FP, and iv) make recommendations for future research and service delivery that may improve and better support women with cancer to make these FP decisions.

Methods

Searching for studies

From the 1st January 2005 up to the 31st January 2016, three electronic databases were systematically searched by two members of the research team (JH and ES): Web of Science (PubMed), Ovid SP Medline and CINAHL via Ebsco. In 2004, NICE guidelines for clinical practice made specific cancer and fertility recommendations for the first time: that “fertility preservation should be offered to all patients with cancer for whom it would be relevant” (NICE 2004). As a result, a search date of 1st January 2005 was chosen to synthesise evidence in the light of this change in clinical practice guidelines. The search terms used were (FP OR Cryopreservation OR Fertility OR Infertility) AND (Cancer OR Carcinoma OR Neoplasm OR Oncolog* OR Tumour) AND (Decision Making OR Qualitative OR Quantitative). Test searches were also carried out; one to determine whether the spelling of tumour would affect results (it did not). Reference lists of relevant papers were also hand searched by JH. Abstracts were also examined in order to determine whether fertility was discussed in relation to a diagnosis of cancer.

Inclusion and exclusion criteria

As this review aimed to include the fullest range of methodologies, quantitative, qualitative and mixed-method studies were included. To enable a broad and comprehensive overview of the current literature, articles were included even if FP was only a minor theme in the article, and not the main topic.

Our target population was adult women aged 16 years or more at the time data was collected on them by their respective study authors. Our rationale for limiting the review to women aged 16 years or more was because typically women aged younger than 16 years follow different clinical pathways i.e. they are often first seen in paediatric settings. Paediatric care pathways are different and these young patients do not have the options for FP that are available to older mature women. Oocyte or embryo freezing procedures require vaginal scanning, which is not typically acceptable in patients less than 16 years. For this population, ovarian tissue cryopreservation is becoming a possible option. Although the sample of patients in the studies selected had to be 16 years or older at the time of their data collection, because of the retrospective nature of most of the studies (i.e. they were survivors of childhood cancer), this meant that some of the women were under 16 years when they received their cancer diagnosis.

The papers selected could include samples of patients with any cancer grade, treated with curative intent, and at any stage of the cancer trajectory (i.e. diagnosis, treatment, post treatment). Articles were excluded if they i) referred to decision-making and FP in the context of males only, ii) referred to decision-making in the context of pregnancy decision-making and late-effects concerns rather than FP specifically, iii) included a target population which had only non-cancer diseases affecting fertility, iv) were a news article, review, opinion piece, commentary, chapter of a thesis or book or only investigated the prevalence, medical or clinical aspects of female cancer and FP, v) were written in a foreign language as funding for translation services was not available, or vi) referred to decision-making and FP from the perspective of health care professionals only. Papers examining both male and female fertility issues were retained if females were reported separately. Similarly, papers that included a mix of cancer and non-cancer diseases were also included if the data for the cancer sample were reported separately. Papers exclusively investigating the medical or clinical features of treatment for infertility in relation to cancer were excluded.

Screening for studies

Two authors (JH and ES) independently reviewed the citations generated by the search, removing duplicates and those publication types deemed ineligible. Following this, abstracts were screened and the full text version of relevant papers were retrieved for further assessment (JH and ES). A sample of reports were reviewed by GJ and NM to ensure that the selection was consistent with the aims of the review and the inclusion and exclusion criteria. Any doubts regarding the inclusion of papers were resolved by consensus between the authors after discussion.

Quality assessment

The Mixed Methods Appraisal Tool (MMAT) which has been designed to appraise and describe the methodological quality of systematic reviews that include qualitative, quantitative and mixed-methods papers was applied to full text papers (Pluye et al, 2011). Given the mix of study designs included in the review, the MMAT was felt to be an appropriate tool in which to appraise the quality of papers across the study design methodologies. The quality of the papers can range from 0% to 100% (100% indicates highest quality) and was calculated using four criteria (Table 2). For qualitative and quantitative studies, each criteria met is 25%, for example, if all four criteria are met the score will be 100%. For mixed methods studies, the scores of the qualitative and quantitative components are combined, with the overall quality score being the lowest score of the study components.

Three authors (GJ, JH and NM) quality assured the papers and discussed the information extracted to ensure agreement over the themes was reached.

Data extraction

A data extraction table was developed and applied to each of the selected papers, that met the inclusion criteria and quality assessment criteria, using a standard format (authors, year, country, approach, design, method, sample and setting, measures, results and summary).

Data synthesis

A process of systematic, thematic analysis and coding of the extracted data was conducted according to the standard principles of thematic analysis (Braun and Clark, 2006). Three authors (GJ, JH and ES) developed textual descriptions, which were tabulated in the data extraction summary form and developed a preliminary list of descriptive themes to identify the main, recurrent, and/or most important themes and/or concepts across multiple studies. A process of iterative discussion then took place between the authors to generate conceptual themes that helped to explain the phenomena being described in the literature, constantly comparing the themes being developed against the data. All three authors engaged in continual dialog to help reach a consensus on the themes identified.

Results

The database search produced 983 papers (Figure 1). After the initial round of screening the duplicates (n=430), a total of 553 paper were screened against title and abstract. A total of 398 ineligible documents, articles in other languages and irrelevant articles were removed. Existing published review articles (n=15) were also separated out at this stage, to be evaluated for potential overlap (as reported in the introduction). A total of 140 articles remained, which were then screened by abstract and full text. At this stage, 94 papers did not meet the inclusion criteria and four papers, assessing oncologists attitudes to FP rather than those of patients were also separated out to be examined independently (as reported in the discussion) (Adams et al, 2013; Duffy et al, 2012; Forman et al, 2010; Shimizu et al, 2012). A total of 42 papers then met the inclusion criteria. A hand-search through the 42 papers' references produced four additional articles, resulting in a total of 46 articles included in the review. One of these studies retrieved manually from the relevant paper references was outside of the ten-year time limit (Thewes et al, 2003) but was kept in because it was considered very relevant to the review. Nothing else was identified as relevant from the reference lists of the reviews that could have been included prior to our start date.

The MMAT appraisal tool was used to assess the quality of the studies. The papers reviewed used four methodologies: quantitative descriptive studies (n=17), quantitative non-randomised designs (n=2), qualitative study designs (n=21), and mixed methods studies (n=6). Quality varied across the papers and within methodologies but a majority of papers scored 75% and/or 100% (n=34). Nine papers scored 50% and three papers scored below 50% (Table 2).

The majority of qualitative studies did not outline their use of reflexive practice, one of the four key scoring criteria for the MMAT, so few studies were able to score 100% for quality. Lower scoring papers were re-assessed. For the purpose of the review, no papers were excluded based on methodological quality as it was felt that all studies contained information that was of value.

Characteristics of the selected studies

Table 3 outlines the study demographic details of the 46 articles, in which 19 papers were quantitative, 21 papers used a qualitative methodology and six papers used a mixed-methods approach. Whilst the 46 papers reflected an international interest, the majority (n=18) originated from the U.S.A, nine studies were Australian, six were from the UK, four were from the Netherlands three studies were multi-national, whilst Sweden and Canada produced two studies each and France and Turkey reported one study each.

Only a few studies cited the exact method of FP chosen. Of these, the sample mainly included women choosing either oocyte and/or embryo freezing. Only one study included a sample of women who chose ovarian tissue freezing (Klock et al, 2009) or ovarian suppression (Hill et al, 2012), although the sample was very small in both studies (n=2).

About half of the studies (49%) reported on FP decision-making issues only in women with breast cancer and these patients were also the majority group in most of the other studies which described a more diverse sample of cancer patients.

Evaluating the age range of the women included in the studies was difficult because in some studies, it was not mentioned or was not clear whether the stated patients' age referred to the age at cancer diagnosis or the age at which they entered into the study. In addition, one study did not report the age range or mean age of their sample (Klock et al, 2009), and another simply reported that their patients were younger than < 50 years without providing further information (Vadaparampil et al, 2012). Most studies reported only the age range of the study participants without citing the mean age of the sample. Whilst the majority of studies included women "of reproductive age", only four studies included women from age 16 (Bastings et al, 2014; Baysal et al, 2015; Crawshaw et al, 2009; Peddie et al, 2012) and two studies included childhood cancer survivors aged between 7 and 21 years (Kim and Mersereau, 2015), and approximately 14 years or more at diagnosis (Wilkes et al, 2010), although they were all aged over 16 years old at the time of data collection.

Sample sizes and study design

Sample sizes varied across the studies and also within the methodologies. Qualitative studies generally have small sample sizes and the majority of such papers in our review (16 out of 21) recruited less than 30 participants. Two studies (Corney et al, 2014; Kirkman et al, 2014) both recruited only ten participants but only included breast cancer patients. Whilst Niemask et al, (2012) described theirs as a qualitative study, they recruited a total of 697 participants across a wide range of cancer types and conducted a survey which included only one open-ended question. Quantitative studies were larger, with an average of 198 participants over 19 studies. The largest study, a postal survey (Letourneau et al, 2012) recruited 918 participants with a large range of cancer diagnoses. Conversely, Peate et al, (2011) reported a sample size of 17, but the study was limited to breast cancer patients only. Six studies out of the 46 in this review used a mixed-methods study design. The majority of these studies used both semi-structured interviews combined with surveys. Gorman et al, (2014), however used focus groups and a web-survey in the research design.

All the studies, except three (Balthazaar et al, 2011; Peate et al, 2011, 2012), were retrospective in design. It was difficult or impossible to determine for some of the studies how many years post-diagnosis and treatment some of the women in the studies were when they were surveyed and/or interviewed, as some papers did not report this information specifically (Garvelink et al, 2013; Klock et al, 2009; Mathur et al, 2013; Yee et al, 2012). Reported time frames varied up to 11 years post-diagnosis (Crawshaw et al, 2009) with an average of 9.5 years post-diagnosis (Neimasik et al, 2012). Most studies acknowledged the possibility of recall bias as a potential weakness in their design.

What factors hinder the decision-making process?

Six key themes and 15 sub-themes which hindered FP decision-making emerged from the analysis (Table 4): 1) fertility information provision (lack of information, timing of the information, patient-provider communication); 2) fears concerning the perceived risks associated with pursuing FP (delaying cancer treatment, aggravating a hormone positive cancer, consequences of a future pregnancy); 3) non-referral from oncology (due to personal situation, having a hormone positive cancer, FP not being a priority, transition between service issues); 4) the dilemma (in survival mode, whether to prioritise one treatment over another); 5) personal status (parity and relationship status); and 6) costs (financial concerns). The findings of the review have been presented in terms of these six overarching themes along with their more detailed sub-themes below. A clinical flow chart has also been provided to demonstrate the key themes in relation to the cancer and FP pathway (Figure 2).

Theme 1: Fertility Information Provision

An over-riding theme identified in the review concerned fertility information provision, both in terms of the lack of written information provided to women, the time at which FP information was received, and patient-provider communication.

Lack of information provision

The majority (72%) of the research studies identified lack of information specific to oncology and FP as a major issue for this study population (Armuand et al, 2012, 2015; Balthazar et al, 2012; Bastings et al, 2014; Baysal et al, 2015; Corney and Swinglehurst, 2014; Crawshaw et al, 2009; Garvelink et al, 2013, 2013(b); Gorman et al, 2012, 2014; Hill et al, 2012; Karaoz et al, 2010; Kim and Mersereau, 2015; Jukkala et al, 2010; Lee et al, 2011; Lewis et al, 2013; Mancini et al, 2008; Mathur et al ,2013; Peate et al, 2011(b), 2012; Peddie et al, 2012; Penrose et al, 2012; Perz et al, 2014; Partridge et al, 2004; Tschudin et al, 2010; Thewes et al 2003, 2005; Yee et al, 2012; Vadaparampil et al, 2012; Wilkes et al 2010). Some papers specified a lack of written information (Armuand et al, 2012; Balthazar et al, 2011, 2012; Bastings et al, 2014; Corney and Swinglehurst, 2014; Garvelink et al, 2013, 2013(b); Hill et al, 2012; Jukkala et al ,2010; Mathur et al, 2013; Wilkes et al, 2010; Yee et al,2012). However, overall, the majority of papers did not specify whether the lack of information provision was in terms of verbal or written information; and the retrospective nature of many of the studies meant it was often difficult to disentangle at which point in the care pathway information was lacking, although generally this related more to a problem within the oncology consultation.

Interestingly, Armuand et al. (2012) reported that men were 14 times more likely to report receiving FP information compared with women. These findings have been supported by Armuand et al, (2015) in the qualitative literature, as only 4 out of 11 women reported having received any communication about FP from their health care professionals. Similarly, Crawshaw et al. (2009) found that patients (teenagers and young adults) reported a negative impact, both at the time of diagnosis and afterwards, where they felt that FP information was considered to be inadequate and/or poorly delivered.

Timing of information provision

The timing of information provision was also seen as hindering the FP decision-making process. There were 21 papers which reported that patients were not receiving FP information at the right time for them and this was a key factor affecting their decision-making (Balthazar et al, 2011; Corney et al, 2014; Corney and Swinglehurst, 2014; Crawshaw et al, 2009; Garvelink et al, 2013; Gorman et al, 2012; Hershberger et al, 2013; Hill et al, 2012; Kirkman et al, 2014; Lee et al, 2011; Partridge et al, 2004; Peate et al 2011, 2011(b), 2012; Penrose et al, 2012; Perz et al, 2011; Thewes et al, 2003; Tschudin et al, 2010; Vadaparamil et al 2012; Wilkes et al, 2010; Yee et al, 2012,). It has been identified that women with cancer should be given detailed information about fertility as early as possible (Corney et al, 2014), and that the optimal time for FP information is shortly after cancer diagnosis and during the treatment planning stage, specifically before the FP consultation appointment (Balthazar et al, 2011; Crawshaw et al, 2009; Garvelink et al, 2013; Hill et al, 2012; Kirkman et al, 2014; Peate et al 2011, 2011(b); Penrose et al, 2012; Partridge et al, 2004; Thewes et al, 2003; Yee et al, 2012, Vadaparamil et al 2012). For example, Vadaparampil et al (2012) concluded that missed clinical opportunities to provide FP information near the time of cancer diagnosis may impact long-term quality of life of the women. However, a grounded theory study of 38 male and female survivors of adolescent cancer found strong support for information provision about FP around diagnosis, regardless of gender, age, incapacity or availability of FP services (Crawshaw et al, 2009).

Additionally, in support of these findings, four qualitative studies (Gorman et al, 2012; Hershberger et al, 2013; Lee et al, 2011; Wilkes et al, 2010) also reported that the ideal time for patients receiving FP was before the start of cancer treatment and up to one week after diagnosis (Lee et al, 2011). Gorman et al. (2012) also reported that although a discussion about fertility at the time of diagnosis was seen as difficult and overwhelming, breast cancer patients expressed a strong desire to be told about FP options before the start of cancer treatment. Hershberger et al. (2013) similarly concluded that women viewed receiving information and education from clinicians as essential during the diagnosis and treatment planning stage.

Other studies concluded that women needed to be given written FP information on multiple occasions, to enable them to re-visit information at different treatment stages (Corney and Swinglehurst, 2014; Hill et al, 2012; Perz et al, 2011; Tschudin et al, 2010). Optimal times specified included shortly after diagnosis, during treatment, at follow-up visits (Corney and Swinglehurst, 2014), and before and after the specialist FP consultation (Hill et al, 2012).

Patient- provider communication

A factor that appeared to hinder the decision-making process is related to dissatisfaction with the consultation and communication between the woman and her healthcare professional. The retrospective nature of many of the studies meant that it was often difficult to determine i) which member of the clinical team, or ii) to which consultation this referred. However, generally there appeared to be an unmet need whereby during consultations, women felt FP options were not discussed or clearly explained enough. For example, Gorman et al. (2012) found that several participants discussed their disappointment that their doctors were hesitant to talk with them about fertility issues. A third of the women in a study of African American breast cancer patients (Lewis et al, 2012) wanted additional emotional support at diagnosis. Some women reported that they felt too rushed to ask questions and initiate discussions during the consultations (Armuand et al, 2015; Bastings et al, 2014; Hill et al, 2012; Lee et al, 2011, Wilkes et al, 2010) which contributed to them feeling unsupported and generally neglected at this time (Wilkes et al, 2010). The study found that having unconditional trust in the clinician’s opinion contributed to women not feeling able to challenge or discuss FP if it was not mentioned during the consultation.

Theme 2: Fear concerning the perceived risks of pursuing FP treatment

Women’s fears concerning the perceived risks of pursuing FP treatment appeared to hinder the FP decision-making process. These fears mainly related to the risks associated with delaying cancer treatment, the possibility of aggravating a hormone positive cancer, and the potential consequences of a future pregnancy.

Fear associated with delaying cancer treatment

The fear associated with delaying cancer treatment related to both i) a perceived immediate threat that it may exacerbate the women’s current cancer status and ii) the perceived longer-term threat of the cancer reoccurring (Crawshaw et al, 2009; Gorman et al, 2012; Kirkman et al, 2014; Klock et al, 2009; Lee et al, 2011; Wilkes et al, 2010). For example, in-depth interviews by Klock et al. (2014) reported that some breast cancer patients chose not to preserve fertility because of the fear that delaying chemotherapy might increase the chances of recurrence. In a UK qualitative study of teenagers and young adults, Crawshaw et al, (2009) reported that women who were offered oocyte freezing refused, primarily to avoid delay to treatment. Similarly, in another UK study, Lee et al. (2011) found that women with existing families felt they could not afford to jeopardise their current children’s quality of life by potentially denying them a mother if they delayed the start of cancer treatment. However, the study findings also revealed that women without children were more willing to take risks by delaying the start of chemotherapy to have fertility treatment.

Fear of aggravating a hormone positive cancer

Two qualitative papers (Lee et al, 2011; Snyder and Tate, 2013) and one quantitative study (Klock et al, 2009) found hormone sensitivity to be a factor in the FP decision-making process, due to the fear of cancer returning For example, Lee et al. (2011) reported from focus group interviews that, unsurprisingly, the priority for most women with breast cancer was survival, and that ovarian stimulation was perceived to carry a significant risk to this and could affect recurrence rates. Similarly, in studies by Snyder and Tate (2013) and Klock et al. (2009), it was found that women with cancer feared taking the additional hormones needed for the banking of oocytes or embryos as this may elevate the likelihood of cancer recurrence and the fear of exacerbating their disease as a result of the ovarian stimulation.

Fears associated with the consequences of a future pregnancy

Also hindering the decision to accept FP were women's fears associated with the consequences of a future pregnancy, post cancer treatment. This fear related to the woman themselves, particularly in terms of their own health status and cancer re-occurrence (Connell, et al 2006; Corney et al, 2014; Lee et al, 2011; Partridge et al, 2004; Wilkes et al, 2010). However, the fear associated with the consequences of a future pregnancy also extended to any potential future child born as a result of their FP treatment (Canada and Schover, 2012; Corney and Swinglehurst, 2014; Gorman et al, 2012; Kirkman et al, 2014; Niemasik et al, 2012; Wilkes et al, 2010). This particularly related to genetic transmission and the future child's own health, in terms of being more prone to cancer, but also possibly to other abnormalities (Corney and Swinglehurst, 2014; Niemasik et al 2012; Wilkes et al, 2010).

These concerns about genetics and family history were evident in women with or without any family history or genetic risks (Gorman et al, 2012).

Theme 3: Non-referral from oncology

Other factors identified as hindering the decision-making process related to clinical barriers. These clinical barriers related to the women's personal status, having a hormone positive cancer, FP being seen as not a priority, and problems with the service and/or transitions between services.

Personal situation

One reason that appeared to prevent a referral to fertility services was the woman's personal status. Two qualitative semi-interview studies in the UK found that some child-free women who were also single felt that clinicians were less likely to consider FP for them (Corney et al, 2014; Corney and Swinglehurst, 2014), possibly because success rates were felt to be lower with oocyte compared with embryo freezing (Corney and Swinglehurst, 2014). Peddie et al. (2012) also reported that some women who were without a long-term partner gained the impression from health professionals that they had little to gain and/or were unsuitable for cryopreservation of gametes and hence ruled out this possibility.

However, conversely, for women who already had children, some women reported that health professionals had ruled out FP for them, under the assumption that they had already completed their families (Peddie et al, 2012). Similarly, Lee et al. (2011) explored focus group interview data to illustrate that women with breast cancer who already had children perceived that health professionals assumed they would not want further children and were therefore they not given the option of FP. This finding has also been supported by Neimasik et al. (2012), who through the use of open-ended questions, found that 16% of women who had one or more children perceived that physicians projected less significance on future fertility.

In some qualitative studies, women hypothesised that their age may have played a role in the lack of referral and discussion about FP, particularly if they were seen as too old and therefore had completed their family (Armuand et al, 2015). In an earlier study, Armuand et al. (2012) found that women under 35 years with no children were significantly more likely to receive FP information. However, on the contrary, a study of teenage and young adult cancer patients reported that some women stated that their doctors wanted to postpone FP discussion with them until they were older (Gorman et al, 2012). Neimasik et al (2012) also found that some younger women reported that their age meant they were not referred for FP.

Having a hormone positive cancer

In relation to having a hormone sensitive cancer, Corney and Swinglehurst (2014) reported that four out of 19 women with breast cancer stated that the main reason for not being freely given the option of FP was having a hormone-sensitive cancer. Patients in a study by Niemasik et al. (2012) reported that their physicians cited risk of cancer recurrence in hormone sensitive cancers as a reason not to preserve fertility.

FP not a priority

A contributing factor which appeared to hinder the decision-making process for women was the perception that their healthcare professionals considered fertility issues a low priority compared to starting cancer treatment and survival (Corney et al, 2014; Corney and Swinglehurst, 2014; Gorman et al, 2012; Thewes et al, 2003; Wilkes et al, 2010). For example, Thewes et al, (2003) and Wilkes et al, (2010) reported from focus groups and interview data that some women often felt there was a discord between their perceived importance of fertility and the importance their doctors attributed to it.

Other problems with the service/ transition between services

Women with cancer have to make time-pressured decisions regarding FP with specialist fertility services whilst undergoing treatment of their cancer with oncology services. Problems with service delivery and transitioning between these two services also hindered the FP decision. Long waiting times to see a fertility specialist and appointment delays until after chemotherapy had been arranged were reported by Corney and Swinglehurst (2014). In addition, Garvelink et al, (2013) reported that women wanted improved communication between treatment centres. Some women stated that information provision was delayed, resulting in either late oncology appointments or late referrals to FP services. Several participants in a study by Gorman et al. (2012) perceived that poor co-ordination of care between different medical centres was a problem for young adult cancer patients. Similarly, participants in a study by Mathur et al. (2013) felt they were being pushed from provider to provider with no-one helping them to make decisions. Yee et al. (2012) also reported that some patients stated there was a delay in getting an FP referral due to seeing different medical consultants.

Theme 4: The dilemma

A dilemma appeared to take place for women, which played an important role in hindering FP decision-making. The dilemma for women related to choosing to be in survival mode and whether to prioritise one treatment over another with the ‘double whammy’.

In survival mode

Many patients reported survival as their primary focus and as an important factor in their decision not to pursue FP (Crawshaw et al, 2009; Lee et al, 2011; Garvelink et al, 2013), and that cancer treatment was a priority over future fertility (Hershberger et al, 2013, 2016; Kirkman et al, 2014; Mathur et al, 2013; Penrose et al, 2012; Perz et al, 2014; Snyder and Tate, 2013; Thewes et al, 2003; Wilkes et al, 2010). For example, Penrose et al. (2012) explored this issue during interviews with both women and men with various cancer types, and reported that 28% of patients stated that they were in “survival mode” at diagnosis and were focussed on treatment options that would maximize their chances of survival.

Whether to prioritise one treatment over another and the ‘double whammy’

For many women, the emotional impact of deciding between two different treatments and the consequences associated with these appeared to hinder the FP decision (Armaund et al, 2015; Corney and Swinglehurst, 2014; Hershberger et al, 2013, 2016; Kirkman et al, 2014; Mathur et al, 2013; Perz et al, 2014; Snyder and Tate, 2013). For example, in one qualitative study, patients described how they did not ask questions about their risk of fertility or tried to avoid thinking about or discussing the risks of infertility associated with their cancer treatment as the emotional impact would be too great (Armaund et al, 2015). Snyder and Tate (2013) also reported some respondents describing an intense emotional experience of having to make FP decisions while grappling with a potentially life-threatening experience.

Similar findings were reported by Corney and Swinglehurst (2014), with women also reporting a lack of emotional support to guide them through these decision dilemmas. Further interview studies by Mathur et al. (2013) and Kirkman et al. (2014) also identified that some women found the initial diagnosis so overwhelming they could not consider fertility, feeling that they were forced to make a choice between the two.

Deciding between the two treatments was sometimes described as a “double-trauma” (Perz et al, 2014). Interview data from Hershberger et al. (2013) also outlined a similar “double-hit” scenario with breast cancer and possible infertility seen as two blows. In a later paper by Hershberger et al. (2016), four women who declined treatment reported that the mental and physical energy needed to engage in FP treatment was beyond their capabilities.

Theme 5: Personal Status

Women’s personal status, in terms of both parity and relationship status, appeared to influence the FP decision-making process.

Parity

Seven papers reported a difference in how patients viewed and accessed the treatment options offered to them, based on whether they had existing children or not (Armuand et al, 2012; Canada and Schover, 2012; Kirkman et al, 2014; Lee et al, 2011; Letourneau et al, 2012; Niemasik et al, 2012; Mersereau et al, 2013). Overall, across these papers, findings revealed that already having children appeared to reduce interest in FP. For example, a quantitative survey found that women with children were less likely to take action to preserve their fertility than women without children (Letourneau et al, 2012) and were also less likely to receive information about FP (Armuand et al, 2012).

Relationship status

The other personal factor which appeared to be a barrier to FP was relationship status and, in particular, being single (Baysal et al, 2015; Corney et al, 2014; Corney and Swinglehurst 2014; Hershberger et al, 2013, 2016; Gorman et al, 2012; Mersereau et al, 2013; Synder and Tate, 2013, Wilkes et al, 2010). Hershberger et al (2013, 2016) reported that an additional burden for single women in their decision-making was having to approach partners, about whose long term commitment they were unsure, to discuss FP. Also attending fertility clinics as a single woman was perceived as difficult because the majority of those attending were young couples (Corney et al, 2014). One qualitative study found that being single was a barrier to FP simply because they were too young to have a partner and not ready to have or even think about children (Wilkes et al, 2010).

Two qualitative studies further explored the impact of relationship status on FP choice and found that women in a stable relationship overall favoured embryo cryopreservation because the fertility outcomes were better with cryopreservation of embryos than with oocytes, whereas for single women oocyte cryopreservation was the only option unless a sperm donor could be found, which was not a realistic option in the short time available before start of treatment (Corney et al, 2014; Corney and Swinglehurst, 2014).

Theme 6: Costs

A factor identified as hindering the FP decision-making process related to financial concerns. The cost of FP appeared to play a key constraining factor in the decision whether to access FP.

Financial concerns

The cost of FP, and the implied effect this has on the decision-making process, was reported as an influential factor in eleven papers (Balthazar, 2012; Hershberger et al, 2013, 2016; Gorman et al, 2012; Hill et al, 2012; Kim et al, 2013; Klock et al, 2009; Mathur et al, 2013; Mersereau et al, 2013; Snyder and Tate, 2013; Yee et al, 2012). Of the papers identified, the issue of cost was deemed to be one of the major constraining factors in accessing FP, and three papers identified cost as the most influential factor impacting upon the decision-making process (Balthazar et al, 2012; Gorman et al, 2012; Hill et al, 2012). However, eight of the eleven studies were from the U.S.A, where fertility health care costs are significant and not routinely covered by insurance. Web-based survey findings have also reported that decisional conflict was higher in those patients who reported that cost was strongly influential in the treatment decision (Kim et al, 2013). This was confirmed by Mersereau et al. (2013) who employed a similar web-based survey, and reported that patients for whom the costs of FP were prohibitive reported higher decisional conflict scores using the Decisional Conflict Scale. The study further demonstrated that women who were not referred for FP counselling, or who were unable to afford the cost of fertility treatment, experienced a significant increase in levels of decisional conflict.

Discussion

The aim of this review was to build upon the existing evidence base and identify the factors that hinder the FP decision-making process for women with any cancer and, in doing so, identify the ways that service delivery can be better improved to support patients.

From our review, a range of diverse external and internal factors were identified. Most of the factors which hindered the process related to service delivery issues and external factors beyond the patients control, such as the provision and timing of FP information and a lack of clear referral pathways from oncology to the fertility clinic. Internal psychological factors such as women's fears concerning the perceived risks associated with pursuing FP also played a role. Some of these risk perceptions appear to be over-estimated and non-evidence based. It was also evident that the combination of a diagnosis of cancer and having to contemplate future infertility has a long-lasting and significant impact on women's lives. This was shown by a range of quantitative indicators such as quality of life and decisional conflict as well as by the detailed narratives of patients captured in the qualitative research studies reviewed.

In agreement with the findings of many of the articles and reviews to date in the area, our review reinforces a clear need for more specific and targeted information provision, both at the time of cancer diagnosis/treatment planning and most importantly, before the fertility consultation, which would better prepare and support women making decisions about their future fertility. Lack of information from the patient's perspective appears important because low levels of fertility-related knowledge has been linked to increased decisional conflict in young patients with breast cancer (Peate et al, 2011b) and a perceived lack of overall support for women (Bastings et al, 2014).

The implementation of patient decision aids may be one way of addressing this issue. PtDAs are one type of decision support intervention. They are information resources supporting people to make decisions between healthcare options (Stacey et al, 2011). They are evidence-based resources, drawing on clinical effectiveness of healthcare options data, studies of patients' decision-making and illness experiences, and evidence from the decision sciences on how people make healthcare choices (Bekker et al, 2013). PtDAs support people to make reasoned decisions, i.e. ones based on accurate information about the consequences of all options, in accordance with their beliefs and trade-offs between their treatment preferences (Rothert et al, 1977, O'Connor and Edwards; 2001, Bekker et al, 1999). Whilst there are many FP resources publically available for women with cancer, few exist to support the FP decision process in women of reproductive age (Mahmoodi et al, 2016). To our knowledge, only two PtDAs have been designed for women with breast cancer specifically, one in Australia and the other one in the Netherlands (Peate et al, 2011; Garvelink et al, 2013b). For example, there are currently no PtDAs available for women in the UK, although one is in the early stages of development and testing (Jones et al, 2017).

Effectiveness studies of these two PtDAs suggests that they may better support women to make FP decisions. The PtDA booklet of Peate et al. (2012), has been found to reduce decisional conflict and regret with the decision made, and increase knowledge about FP for breast cancer patients, and the Dutch evidence-based web-based PtDA about FP for women with breast cancer has been found to improve information provision in the Netherlands and increase knowledge about FP for breast cancer patients (Garvelink et al, 2014). To our knowledge, no other trials have been conducted to explore the effectiveness of PtDAs within the context of FP and cancer.

It is possible therefore, that a new PtDA for women with any cancer, that can be administered both at the time of diagnosis/cancer treatment planning stage in the oncology clinic before they see a fertility specialist, may be of value. In particular, the value would relate to the provision and timing of evidence based information (Theme 1), addressing some of the fears concerning the perceived risks of pursuing FP treatment (Theme 2) and the 'dilemma' of whether to prioritise one treatment over another (Theme 4). However, it is important that the development of any future new PtDA is not just a practical exercise but also makes explicit the use of decision theory during its development. A number of normative and descriptive decisions theories exist (Elwyn et al, 2010). To ensure that the theory-practice gap is addressed in relation the development of PtDAs and other decision support interventions, using theoretical frameworks to inform development is recommended (Elywn et al, 2010). Based upon the findings of this review, the authors are currently developing a new FP PtDA, for women aged 16 years or over with any cancer, and aim to follow this guidance for the integration of decision-theory during its development (Jones et al, 2017). It will be interesting to see how well it fulfils these unmet needs for women during its acceptability and evaluation phases.

Despite the wide variation in samples, sample size and research methodologies within the papers, overall, women seemed to have the same internal concerns which hindered the FP decision. Fear of recurrence was both a concern of women attempting to balance the need for survival with the need to delay treatment in order to preserve fertility and of the oncologists attempting to quantify the risk of different treatment regimens and timelines.

Although most of the studies found that survival was seen as more important than preserving fertility, childless women may be more prepared to take a risk but conversely, oncologists may be less willing to sacrifice survival for fertility than their patients. There is some evidence that single women may experience more difficulties, both in accessing a fertility consultation as well as having less preservation options, and this may lead to long-lasting and persistent distress about child-bearing. Conversely, it is also reported that women with children either feel they cannot risk their long-term survival by preserving fertility or report that they perceive health professionals as less willing to refer them to fertility services.

Linked to fears of recurrence, hormone receptor status is a significant factor hindering FP decision-making for women with breast cancer, the most common cancer in this review. For oncologists, this was also a consideration when deciding whether FP was feasible. However, several papers reported both patients and health professionals overestimated the risks associated with FP treatment generally. Balthazar et al. (2011) found that only 17% of female patients with wide ranging cancer types knew that FP and pregnancy did not increase the risk of cancer recurrence. This is despite the fact that an association between increased risk of recurrence and pregnancy after cancer has not been identified and pregnancy may even have a protective effect (Blakely et al, 2004; Ives et al, 2007; Jeruss et al, 2009).

Patients also over estimated their infertility risk (Partridge et al, 2004; Penrose et al, 2012). Partridge et al. (2004) found through use of global web-based surveys that a substantial proportion of women diagnosed with breast cancer overestimated their risk of becoming post-menopausal after treatment. Semi-structured interviews with both men and women revealed that 33% of participants assumed that treatment would definitely make them infertile (Penrose et al, 2012). Whilst all healthcare information should be evidence-based, it may be that by presenting the information within the context of a decision support intervention (e.g. within a PtDA), may help reduce the risks perceived by women and support better decision-making. This evaluation is recommended for future research.

We identified that external service delivery problems hindered the FP decision-making process. A recent paper, particularly in relation to the UK has also reported that current service delivery for women in this area is poor (Anderson and Davies, 2016). One particular issue highlighted in our review was in relation to the perceived lack of referral to fertility services from oncology and lack of FP discussions during the oncology consultation which women felt was based upon their personal situation e.g. age, relationship status, parity, the type of cancer they had (hormone positive) and the perception that oncologists placed much more weight on survival than on the late effect of possible infertility.

Indeed, a recent study by Breast Cancer Care (2014) reported that more than a third of specialist breast cancer doctors and nurses surveyed said that they did not discuss the risk of treatment with young female breast cancer patients. Of these healthcare professionals, 26% also said that there was no clear system for directing patients to fertility clinics in the UK. If the findings of this survey reflect theexperiences of women across the country, the charity says indicated that about 5000 young breast cancer patients could be missing out on FP each year (Breast Cancer Care, 2014).

Other research exploring the perspectives of oncologists supports the reasons for avoidance of discussion concerning FP by the oncologist and for non-referral of women to a fertility clinic (Adams et al, 2013; Duffy et al, 2012; Forman et al, 2010; Shimizu et al, 2012). One UK study of 100 oncologists (Adams et al, 2013) reported that 87% of oncologists expressed a need for more specialist FP information and only 38% of oncologists surveyed stated that they routinely provided patients with written FP information. Similar findings have been reported in the USA (Duffy et al, 2012; Forman et al, 2010). Duffy et al. (2012) reported that only 18% of 344 oncologists reported having specific FP information for patients. Only about half of respondents reported moderate or high confidence in their knowledge about FP options. Duffy et al. concluded that oncologists' confidence in their knowledge regarding FP options in the study was "moderate at best". In another paper, Shimizu et al. (2013) reported in a cross-sectional survey with 843 Japanese breast cancer specialists, showing that physicians who had better knowledge and positive attitudes toward FP were more likely to discuss future fertility with patients and to make referrals to reproduction specialists.

Therefore, from the existing literature, the need for more resources to support oncologists with the FP discussion and the multi-disciplinary teams involved in women's care has been recommended and developed (Woodruff, 2014). At a minimum, it is of importance that healthcare providers have access to adequate training programs and up-to-date clinical guidelines so that they can be fully informed of oncofertility standards of care for this patient group (Johnson and Gracia, 2014). For example, the Oncofertility Consortium have developed a wide range of communication tools to support oncology and fertility healthcare professionals (LaBrecque et al, 2014).

The findings from this review support these initiatives but also recommends that the implementation of any educational tools targeted at improving the communication skills are designed to improve collaborative decision-making and deliver care that is patient-centred. Given that one of the barriers to the FP decision identified from this review, related to 'transition with service issues' between oncology and fertility services, one particularly exciting shared-decision model moves beyond the simple physician-patient dyad to encompass the interdisciplinary teams involved in a patient’s care (Knowledge to Action) (Legare et al, 2011). Whilst the model was originally developed within primary care, toolkits embedded within this concept may offer real benefit to address the transition to service issues at a secondary care level, and more research to explore this is recommended.

A three-step model to promote shared-decision-making within clinical practice has also been proposed. It focuses on ‘Choice talk’ (making sure the patient knows reasonable options are available), ‘Option talk’ (providing the patient with more detailed information about the options) and ‘Decision talk’ (supporting the patient to form preferences and make the best decision for them) (Elwyn et al, 2012). The model also includes the integration of PtDAs and providing training to healthcare professionals (particularly the oncology care team) in this model, supplemented by a PtDA, may help overcome many of the barriers to the FP decision identified from this review, and again this warrants further research and evaluation.

Despite the different countries being compared, cost was cited as a factor which influences whether women decide to undergo FP. However, nine studies out of the eleven we identified which report cost as a factor originated from the USA where healthcare costs associated with FP can be prohibitive. The other two studies were carried out in Canada where health treatment costs are variable. For women in the UK diagnosed with cancer, NHS funding may be available, but the amount of funding and the criteria for treatment varies between Clinical Commissioning Groups (CCGs) and different regions. As a consequence, equity of funding has been recommended for the UK (Anderson and Davies, 2016) and this change in service provision may help remove ‘cost’ as a factor hindering FP decision-making in the future. In the meantime, the provision of specific funding information, applicable to the treatment centre, early in the FP care pathway is recommended.

The main factor influencing the choice of fertility option, embryo versus oocyte cryopreservation, was relationship status. If women were in a relationship then embryo cryopreservation was overall the favoured choice, mainly because the odds were seen as better; and for single women, oocyte cryopreservation was regarded as the only option (Corney and Swinglehurst, 2014). Oocyte vitrification has dramatically improved the success of oocyte cryopreservation, enabling fertility preservation to be a promising option for these women. Another relatively new approach to preserving a woman's fertility is ovarian tissue cryopreservation, in which the outer layer of an ovary, which contains a large number of immature oocytes, is collected laparoscopically and frozen for future use. While still considered an experimental procedure, the approach is performed to preserve fertility for pre-pubertal girls, for women who need urgent treatment and hence do not have time to undergo ovarian stimulation and oocyte retrieval or for women who are advised not to use fertility drugs due to perceived risk with a hormone sensitive cancer. Although this new approach is currently not routinely available to all women with cancer in the UK, it could become the preferred option for many patients, particularly if it becomes possible to mature oocytes in vitro after collection from the tissue sample. Ovarian tissue cryopreservation could be seen as less stressful than ovarian stimulation and oocyte retrieval for women, and could obviously be utilised regardless of relationship status, by women considering FP following a cancer diagnosis.

One of the main reasons for pursing FP appeared to be the simple desire to 'keep options open' as a 'back-up or 'insurance' plan (Mathur et al, 2013; Snyder and Tate, 2013) and therefore supporting more women with FP material and to have referral to a fertility clinic provides the opportunity for women to have these discussions (Armuand et al, 2015). This is particularly important because even just being referred for a FP consultation has been shown to be associated with less decisional conflict in the future (Mersereau et al, 2013). Similarly, receiving counselling from both the oncology team and FP services appears to reduce decisional regret (Letourneau et al, 2012). Therefore, ensuring patients have access to counselling is important. However, in the current literature, it appears (or is unclear) that the counselling has been carried out by the reproductive/oncology expert (Letourneau et al, 2012; Bastings 2014; Neimisk, 2012) rather than a counsellor. It is recommended that women also have access to these trained professionals who are qualified to deliver psychological support, especially as a sub-theme generated from the review was a perceived lack of emotional support during the decision-making process.

It is unclear to what extent moral, ethical and/or religious beliefs play a part in the decision-making process, as this was only explicitly reported in one of the papers assessed in this review (Hershberger et al, 2016). This may reflect the predominately Caucasian origins of the women included in the research, or that women are not being asked specifically to what extent these issues played a role in their decision-making. More research to explore the ways in which ethnicity and/or religious beliefs influence the FP decision-making process would be valuable to ensure standardised care across minority groups. Oncologists have also cited poor prognosis as a reason for non-referral to the fertility clinic (Adams et al, 2013; Shimizu et al, 2013; Duffy et al, 2012) but more research is needed to ascertain the ways in which this may hinder referral and FP decision-making from the oncologist and patient perspective.

Strengths and Limitations

We have attempted to synthesise and summarise the current body of knowledge on the factors which hinder FP decision-making by women with cancer of reproductive age and in doing so, identify means for improvement of service delivery to better support female cancer patients. This narrative review has identified a large body of literature which encompasses a range of study methodologies, qualitative and quantitative and mixed methods, and has included studies of women with any cancer whilst recognising that most studies have been restricted to women with breast cancer.

Whilst we attempted to undertake a comprehensive and systematic search, we are aware that our databases were mainly ‘health focused’ and therefore some papers may have been missed. We have used a thematic approach to assess and synthesise the information in the 46 papers reviewed and to provide insights into the FP decision-making process. We have not reported qualitative and quantitative studies separately but rather have used an aggregative synthesis approach to summarise with a narrative review of the evidence (Dixon-Woods et al, 2006).

The studies were heterogeneous, with a wide variety of inclusion criteria. Some included men and women, diseases other than cancer, differing outcome measures and study designs. A limitation is that the literature to date has primarily been focused on women choosing whether to choose fertility preservation or not, rather than either oocyte or embryo freezing, or didn’t specifically report the methods of FP in the study. Overall, the quality of papers was good, but the current evidence base is limited by a lack of prospective studies, and the paucity of data collected and reported on cancer populations outside of women with breast cancer. For these reasons, there was insufficient evidence to appraise whether there were differences in factors affecting women´s decisions according to their cancer diagnosis or by FP technique. Many of the studies had small sample sizes but this is to be expected within this field of research.

Conclusions and implications for future research

In conclusion, a number of interventions may be useful in addressing the wide range of internal and external factors that impact on the FP decision-making process (e.g. the implementation of PtDAs, education resources to improve communication and patient-centred care, referrals to trained FP counsellors within both oncology and fertility services and simply ensuring there is time to have the FP discussion during the oncology consultation) but it is unlikely that one intervention alone will remove all the barriers for these women identified from the review. It is recommended that the development/implementation of any such decision support interventions are grounded within a theoretical shared-decision framework to help bridge the theory-practice gap within the decision-making field.

To continue to extend recommendations for service delivery, more research is needed to explore further how best to facilitate decision-making in the context of technologies other than oocyte and embryo freezing. Exploration of the current barriers, both psycho-social and practical, that prevent some patients from accepting FP will also help care providers to do better for their patients in the future. Finally, the extent to which a poor prognosis, and moral, ethical and religious beliefs influence the FP decision-making process also warrants further research.

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Authors' Roles:

GJ: conceived the idea, secured funding, wrote the protocol, participated in the data collection, critical appraisal and data analysis and wrote the manuscript for publication.

JH: participated in the protocol development, undertook the searches, participated in data collection, critical appraisal and data analysis and helped write the manuscript for publication.

NM: participated in the critical appraisal and data analysis and helped write the manuscript for publication.

ES: undertook the searches and participated in data collection, critical appraisal and data analysis and manuscript drafting.

JS: participated in the protocol development and manuscript drafting.

WL: participated in the protocol development and manuscript drafting.

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Conflict of Interest

None declared.

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Figures and Tables

Figure 1: Flowchart detailing literature search

Table 1: Details on the existing reviews which have synthesised the evidence relating to fertility preservation decision-making and cancer

Table 2: MMAT Quality Appraisal exercise results

Table 3: Study demographic details

Table 4: Themes and sub-themes illustrating factors which hinder the fertility preservation (FP) decision-making process

Figure 2: Clinical flow chart illustrating internal and external barriers (themes) hindering the FP decision-making process within oncology and fertility services