From generalist to specialist: A qualitative study of the perceptions of infertility patients

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Abstract Few studies explore in-depth accounts of women's and men's experiences with, and transitions between, obstetrician/gynaecologists (OB/GYNs) and reproductive endocrinologists during infertility diagnostic and treatment processes. This study examined this subject matter with data from qualitative, in-depth, semi-structured interviews. Between April 2007 and March 2008, the first author interviewed 20 women and eight men from a large midwestern metropolitan area in the USA who had used, or were in the process of using, any fertility treatment in the 5 years preceding the interview. Six couples and 16 individuals were interviewed, resulting in narratives of 22 distinct infertility journeys. The main complaints made by respondents about OB/GYNs were that they were insufficiently concerned with providing timely treatment and that they paid insufficient attention to male partners. Women felt that their concerns were taken more seriously by reproductive endocrinologists, but complained of insensitivity, depersonalization and misinformation, and were suspicious of a profit orientation.

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Introduction

Approximately 8% of women of childbearing age in the USA meet medical criteria for infertility, and approximately half of them seek fertility treatment (Chandra et al., 2013, 2014). Experiencing fertility problems can be stressful for women and men (De Berardis et al., 2014; Pasch et al., 2016; Péloquin et al., 2018) as they constitute barriers to achieving many people's central life goal: starting or extending a family. Fertility treatment is also stressful and the 'burden of care' can be a major factor in discontinuing treatment (Becker and Nachtingall, 1991; Brandes et al.,...
The burden of care, or burden of treatment, has been associated with the physical, financial, temporal and psychosocial management of chronic illness (Sav et al., 2012). It is thus important to study patient perceptions of, and satisfaction with, fertility treatment processes to help reduce the burden of care.

One important step along the infertility journey for many is the transition from generalist to specialist, yet few studies explore in-depth accounts of women’s and men’s experiences with, and transitions between, obstetrician/gynaecologists (OB/GYNs) and reproductive endocrinologists during infertility diagnostic and treatment processes. Thus, this study used in-depth qualitative interview data to analyse women’s and men’s satisfaction with fertility treatments with generalists and specialists.

**Patient satisfaction with fertility treatment**

A growing body of research focuses on patient satisfaction with fertility treatment, although measuring patient satisfaction is complex (Sitzia, 1999; Sofaer and Firminger, 2005). Most fertility patients report relative satisfaction with their care, but also see room for improvement (Gonen, 2016; Klitzman, 2018b; Mourad et al., 2009, 2010; Schmidt et al., 2003; Shandley et al., 2020; Souter et al., 1998; van Empel et al., 2010). Many studies on patient satisfaction focus on patient-centred care, the definition of which has substantial agreement globally (Dancet et al., 2012). Patient satisfaction with fertility treatment is associated with timely access to care, good communication and information, effective organization, feeling that providers are competent and experienced, receiving accurate diagnoses, personalized care, and being treated respectfully and involved in decision-making (Apers et al., 2017; Borghi et al., 2019; Dancet et al., 2010; Groh and Wagner, 2005; Haagen et al., 2008; Hammarberg et al., 2001; Klitzman, 2018b; Leite et al., 2005; Leone et al., 2018; Malin et al., 2001; Mourad et al., 2009, 2010; Redshaw et al., 2007; Schmidt et al., 2003; Shandley et al., 2020; Smeenk et al., 2004; Souter et al., 1998).

Pregnancy success increases the chances of satisfaction among fertility patients (Dancet et al., 2010; Schmidt et al., 2003; Shandley et al., 2020), but even patients who have not achieved a successful pregnancy tend to report treatment satisfaction if they perceive that everything medically possible had been attempted (Malin et al., 2001). Lack of patient satisfaction may stem from undesired medical outcomes (van Langenberg and Adams, 2012) and/or unmet expectations (Jackson et al., 2001). One common cause of dissatisfaction is perceived unnecessary treatment delay (Dancet et al., 2010; Malin et al., 2001). Timely treatment is important, not only because patients want this, but also because fecundity decreases with age. Patient-centred care and quality of life are positively correlated, yet the causal direction of the relationship is unclear (Aarts et al., 2011; Apers et al., 2017; Gameiro et al., 2013). Thus, while it is important to continue research on more effective fertility treatments, it is equally important to consider the satisfaction of fertility patients and patient-centered care.

Most patient satisfaction studies rely on cross-sectional survey data, which are useful but fail to capture the dynamic nature of the fertility treatment process (Gerrity, 2011; Klitzman, 2018b). Based on the National Survey of Fertility Barriers, Greil et al. (2013) found that 11% of ever-infertile women considered treatment and stopped there, 8% talked to a doctor but went no further, 10% had tests but no treatments, 13% had treatments but did not use assisted reproductive technology (ART), and 5% used ART. Both scholars (Klitzman, 2018a; Malik and Coulson, 2010) and patients (Palmer-Wackerly and Krieger, 2015) describe infertility as a journey characterized by multiple emotional, physical and financial struggles. Most individuals and couples who have pursued fertility treatments have faced roadblocks, detours, changes in personnel, and often long waits during their infertility journeys.

One important step along the infertility journey is the transition from generalist to specialist, usually a reproductive endocrinologist. General patient satisfaction studies on patients with chronic conditions have shown that quality of care was rated more highly by patients seen by a specialist for their specific chronic condition (Diets et al., 2001), including infertility (Souter et al., 1998). A systematic review (Harrold et al., 1999) revealed that specialists, compared with generalists, were reported to be more knowledgeable about conditions encompassed within their specialty, and used more diagnostic tests and procedures.

Most fertility clinic patients are referred by other doctors (Marcus et al., 2007), including general practitioners (GPs), OB/GYNs, paediatricians, geneticists, psychologists and oncologists (Klitzman, 2018a). Most fertility patients first contact GPs in Canada and the UK (Ballard et al., 2006; Daniluk, 2001; Hinton et al., 2012) and OB/GYNs in the USA (Greil, 1991).

Transitioning from generalist to specialist can be problematic, hindered by unclear boundaries, conflicts of interest between generalists and specialists, and generalists’ lack of nuanced knowledge about infertility, including the importance of timely treatment (Cain and Jonsen, 1992; Klitzman, 2018a). Research from Canada, the UK and the USA revealed that generalists are often reluctant to refer to specialists, and that patients must often insist on a referral or find a fertility specialist independently (Daniluk, 2001; Greil, 1991; Hinton et al., 2012; Klitzman, 2018a). Fertility clinics have higher patient satisfaction ratings than more general practices (Souter et al., 1998).

The aforementioned studies are either purely theoretical (Cain and Jonsen, 1992), focus on generalists (Hinton et al., 2012), include women alone (Souter et al., 1998), or do not concentrate on patient perceptions of generalists versus specialists (Daniluk, 2001; Greil, 1991; Klitzman, 2018a; Souter et al., 1998). As such, the purpose of the present study is to provide in-depth accounts of women’s and men’s experiences with, and transitions between, OB/GYNs and reproductive endocrinologists during infertility diagnostic and treatment processes.

**Materials and methods**

This study is based on qualitative, in-depth, semi-structured, interview data. Between April 2007 and March 2009; Domar et al., 2010; Gameiro et al., 2012; Olivius et al., 2004; van Empel et al., 2011; Verberg et al., 2008). The burden of care, or burden of treatment, has been associated with the physical, financial, temporal and psychosocial management of chronic illness (Sav et al., 2012). It is thus important to study patient perceptions of, and satisfaction with, fertility treatment processes to help reduce the burden of care.

One important step along the infertility journey for many is the transition from generalist to specialist, yet few studies explore in-depth accounts of women’s and men’s experiences with, and transitions between, obstetrician/gynaecologists (OB/GYNs) and reproductive endocrinologists during infertility diagnostic and treatment processes. Thus, this study used in-depth qualitative interview data to analyse women’s and men’s satisfaction with fertility treatments with generalists and specialists.
2008, the first author interviewed 20 women and eight men (more women volunteered for the study) from a large midwestern US metropolitan area who had used, or were in the process of using, any fertility treatment in the 5 years preceding the interview. Everyone in the sample utilized fertility treatment in the context of US privatized medicine, and all respondents had some form of private insurance. Some people’s private insurance covered some treatments, whereas others paid high out-of-pocket prices. The majority of the sample were middle-class and could afford some out-of-pocket costs, but they also decided against some treatments based on cost. Six couples and 16 individuals were interviewed, resulting in 22 distinct infertility journey narratives. The study was approved by university review boards, and participants were recruited through university list-serves and newsletters, personal connections, community bulletin boards and snowball sampling. All participants signed informed consent statements and were given pseudonyms. Interviews were recorded digitally by the first author and transcribed under her supervision. Interviews occurred in respondents’ homes and offices, and in the interviewer’s office. When no other options were available, two interviews were conducted by telephone, and one at the interviewer’s home. Interviews lasted for approximately 1 h for an individual or 2 h for a couple if they were interviewed together due to scheduling issues. Four couples were interviewed together, and two were interviewed separately. No incentives were given to participants. Table 1 shows the participant demographics.

Data were analysed using the grounded theory approach, which aims to reveal and raise analytic issues about meanings that participants give to phenomena. This inductive approach builds conceptual themes from respondent accounts rather than testing or verifying existing theories (Charmaz, 1990). Each line was coded, looking at respondents’ accounts of experiences with physicians and fertility clinic staff. The lead author and two research assistants (RAs) read and re-read the interviews and had multiple discussions when preliminary coding identified several potential analytic categories. Additional readings of the interviews were conducted to find and further situate additional excerpts within the context of the interview to refine the category and outline its various dimensions. The RAs and professor discussed ambiguous cases and either reached consensus for inter-rater reliability or decided not to include the quote (in the few cases of unresolved disagreement). As all interview questions were answered by all respondents, there was a certain amount of systematic and comprehensive coding. However, given the variation in answers, in addition to supplementary answers and probes, coding was fluid and subject to change. OB/GYN and reproductive endocrinologist office staff were only counted once within each theme; if there were several quotes in a theme from the same respondent about the same physician, they were only counted once as an example/counterexample of the theme.

Results

Starting the process

Women were often the initiators of seeking medical help, many associating fertility with women’s bodies. Most women initially brought their fertility concerns to their OB/GYNs, some as part of an appointment that was already scheduled for other purposes. Other women made a special appointment because getting an appointment with an OB/GYN was easier and quicker than seeking an infertility specialist. Moreover, they hoped that their OB/GYNs, as pregnancy experts, would be able to resolve the potential problem with less invasive and less costly treatments, thinking (or hoping) that the problems were minor. Thus, the system is set up to deal more readily with women’s fertility than men’s fertility as women go to OB/GYNs on a nearly annual basis.

Only one couple, Peter and his wife, went directly to a reproductive endocrinologist without talking first to a generalist about infertility, because they were older and Peter’s wife had experienced two miscarriages. Additionally, one young woman, suspecting fertility issues due to menstrual irregularities, wanted to begin with a reproductive endocrinologist, but due to the reproductive endocrinologist’s waiting list, went to an endocrinologist and then an OB/GYN.

Six women and one man began their treatment journeys with primary care physicians. Two women went to their GPs complaining of other health issues that they did not think were fertility-related and eventually pursued fertility issues with specialists when those issues were discovered. The others approached their GPs with fertility-related issues. The man was very proactive and asked his doctor for sperm testing before he and his wife further pursued specialist fertility care, which was interesting given that his wife was more interested in having children. Two women were dissatisfied with their GPs and switched to OB/GYNs, and the other GPs referred their patients to OB/GYNs.

Waiting with the OB/GYN

Some women, like Cameron (age 29 years), Marita (age 26 years) and Tonia (age 30 years), were treated immediately by OB/GYNs with Clomid and became pregnant within 6 months. Cameron’s OB/GYN treated her due to her own insistence, or what she called ‘impatience’. Most interviewees, however, reported that their OB/GYNs recommended waiting for 1 year before starting treatment. For example, when Hillary, a 31-year-old registered nurse, revealed her infertility suspicions to her OB/GYN, she was told to ‘try harder’. It is standard procedure to delay fertility treatment until patients have attempted to become pregnant for 6 months (older patients) or 1 year (younger patients), but it appears that many OB/GYNs were disinclined to count the time that patients reported ‘trying’ as part of the waiting period.
Table 1  Demographics of participants.

| Pseudonym       | Male/female | Race    | Partnership | Age (years)\(a\) | Treatment duration\(b\) | Live birth | Birth type |
|-----------------|-------------|---------|-------------|-------------------|--------------------------|------------|------------|
| Ada             | F           | White   | Hetero      | 33                | 1 year                   | N/A        | N/A        |
| Bob Hollander   | M           | White   | Hetero      | 54, 60            | 3.5 years (T1) 6 months (T2) | Y          | Single     |
| Christine       | F           | White   | Hetero      | 41, 47            | 3.5 years (T1) 6 months (T2) | Y          | Single     |
| Hollander       |             |         |             |                   |                          |            |            |
| Cassandra       | F           | White   | Hetero      | 26                | 2 years\(c\)              | N           | N/A        |
| Leslie          | F           | White   | Hetero      | 39                | 2 years\(c\)              | N           | N/A        |
| Cary            | M           | White   | Hetero      | 40                | 2 years\(c\)              | N           | N/A        |
| Cameron         | F           | White   | Hetero      | 29, 32            | < 6 months (T1) < 6 months (T2) | Y          | Single     |
| Edward          | M           | White   | Hetero      | 30                | 1.5 years               | N           | N/A        |
| Ellen           | F           | White   | Hetero      | 29                | 1.5 years               | N           | N/A        |
| Ella            | F           | White   | Hetero      | 34                | 4 years                  | Y          | Single     |
| Erin Garcia     | F           | White   | Hetero      | 29, 33, 35        | 2.5 years (T1) 6 months (T2) 1 attempt (T3) | Y          | Single     |
| Ramon Garcia    | M           | Hispanic| Hetero      | 31, 35, 37        | 2.5 years (T1) 6 months (T2) 1 attempt (T3) | Y          | Single     |
| Hillary         | F           | White   | Hetero      | 31                | 1 year                   | Y          | Triplets   |
| Iris            | F           | White   | Hetero      | 29                | 6 years                  | Y          | Single     |
| Jaime           | F           | White   | Hetero      | 26                | 9 months\(c\)            | N           | N/A        |
| Jalila          | F           | Arab    | Lesbian     | 28                | 2 years                  | Y          | Single     |
| Julie Marley    | F           | White   | Hetero      | 30                | 2 years\(c\)              | N           | N/A        |
| Kevin Marley    | M           | White   | Hetero      | 29                | 2 years\(c\)              | N           | N/A        |
| Marita          | F           | Latina  | Hetero      | 26, 28            | 6 months (T1) 6 months (T2) | Y          | Single     |
| Mai             | F           | White   | Hetero      | 24                | 4 years                  | N           | N/A        |
| Patty           | F           | White   | Lesbian     | 33, 37            | 2 years (T1) 1 year (T2)  | Y unknown  | Single     |
| Peter           | M           | White   | Hetero      | 39                | 1–2 years               | Y          | Twins      |
| Reece           | F           | White   | Hetero      | 30                | 4 years                  | N           | N/A        |
| Robin Vick      | F           | White   | Hetero      | 28                | 3 years                  | Y          | Twins      |
| Kirk Vick       | M           | White   | Hetero      | 29                | 3 years                  | Y          | Twins      |
| Sasha           | F           | White   | Hetero      | 35                | 3–4 months              | Y          | Single     |
| Terry           | M           | White   | Hetero      | 30                | 1 year                   | N           | N/A        |
| Tonia           | F           | Hispanic| Hetero      | 30                | <6 months                | Y          | Single     |

T1, Time 1 (first round of fertility treatment); T2, Time 2 (second round of fertility treatment); T3, Time 3 (third round of fertility treatment). Adjacent shaded rows represent partnerships.\(a\) Approximate age at onset of treatment process.\(b\) Treatment duration periods are rounded and approximated. The time period begins with the diagnostic process until the conclusion of treatments or time of interview if currently still in treatment and include short waiting periods in between treatments.\(c\) Treatment ongoing.
OB/GYNs may lack of a sense of urgency because most of their clients do not present for infertility issues. OB/GYNs may think of ‘normal’ women’s bodies as being able to become pregnant relatively easily; an assumption that was shared by many women who began their treatment with OB/GYNs. Cassandra, for example, ‘didn’t anticipate a lot of problems’, probably due, in part, to her young age (26 years). Marita (age 26 years) believed that society generally also views women’s bodies as having the capacity to become pregnant easily, and felt guilty for perpetuating this idea when she was pregnant in public: ‘When people see a pregnant woman you don’t go “I wonder if it’s easy for her to get pregnant?” Why would you…? …I am perpetuating that myth just by walking around pregnant.’ The presumption of normality, however, may be challenged under certain circumstances. Some women were referred to a specialist quickly if they presented with symptoms that OB/GYNs perceived as indicators of specifically defined diseases, such as Cassandra’s severe endometriosis and Sasha’s history of miscarriage (paired with her age of 35 years).

OB/GYNs understand that women’s fecundity starts to decline at around 25 years of age and decreases more sharply after 35 years of age (Leridon, 2008). The folk version of this knowledge, ‘the theory of the aging egg’, draws the boundary between normal and ‘at risk’ at 35 years of age, which can Ironically lead to treatment delay for younger women with fertility issues. Reece discussed her OB/GYN: ‘They felt like I was young, in my thirties and just to kind of wait.’ However, the ‘magic number’ of 35 was not applied to everyone. Cameron was under 30 years of age, but her OB/GYN started her on fertility drugs after only a few months due to Cameron’s insistence. Ellen, also under 30 years of age, went to an OB/GYN because of the long waiting list to see a reproductive endocrinologist, and her new OB/GYN advised her not to wait because of her irregular menstrual cycle. On the other hand, Christine (in her mid-40s) and her husband (in his late 50s) felt that their OB/GYN who treated them for 2 years should have provided a specialist referral sooner, based on their medical issues, ages and, particularly, Christine’s desire for biological children.

A focus on women

One potential problem with the presumption that aging eggs are a major source of infertility is that this may lead OB/GYNs to pay insufficient attention to men’s bodies, but this is unsurprising because their training and daily practice focuses on women. It is notable, however, that there is no comparable ‘aging sperm’ theory (Fausto-Sterling, 1992), despite studies revealing associations between deteriorating sperm quality and aging (Almeida et al., 2017; Matorres et al., 2011). Based on listening to women’s accounts in her infertility support group, Ellen (age 29 years) found the tendency to focus almost exclusively on women problematic:

I go to a support group. …The problem…lies with the husband somehow, and they still put those women on fertility drugs, which just blows my mind… they are putting a healthy woman on all those drugs. That…is…disappointing. That it’s always the woman’s problem even if it’s not the woman’s problem.

Other women felt that their body, not that of their male partner, was viewed as abnormal. When Cameron, a 29-year-old woman, was asked why her husband had not been tested, she answered, ‘…that’s a good question, I don’t know. He has never impregnated anyone’, reflecting that she, too, had assumed that her body was the problem. It is worth noting that Cameron became pregnant soon after taking drugs prescribed by her OB/GYN; it is possible that if she had continued the treatment process, her husband might have been tested. Ella, a 34-year-old, endured 4 years of multiple miscarriages with physicians focusing solely on her body, ultimately to discover that her husband had a chromosomal disorder.

Feeling dismissed

The lack of urgency of OB/GYNs about not getting pregnant was greeted positively by some women. Cassandra (age 26 years) was relieved to wait 1 year because it meant avoiding potentially invasive procedures, even though she was more invested in having children than her husband. In contrast, Reece (age 30 years) interpreted the recommendation to wait as implying that her gynaecologist was not ‘really concerned’ and thought that she was overly worried about infertility. Mai (age 24 years) had to convince her OB/GYN to be more proactive after other GPs assumed that her problems were psychological:

They told me to take some Zoloft… I was not depressed. Nobody was listening…. I was tired of not being listened to. I stomped my foot and shook my fist at my gynaecologist…. told the doctor to start listening to me. I told the doctor my symptoms. I gained 60 pounds in 1 year… was sick all the time. I looked terrible. My skin was white and pasty. I used to be young….healthy and attractive. Marriage is not supposed to take that big a toll on you.

Some women’s sense of dismissal came from feeling depersonalized by OB/GYNs, although this was more often directed at reproductive endocrinologists (see below). For example, Cassandra (age 26 years) reported that her OB/GYN relied on ‘bloodwork and numbers’:

…numbers need to be placed in the context of a person’s history. I was not pleased with the doctor who would not look at…patterns in my charts and really see me as an individual instead of one member of this larger population.

Others felt that their physicians lacked empathy. Erin (age 29 years) and Ramon (age 31 years) did not appreciate a ‘cold’ midwife in their OB/GYN’s office, and Ellen (age 29 years) expressed a similar concern:

The woman saw…my…file, that I was going through fertility treatment and she…said all the wrong things,… that she had 3 boys and something to the effect of ‘you’re lucky; there’s a lot of days where I wish I didn’t have kids’. And I was thinking, ‘I’ll take your children if you seriously mean that, but you don’t’. And I think
she saw that what she said upset me so then she tried to make it better by saying, 'But I do understand that it's such a special thing that two people come together and create something’. And I’m thinking, 'What if we can’t do that?’. I started crying, and it was bad.

Many women felt that their diagnoses and/or care, particularly by OB/GYNs, was delayed due to their physicians’ lack of trust in their knowledge of their own bodies. Julie (age 30 years) mentioned being dismissed by her OB/GYN as possibly being the reason for her unsuccessful treatment: ‘I kept trying to tell him that I’m a late ovulator. I know this. The doctor just never took to it. He would always stop [treatment] too soon or check too late.’ Jalila’s (age 28 years) OB/GYN dismissed her self-diagnosis of polycystic ovarian syndrome (PCOS). Cassandra (age 26 years) charted her monthly cycles and was insistent about having her lay knowledge respected. She went through a few OB/GYNs until she found someone who was open to her charting.

These negative experiences, along with the inability to become pregnant, led some women to eventually seek the expertise of a reproductive endocrinologist. Reproductive endocrinologist evaluations often served as the means of evaluating the treatment that patients received from their OB/GYNs; it was not always apparent whether OB/GYNs had been pursuing appropriate diagnoses until specialists gave different diagnoses/treatments. For example, Jalila’s self-diagnosed PCOS that had been dismissed by her OB/GYN was confirmed by the reproductive endocrinologist. Erin (age 29 years) was frustrated after several OB/GYN visits that consisted of some tests and fertility drugs. Finally, one physician diagnosed her with PCOS, which led her to seek out a specialist independently, who also found male factor infertility.

At the fertility clinic

Upon arrival at the fertility clinic, women witnessed an increased sense of urgency. During her second attempt, Patty reported her reproductive endocrinologist saying, ‘Let’s face it. You’re 37 years old. Some women’s bodies prepare to shut down. You may be preparing’. This increased pace of care was also experienced by women under 35 years of age. Specialists treat many women in their early 30s and younger. US national data show that the majority of those using either fresh or frozen embryos were under 35 years of age (Centers for Disease Control and Prevention, 2018). Of the eight women in this study who used ART, five were aged < 35 years when they initiated medical help-seeking.

As reproductive endocrinologists routinely treat patients who require medical assistance to become pregnant, they may be primed to view women’s bodies as ‘abnormal’, which ironically legitimizes and normalizes women’s concerns. Some women expressed relief that reproductive endocrinologists were more attentive to what they were saying and to their recorded symptoms. As Mai (age 24 years) recounted: ‘He looked at my chart for a minute and a half … told me I had polycystic ovarian disease. Nobody said anything about it in 5 years!’

Moreover, women felt like the reproductive endocrinologists were more proactive about pursuing a diagnosis; for example, by ordering more tests. Sasha (age 35 years) was one such person, but she also mentioned the possibility of some over-testing at the fertility clinic. Edward (age 30 years) also questioned the high utilization of technologies. Although his sperm tested normal, the fertility clinic tested and treated it before every insemination: ‘At [hospital name] they will test everything if they have the ability and technology. They would rather do the test, regardless of whether it is indicated or not.’

Reproductive endocrinologists may move quickly due to the availability of high impact treatments (Balasch; 2000; Brosens et al., 2004). Bob and Christine’s specialist moved quickly (probably due to their advanced ages) with the motto ‘you try twice, then… on to the next step’ (or stay at the highest level for a while). They had two unsuccessful donor sperm inseminations, then tried in-vitro fertilization (IVF) twice with his sperm and donor egg, which resulted in one miscarriage and no pregnancy the second time. This led the doctor to the assumption that the sperm were not viable despite the recent pregnancy. Bob and Christine then progressed to donor egg and donor sperm for three rounds of IVF until achieving a successful pregnancy.

On the other hand, some women felt that the preferences of reproductive endocrinologists for highly technical diagnostic testing or standardized treatments led them to discount patients’ own narratives. Cassandra (age 26 years) recounted a discussion with her reproductive endocrinologist about a medication that gave her severe side effects:

‘Seventy-five probably is what they gave me… the smallest dose, and I… told them at the outset, ‘I’m very sensitive to medications’. They said, ‘Well, this is the lowest dose we give to patients’. I… feel like they didn’t listen to me, and… they should have started me out lower.

Mai (age 24 years) talked about a reproductive endocrinologist who did not respond well to having his expertise challenged by her, and an emergency room (ER) physician who treated her for a side effect from her fertility medication:

He [ER doctor] said that I couldn’t take the medication anymore, because the dosage was… too high. … too much too soon. He [reproductive endocrinologist] should have eased me into it. It shut my system down and burst a little vein in my head. He [ER doctor] told me I had to stop taking right then… I stopped taking it and went… to see [reproductive endocrinologist]. He [reproductive endocrinologist] said if I was not going to take the medication and not listen to him, then I was not serious about getting healthy.

Feeling dismissed by her reproductive endocrinologist, Mai switched to nurse and midwifery care and Eastern medicine.

In addition to raising health concerns, dismissing women’s knowledge and experiences may also contribute to the overconsumption of diagnostic testing, which ironically potentially delays diagnoses. Sasha (age 35 years) explained that her reproductive endocrinologist dismissed her menstrual cycle charting data, and lamented that if he had paid attention to the charts, some of the diagnostic testing, which she described as ‘too much, too quickly’, could have been avoided:
From the charts, you could see that my temperature, based on this book...and...’Fertility Friend’...wasn’t rising like it should after you ovulated. It was a low rise...an indication of low progesterone. But my fertility doctor didn’t believe in charts. He was like, 'Whatever, that doesn’t tell me anything'. I probably could have foregone some of the...testing...that showed that I had low progesterone.

Sasha 'expected' this behaviour 'out of a Western doctor', and took the initiative to complement her fertility treatments with acupuncture and continue menstrual charting, which was reinforced by a friendship network that was also charting.

Alongside an over-reliance on technology and mistrust in women’s own bodily knowledge comes a certain amount of depersonalization, defined in medical sociology as a process where many biomedical clinicians fail to fully acknowledge the individual patient, but rather refer to, and treat, the patient based on statistical probabilities and biological processes (Broom and Tovey, 2007). The respondents in the present study felt depersonalized by both OB/GYNs and reproductive endocrinologists, but reported both more negative, depersonalization encounters and more positive, personalized experiences with reproductive endocrinologist offices.

On the positive side, Julie (age 30 years) described her reproductive endocrinologist as 'nice and funny', and Patty (age 33 years) and Sasha (age 35 years) felt that they received more personalized care from reproductive endocrinologist office staff than from OB/GYNs. Moreover, for some people, the physician’s personal, caring attitude made a generally depersonalized fertility process more tolerable. Although Kirk (age 29 years) and Robin (age 28 years) said they sometimes felt like they were on an assembly line due to the need to align treatments with Robin’s reproductive cycle, they still felt that the reproductive endocrinologist office staff cared about them more than their OB/GYN.

Peter (age 39 years) and his wife saw the general process of fertility treatments as impersonal: ‘Just give it time.’ That’s awful! Here is this thing they see. I was pretty numb...they see. I was pretty numb and...didn’t hear anything.

Edward (age 30 years) was bothered by his wife’s reproductive endocrinologist’s ‘dehumanizing’ treatment: There wasn’t a lot of focus on our individual situation by the medical people, at least that’s the impression...I got. It was more the focus on ‘this is what we do’ and you’re going through what they do rather than think about ‘this is who you are, let’s focus on you’...I’m fine with the medical stuff, but...wish they would focus more on individual patients...try to give the best possible experience rather than focusing on the treatments and how we can best give treatments to...patients.

Consequently, some people, like Patty (age 33 years), questioned the efficacy of the medications if they were being treated ‘like one of a million’. She described her reproductive endocrinologist reaching for a prescription pad: ‘They were pre-printed..., and all she had to do was put my name in them. They already had the dosage, and the medicine, and signatures. I thought, ‘Is this really gonna work?’

Jalila (age 28 years) gave similar example from when her PCOS self-diagnosis was dismissed by the OB/GYN and then a reproductive endocrinologist seemingly randomly prescribed Clomid:

...did not do a good job of listening to me...I went into our initial consultation with [reproductive endocrinologist]; I said I don’t have any kind of diagnosis but really think I have PCOS and here are seven reasons why. She said ‘oh that’s fine, we have Clomid’ that will fix whatever we find. After...nothing was happening she called us into a consultation and...wanted to tell us about this thing called PCOS and I said ‘really, really, really’. She talked to me about not eating sugar and I said I don’t even eat f*****g carrots. Like clearly you have not heard anything I have said, and why have we just wasted the last few months?

Another depersonalization issue expressed by women was disappointment in the insensitivity of physicians about their feelings, and seeming lack of understanding of the emotional aspects of infertility. Several people regretted not having counselling, particularly around the sensitive issue of miscarriage. Although Patty’s (age 33 years) wife wanted children more than Patty, Patty became very invested in becoming pregnant and recalled her reproductive endocrinologist casually telling her that she will probably miscarry:

He kept telling me that I would probably abort on my own: ‘Just give it time.’ That’s awful! Here is this thing that I wanted so desperately.

Cassandra (age 26 years) described her visit to a reproductive endocrinologist’s office after she miscarried in a hotel room alone, away from home, after undergoing treatment for 2 years: Our dog was dead. Our baby was dead. I felt physically so sick...I went in, and they did a scan. What amazed me was the clinical precision with which they told me all these things. There is really no empathy...I guess that is to protect themselves from riding the ups and downs of every patient...they see. I was pretty numb and...didn’t hear anything.
Cassandra also described that a reproductive endocrinologist nurse tried to be positive, yet, in the process, actually dismissed her miscarriage concerns:

She said, ‘Well, at least you had a chance to get pregnant. A lot of women never get that far’. I thought, ‘This is my experience. I’m not comparing with what other women have done’. If I did, … my God, I could look at my mother and say, ‘She never had to go through anything that I went through, and … has 4 children’.

Jalila (age 28 years) also described a time when she felt emotionally and physically assaulted. A reproductive endocrinologist technician was very ‘rough’ with her vaginal sonogram, and then matter-of-factly told Jalila that the medication she was taking was not working, pulled the sonogram out, turned the lights on, and left the room. Jalila felt like it was ‘completely dehumanizing with my consent’. She continued, ‘I felt like okay I am just one more vagina and I think that was my worst day’.

Cassandra said that her depersonalized reproductive endocrinologist experiences led her to develop a ‘mistrust of conventional medicine, particularly the inability of Western doctors to see the relationship between … the mind and the body’. Yet she still has a ‘great deal of trust in science and in the scientific method’ and she respected ‘doctors who pursued medicine from that point of view’.

Unfortunately, she felt that those doctors were in the minority. Cassandra’s (age 26 years) frustration was directed towards her reproductive endocrinologist that was not insistent about tests and left the testing decision up to her. Terry (age 30 years), whose wife had the fertility issue, believed that some reproductive endocrinologists may be profit-oriented, but felt that her reproductive endocrinologist was motivated by a desire to help her become pregnant:

I don’t think he would have told me that just to collect another 10,000 dollars which some may have done. I really believe that he wanted this to work and this was a possibility.

Feeling left in the dark

Several respondents expressed dissatisfaction with feeling misinformed, inadequately informed, or even misled by their reproductive endocrinologists. Robin felt misinformed about normal cycle lengths. This delayed her move to a reproductive endocrinologist, who found male factor infertility, although Robin still assumes responsibility for infertility. Jamie complained of an emotionally ‘rough’ miscarriage process because she was misinformed by her reproductive endocrinologist about what to expect. Cary (age 40 years) wondered if ‘the reproductive endocrinologist didn’t lie to us before Christmas’ in order not to ruin their holiday cheer.

Terry (age 30 years) felt optimistic about treatment because the reproductive endocrinologist talked about past patients’ success stories and thus ‘felt cheated’ due to his wife’s unsuccessful treatment. Similarly, Edward (age 30 years), whose wife had the fertility issue, believed that the reproductive endocrinologist intentionally misled him to maintain his optimism, which he believes hindered his ability to deal with the emotional hardships caused by failure to conceive because he was very emotionally invested in having a biological child:

At the beginning they gave the impression that this was going to work for us…this is just a guess, there’s an assumption that if they can make you feel better about it then you’re gonna be more likely to conceive. Maybe they think the best thing to do is tell you, ‘Oh yeah this will be just fine’ rather than be realistic with you. Which is interesting, because, if people would have been more realistic up front, there’s a very good chance we might have actually dealt with the whole thing better.

Cassandra (age 26 years) and Mai (age 24 years) felt that their reproductive endocrinologists ‘misled’ them by not divulging drug side effects (Leyser-Whalen, 2014). This ended up having dire consequences for Mai:
He gave me some Glucophage... said I would feel better in 6 weeks, and we would talk about getting pregnant. Two trips to the ER, a brain haemorrhage later, I was not feeling better. He neglected to tell me that metformin has adverse effects in 10% of women. 1% have severely negative effects. I’m that 1%.

Other women felt inadequately informed about medications more generally. Ellen (age 29 years) described disappointment with her experience with a large fertility clinic:

...they would send you in the mail, at the end of your cycle, prescriptions for new drugs for your next cycle with a form letter saying ‘we hope you don’t need these but here’s the prescription if you do’. Before I had talked to a doctor, they sent me prescriptions. One month they sent me prescriptions for Clomid, two shots, progesterone suppositories and a bunch of needles. And nobody told me why I was getting the prescription... how to give myself... where to give myself shots... they hadn’t consulted with me about the risks, the benefits, about anything so I was really upset about that.

Hillary (age 31 years) twice received prescriptions that were the wrong dosage. One time, her pharmacist thought the dose was too high and refused to fill the prescription. Hillary said that when she called the clinic to ask about the medication, ‘they pulled my chart and decided that I didn’t need it’. She also describes a second instance:

...gave me the... shot to inject. They said here’s the powder, here’s the liquid, mix them, do it and use the whole vial. So I read the directions on the bottle; a dose was like a fourth of the vial, not the whole thing. I tried to call them after hours and they didn’t have anybody that was on call. I was afraid to overdose myself by giving myself that whole bottle even though that’s what the whole prescription would have been.

Discussion

The Institute of Medicine (2001) identified patient-centred care as one of six aims of the healthcare system. The present results are important if one is committed to patient-centred care as they further clarify fertility patient-centred care in relation to physician type in the hope of helping physicians to bridge evidence-based and patient-centred practices for women and men. Like other studies, the present study identified patient concerns about technical and emotional aspects of fertility treatments, and that when needs were not met, some patients pursued alternative medicine (Haagen et al., 2008). In addition to the need for accurate diagnoses and patient-centred care, new themes were identified, along with more specific subthemes related to diagnosis, treatment and communication.

This study contributes to the literature by providing an explicit comparison of women’s and men’s experiences with OB/GYNs versus reproductive endocrinologists. Like Souter et al. (1998), the present study found that respondents did not appear to have strong expectations about attending a general gynaecology clinic versus a specialist infertility clinic. It cannot be stated definitively that patients were more or less satisfied overall with generalists or specialists, due to the different patterns of patient concerns about each type of physician.

The findings on generalists resemble Klitzman’s (2018a) concerns about transitioning between generalist to specialist, including a failure to appreciate the need for timeliness, the tendency for lengthy continuation of ineffective treatments, and insufficient attention to male partners. Patients felt that physicians, mostly OB/GYNs, overlooked their concerns, presumably based on the idea that women’s bodies can easily become pregnant, and some younger women’s complaints of diagnostic delay were attributed to an ‘aging egg’ perspective. The present authors neither believe that physicians consciously uphold these ideas nor that they have nefarious intentions. Rather, these schemas reflect the larger gendered structures upon which the practice of medicine was built and which it continues to reinforce. This gendered medical gaze can even be internalized by women themselves (Gerrits, 2014); as shown in the results section, some women did not question that their body, rather than their husband’s body, was the sole focus of diagnosis and testing. Thus, it is recommended that efforts should be made to encourage generalists to pay greater attention to male bodies and take younger women’s concerns more seriously. An increased focus on male bodies may also help to alleviate some of the stigma that women feel about infertility, although women can still assume the stigma of infertility to protect their male partners (Miall, 1986), but this issue must be addressed carefully so as not to add to the current stigma associated with male infertility. Although this study is among the minority in infertility research that include men, the data were heavily skewed towards women (20 women and eight men in the sample); as such, there is still an ongoing need to include men in infertility research.

It is recommended that future social science and clinical research should continue to address gendered differences in the testing, treatment and perceptions of male partners.

Given patient frustrations with the timing of treatments and referrals, and the importance of time as a factor in patients’ experience of the burden of care (Sav et al., 2013), clinical guidelines concerning best transition times from lower to higher levels of care are also recommended. Willingness to follow these guidelines may be hindered by the privatized nature of the US healthcare system. As other studies note (Cain and Jonsen, 1992; Klitzman, 2018a), some generalists may take monetary considerations into account when deciding on when to refer (and thus ‘lose’) a patient to a specialist.

Regarding the findings on reproductive endocrinologists, women felt that their issues were addressed more seriously by reproductive endocrinologists, but complained of insensitivity, depersonalization and misinformation, and they were suspicious of a profit orientation. This is important because doctor–patient communication has been linked with the burden of care in the financial and psychosocial management of chronic illness (Sav et al., 2012). Many have highlighted the importance of good physician–patient communication (Dancet et al., 2010, 2012; Gameiro et al., 2013; Mourad et al., 2009, 2010; Souter et al., 1998). Ong et al. (1995) emphasized three purposes of doctor–patient communication: (1) good interpersonal relationships; (2) information exchange; and (3) treatment-related decision-making. Patients in the present sample often felt ill-
informed, with subthemes revealing that patients felt misled about fertility treatment success rates or suspicious of a profit orientation. ‘Exchanging information’ is different from ‘imparting information’; the former implies bilateral communication.

The misinformation issues and the perceived overutilization of tests/procedures may be alleviated if physicians better explain the purpose of tests/procedures in an information exchange. This, however, runs the risk of further medicalizing the knowledge that patients acquire, which situates knowledge and solutions in biomedical terms and makes patients more inclined to continue treatment (Gerrits, 2014). Daniluk (2001) found that couples could reflect on their medical decisions more objectively only after they had stopped pursuing fertility treatment. Thus, perhaps physicians recommending waiting times may be good for people’s autonomous decision-making, but this may be met with patient resistance given the felt urgency of the situation and their critiques of a lack of concern with timeliness on the part of OB/GYNs.

Another emergent subtheme was the sense that physicians, particularly OB/GYNs, were unconcerned with women’s own bodily knowledge. Women do not merely want to be informed. They want to be listened to and treated as experts on their own bodies; this may help to explain why more educated patients and those of higher socioeconomic status are less satisfied with fertility treatment compared with less privileged women (Schmidt et al., 2003). Treating patients as equals presents a dilemma for physicians, in an inherently unequal relationship where the perception is that the responsibility to bring about a successful pregnancy lies almost completely with the physician. Thus, there is a fundamental tension between patients’ and doctors’ decision-making control when doctors are ultimately responsible for treatment outcomes (Becker and Nachtigall, 1991), or, as Gerrits (2014) points out, patient-centred care can create new, complex physician–patient power dynamics. Somehow, physicians must find a way to make patients feel that they are respected, that their knowledge is valued, and that their doctors appreciate what they are going through, while still guiding them towards medically appropriate choices. This is particularly important as individuals and couples make many medical decisions during their fertility journey, which can last years.

These communication issues may be particularly important for patients who have ‘uninformed expectations’. Such patients may be incapable of communicating, or are reluctant to communicate, their expectations, either because they may not have clear expectations or because they do not wish to substantiate their feelings or cannot express them. Given the potential for uninformed expectations, patients should be educated about appropriate expectations for care (particularly technical features), and motivated to judge the quality of care they are receiving (Sofaer and Firminger, 2005). Given the time demands on physicians, this may be a need that counsellors can help fill. Physicians and healthcare staff, however, should not be the only sources of information provided to patients to avoid a one-sided or overly medicalized view.

The perception of physician and staff insensitivity reported by some respondents mirrors the findings of other studies on emotional hardships in all stages of the fertility treatment process (Verhaak et al., 2007). A very large fertility patient satisfaction survey in the UK revealed that most women felt that their emotional needs were overlooked (Souter et al., 1998). Patient-friendly physicians can help to alleviate the psychological burden (Dancet, 2011); thus, it is recommended that physician offices should consider staff sensitivity training. However, it is known that physicians are extremely busy, so it is also recommended that mechanisms should be created to facilitate accessing professional mental health services. Domar et al. (2010) found that the top-rated patient suggestion for stress reduction was easy and immediate access to psychologists or social workers. This is particularly relevant for patients in countries where fertility counselling is not mandatory; one study found that countries with a requirement for pre-IVF counselling and available counselling during all stages of treatment had some of the lowest percentages of patient dissatisfaction among men and women (Schmidt et al., 2003). It is also recommended that counselling should focus on couples, because infertility causes relationship stress (Luk and Loke, 2015; Nelson et al., 2008; Pasch and Sullivan, 2017).

In 1985–1986, Greil (1991) interviewed 22 infertile couples in the USA about their fertility treatment experiences, finding that all but one of the women in his sample broached their fertility problems with an OB/GYN. As far as he could tell, none of his sample were referred to a reproductive endocrinologist by an OB/GYN. He found that many interviewees felt dissatisfied with the slow pace of treatment, and that many women therefore became active agents in their own health care. Once people got to the reproductive endocrinologist, they were more satisfied with the pace and quality of their treatment, but they had complaints about depersonalization. Although it seems that not much has changed in 30 years, more OB/GYNs are referring patients to fertility clinics, and, although patients complain about the slow pace of treatment, the process does seem to have sped up somewhat.

Although some important differences were found between patient experiences with OB/GYNs and reproductive endocrinologists, generalizations should be made with extreme caution from this small qualitative study. The study sample was mainly white and of high socioeconomic status, so it cannot be claimed that the sample was representative of the US population. Further research into infertility experiences of people of colour and those who are less privileged is recommended. The present data included multiple physicians as the study patients went to many different physicians and some individual patients visited several physicians. It is recommended that future studies should collect larger-scale quantitative data that respect the dynamic quality of the infertility journey. It is also recommended that interview and survey data should be collected from physicians to understand their challenges. Despite the limitations of this study, the findings should be of interest to social scientists, policy makers and health practitioners.
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