Published in final edited form as:
Psychooncology. 2017 January ; 26(1): 4–14. doi:10.1002/pon.4092.

Healthcare Professionals' Views on Discussing Fertility Preservation with Young Cancer Patients: A Mixed Method Systematic Review of the Literature

Cecilia Vindrola-Padros[1], **Karen E. Dyer**[2], **John Cyrus**[3], and **Irene Machowa Lubker**[3]

[1]Department of Applied Health Research, University College London, London, United Kingdom

[2]Department of Health Behavior and Policy, Virginia Commonwealth University, Richmond, VA, United States of America

[3] Tompkins-McCaw Library, Virginia Commonwealth University Libraries, Richmond, VA, United States of America

Abstract

Objective—In spite of efforts to guarantee that patients are adequately informed about their risk of fertility loss and offered treatment for fertility preservation (FP), previous studies have reported that this topic is not routinely discussed with patients, especially with younger patient populations. A mixed method systematic review was undertaken to explore the factors shaping the discussion of FP with children (0-15 years) and adolescents/young adults (16-24 years) with cancer.

Methods—Six databases were searched independently using a combination of keywords and controlled vocabulary/subject headings relating to cancer and fertility. Inclusion criteria consisted of: 1) being published in a peer-reviewed journal; 2) a focus on healthcare professionals' (HCPs') beliefs, attitudes or practices regarding fertility issues in cancer patients; 3) primary data collection from HCPs; and 4) a focus on HCPs who provide services to young patients. Of the 6276 articles identified in the search, 16 articles presenting the results of 14 studies were included in the final review.

Results—Common themes reported across studies indicate that five main factors influence HCPs' discussion of FP with young cancer patients: 1) HCPs' knowledge; 2) HCPs' sense of comfort; 3) Patient factors (i.e., sexual maturity, prognosis, partnership status, and whether or not they initiate the conversation); 4) Parent factors (i.e., HCPs' perception of the extent of their involvement); and 5) Availability of educational materials.

Conclusions—Future work should ensure that HCPs possess knowledge of cancer-related FP and that they receive adequate training on how to consent and discuss information with young patients and their parents.

Corresponding author Dr Cecilia Vindrola-Padros, Department of Applied Health Research, University College London (UCL), 1-19 Torrington Place, London, WC1E 7HB, United Kingdom, c.vindrola@ucl.ac.uk, Tel: +44 (0)20 3108 3232.

CONFLICT OF INTEREST
The authors declare no conflicts of interest.

ETHICS
No ethics approval was required as this is a systematic review.

Keywords

cancer; fertility; oncology; young patient; healthcare professionals; systematic review

INTRODUCTION

A significant amount of the work carried out by healthcare professionals (HCPs) caring for cancer patients involves helping patients manage the long-term effects of treatment. One of the most common of these effects in young people is temporary or permanent fertility loss. The extent of the impact on an individual's reproductive capabilities depends upon the type of cancer, the age of the patient, and the specific therapies administered (1,2). Fertility loss can have devastating emotional consequences for patients and can create a strain on their social relationships and disrupt their plans for the future (3).

At the same time, a subset of assisted reproductive technologies (ARTs), termed "fertility preservation," has become available in recent decades and offers newly diagnosed individuals the option of freezing their reproductive gametes and tissues (i.e., sperm, eggs, embryos, ovarian tissue, or testicular tissue) before treatment begins (4). After treatment, those materials can be accessed to create a genetically-related pregnancy using in vitro fertilization (IVF) or other methods (5). Guidelines have been put in place in different countries to ensure that patients are adequately informed of their risk of fertility loss and are offered treatment for fertility preservation (FP) if available (1). Professional organizations have highlighted healthcare professionals' duty to identify patients at risk, disclose the necessary information, provide referrals to specialists, or offer available treatments (6,7).

In spite of these guidelines and general awareness among healthcare professionals of the consequences of cancer treatment on fertility, several studies have indicated that this topic is not widely or routinely discussed with patients (7-9). Previous research has found that healthcare professionals fail to carry out these discussions due to their lack of knowledge about fertility preservation procedures, guidelines, facilities, costs, and educational materials for patients designed to facilitate the discussion (10-12). Other factors identified as barriers are embarrassment, beliefs about the efficacy of fertility preservation procedures and the degree to which they will delay cancer treatment, or the fact that they might not consider these discussions to be part of their professional role (13,14). HCPs' decision to discuss fertility loss and options for fertility preservation is also influenced by patient factors such as their prognosis, partnership status, sexual orientation, financial capacity, cultural background, age, ability to cope with the diagnosis, and insurance coverage (15). HCP communication factors are important because the type and method of discussion about fertility preservation plays a critical role in patient decision-making and follow-through (16). Furthermore, institutional factors play a role in the uptake of fertility preservation, such as the availability of fertility specialists and facilities (17,18).

In the case of young patient populations such as children, adolescents, and young adults, previous research has indicated that additional factors might play a role in healthcare professionals' ability and willingness to discuss their risk of fertility loss and the fertility preservation procedures available to them. Current guidelines such as ASCO and the NCCN

Clinical Practice Guidelines in Oncology for Adolescent and Young Adult Oncology have only recently recommended that HCPs provide information on fertility preservation to all post-pubertal young patients before their treatment begins (19). In the case of pre-pubertal girls and boys, most fertility preservation procedures are still experimental, so healthcare professionals might not initiate discussions on fertility loss because they cannot provide patients with fertility preservation options (20-22). Fertility preservation is a sensitive topic to discuss with this patient population as it involves talking about bodily changes and sexual practices (such as masturbation and sexual activity) and making assumptions about the sexual maturity of the patient (23). These discussions are further complicated by the fact that, in some cases, parents might want or need to be involved. This means that healthcare professionals need to be knowledgeable of the legal rights and responsibilities of all parties in order to make decisions on who to involve in conversations on this topic and how these conversations should be carried out (23-25). Furthermore, the level of involvement of parents might vary according to the child’s age or their sense of autonomy, making the strategies used with pediatric patients unsuitable for addressing the same issue with adolescents and young adults (25).

Research with children, adolescents, and young adults has indicated that reproductive health is an area of concern for this patient population (26,27) and many young patients are dissatisfied with the way information on fertility is communicated to them by healthcare professionals (28). In light of the unique needs of this population relating to age and life stage, this systematic review was designed to explore the factors shaping HCP discussion of FP with children, adolescents, and young adults with cancer. It includes studies that collected primary data directly from healthcare professionals with the purpose of identifying factors that might act as barriers or enablers in the communication of information on fertility loss and preservation to young patients.

To our knowledge, this is the first systematic review on HCP’s discussion of fertility preservation with children, adolescents, young adults, and their families. Previous systematic reviews on fertility preservation have mainly focused on patients’ views or include healthcare professionals’ experiences as a small part of larger reviews (3,29-31). In cases where these reviews do report on studies documenting healthcare professionals’ views, they only include five (3) or six studies (30) and do not distinguish between different patient age groups.

METHODS

Search Strategy

The authors, two social scientists (CVP and KD) and two medical research librarians (JC and IL), conducted a review of published literature using multiple databases in January 2014: PubMed, Web of Science, PsycINFO, CINAHL, Social Science Abstracts and POPLINE. A second search was conducted in December 2014 to update the content. The search used a combination of keywords and controlled vocabulary/subject headings for the concepts of cancer and fertility where appropriate (Appendix 1). Results were combined into RefWorks, and duplicates were removed. The reference lists of included articles were screened to identify additional relevant publications. Grey literature was not included in the review. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement and AMSTAR were used to guide the review (32,33). A review protocol was developed for internal use, but it has not been published.

Study Selection

Two authors (CVP and KD) screened the articles in three phases (title and article type, abstract, and full text) based on the following inclusion criteria: 1) published in a peer-reviewed journal; 2) focused on HCPs' beliefs, attitudes or practices regarding fertility issues in cancer patients; 3) involved primary data collection from HCPs; and 4) focused on HCPs who provide services to young cancer patients under the age of 24. Young cancer patients were defined as either children (0-15 years) or young people (16 to 24 years). We based this definition of young cancer patient on the latest guidance issued by the National Institute for Health and Care Excellence (NICE) which aims to set care standards across the UK (NICE 2014). We did not limit the selection of studies by research design and included quantitative, qualitative, and mixed-methods studies.

Data Extraction

The included articles were analyzed using a data extraction form developed in RedCap (Research Electronic Data Capture) (34). The categories used in the data extraction form are summarized in Appendix 2. The form was developed after the initial screening of full-text articles. It was then piloted independently by two researchers (CVP and KD) using a random sample of five articles. Disagreements between them were discussed until consensus was reached. The form was refined based on the findings from the pilot.

Quality Assessment

The methodological quality of all studies was critically appraised using the Mixed Methods Appraisal Tool (MMAT) (35-37). The MMAT was developed to allow systematic reviewers to assess the methodological quality of diverse study designs, including qualitative, quantitative, and mixed methods. It is content validated and has been used in more than 50 published systematic reviews to date (37). Following Souto et al. (37) and Pace et al. (35), two of the authors independently reviewed each study to assess methodological quality. They then discussed responses and inter-rater reliability was estimated pre- and post-discussion using the kappa statistic (k) (Landis and Koch 1977) in which $k < 0$ (poor agreement); $k = 0$-0.20 (slight agreement); $k = 0.21$-0.40 (fair agreement); $k = 0.41$-0.60 moderate agreement; $k = 0.61$-0.80 (substantial agreement); and $k = 0.81$-1.00 (near-perfect agreement).

RESULTS

Identification of Studies

The initial search yielded 5894 published articles (343 from CINAHL, 122 from PsycINFO, 4495 from PubMed, 5 from Social Science Abstracts, and 929 from Web of Science). These were screened based on title and type of article, resulting in 469 (Figure 1). Screening based on abstracts left 72 articles for full-text review. This phase in screening led to 14 articles that presented the results of 13 studies. Prior to publication of this review, a final search was conducted for articles published through December 2014. The same procedures used in the first search were followed, resulting in a total of 383 additional articles. Screening based on title and type resulted in nine articles, while screening by abstract led to three. Full-text review led to the inclusion of two articles. Thus, the final review included 16 articles representing 14 studies out of a total of 6276 published articles.

We excluded articles that only mapped available clinic services as well as retrospective chart reviews, case studies, conference abstracts, literature reviews, editorials, and commentaries because they did not collect primary data directly from healthcare professionals. No limits to language or date of publication were applied to the search.

Study Characteristics

The characteristics of the 14 studies included in the review are presented in Table 1. Most studies were conducted in North America (9) or Western Europe (4), specifically the USA (8), United Kingdom (2), Canada (1), and the Netherlands (2). One study took place in Australia.

The majority of studies had quantitative designs (8), while 5 were qualitative and one used a mixed methods design. By far the most common quantitative data collection method was the self-administered, close-ended questionnaire (7) or sections of questionnaires (1, in the case of the mixed methods study). Qualitative methods included interviews (4) and open-ended surveys (1) or sections of surveys (1, in the case of the mixed-methods study).

Oncologists were participants in the majority of studies (11). Other populations included nurses/nurse practitioners (6) radiation oncologists (2), and allied healthcare workers (1). One study also surveyed parents in addition to the healthcare professionals.

Quality Assessment

The studies used different types of designs, data collection methods, and analysis techniques. The results from the quality assessment are presented in Table 2. Inter-rater agreement between the two raters was 96.7%, with a Cohen’s Kappa indicating near-perfect agreement ($k = 0.88$; $p < 0.001$; 95% CI). Disagreements between the raters were generally related to two components in the qualitative studies appraisal section, in which raters are asked to evaluate authors’ consideration of how findings relate to the study context or to the researchers’ influence.

Findings: Factors Affecting the Discussion of Fertility Preservation with Children and Young People

The studies included in this review pointed to a wide range of factors playing a role in healthcare professionals’ discussion of fertility preservation with children, young people, and their families. We grouped the most common ones in five main categories: 1) knowledge, 2) sense of comfort, 3) patient factors, 4) parent factors, and 5) availability of educational materials. Table 3 summarizes these main findings.

Knowledge

Knowledge was identified by healthcare professionals in all studies as one of the main factors affecting the discussion of fertility preservation with children and young people. Three studies found a high level of awareness among healthcare professionals of the effects of cancer treatment on fertility and fertility preservation options (20,22,38). However, gaps in knowledge were found in relation to existing guidelines (17,21,25,39), fertility preservation procedures (22,25,38,40-42), costs (41,43), fertility facilities and specialists (38,43), educational materials for patients (25,44), how to carry out the informed consent process with young people and parents (24), and how to have general discussions on this topic with this particular patient population (25). Four studies found differences in professionals' knowledge of fertility preservation procedures in relation to gender, concluding that knowledge on the options available for girls and young women are less known (21,22,38,45).

Sense of comfort

In four studies, healthcare professionals reported embarrassment discussing the topic of fertility preservation with children, young people, and/or their parents (24,25,42,44,45). Embarrassment was linked to the fear of introducing a topic of discussion that might not be considered “appropriate” for the age or sexual maturity of the patient (45). Healthcare professionals did not feel comfortable asking the young person questions about their sexual practices, such as masturbation or if they were sexually active (40), either in private or in front of their parents (42). They also expressed concerns about suggesting the use of fertility preservation procedures, such as sperm banking, which could require the use of erotic materials (44).

Patient factors

Healthcare professionals were less likely to initiate discussions on fertility preservation with young patients if they had a negative prognosis (17,39,43,44), were HIV positive (41,43,44), could not afford treatment costs (20,21,25,39,43), or were considered too young (20). Eight studies found that healthcare professionals expressed doubts on how to carry out conversations on fertility preservation with young patients, who should be involved and when these conversations should happen. The healthcare professionals interviewed by DeVries et al. (23) reported always wanting to have a separate conversation with the adolescent patients on sperm banking. Similarly, the study carried out by Vadaparampil et al. (45) highlighted that HCPs thought it was the young patient's right to be involved in conversations concerning their fertility. Three studies found that HCPs were more likely to discuss the topic if the patient brought it up (41,43,44).

Parent factors

Ten studies touched on issues related to the role of parents during discussions on fertility preservation. In most cases, healthcare professionals believed there were instances where parents' opinions contradicted those of the young patient. This raised ethical concerns regarding the degree to which they should be involved in conversations about the young patient's fertility preservation. Three studies indicated that parents' ability to make appropriate decisions could be potentially compromised by the anxiety produced by coping with their child's cancer (17) and their desire to limit delays in their child's medical treatment (sometimes at the expense of minimizing the long-term effects of treatment such as fertility loss) (25,45). Their presence during these conversations also created embarrassment for the young patient and the parent, and healthcare professionals felt that discussion of this topic could produce additional distress for families (17,25,39,42,45). In some cases, healthcare professionals believed that parents limited young people's ability to make fully informed decisions on the preservation of their fertility by filtering the information they received from healthcare professionals (23). As a result, two studies questioned if parents should be involved in conversations about the young patient's fertility preservation (24,25) and three studies found that healthcare professionals did not feel it was necessary to have parental consent to discuss this matter with the patient, even if he or she was under the age of 18 (17,41,43).

Educational resources for patients and families

Seven studies found that healthcare professionals reported not having adequate educational material to distribute to patients during fertility preservation discussions (22,40-45). In two of these studies, healthcare professionals indicated they would be more likely to discuss this topic with their patients if they had these types of materials at their disposal (41,43).

DISCUSSION

This systematic review identified a range of factors across studies that play a role in HCPs' discussion of fertility preservation with young patients and their families. We found that HCPs had general awareness of the risk of fertility loss produced by cancer treatment, but gaps in knowledge were identified in particular areas, specifically: the suitability of certain procedures for young patients, the steps involved in carrying out FP procedures (particularly sperm banking), practice guidelines, and the availability of suitable educational materials to hand out to patients and their families. In one study, the topic of potential fertility risk was not even discussed because the patient was considered too young for the available fertility preservation options (20). Authors highlighted gaps in knowledge as a source of concern because they led to misconceptions about which patients were suitable for FP procedures, created barriers in the transmission of information from HCP to the young patient and family, and ultimately affected young people's capacity to make informed decisions about their treatment and quality of life (38,42,43).

One of the important findings of this review was the lack of knowledge reported by HCPs on the fertility preservation options available for girls and young women. This issue coincides with findings from a recent study of the fertility information needs of teenagers and young adults with cancer where female patients reported problems with and even lack of sharing of information on fertility by HCPs (31). In several cases, it was up to the female patients to raise the issue for discussion (31).

HCPs' sense of comfort was also an important factor influencing their willingness and ability to discuss the topic. When HCPs reported embarrassment or discomfort discussing the topic with the young patient and/or parent, they were less likely to do so. Some studies with adult patients have identified "embarrassment" as a potential barrier in the communication of information on FP to patients (39). In the case of children and young people, embarrassment was mainly produced by the fact that talking about FP entails asking questions about the young person's sexual practices, sometimes in front of their parents. Discussions about FP also touch on the young person's future childbearing plans, an issue that patients and parents may not have yet contemplated (17).

Discussions about FP with young people are also shaped by the HCPs' perception of who should be involved in these conversations. The decision to involve children, adolescents, and young adults is dependent upon HCPs' views on the level of autonomy that should be afforded to young people. Several of the studies included in this review pointed to HCPs' belief that young people should be included in conversations and decision-making about their fertility and should be given the opportunity to discuss these issues with HCPs regardless of their parents' opinions or wishes (17,23). Our review also pointed to the need to consider the diversity within this patient population and acknowledge the fact that the communication strategies used in pediatric settings might not be suitable for adolescents and young adults (25). Discussions on fertility risk and preservation options, therefore, need to be tailored to the particular characteristics of the young patient, where information is shared openly and honestly (46), but sensitively. This is especially relevant for the case of adolescent and young adult patients who, as Quinn and Vadaparampil have argued, "are not quite pediatric patients but not yet legal adults" (25).

The findings from this review point to a potential facilitator of open discussions about FP between HCPs and young patients: the development and widespread dissemination of educational materials on FP specifically tailored for children, adolescents, young adults, and their families. Previous work on the development of educational materials for AYA populations on sperm banking has indicated that these materials can help address HCPs' knowledge gaps, reduce discomfort when discussing the topic and empower patients to ask questions about their risk of fertility loss and procedures available for fertility preservation (47).

Findings from this review should be interpreted with its limitations in mind. The literature search was initially carried out in January 2014 and updated in December 2014, but any articles published after this date were not included. Furthermore, although we used multiple broad search terms, it is possible that we missed articles that did not use these terms. The review focused on published articles, leaving out potentially relevant sources in the grey literature. The reviewed studies covered a wide range of designs and methodologies, making it difficult to draw general conclusions. The quality assessment of the studies included in the review pointed to evident inconsistencies in reporting information on the reasons why eligible participants chose not to take part in the study, how findings relate to the context in which data are collected, and how findings relate to the researchers' influence. Most studies did not specify the ages of the patients the healthcare professionals cared for, making it difficult to identify differences in the factors affecting the discussion of fertility preservation with child, adolescent, and young adult patients.

CONCLUSIONS

This review has indicated that even though attempts have been made to encourage HCPs to openly discuss fertility issues with young cancer patients, important factors exist that determine if and how this discussion takes place. Research with adolescents and young adults has indicated that open communication is a critical component of their treatment, as it promotes concordance and is linked to more positive treatment experiences (48-50). Open communication involves several factors: providing information directly to the patient, allowing time for cognitive processing and question-asking, delivering information in **a** caring manner, and providing the patient with age-appropriate educational materials (51). Future work needs to be undertaken with HCPs to ensure they have knowledge of fertility preservation during cancer treatment (including procedures, costs, and the availability of age-appropriate educational materials), and that they receive adequate training on how to consent and discuss information with young patients and their parents (52).

Acknowledgments

Funding

Karen E. Dyer received funding from the National Cancer Institute R25-CA093423-07 (Training Program in Behavioral and Health Services Cancer Control Research).

APPENDIX 1

Sample Keywords and Controlled Vocabulary/Subject Headings Used in Search

Sample search strategy for PubMed / MEDLINE
("fertility"[MeSH] OR "infertility"[MeSH] OR "fertility preservation"[MeSH] OR "reproductive health"[MeSH] OR "fertility preservation"[MeSH Terms] OR "reproductive health"[MeSH Terms] OR "fertility preservation"[tiab] OR "fertility preserving"[tiab] OR oncofertility OR fertil*[tiab] OR infertil*[tiab] OR sterility[tiab] OR (egg[tiab] AND freez*[tiab]) OR (sperm[tiab] AND bank*[tiab]) OR (embryo[tiab] AND freez*[tiab]) OR (ovar*[tiab] AND tissue[tiab] AND freez*[tiab]) OR ((testic*[tiab] OR testes[tiab]) AND tissue[tiab] AND freez*[tiab]))
AND (cancer[tiab] OR neoplasm[tiab] OR "neoplasms"[MeSH] OR "radiotherapy"[MeSH] OR "antineoplastic agents"[MeSH] OR "antineoplastic combined chemotherapy protocols"[MeSH] OR "radiation injuries"[MeSH])
AND (teen[tiab] OR adolescent[tiab] OR child[tiab] OR "young adult"[tiab] OR young*[tiab] OR childhood[tiab] OR infant[MeSH] OR child[MeSH] OR adolescent[MeSH] OR young adult[MeSH])

APPENDIX 2

Categories Used in the Data Extraction Form (Selected Items)

Fields Used in RedCap Data Extraction Form	**Response Boxes**
Country where the study took place	
Participants (HCP specialty)	Oncologists Surgeons Hematologists Doctors (not specified) Radiation oncologists GYN Nurses Other
Definition of young patient (age range)	

Fields Used in RedCap Data Extraction Form	**Response Boxes**
Study design	Quantitative Qualitative Mixed-methods
Qualitative research methods	Interviews Questionnaires Observations Focus groups Medical chart review Other
Quantitative research methods	Online surveys Telephone surveys Face-to-face surveys Mailed surveys Clinical measures Other
Reasons for not communicating information or referring patient	Uncertain prognosis Clinical features of the cancer Type of treatment Patient is too old Patient is too young Patient marital or family characteristics Patient’s Fatherhood or motherhood goals Patient’s positive outlook Not part of the HCP’s professional role FPT would delay treatment Lack of HCP knowledge about FP options Attitude (low priority) Attitude (willingness to discuss) Financial issues/too expensive Not covered by insurance Lack of information on where to refer patient Difficulty explaining information Embarrassment or uncomfortable discussing Sexual orientation Patient ethnicity/cultural beliefs Patient information overload Fertility will be restored Lack of guidelines Ethical issues (what happens if the patient dies?) Beliefs about the efficacy of FPT Other patient-related factors Institutional/structural factors Other
Reasons why HCPs felt patient would not choose a FPT	Patient’s views on their family Patient’s outlook on life Financial issues Ethnicity/cultural beliefs Uncertain prognosis Sexual orientation Other
Tools that help HCPs in disclosure and/or referral	Fertility expert in MDTs Information or decision aid for patients Clear referral guidelines Information on FP part of routine practice Information on FP is provided multiple times (not just at diagnosis) Other
Percentage of HCPs that discuss FP with patient	
Type of HCP knowledge assessed	Practice guidelines Fertility preservation procedures Fertility clinics Referral processes Resources for patients (education, financial) Where information can be found Risk of infertility produced by the treatment Other

Fields Used in RedCap Data Extraction Form	**Response Boxes**
Information sources for HCPs	Scientific literature Professional guidelines Discussions with fertility specialists Own clinical experience Continuing education programs Patient education materials Other
What does current practice entail?	Provision of oral information Provision of written information Patient-nurse conversations Patient-doctor conversations Discussion in MDT meetings Request of input from fertility specialists Use of guidelines FP not discussed Other
Recommendations for changes in practice/guidelines	
Limitation identified in article	

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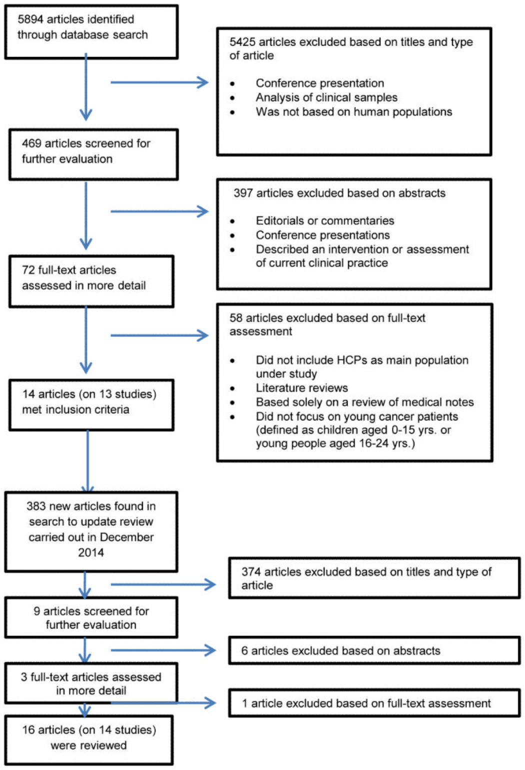

Figure 1.

Study Selection Procedure

Table 1

Studies Included in the Review

Authors	**Country**	**Study Design**	**Population**	**Data Collection Methods**	**Factors playing a role in the discussion of FP**
Anderson et al. (2008)	UK	Quantitative	Oncologists for 1030 new patients (exact number of oncologists not reported)	Data sheet filled out for each new patient registered	*Patient factors*: age, gender
Clayton et al. (2008)	USA	Quantitative	210 pediatric oncology nurses	Self-administered questionnaires	*Patient factors*: marital status, have children
Crawshaw et al. (2004)	UK	Qualitative	22 doctors, nurses, scientists and social workers working in assisted conception or pediatric oncology	Semi-structured interviews	Sense of comfort Knowledge of consenting pediatric patients
De Vries et al. (2009)	Netherlands	Qualitative	14 pediatric oncology physicians; 15 parents of male adolescent cancer patients	Semi-structured interviews	*Parent factors*: parental role and degree of involvement of the young person
Goodwin et al. (2007)	USA	Quantitative	16 pediatric oncology physicians, 14 nurses or nurse practitioners	Self-administered questionnaires	Knowledge of the effects of treatment *Patient factors*: timing of treatment
Kohler et al. (2011)	USA	Quantitative	209 pediatric oncology specialists (93% pediatric oncologists, 3% nurse or nurse practitioners, 1% reproductive endocrinologists, 3% other)	Online questionnaires	Knowledge of guidelines *Patient factors*: gender
Nagel & Neal (2008)	Canada	Qualitative	17 oncology nurses and 3 reproductive health nurses	Open-ended, self-administered questionnaire	Sense of comfort Knowledge of process and consequences of treatment Availability of educational resources for patients
Overbeek et al. (2014)	Netherlands	Quantitative	37 pediatric oncologists	Mailed survey	Knowledge of FP options *Patient factors:* prognosis, distress Availability of educational materials to counsel patients
Quinn et al. (2009a)*	USA	Qualitative	Pooled data from 2 studies: 26 pediatric oncologists and 28 adult oncologists	Semi-structured interviews	Knowledge of FP options *Patient factors*: perception of distress, prognosis *Parent factors*: perception of distress
Reebals, Brown & Bruckner (2006)	USA	Quantitative	27 nurses and nurse practitioners caring for male adolescent cancer patients	Self-administered questionnaires	Knowledge of FP procedure
Schover et al. (2002)*	USA	Quantitative	162 oncology physicians and fellows (63% medical oncologists, 21% surgical oncologists, and 16% radiation oncologists)	Mailed questionnaires	Knowledge of FP procedure Knowledge of costs *Parent factors*: involvement in the consent process *Patient factors*: involvement in the consent/assent process
Thompson, Holland, & Joubert (2013)	Australia	Mixed methods	60 oncology professionals (15 allied health workers, 32 nurses, 6 oncologists, 7 from	Questionnaire with close-ended and open-ended questions	Sense of comfort Knowledge of fertility preservation

Authors	**Country**	**Study Design**	**Population**	**Data Collection Methods**	**Factors playing a role in the discussion of FP**
			Victoria AYA Cancer Service)		*Parent factors*: Involvement of parents in the consent process Availability of educational materials
Vadaparampil et al. (2007) Vadaparampil et al. (2008b)	USA	Quantitative	115 pediatric oncology nurses	Self-administered questionnaires	Sense of comfort *Patient factors*: HIV status, marital/partnership status, patient initiated conversation, sexual maturity, prognosis, timing of treatment *Parent factors*: interest in the topic Availability of educational materials
Vadaparampil et al. (2008a) Quinn et al. (2009b)	USA	Qualitative	24 pediatric hematologists/oncologists	Semi-structured interviews	Sense of comfort Knowledge of how to have discussions with young people *Patient factors*: cultural background, receptiveness, age, insurance *Parent factors*: receptiveness and cultural background Availability of educational resources

[*] This article includes data from HCPs treating both adult and young patients. It was included in this review because it discusses the specific factors influencing the discussion of fertility preservation with children and young people.

Table 2

Quality assessment

STUDY	MMAT Score
Quantitative	
Anderson (2008)	****
Clayton (2008)	****
Goodwin (2007)	***
Kohler (2011)	**
Overbeek (2014)	***
Reebals (2006)	**
Schover (2002)	***
Vadaparampil et al. (2007; 2008b)	****
Qualitative	
Crawshaw (2004)	** (lower) *** (higher)
De Vries (2009)	** (lower) *** (higher)
Nagel (2008)	***
Quinn et al. (2009a)	**
Quinn et al. (2009b); Vadaparampil et al. (2008a)	****
Mixed Methods	
Thompson (2013)	***

Table 3

Summary of main findings

Factor	Main findings
Knowledge	Knowledge gaps were found in relation to: • Guidelines • Fertility procedures (especially options for girls and young women) • Costs • Facilities and specialists • Educational materials • Discussions with young patients • Informed consent process
Sense of comfort	HCPs reported feeling embarrassed about discussing the topic with young people and their parents. Sense of comfort was associated with: • HCPs' knowledge • Cultural/language barriers • HCPs' perception of patient's and parent's distress • Success rate of FP procedure • Cost of FP procedure • Parents' presence in the discussion • Closeness in age to the patient
Patient factors	Patient factors associated with discussing the topic included: • Prognosis • HIV status • Cost • Age
Parent factors	HCPs' views on the inclusion of parents in conversations on fertility preservation varied, but, in most cases, HCPs believed young patients' preferences should be prioritized
Educational resources for patients and families	Lack of educational material (or knowledge of where to find it) was a reported barrier in discussing this topic with young patients and their parents