An Overview of Infertility in the Muslim Refugee: Psychosocial Implications and Barriers to Care

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Background

Infertility, defined as the inability to conceive after at least one year of regular unprotected sexual intercourse, affects approximately 70-80 million couples worldwide.[1, 2] Infertile couples face a variety of psychological and social consequences, and for refugee populations the distress of infertility may be exacerbated by stressful life circumstances, the cultural importance of childbearing, and multiple barriers to treatment.[3-5] For Muslim refugees in particular, infertility carries significant social stigma, and religious doctrines limit the options available for treatment.[3] This paper examines the psychosocial impact of infertility among Muslim refugees and explores barriers to care for this population.

Impact of infertility

Middle Eastern societies are often described as "pronatalist," referring to the high societal value placed on having children.[3, 6] Childbearing is viewed as an accomplishment of adulthood and brings happiness and fulfillment to a marriage.[4, 6] Couples are expected to bear children early in marriage, and children provide social status and security later in life.[3, 6] For refugee populations in particular, children may bring a sense of hope to families who have fled from genocide and war.[5]

For Muslim couples, infertility may bring severe stigma, scrutiny, and social isolation from their communities.[4, 7] Infertility also may cause marital discord, and some women from developing countries may experience domestic violence as a result of not conceiving.[7] If one partner is identified to be infertile, the other partner's desire for children may lead them to leave their infertile spouse.[4, 7]

Because infertility is described in Islamic scripture as a God-given impairment, profound feelings of guilt may result from the inability to conceive, as it may be perceived as a punishment from God. For example, an Iraqi man who after arriving in the US had multiple sexual partners, revealed in an interview that he viewed his infertility as possibly being punishment for his behavior, telling his interviewer, "maybe I 'spent' all of my sperm back before marriage, because I had an active sex life.... I did what I did, but it wasn't right… maybe God wants to punish me."[4]

Interestingly, while it is estimated that less than half of infertile women in industrialized nations seek treatment for infertility, the profound stigma and distress caused by infertility among couples from developing nations often drives them to seek fertility treatment relatively early, at

times within 6 months of unsuccessfully trying to conceive.[7]

Management of infertility for the Muslim patient

Causes of infertility

Infertility can be caused by a multitude of factors, which are often divided into female factors (ovulatory dysfunction, tubal obstruction, uterine abnormalities, peritoneal factors, cervical factors) and male factors (systemic disease/infection, anatomic variances, genetic abnormalities, toxin exposure, sperm antibodies).[2] It is estimated that one-third of infertility is due to female factors, one-third is due to male factors, and the remaining one-third is either unexplained or a combination of male and female factors.[8]

Patients from developing countries may have additional risk factors for infertility. For instance, tubal scarring as a sequelae of prior pelvic infection (such as from an untreated sexually transmitted disease or from infections after childbirth/abortions) may be more common in patients from a developing country who had limited access to health care.[5, 7] Additionally, environmental factors such as dietary deficiencies and exposure to arsenic, heavy metals, industrial chemicals, and other toxins may contribute to reduced fertility.[7] In some cases, the historical practice of consanguineous marriages between cousins in certain Middle Eastern populations may result in genetic mutations affecting male fertility.[4, 6]

Evaluation and treatment of the Muslim patient with infertility

The evaluation of infertility first begins with a thorough history and physical. According to an algorithm by the American Academy of Family Physicians, referral to infertility specialists or referral for assisted reproductive technologies (ART) is the final step in the initial evaluation of infertility.[2] ART is defined by the World Health Organization as "all treatments or procedures that include the in vitro handling of both human oocytes and sperm or of embryos for the purpose of establishing a pregnancy."[9] This includes in-vitro fertilization, and its counterpart, intracytoplasmic sperm injection (ISCI), where dysfunctional sperm is injected into an oocyte to treat male factor infertility.[9]

It should be noted that although in the Qur'an infertility is regarded as an impairment given to an individual by God, the development of ART is considered a "gift" from God to help infertile couples conceive.[10] Fatwas (authoritative clerical opinions) have deemed ART permissible[6, 10,11] but some clerics (particularly Sunni religious authorities) have released fatwas banning the use of donor gametes due to concern that use of donor eggs or sperm would result in an unclear lineage for families and risk possible incest among donor children.[3, 6, 10] On the other hand, some Shia clerics have released fatwas authorizing the use of donor gametes, and as a result the only two Muslim nations where donor gametes are used are Shia-dominant Lebanon and Iran.[6, 10] Even still, Muslim men have a strong desire to be biological fathers to their children and are often opposed to sperm donation.[6] Muslim men have various reasons for opposing the use of sperm donors, such as concern that

the paternity of their children would be unknown, feelings of emasculation, or worries about inheritance and legitimacy of their children in a patrilineal society.[6] Egg donation may be viewed more favorably by some Muslims as paternity would be clear.[6] Additionally, some rationalize egg donation by comparing it to polygyny, which historically has been permissible in Muslim societies.[6]

In addition to limitations on the use of donor gametes, adoption is prohibited by religious doctrine.[3, 6, 11] Therefore, a devout Muslim couple struggling with infertility would not consider adopting a child to begin or expand their family.[6, 11] As a result, for many Muslim couples who require ART, the only hope for a child is success with ART with their biological gametes.[3, 11] Unfortunately, this costly procedure does not guarantee a child, as IVF and ICSI carry a success rate of approximately 20-25%.[11] As a result, if a couple does pursue ART and is still unable to conceive, they may be met with more disappointment.

Barriers to care

Cost

Likely the most prohibitive factor for accessing ART is cost. In 2013, the average cost of one cycle of ART in the United States was over $12,400, which is unaffordable for refugees who may live in poverty and may be uninsured.[4, 5, 12] Structured interviews of infertile Arab American men living in a poor suburb on the outskirts of Detroit revealed that most men interviewed regarded high cost as the main barrier to receiving ICSI. Some even considered returning to the Middle East for treatment, where the cost of treatment is much lower (at the time of the study, $3000 per cycle) and sometimes subsidized by the government. However, the cost of travel to the Middle East was too expensive to make this a reasonable option.[3] Men also shared that to afford ICSI they would have to get a loan or borrow money from family and friends.[3] Yet immigrants may experience difficulty obtaining loans or credit,[1] which may keep ART inaccessible for refugees.

Even with insurance, the high cost of ART may be prohibitive. Fifteen states (Arkansas, California, Connecticut, Hawaii, Illinois, Louisiana, Maryland, Massachusetts, Montana, New Jersey, New York, Ohio, Rhode Island, Texas and West Virginia) have “infertility insurance laws” that require insurance companies to either offer or cover infertility treatment.[1, 5, 13] However, these mandates vary widely by state, and coverage often does not include ART.[1, 13] Additionally, because these mandates are state law, insurance plans that fall under federal law, as well as plans that are from businesses who “self-insure,” are exempt from state infertility coverage mandates.[13] Refugee Medical Assistance, which provides healthcare coverage for a maximum of eight months, does not provide any infertility coverage.[5] Medicaid and state-funded safety net insurance programs will usually only provide coverage for the diagnosis of infertility, not treatment.[5] A survey of state Medicaid programs found that of the 41 responding states, diagnostic testing for infertility was covered in 9 states (Alabama, Arkansas, Connecticut, Hawaii, Maryland, Massachusetts, Michigan, Minnesota, and Nebraska).[14] Additionally, Oklahoma provides coverage of diagnosis of infertility for women (but not men) who are eligible for Medicaid coverage of family planning services via a family planning waiver or State Plan Amendment (SPA).[14] The only

state Medicaid program that covers a form of infertility treatment is that of Nebraska, which will cover the use of medications (such as clomiphene) only for women with an underlying medical problem.[14]

For couples that *can* afford to initiate ART, multiple cycles are often required, and even so, success is not guaranteed. Among couples for whom ART was unsuccessful, financial reasons were cited as the most important reason for stopping treatment.[11] There are some organizations that provide grants for infertile couples who are legal permanent US residents such as the Pay It Forward Fertility Foundation, the Madeline Gordon Gift of Life Foundation, and the Tinina Q. Cade Foundation.[5] Refugees are eligible for these grants only after they receive approval of their application for permanent residency.[5]

Language and cultural barriers

The language barrier creates a significant obstacle for discussing infertility and management with refugee patients.[5, 10] Interpreters may not be well-educated in the proper medical terminology related to reproduction and infertility, and as a result concepts may become "lost in translation" and misunderstandings may ensue.[5] While it would be helpful to have multiple follow-up visits to clarify any misunderstandings and to provide comprehensive patient education, in reality this may be difficult for both the provider and the patient.[5] For instance, refugee patients may have to walk or use public transportation to get to appointments, may have difficulty navigating the hospital or clinic, and may need time off work to attend appointments, which may make scheduling multiple follow-up appointments difficult.[5] From a provider standpoint, such counseling visits may require 30-45 minutes with use of an interpreter, which may provide logistical challenges.[5]

Other cultural barriers include Muslim women's preference for female providers.[3, 10] Muslim women may be hesitant to address their sexual health concerns with male providers, and doing so may be distressing or uncomfortable.[10] As a result, they may seek only female providers, or may avoid seeking health care at all.[10]

Unfortunately, stereotypes and implicit biases on behalf of providers may negatively impact the provider-patient relationship.[3, 5] In a small study of Arab immigrants and refugees living outside Detroit, some participants reported negative experiences with non-Arab health care providers, including Arab women who reported that male physicians negatively stereotyped them as pious, hyperfertile, or being oppressed by their husbands.[10] Muslim men may also be subjected to the negative stereotypes of hypersexuality and hyperfertility.[3] As a result of these stereotypes and associated implicit biases, providers may unintentionally ignore infertility concerns in Muslim patients, potentially leading to a delay (or even denial) of appropriate workup and treatment.[3, 5]

Furthermore, refugees' limited health literacy can be a barrier to care as patients may have a limited understanding of physiology, medical terminology, and treatment options.[1, 3, 5] Misconceptions about the role of Western medicine in management of infertility may result in unrealistic expectations from refugee patients. Some patients may have heard of a miraculous procedure or operation that they believe will be accessible in the US and will cure them of their infertility. As an

example, an Iraqi male refugee with infertility wondered if he would be able to have a testicular transplant, as he had heard a story of a California football player who supposedly underwent this operation after testicular trauma.[4] As a result of these misconceptions, patients may feel disappointed or frustrated once they come to understand the reality of their treatment options.

Discussion

Despite over 270,000 refugees in the United States,[15] there is a lack of research into infertility among refugees, even less so among Muslim refugees. The existing literature often includes poignant clinical vignettes or patient interviews that reveal the profound psychosocial impact that infertility has on patients.[3-5] An understanding of the obstacles that refugee patients face in their pursuit of fertility is critical to helping patients navigate the US healthcare system. With the knowledge of cost being a barrier, providers should ensure that they are evaluating and treating infertility in the most effective and cost-conscious way. In early evaluation of unexplained infertility, providers should be sure to counsel couples on the ideal timing for sexual intercourse; based on patient preferences, the recommendation can vary.[2, 16] It may be helpful for providers to reassure patients that half of couples who do not become pregnant within the first year of trying to conceive will conceive in the second year.[2] Additionally, providers should encourage lifestyle changes such as smoking cessation, and weight loss with a goal BMI of less than 30 kg/m^2.[2] For patients requiring further evaluation of infertility, the diagnostic algorithm from the American Academy of Family Physicians can be useful in guiding clinical decision-making in a cost-effective manner.[2]

Furthermore, recognizing that the psychosocial distress caused by infertility can be significant for Muslim refugees, providers may consider referring patients for psychological or behavioral health counseling. Counseling is generally encouraged for infertile couples, as the angst from infertility may only serve to worsen the situation by reducing libido and causing significant stress.[2] In particular, Muslim refugees struggling with infertility may benefit from counseling as the inability to bear children may result in social isolation and create a strain within their marriage.[4, 7]

Recognizing the language and cultural barriers that exist, healthcare systems should aim to ensure that language interpreters are educated in vocabulary specific to infertility and its management.[5] Providers may consider having patient education materials available in Arabic or other languages for literate patients to guide discussions and help patients gain a better understanding of reproduction and fertility.

Conclusions

An understanding of the social and psychological importance of childbearing to Muslim patients is of the utmost importance when considering the effects of infertility in this population. The management of infertility in this population demographic is complicated by unique challenges, such as a strong personal desire and social pressure to have children, cultural and language barriers, and cost barriers to treatment. Yet despite these obstacles, through cost-conscious evaluation, patient education, and

compassionate, culturally competent care, healthcare providers can provide support and guidance for Muslim refugee patients in one of their most vulnerable moments.

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