

ETHICS CASE

Is Lower Quality Clinical Care Ethically Justifiable for Patients Residing in Areas with Infrastructure Deficits?

Commentary by Marcia C. Inhorn, PhD, MPH, and Pasquale Patrizio, MD, MBE

Abstract

Reproductive health services, including infertility care, are important in countries with infrastructure deficits, such as Lebanon, which now hosts more than one million Syrian refugees. Islamic prohibitions on child adoption and third-party reproductive assistance (donor eggs, sperm, embryos, and surrogacy) mean that most Muslim couples must turn to in vitro fertilization (IVF) and intracytoplasmic sperm injection (ICSI) to overcome their childlessness. Attempts to bring low-cost IVF-ICSI to underserved populations might help infertile couples where no other services are available. However, a low-cost IVF-ICSI protocol for male infertility remains technically challenging and thus may result in two standards of clinical care. Nonetheless, low-cost IVF-ICSI represents a form of reproductive justice in settings with infrastructure deficits and is clearly better than no treatment at all.

Case

Dr. Moussa, a reproductive endocrinologist and infertility specialist, has arrived in Lebanon. Although he is a native of Beirut, the capital city, he has spent much of his life training and working in the United States. Now a well-known specialist, he is sponsored by a university in Lebanon to consult about how best to treat infertility across the country. Specifically, Dr. Moussa is discussing in vitro fertilization (IVF) plus direct injection of sperm into an egg, a method called in vitro fertilization plus intracytoplasmic sperm injection (IVF-ICSI). His team in the United States has developed an IVF-ICSI protocol that can be done in a mobile laboratory.

Meeting with fellow clinicians in Beirut, Dr. Moussa begins, "As you know, Lebanon is known for having high rates of male-factor infertility and for having a large number of IVF clinics. Many of those clinics and laboratories are clustered in Beirut [1-3], where we have dedicated electricity with no interruptions in service and state-of-the-art procedure rooms for oocyte retrieval. Here it's easy to get patients the clinic care and lab services they need. But high rates of male-factor infertility are also here," he points on a map to towns in the Beka'a Valley, east of Beirut and near the border with Syria. This area has limited and frequent interruptions in electricity supply, limited road access, and, due to

influx of Syrian refugees since 2012, significant civil and political instability [4]. “Together,” Dr. Moussa continues, “via mobile laboratory, we could bring IVF-ICSI to the patients in the Beka’a Valley who can’t get to us and our labs in Beirut. The only drawback is that the rates of IVF-ICSI success are lower when done in the mobile laboratories than when done in the Beirut-based laboratories [5]. I think you’ll agree, however, that it’s better than these patients having no access at all to IVF-ICSI.”

“I’m not sure I do agree,” said one member of the group. “I have many more questions about how this would work and whether it’s ethical to have two different standards of care, based on the quality of the lab service.”

Commentary

Reproductive health services, including infertility care, are important in countries with infrastructure deficits. Such is the case of Lebanon, a country that experienced 25 years of civil war and occupation (from 1975 to 2000), and is now facing a new crisis—namely, the influx of more than one million Syrian refugees fleeing from the civil war in their home country [6]. Dr. Moussa is rightfully concerned about the dearth of health care facilities in Lebanon’s Beka’a Valley, where more than 350,000 refugees are now living along the border [7].

Dr. Moussa’s recommendation for low-cost [assisted reproductive technologies](#) (ARTs) is in keeping with the 1948 United Nations (UN) Universal Declaration of Human Rights, Article 16:1, which states: “Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family” [8]. Furthermore, in 2001, the World Health Organization (WHO) meeting titled “Medical, Ethical and Social Aspects of Assisted Reproduction” [9] recommended that “infertility should be recognized as a public health issue worldwide, including in developing countries,” and that “research is needed on innovative, low-cost ART procedures that provide safe, effective, acceptable and affordable treatment for infertility” [10]. Although neither document discusses the mode and type of delivery of infertility care in conflict zones, both the UN and the WHO specify the positive right to fertility, including in developing nations. The UN further specifies that this right is irrespective of race, nationality, or religion [8]. Thus, Dr. Moussa’s call to develop a low-cost IVF-ICSI program in the Beka’a Valley is reflective of ethical principles developed by the world’s leading international health and social justice organizations. Furthermore, such a program has the humanitarian goal of addressing refugee reproductive health services in the now-conjoined Syrian-Lebanese conflict [6].

However, if Dr. Moussa brings a mobile, low-cost IVF-ICSI program to the Beka’a Valley, the standard of care, as reflected in clinical pregnancy success rates, will possibly be lower than in Beirut’s well-established IVF clinics. Thus, the ethical dilemma of two standards of IVF-ICSI care is a crucial sticking point for his program.

Dr. Moussa's argument, however, is ethically sound: namely, lower-quality IVF-ICSI care is better than no care at all. By virtue of its low-cost and portability, a mobile IVF-ICSI protocol would bring with it the possibility of overcoming infertility among those whose chances are otherwise nonexistent. IVF-ICSI works through direct injection of a spermatozoon into a human oocyte, facilitating fertilization and leading to the potential creation of a human embryo. With IVF-ICSI, even azoospermic men who have no evidence of sperm in their ejaculate can father a biogenetically related child if sperm are produced in and retrieved from their testicles. Because the program is offered at low cost, IVF-ICSI cycles can also be repeated, thus increasing the chances for success. This program is especially important for underserved populations, including refugee populations, whose desire and need for children may be high, given all that they have lost [11].

The ultimate goal of the low-cost IVF-ICSI program is to establish effective, safe, and affordable treatment, thereby representing a form of reproductive justice. This goal is especially critical in the Muslim world, where other paths to parenthood, including third-party reproductive assistance and child adoption, are generally not available [12-14]. In Muslim-majority countries, the medical treatment of infertility is thus vital, since it is the only way for most infertile Muslim couples to become parents [13].

Islam, Male Infertility, and Moral Opposition to Sperm Donation

As a native of Lebanon, Dr. Moussa is likely aware of the particular religious and moral sensibilities that make treatment of infertility through ART especially crucial. Across most of the Sunni Muslim world, which encompasses about 87-90 percent of the world's Muslim population [15], child adoption is not religiously condoned as a legal path to parenthood [12]. Similarly, third-party reproductive assistance—either through egg donation, sperm donation, embryo donation, or gestational surrogacy—is considered *haram*, or religiously forbidden [13]. Although third-party reproductive assistance, especially egg donation, has been approved through religious *fatwa* decrees issued by some of the most prominent Shia Muslim clerics, including in Lebanon, sperm donation has been rejected by all but one Shia ayatollah in Iran [14]. This is because knowing one's *nasab*, or exact genealogy or lineage, is considered a moral imperative in Islam. Thus, sperm donation causes genealogical "mixture" or "confusion" and unknown paternity. Sperm donation resulting in unknown paternity is considered religiously immoral in most Muslim societies, which are organized patrilineally (i.e., individuals' kinship belonging, inheritance rights, and family names are all conferred through the father's side of the family). Given this religious opposition to sperm donation, infertile Muslim men in Lebanon, whether Sunni or Shia, are usually extremely unwilling to consider sperm donation as a solution to their infertility [16].

Infertile Lebanese Muslim men reject this option on four moral grounds. First, sperm donation destroys a child's *nasab*, or genealogy, which is considered unjust to the donor child and harmful to the child's psychology. Second, such a child of unknown paternity is considered to be *walad il-zina*, or literally a "son of sin" (i.e., a bastard). Most Muslim men are clear that a *walad il-zina* "won't be my son" [17]. Third, using donor sperm—and introducing that sperm into a wife's womb—is tantamount to *zina*, or adultery. Even though no illicit "touch or gaze" occurs in donor insemination, most Muslim men consider intrauterine donor insemination to be a major violation of marital trust, destroying the sexual intimacy of the conjugal relationship [16]. Finally, Muslim men fear the potential for incest, if the offspring of an anonymous sperm donor unintentionally meet and marry later in life [13, 14, 16].

Dr. Moussa likely realizes that most Muslim men will never consider the relatively simple and low-cost technique of donor insemination to overcome their infertility, but he is also aware of the fact that male infertility is one of the most common infertility problems presenting to Middle Eastern IVF clinics (60-90 percent of cases) [16]. Male infertility cases in Lebanon and other Middle Eastern countries are usually genetic in nature; they often cluster in families and are linked to cultural practices of consanguineous (cousin) marriage [18]. As a result, these genetic cases of male infertility are often severe, involving very low sperm count and motility, poor morphology, and nonobstructive azoospermia [16]. Because most genetic problems of male infertility do not respond to standard treatments (hormones, other medications, or behavioral therapies), IVF-ICSI is the only hope for fatherhood among most infertile Muslim men, given their opposition to sperm donation.

IVF-ICSI and Its Challenges

Effectiveness. Like any form of assisted reproduction, IVF-ICSI cannot guarantee a pregnancy [16]. Even under the best conditions, IVF-ICSI might not succeed on the first attempt, thus requiring costly repetition. IVF-ICSI is also highly dependent upon the hormonal stimulation and extraction of healthy oocytes from women's bodies. Whereas the fertility potential of older men can often be enhanced through IVF-ICSI [13], women's fertility is highly age sensitive, with oocyte quality declining at later stages of the reproductive life cycle. Finally, when it does succeed, IVF-ICSI may be perpetuating genetic defects into future generations. In those rare instances in which male infertility is due to microdeletions of the Y chromosome, these and other genetic disorders can be passed by IVF-ICSI to male offspring. The [ethics of passing genetic mutations](#) to children has been an increasing cause for concern [19].

Cost and access. Dr. Moussa appears to be particularly concerned about IVF-ICSI costs and problems of access in Lebanon. Although Beirut is home to a number of high-functioning and high-performing IVF clinics, it is an expensive city, and most IVF clinics there are privately owned and operated [16]. In 2002, a single cycle of IVF could start at

US\$1,272 and exceed a global average (excluding the US) of US\$3,500 per cycle [20]. In a country where 70 percent of the population generates an annual income of less than US\$10,000, according to World Bank data [21], affording IVF-ICSI is difficult for most Lebanese couples, who often deem it a “last resort” when no other solution can be found [16]. For the destitute Syrian refugee population now living on the Lebanese-Syrian border, obtaining IVF-ICSI may be virtually impossible due to the cost of treatment and the 77-kilometer distance to Beirut. Reliable forms of public transportation are limited and costly, and travel is now risky because of crumbling infrastructure and random acts of political violence.

The Low-Cost IVF (LCIVF) Movement

Dr. Moussa is thus proposing a brave solution—namely, bringing a mobile IVF-ICSI clinic and laboratory to the Beka’a Valley. In doing so, he likely intends to make Lebanon a part of the growing global movement for low-cost IVF (LCIVF). LCIVF has emerged over the past decade, with many initiatives being proposed to help couples who cannot afford treatment [2]. Its goal is to make safe, affordable, effective IVF accessible to all of those who need it, primarily infertile couples living in resource-poor settings like Lebanon.

One example of such an initiative is the nonprofit organization, headquartered in Belgium, called the Walking Egg. Founded by IVF clinician-activist Willem Ombet, the Walking Egg was one of the first to develop a transportable LCIVF laboratory system [22], significantly reducing the cost of IVF [22]. Clinical success rates with the Walking Egg system have exceeded 30 percent [23]. However, other attempts to create LCIVF protocols have failed to yield such promising results [5]. Thus, even if Dr. Moussa and his Beirut colleagues are able to transport the low-cost IVF-ICSI protocol to the Beka’a Valley, it is uncertain what percentage of patients can actually be helped by this low-cost method.

A major problem is that low-cost IVF-ICSI is more technically demanding than LCIVF alone. IVF-ICSI requires a micromanipulator with a high-powered microscope, a micro-injector, and skilled embryologists who are able to inject spermatozoa into oocytes under controlled laboratory conditions. Thus, to date, no reliable low-cost IVF-ICSI method has been developed [2]. Indeed, Dr. Moussa’s low-cost IVF-ICSI protocol might have limited efficacy in solving most of the male infertility cases that he would encounter in the Beka’a Valley.

The Two Standards of Care Dilemma

Dr. Moussa is ethically justified in his belief that overcoming at least some cases of male infertility is better than overcoming no cases at all. Put another way, he is arguing that a lower quality of clinical infertility care is ethically justifiable. Why? On the one hand, infertility is not a life-threatening condition, wherein low-quality care could cost the life of the individual patient. Furthermore, the quality of patient care delivered to poor

infertile couples in the Beka'a Valley can remain high, even if the success rates of treatment remain low. If using a cheaper and simpler IVF-ICSI protocol would be an improvement over the total absence of treatment in the resource-poor, infrastructure-challenged Beka'a region, then it is not morally wrong for Dr. Moussa to recommend this protocol to patients. Without Dr. Moussa and his team, such patients would have no other way of accessing care and overcoming their infertility problems.

Furthermore, as part of this low-cost protocol, patients would receive infertility diagnoses and a better understanding of the medical nature of their infertility conditions. This knowledge, in and of itself, can be empowering. In the Middle Eastern region, the medicalization of male infertility has helped to diminish one cause of its stigma—namely, the mistaken conflation of infertility with impotence [13, 16]. Increased awareness of male infertility has led to its growing recognition as a medical problem to be treated [16].

Finally, a low-cost IVF-ICSI program would be welcomed with open arms in the Beka'a Valley. Most pious Muslim couples there likely consider medical conditions such as infertility to be God given, and they also believe that God creates solutions such as IVF-ICSI to overcome their suffering [24]. Thus, infertile Muslim couples are often active in seeking medical solutions [13]. By locating a mobile program on the Lebanese-Syrian border, Dr. Moussa and his team could provide relief to thousands of childless Muslim couples who have otherwise been living under stress and uncertainty.

Nevertheless, Dr. Moussa is questioned by his fellow clinicians in Beirut about whether providing two standards of care is ethical. Because the low-cost IVF-ICSI program would be delivered to poor Lebanese and Syrian refugee patients, who are unable to pay for better services or to access those services within a conflict zone, it might provide false hope to a population that has already suffered tremendously. As with any reproductive treatment, proper [informed consent](#) should be put in place to fully explain the possible limitations of the treatment provided by the mobile IVF-ICSI protocol. Properly executed informed consent procedures should help patients exercise their autonomy in choosing a treatment and should include clarification that treatment might not succeed.

Infertility and Health Disparities

The two-standards-of-care dilemma is not found in Lebanon alone. Dr. Moussa has spent most of his life as a medical student and clinician in the US, where health care services have never been distributed equitably. In the case of infertility services, most poor and minority Americans, including resettled Arab refugee couples living in areas of concentrated poverty, have much less access to IVF-ICSI than educated white couples, even in the 15 US "mandate states" where IVF is either fully or partially [covered by health insurance](#) [11]. As of 2003, it was estimated that only 24 percent of North Americans' ART needs were being met [25]. Many infertile Americans cannot begin to

afford treatment given that the average gross cost of a single IVF cycle in 2006 was 50 percent of annual disposable income, the highest in the world [26]. Furthermore, it took until January 2017 for the US government to begin to provide affordable IVF-ICSI services to US military veterans, including those who had served and were severely injured in the US-led wars in Iraq and Afghanistan [27].

These disparities in access to effective treatment for infertility are unjust and reflect substantial economic, racial, ethnic, and geographic disparities [28]. Such infertility treatment disparities are receiving increasing attention from the ethics committee of the American Society for Reproductive Medicine [29]. In addition, a growing movement in North America, called Friends of Low-Cost IVF, is calling for more affordable IVF in an effort to expand access [2].

Conclusion

One conception of distributive justice suggests that saving lives takes priority over creating lives; the needs of the many should take precedence over those of the few. When resources are limited, elective care for nonlife-threatening conditions such as infertility is a low priority on the overall resource-allocation scale. Nonetheless, infertility treatment disparities *are* unjust. When such disparities are present, reproductive justice dictates that some infertility treatment is better than no treatment at all.

Overcoming infertility through low-cost IVF-ICSI is a small step in the right direction, even in societies such as Lebanon, with its infrastructure deficits and growing Syrian refugee crisis. Sadly, infertility treatment disparities in Lebanon will persist until (a) the tragic Syrian civil war ends, (b) the refugee crisis abates, (c) American troops are withdrawn from the Middle East region, and (d) peace prevails across this troubled land [11].

Perhaps when the aforementioned conditions are met, Syrian refugees will be able to return home to IVF-ICSI services in their own country. Poor infertile Lebanese couples from the Beka'a Valley will also be able to make their way safely to Beirut, where excellent, state-of-the-art IVF facilities already exist [16]. Until that day comes, however, Dr. Moussa's attempt to bring a low-cost IVF-ICSI program to the Beka'a Valley is an ethically sound act of reproductive justice. Although two standards of clinical care might result—with high-quality care in Beirut and lower-quality care in the Beka'a Valley—those patients who *are* helped by Dr. Moussa's low-cost IVF-ICSI program will be tremendously grateful, especially those to whom precious "test-tube" babies are born.

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