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Abstract

Women undergoing cancer treatments and their healthcare providers encounter challenges in fertility preservation (FP) discussions and decision-making. A systematic review of qualitative research was conducted to gain in-depth understanding of factors influencing FP discussions and decision-making. Major bibliographic databases and grey literature in English from 1994-2016 were searched for qualitative research exploring patient/ provider perspectives on barriers and facilitators to FP decision-making. Two researchers screened article titles, abstracts and full-texts. Verbatim data on research questions, study methodology, participants, findings, and discussions of findings were extracted. Quality assessment and thematic analysis were conducted. The search yielded 74 studies dating from 2007 onwards; 29 met the inclusion criteria. Analysis revealed three types of barriers: 1) FP knowledge, skills and information deficits contributed to discomfort for providers and discontent for patients; 2) psychosocial factors and clinical issues influenced providers' practices around FP discussions and patients' decision-making; and 3) material, social and structural factors (e.g. lack of resources and accessibility), posed challenges to FP discussions. Potential facilitators to FP discussions and decision-making were also identified. A discussion of ways to improve physician's knowledge and facilitate women's decision-making and access to FP is presented, along with areas for policy development and further research.

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Key words: fertility preservation, patient-provider perspectives, facilitators, decision-making, systematic review, cancer

Introduction

Many cancer therapies have the potential to irreversibly compromise women's reproductive potential (Levine, Kelvin, Quinn, & Gracia, 2015). This has significant implications for young women who have not yet achieved family-building goals and who desire biological children (Armuañ, Wettergren, Rodriguez-Wallberg, & Lampic, 2014). Systemic chemotherapy and radiation treatments can result in higher risks of infertility, including diminished natural ovarian reserve, early onset menopause, increased rate of uterine dysfunction and acute ovarian failure (Duffy & Allen, 2009; Wallace, 2011; Wo & Viswanathan, 2009). Additionally, treatments for some hormone-receptive cancers may require prolonged endocrine therapy and a delay in pregnancy, further limiting a woman's reproductive capacity due to natural follicle depletion in the ovarian reserve with age (Anderson & Wallace, 2011; Coccia et al., 2012). Surgical treatment for gynecological cancers may require partial or complete removal of the reproductive organs, thus reducing or eliminating a woman's ability to conceive and carry biological children.

Fortunately, advances in reproductive technologies have provided women with options for fertility preservation (FP). Clinical FP guidelines, including those from the American Society of Clinical Oncology (ASCO), American Society for Reproductive Medicine, Clinical Oncology Society of Australia, National Institute for Clinical Excellence, the Royal College of Physicians, the Royal College of Radiologists and Royal College of Obstetricians and Gynaecologists among others, recommend that FP is discussed with all patients of reproductive age, including options for referrals to fertility specialists (AYA Cancer Fertility Preservation Guidance Working Group; Ethics Committee of the American Society for Reproductive Medicine, 2005; Loren et al., 2013; O'Flynn, 2014; Royal College of Physicians, Royal College of Radiologists, & Royal College of Obstetricians and Gynaecologists, 2007). Although discussions about the effects of cancer treatment on fertility may be challenging, evidence shows that young women with cancer want to be informed about fertility issues (Thewes, Meiser, Rickard, & Friedlander, 2003; Thewes et al., 2005). Women seek support for potential FP from their healthcare providers (Gorman, Usita,

Madlensky, & Pierce, 2011; Partridge et al., 2004), and most women prefer to make FP decisions in consultation with their providers (Peate et al., 2011). However, research indicates that women may receive limited information on fertility risks, and only a small number are referred for fertility consults (Goossens et al., 2014; Quinn, Vadaparampil, Lee, et al., 2009; Yee, Buckett, Campbell, Yanofsky, & Barr, 2012).

Reviews addressing various aspects of fertility care for young women with cancer have been published (Deshpande, Braun, & Meyer, 2015; Goncalves, Sehovic, & Quinn, 2014; Goossens et al., 2014; Howard-Anderson, Ganz, Bower, & Stanton, 2012; Peate, Meiser, Hickey, & Friedlander, 2009; Sobota & Ozakinci, 2014), and provide insight into attitudes (Goncalves et al., 2014), fertility-related concerns (Howard-Anderson et al., 2012; Peate et al., 2009), psychological well-being and quality of life outcomes (Deshpande et al., 2015; Sobota & Ozakinci, 2014), and preferences for receipt of fertility-related information (Goossens et al., 2014). A recent mixed-methods review synthesized factors that affect fertility preservation care into broad extrinsic and intrinsic factors and explored patient and provider perspectives (Panagiotopoulou, Ghuman, Sandher, Herbert, & Stewart, 2015). However, there remains a gap in specific examination of the convergences and divergences in providers and patients' FP experiences and perspectives, which are important to understand for delivery of appropriately targeted supports, as well as a gap in understanding of facilitators of FP practice from the perspective of health care providers.

Therefore, this systematic review aimed to extend research on barriers and facilitators to FP discussions and decision-making and to understand commonalities and differences between patients and oncology healthcare providers' perspectives. The review focused on qualitative research in response to the growth of qualitative literature in the health sciences and the need for examination and inclusion of diverse forms of data in evidenced-based practice (Sandelowski, Barroso, & Voils, 2007). By having a broad date range for article inclusion, the review also assessed change in qualitative themes over time.

Methods

Search Strategy / Study Selection

A systematic review of English language articles published between January 1994 and March 2016 was conducted. MEDLINE, PsycINFO, CINAHL, the Cochrane Central and

Embase were searched using a combination of ‘cancer’, ‘cancer treatment’, ‘fertility-preservation’, and ‘decision-making’ medical subject headings, text words and synonyms (Supplementary Table 1). Qualitative and cross-sectional questionnaire studies with open-ended questions (only open-ended components were eligible for analysis) presenting patient or healthcare providers’ experiences about and barriers / facilitators to FP discussions and/or decision-making were included. Two researchers independently screened article titles, abstracts and full-texts. Reference lists of included articles were screened for relevant publications. A grey literature search (Supplementary Table 2) was conducted and content experts informed a comprehensive list of additional resources to ensure all relevant studies were identified.

Quality Assessment

Two researchers independently assessed the quality of included studies using the Critical Appraisal Skills Program ((CASP), 2013) for qualitative studies and a modified version of the STROBE checklist for cross-sectional studies (von Elm et al., 2007). These instruments have been previously used for quality appraisal in systematic reviews ((CASP), 2013; Peate et al., 2011). Discrepancies were resolved through discussion with a third researcher. Quality assessment scores were reviewed and articles classified as poor, medium, or high quality. Poor quality studies were excluded.

Data Extraction and Analysis

Two researchers independently conducted data extraction and analyses. Discrepancies were discussed with a third researcher and consensus achieved. Thematic analysis was conducted to identify barriers and facilitators to FP decision-making (Kastner et al., 2012). Each paper was read multiple times to facilitate familiarity. Verbatim data on research questions, study methods, sampling, participants, study contexts, findings, and discussions of findings were extracted. A previously designed taxonomy of influential factors to shared decision-making in general clinical settings was used to help with development of the initial coding scheme (Légaré et al., 2006). Codes were generated from each study and then systematically and iteratively compared across studies to develop a general coding scheme. Reviewers discussed data that did not fit the scheme and revised codes as necessary. Through an iterative analytic process of identifying codes and their contents, searching for commonalities and differences in experiences and perspectives, and through discussions within the research team, descriptive themes representing barriers and facilitators to FP discussions and decision-making were identified.

Insert Figure 1 about here

Results

Description of Studies

Of the 5,102 records retrieved, 29 articles met inclusion criteria (Figure 1). All included studies were published after 2007. Twenty-six studies used a qualitative design (Armund, Wettergren, Rodriguez-Wallberg, & Lampic, 2015; Corney & Swinglehurst, 2014; M. A. Crawshaw, Glaser, Hale, & Sloper, 2009; Ehrbar et al., 2016; Garvelink et al., 2013; P.E. Hershberger, Finnegan, Altfeld, Lake, & Hirshfeld-Cytron, 2013; P. E. Hershberger, Sipsma, Finnegan, & Hirshfeld-Cytron, 2016; Keim-Malpass et al., 2013; King, Quinn, Vadaparampil, Gwede, et al., 2008; King, Quinn, Vadaparampil, Miree, et al., 2008; Kirkman et al., 2013; Kirkman et al., 2014; Komatsu et al., 2014; Lee et al., 2011; Peddie et al., 2012; Penrose, Beatty, Mattiske, & Koczwar, 2012; Quinn & Vadaparampil, 2009; Quinn et al., 2007; Quinn, Vadaparampil, King, et al., 2009; Russell, Galvin, Harper, & Clayman, 2016; Snyder & Tate, 2013; Snyder, Thazin, Pearse, & Moinuddin, 2010; Ussher, Cummings, Dryden, & Perz, 2016; Vadaparampil, Quinn, King, Wilson, & Nieder, 2008; Wilkes, Coulson, Crosland, Rubin, & Stewart, 2010) and three used a survey design with open-ended questions (Hill et al., 2012; Niemasik et al., 2012; Yee, Abrol, McDonald, Tonelli, & Liu, 2012) (Table 1). The included studies variously examined patients and providers' attitudes, experiences and perspectives, communication practices, fertility concerns, referrals, counseling/information provision, FP decision-making, and barriers and facilitators. Fourteen studies included participants with mixed types of cancers (Armund et al., 2015; M. A. Crawshaw et al., 2009; Ehrbar et al., 2016; Garvelink et al., 2013; Gorman, Bailey, Pierce, & Su, 2012; P.E. Hershberger et al., 2013; P. E. Hershberger et al., 2016; Keim-Malpass et al., 2013; Niemasik et al., 2012; Peddie et al., 2012; Penrose et al., 2012; Russell et al., 2016; Wilkes et al., 2010; Yee, Abrol, et al., 2012), seven included breast cancer survivors (Corney & Swinglehurst, 2014; Hill et al., 2012; Kirkman et al., 2013; Kirkman et al., 2014; Lee et al., 2011; Snyder & Tate, 2013; Snyder et al., 2010), and one included cervical cancer survivors (Komatsu et al., 2014). Studies examining providers included medical oncologists, hematologists, surgeons, obstetricians/gynecologists, and oncology nurses and social workers (King, Quinn, Vadaparampil, Gwede, et al., 2008; King, Quinn, Vadaparampil, Miree, et al., 2008; Peddie et al., 2012; Quinn & Vadaparampil, 2009; Quinn et

al., 2007; Quinn, Vadaparampil, King, et al., 2009; Ussher et al., 2016; Vadaparampil et al., 2008).

Insert Table 1 about here

As rated against the CASP, more than half the qualitative studies did not provide clear justification for their choice of design (Corney & Swinglehurst, 2014; M. A. Crawshaw et al., 2009; Garvelink et al., 2013; Keim-Malpass et al., 2013; Kirkman et al., 2013; Kirkman et al., 2014; Komatsu et al., 2014; Lee et al., 2011; Peddie et al., 2012), and the relationship between researcher and participants was adequately considered in only 10 studies (Armuaud et al., 2015; Corney & Swinglehurst, 2014; Keim-Malpass et al., 2013; Kirkman et al., 2013; Komatsu et al., 2014; Peddie et al., 2012; Penrose et al., 2012; Quinn et al., 2007; Quinn, Vadaparampil, King, et al., 2009; Wilkes et al., 2010) (Supplementary Table 3). Despite these faults, all studies were of high or medium quality. Therefore, none were excluded on the basis of quality. The three survey studies scored well on the background, study design, outcomes, interpretation and generalizability domains. However, two areas, efforts to address potential sources of bias and justification for sample size, were not well reported by most studies (Supplementary Table 4).

Findings

Three main themes characterizing barriers to FP decision-making were identified across the 29 studies: 1) FP knowledge, skills, and information deficits, 2) psychosocial and clinical concerns, and 3) material, social and structural factors including economic and parental status. Although not explicitly discussed in most included studies, our analysis revealed several potential facilitators to FP discussions and decision-making.

Barriers to FP discussion and decision-making

Knowledge, Skills, and Information Deficits

Analysis of provider perspectives and experiences revealed knowledge, skills and information deficits were prevalent across all disciplines. Studies reported providers have limited awareness of FP procedures including the time required for completion, costs / insurance coverage (King, Quinn, Vadaparampil, Gwede, et al., 2008; King, Quinn, Vadaparampil, Miree, et al., 2008; Peddie et al., 2012; Quinn & Vadaparampil, 2009; Quinn et al., 2007; Quinn, Vadaparampil, King, et al., 2009; Ussher et al., 2016; Vadaparampil et al., 2008), referral processes/ locations of fertility clinics (Loren et al., 2013; 2013; Quinn, Vadaparampil, Bell-Ellison, Gwede, & Albrecht, 2008; Tschudin & Bitzer, 2009; Ussher et al., 2016), and limited

knowledge of practice guidelines and use of guidelines at their own institutions (King, Quinn, Vadaparampil, Gwede, et al., 2008; King, Quinn, Vadaparampil, Miree, et al., 2008; Quinn & Vadaparampil, 2009; Vadaparampil et al., 2008). Others reported receiving minimal training on FP counseling – reporting that what they knew was learned on the job (King, Quinn, Vadaparampil, Miree, et al., 2008; Quinn, Vadaparampil, King, et al., 2009). Likewise, some studies reported that allied care providers such as oncology nurses and social workers were not aware of FP and/or did not think about it, felt they did not have enough training to initiate or conduct such discussions, and assumed physicians were engaging patients in discussions (King, Quinn, Vadaparampil, Gwede, et al., 2008; King, Quinn, Vadaparampil, Miree, et al., 2008). Healthcare providers reported feeling challenged by the complexity of FP options alongside differences in cultural and religious beliefs (Quinn & Vadaparampil, 2009; Quinn, Vadaparampil, King, et al., 2009; Vadaparampil et al., 2008). Lack of knowledge and familiarity with FP likely contribute to discomfort with engaging patients in FP discussions (King, Quinn, Vadaparampil, Miree, et al., 2008; Quinn, Vadaparampil, King, et al., 2009; Russell et al., 2016; Ussher et al., 2016; Vadaparampil et al., 2008).

Studies also suggested how healthcare providers' perceptions might contribute to patients' information deficits. Some providers did not discuss fertility-related matters with patients because they did not perceive it was their responsibility (King, Quinn, Vadaparampil, Gwede, et al., 2008; King, Quinn, Vadaparampil, Miree, et al., 2008; Peddie et al., 2012; Quinn et al., 2007; Ussher et al., 2016). For example, in one study, surgeons perceived that such discussions were the purview of oncologists who ostensibly have more clinical knowledge about administered treatments that posed risks to fertility (Quinn et al., 2007). Studies also suggested that healthcare providers may not initiate FP discussions if they perceived infertility risks were small, cancer therapies would not affect fertility, and/or success rates of FP technologies were low or ineffective (Peddie et al., 2012; Quinn et al., 2007). The studies also suggested that providers may hesitate to initiate FP discussions (Corney & Swinglehurst, 2014; Gorman et al., 2012; King, Quinn, Vadaparampil, Gwede, et al., 2008; King, Quinn, Vadaparampil, Miree, et al., 2008; Peddie et al., 2012; Quinn & Vadaparampil, 2009; Quinn et al., 2007; Vadaparampil et al., 2008; Yee, Abrol, et al., 2012) when or if they perceived it was not high priority for patients or if they perceived that patients' fears about diagnosis and treatment meant treatment and survival were patients' main priorities.

These issues were also reflected in women's experiences of FP discussions and decision-making. Participants reported they either received no information or inadequate information to make informed FP decisions (Armstrong et al., 2015; Ehrbar et al., 2016; Gorman et al., 2012; P.E. Hershberger et al., 2013; Niemasik et al., 2012; Penrose et al., 2012; Russell et al., 2016; Wilkes et al., 2010). For example, in some studies, women reported that they did not receive adequate and/or reliable information about FP options, infertility-related risks, or risks of cancer recurrence associated with fertility treatments (Armstrong et al., 2015; Gorman et al., 2012; P.E. Hershberger et al., 2013; P. E. Hershberger et al., 2016; Kirkman et al., 2013; Niemasik et al., 2012; Penrose et al., 2012; Wilkes et al., 2010; Yee, Abrol, et al., 2012). Studies revealed women struggled with managing conflicting information coming from multiple clinicians involved in their care. Some felt they had to choose between providers (P.E. Hershberger et al., 2013; Lee et al., 2011), and that they had to 'put [their] faith' in one provider or the other (P.E. Hershberger et al., 2013). The experience of receiving inadequate and confusing information exacerbated women's concerns about the relationship between pregnancy and cancer outcomes (P.E. Hershberger et al., 2013; Lee et al., 2011; Penrose et al., 2012). When women turned to Internet sources to supplement information received from providers, they experienced difficulty finding material relevant to their situations, and expressed concerns about reliability (P.E. Hershberger et al., 2013).

Psychosocial / Clinical Concerns

The synthesis showed that psychosocial factors such as physicians' beliefs, assumptions and clinical concerns (e.g., poor prognoses, treatment urgency) also influenced providers' practices regarding FP discussions and women's decision making (King, Quinn, Vadaparampil, Gwede, et al., 2008; Peddie et al., 2012; Quinn et al., 2007; Ussher et al., 2016; Vadaparampil et al., 2008). Providers expressed concerns about information overload and felt discussions would be challenging because patients were vulnerable at the diagnosis and pre-treatment stages and unlikely to absorb detailed FP information (King, Quinn, Vadaparampil, Gwede, et al., 2008; Peddie et al., 2012). They assumed these discussions, raised in the context of cancer diagnoses, might exacerbate patients' stress and anxiety (King, Quinn, Vadaparampil, Miree, et al., 2008; Peddie et al., 2012; Quinn, Vadaparampil, King, et al., 2009; Ussher et al., 2016). Such discussions might, for example, raise complex questions about heredity, which could influence

patients to pursue genetic testing and/or confuse and heighten anxiety and distress potentially complicating and/or delaying treatment (King, Quinn, Vadaparampil, Miree, et al., 2008).

Women expressed similar concerns. For example, women's decisions were informed by concerns about heredity and genetics (P. E. Hershberger et al., 2016), and found FP decision-making stressful (P.E. Hershberger et al., 2013; P. E. Hershberger et al., 2016; Kirkman et al., 2013; Kirkman et al., 2014; Lee et al., 2011; Peddie et al., 2012; Snyder & Tate, 2013). Women also described feeling frightened, and pressured by having to make decisions quickly ((CASP), 2013; Carty et al., 2014; M. Crawshaw, 2013; Deshpande et al., 2015; Garvelink et al., 2013; Goossens et al., 2014; P.E. Hershberger et al., 2013; Kastner et al., 2012; Kirkman et al., 2013; Kirkman et al., 2014; Lee et al., 2011; Légaré et al., 2006; Peddie et al., 2012; Quinn et al., 2008; Quinn et al., 2007; Snyder & Tate, 2013; von Elm et al., 2007). Physicians' uneasiness with treatment delays related to FP was mirrored in patients' accounts of decision-making. Studies reported that maximizing survival (Armund et al., 2015; Ehrbar et al., 2016; P. E. Hershberger et al., 2016; Peddie et al., 2012; Quinn et al., 2007), uncertain prognosis (King, Quinn, Vadaparampil, Gwede, et al., 2008; Quinn, Vadaparampil, King, et al., 2009), concerns that treatment delays might negatively impact long-term survival (Lee et al., 2011; Penrose et al., 2012; Snyder & Tate, 2013; Wilkes et al., 2010), and iatrogenic effects of FP were primary considerations in women's decisions (P. E. Hershberger et al., 2016; Lee et al., 2011; Penrose et al., 2012; Snyder & Tate, 2013; Wilkes et al., 2010). Although survival was patients' primary priority (M. A. Crawshaw et al., 2009; Ehrbar et al., 2016; Gorman et al., 2012; Keim-Malpass et al., 2013; Komatsu et al., 2014; Lee et al., 2011; Peddie et al., 2012; Penrose et al., 2012; Snyder & Tate, 2013; Wilkes et al., 2010; Yee, Abrol, et al., 2012), fertility, and correspondingly, the desire and hope of being a parent after cancer, were also important to women (Ehrbar et al., 2016; P. E. Hershberger et al., 2016; Niemasik et al., 2012; Penrose et al., 2012). Fertility was perceived as a component of femininity and central to a women's identity (Ehrbar et al., 2016; Ussher et al., 2016). Women also expressed apprehension about success rates of FP, effects of FP technologies on the health of future children, vertical transmission of cancer genes, and the potential for cancer recurrence (Ehrbar et al., 2016; Gorman et al., 2012; P. E. Hershberger et al., 2016; Komatsu et al., 2014; Niemasik et al., 2012; Wilkes et al., 2010). The latter was especially troubling for women with hormone receptive cancers considering FP options requiring ovarian stimulation (Corney & Swinglehurst, 2014).

Material, Social and Structural Factors

Lack of FP-related educational resources (King, Quinn, Vadaparampil, Gwede, et al., 2008; Quinn & Vadaparampil, 2009; Quinn et al., 2007; Quinn, Vadaparampil, King, et al., 2009; Vadaparampil et al., 2008), time (Ehrbar et al., 2016; P. E. Hershberger et al., 2016), accessibility to clinics (P. E. Hershberger et al., 2016; King, Quinn, Vadaparampil, Gwede, et al., 2008; Quinn, Vadaparampil, King, et al., 2009) costs in regions without FP coverage, (Gorman et al., 2012; King, Quinn, Vadaparampil, Gwede, et al., 2008; King, Quinn, Vadaparampil, Miree, et al., 2008; Niemasik et al., 2012; Quinn & Vadaparampil, 2009; Quinn et al., 2007; Quinn, Vadaparampil, King, et al., 2009; Snyder & Tate, 2013; Vadaparampil et al., 2008), age (King, Quinn, Vadaparampil, Gwede, et al., 2008; Peddie et al., 2012), marital/parent status (Corney & Swinglehurst, 2014; King, Quinn, Vadaparampil, Miree, et al., 2008; Lee et al., 2011; Snyder & Tate, 2013), and culture/religion (Ehrbar et al., 2016; Quinn & Vadaparampil, 2009; Quinn, Vadaparampil, King, et al., 2009; Vadaparampil et al., 2008) were identified as additional factors posing challenges to FP discussions and decisions-making. Studies reported that oncologists found FP discussions awkward in part because they had no resources to refer to, and because available resources were inappropriate for some patient population (Quinn & Vadaparampil, 2009; Vadaparampil et al., 2008). Workload and shortage of time in clinical encounters exacerbated impediments to FP discussions; healthcare providers said they did not have enough time in clinical/diagnostic consultations to discuss everything with patients (King, Quinn, Vadaparampil, Gwede, et al., 2008; Quinn et al., 2007). Likewise, women who received information about FP described feeling rushed and experienced difficulties in making decisions under constrained timelines (Kirkman et al., 2013; Lee et al., 2011). With respect to accessibility, some studies reported that there were no readily accessible FP clinics, even if oncologists wanted to provide patients with opportunities to pursue (King, Quinn, Vadaparampil, Gwede, et al., 2008; Quinn, Vadaparampil, King, et al., 2009).

The high costs of FP procedures and lack of insurance coverage in some regions, exacerbated inaccessibility to FP and served to inhibit discussions with patients (King, Quinn, Vadaparampil, Miree, et al., 2008; Quinn & Vadaparampil, 2009). Providers in these regions thought raising FP may constitute an ethical dilemma if patients could not afford it (King, Quinn, Vadaparampil, Miree, et al., 2008; Quinn & Vadaparampil, 2009; Quinn, Vadaparampil, King, et al., 2009). Notably, six provider studies from the United States identified costs as a possible

barrier to FP (King, Quinn, Vadaparampil, Gwede, et al., 2008; King, Quinn, Vadaparampil, Miree, et al., 2008; Quinn & Vadaparampil, 2009; Quinn et al., 2007; Quinn, Vadaparampil, King, et al., 2009; Vadaparampil et al., 2008) compared with only three survivor studies (Gorman et al., 2012; Niemasik et al., 2012; Snyder & Tate, 2013). Although socio-economic status, age, marital and parent status are material barriers to FP, clinicians' assumptions about patients based on these social categories represented additional hurdles (Ussher et al., 2016). These assumptions not only affected the nature and quality of information provided to patients, they resulted in exclusion of patients from decision-making. Studies reported that some younger women without (stable) partners did not receive FP counseling or were told not to not worry about reproductive risks because treatment effects would be temporary (Ehrbar et al., 2016; Niemasik et al., 2012; Penrose et al., 2012).

Along with costs, studies found age and marital status figured into whether healthcare providers discussed or referred patients for FP (King, Quinn, Vadaparampil, Gwede, et al., 2008; King, Quinn, Vadaparampil, Miree, et al., 2008; Peddie et al., 2012). For example, providers were less likely to raise FP with single women (P. E. Hershberger et al., 2016; King, Quinn, Vadaparampil, Miree, et al., 2008). These women not only experienced time pressures, but their decision-making was complicated by the FP choices available to them (Niemasik et al., 2012; Yee, Abrol, et al., 2012). "Older" women felt that physicians assumed they would no longer be interested in having children, and "younger" women felt neglected *vis-a-vis* these discussions (Niemasik et al., 2012). Women who had children felt clinicians placed less emphasis on FP (Lee et al., 2011; Niemasik et al., 2012; Quinn et al., 2007) and reported being told to be satisfied with the children they already had (Kirkman et al., 2013; Niemasik et al., 2012). Women without partners felt their concerns were not adequately addressed during FP discussions (Corney & Swinglehurst, 2014; Niemasik et al., 2012). Finally, cultural and religious beliefs played a role in FP discussions (Ehrbar et al., 2016; Quinn & Vadaparampil, 2009; Quinn, Vadaparampil, King, et al., 2009; Vadaparampil et al., 2008).

Facilitators to FP discussion & decision-making

Although not explicitly researched in most included studies, this review revealed several potential facilitators to FP discussions and decision-making. For example, patient awareness of FP, interest in avoiding future regret and maintaining a sense of control (P. E. Hershberger et al., 2016) were raised as critical drivers of FP discussions. FP discussions could also be enabled by

healthcare providers' knowledge and skills, which may be improved through educational interventions (King, Quinn, Vadaparampil, Miree, et al., 2008). Increased provider awareness and comfort with FP issues could enable proactive and open discussions with patients (Garvelink et al., 2013; Kirkman et al., 2013; Wilkes et al., 2010; Yee, Abrol, et al., 2012). Some studies alluded to the importance of avoiding assumptions about patients' fertility needs and desires based on social status characteristics (Corney & Swinglehurst, 2014; Lee et al., 2011; Niemasik et al., 2012). Patients noted their need for healthcare providers to be willing to listen to their personal values and aspirations (Kirkman et al., 2013), to be open to honest, non-judgmental communication, and to create environments that facilitate empowerment (P.E. Hershberger et al., 2013).

Research indicates that informing patients of potential infertility risks and FP options as early as possible could facilitate decision-making and improve patient experience (M. A. Crawshaw et al., 2009). However, providers felt discussions should not be at initial consultation and patients preferred that it was done at appointments separate from those related to cancer management (King, Quinn, Vadaparampil, Gwede, et al., 2008; Kirkman et al., 2013; Lee et al., 2011; Vadaparampil et al., 2008). Well-timed discussions could give patients the space to focus on understanding their diagnosis and treatment before engaging with the complexities of FP (King, Quinn, Vadaparampil, Gwede, et al., 2008; Vadaparampil et al., 2008).

Finally, informing patients of ongoing risks throughout treatment and follow up (Corney & Swinglehurst, 2014; Wilkes et al., 2010; Yee, Abrol, et al., 2012), offering suggestions for reliable internet resources, and experiential information such as support groups (Garvelink et al., 2013) might facilitate FP decision-making, improve patient experiences, and reduce regrets and distress. Indeed, a significant number of studies suggested the importance of social relationships as a key factor in FP decision-making (M. A. Crawshaw et al., 2009; Komatsu et al., 2014; Snyder & Tate, 2013; Snyder et al., 2010; Wilkes et al., 2010). Additionally, widely available (e.g. at community hospitals and cancer centers) patient educational resources, particularly low-literacy and culturally-appropriate materials (King, Quinn, Vadaparampil, Miree, et al., 2008; Vadaparampil et al., 2008) could aid provider-patient communication and education (Ehrbar et al., 2016; Ussher et al., 2016). Multidisciplinary, integrated cancer care including specialized counseling services would be beneficial to women's experience of cancer care and support FP decision-making (Hill et al., 2012). Finally, access to financial supports for FP processes could

improve accessibility to FP (P. E. Hershberger et al., 2016; King, Quinn, Vadaparampil, Miree, et al., 2008).

Discussion

This systematic review illuminates multiple inter-related factors constituting barriers and facilitators to FP discussions and decision making among women undergoing cancer treatment and health care providers. Spanning more than a decade, the research included in this qualitative review shows that, challenges in managing psychosocial, informational and structural elements of FP discussions and decision making are persistent and transcend specific approaches to FP.

This review highlights overlap between patient and providers' perceptions of challenges in FP discussions and decision-making. Psychosocial and clinical factors such as diagnosis and treatment-related distress; survivorship, FP-related iatrogenic and treatment urgency concerns; material, social, and structural factors such as single status, lack of and/or conflicting information; inaccessibility of clinics, and poor care coordination that sometimes resulted in insufficient time to make FP decisions were common concerns.

These barriers interact with each other with broader health implications. For example, the high costs of FP procedures in some health care systems (Rashedi et al., 2017) may engender erroneous assumptions about patients' socio-economic status (ability to pay) and result in information deficits for patients when physicians do not raise FP. Notwithstanding physicians' beliefs that raising FP in the context of concerns about patients' economic status presents an ethical problem, avoiding discussions has implications for patients' decision-making and long-term well-being. The potential role of FP cost as a barrier is applicable in regions that do not have insurance coverage or government funded FP programs.

In addition to overlapping concerns, the review highlights an important disconnect between patients and providers in their perceptions of what patients want or need in the way of information and advice about FP. For example, more provider- than survivor-focused studies mentioned costs as a possible barrier. Findings also suggest that assumptions about marital status, age, and other socio-demographic factors are driving providers' discussions about FP, thereby biasing clinical practice. In light of the variety of modern family systems, extended ages for childbearing, and advances in FP technologies, these assumptions need to be challenged. Equitable care would be informing all women of childbearing age who are about to undergo cancer treatment of their right to FP information and support.

Previous systematic reviews have focused on psychosocial and quality of life-related outcomes of women undergoing FP (Deshpande et al., 2015; Sobota & Ozakinci, 2014), and apart from one study (Panagiotopoulou et al., 2015) have focused solely on barriers to FP practices. Through this synthesis, we were able to validate the previous research on barriers and extend the research on facilitators that positively influence health practitioners' FP practice, such as training to increase awareness of FP practices and partners, and reduce provider bias. Further work on interventions to support FP practice and patients' understanding of FP is needed. For example, providing all patients of child-bearing age with a FP decision aid as standard practice, may help to overcome clinician barriers and patients' concerns with broaching the topic of FP. Educating health practitioners on FP support channels and appropriate referrals may address issues related to appropriate and timely care.

Further research is also needed on unique patient populations. The majority of research focuses on breast cancer patients (Corney & Swinglehurst, 2014; Hill et al., 2012; Kirkman et al., 2013; Kirkman et al., 2014; Lee et al., 2011; Snyder & Tate, 2013; Snyder et al., 2010), and more research is needed for women with gynecologic and hematologic malignancies, as these groups have unique FP needs and challenges. Only one study considered LGBTQ populations or sexual orientation in FP (Russell et al., 2016), and few studies mentioned moral and ethical challenges pertaining to the cost and type of FP, among others. Again, these issues point to FP knowledge/skills deficits for healthcare providers and complicating factors for some women.

The review suggests the need for primary research that explicitly addresses experiences of providers in smaller centers and community settings where literature suggests access to FP resources and FP knowledge / skills may vary (Clayman, Harper, Quinn, Reinecke, & Shah, 2013). The ongoing efforts by professional organizations such as ASCO, the National Comprehensive Cancer Network, and the Oncofertility Consortium, to develop resources and training programs to improve knowledge related to FP for patients and professionals are worth noting here. Finally, there was an under-representation of health professionals such as nurses and social workers in our final sample of studies. Research on these healthcare providers could shed further light on facilitators to FP decision-making.

Strengths and Limitations

The review was strengthened by the focus on qualitative data and its analytic approach to provide in-depth understanding of factors supporting or limiting FP discussion and decision-

making, as well as its comparison of patient and provider perspectives. The review was limited by the search criteria and focus on women only. However, we focused on this group because of the complex and unstandardized approaches to FP available to women compared to men. Unlike previous review articles (M. Crawshaw, 2013; Quinn et al., 2008), we included all studies of women of child-bearing age to gain a diversity of perspectives and a more thorough understanding of FP issues in the context of cancer treatment. Although we performed a systematic literature search, qualitative articles are not well-indexed so some eligible studies may have been missed. We included only studies published in English and there may be pertinent research findings published in other languages.

Conclusion

The review findings highlight overlap in perceived barriers between healthcare providers and patients in FP discussion and decision making. Findings suggest that even as FP methods advance, deficits in information, knowledge sharing and skills, structural, material and social barriers and psychosocial and clinical concerns all play into decisions about whether and how to discuss FP and subsequent FP decisions. Findings suggest that interventions aimed at these areas of concern, in addition to ongoing developments in FP technology are needed to improve patient and provider discussions and decision-making. Multi-level policy and practice approaches to improve training, access to FP services and knowledge translation plans including strategies for information sharing are needed to support FP discussions as standard practice in oncology.

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Figure Legends

Figure 1. PRISMA diagram of included articles.

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Table 1. Characteristics of included studies reporting barriers that influence fertility preservation decision-making.

Author Year Location	Method; Study design; Data collection	Patient Perspective					Provider Perspective	
		n	Sex	Age [†] at Dx	Age [†] at Study	Cancer	n	Specialty
Crawshaw ⁴⁴ 2009 UK	Qualitative; cross-sectional; interviews	38	B	15.9	21.5	Not limited	-	-
Snyder ³⁹ 2010 USA	Qualitative; cross-sectional; interviews	52	F	32.4	34.8	Breast	-	-
Wilkes ³⁵ 2010 UK	Qualitative; cross-sectional; interviews	18	B	21.8	35.6	Not limited	-	-
Lee ³⁰ 2011 UK	Qualitative; cross-sectional; interviews	24	F	< 40	23-39	Breast	-	-
Gorman ⁵⁵ 2012 USA	Qualitative; cross-sectional; focus groups	22	F	16.8	18-34	Not limited	-	-
Hill 2012 Canada ⁵⁴	Mixed methods; cross-sectional; questionnaire	27	F	30.7	30.7	Breast	-	-
Penrose 2012 Australia ³⁴	Qualitative; cross-sectional; interviews	25	B	38.8	38.8	Not limited	-	-
Niemasik ⁵² 2012 USA	Mixed methods; cross-sectional; questionnaire	1,041	F	31.8	41.3	Leukemia, HL NHL, Breast, GI	-	-
Keim-Malpass ⁴³ 2013 USA	Qualitative; phenomenological analysis of internet blogs	16	F	31.7	NR	Not limited	-	-

Author Year Location	Method; Study design; Data collection	Patient Perspective					Provider Perspective	
		n	Sex	Age [†] at Dx	Age [†] at Study	Cancer	n	Specialty
Garvelink ⁴² 2013 Netherlands	Qualitative; cross-sectional; interviews	34	F	21-40	22-41	Not limited	-	-
Yee ⁵³ 2013 Canada	Mixed methods; cross-sectional; questionnaire	41	F	33.1	NR	Not limited	-	-
Hershberger 2013 USA ³⁸	Qualitative; cross-sectional; interviews	27	F	NR	28.7	Not limited	-	-
Kirkman 2013 Australia ³¹	Qualitative; cross-sectional; interviews	10	F	31.4	35.7	Breast	-	-
Snyder ²⁸ 2013 U	Qualitative; cross-sectional;							
Kirkman ⁴¹ 2014 Australia	Qualitative; cross-sectional; interviews	10	F	31.4	35.7	Breast	-	-
Komatsu ³³ 2014 Japan	Qualitative; cross-sectional; interviews	15	F	NR	31.6	Cervical	-	-
Corney ³² 2014 UK	Qualitative; cross-sectional; interviews	19	F	30.1	24-44	Breast	-	-
Armund ⁴⁷ 2015 Sweden	Qualitative; cross-sectional; interviews	21	B	32.5	20-45	Not limited	-	-
Ehrbar ⁴⁸ 2016 Switzerland	Qualitative; cross-sectional; focus group	12	F	NR	36.3	Not limited	-	-
Hershberger ⁴⁵	Qualitative; cross-sectional;	27	F	NR	19-40	Not limited	-	-

Table 1. Characteristics of included studies reporting barriers that influence fertility preservation decision-making (continued).

Author Year Location	Method; Study design; Data collection	Patient Perspective					Provider Perspective	
		n	Sex	Age [†] at Dx	Age [†] at Study	Cancer	n	Specialty
2016 USA	interviews							
M. Russell ⁵¹ 2016 USA	Qualitative; cross-sectional; interviews	56	B	26.6	32.5	Not limited	-	-
Quinn ²⁷ 2007 USA	Qualitative; cross-sectional; interviews	-	-	-	-	-	16	Oncologists ¹
King ⁴⁹ 2008 USA	Qualitative; cross-sectional; interviews and focus groups	-	-	-	-	-	36	Oncology nurses ¹
King ⁵⁰ 2008 USA	Qualitative; cross-sectional; interviews and focus group	-	-	-	-	-	7	Oncology social workers ¹
Vadaparampil ³⁷ 2008 USA	Qualitative; cross-sectional; interviews	-	-	-	-	-	24	Pediatric Oncologists ²
Quinn ³⁶ 2009 USA	Qualitative; cross-sectional; interviews	-	-	-	-	-	54	Oncologists ²
Quinn ⁴⁰ 2009 USA	Qualitative; cross-sectional; interviews	-	-	-	-	-	24	Pediatric Oncologists ²
Peddie ²⁹ 2012 UK	Qualitative; cross-sectional; interviews	34	B	NR	30.5	Not limited	15	Cancer care professionals ¹
Ussher 2016 Australia ⁴⁶	Mixed methods; cross-sectional; survey and interviews	-	-	-	-	-	Survey-263 Interviews- 49	Cancer care professionals ²

Abbreviations: Dx, diagnosis; F, female; B, both; NR, not reported; HL, Hodgkin lymphoma; NHL, non-Hodgkin lymphoma; GI, gastrointestinal.

[†]Reported as mean age if available from primary study, otherwise reported as age range.

¹Single-centre, ²multi-centre participant recruitment.

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