Gatekeepers for infertility treatment? Views of ART providers concerning referrals by non-ART providers

Robert Klitzman

Columbia University, New York, NY, USA

Abstract Many patients who might benefit from treatment using assisted reproductive technology (ART) do not receive it, raising critical questions of why, and how best to overcome existing barriers. In-depth interviews of approximately 1 h each were conducted with 27 ART providers (17 physicians and 10 other healthcare providers). These interviewees suggest that non-ART providers may serve as gatekeepers in a complex system, involving not only individual-level, but also dyadic and institutional, processes and factors related to provider–patient relationships. Differences emerge concerning ‘who’ refers patients for ART (e.g. what types of provider), ‘how’ (amount, type and specificity of information offered), ‘when’ (delayed or not) and ‘why or why not’, and how patients respond to referrals, once made. At least seven types of clinician (general practitioners, obstetricians/gynaecologists, paediatricians, geneticists, psychologists and oncologists) may refer patients. Barriers to referral include indistinct boundaries between specialties and provider discomfort discussing reproduction and sex. These data, the first to explore dynamic factors and processes related to provider–patient relationships and interactions in referrals of patients for ART, suggest several key issues (e.g. non-ART providers’ roles as gatekeepers), and implications for future education, practice, guidelines and research, highlighting a research agenda, and the need for targeted education for different groups of clinicians.

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Introduction

Many infertile patients who want to have children and might benefit from treatment using assisted reproductive technology (ART), such as in-vitro fertilization (IVF), do not receive these interventions, raising critical questions of why, and how best to overcome barriers that may exist. Infertility specialists can offer effective diagnostic procedures and treatments, but in most countries, only about half of infertile women who want to have children appear to seek professional help, even if covered by insurance (Greil et al., 2011). Greil and McQuillan (2004)
found that of 196 infertile women, 63% were trying to get pregnant. In a USA national survey of 22,662 women aged 15–44 years, 64% and 58% of women with infertility or impaired fecundity, respectively, who did not already have children intended to have a child (Chandra et al., 2013). Yet although 10% of couples are infertile, only 2% of infant births in the USA and several other countries use ART (Centers for Disease Control and Prevention, 2016). Among 67 subfecund USA women trying to get pregnant, only 11% saw a doctor, received advice or had diagnostic tests, and only 4% sought treatment (Greil and McQuillan, 2004). Among French women who had been involuntarily infertile for at least 24 months, only 47.9% had a medical consultation for the issue, which increased with patient’s level of education, and only 45% of those who sought medical advice ended up receiving infertility treatment (Moreau et al., 2010). In an internet study of women (48.1% from the UK, 38% from the USA and 13.8% from elsewhere) trying to conceive for an average of 12.42 months (range 0–132 months), recruited through a website for couples trying to have children, only 44% had consulted a physician (Bunting and Boivin, 2007). Some people with infertility may, of course, not wish to have offspring, or may choose to adopt children. But for the many who do want to have children, a range of ART – from surgery (e.g. repairing fallopian tube obstruction or sperm retrieval), to use of gestational surrogates, to IVF – can potentially help, providing one set of options. ART does not ‘cure’ infertility, since underlying medical problems themselves might cause infertility. However, ART can provide treatments that help to ‘cure’ the status of being childless.

While a major obstacle is frequently the cost of ART (Iaconelli et al., 2013), other barriers also appear to exist. Even among infertile women with household incomes 300% above the poverty level, 46.3% never used infertility services. Among infertile women with private health insurance and a household income above the poverty level, 46%, 55.0% and 58.5% were referred to a specialist, a reproductive endocrinologist (RE) or an obstetrician/gynaecologist (OB/GYN), and 32.6% were referred by their general or primary care provider (PCP)/general practitioner (GP) (Lass and Brinsden, 2001). In an internet survey of British patients, recommendation by a physician was the third reason for choosing a particular IVF clinic, after published success rates and quality of service (Marcus et al., 2005), and 25% had received treatment at more than one clinic.

Yet the existing literature has not explored whether providers themselves have any role and if so, what (i.e. how clinicians view and make decisions regarding these issues, and what type of processes, if any, are involved). Many questions thus emerge about when and how the process of referral occurs (e.g. how patients even come to know about their potential need for IVF if they wish to have children; and which providers refer patients and when, why and how). Strikingly, extensive literature searches have identified no prior examination of these questions.

In other medical fields, referrals of patients to specialists are affected by a range of factors, including characteristics of the referring physicians, the patients and the particular type of specialist (Forrest et al., 2006), but how referrals occur for IVF has apparently not been examined.

A handful of studies have suggested that barriers to ART referrals may exist. A considerable proportion of OB/GYNs, for instance, would discourage use of ART if the woman intends to be a single parent (17%), is lesbian (14%) or is unmarried to a male partner (14%). Male doctors and religious doctors were about twice and four times more likely, respectively, to discourage ART in the above scenarios (Lawrence et al., 2010).

Providers’ knowledge and attitudes in various fields concerning particular aspects of ART, such as preimplantation genetic diagnosis (PGD), may also impede referrals. Individuals who have deleterious autosomal-dominant mutations, or who are carriers for recessive conditions, along with their spouses may seek PGD and thus IVF, but may not know of PGD unless it is suggested by a provider. Yet non-ART physicians have been found to have little about this procedure. Among 220 internists, for instance, 4.9% had suggested PGD to a patient, but only 7.1% felt qualified to answer patients’ questions about PGD, and physicians’ views were associated with the number of years since they had completed their training and other factors (Klitzman, 2015; Klitzman et al., 2013). Among 163 neurologists, 24% and 6%, respectively, had ever discussed the possibility of prenatal genetic testing or PGD with patients, but only 5% felt qualified to answer questions about PGD (Klitzman et al., 2014).

Little research has examined how patients choose IVF providers. One study, in Turkey, found that IVF patients chose their private hospital based on hospital expertise, desire to continue with the same physician and pregnancy success rates (Cengiz et al., 2015). Research on patient-centred IVF care has focused on the treatment that patients receive, showing that patients place greater value on patient-centredness than physicians (van Empel et al., 2011). Crucial questions remain as to how these issues may be involved earlier in the process of accessing treatment (i.e. how patients even know to seek treatment, and from where).

In other areas of medicine, patients’ choices of hospital for major procedures are affected by demographics, resources and type of medical condition (Kurz and Wolinsky, 1985). Pregnant women choose a hospital for delivery, for instance, based on their sociodemographics, health status
and perceptions of the hospital’s quality (Morgan et al., 1999). But how infertile women find their way to treatment raises separate questions as they are not yet pregnant, and may not even be aware that they may benefit from such treatment.

Referrals may play an important role in infertility treatment since infertile patients who want to have children may not even know to look for a fertility specialist if their doctor does not raise the possibility. Thus, for many patients, the first step in receiving infertility treatment may be getting a referral. Little is known about the processes that shape whether, which and how patients receive such referrals.

A few insights may be gleaned from research on other issues. For instance, cancer patients undergoing chemotherapy or radiation therapy, which may harm gametes, may also benefit from ART referrals for fertility preservation (FP), but frequently do not receive these recommendations. Despite American Society of Clinical Oncology guidelines that oncologists should refer cancer patients of reproductive age for FP, only about half of oncologists have been found to do so (Loren et al., 2013; Quinn et al., 2009). One-third of female cancer patients learn about FP on their own, or through friends and family, rather than from their oncologist (Yee et al., 2012). Oncologists have appeared to be more likely to refer for FP if they were female, had favourable attitudes towards FP, and had patients ask about FP (Mehrotra et al., 2011). Lack of access to an infertility specialist, belief that patients were not interested in FP, lack of insurance for FP and time constraints have also been significantly associated with failure to refer patients. Qualitative interviews suggest that other factors include physicians’ lack of training, education and materials about FP (Quinn et al., 2009).

Many questions remain concerning what processes are involved in oncology patients’ referrals; when and how these referrals do or do not occur; what other obstacles, if any, may exist; whether these barriers can be addressed in any way; and if so, how.

Moreover, cancer therapy patients constitute only a small proportion of the individuals who might benefit from consultations with a reproductive endocrinology and infertility specialist (REI), raising critical questions of whether these or other barriers or issues might also arise concerning potential referrals of other infertile patients. For the majority of patients – who are not single, gay, lesbian, unmarried or undergoing cancer treatment – no studies have been published concerning the processes, nature, barriers and facilitators of referrals.

Questions thus persist that have not been examined in the published literature regarding which doctors refer patients, and how, where and why they do so. Thus, as part of a study on how providers and patients view, and make decisions on, several critical aspects of ART, issues concerning referral processes arose consistently and were examined in detail. These results are presented in this paper.

Materials and methods

In brief, as described more fully elsewhere (Klitzman, 2016a, 2016b, 2016c, 2016d, 2016e, 2017) and as summarized in Table 1, 37 in-depth semi-structured telephone interviews of approximately 1 h each were conducted with 27 ART providers – 17 physicians and 10 other providers (seven mental healthcare providers, two nurses and one other), of whom one physician and three other providers were also themselves patients – and 10 additional patients.

The methods adapted elements from Grounded Theory (Strauss and Corbin, 1990), and hence were informed by techniques of ‘constant comparison’, with data from different contexts compared for similarities and differences, to see if they suggest hypotheses. During the ongoing process of interviewing, the Principal Investigator (PI) constantly considered how participants resembled or differed from each other, and what social, cultural and medical contexts and factors might contribute to differences.

Participants

Providers and patients were recruited through listservs, e-mail and word-of-mouth. Providers were also recruited through national meetings of the American Society for Reproductive Medicine (e.g. PGD and mental health provider interest group meetings). The PI attended these meetings and approached attendees to ascertain if they might be interested in participating in an interview study, and if so, the PI subsequently emailed them some information. Most of those asked agreed to participate, and did so. The PI also asked interviewees if they knew of colleagues around the country whom he might also contact concerning the possibility of participating in the study, and the PI then contacted these additional providers by e-mail to ascertain their interest in participating.

A mental health listserv was also used, which is received by approximately 60 members (not all of whom are active), of whom 15 responded, and the first eight respondents were interviewed. Patients were recruited through announcements of the study that were distributed through patient advocacy organizations and providers. Additional, briefer interviews were conducted as background, for informational purposes, with eight physicians, nine mental healthcare providers and 14 patients; these informed, but were not included in, the final formal data analysis. Thus, in all, 25 physicians, 19 other providers and 24 patients were interviewed, of whom 17 physicians, 10 other providers and

| Participant type                  | Male (n) | Female (n) | Total (n) |
|----------------------------------|----------|------------|-----------|
| Physicians                       | 14       | 3          | 17        |
| Physicians who are also patients  | 0        | 1          | 1         |
| Type of practice                 |          |            |           |
| University affiliated            | 5        | 1          | 6         |
| Private practice                 | 9        | 2          | 11        |
| Other ART providers              | 1        | 9          | 10        |
| Other providers who are also patients | 0    | 3          | 3         |
| Patients                         | 1        | 9          | 10        |
| Total                            | 16       | 21         | 37        |

ART, assisted reproductive technology. *For example, mental healthcare providers, nurses.*
10 patients participated in the formal interviews that were transcribed and systematically analysed, as described below, and that constitute the data presented in this paper. Interviews for the formal data analyses were conducted with each group until ‘saturation’ was reached (Guest et al., 2006). Interviewees were from across the USA. The Columbia University Department of Psychiatry Institutional Review Board approved the study, and all participants gave informed consent.

Instruments

The PI drafted the semi-structured interview questionnaire, drawing on prior literature, and explored patients’ and providers’ views, experiences and decisions concerning multiple aspects of ART, including views, decisions, interactions and experiences concerning patient referrals (see Appendix A for sample questions.) These clinicians described multiple patients they had treated, and interactions with colleagues; and patients often described interactions with multiple providers and other patients.

Data analysis

After all of the interviews were completed, subsequent analyses were conducted in two phases, primarily by the PI and two trained research assistants. In Phase I, these individuals independently examined a subset of interviews to assess factors that shaped participants’ experiences, identifying categories of recurrent themes and issues that were subsequently given codes. Each interview was read, systematically coding blocks of text to assign ‘core’ codes or categories (e.g. instances where referrals occurred, and delays in these referrals). While reading the interviews, a topic name (or code) was inserted beside each excerpt of the interview to indicate the themes being discussed. The coders then worked together to reconcile these independently-developed coding schemes into a single scheme. Afterwards, a coding manual was prepared, defining each code and examining areas of disagreement until consensus was reached. New themes that did not fit into the original coding framework were discussed, and modifications were made to the manual when deemed appropriate.

In Phase II of the analysis, the two coders independently content-analysed the data to identify the principal subcategories and ranges of variation within each of the core codes. The coders reconciled the subthemes identified by each coder into a single set of ‘secondary’ codes and an elaborated set of core codes. These codes assess subcategories and other situational and social factors. Subcodes included, for instance, reasons for obstacles or delays in referrals (e.g. low understanding of infertility or PGD among providers in other fields).

Codes and subcodes were used in analysis of all of the interviews. Two coders analysed all interviews. Where necessary, multiple codes were used. Areas of disagreement were examined through closer analysis until consensus was reached through discussion. Consistency and accuracy in ratings were checked regularly by comparing earlier- and later-coded excerpts.

To ensure that the coding schemes established for the core and secondary codes are both valid (i.e. well grounded in the data and supportable) and reliable (i.e. consistent in meaning), they were systematically developed and well documented. Data were also examined in the context of issues in the literature, posing questions and collecting sufficient details to substantiate points that arose. Text from the interviews is presented below to allow readers to appreciate the richness of the data obtained. These data also have a degree of face validity, further substantiating their trustworthiness.

Results

In brief, as outlined in Fig. 1 and described more fully below, several themes emerged concerning who refers patients for ART, how, when, and why they do or do not do so; and how patients respond to referrals that are made. These data suggest that a complex system of referrals may exist.

‘Who’ refers patients for ART?

At least seven types of other healthcare providers can potentially refer patients to an REI for ART – most commonly OB/GYNs, but also oncologists, GPs, generalists and genetic counsellors. Yet these clinicians may not always refer patients, or not do so when and how they should for particular indications. In each of these other disciplines, various factors can facilitate or impede ART consultations.

Over time, many infertile patients may, in fact, consult multiple providers, embarking on multistaged journeys, interacting with long-standing providers about infertility in various ways, entering and taking breaks in treatment, and receiving and/or following various recommendations for referrals.

Many patients may start to address infertility by consulting with their on-going OB/GYN, who can thus play a critical role as ‘gatekeeper’. Yet with time, patients may end up discussing infertility with several providers, going back and forth from their long-term OB/GYN to one or more REIs, and then back to their OB/GYN.

Patients often come to trust their OB/GYN over several years, and thus especially value and rely on this physician’s opinion, and confer about different approaches to infertility. Even after a referral has occurred, patients may reconsult with their long-term OB/GYN about an REI’s treatment plan and recommendations.

Patients may thus check back with their OB/GYN periodically or when making critical decisions, suggesting that referrals do not necessarily constitute a one-time event, but rather an on-going process, over time, and as part of a network with feedback loops.

Physicians in several other fields can also potentially refer patients for ART, but may or may not do so. Oncologists, for instance, can recommend or encourage patients to use ART for gamete preservation before chemotherapy, but may not always do so sufficiently well or often. As one physician who works in a private facility said:

The oncologist in the area may collect sperm from young men before blasting them with chemo, but is not thinking about the
young girl: the cancer treatment is going to kill her ovaries. You need to be thinking about ovarian cryo-preservation, which is a reality now. Oncologists should at least counsel the young woman that we’re going to use medications or radiation which will eliminate her reproductive capability. If that’s important, we may be able to have put aside either ovarian tissue or eggs for future years. But the oncologists get so focused on the cancer treatment that by the time I see the patients, they have already had four courses of chemotherapy and it’s too late.

Thus, oncologists may, in fact, refer patients for fertility preservation, but do so belatedly. More integrated care may thus benefit patients.

GPs could also refer patients for ART, and some readily do so. A university-affiliated physician said:

Generalists immediately refer patients to an urologist, and don’t really take an active role. Very rarely does a generalist ask for a hormone test and semen analysis.

Providers may end up giving inaccurate or insufficient information, partly because the information may change over time. As one physician, who works in a private clinic, said:

Failure to refer 42-year olds happens a lot less lately – whether because patients have figured it out on their own, or older doctors have now retired.

Other clinicians may vary widely in how they refer patients for fertility treatment, in terms of whether they give specific names and contact information for ART specialists or vague information about the existence of various ART as options; and whether they encourage patient follow-through on such referrals, and/or initiate diagnostic tests and/or treatment.Providers can range from clearly and readily referring patients for ART, to merely mentioning the possibility of infertility treatment in passing, offering little, if any, information, detail or encouragement about it:

I wish I’d known about IVF before, but I didn’t. My wife’s OB/GYN had mentioned it, but didn’t have any office literature. All they said was there’s ‘a reproductive place in another city. We can refer you, and you can go and talk to them.’ I only found out through internet research.

Providers in other fields may differ in not only whether, but when they refer patients for ART, at times delaying due to limited knowledge about the availability or effectiveness of treatment and/or other barriers. These clinicians may not inform or encourage infertile patients...
about IVF options early enough. As a physician in a private facility said:

The most important thing for a provider who does not routinely treat infertility is to know when to refer. If you have to know one simple thing, it’s to send somebody out.  

[Physician #7]

Physicians outside of ART may not perceive the need for patients to consult with a fertility specialist in a timely way. As one 25-year-old woman, trying to get pregnant for 5 years with her 26-year-old husband, reported:

My husband’s sperm count is very low and I have polycystic ovarian syndrome. But my doctor said, ‘Why not just keep trying the natural way?’ I didn’t go back to him. Doctors say, ‘you’re young and you have time.’ But I don’t feel like that.  

[Patient #1]

She wanted to go to graduate school eventually, but to have a child first.

At other times, providers who do not specialize in ART may delay referrals until it is too late. As a physician in a for-profit facility said:

That’s still a hurdle with OB/GYNs: some OB/GYNs say, ‘Oh, you’re 42, you’re going to be fine!’  

[Physician #9]

Primary care doctors, OB/GYNs and other providers outside of ART may not adequately initiate or consider conversations with patients about family-building plans. As one mental healthcare provider said:

OB/GYN, internists and family practitioners have to start waking up to the fact that they have to counsel women about what their reproductive life cycle is like, and not wait to ask a 35-year-old: ‘What are your family-building plans? Is this important to you?’ You don’t want to wait until they’re 35. God forbid, we mention to kids in high school health class that fertility drops with age. That’ll never happen.  

[Other provider #3]

‘What’ is offered: referral vs diagnoses or treatment

Many non-ART specialists may begin to order certain diagnostic tests and treatment interventions for infertility, but the extent can vary. Partly given rapidly-evolving ART, these providers may range in whether they simply refer patients immediately or initiate various diagnostic tests or treatment, and if so, which and when. These physicians may vary based on their fields, interest and comfort. They may perform various procedures, but these may not be systematic, ordering certain diagnostic tests or treatments but not others. As a private practice physician said:

Gynaecologists are performing laparoscopies without even doing sperm counts...OB/GYNs in town ask me if they have to do an amniocentesis if they did PGS [preimplantation genetic screening]. They absolutely do! Physicians and surgeons themselves come in as patients at the age of 43 and tell me they can run a marathon, and wonder why their pregnancy rate is less than 1%. So there is very little understanding about ovarian reserve and decreasing fertility rates with age. It’s taught in medical school, but not everybody listens. I don’t think I listened too well about orthopaedics!  

[Physician #11]

Treatment initiated by providers in other fields may thus be partial or suboptimal (e.g. prescribing medications without first conducting appropriate diagnostic tests to assess whether the couple’s cause of infertility is due to male or female factors). A private physician said:

You can get somebody pregnant with unmonitored Clomid, but the likelihood is less. I’ve seen couples who’ve had Clomid for 6 months who never had semen analysis. We can probably maximize their treatment and minimize the duration.  

[Physician #7]

OB/GYNs may also not do all they can for various clinical problems, such as recurrent miscarriage. A university-affiliated physician said:

For a patient having a couple of miscarriages, the OB/GYN says, ‘just try again,’ and does some basic antiphospholipid screen, but doesn’t send them off for karyotypes to see if there are translocations.  

[Physician #5]

‘Why’ referrals do not occur

Provider-related obstacles

Knowledge and attitudes among non-ART providers. Clinicians in other fields may range widely in their knowledge, awareness and attitudes concerning ART due to varying professional and personal factors that can shape whether and why these providers refer patients. Providers in other specialties may have gaps in their knowledge of ART in general and/or specific aspects, such as success rates, PGD or FP.

GP and physicians in several other fields who might potentially refer patients for ART may have gaps in their knowledge about, for instance, the definition, diagnosis and treatment of infertility. As another university-affiliated physician said:

Many generalists don’t know a lot about sophisticated aspects of male and female infertility. Paediatricians certainly have no training. Generalists do not commonly go to courses on infertility, because they don’t see it every day. We should teach them what it means to be infertile: actively having intercourse for a year or more, and not achieving pregnancy means you’re infertile. That’s the time to refer patients. Gynaecologists and urologists have a much better understanding of that because they get training in it.  

[Physician #8]

Physicians outside of ART may thus lack understanding of not only whether to refer patients for ART, but when to do so for a particular patient. Paediatricians and other non-ART physicians may be involved because they treat patients who have genetic conditions that can be avoided in future children through IVF/PGD. Paediatricians, for instance, can potentially inform the parents of children affected by these
conditions that the mutation can be selected out, such that future children will not also have it.

Providers in other fields, including OB/GYNs may misunderstand the success rates of IVF, either overestimating or underestimating them, which can affect whether, how and when these clinicians discuss ART with patients. As a university-affiliated physician said:

I recently asked OB/GYNs: 'If you refer a woman to an IVF clinic, what’s the chance one would deliver a baby?' They said, ‘About a 70–90% chance per cycle.’ So even this group, which you would think would be somewhat informed, was way off-base. Unfortunately, that perception – that IVF is always going to work – is out there, even in an educated population. So informing people about realistic expectations – which SART [Society for Assisted Reproductive Technology] has furthered – is helpful.

((Physician #12))

Clinicians outside of ART may lack adequate understanding of not only success rates, but also of certain key procedures. Problems emerge because providers in other fields may know certain aspects of ART but not others (e.g. they may be very aware of IVF in general, but not PGD). As a private physician said:

Even the OB/GYNs very seldom think about high-tech options when a patient has recurrent miscarriage.

((Physician #5))

Physicians in other specialties, such as paediatrics, neurology and internal medicine, may know little about PGD, and may not consider it because they focus instead on current, not future, pregnancies. As a university-affiliated physician said:

For paediatricians or internists, future pregnancies might be an afterthought – though they are getting a little bit better at thinking about it. Most of their focus is on evaluating and treating the diagnosed individual. For some paediatricians, it may slip their memory to refer someone for the purpose of avoiding problems in future pregnancies. OB/GYNs, too, should think about this more.

((Physician #1))

Providers outside of ART may have gaps in their knowledge regarding not only infertility, but also genetics, and hence may not always be fully aware of recent advances, especially regarding rare mutations. As one patient, who was eventually found to carry a relatively rare genetic abnormality, said:

Even the new doctor has never really heard of it. He didn’t seem clueless, but it didn’t seem like he’d heard of it. So it’s good to educate the doctors too.

((Patient #3))

Patients can try to increase physicians’ awareness regarding these options, but may not always succeed.

Clinics may refer patients to genetic counsellors who know about PGD, although not all counsellors may do so. As a university-affiliated physician said:

We tend to use genetic counsellors that have familiarity with these techniques. But a lot out there don’t.

((Physician #12))

PGD may help many patients who are at risk of transmitting serious mutations.

Providers in other fields may know a little about various procedures, but not fully understand these techniques, and the appropriate and specific uses, or realistic benefits or limitations. Such physicians may recognize needs for better information and education. As another university-affiliated physician said:

A lot of doctors just don’t know about it. Others know a little about it, but not enough to really give an informed opinion. Very few providers really know, and can effectively tell patients what it’s all about.

((Physician #6))

Providers in other fields may have overly high expectations of certain procedures. For patients at risk of transmitting a lethal mutation for offspring, for instance, providers may see PGD as a panacea, without comprehending the complexities, difficulties and potential limitations involved, and may come to recognize and appreciate these only with increasing time and clinical experience.

The knee-jerk reaction is always awe: ‘It’s amazing we have this technology. The assumption is that it’s a panacea. This is what we’ve been looking for: it’s going to solve all of our problems for families with genetic disorders.’ Then they get some experience or hear back from the patients. The reality sets in: it’s not as easy as they thought. Patients get misled by thinking it’s a trivial procedure – the perfect solution.

((Physician #6))

Clinicians in other fields may not grasp or convey to patients the degree of inherent technical limitations. Patients may then end up having unrealistic expectations. As a university-affiliated physician observed:

Sometimes patients come to us with higher expectations than they should, because some genetic counsellors, geneticists and paediatricians look at IVF very intuitively – that we should be better. They’re not aware of how we’re not succeeding with PGS and balanced translocations, for instance.

((Physician #10))

Limited knowledge may arise because these providers are relatively new and still evolving. Ongoing, updated training on fertility may be needed. As a private physician said:

The medical community in general does not have a good understanding of reproductive preservation and cancer treatment of patients, and what is available. They sort of remember that they once read something about it, but don’t see it as a reality when they see a patient.

((Physician #5))

Overlap and competition between fields as barriers

Fields may vary in how much they ‘overlap’ and compete with each other, and non-ART providers may try to address patients’ infertility themselves for extended periods. OB/GYNs, for instance, may begin to provide certain treatments. Yet the effectiveness and hence ideal course of such
treatments may vary considerably. Unfortunately, patients may, in retrospect, end up spending much valuable time and money pursuing earlier, ineffective approaches. As a private physician said:

If patients hadn’t spent too much money on not-very-effective infertility treatment, they might be in a position to pay now. That’s why it’s important to send them to a specialist right away – you save the patient money.

[(Physician #15)]

As described earlier, physicians saw such ‘not-very-effective infertility treatment’ as including treating women for perceived infertility without first performing diagnostic studies to determine whether the man, rather than the woman, might be the cause of the couple’s difficulty conceiving, and not performing diagnostic evaluations (e.g. karyotyping) to assess possible causes of recurrent miscarriage.

Yet several barriers can impede OB/GYNs from referring patients to REIs. As a private practice mental health professional said:

There are politics about gynaecologists not wanting to pass patients on to REIs, and keeping these patients longer than they should. There are different interests – doctors making money, doing different things. People want to feel free – not be told what to do.

[(Other provider #5)]

Financial factors may also play a role in OB/GYNs not referring earlier. Patients undergoing IVF and PGD may consequently not receive optimal care and diagnosis. As a private physician commented:

OB/GYNs probably shouldn’t be taking care of these patients. But there’s conflict: the OB/GYN might want to take care of them – it’s revenue. Yet the patients would benefit from early referral.

[(Physician #7)]

Some physicians may thus want to try treating patients themselves, rather than referring them to other providers, to gain more ‘revenue’ and ‘make’ money.

Patient-related obstacles

As described above, patients may also perceive and experience these issues, for instance in the form of physicians providing only limited information concerning possible referrals. For example:

My wife’s OB/GYN had mentioned it, but didn’t have any office literature... I only found out through internet research.

[(Patient #2)]

Patients may also fail to contact an REI to whom they are referred, or may drop out of treatment once started:

Only about 25% of infertile couples actually ever make it to the office, and less than half of those will ever pursue a cycle.

[(Physician #9)]

Yet little is known about patients who neither receive referrals nor follow-through on them. These issues can be difficult to gauge since patients who end up seeing an REI have, in part, self-selected to do so. Many potential patients may simply not learn about PGD or other procedures. As one university-affiliated physician said:

By the time our patients get here, they are pretty well-educated. I don’t know how many don’t get here because they don’t get the opportunity to know about it. It’s hard to know how much we’re missing. A lot of people either don’t know that this even exists, or they have misconceptions about IVF and its success. Some people see it as science fiction.

[(Physician #10)]

Even when referred, patients may not follow-through with going to the REI or completing treatment cycles because of costs, physical or mental burdens, or other factors.

Costs can be a major obstacle; yet restricted insurance coverage may not account for all such limitations. Knowledge about reproduction among patients and the public in general also needs to be enhanced, especially regarding the harsh realities of the biological clock (i.e. a woman’s fertility plummets after 35 years of age and a man’s fertility declines after 40 years of age). Patients may have limited education about key aspects of infertility, impeding communication and potentially referrals from internists and others. As one patient said:

Women need to be educated on fertility. I knew that once you hit 40, your odds go down, but that was the extent of my knowledge. Beyond that, I thought that people who want to get pregnant get pregnant, and have a baby and live happily ever after. There’s so much more to it that women are unaware of.

[(Patient #5)]

Patients may also be uncomfortable raising or pursuing infertility with their other providers. A university-affiliated physician said:

Some patients are embarrassed to discuss infertility. They may be more comfortable talking about their sexual ability, but Viagra and infertility are not the same! Fertility doesn’t often come up. Once it is discussed, patients say, ‘We’re not getting pregnant. We’re trying. Whom should I go to see?’

[(Physician #8)]

Thus, not just financial, but psychological and emotional obstacles may impede patients from seeking care.

Men may face particular hurdles in getting treatment, given beliefs and expectations about machismo, and hence stigma and shame about discussing or getting treatment for infertility. When they learn from a doctor that they may not be able to have children, many men may get depressed and not pursue further evaluation or options:

For women, it’s bad enough – and for men, probably even worse. They don’t want to go through these exams: it’s humiliating. Some remain silent and fail to get help. Fortunately, we have been able to establish a pregnancy for a number of men who were told they could never get their spouse pregnant – that nothing could be done. For years, they just didn’t seek any help. One young man was told there was ‘no possibility’ he would ever get his wife pregnant. They waited for a couple of years because
A wide variety of clinicians may refer patients to REIs, but do so for different reasons. Across these clinician types, several barriers and facilitators may exist that are both similar and different. Development of specific, targeted education and interventions for each group of providers may thus be beneficial. These data may hence have important implications for improving practice and education of ART among non-ART providers (e.g., PCPs, OB/GYNs, paediatricians, geneticists, genetic counsellors, mental health providers and oncologists) and patients.

As depicted in Fig. 1, these data suggest that referrals of patients for infertility treatment can occur within intricate, dynamic social systems, in which a variety of healthcare professionals and others may refer patients, with these referrals ranging in what is offered (e.g. names of providers vs diagnoses or treatment), how the referral is offered (e.g. specifically or vaguely; and with high, low or no encouragement) and when it is made (i.e. delayed or timely). Within this system, several obstacles to referrals may exist, related both to clinicians who may make these referrals (e.g. gaps in knowledge, potential competition between providers) and to patients (who may feel embarrassed to discuss infertility problems, or face religious or other obstacles, or limited resources). Physicians who are not ART specialists might have personal views that differ from those of infertile patients who want to have biological children. The present data suggest that these other doctors may encourage patients to continue to try to conceive naturally, prior to beginning treatment; or may provide or recommend suboptimal treatment, needlessly delaying patients who wish to have biologically-related children. These patient and provider obstacles may thus affect whether, when, how and by whom referrals get made. These referrals may, in turn, increase patient or provider comfort discussing these issues. This dynamic system has implications for enhancing education of patients and providers, guidelines and future research on these issues.

These data suggest several issues that have not been reported in the prior literature. First, obstacles to patients receiving infertility treatment arise not only because of individual-level factors (e.g. cost), but dyadic processes involving non-ART clinicians who often serve as gatekeepers for infertility treatment. Second, at least seven types of provider may refer patients for infertility treatment, and thus serve as gatekeepers. Third, referrals for infertility treatment may differ in how they are made and what they consist of [i.e. how much and what type of information (e.g. specific or vague) is offered by non-ART providers], and how they refer patients (i.e. whether they mention the possibility of consultation with an infertility specialist in passing, or encourage or follow-up with patients). Fourthly, providers may differ in when they refer patients for infertility treatment (i.e. whether they delay doing so, and if so, how often and for how long), and whether they first perform any diagnostic evaluations or treatment before making a referral, and if so, what. Fifthly, clinicians may differ in terms of why they fail to refer patients to fertility specialists as often and rapidly as they might (e.g. because of their own discomfort discussing reproduction and sex; and/or gaps in their knowledge concerning aspects of ART, such as PGD or genetics).

Referrals to REIs may come not only, or even primarily, from PCPs, but also from OB/GYNs, and a variety of other specialists. Aspects of these referrals both resemble and

**Implications: educational needs and challenges**

Training of other providers about the need to refer patients appropriately may be critical, but poses challenges of whom, what, when and how best to teach. As a university-affiliated physician said:

> Education is greatly needed, but it’s hard to know exactly when and how to educate these folks. The easiest answer is probably that they should at least be able to say that IVF is an option, and direct patients to good information.

[Physician #6]

Yet significant barriers may exist to sufficiently communicating with, and educating, providers in other fields. Doctors outside of ART may not only have limited awareness of these issues, but may be busy and/or not readily open to additional training. A university-affiliated physician said:

> If doctors are asking for a talk on reproduction, then the speaker can bring up these issues. But you can’t go knocking on doors saying, ‘Can I talk to your staff for a few minutes about PGD?’ They see a lot of things on the Science Channel, but it’s still: connect the dots. Awareness needs to increase. It may be a reality in their own community and they don’t even know about it.

[Physician #5]

Questions surface regarding what the appropriate content and amount of education should be for providers in other fields (i.e. what goals are feasible and realistic). Educating non-ART clinicians much more about ART may not be wholly realistic. A university-affiliated physician said:

> It’s an awful lot of information to know. If I had to know as much as an internist, it would be asking too much. Doctors are pretty smart. They don’t like talking about things they aren’t very comfortable with. They recognize they can cause more harm than good.

[Physician #4]

Obstacles to optimal referrals may thus arise because various other providers may need a considerable amount of knowledge which can take time to become aware of or learn. Clinicians may have only partial, incomplete knowledge and also feel uncomfortable discussing these issues with patients.

**Discussion**

These data, the first to explore the dynamic factors and processes involved in referrals of patients to fertility specialists, suggest several critical issues concerning who refers patients and when, how, and why or why not. Specifically, a wide variety of clinicians may refer patients to REIs, but do so...
differ from each other. The prior infertility literature has explored a few aspects of obstacles in referrals by oncologists, but not referrals to REIs by these other types of non-ART providers, and similarities and differences that may arise.

Within these complex social systems in which referrals occur, patients may first have to mention infertility problems to a provider, or be informed by a specialist in another field (e.g. paediatrics, internal medicine or neurology) of the presence of a mutation for which PGD may be performed. Over time, patients may follow-up on that referral to a specific provider, or choose a different provider (Marcus et al., 2005).

Male and female patients with infertility who want to have children often confront psychological stresses, and cope differently with these issues (Peterson et al., 2006). Women, more so than men, may face challenges concerning referrals, since a couple may see the woman’s failure to become pregnant as ‘the problem’. Moreover, many women who were fertile when younger delay having children, due to careers or other reasons, and may then encounter problems getting pregnant, and hence seek treatment. Indeed, among adults aged 25–44 years, 17% of women compared with 9.4% of men have used infertility services (Chandra et al., 2013). Women also report more stress than men in confronting infertility (Greil, 1997), seek more social support, and engage in more positive re-appraisal and escape/avoidance (Jordan and Revenson, 1999), while men may engage in more distancing (Peterson et al., 2006). These variations in coping strategies may lead to differences in how exactly men and women seek, and follow-through with, referrals.

While other data indicate that non-ART providers refer patients for ART treatment, the present data suggest that these providers may, in fact, serve as gatekeepers who can play complex roles shaped by several factors, barriers and facilitators, affecting whether, when, and how patients end up consulting fertility specialists. In other areas of medicine, gatekeeping functions have been described, and can pose challenges, often impeding access of care. Healthcare systems frequently use PCPs as gatekeepers to control access to specialists, and thereby costs (Grumbach et al., 1999; St. Peter, 1997), but generate mixed feelings among both patients and providers. In a study of 12,707 patients, most preferred to see care initially from a PCP, rather than a specialist, but 23% felt that their PCP impeded the ability to consult a specialist (Grumbach et al., 1999). Specialists, generally, have also been found to be ambivalent about other physicians’ roles as gatekeepers (Peña Dolhun et al., 2001). Among specialists in seven areas, 40% thought that gatekeepers improve care coordination, and about half thought that gatekeepers increased the odds of patients receiving preventive care, yet 44% thought that gatekeepers undermine specialists’ relationships with patients (Peña Dolhun et al., 2001).

In other areas of medicine, PCPs have been found to misdiagnose patients and order unnecessary tests and procedures prior to making referrals to specialists. For example, PCPs who referred patients to a tertiary care centre for hand evaluations had correctly diagnosed only 34% of these patients and 15% of certain conditions, and 90% of the advanced imaging ordered by PCPs and 70% of the PCPs’ interventions were considered unnecessary (Hartzell et al., 2013). With other specialists, such as cardiologists, mutual communication with PCPs has been found to be beneficial (Bjornsson et al., 2013).

These issues have not heretofore been examined with regards to ART. The present data are consistent with results of studies of referrals by PCPs to specialists in other fields, suggesting that similar phenomena may operate regarding infertility treatments. Yet REIs differ from other types of specialist (e.g. endocrinologists or cardiologists) who may treat patients for a chronic condition continuously over several decades, while REIs generally treat patients for much briefer periods (e.g. only a few years). Insurers also require gatekeepers for other specialists, whom insurers reimburse; yet, since insurance coverage is far rarer for infertility, more variation may occur in whether, how and when referrals occur.

To account for disparities between women in seeking fertility treatment, a help-seeking model has been suggested, related to socio-economic, and predisposing and enabling factors, leading infertile women to perceive a problem, consider options and then seek help (White et al., 2005, 2006). But the present data suggest that additional questions may arise concerning what ‘seeking help’ actually means (i.e. what happens when women actually look for assistance, from whom they seek it, when and with what persistence, whether they only enquire about possible help or actually initiate and follow-through with treatment referrals and recommendations, what type of answers they receive, and what individual-, dyadic- and institutional-level barriers and facilitators arise as patients progress from seeking assistance to getting treatment and having a child. Moreover, while White et al. focus on married heterosexual women (White et al., 2005), the present data suggest that other patients (e.g. unmarried men) may also confront these issues, and potentially additional obstacles.

The present data also suggest that non-ART providers may feel ‘uncomfortable’ discussing and addressing ‘taboo’ areas such as reproduction, sex and infertility. Indeed, among family practice physicians, for instance, only 48% of females and 58% of males have been found to be very comfortable obtaining a sexual history from a patient of the opposite gender (Lurie et al., 1998). This discomfort may reflect stigma and shame about these topics, and low knowledge among these providers that may, in turn, also result from such discomfort. This sense of stigma and shame among both doctors and patients may impede mutual communication. Certain groups of patients may face particular obstacles. Single women may feel added stigma and shame (i.e. that they have somehow ‘failed’ to find a heterosexual partner). Gays and lesbians have more mental health problems than the general population, due to internalized homophobia and minority stress (Meyer, 2003) which may also contribute to these challenges.

The present data also underscore barriers to oncology specialists and nurses referring patients for FP, and suggest additional critical factors regarding what the referral consists of (what exact information providers give), when it occurs, whether it is sufficient (e.g. including a specific name and contact information) or is made only in passing, whether non-ART clinicians perceive or address patient embarrassment about infertility, and how successful they think ART will be. Although prior literature suggests that
referrals for FP were associated with oncologists’ perceptions of patients’ interest or enquiries concerning FP; the present study suggests that patients may, in fact, be unaware of, or feel uncomfortable discussing, fertility treatment. Studies have examined patient embarrassment concerning FP among adolescent males under 18 years of age (Chapple et al., 2007), but not among patients over 18 (Goossens et al., 2014; Sobotka and Zakinci, 2014). The current study suggests that adult patients may also feel embarrassment or discomfort.

Conclusions

These data may have several implications for future practice, research guidelines and education. These findings suggest a critical need for future research and a research agenda, specifically to investigate further, using larger samples, how frequently patients do or do not discuss infertility problems with PCPs or other physicians and obtain referrals; the exact nature, strength and specificity of these referrals; how often providers delay or provide the name of a specific REI vs non-specific or not wholly accurate and up-to-date information, or refer patients only in passing, without sufficient encouragement or follow-up; and how and with what frequency providers other than REIs discuss, diagnose or treat infertility. These data highlight the need to examine what diagnostic tests or treatments non-ART providers do or should perform; and when, how often and which patients follow-up, and why (e.g. due to not only individual, but social, dyadic and structural reasons). The present data also suggest a need for future research to explore more fully whether and how women and men may differ in seeking and following through with referrals, and what other factors may be involved.

While critics might argue that referrals from various types of non-ART provider are wholly different, and should be examined separately rather than together, these potential recommendations for treatment appear to present several similar challenges that warrant exploration together (i.e. questions of how, when, why and for whom referrals occur, and how patients respond). Future studies can also examine more fully referrals from each of these sets of providers separately, and probe possible differences.

These findings highlight the need for professional or other organizations to clarify and develop consensus and/or guidelines concerning when and to what degree these other types of provider should diagnose, treat or refer infertile patients, and how best to facilitate interprofessional relationships and collaborations. These data also suggest possible benefits of improving practices among OB/GYNs to ensure that they order appropriate diagnostic tests before initiating treatment. This study also raises broader questions about the respective roles of professionals in different fields. Consideration of these questions may be sensitive or controversial, but can benefit innumerable patients who may otherwise receive suboptimal care. Enhanced education of providers in other fields concerning the nature, benefits and risks of appropriate treatment may thus be helpful.

Although research has started to explore barriers to referrals from oncologists, the present data highlight the need for such studies concerning clinicians from other fields, such as neurologists who may consult patients of reproductive age concerning mutations associated with neurological disease (e.g. Huntington’s disease), yet have limited understanding of PGD.

The present study highlights possible needs for targeted education for different types and specialties of clinician. Many patients who are referred without adequate information and encouragement may end up not pursuing infertility treatment. While many physicians are uncomfortable discussing sexual activity and dysfunction with patients (Lurie et al., 1998), the present data suggest that such physician and patient discomfort may hamper referrals. Increased education and awareness of these issues among ART and non-ART providers, and efforts to enhance these interactions, may help.

In other areas of medicine, both local and systemic strategies for overcoming barriers to referrals have been explored, such as improving interactions between appropriate professional organizations, and developing appropriate standards and dialogue (Baerlocher and Detsky, 2009; Beaulieu et al., 2009; Huckman and Pisano, 2005; Levin et al., 1999). These methods may also aid infertility referrals.

These data have several potential limitations. A critic might contend that these individuals were the ‘wrong people’ to interview and may be biased, and that doctors who make referrals should be interviewed instead. However, the present study, in providing the first data of any type on this topic, serves as an important first step, elucidating and filling in considerable gaps in the literature (e.g. why many infertile patients who want children do not obtain treatment), and suggesting critical issues and a research agenda for future studies (e.g. of additional groups such as OB/GYNs) to investigate these realms further, and in other countries. Clinicians here present their impressions of these issues, which subsequent research can probe further among other groups.

Moreover, the other providers included here (e.g. mental health professionals) offer important observations, besides those of physicians, concerning these issues. Among ART programmes, only about one-third are affiliated with a hospital or university, and two-thirds are private (Klitzman et al., 2009). The current study included providers from both private and non-profit (i.e. university- or hospital-affiliated) institutions, and these issues concerning referrals arose repeatedly among both groups, as well as among patients. No consistent pattern of systematic differences in attitudes appeared to emerge between non-profit and private providers. Moreover, even if these fertility providers may be influenced in some way by any potential biases, the fact that they hold these attitudes is important to recognize and examine, as it might affect relationships and patterns of referral between providers both here and more broadly, raising additional questions for future studies. One could argue that only patients should be interviewed about these issues, rather than providers. However, providers have important and, in many ways, unique perspectives, as while patients may only know about their own particular single case, clinicians generally observe hundreds of patients, and are thus able to comment far more fully on these issues, elucidating and providing critical perspectives on general patterns of behaviour. Hence, providers, drawing on their experiences with many patients, as opposed to single patients, were generally far more aware of these issues. Nonetheless, this report also includes the views of patients.
Although the sample size is insufficient for statistical analysis of variation between different groups (e.g. providers in different geographic regions), it is adequate for qualitative research to elucidate the issues and themes that emerge, and is consistent with standard practices for qualitative research, for which six to 12 participants per ‘cell’ is generally adequate (Guest et al., 2006). These issues can be investigated quantitatively in future studies with larger samples. Although it is potentially conceivable that providers with certain attitudes may have been more likely to participate for some reason, skewing the results, the interviewees in this study demonstrated a full range of attitudes. Nonetheless, future studies using larger samples can explore such possibilities more fully. These data highlight the need for larger quantitative studies of several groups (which the present study can potentially guide), including OB/GYNs, GPs, genetic counselors and REIs, to examine more fully these potential barriers to referrals. However, clinicians are very busy, and recruiting larger numbers of them can pose challenges, no doubt accounting, in part, for the lack of any prior studies examining these critical questions. Healthcare providers are increasingly difficult to recruit for surveys, as indicated by response rates declining over time (Cho et al., 2013; Cull et al., 2005). Given the absence of such larger quantitative studies, the present data are thus very valuable, suggesting needs for education and attention regarding these issues. These data also arguably have a certain face validity, illuminating challenges that many providers confront.

While a critic might argue that the findings of this study could all have been imagined without conducting any research, as they are ‘obvious’, it is of note that these findings have not been presented in the published literature to date. Moreover, these data add considerably to the published literature, helping to explain current gaps. Studies have also demonstrated that some critics view many psychosocial research findings as ‘obvious’ when that is not the case. Indeed, some individuals even ‘view contradictory research results as obvious’ (Gage, 1991). Criticism of much sociological research as ‘obvious’ may also reflect the face validity of the research findings, rather than the lack of need for the research. Moreover, claims of ‘obviousness’ have been used to oppose needs for empirical social science research that can nonetheless help to formulate policy and practice (Gage, 1991). Furthermore, although some clinicians may possibly be aware of some of these issues, incorporation of these phenomena into the published literature is critical, since many providers are newly entering the field and/or doubtlessly remain unaware. Given the absence of any other data regarding whether, how and when non-ART providers serve as gatekeepers, these data are thus of value.

A critic might argue that these clinicians’ impressions are invalid as they are based on these individuals’ own perceptions, and often include complaints about other providers’ poor decisions, advice or knowledge. Yet the fact that these clinicians strongly and consistently made these comments is of note. One can simply ignore all of these comments and observations; however, they fill in gaps in the prior literature, and are consistent with data concerning potential impediments to referrals to specialists in other fields. Moreover, no published data contradict the views of these interviewees. These data are thus worth noting and raise hypotheses, questions and directions for future research.

In summary, these data suggest the existence of dyadic and institutional barriers in referrals of patients to REIs, and point to key implications for enhancing practice, research, education and guidelines.

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Appendix A. Sample questions for providers

- What challenges have you observed concerning patients receiving assisted reproductive technology (ART)?
- Have you observed challenges concerning referrals of ART patients for treatment? If so, where and when? What happened?
- Do you see areas for improving treatment, education or guidelines concerning ART? If so, what?
- What additional thoughts do you have about these issues?

References

Baerlocher, M.O., Detsky, A.S., 2009. Professional monopolies in medicine. JAMA 301 (8), 858–860. https://doi.org/10.1001/jama.2009.223.
Beaulieu, M.D., Samson, L., Rocher, G., Rioux, M., Boucher, L., Del Grande, C., 2009. Investigating the barriers to teaching family physicians’ and specialists’ collaboration in the training environment: a qualitative study. BMC Med. Educ. 9, 31. https://doi.org/10.1186/1472-6920-9-31.
Bjornsson, S., Sigurdsson, J.A., Sivararsdottir, A.E., Gudmundsson, G.H., 2013. Gatekeeping and referrals to cardiologists: general practitioners’ views on interactive communications. Scand. J. Prim. Health Care 31 (2), 79–82. https://doi.org/10.3109/02813432.2013.784543.
Bunting, L., Boivin, J., 2007. Decision-making about seeking medical advice in an internet sample of women trying to get pregnant. Hum. Reprod. 22 (6), 1662–1668.
Cengiz, E., Ozsari, H., Akyuz, I., Tuzcuoglu, A., Hosgor, H., 2015. Private hospital choices of infertile patients that received IVF treatment: a pilot study. Eur. Sci. J. 246–264 (November, Special Edition).
Centers for Disease Control and Prevention, 2016. ART Success Rates. [Updated May 4, 2017]. Available from: http://www.cdc.gov/art/reports/index.html, Accessed date: 27 June 2017.
Chandra, A., Stephen, E.H., 2010. Infertility service use among US women: 1995 and 2002. Fertil. Steril. 93 (3), 725–736. https://doi.org/10.1016/j.fertnstert.2008.10.049.
Chandra, A., Copen, C.E., Stephen, E.H., 2013. Infertility and impaired fecundity in the United States, 1982-2010: data from the National Survey of Family Growth. Natl. Health Stat. Rep. (67), 1–18 Aug 14, 1 p following 19. Permanent link. http://purl.fdlp.gov/GPO/gpo46851.
Chapple, A., Salinas, M., Ziebland, S., McPherson, A., Macfarlane, A., 2007. Fertility issues: the perceptions and experiences of young men recently diagnosed and treated for cancer. J. Adolesc. Health 40, 69–75.
Morgan, T.J., Turner, L.W., Savitz, L.A., 1999. Factors influencing obstetrical care selection. Am. J. Health Stud. 15 (2), 100–106.

Peña Dolhun, E., Grumbach, K., Vranizan, K., Osmond, D., Bindman, A.B., 2001. Unlocking specialists' attitudes toward primary care gatekeepers. J. Fam. Pract. 50 (12), 1032–1037.

Peterson, B.D., Newton, C.R., Rosen, K.H., Skaggs, G.E., 2006. Gender differences in how men and women who are referred for IVF cope with infertility stress. Hum. Reprod. 21 (9), 2443–2449.

Präg, P., Mills, M.C., 2015. Assisted reproductive technology in Europe. Usage and regulation in the context of cross-border reproductive care. Fam. Soc. 43, 1–23.

Quinn, G.P., Vadaparampil, S.T., Lee, J.H., Jacobsen, P.B., Bepler, G., Lancaster, J., Keefe, D.L., Albrecht, T.L., 2009. Physician referral for fertility preservation in oncology patients: a national study of practice behaviors. J. Clin. Oncol. 27 (35), 5952–5957. https://doi.org/10.1200/JCO.2009.23.0250.

Sobota, A., Zakinci, G., 2014. Fertility and parenthood issues in young female cancer patients – a systematic review. J. Cancer Surviv. 8, 707–721. https://doi.org/10.1007/s11764-014-0388-9.

St. Peter, R.F., 1997. Data Bull (Cent Stud Health Syst Change). 1997(Fall), 7, 1-2.

Strauss, A., Corbin, J., 1990. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. Sage Publications, Newbury Park, CA.

White, L., McQuillan, J., Greil, A.L., Johnson, D.R., 2005. Infertility: testing a helpseeking model. Soc. Sci. Med. 62 (4), 1031–1041 (2006 Feb, Epub 2005 Dec 19).

White, L., McQuillan, J., Greil, A.L., 2006. Explaining disparities in treatment seeking: the case of infertility. Fertil. Steril. 85 (4), 853–857. https://doi.org/10.1016/j.fertnstert.2005.11.039.

Yee, S., Abrol, K., McDonald, M., Tonelli, M., Lin, K., 2012. Addressing oncofertility needs: views of female cancer patients in fertility preservation. J. Psychosoc. Oncol. 30 (3), 331–346. https://doi.org/10.1080/07347332.2012.664257.

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