

Marginalized, Invisible, and Unwanted: American Minority Struggles with Infertility and Assisted Conception

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Introduction

For most Americans, the term 'infertility' conjures up images of wealthy, white, well-educated couples seeking high-tech, medical interventions. A skewed master narrative dominates perceptions of infertility in the US, such that views of infertility are deeply inflected by race and socio-economic filters. Medical and social science scholars have helped to maintain and perpetuate this dominant narrative by conducting research with the most readily accessible study populations: namely, white, economically privileged couples attending infertility treatment clinics (Abbey et al, 1991). This is true even among anthropologists who are concerned with issues of social and cultural diversity. Of the five book-length ethnographies devoted to infertility and assisted conception in the US, all have documented the struggles of white professional couples to make the 'elusive embryo' (Greil, 1991; Sandelowski, 1993; Becker, 1997, 2000; Thompson, 2005).

As a result, ethnic minorities' experiences of infertility and infertility treatment – including their attempts to access assisted reproductive technologies (ARTs) – are almost entirely missing from the social scientific literature. Seline Szkupinski Quiroga's (2007; n.d.) recent anthropological work is exceptional in this regard; she has documented the infertility and ART experiences of ethnically diverse couples in California, including the explicit fears of 'race mixing' that colour the practices of third-party gamete donation and surrogacy among physician providers.

Given the invisibility of ethnic minorities in the US infertility literature, we

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offer this chapter as a corrective. First, we attempt to theorize infertility as a potent form of 'health disparity' in the US: to wit, ethnic minorities suffer from higher rates of infertility, but receive fewer diagnostic and treatment resources. As such, minority infertility serves as a case *par excellence* of 'stratified reproduction', or the ways in which fertility is differently valued according to one's power and privilege within mainstream US society (Ginsburg and Rapp, 1995). We then proceed to the findings of our own studies of infertility among three marginalized, ethnic minority populations – namely, African Americans (conducted by Ceballo), Latino/a Americans (conducted by Nachtigall and colleagues) and Arab Americans (conducted by Inhorn): As we will argue, these ethnic minority groups continue to be *marginalized* in mainstream US society. Their infertility and suffering remains *invisible*, including to social scientists. And the barriers they face in accessing appropriate infertility care index the very *unwantedness* of more 'black and brown babies' in a post-9/11 setting where xenophobia and anti-immigrant sentiment remain high, including in contemporary political discourse.

Infertility and health disparities

As is now recognized by the US National Institutes of Health (NIH), infertility prevalence rates are part and parcel of the overall picture of health disparities that continue to plague ethnic minority populations in the US¹. In America, couples who are less well educated, lower income and from underprivileged minority groups are most likely to struggle with infertility (Aral and Cates, 1983; Scritchfield, 1995; Greil, 1997; Chandra and Stephen, 1998; Meyer, 1999; Molock, 1999; Jain and Hornstein, 2005). Why? Researchers have pointed to a variety of occupational hazards, environmental risks, and lifestyle factors, including smoking and obesity, that may predispose poor, ethnic minority populations to infertility (Harris, 2006; Inhorn and Fakh, 2006). In addition, delays in treatment of reproductive tract infections – including those that are sexually transmitted and those that result from poor-quality medical care – may predispose minority women to reproductive problems that can result in infertility, including pelvic inflammatory disease and ectopic pregnancy (Molock, 1999).

Unfortunately, those most likely to be infertile in the US are also those least likely to seek highly specialized medical services. Among infertile women, acquiring medical services is positively associated with older age, a college education, a high income and having a Euro-American white racial background (Stephen and Chandra, 2000; Feinberg et al, 2007). Even in Massachusetts, a state with mandated comprehensive insurance coverage for infertility and assisted conception, couples who seek medical care for infertility tend to be highly educated, of upper socio-economic status, and from white, Euro-American backgrounds (Jain and Hornstein, 2005). For instance, among 561 women who attended an infertility clinic at Brigham & Women's Hospital in Boston, Massachusetts, more than 60 per cent of the patients had household incomes over \$100,000, compared with only 18 per cent in the state's general population (Jain and Hornstein, 2005).

Economic barriers to access are a major part of this story of underutilization. More than 420 in vitro fertilization (IVF) clinics exist in the US alone, and 107,000 ART procedures give rise to 40,000 IVF babies annually (Centers for Disease Control and Prevention, 2004). However, in the US in 2002, the mean cost per IVF cycle was estimated at \$9547 – in a country where the gross national income per capita in the same year was only \$33,360 (Jain, 2006). Moreover, this does not account for the fact that there is wide variation in ART pricing *between* clinics, many of which charge well over \$10,000, and as much as \$20,000, per ART cycle in the US today. While such costs are increasingly being covered by the US insurance industry, thereby allowing some middle-class and even working-class couples to access ARTs (King and Meyer, 1997), many insurance plans provide only minimal coverage for IVF and related services. Although insurance plans may pay for the costs of blood work and ultrasounds, the expensive hormonal medications and the ART procedures themselves may not be covered under most health insurance policies. In short, because of the lack of universal insurance coverage in the US, ARTs remain a private, fee-for-service form of healthcare delivery in most American states, accessible largely to white, middle- to upper-class infertile couples.

Furthermore, as ARTs have come to dominate reproductive medicine and to dictate practice trends, attention to low-technology infertility treatment has all but disappeared in the US. As a result, low-income infertile women and men face increasing difficulty in obtaining even the most basic diagnostic services (Becker, 2000). Access to infertility treatment services, even ‘low-tech’ ones, may be limited or even non-existent (Zambrana, 1987; Rodin and Ickovic, 1990; Inhorn and Fakih, 2006). As noted by Nsiah-Jefferson and Hall (1989, p95),

Members of minority communities have an equal or even greater need for programs to treat infertility, but ... these needs have not been defined as a legitimate concern and ... treatments are generally not available to low-income women, who are disproportionately nonwhite. Going beyond this clear mismatch between the needs and services available, the ... issue for low-income women and women of color comes down to the social construction of infertility as a ‘social problem.’ Why have the infertility problems of minority communities been ignored? What are the implications for the daily life and social status of low-income women and women of color?”

These questions point to a potent ideological issue – namely, the existence in the US of what some have called ‘stratified reproduction’ (Ginsburg and Rapp, 1995) and others have called a ‘eugenic logic of IVF’ (Steinberg, 1997); to wit, ARTs are being used to enhance the fertility of married white elites, thereby producing ‘white babies for married couples who are able to pay for them’ (Nsiah-Jefferson and Hall, 1989). In the white majority view, infertility is seen as a ‘non-issue’ for low-income and minority couples, who are seen as being ‘hyper-fertile’ and undeserving of further children (Roberts, 1997; Ceballo, 1999; Inhorn and Fakih, 2006). Indeed, the fact that infertility treatment services are largely restricted to white elite couples in the US provides a salient example of stratified reproduction, or ‘the arrangements by which some reproductive

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futures are valued while others are despised' (Ginsburg and Rapp, 1995, p3).

For African Americans in particular, negative stereotypes about black women's sexuality carry deeply entrenched historical roots (Roberts, 1997; Collins, 2000). Consequently, tenacious racial stereotypes play a significant role in many African-American women's experiences with infertility. Historically, African-American women were exploited economically for their labour as slaves, as well as sexually exploited and raped by white men (King, 1988). Collins (2000) posits that negative stereotypes about female slaves' hypersexuality and hyperfertility provided a justification for their sexual exploitation. African-American women today live with these lingering stereotypes in the form of negative public images that characterize their sexuality and reproductive abilities as flawed, irresponsible and dangerous. Social stereotypes of African-American women depict them as sexually promiscuous or aggressive; overly fecund and irresponsibly having too many babies; and neglectful, lazy mothers (Collins, 2000). Indeed, in *Killing the Black Body*, Dorothy Roberts (1997) contends that many public policies have deliberately punished African-American women precisely for having children.

It is not surprising, then, that public images of infertility hardly ever include African-American women, or other women of colour (e.g. Latinas, Native Americans, Arab-American Muslim women) (Quiroga, 2007). Their 'invisibility' in the world of American infertility – in infertility clinics, in infertility support groups, in media stories and in infertility scholarship – bespeaks a very potent form of stratified reproduction (Ginsburg and Rapp, 1995), indeed, outright racism in American society.

The consequences of this invisibility and marginalization may be devastating for minority infertile couples, especially those coming from subcultural groups where parenthood (and particularly motherhood) is glorified and children are highly valued, including for their tangible contributions to family life. On a social and cultural level, many minority groups in the US can be described as 'pro-natalist', in that children and parenthood are seen as desirable social attributes. Couples may be expected to have children early within marriage, and may have larger numbers of children in the household and younger age structures than the US population at large (Inhorn and Fakih, 2006). Children may be perceived as a source of social status, power and immortality, particularly when family structures are patriarchal and patrilineal (Inhorn and Fakih, 2006). Thus, infertility may precipitate a social crisis for both men and women in childless marriages, whose very social identities are determined by their ability to reproduce. Although women may carry the greatest social burden of infertility, in terms of blame for the reproductive failing, marital duress and social ostracism, men may also suffer over their own infertility and childlessness, particularly because infertility and impotency are popularly conflated, and paternity may be seen as bound to manhood among ethnic minority populations (Lloyd, 1996; Webb and Daniluk, 1999; Inhorn, 2002, 2003a, 2003b, 2004; Inhorn and Fakih, 2006). Among these subcultural groups, crises of infertility may be handled through religiously based coping. For example, many researchers have illuminated the central role played by the church and Christian religious participation in negotiating health problems in the African-American community (Chatters and

Taylor, 1989; Levin et al, 1995; Chatters, 2000; Mattis, 2002). Similarly, Islam provides solace for many Muslim couples facing the crisis of infertility (Inhorn 1994, 1996, 2003a; Inhorn and Fakih 2006).

Research settings, methods, and study populations

Given this context, this chapter seeks to examine the experiences of infertility and assisted conception among three minority ethnic groups, living in two major urban centers in the US (metropolitan Detroit, Michigan, and the San Francisco Bay Area, California). In Michigan, African Americans were contacted primarily through the obstetrics and gynecology department of a large university teaching hospital, while Arab Americans were contacted through a private, Arab-serving IVF satellite clinic in the ethnic 'enclave' community of Dearborn. In California, Latinas and Latinos were contacted while attending the infertility clinic of a large, university-affiliated county general hospital.

In each case, in-depth, semi-structured, and, in most cases, tape-recorded interviews were conducted with 50 African-American women, 88 Latina women and 33 Latino men, and 23 Arab-American women and 40 Arab-American men, for a total of 234 individuals (161 women, 73 men).² It is important to note that most of the respondents were married, although many of the interviews were conducted with individuals alone. The goals of the research were to explore the experiences of infertility, the impact on social and psychological well-being, the use of treatment services and the coping strategies used to face this life problem.

Most of the research subjects did not have higher degrees, and some had not completed high school, particularly those who had immigrated to the US from Latin America and the Middle East. Conditions of poverty were common throughout the study sample, reflecting national patterns. Even though a significant percentage of African Americans, Latino/as, and Arab Americans have achieved middle-class status or higher in the US, most members of these groups are lower-income, with many families existing below the national poverty line (Wayne State University, 2004).

It is also important to note that in Michigan, African Americans and Arab Americans have been severely affected in recent years by changes in the urban industrial workforce, particularly the 'slow death' of the US automobile industry in cities like Detroit and Flint, Michigan. The closing of factories and the outsourcing of US manufacturing jobs to foreign countries has dealt a devastating blow to the Michigan economy, particularly for poor and minority urban families. In this study, many infertile couples were struggling to make ends meet, and, by 2007, some who had been gainfully employed in the auto industry had lost their jobs and were existing on unemployment compensation. Similarly in California, Latino immigrants tend to occupy the lowest economic rungs of society, working primarily in low-paying service, domestic, construction and agricultural sectors. Furthermore, US immigration policies militate against full citizenship rights for many Latinos, who exist on the margins of American society as 'illegal aliens'. Among all of these minority populations, many families lack health insurance, with negative implications for health and well-being.

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Indeed, economic impoverishment and accompanying low social class status are major problems for all three of these ethnic minority populations within the landscape of America. Poverty affects the ability of African Americans, Latino/as and Arab Americans to seek higher education, improve their standard of living, and access affordable health care, including for problems of infertility, as we shall see.

African Americans

Many obstacles hinder African-American couples from seeking medical care for infertility, including economic disadvantage, an absence of referrals, lack of knowledge about services and treatments, poor insurance coverage, a variety of cultural sanctions and a healthy suspicion of the medical establishment based on long histories of discriminatory treatment (Caesar and Williams, 2002). African-American women who do seek medical treatment tend to have experienced difficulty conceiving for longer periods of time compared to their white counterparts (Jain, 2006). Furthermore, infertility clinics are typically selective about whom they will treat, limiting services to married, heterosexual couples who can afford private, fee-for-service healthcare.

For many of the African-American women in this study, fertility was initially assumed and taken for granted; thus, the diagnosis of an infertility problem was typically experienced as a highly stressful, devastating life event. Most of the women experienced infertility as a trauma that tore at the very foundations of their sense of self and womanhood. Anxious to overcome the problem, 90 per cent of the African-American women in the study had discussed their infertility with a physician. However, numerous barriers prevented the majority from undergoing any form of assisted conception. These included the high costs of medical treatments, lack of knowledge about such treatments, lack of access to knowledgeable infertility specialists, and husbands' refusal to participate or to continue seeking medical interventions.

Financial barriers were particularly prominent for African-American couples in the study. One woman, who had been trying to become pregnant for three years, discussed the perceived financial burden of infertility treatment by saying:

White women are like – 'Look, me and my husband, we're going to get a thirty thousand (dollar) loan, and we'll get the IVF and we'll have kids.' But black people are like, 'Look, I can't afford that. I just barely have health insurance.'

Another woman explained:

If they could look and tell me what was wrong, I didn't have any money for them to fix it. So it didn't matter.

Some women in the study attempted to 'negotiate' with their healthcare providers in order to afford some form of treatment. Creative solutions included

buying hormonal medications on a daily basis, or 'on instalment'. One woman, who was denied the possibility of purchasing 'by the vial', poignantly described the experience of holding a full box of expensive medication in her hands before having to return it. She compared the experience to

... giving up every chance I ever had of having a baby. I felt like I was giving up a baby, giving it back. And I was walking really slow. I was really depressed. Just walking down the hall and trying not to cry in front of anybody... I gave it to them real slowly. I said, 'I'm sorry I can't afford it', you know, and I felt bad. And he (the doctor) felt bad.

Many African-American women in the study struggled with their infertility in silence and isolation. While reproductive difficulties are often an extremely private matter for many people of any race, the depth of the loneliness among infertile African-American women in this study had an important racial and cultural component. Black women's solitary experiences with infertility are in keeping with social stereotypes about African-American women's sexuality, as well as public images of the typical white infertile American couple. Such images are directly reinforced in some US infertility treatment settings. For example, in viewing the publicly posted photos of IVF babies at a hospital's infertility clinic, one African-American woman explained,

I saw all these pictures of these babies, but I didn't hardly see any black babies and I thought, 'These doctors are helping people have babies, and are they just like picking certain people to help?' And I also thought, 'These people don't want to see any black babies.'

Moreover, some of the African-American women in this study had internalized the racial stereotypes they had faced as African-American women. A few women thought that they were the 'only one' – 'the only black woman walking the face of the earth who cannot have a baby' (Ceballo, 1999). One woman compared herself to other black women, saying,

For so many of my sisters, it's just not a problem getting pregnant, you know? The problem is trying not to get pregnant. And that was just so hard to deal with.

Another African-American woman had come to the conclusion that infertility must be 'a white thing'.

As a result, a few of the African-American women who participated in this study had never before discussed their feelings and experiences with anyone outside of their close family members, choosing instead out of shame or embarrassment to struggle through the pain in isolation. One woman in the study agreed to be interviewed because she endured 11 years of infertility by herself. She declared,

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I will share my story with you because there wasn't anybody for me to share (with)... There wasn't anybody black to share with me. There wasn't anybody that understood.

Many of the women believed that no one else could understand their experiences, unless they, too, had been infertile. As one woman explained, 'I had a wall up to everyone else.'

Not surprisingly, the pain of infertility strained and shattered relationships, sometimes with husbands, other family members and close friends.

In order to endure the pain and isolation of infertility, African-American women in the study tended to cope through religiosity and spirituality, which were often described as an indispensable part of their lives. Many of the women in this study found solace in viewing infertility as part of God's plan. For instance, one woman described how she

...prayed a lot and thought that what we were doing was the right thing ... that having a family is something we wanted and that it was smiled upon by God. I would always pray little prayers, like throughout the day, especially if I was feeling really discouraged. And that was helpful. It brought me a sense of peace.

Yet, religious faith was not a completely unambiguous presence in these women's lives. Some women expressed a more complex and ambivalent relationship with God and their church communities. For example, in response to her infertility, people often reminded one woman in the study that, 'God works in mysterious ways'. Her reaction to this proverb was that,

God works in mysterious ways, but I also know that if you don't have an egg, okay, well, I don't think I'm Mary. I don't think that's going to happen. She admitted that she was mad with God, and I think I'm being punished.

Latino/as

Whereas African-American women in the study belonged to a variety of Protestant Christian denominations, more than 85 per cent of the Latino/a women and men in the study were Catholic, and they subscribed to the belief that it is a duty to God to have children. Among Latinos, both women and men believed that a child was the basis of the marital relationship: a child was thought to create a bond between the couple and legitimize the relationship. Given the centrality of children in the couple relationship, almost everyone in the Latino study began trying to conceive as soon as they decided that they were in a relationship, often before marriage. Slightly less than half of those interviewed were living together but were not married; as they explained, they first wanted to test their fertility together.

When conception did not occur, infertility was a devastating experience for Latino couples, with far-reaching effects on women and men individually, as well as on the couple. Latino cultural assumptions about men's and women's roles underpinned the marital dynamics of couples unable to conceive. Childless marriages were considered a failure, and there was a widespread expectation that the relationship would end if no children were born. Even long-term relationships were threatened by infertility, as women and men became demoralized by repeated failures to conceive and increased fault-finding with each other. There was a high degree of marital conflict because of childlessness, often revolving around who was to blame for the infertility.

Because parenthood continues to be a strong cultural expectation for Latinos, and childless families are viewed as incomplete, women and men faced derision and public scrutiny. As a result, the gender identity of both women and men was undermined. The inability to become a mother was at odds with basic Latino philosophies about womanhood, such as *marianismo*, or the idea that a woman's self-esteem is manifested in her ability to be a generous mother and maintain strong traditions of family (Comas-Diaz, 1989). Latina girls continue to be socialized for marriage and childrearing to the exclusion of work-related or school-related roles (East, 1998). Therefore, unwanted childlessness leaves a void for most Latina women that nothing else can fill.

Recent work suggests that Latino men have much broader roles than stereotypes of *machismo* have portrayed (Gutmann, 1996; Torres et al, 2002). Yet, the presence of infertility in the couple relationship was a considerable threat to men's masculinity, even if they did not themselves have an infertility factor. The stigma of male infertility was even greater than for female infertility. Men who did not have children were thought to have compromised sexuality, and men reported that they had been denigrated by others, through questions such as, 'What's wrong? Can't you do it?' Given the emphasis on virility in notions of *machismo* (Torres, 1998), and the confusion that men in the general US population often have between virility and potency (Nachtigall et al, 1992), the finding of a low sperm count was deemed a great threat to men's masculinity. Not surprisingly, women in the study reported that men were often unwilling to submit to a semen analysis. Infertility is thus a challenge to Latino male role expectations, and a source of culturally induced shame and anger, as has been found for men in the general infertility population (Nachtigall et al, 1992), as well as in other cultures (Inhorn, 2002, 2003a, 2003b, 2004).

Given this pressure to conceive, it is no surprise that both men and women vowed to persevere until they conceived a child. Yet, as with the infertile African Americans described above, low-income Latinos in the study faced a number of challenges that impeded their ability to receive medical treatment for infertility. Over half of this sample reported years of trying to conceive before seeking medical intervention. Reasons given for not seeking care sooner included: lack of economic resources; belated awareness of existing resources; the conviction that difficulty conceiving is a private matter; and the belief that conception may take time and perseverance will pay off.

Furthermore, a primary impediment to treatment-seeking was communication. Language and cultural barriers resulted in patients having difficulty both in

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understanding diagnoses and treatments, and in communicating their questions, concerns and experiences to physicians. For example, Latina women in this study did not want to be called 'infertile', or to have their problem referred to as 'infertility'. They believed that the term meant that there was no hope to have a child, and that the label would jinx their efforts to conceive.

As described earlier, all of the Latino/as in this study were interviewed at an infertility clinic in a large public teaching hospital. Unfortunately, an arcane and disorganized hospital bureaucracy resulted in patients having difficulty with appointment scheduling, follow-up visits and timed laboratory procedures. Furthermore, as with the African-American population, the low-income Latino men and women in this study had limited economic resources, and could not pursue medical treatment beyond the most basic level.

An interesting difference emerged between Latina women raised in the US and women who had immigrated to the US as adults. Women raised in the US considered healthcare to be a right, were more assertive in seeking infertility care, and had an overall plan that they intended to pursue in order to become pregnant. In contrast, immigrant women expressed more gratitude for the care they received, took less initiative in considering other biomedical possibilities, and most did not have a plan that went beyond what the clinic could offer them. When couples had exhausted the treatment available at this clinic, only a few had other economic resources to pursue additional treatment. For example, only one couple in the study had undergone IVF, in this case in Mexico. Only a few couples had any additional financial resources with which to pursue private medical treatment.

As a result of these many barriers to effective infertility care, women in this study tended to rely on traditional infertility treatments, sometimes simultaneously with biomedicine. Humoral medicine was the most popular option. Used in many parts of the world (e.g. Inhorn, 1994), humoral medicine relies on a system of oppositions, such that problems thought to be caused by 'cold' must be treated through 'hot' remedies. The primary infertility-related diagnosis Latina women received from traditional practitioners was 'cold womb'. The primary treatment for cold womb was massage, followed by herbal medicine, usually in the form of a hot tea, accompanied by staying warm, usually at home.

The majority of women in this study reported that they had been to a masseuse, or sobadora, at some point in their quest for conception, often while seeking biomedical care. Sobadoras are common throughout Mexico and Central America. Some women reported that their mothers took them for massage when they reached puberty, to ascertain if they were in good reproductive health. Such sobadoras also practice in Latino communities in the US; for example, several could be found near the infertility clinic site.

Latina women in this study generally attempted to find solutions to their infertility that were familiar and within their economic means. The inability of this population to afford assisted conception furthered feelings of desperation and efforts to try anything. Women in particular found it hard to imagine a life without children. They reported that they intended to continue trying to conceive until they reached menopause. Some women in the study who were in their 40s had been trying to conceive for more than 20 years. Only a few women

had jobs that they found interesting, and no one thought a good job would be an acceptable alternative to having children. Every woman continued to hope for conception and reported feeling desperate at the idea of never conceiving. Women also questioned whether their relationships could succeed without a child.

Interestingly, Latino men were more willing than women to consider adoption. The majority of women felt that to try to adopt was to give up hope of having a biological child. They were also concerned that their extended families would not accept an adopted child. However, after years of no conception, some women in the study had considered adoption as they gave up hope of ever having a biological child. Unfortunately, most couples in the study could not afford to adopt, either in the US or abroad. They did not have the economic means, as adoption can cost even more than assisted conception. Adoption in countries of origin was not deemed possible without considerable funds to underwrite the expense.

Arab Americans

As in the Latino/a study, Arab Americans can be described as pronatalist, in that children and parenthood are seen as desirable, even necessary social attributes. Couples of Middle Eastern descent living in the US are expected to have children early within marriage, as reflected in the relatively high marriage and fertility rates in this population (Schopmeyer, 2000). For Arab Americans, children are a source of social status. For Arab-American men in particular, social power is achieved in patriarchal, patrilineal family structures through the birth of children, especially sons, who will perpetuate patrilineal structures into the future (Inhorn, 1996). Thus, infertility may precipitate a social crisis for both men and women in childless marriages, whose very social identities are determined by their ability to reproduce.

As with African Americans and Latinos, Arab Americans may turn to their religions, usually Islam, to make sense of their suffering. The Islamic scriptures describe infertility as a God-given condition, thereby providing a satisfying religious reason for why some individuals are infertile (Inhorn, 1994, 2003). However, the Islamic scriptures also disallow alternative modes of family formation, including legal adoption (Serour, 1996; Bargach, 2002). Assisted conception with third parties (i.e. gamete donation and surrogacy) is also disallowed within the dominant Sunni branch of Islam (Serour, 1996; Inhorn, 2003). Thus, unlike other infertile couples in the US, who may resort to donor insemination and adoption to overcome their childlessness, infertile Arab-American Muslim couples generally have no other way of becoming parents except through medical treatment, which is encouraged in Islam as a religious obligation (Kulwicki, 1996).

As with African-American and Latino couples, Arab Americans may have great difficulty accessing affordable infertility care. Most of the Arab-American couples in the study were either economic immigrants from Yemen, who had come to Michigan to work in the auto industry, or political refugees from

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Lebanon and Iraq, who had experienced war and persecution in their home countries. Few of these individuals were fluent in English, and some were illiterate in both English and Arabic. In virtually all cases, Arab Americans in the study had sought out diagnostic and treatment services from a fellow Arab-American (Muslim) physician, which whom they could feel cultural and linguistic rapport as fellow Arabs and fellow Muslims. Nonetheless, most of the men and women in the study lacked Western understandings of reproductive physiology, which represented major barriers to negotiating infertility care. Furthermore, many Arab-American women (and their husbands) were uncomfortable receiving gynecological care from a male physician, because of cultural notions of modesty and shame. Thus, the clinic made extra attempts to employ female support staff.

As with the Latina study population, poverty was the major deterrent to receiving effective infertility care among the Arab Americans in the study. The majority of women did not work, partly because of cultural expectations, but also because of lack of English and driving skills. Most of the men in the study were working in low-wage, blue-collar or service sector occupations, mainly as gas station attendants, dishwashers and busboys in Middle Eastern restaurants, truck drivers, construction workers, auto mechanics or store clerks. Thus, salaries were generally low in this study population, with many couples 'eeking out' subsistence lives.

Furthermore, most Arab-American couples did not have private health insurance that would cover the costs of infertility diagnosis and treatment (in a state that does not mandate insurance coverage for infertility services). Most couples did not own credit cards. As a result, virtually all of their financial transactions in the infertility clinic setting were handled in cash, which was exchanged over the counter at the end of clinic visits.

Relatively few couples in the study were able to pay for infertility treatments, especially ARTs. Indeed, for many, the economic barriers to seeking ARTs were insurmountable, even with discounts that were sometimes offered out of sympathy. As a result, only seven intracytoplasmic sperm injection (ICSI) cycles had been completed among the 50 couples in the Arab-American study, and only two cycles had resulted in living offspring. The vast majority of couples reported no spontaneous pregnancies and no initiation of ART cycles, despite more than five years of marriage in most cases.

Most couples in the study were deeply demoralized, because conceiving a biological child was unlikely without some sort of financial miracle. As one man explained his situation, 'Money is the problem. If anybody who is infertile can afford to do it [ARTs], he would do it. But even if we need [ARTs], we cannot afford to do it right now. The doctor gave us a discount and said it will cost only \$7000. But I don't have even \$100. What can we do?' Such economic barriers were true even among those who had received advanced educations in their home countries and were able to speak English fluently. Education and English fluency were no guarantee of good jobs and financial security, particularly for those who had come to the US as political refugees.

In short, Arab-American couples in this study uniformly desired children, were concerned about the future of their marriages in an ethnic enclave commu-

nity where marital fertility was expected and scrutinized, and were willing and encouraged by their religion to undertake biomedical treatments in order to solve their infertility problems. Yet, as Muslims, none of them could accept donor technologies as an option, and very few would contemplate adoption, which is explicitly forbidden in the Islamic scriptures. Severe economic constraints impinged upon their abilities to seek even low-tech forms of infertility care, a problem that they routinely lamented in interviews. Indeed, most couples in the study cited the high cost of treatment in the US as their main barrier to care, and many of them had at least contemplated returning to the Middle East, where the cost of a single ART cycle is generally less than \$3000 (or, in some countries, may be subsidized by the state). However, for most, even the cost of a return trip to the Middle East was prohibitively expensive, and many couples refused to return home (generally to Iraq or Lebanon) out of fear for their lives.

Arab-American men and women often remarked that they could never afford to undertake assisted conception, either in the US or abroad, without borrowing large sums of money from friends, family or a bank. The few couples who had undertaken ARTs had usually received such a loan in order to subsidize a single cycle. When the cycle failed to lead to conception, they described their shock and demoralization. For example, one young Iraqi couple, who had saved up enough money to try one cycle of IVF, were faced with the loss of the husband's auto shop job at the same time that the wife experienced a serious IVF complication (i.e. ovarian hyperstimulation syndrome). She was hospitalized for a week without health insurance. At the time of the interview, the couple was praying that a local Islamic charity would cover the \$30,000 hospital bill.

This is the worst time ever in both of our lives, she said. I never got that much sick before. This is the most toughest time I've ever had.

In general, Arab Americans in this study described their lives as 'hard' and 'stressful', given the traumatic conditions that had led them to flee their home countries and their inability to return safely home because of ongoing political violence. Once in America, they had also faced problems of economic hardship, exclusion and discrimination. Most of the Arab-American couples in the study were 'unassimilated' into US society at large, were unable to speak English fluently and were unable to mingle freely outside the protective enclave of their ethnic community.

It is important to note that a long history of racial discrimination, negative stereotyping and hate crimes against Arab Americans have been documented by researchers (Suleiman, 1999; Leonard, 2003; McCloud, 2003). However, the events of 11 September 2001 have clearly reversed the generally assimilationist efforts of Arab Americans to 'blend' into white US society as an 'invisible' (and racially unmarked) ethnic minority population (Naber, 2000). Today, 'Arabs' are vilified by many white Americans, who regard Arab men as particularly dangerous, untrustworthy, inherently violent and religiously fanatical. These caricatures of Arab-American men also include images of male hypersexuality and hyperfertility; to wit, Arab-American men and Muslim men in general are seen as

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polygamous fathers of children from multiple wives, harkening back to Western Orientalist fantasies of the harem (Said, 1978). If Arab-American men are portrayed as hyperfertile polygamists in the Western popular imagination, then the very possibility that they might suffer from real infertility problems within stable, loving, monogamous marital unions may lead to the convenient denial of their legitimate infertility problems. Indeed, in the post-9/11 landscape, research on Arab-American health has been sidetracked, resulting in 'a critical need for Arab Americans and the research community to take up the challenge of actively developing and funding research, education, and intervention programs' (Hassoun, 1999, p174).

Conclusion

As shown in this comparison of infertility among African Americans, Latino/as and Arab Americans in the US, all three ethnic minority populations experience the effects of stratified reproduction, including poverty, lack of access to affordable, high-quality reproductive healthcare, and marginalization within US society as a whole. Sadly, all of these populations share in common their poor health status *and* the combination of fear and prejudice displayed by many white Americans. All of these populations face significant reproductive disruptions, but are despised as reproducers in a racist/classist/xenophobic society. Only with further studies of infertility among ethnic minority populations in the US can we begin to combat these forms of stratified reproduction and to shed light on the very humanity and dignity with which members of these oppressed minority groups strive to overcome the many barriers that face them – including those that prevent the infertile from becoming loving parents.

Notes

- 1 A scientific workshop, entitled 'Health Disparities in Infertility', was held on 10–11 March 2005, at the National Institutes of Health in Bethesda. Several of the papers from the workshop were subsequently published in *Fertility and Sterility*, vol 85, no 4, April 2006.
- 2 In the Arab-American study, most participants were uncomfortable being tape-recorded. Thus, handwritten notes were taken and transcribed following interviews.

References

- Abbey, A., Andrews, F. M. and Halman, L. J. (1991) 'Gender's role in responses to infertility', *Psychology of Women Quarterly*, vol 15, pp295–316
- Aral, S. O. and Cates, W. (1983) 'The increasing concern with infertility: Why now?', *JAMA: Journal of the American Medical Association*, vol 250, no 17, pp2327–2331
- Bargach, J. (2002) *Orphans of Islam: Family, Abandonment, and Secret Adoption in Morocco*, Rowman Littlefield, Oxford
- Becker, G. (1997) *Healing the Infertile Family: Strengthening Your Relationship in the Search*

- for Parenthood, University of California Press, Berkeley, CA
- Becker, G. (2000) *The Elusive Embryo: How Women and Men Approach New Reproductive Technologies*, University of California Press, Berkeley, CA
- Caesar, L. G. and Williams, D. R. (2002) 'Socioculture and the delivery of health care: Who gets what and why', *The ASHA Leader*, vol 7, pp6–8
- Ceballo, R. (1999) "'The only black woman walking the face of the earth who cannot have a baby': Two women's stories', in M. Romero and A. J. Stewart (eds) *Women's Untold Stories: Breaking Silence, Talking Back, Voicing Complexity*, Routledge, New York
- Centers for Disease Control and Prevention (2004) *Assisted Reproductive Technology Success Rates: National Summary and Fertility Clinic Reports, 2001*, Centers for Disease Control and Prevention, Atlanta, GA
- Chandra, A. and Stephen, E. H. (1998) 'Impaired fecundity in the United States: 1982–1995', *Family Planning Perspectives*, vol 30, pp34–42
- Chatters, L. M. (2000) 'Religion and health: Public health research and practice', *Annual Review of Public Health*, vol 21, pp335–367
- Chatters, L. M. and Taylor, R. J. (1989) 'Age differences in religious participation among black adults', *Journal of Gerontology*, vol 44, no 5, ppS183–S189
- Collins, P. H. (2000) *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*, 2nd edn, Routledge, New York
- Comas-Diaz, L. (1989) 'Culturally relevant issues and treatment implications for Hispanics', in *Crossing Cultures in Mental Health*, Society for International Education Training and Research, Washington DC
- East, P. L. (1998) 'Racial and ethnic differences in girls' sexual, marital, and birth expectations', *Journal of Marriage and the Family*, vol 60, pp150–162
- Feinberg, E. C., Larsen, F. W., Wah, R. M., Alvero, R. J. and Armstrong, A. Y. (2007) 'Economics may not explain Hispanic underutilization of assisted reproductive technology services', *Fertility and Sterility*, vol 88, pp1439–1440
- Ginsburg, F. D. and Rapp, R. (1995) *Conceiving the New World Order: The Global Politics of Reproduction*, University of California Press, Berkeley, CA
- Greil, A. L. (1991) *Not Yet Pregnant: Infertile Couples in Contemporary America*, Rutgers University Press, New Brunswick, NJ
- Greil, A. L. (1997) 'Infertility and psychological distress: A critical review of the literature', *Social Science & Medicine*, vol 45, no 11, pp1679–1704
- Gutmann, M. C. (1996) *The Meanings of Macho: Being a Man in Mexico City*, University of California Press, Berkeley, CA
- Harris, L. (2006) 'Challenging conception: A clinical and cultural history of in vitro fertilization in the United States', PhD thesis, University of Michigan, Ann Arbor, MI
- Hassoun, R. (1999) 'Arab-American health and the process of coming to America: Lessons from the metropolitan Detroit area', in M. Suleiman (ed) *Arabs in America: Building a New Future*, Temple University Press, Philadelphia, PA
- Inhorn, M. C. (1994) *Quest for Conception: Gender, Infertility, and Egyptian Medical Traditions*, University of Pennsylvania Press, Philadelphia, PA
- Inhorn, M. C. (1996) *Infertility and Patriarchy: The Cultural Politics of Gender and Family Life in Egypt*, University of Pennsylvania Press, Philadelphia, PA
- Inhorn, M. C. (2002) 'Sexuality, masculinity, and infertility in Egypt: Potent troubles in the marital and medical encounters', *Journal of Men's Studies*, vol 10, pp343–359
- Inhorn, M. C. (2003a) *Local Babies, Global Science: Gender, Religion, and In Vitro Fertilization in Egypt*, Routledge, New York
- Inhorn, M. C. (2003b) "'The worms are weak': Male infertility and patriarchal paradoxes in Egypt", *Men and Masculinities*, vol 5, pp238–258
- Inhorn, M. C. (2004) 'Middle Eastern masculinities in the age of new reproductive tech-

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- nologies: Male infertility and stigma in Egypt and Lebanon', *Medical Anthropology Quarterly*, vol 18, pp34–54
- Inhorn, M. C. and Fakihi, M. H. (2006) 'Arab Americans, African Americans, and infertility: Barriers to reproduction and medical care', *Fertility and Sterility*, vol 85, no 4, pp844–852
- Jain, T. (2006) 'Socioeconomic and racial disparities among infertility patients seeking care', *Fertility and Sterility*, vol 85, no 4, pp876–881
- Jain, T. and Hornstein, M. D. (2005) 'Disparities in access to infertility services in a state with mandated insurance coverage', *Fertility and Sterility*, vol 84, no 1, pp221–223
- King, D. K. (1988) 'Multiple jeopardy, multiple consciousness: The context of a Black feminist ideology', *Signs*, vol 14, no 1, pp42–72
- King, L. and Meyer, M. H. (1997) 'The politics of reproductive benefits: US insurance coverage of contraceptive and infertility treatments', *Gender & Society*, vol 11, pp8–30
- Kulwicki, A. (1996) 'Health issues among Arab Muslim families', in B. Aswad and B. Bilge (eds) *Family and Gender among American Muslims: Issues Facing Middle Eastern Immigrants and Their Descendants*, Temple University Press, Philadelphia, PA
- Leonard, K. I. (2003) *Muslims in the United States: The State of Research*, Russell Sage Foundation, New York
- Levin, J. S., Taylor, R. J. and Chatters, L. M. (1995) 'A multidimensional measure of religious involvement for African Americans', *The Sociological Quarterly*, vol 36, no 1, pp157–173
- Lloyd, M. (1996) 'Condemned to be meaningful: Non-response in studies of men and infertility', *Sociology of Health and Illness*, vol 18, pp433–454
- Mattis, J. S. (2002) 'Religion and spirituality in the meaning-making and coping experiences of African American women: A qualitative analysis', *Psychology of Women Quarterly*, vol 26, pp308–320
- McCloud, B. (2003) 'Islam in America: The mosaic', in Y. Y. Haddad, J. I. Smith and J. L. Esposito (eds), *Religion and Immigration: Christian, Jewish, and Muslim Experiences in the United States*, AltaMira, Walnut Creek, CA
- Meyer, C. S. (1999) 'Family focus or career focus: Controlling for infertility', *Social Science & Medicine*, vol 49, pp1615–1622
- Molock, S. D. (1999) 'Racial, cultural, and religious issues in infertility counseling', in L. H. Burns and S. N. Covington (eds) *Infertility Counseling: A Comprehensive Handbook for Clinicians*, Parthenon Publishing, New York
- Naber, N. (2000) 'Ambiguous insiders: An investigation of Arab American invisibility', *Ethnic and Racial Studies*, vol 23, pp37–61
- Nachtigall, R. D., Becker, G. and Wozny, M. (1992) 'The effects of gender-specific diagnosis on men's and women's response to infertility', *Fertility and Sterility*, vol 57, pp113–121
- Nsiah-Jefferson, L. and Hall, E. J. (1989) 'Reproductive technology: Perspectives and implications for low-income women and women of color', in K. S. Ratcliff (ed) *Healing Technology: Feminist Perspectives*, University of Michigan Press, Ann Arbor, MI
- Quiroga, S. S. (2007) 'Blood is thicker than water: Policing donor insemination and the reproduction of whiteness', *Hypatia*, vol 22, pp143–161
- Quiroga, S. S. (n.d.) 'Disclosure, social support, and identity work among infertile couples', Unpublished manuscript
- Roberts, D. (1997) *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty*, Vintage, New York
- Rodin, J. and Ickovic, J. R. (1990) 'Women's health: Review and research agenda as we approach the 21st century', *American Psychology*, vol 45, pp1018–1034
- Said, E. (1978) *Orientalism*, Vintage, New York

- Sandelowski, M. (1993) *With Child in Mind: Studies of the Personal Encounter with Infertility*, University of Pennsylvania Press, Philadelphia, PA
- Schopmeyer, K. (2000) 'A demographic portrait of Arab Detroit', in N. Abraham and A. Shryock (eds) *Arab Detroit: From Margin to Mainstream*, Wayne State University Press, Detroit, MI
- Scratchfield, S. A. (1995) 'The social construction of infertility: From private matter to social concern', in J. Best (ed) *Images of Issues: Typifying Contemporary Social problems*, 2nd edn, Aldine de Gruyter, Hawthorne, NY
- Serour, G. I. (1996) 'Bioethics in reproductive health: A Muslim's perspective', *Middle East Fertility Society Journal*, vol 1, pp30-35
- Steinberg, D. (1997) 'A most selective practice: The eugenic logics of IVF', *Women's Studies International Forum*, vol 20, pp33-48
- Stephen, E. H. and Chandra, A. (2000) 'Use of infertility services in the United States: 1995', *Family Planning Perspectives*, vol 32, pp132-137
- Suleiman, M. W. (ed) (1999) *Arabs in America: Building a New Future*, Temple University Press, Philadelphia, PA
- Thompson, C. (2005) *Making Parents: The Ontological Choreography of Reproductive Technologies*, MIT Press, Cambridge, MA
- Torres, J. B. (1998) 'Masculinity and gender roles among Puerto Rican men: A dilemma for Puerto Rican men's personal identity', *American Journal of Orthopsychiatry*, vol 68, pp16-26
- Torres, J. B., Solberg, V. S. H. and Carlstrom, A. H. (2002) 'The myth of sameness among Latino men and their machismo', *American Journal of Orthopsychiatry*, vol 72, pp163-181
- Wayne State University College of Urban, Labor and Metropolitan Affairs (2004) 'Arab, Chaldean, and Middle Eastern children and families in the tri-county area', *Detroit Metropolitan Census 2000*, Fact Sheets Series 4, February, pp1-30
- Webb, R. E. and Daniluk, J. C. (1999) 'The end of the line: Infertile men's experiences of being unable to produce a child', *Men and Masculinities*, vol 2, pp6-25
- Zambrana, R. E. (1987) 'A research agenda on issues affecting poor and minority women: A model for understanding their health needs', *Women & Health*, Winter, pp137-160

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