

### 3 Reproductively Disabled Lives

#### *Infertility, Stigma, and Suffering in Egypt and India*

MARCIA C. INHORN  
ADITYA BHARADWAJ

In 1994, the International Conference on Population and Development (ICPD) was held in Cairo, effectively initiating a broad new approach to women's health in the non-Euro-American world. The Cairo initiative, dubbed "Reproductive Health," placed reproductive impairment on the population and global health agenda for the very first time. Infertility, or the inability to conceive a desired child, was officially recognized as an impediment to family planning, in the true sense of that term, and was also deemed an important cause of social suffering, especially for the world's women.

The placing of infertility on the global reproductive-health agenda has been a true boon to the scholarly community, which has subsequently received increased research funding to study infertility in non-Euro-American contexts. But the question remains: Has such global recognition improved the lives of those suffering from infertility on the local level? The answer to this question is much less clear. To begin with, despite the broad definition of reproductive health put forward at the Cairo conference, the Reproductive Health initiative still remains focused on population reduction through family planning. Indeed, some critics argue that the term "reproductive health" has simply replaced the term "family planning" in population and international-health discourses (Hartmann 2002), resulting in little substantive change at the level of actual programs for either fertile or infertile women. Furthermore, although the ability to conceive a desired child may now be conceptualized as a fundamental "reproductive right" following the Cairo conference, such reproductive-rights discourse is based on Eurocentric liberal-bourgeois notions of reproductive "choice" that may not be applicable or operationalizable in many non-Euro-American societies around the world. For the infertile in particular, reproductive choices are limited by both biology and by the severe

constraints on access to appropriate infertility treatments—constraints that the Reproductive Health initiative has done little to overcome. Even more fundamentally, becoming a parent is rarely a choice for most men and women in non-Euro-American societies, where reproduction, both biological and social, is a cultural imperative, and where parenthood, for both women and men, is an integral aspect of adult personhood (Inhorn and Van Balen 2002). Because reproductive-health discourses are still predicated on Western-generated notions of the right to choose (be it contraception, abortion, infertility treatments, or parenthood itself), they do not necessarily accord very well with the lives of infertile women and men around the world, whose reproductive choices may be very limited indeed.

This Euro-American liberal notion of rights is similarly manifested in the disability-rights movement, which is beginning to gain momentum internationally (Ingstad 1995; Whyte and Ingstad 1995). Perhaps unfortunately, infertility has never been officially defined, either before or after the Cairo conference, as a disability-rights issue, despite its profoundly disabling social consequences. Nor has it been conceptualized, theorized, or politicized as a form of bodily disablement. As a consequence, infertility has failed to capture the imagination of the disability-rights community as a platform for political struggle. Indeed, Euro-American-generated disability-rights discourse, like the reproductive-rights discourse described above, assumes at some rudimentary level a body of autonomous individuals who are free to make choices and who can come together in a concerted way to vocalize their resistance as political agents. Yet, in many non-Euro-American societies, individual agency is often subsumed within larger collectivities such as the family, and thus strategies of everyday resistance are not openly political within cultural constraints framing and offering differing opportunities for action and expression. As a result, the infertility-patient-led support groups that are now a political fixture in many Euro-American societies—where they press for additional research and governmental recognition while monitoring the excesses of the medical and pharmaceutical industries (Becker 2000; Van Balen 2002)—are rarely, if ever,<sup>1</sup> found in the non-Euro-American world. There, such patient-led political mobilization may violate numerous cultural norms, including the need for patient confidentiality (Inhorn 2003a), and may even be seen as personally dangerous among infertile individuals who fear participation in larger political collectivities. Thus, in the non-Euro-American world, infertility has not been part of either patient-rights or disability-rights activism, in which reproductively disabled people act together as a coherent

minority group, demanding an end to discrimination and injustice. Even in Euro-America, where disability-rights activism has gained considerable momentum following the political victory of the passage of the Americans with Disabilities Act in 1990 (Davis 1997), infertility is seldom included as a disability-rights issue.

This omission of infertility *as disability* is rather surprising when one considers this basic fact: The social ramifications of infertility in both Euro-American and other societies around the world accord quite well with both the United Nations and the World Health Organization definition of "handicap," troubled as that definition may be (Wendell 1997).<sup>2</sup> According to the UN and WHO, a handicap is "a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors, for that individual" (WHO 1980; UN 1983). Infertility is an inherently socially handicapping condition, which disrupts the ability of individuals to fulfill normative social roles as mothers and fathers. As such, it is a profoundly disabling condition for both men and women, and especially the latter. In the non-Euro-American world, the stigma and social ostracism that may redound from infertility and childlessness are often so acute that they lead to social disablement in the multiple realms of marriage, family, friendship, and community life. Particularly for women, who often experience infertility as a disabling "master status" (Greil 1991a), the social oppression accompanying infertility may include reproductive blame even in the face of male reproductive impairment; emotional and physical abuse perpetrated by husbands, in-laws, and community members; and divorce and abandonment, with perilous consequences for infertile women who are economically dependent upon men (Inhorn 1994, 1996; Bharadwaj 2001; Boerma and Mgalla 2001; Inhorn and Van Balen 2002).

If infertility leads to social oppression, as we would argue here, then infertility should certainly be viewed as a form of disability. Recent definitions of disability foreground the notion of "oppression" as the key variable linking all disabled people together. As noted by Wendell (1997:264): "Disabled people share forms of social oppression, and the most important measures to relieve that oppression have been initiated by disabled people themselves. Social oppression may be the only thing the disabled have in common; our struggles with our bodies are extremely diverse."

Indeed, in virtually every society in which infertility has been described, infertile individuals struggle with their barren bodies, attempting to make themselves fertile producers of progeny. Efforts to identify a cause for this particular misfortune often take the infertile, particularly women, on

quests to both ethnomedical and biomedical specialists (Inhorn 1994; Gerrits 2002; Jenkins et al. 2002; Riessman 2002; Sundby 2002). In the world of biomedicine, individuals often learn of the numerous potential biological impediments to fertility in both men and women—a list that grows longer each year as various failures of fertilization and implantation are ferreted out in in-vitro fertilization and reproductive biology laboratories around the world (Bentley 2000; Bittles and Matson 2000; Fishel et al. 2000). Such failures of biology—or the failure of one's reproductive body to cooperate with the reproductive body of another—are experienced by most infertile individuals as tremendous *social failures*. Indeed, as described in the recent monograph *Infertility in the Modern World: Present and Future Prospects* (Bentley and Mascie-Taylor 2000), infertility is an inherently biosocial problem, with the biological problem of infertility impinging in a profound manner upon the social lives of its sufferers. Infertility and its treatment are similar to other disabilities in the social realm: infertility places a fundamental restriction on social life and growth, in that children are central to the extension of sociality. Furthermore, these social ramifications and restrictions are usually much more pronounced in the non-Euro-American world. To wit:

[Infertility] often has social and economic consequences in developing nations that far outweigh the consequences for infertile couples in most industrialized nations. In addition the social luxury of choosing to remain childless is simply not an option for many women and men where having children provides security for old age, social rank, and a source of labour for household activities and subsistence. Above all who can quantify the indescribable source of emotion, pleasurable and otherwise, that most children engender in their biological and social parents? It is perhaps this, above all else, that drives individuals to take extreme measures to achieve . . . parenting in the modern world. (Bentley and Mascie-Taylor 2000:12–13)

It is our task in this chapter to describe some of these social effects in two of the most populous (and hence pronatalist) countries of the developing world. These countries are Egypt and India, where the authors have undertaken ethnographic research. There, the biological impediments to successful fertility become inevitable preconditions for social disability and oppression. Infertility in Egypt and India marginalizes those who live with this problem—a problem that is often incurable.<sup>3</sup> For women in particular in both of these societies, infertility exerts a form of institutionalized biological determinism, whereby a woman's cultural persona is characterized by her biological inability to conceive and deliver. As an engulfing master

status, infertility becomes the basis of her social identity, whereby she is seen as an inauspicious, polluted, even dangerous, barren woman. Thus, infertility imputes severe impairments on gendered personhood in Egypt and India, leading to marital duress as well as desperate medical measures to overcome the social stigmatization and ostracism. These desperate medical measures, furthermore, are highly class-specific and gender-specific. Like other technologies for disability, the assisted reproductive technologies (ARTs) to overcome infertility are differentially distributed and appropriated globally. Thus, poor infertile women are barred access to ARTs in places like Egypt and India, while affluent women also face a number of negative and highly gendered social consequences emerging from the recent globalization of ARTs to their local societies. Furthermore, this emergence of ARTs as a global solution to the problem of infertility gives infertility *as a disability* some special characteristics. Namely, both the impairment of infertility and its rehabilitation through ARTs are tightly enmeshed in local politics of social personhood. As we will see for both Egypt and India, ARTs challenge deeply held convictions about the nature of human life and of disability itself, perhaps more radically than do responses to many other disabilities.<sup>4</sup>

Following a brief description of the study sites and methodology, we will examine some of the disabling consequences of infertility and its treatment for both women and men in India and Egypt, comparing these two non-Euro-American societies with each other and with Euro-America. Specifically, we will compare and contrast our own non-Euro-American data with those found in Arthur L. Greil's (1991a) "A secret stigma: The analogy between infertility and chronic illness and disability," the only piece of Euro-American research that explicitly examines infertility *as disability* in the U.S. setting. We will argue that, despite many cross-cultural similarities in all three sites, the socially disabling impacts of infertility in the realms of personhood and marriage are much more profound in non-Euro-American settings, leading infertile Egyptians and Indians on often morally contentious quests for conception in highly medicalized infertility-treatment settings.

#### THE RESEARCH

This chapter is based on medical anthropological research undertaken independently by the authors in Egypt and India. The Egyptian data are drawn from two distinct periods of research during the late 1980s and mid-1990s. In the first period (1988–89), Marcia Inhorn conducted 15 months of anthropological fieldwork on the general problem of infertility in Egypt,

basing her research in Alexandria, Egypt's second largest city. Working through the University of Alexandria's large public OB-GYN teaching hospital, popularly known as Shatby, she conducted in-depth semistructured interviews with 100 infertile women and 90 fertile ones. Eventually, she made her way into the communities and homes of these women, where she conducted less formal interviewing and participant observation. With few exceptions, these women were poor, uneducated, illiterate, or only semiliterate housewives who were not employed in wage labor and were economically dependent upon their unskilled laboring husbands. Many of these poor urban women were seeking treatment at Shatby Hospital not only because the infertility services there were free, but specifically because of the hospital's widely publicized claims to a free government-sponsored in-vitro fertilization (IVF) program.

The second period of research occurred in 1996, in the midst of the "IVF boom period" in Egypt. By that time, Egypt was in the midst of massive reproductive-technology transfer, with new urban IVF centers cropping up in private hospitals and clinics on a regular basis. In the midst of this IVF explosion, the author spent the summer of 1996 in Cairo conducting in-depth semistructured interviews with 66 mostly middle-class and upper-class women and their husbands; most of them were undergoing IVF or related technologies at two of the major IVF centers in this city of nearly 20 million inhabitants. The patients presenting to these IVF clinics were generally well educated, professional, comparatively affluent women who were often accompanied by their husbands. Indeed, in 40 percent of the interviews conducted in these IVF clinics, husbands were present and participated in discussions, often enthusiastically. Moreover, whereas interviews in the first study were conducted entirely in the Egyptian colloquial dialect of Arabic, many of the women and men who participated in the second study spoke fluent, even flawless, English as a result of their advanced educations, and they chose to conduct the interview in their second language. Thus, the Egyptian research incorporates both a diachronic and a class-based comparison of infertile women seeking treatment in the two largest cities of Egypt.

The ethnographic data from India are drawn from a multisited research project undertaken by Aditya Bharadwaj to examine the day-to-day working of infertility clinics, as well as the views of infertility-treatment seekers and infertility experts in five Indian cities (Bharadwaj 2001). His research was carried out over a period of 15 months in 1997–98. Bharadwaj conducted 45 in-depth semistructured but open-ended interviews with both individuals and couples attending three IVF clinics in the cities of

Delhi, Jaipur (Rajasthan), and Mumbai. Nineteen of these interviews were conducted in English and the rest in Hindi, with later translation and transcription of tape recordings. In 46 percent of these interviews, couples were interviewed together, while 28 percent of husbands and 21 percent of wives were interviewed without their partners. An additional 5 percent of informants were interviewed with an accompanying family member present. No conscious effort was made to interview individuals either separately or as couples. In most cases, due to the sensitive nature of the research or problems of access (e.g., husbands at work, wives undergoing an IVF procedure), it was not always possible to interview couples together.

As with the Egyptian IVF study, this Indian study is also clinic-based. In both studies, the possibility of follow-up interviews and participant observation outside the clinics was minimal, due to the sensitive nature of material, informants' desires for secrecy, and inaccessibility of some individuals who were coming to these IVF centers over great distances. Because undergoing IVF in both of these societies is accompanied by considerable personal difficulties (financial, familial, physical, etc.), as well as profound social stigma (Bharadwaj 2001; Inhorn 2003a), infertile individuals were often willing to be interviewed—or even seen with the researcher—only within the safe confines of the clinic. In India, infertile IVF seekers were often so reluctant to share personal information with the researcher that the most basic demographic data, including subjects' names, class/caste background, and employment/income profile, could not be easily obtained. Fourteen individuals who did openly share information on their class and economic backgrounds were either very affluent, or at least middle-class professionals, working and living in major metropolitan areas. The remainder of the respondents were putting themselves through some degree of financial hardship in order to fund their IVF trials. The same was true in Egypt, where even upper-middle-class IVF seekers experienced financial pressures.

It is also significant that all respondents in the Indian study were Hindus, compared with the predominantly Muslim study population in Egypt. As we shall see in this chapter, religiously based moral systems are significant in the realm of infertility, affecting both the forms of social oppression surrounding this condition and acceptable measures to overcome it as well.

#### INFERTILITY AND PERSONHOOD

In both Egypt and India, infertility is a deeply disabling social handicap. Whereas the notion of "disability" bespeaks the consequences of reproductive incapacity on the physical body, the idea of "handicap" actualizes and

locates infertility within the social body (Scheper-Hughes and Lock 1987), where the infertile must "live" their reproductive impairment within the midst of society at large. Taken together, these linked notions of disability and handicap embody and interpenetrate the private and public realms of stigma, suffering, and social injustice, which are the common experiences of infertility for both women and men in these two countries.

In both Egypt and India, infertility is an inherently stigmatizing condition, particularly for women, who bear the physical evidence of the failure to conceive. In his seminal essay *Stigma: Notes on the Management of Spoiled Identity*, Goffman (1963:3) defined a stigma as:

An attribute that makes [her] different from others in the category of persons available for [her] to be, and of a less desirable kind—in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. [She] is thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive.

A stigma, then, is an attribute of a person that is deeply discrediting to social identity. How soon a stigma discredits one's very personhood depends upon its visibility. Thus, Goffman describes the various "abominations of the body" (e.g., physical deformities) that are quite visible and make disabled persons immediately discredited, versus those "blemishes of individual character" and "tribal stigmas" that are less easy to perceive. Following Goffman, Greil (1991a:22) describes infertility as a "secret stigma" for women and men in the United States, for a variety of reasons:

Unlike paraplegics or the blind, but like diabetics and epileptics, the infertile possess a *secret stigma* in that they display no obvious stigmatizing features and that it is relatively easy for them to pass as normal. In addition, for most of the infertile, there are no *physically imposed* mobility barriers to full participation in one's normal round of life. Finally, the infertile have a condition that is neither visibly discrediting or obviously discreditable. Unlike those with epilepsy, for example, who must be concerned that an inopportune seizure might reveal their stigmatizing condition to others, the infertile are relatively free to keep their stigma secret.

On the contrary, in Egypt and India, a woman's infertility is never a secret. From the moment she marries, she is scrutinized by other female members of her own and her husband's family for the first signs of pregnancy. This form of bodily monitoring and surveillance begins almost immediately upon marriage but continues throughout the reproductive

life of an infertile woman. As long as she does not show the visible signs of pregnancy—manifest most dramatically in the pregnant belly—she remains discredited within her social world. Similarly, for men, infertility makes visible the double failures of masculinity. Namely, men whose wives are not obviously pregnant may be discredited as lacking fertile sperm or as lacking erect phalluses capable of impregnating a woman. Among men, then, infertility bespeaks the emasculating possibilities of both male infertility and impotency (Inhorn 2002, 2003b, 2004). Ultimately, then, in both Egypt and India, human conception and sexuality are made visibly public through pregnancy and childbirth, which are both expected within marriage and closely monitored. The corresponding absence of offspring in a marriage is a highly visible reminder of an unacceptable failure in these dual realms, both of which are seen as central to the reproduction of social life (Inhorn 2002, 2003b, 2004; Bharadwaj 2003).

Whether it is the man or woman who is infertile in any given couple,<sup>5</sup> it is women who generally bear the brunt of social scrutiny, intimidation, and ostracism. In patriarchal pronatalist societies such as Egypt and India, women are expected to become mothers within marriage, with little choice to pursue other avenues such as satisfying professional careers apart from motherhood. Thus, the achievement of adult personhood for women rests on their attainment of motherhood. Without motherhood, infertile Egyptian and Indian women fail to uphold the “identity norms” or “norms of being” (Goffman 1963) that are deeply felt and socially shared by almost all members of society. Although fatherhood is also a cultural mandate for men in both societies, fatherhood is less central to the lives of adult men. On the one hand, most men pursue other avenues of adult fulfillment, including employment, peer networks, religious participation, and the like. In addition, although many men in Egypt and India are loving, devoted, and openly affectionate fathers, the major day-to-day tasks of childrearing and nurturance are primarily women’s responsibilities.

In both Egypt and India, women who cannot achieve the role of mother are literally defined by this failure. An infertile woman’s biological impairment becomes her “master status,” the overarching feature of her social identity. In the United States, Greil (1991a:27) describes infertility as a master status for American women as well, noting that among the women he studied “infertility came to permeate every aspect of their lives.” But Greil is also careful to point out that the “spoiled identity” of infertile American women emerges largely through a process of “self-labelling,” or “the inability to live up to one’s own expectations of self” (Greil 1991a:34). Outright discrimination and negative attributions toward the infertile

made by others are relatively rare, and may consist of insensitive comments made by fertile women who did not realize that an infertile woman was in their midst. In other words, in the United States, infertile women may *feel* the “loss of self” (Charmaz 1983) and diminutions of personhood that are characteristic of stigmatization, but much of this stigmatization is internally rather than externally generated.

In Egypt and India, on the other hand, infertile women are stigmatized by others, who may openly remind the infertile woman that she is less than other women, neither a full adult, a full woman, nor a full human being. In India, infertile women are often viewed by others as inauspiciously polluted and may be avoided as a result. In Egypt, infertile women are seen as potentially dangerous, for they may harm other people’s children through their uncontrollable envy (and the subsequent casting of the evil eye). Indeed, in both Egypt and India, of all the types of persons that one could be, there are very few less desirable social identities than that of the infertile woman, giving this particular identity all of the classic features of a stigma.

Not surprisingly, infertile Egyptian and Indian women may be taunted about their barren, inauspicious status. In Egypt, fertile women of the lower classes often hurl unkind epithets at infertile women in their families or neighborhoods (e.g., calling them *dhakar*, “male”). As one woman with seven children explained: “Some people talk and say, ‘Two men are living together. She’s the same as he is. She’s like barren land.’” Another fertile woman added: “People hurt her. They tell her, ‘You don’t have children. You are like the rooster that does not break the hen and doesn’t have children. You are a homosexual rooster.’ Lots of people say these things.” Even among upper-class Egyptians, infertile women are reminded by others of their childless status. One wealthy infertile woman, Amira,<sup>6</sup> explained how her neighbor subtly insulted her:

Just now, before I came here [to the IVF center], I met a neighbor. “What’s this? You didn’t go to Alex on vacation?” I said, “My husband doesn’t have vacation.” She said, “What vacation! You can go any time, because you don’t have children. I have to go now [while her children are out of school].” Sometimes I meet her in the market, and I say, “I don’t know what I’m going to cook today,” and she says, “Cook anything! You are only two. You can go to MacDonald’s if you want to.”

Similarly, the experience of an Indian couple named Arvind and Parul, who were interviewed together in a Rajasthani IVF clinic, is telling of the social discrimination and harassment experienced by infertile Indian women within their husbands’ families and communities:

ADITYA BHARADWAJ (AB): What was the problem?

ARVIND: Nothing happened and then you have to listen to things because of society.

AB: What do you mean by "because of society"?

ARVIND: You know a woman's position is as good as nothing. Like other women interfere, like you don't have a child, you are barren [*banj*].

AB: Who are these women who talk like this?

PARUL: In the family [*Ghar ghrihasti mai*], relatives, near ones, even neighbors.

AB: What do they say?

PARUL: They say he will leave you, you don't have children, why aren't you having any?

Men, on the other hand, often escape such virulent social scrutiny and condemnation by grafting their own infertility onto the bodies of their fertile wives. In both societies, women are usually blamed for infertility, whether or not they are the infertile partner. But a common pattern in both Egypt and India (and a number of other societies, including some in the West) is for perfectly fertile, healthy wives to knowingly assume the blame for their husbands' infertility in order to protect these men from the assumed public humiliation of this emasculating condition. Among both lower-class and upper-class women in the Egyptian study, wives typically reported that they "covered" for their husbands in this way (Inhorn 1996, 2002, 2003b). Similarly, in India, most infertile husbands condemned their wives to carry the social burden of male infertility by failing to confess this condition to others (Bharadwaj 1999). This cross-cultural pattern of social misrecognition in the case of male infertility may be linked in large part to the common, although incorrect,<sup>7</sup> conflation of male infertility and impotency, the latter being perhaps even more stigmatizing than the former.

#### INFERTILITY AND MARRIAGE

In childless Egyptian and Indian marriages where the husband is fertile but the wife is not, men may receive tremendous social pressure, within their own families and among their social peers, to abandon an infertile wife through informal repudiation or formal divorce or, in the case of Muslim men, to take a second wife through polygynous remarriage. Although marital duress among infertile couples has also been reported by Greil and others in Euro-American settings (Daniluk 1988; Greil et al. 1989; Abby et al. 1991; Nachtigall et al. 1992; Van Balen and Trimbos-Kemper 1995; Greil 1997), female infertility resulting in male-initiated divorce is not a

common occurrence and has rarely been reported in the Euro-American infertility literature.

In contrast, in many non-Euro-American societies around the world, including Egypt and India, men with infertile wives are literally expected to divorce them. Family interference, particularly on the part of husbands' relatives, is an enduring feature of the marriages of many childless couples in these societies. For example, in Egypt, many infertile women consider their mothers-in-law the bane of their existence. Not only do they pressure their sons to remarry—thereby providing offspring to strengthen the patrilineal extended family—but they also torment their infertile daughters-in-law, routinely chastising them for failing to "produce" for the husband and his family.

The threat of marital abandonment, coming from in-laws or even directly from husbands, is a fear that underscores the lives of many infertile women in Egypt and India, who are trapped in infertile bodies and marriages beyond their control. In Egypt, where a wife's infertility is deemed under Islamic personal-status laws to be a major ground for divorce (Inhorn 1996), Muslim women, especially of the lower classes, literally live in fear that their marriages will "collapse," as men succumb to such social pressure and pursue their desires for children with a new wife. Although women, too, may remarry if a husband is proven to be infertile, the enduring stigmatization of a female-initiated divorce means that few Egyptian women will ask for divorce unless their marriages are truly unbearable. Thus, Muslim women see themselves as maritally vulnerable,<sup>8</sup> as revealed in the following comments made by two lower-class infertile women in Egypt:

If infertility is from the wife, 100 percent he will go and marry and leave her. If it's from him, the wife always has to support him because there's nothing she can do.

Most men don't accept the fact of not having children, which is why they get married one or two or three times to have children and build a family. The husband always has the power; it's in his hand if he wants to marry or remarry, because sometimes a woman asks for a divorce and still the husband doesn't divorce her. So the woman is always the loser, because he has the power.

Similarly, in India a woman's infertility is deemed a justifiable reason for a husband to abandon his wife and return her to her natal family. For example, Jeffery and Jeffery's (1989:87) study of women and childbearing in northern India describes how failure to bear children is often "just cause for a man to return his wife to her parents and several women in

Dharmnagri and Jakri (who ultimately bore children) recall worrying about times when their husbands were pestered to replace them."

In the present study of IVF-clinic patients in India, one infertile woman, who worked as a nutrition consultant for a nongovernmental organization, recounted how it was assumed by women in the villages she visited that she would be cast out of her marital home and ultimately be in need of her own father's protection:

I meet people in the villages, like, in fact I take this problem of not having a child very philosophically and can laugh about it, discuss it . . . even at the grassroots level. I met a, you know, like I was talking to village women and one of them was a traditional birth attendant. She asked me "Are you married?" I said yes. "How long?" I said five years. She said, "Do you have any children?" No! The second question she asks me—she didn't ask me about my husband or something—she says "Do you have your father alive?" Yes, my father is very much there. You know, those kind of things, like, in her own way, it wasn't judgmental, she wasn't looking down on me, but she was empathizing with my situation. She said "Where will this girl go?" So I laughed it off and all that.

The traditional-birth attendant described in this story was voicing an all-too-familiar fear that also permeates the lives of infertile Indian women. The force of community disapproval can, in fact, irretrievably disable the lives of infertile couples, whose only desire is to be left alone. A highly educated doctor named Rajkumar, interviewed in a Mumbai infertility clinic, spoke of the torment he and his wife were enduring at the time:

It is a *majboori* [compulsion, to seek treatment]—what can you do?! I am a doctor, my wife is a doctor. We don't have any problem, but the society always interferes in your life. The need to ask—"You don't have children; why?"—is always there. Even the patients said, "O! the *doctrni* [lady doctor] is barren!" So you do feel. The patients who come say, "This doctor is barren, what treatment can she possibly offer us? I don't want to be delivered by her." . . . I [as a result] don't stay for more than two years in a place. I ask for a transfer; before someone says anything it is better to go to a new place, so that nobody should say that the doctor doesn't have any children. In the past, whenever my wife went for deliveries, she was told, "Don't let this woman touch you, she is a *banjh* [barren woman]." She feels it [*sic*]. So we had to get a transfer because people found out that this *doctrni* is unable to produce children, that she is barren.

The stigma of infertility and the force of social ostracism can penetrate and even subvert otherwise fixed social hierarchies in India. Social markers of

class and caste, as well as elite professional boundaries, are no safeguards against social stigma and disablement, as seen in the case of Rajkumar and his infertile physician wife. The oppressive cultural expectations of fertility, therefore, make ideas such as "reproductive rights," "agency," "privacy," and "choice" deeply problematic in contemporary India, even among the upper class. In a cultural context where a continuing absence of children in a marriage becomes sufficient grounds for social interference, "selective disclosure" of one's infertility in an attempt to manage one's "spoiled identity" is simply untenable. Riessman, in fact, has quite rightly argued that Goffman's model of stigma "management" does not work well in non-Euro-American contexts such as India, given its presumption of "a self-determining, autonomous individual with choices and a mass society that allows for privacy" (Riessman 2000:113).

Faced with such culturally entrenched stigma and socially debilitating community ostracism, it is not uncommon for Indian couples to withdraw into a world of their own. Unable to bear the continuing torment of social disparagement, a couple from Gujarat, Ram and Sujata, had stopped going to social functions, a highly unusual state of affairs for an Indian couple:

RAM: Sometimes it makes us very sad. People ask things like, "When will you have a baby?" We get very depressed but still we have got a hope, that's why we are here and we are taking every care, rest is up to Almighty.

AB [TO RAM'S WIFE, SUJATA]: What has your experience been like?

RAM: We avoid people.

AB: Has it affected your social life?

RAM: It has. We will not go . . . we will not mix in social functions.

SUJATA: Unnecessary talk all the time.

RAM: Sometimes all people are not equal, some may talk in polished language, some might talk in a rough way. People will not understand that this is also a kind of disease, but this particular disease they will take it some other way. People are having cancers, people are having TB, people are having kidney problems, people are having brain hemorrhage, so many things, but this particular they will take the other way.

AB: Why do you feel that is the case?

RAM: That we felt sometimes. That is why we generally will not go to social functions. We have cordial relations with everyone otherwise. Not that we are not friendly relations [*sic*], I am also very social man. We will not go to meet people often.

Similarly, in Egypt, relative withdrawal from community life was a common response of infertile women and couples in the study, who simply

found it less draining to resist this form of social oppression through avoidance than to attempt “assimilation” into the community of “normals” (e.g., by befriending fertile couples with children and working hard to normalize their social relationships with them). Egyptian husbands were often very supportive and protective of their infertile wives in this regard, as is seen also in the Indian cases described above. Indeed, one of the major findings of the Egyptian research was the significant degree to which Egyptian men do, in fact, resist family and community pressure to replace their infertile wives through polygyny or divorce (Inhorn 1996, 2003a). Infertile marriages in Egypt, among both lower and upper social classes, are often characterized by a remarkable degree of “conjugal connectivity”—or a sense of marital enmeshment that comes from the intimacy of shared suffering and longing. Furthermore, when children are not forthcoming in a marriage, marital partners have more time to focus on each other and may, in fact, pamper an infertile spouse (particularly an infertile husband) as if he/she were the missing child in the marriage. Among both poor and elite couples in Egypt, many childless marriages could be described as highly companionate, defying the cultural expectations of marital demise that are thought to follow upon a medical diagnosis of infertility (especially of the wife). This does not mean that all childless marriages in Egypt or India survive; indeed, some do not.<sup>9</sup> Moreover, new forms of medical treatment, especially for male infertility, may paradoxically *increase* the risks of male-initiated divorce, for reasons that will become painfully clear in the following section.

#### INFERTILITY AND MEDICALIZATION

The social stigmatization of infertility and the accompanying threats of this disabling condition to both personhood and marriage are what drive most infertile women, and sometimes infertile men, on a “quest for conception” (Inhorn 1994) that may be relentless and ultimately unfruitful. In most non-Euro-American societies where this therapeutic quest has been described, infertile women typically avail themselves of numerous remedies for infertility, based in both natural and supernatural systems of belief and healing (Inhorn and Van Balen 2002). In Egypt, where an elaborate armamentarium of ethnogynecological therapies for infertility dates back literally 5,000 years, poor infertile women continue to avail themselves of such traditional therapies, which have been described in some detail elsewhere (Inhorn 1994). Increasingly, however, poor women in both Egypt and India rely on the infertility services provided by biomedical practitioners,

some of whom may be specialized in infertility and reproductive medicine. Indeed, in both countries today, infertility is “big business” for biomedical specialists, who may offer the newest high-tech forms of assisted conception to affluent clients in urban areas (Bharadwaj 2001a; Inhorn 2003a). As these clinics are private affairs, generally lacking any form of state subsidy, patients presenting to them tend to be elites, who can afford expensive assisted reproductive technologies (ARTs) such as in-vitro fertilization (IVF).<sup>10</sup> Nonetheless, even elite infertile couples who turn to assisted conception in the hope of being assisted out of their long, protracted battles with infertility struggle financially, physically, and emotionally during the typically draining periods in which they are undertaking an IVF cycle. In the hope of salvaging their fertility through biomedical interventions, infertile couples in both Egypt and India may prolong the agony of their social suffering by resorting to biomedically desperate measures that may or may not secure an end to their socially disabling handicap.

In this respect, infertile Egyptian and Indian couples are similar to Euro-American couples who look to medicine, and particularly assisted conception, as a solution to their suffering. As reported by a number of ethnographers working in Euro-American settings (Greil 1991b; Sandelowski 1991; Franklin 1997; Becker 2000; Thompson 2005), infertility has become increasingly medicalized, particularly with the advent of ARTs such as IVF (Sandelowski and de Lacey 2002). However, in Euro-American societies, couples may pursue other options, including “child-free living” or adoption, once they come to accept the fact that their infertility cannot be solved through medical means. In both Egypt and India—and probably in many other pronatalist societies in the non-Euro-American world—there are no other truly viable options for infertile couples, given that couples are *never* expected to live “child-free,” nor are they culturally condoned to adopt abandoned or orphaned children.<sup>11</sup> Indeed, for Muslims in both Egypt and India—as well as for most Hindus and Christians in those countries—adoption is decidedly *not* an option, given the Islamic scriptural prohibitions against this practice, as well as rather profound cultural proscriptions against adoption in both countries (Inhorn 1996, 2003a; Bharadwaj 2003). In India, children given up for adoption are predominantly conceived in premarital or extramarital relationships (Bharat 1993) and hence seen as “bastard children.” To absorb such socially disabled children in infertile marriages is even more debilitating for stigmatized couples. While “child-free” living is not an option, many choose the stigma of barrenness or infertility over exposing an adoptee to a life of ostracism, jibes, and ridicule. Many others either adopt or foster children from within the wider family.



In Egypt, similarly, most infertile couples would prefer to remain in a stigmatized state of childlessness than to parent an orphan. Although the Islamic scriptures encourage kind treatment of orphans, legal adoption as it is known in the West is formally prohibited by Islam (Sonbol 1995). Furthermore, most orphans are assumed to be the products of premarital or extramarital adultery, *ibn haram*, literally "son of sin." Orphans, whether physically healthy or disabled, are considered of "bad blood," illegitimate, and even evil beings (ibid.). Hence, few Egyptians, poor or elite, are willing to consider bringing such "strangers" into their families.

Given this situation, infertile Egyptian and Indian couples—isolated, forlorn, and bereft of any possible social futures for alternative family-building—often seek to remedy intractable infertility by actively seeking medical help. Couples like Ram and Sujata, whose case was described above, see the medicalization of their infertility as the only tenable option in the face of growing social opposition to their childlessness. Society's inability to see infertility as a "disease," "disability," or "handicap"—comparable to the common and socially acceptable conditions of cancer, tuberculosis, kidney problems, or strokes in India—is particularly disconcerting for Ram. He obliquely hints at how (in) fertility and sexual dysfunction are often conflated, when he states, "this [infertility] they [society] will take the other way." In Ram's case, he had undergone corrective surgery for impotency, which apparently cured his sexual dysfunction. But throughout the interview, he remained tight-lipped about his own experience of social ridicule. Even though the truth of his impotency was not common knowledge in his family or community, his sensitivity toward his own past sexual disability compounded the anxiety of social disapproval, as his wife's inability to achieve pregnancy had implicated his manhood yet again.

This perhaps explains why some Indian men, like some Egyptian men (Inhorn 2002, 2003a, 2003b), abandon their barren wives and remarry in order to escape the cultural conflation between their own sexuality and fertility. This may also explain why many infertile Indian men of Hindu or Christian background—*unlike* Indian or Egyptian Muslim men—accept the use of donor sperm in assisted conception. Such desperate measures as "accepting any sperm" (as one Indian clinician put it) become a way of escaping "public disability," only to reinstate it within the private conjugal realm. Reluctantly accepting donor sperm is the closest that some Indian men can come to acknowledging, in the private clinical encounter, that they are the cause of the couple's infertility and social disability. A sense of

anxiety in "owning up" to the IVF status of their offspring also compounds the "taboo on speech" (Das 1995) that couples, and in some cases their family members, come to observe when seeking IVF, especially with donated gametes (Bharadwaj 2003). Dr. Shanta, an IVF practitioner based in Delhi, described the secretive world of such couples, who, in bringing new life into the world, typically misrecognize the circumstances leading up to the child's birth:

Fifty percent of the patients don't tell after the baby is born that it was an IVF baby at any social gathering, in front of another lady, never. Even when they talk to someone in private, they make sure they tell that person not to tell anybody that this is an IVF baby. They think there is stigma attached to the baby. . . . Our society is still not so liberated that they accept adoption. They [couples] accept taking donor oocyte, they accept artificial insemination by donor semen, anything. But they want to deliver the baby so the whole world can see that she has delivered a baby. So many men have got very near normal sperm but out of sheer frustration they say, "Oh, use any sperm you want. I want a baby." They just don't care! They just want to prove their fertility, that is all. . . . a woman at some stage in the family wants to prove it . . . the man just wants to prove to the world that his wife has produced a child, that he is capable of fathering a child.

There is some truth to Dr. Shanta's assertions about the use of donor gametes. In the Indian study, a great majority of couples, when asked to share their views on donor-gamete conception, felt it was acceptable as long as it was kept quiet. On the issue of the donor himself/herself, the unanimous response of these couples was that they were happy to let the doctor source a suitable donor, and they claimed that they had no personal preferences in the matter. These couples were very much less concerned about the sourcing of eggs and sperm for inducing conception than about the eventual birth of a child.<sup>12</sup> An open acceptance of the "other" in the reproduction of the "self," however, was a gradual process in the lives of most of these couples, as a Mumbai-based IVF practitioner, Dr. Sachin, clarifies:

The basic idea is that somebody is violating your marital relationship, a third party. That feeling itself is not very easy to accept. If I put myself in a patient's place I understand how they would feel. Here the marriage is considered as the ultimate bond and to have a child with donated gametes does upset a lot of couples. But then again once they reach the age of 35–36, they know they've no other option besides adoption. In adoption they get a child whose background is not known. Here, okay, at least egg or the sperm, at least one of the gametes is their own, plus the woman has the satisfaction of delivery. Donated gamete

is acceptable as long as it remains confidential and the husband and wife are very sure of each other. They understand what they are going in for without any cheating—that is, one person is not told and it's done. You know, things like that should not be done.

In Egypt, on the other hand, the situation surrounding third-party donation is completely different, underlining the importance of understanding the “local moral worlds” (Kleinman 1995) in which infertile and otherwise disabled individuals make sense of new medical technologies that come their way. As described at length in *Local Babies, Global Science: Gender, Religion, and in-Vitro Fertilization in Egypt* (Inhorn 2003a), Islamic religious authorities in Egypt and in other parts of the Sunni Muslim world (Meirow and Schenker 1997) have declared that IVF and similar therapies are an acceptable line of treatment—as long as they are carried out by medical experts *with sperm from a husband and ova from a wife* with “no mixing with other cells from other couples or other species, and that the conceptus [the embryo] is implanted in the uterus of the same wife from whom the ova were taken” (Aboulghar et al. 1990:266). In other words, Sunni Muslim religious scholars have clearly spelled out which individuals undergoing reproductive therapies have the right to claim the status of “mother” and “father”—namely, only the *biological* mother and father, who thereby maintain “blood ties” to their IVF offspring. Sperm, ova, and embryo donation, as well as surrogacy, are strictly prohibited.<sup>13</sup>

In Egyptian IVF centers, most patients are relative experts on the local religious opinion regarding IVF. Stating that the religious aspect of IVF is its “most important” element, Egyptian IVF patients in the study explained that sperm, egg, or embryo donation leads to a “mixture of relations.” Such mixing severs blood ties between parents and their offspring; confuses issues of paternity, descent, and inheritance; and potentially leads to incestuous marriages of the children of unknown egg or sperm donors. Thus, the thought of using donor sperm from a bank was simply reprehensible and was tantamount in their minds to committing *zina*, adultery. For many Egyptian elites, this was one of the main reasons preventing them from traveling abroad to seek IVF and other assisted reproductive technologies. As one wealthy woman explained:

If I go abroad, and I have something wrong [infertility], they take my eggs and his sperm and put [them] in another woman, the “carrier.” And they have “the bank of the sperms”—if you want him yellow [blonde], fair, black, dark hair. What is this? Nonsense! No way! For Muslims, this is wrong, and for Christians everywhere, too. But everyone does it there in the U.S. and Europe. I have no idea why, because

the punishment of this is horrible. It's like when someone makes love to a woman without marriage. It's *zina*, adultery. It's not his son. Maybe these mistakes are made abroad, but not *here*. Here, no way! Because all the doctors are Muslims, and it will be *their* punishment. So they are religious, too. “There can be no halves for God.” [I.e., everything must be done wholly right, not halfway.]

Indeed, in Egypt, much of this righteous moral discourse about IVF is now constructed in relation to discourses about the moral corruption occurring in the Christian West. In Egypt, news stories and television movies imported from America and Europe show women who “rent their wombs” only to struggle over the custody over the children they bear, or infertility doctors who impregnate hundreds of women with their own sperm only to be sent to prison, or IVF mothers who bear black and white twins by two fathers because of careless sperm admixtures in “Western” IVF laboratories. Proclaiming that this would never happen in Egypt—where patients can trust that their IVF doctors are good, religious Muslims—patients in Egyptian IVF centers described these stories, all of which happen to be true, with a kind of righteous incredulity. They concluded, often apologizing to the American anthropologist researcher, that “each society has its own traditions and customs.” Indeed, the fact that the Egyptian case is so different from the Indian case described above—as well as from the Euro-American societies where these forms of third-party donation (and negligence [Reame 2000; Robertson 1996]) do happen—bespeaks this basic truth: that the assisted reproductive technologies are, in fact, subject to the traditions and customs of each society, and particularly to the prevailing social norms governing each local moral world.

However, from a Euro-American perspective, there may be a down side to the restrictive moral code governing the use of assisted reproductive technologies in the Muslim world—one that affects Sunni Muslim women in particular. On the one hand, Islam glorifies motherhood and all it entails (Schleifer 1986), insisting that women are endowed with a “natural maternal instinct” and that children are the “decorations of worldly life.” Yet, infertile women who attempt to achieve glorious motherhood through resort to reproductive technologies are quite narrowly limited in their technological options by virtue of a religious code that prohibits third-party donation and surrogacy. Moreover, these constraints on achieving motherhood seem even greater when one considers two other important factors: namely, the Islamic prohibitions on adoption and the gender ramifications of the “newest” new reproductive technology designed to overcome male infertility.

With regard to this last point, over the past decade, intracytoplasmic sperm injection (ICSI) has revolutionized the treatment of male infertility by allowing even the most infertile men to father biological children. As long as one viable spermatozoon can be retrieved from the male body—even through painful testicular biopsies or aspirations—this spermatozoon can be injected directly into the ovum under a high-powered microscope in an IVF laboratory. In Egypt, this newest variant of IVF has been available since 1994 and has led to the virtual flooding of Egyptian IVF clinics with long-term cases of intractable male infertility. Unfortunately, many of the wives of these Egyptian men, who have “stood by” their infertile husbands for years, even decades in some cases, have grown too old to produce viable ova for the ICSI procedure. Because Islamic religious mandates in Egypt forbid any kind of egg donation or surrogacy, couples with a reproductively elderly wife face four difficult options: to remain together permanently without children, to permanently foster an orphan, to partake in a polygynous union with a younger, more fertile woman,<sup>14</sup> or to divorce outright so that the husband can remarry such a woman. Unfortunately, more and more highly educated upper-class men are choosing the last option—believing that their own reproductive destinies may lie with younger “replacement” wives who are allowed to men under Islam’s personal-status laws. Certainly, these laws—coupled with the Islamic position on the need for biological parenthood in the practice of IVF and ICSI—place infertile Egyptian women and the old wives of infertile Egyptian men in an extremely precarious position vis-à-vis their reproductive and marital futures.

Thus, in some senses, the introduction of a revolutionary new infertility technology in Egypt and other parts of the Muslim world has introduced a sad new twist to gender and marital politics, suggesting that these medical technologies are anything but morally neutral and value-free. The need to critically assess the social effects of these technologies seems abundantly clear, particularly as these new reproductive technologies spread around the globe to places like India and Egypt, where their implications for the reproductive—and social—health of reproductively impaired men and women are truly profound.

#### CONCLUSION

We began this chapter by asking what the post-Cairo Reproductive Health initiative had done for infertile people, and particularly infertile women, around the globe. Coming full circle, we would like to end our discussion of infertility *as* disability by asking the same question: What can be done?

In our view as medical anthropologists who have studied infertility and the assisted reproductive technologies in two non-Euro-American “developing” societies, the most salient and clear-cut need is for the Reproductive Health initiative to tackle the prevention of the many *preventable* causes of infertility—in Egypt, India, and many other parts of the non-Euro-American world. Indeed, primary prevention of infertility—particularly early and effective treatment of reproductive-tract infections that lead to tubal infertility in women (Sciarra 1994)—is clearly the key to avoiding most of the serious social sequelae of infertility, including the gendered suffering, relentless treatment-seeking, and very problematic resort to ARTs described in this chapter. This means that the Reproductive Health initiative must target *men* as well as women, for men are often the ones who carry sterilizing sexually transmitted diseases to their wives, even rendering them infertile on their wedding nights.

Nonetheless, because not all infertility can be prevented—and this is particularly true of male infertility, which contributes to more than half of all infertility cases around the world (Irvine 1998)—there will always be a demand for the latest, most modern reproductive technologies to overcome this problem, even in resource-poor locations of the non-Euro-American world such as Egypt and India. At the present time, the assisted reproductive technologies are the only viable medical solution for the millions of cases of tubal and male infertility worldwide. Thus, a broadened Reproductive Health initiative might assume some form of responsibility for monitoring the global development and transfer of these technologies, making them more affordable and equitable in terms of their distribution to the millions of infertile sufferers in the developing world. Although these technologies are clearly *not* a panacea for overcoming infertility—because of their relatively low success rates and their substantial risks to women’s bodies (as pointed out by generations of feminist scholars in the West [Thompson 2002])—they are currently the only solution for infertility in many parts of the world where adoption is disallowed and parenthood culturally mandated. Indeed, in the sweet, wrinkled faces of test-tube babies in both Egypt and India, one sees the success of these technologies in bringing an end to the misery that *is* the lived experience of infertility.

Furthermore, the very presence of these technologies in non-Euro-American societies—and the media glorification that surrounds the birth of test-tube “miracle babies” in places like Egypt and India—has, to some degree, introduced the problem of infertility and its high-tech treatment to the public, providing new national discourses on the problem of infertility, creating sympathy for its sufferers, and leading to a process of gradual

normalization for both infertility and ART treatment-seeking (Bharadwaj 2000, 2002; Inhorn 2003a). The very fact that the parents of both Egypt's and India's first test-tube babies have "gone public" via the national media suggests that the very presence of these new technologies, coupled with media fascination over them, may lead to more tolerant attitudes toward both infertility and ARTs over time. In this way, new reproductive technologies have gone beyond solving individual problems of infertility by leading to new public awareness of infertility in both societies. That this process has also happened with other therapeutic and rehabilitative technologies in many other societies suggests that a broader social process of technology-driven public awareness of disability is clearly at work.<sup>15</sup>

Having said this, it is important to point out that media representations of infertility in both Egypt and India are quite centrally entrenched in the biomedical disease model of the condition. Media reports in these countries help to perpetuate the public perception that impediments to fertility can be medically corrected by ARTs, such that no woman or man need be childless any more! Such uncritical glorification in the media is, in fact, based on an erasure of the disability model of infertility, which, if popularized, could well open the way to alternatives like adoption or fostering, or at least create new public dialogues on the subject. However, because the media "hard sell" in both Egypt and India is about high-tech baby making and the promotion of particular IVF clinics and their doctors (Bharadwaj 2000, 2002; Inhorn 2003a), it serves to entrench, rather than unseat, the disease model of infertility, thereby blocking creative alternatives, such as disability-rights activism, infertility self-help groups, fosterage and adoption, and even child-free living.

In other words, without romanticizing the power of either the media or technology to influence public perceptions, it is nonetheless important to point out that the emergence of NRTs and their media glorification in Egypt and India have perhaps undermined more creative cultural responses to the biosocial problem of infertility. In neither society at the current time are public debates emerging to promote alternatives to ARTs, particularly adoption or child-free living. Even if these debates were to emerge, they would likely be restricted to urban elites—most notably, the so-called progressive intelligentsia in India, or educated cosmopolitan, secular Muslims in Egypt. Thus, in both societies, efforts to critically grapple with the infertility problem are currently being made only by the biomedical communities, who more and more are offering ARTs as the only real solution to infertility.

However, because ARTs do not work for most of those who suffer from infertility, and because ARTs are inaccessible to the vast majority of

infertile couples who might benefit from them, ARTs are clearly not the answer to infertility in resource-poor societies such as Egypt and India. In our view as infertility scholars, it is time for both the reproductive-health and international disability-rights movements to take a bold stand by prioritizing infertility on their political platforms, asking what can be done to help the infertile people of the world. By *not* doing so, they effectively condemn millions of infertile citizens, including men but particularly women, to lives of pointless pain and suffering. For, as we have seen in this chapter, infertility is no trivial matter for most men and women in the pronatalist societies of the Third World. Infertility may ruin reputations, marriages, livelihoods, physical health, and long-term security in ways that are truly disastrous. In short, infertility is a particularly pernicious form of social disability—one that engulfs whole lives in endless circles of treatment-seeking, social stigmatization, and human suffering, and one that needs to be duly acknowledged as we enter the new millennium.

#### NOTES

1. To our knowledge, there are no patient-led infertility self-help groups of this kind in any country outside of Euro-America.

2. As noted by Wendell (1997:263), the UN/WHO definition makes a "shaky" distinction between the physical and social aspects of disability and does not contextualize the notion of "normality," which "depends upon the society in which standards of normality are generated."

3. Most cases of infertility are, in fact, incurable, in that the actual biological impairments causing failures of conception cannot be repaired. Thus, today, most of the treatments for infertility do not truly cure this condition; rather, they solve it by bypassing the physiological impediments to conception, such as blocked fallopian tubes.

4. This was pointed out to us by Susan Reynolds Whyte, who suggested that the debate over cochlear implants to restore hearing in the deaf might be the only comparable example.

5. Male infertility contributes to more than half of all cases of infertility in the world and is the sole cause of reproductive dysfunction in at least 30 percent of all cases (Irvine 1998).

6. All names used in this chapter are pseudonyms.

7. Although male infertility and impotency (erectile dysfunction) are commonly conflated in the popular imagination, most cases of male infertility are *not* caused by male sexual dysfunction. Rather, male infertility is usually related to various defects of sperm (i.e., in count, motility, and morphology), the etiology of which remains unclear (Irvine 1998).

8. The minority Coptic Christian community in Egypt, comprising approximately 5–10 percent of the Egyptian population, is religiously disallowed

from divorcing. Thus, Egyptian Copts are often active infertility-treatment seekers, given that divorce is "no way out" of their reproductive problems.

9. During the summer of 1996, Marcia Inhorn's infertile research assistant was callously divorced by her husband of ten years once he learned with certainty that his wife would never be able to bear his children.

10. In Egypt, the cost of an average cycle of IVF in 1996 was \$2,500–\$3,000, in a country where per-capita income was only \$1,200 (Population Reference Bureau 1999). In India, an average cycle of IVF in 1997–98 was \$850–\$1,000, in a country where per-capita income in 2000 was only \$450 (World Bank 2000).

11. In some parts of sub-Saharan Africa and Oceania, child fosterage within the family is a common cultural pattern and helps infertile couples to achieve their parenting desires. Even so, infertile couples who are foster parents within such societies may still pursue costly medical remedies in the hopes of conceiving their own biological children.

12. Compare this to an Indian interviewee in Hirsch's southeastern England study (1999:121) who insisted that the possibility of anonymous genetic material would be unthinkable in Indian culture: "Now they want to know, if it's an anonymous sperm, will you know which caste it comes from? So it's completely out of the question, they will never accept it. Never accept it, even if they are given 100 per cent verity it's a high caste, they still won't accept it."

13. By the end of the 1990s, religious authorities of the minority Shi'a sect of Islam approved the use of donor gametes, particularly donor egg. Thus, donor egg and embryo programs can be found in the Shi'a-majority countries of Lebanon and Iran, although acceptance of donor sperm remains more problematic (Inhorn 2004).

14. Very few Egyptian women today will accept being a cowife in a polygynous marriage. Even among poor women, most say they would rather be divorced than to "share" their husband with a cowife.

15. This was also pointed out to us by Susan Reynolds Whyte.

## REFERENCES

- Abbey, Antonia, Frank M. Andrews, and L. Jill Halman. 1991. Gender's role in responses to infertility. *Psychology of Women Quarterly* 15(2):295–316.
- Aboulghar, M. A., G. I. Aboul Serour, and R. Mansour. 1990. Some ethical and legal aspects of medically assisted reproduction in Egypt. *International Journal of Bioethics* 1:265–68.
- Becker, Gay. 2000. *The Elusive Embryo: How Men and Women Approach New Reproductive Technologies*. Berkeley and Los Angeles: University of California Press.
- Bentley, G. R. 2000. Environmental pollutants and fertility. In *Infertility in the Modern World: Present and Future Prospects*, ed. G. R. Bentley and C. G. Nicholas Mascie-Taylor, 85–152. Cambridge: Cambridge University Press.
- Bentley, G. R., and C. G. Nicholas Mascie-Taylor, eds. 2000. *Infertility in the Modern World: Present and Future Prospects*. Cambridge, United Kingdom: Cambridge University Press.
- Bharadwaj, Aditya. 1999. Barren wives and sterile husbands: Infertility and assisted conception in India. Paper presented at the conference "Gender, health, and healing: Reflections on the public and private divide," University of Warwick, April 23–24.
- . 2000. How some Indian baby makers are made: Media narratives and assisted conception in India. *Anthropology and Medicine* 7:63–78.
- . 2001. Conceptions: An exploration of infertility and assisted conception in India. PhD thesis, University of Bristol.
- . 2002. Conception politics: Medical egos, media spotlights, and the contest over test-tube firsts in India. In *Infertility around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*, ed. M. C. Inhorn and F. van Balen, 315–33. Berkeley and Los Angeles: University of California Press.
- . 2003. Why adoption is not an option in India: The visibility of infertility, the secrecy of donor insemination, and other cultural complexities. *Social Science and Medicine* 56:1867–80.
- Bharat, S. 1993. *Child Adoption in India—Trends and Emerging Issues: A Study of Adoption Agencies*. Bombay: Tata Institute of Social Sciences.
- Bittles, A. H., and P. L. Matson. 2000. Genetic influences on human infertility. In *Infertility in the Modern World: Present and Future Prospects*, ed. G. R. Bentley and C. G. Nicholas Mascie-Taylor, 46–81. Cambridge: Cambridge University Press.
- Boerma, J. Ties, and Zaida Mgalla, eds. 2001. *Women and Infertility in Sub-Saharan Africa: A Multi-disciplinary Perspective*. Amsterdam: Royal Tropical Institute.
- Charmaz, K. 1983. Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness* 5:168–95.
- Daniluk, Judith C. 1988. Infertility: Intrapersonal and interpersonal impact. *Fertility and Sterility* 49:982–90.
- Das, Veena. 1995. National honor and practical kinship: Unwanted women and children. In *Conceiving the New World Order: The Global Politics of Reproduction*, ed. F. D. Ginsburg and R. Rapp, 212–33. Berkeley and Los Angeles: University of California Press.
- Davis, L. J. 1997. Introduction. In *The Disability Studies Reader*, ed. L. J. Davis, 1–6. New York: Routledge.
- Fishel, S., K. Dowell, and S. Thornton. 2000. Reproductive possibilities for infertile couples: Present and future. In *Infertility in the Modern World: Present and Future Prospects*, ed. G. R. Bentley and C. G. Nicholas Mascie-Taylor, 17–45. Cambridge: Cambridge University Press.
- Franklin, Sarah. 1997. *Embodied Progress: A Cultural Account of Assisted Conception*. London: Routledge.

- Gerrits, Trudie. 2002. Infertility and matrilineality: The exceptional case of the Macua of Mozambique. In *Infertility around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*, ed. M. C. Inhorn and F. van Balen, 233–46. Berkeley and Los Angeles: University of California Press.
- Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs: Prentice-Hall.
- Greil, Arthur L. 1991a. A secret stigma: The analogy between infertility and chronic illness and disability. *Advances in Medical Sociology* 2:17–38.
- . 1991b. *Not Yet Pregnant: Infertile Couples in Contemporary America*. New Brunswick: Rutgers University Press.
- . 1997. Infertility and psychological distress: A critical review of the literature. *Social Science and Medicine* 45:1679–1704.
- Greil, Arthur L., Thomas A. Leitko, and Karen L. Porter. 1989. Infertility: His and hers. *Gender and Society* 2:172–99.
- Hartmann, Betsy. 2002. Charting a path ahead: Who defines women's health and how? Paper presented at the conference "Defining women's health: An interdisciplinary dialogue," Harvard University, May 4, 2002.
- Hirsch, Eric. 1999. Negotiating limits: Interviews in south-east England. In *Technologies of Procreation: Kinship in the Age of Assisted Conception*, 2nd ed., ed. J. Edwards, S. Franklin, E. Hirsch, F. Price, and M. Strathern, 91–121. London: Routledge.
- Ingstad, Benedicte. 1995. Mpho ya modimo—A gift from God: Perspectives on "attitudes" toward disabled persons. In *Disability and Culture*, ed. B. Ingstad and S. R. Whyte, 246–63. Berkeley and Los Angeles: University of California Press.
- Inhorn, M. C. 1994. *Quest for Conception: Gender, Infertility, and Egyptian Medical Traditions*. Philadelphia: University of Pennsylvania Press.
- . 1996. *Infertility and Patriarchy: The Cultural Politics of Gender and Family Life in Egypt*. Philadelphia: University of Pennsylvania Press.
- . 2002. Sexuality, masculinity, and infertility in Egypt: Potent troubles in the marital and medical encounters. *Journal of Men's Studies* 10:343–59.
- . 2003a. *Local Babies, Global Science: Gender, Religion, and in-Vitro Fertilization in Egypt*. New York: Routledge.
- . 2003b. "The worms are weak": Male infertility and patriarchal paradoxes in Egypt. *Men and Masculinities* 5:236–56.
- . 2004. Middle Eastern masculinities in the age of new reproductive technologies: Male infertility and stigma in Egypt and Lebanon. *Medical Anthropology Quarterly* 18:162–82.
- Inhorn, M. C., and F. Van Balen, eds. 2002. *Infertility around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*. Berkeley and Los Angeles: University of California Press.
- Irvine, D. S. 1998. Epidemiology and aetiology of male infertility. *Human Reproduction* 13 (Supplement):33–44.
- Jeffery, Roger, and Patricia Jeffery. 1989. *Labour Pains and Labour Power: Women and Childbearing in India*. London: Zed Books.

- Jenkins, Gwynne L., with Silvia Vargas Obando and Jose Badilla Navas. 2002. Childlessness, adoption, and *milagros de Dios* in Costa Rica. In *Infertility around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*, ed. M. C. Inhorn and F. van Balen, 171–89. Berkeley and Los Angeles: University of California Press.
- Kleinman, Arthur. 1995. *Writing at the Margin: Discourse between Anthropology and Medicine*. Berkeley and Los Angeles: University of California Press.
- Meirow, D., and J. G. Schenker. 1996. The current status of sperm donation in assisted reproduction technology: Ethical and legal considerations. *Journal of Assisted Reproduction and Genetics* 14:133–38.
- Nachtigall, Robert D., Gay Becker, and Mark Wozny. 1992. The effects of gender-specific diagnosis on men's and women's response to infertility. *Fertility and Sterility* 54:113–21.
- Population Reference Bureau. 1999. World population data sheet: Demographic data and estimates for the countries and regions of the world. Washington, D.C.: Population Reference Bureau.
- Reame, Nancy King. 2000. Making babies in the twenty-first century: New strategies, old dilemmas. *Women's Health Issues* 10:152–59.
- Riessman, Catherine Kohler. 2000. Stigma and everyday resistance practices: Childless women in south India. *Gender and Society* 14(1):111–35.
- . 2002. Positioning gender identity in narratives of infertility: South Indian women's lives in context. In *Infertility around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*, ed. M. C. Inhorn and F. van Balen, 152–70. Berkeley and Los Angeles: University of California Press.
- Robertson, John A. 1996. Legal troublespots in assisted reproduction. *Fertility and Sterility* 65:11–12.
- Sandelowski, Margarete. 1991. *With Child in Mind: Studies of the Personal Encounter with Infertility*. Philadelphia: University of Pennsylvania Press.
- Sandelowski, Margarete, and Sheryl de Lacey. 2002. The uses of a "disease": Infertility as rhetorical vehicle. In *Infertility around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*, ed. M. C. Inhorn and F. van Balen, 33–51. Berkeley and Los Angeles: University of California Press.
- Scheper-Hughes, Nancy, and Margaret Lock. 1987. The mindful body: A prolegomenon to future work in medical anthropology. *Medical Anthropology Quarterly*, n.s., 1:6–41.
- Schleifer, Aliah. 1986. *Motherhood in Islam*. Cambridge: Islamic Academy.
- Sciarra, J. 1994. Infertility: An international health problem. *International Journal of Gynecology and Obstetrics* 46:155–63.
- Sonbol, Amira al-Azhary. 1995. Adoption in Islamic society: A historical survey. In *Childhood in the Muslim Middle East*, ed. E. W. Fernea, 45–67. Austin: University of Texas Press.

- Sundby, Johanne. 2002. Infertility and health care in countries with less resources: Case studies from sub-Saharan Africa. In *Infertility around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*, ed. M. C. Inhorn and F. van Balen, 247–60. Berkeley and Los Angeles: University of California Press.
- Thompson, Charis M. 2002. Fertile ground: Feminists theorize infertility. In *Infertility around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*, ed. M. C. Inhorn and F. van Balen, 52–78. Berkeley and Los Angeles: University of California Press.
- . 2005. *Making Parents: The Ontological Choreography of Reproductive Technologies*. Cambridge, Mass.: MIT Press.
- United Nations [UN]. 1983. *World Programme of Action Concerning Disabled Persons*. New York: United Nations.
- Van Balen, F. 2002. The psychologization of infertility. In *Infertility around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies*, ed. M. C. Inhorn and F. Van Balen, 79–98. Berkeley and Los Angeles: University of California Press.
- Van Balen, F., and T. C. M. Trimpos-Kemper. 1998. Involuntary childless couples: Their desire to have children and their motives. *Journal of Psychosomatic Obstetrics* 16:137–44.
- Wendell, Susan. 1997. Toward a feminist theory of disability. In *The Disability Studies Reader*, ed. L. J. Davis, 260–78. New York: Routledge.
- Whyte, S. R., and B. Ingstad. 1995. Disability and culture: An overview. In *Disability and Culture*, ed. B. Ingstad and S. R. Whyte, 3–32. Berkeley and Los Angeles: University of California Press.
- World Bank. 2000. *World Bank Report*. www.worldbank.org.
- World Health Organization [WHO]. 1980. *International Classification of Impairments, Disabilities, and Handicaps*. Geneva: World Health Organization.

## 4 The Chosen Body and the Rejection of Disability in Israeli Society

MEIRA WEISS

The Zionist revolution that aimed to create a new people for a new land had a unique bodily aspect. For central Zionist thinkers at the beginning of the twentieth century, returning to the land of Israel and becoming involved in agriculture was supposed to restore the health of Jewish bodies. Agriculture, land, territory, and military power were seen as antidotes to what was perceived as the passivity and “spirituality” of Jews and Judaism in the diaspora. In Max Nordau’s term, coined as early as 1898, Zionism was to be “Judaism with muscles.”<sup>1</sup> This glorification of the physical body has had implications for the devaluation of the disabled body. In this chapter I extend my reading of the body in Israeli society to include disability issues.

My focus on the body as a mirror of social paradigms and a performative cultural script reflects socioanthropological insights that have emerged in the second half of the twentieth century (Martin 1990, 1994). Traditionally, “the body” has been treated by social scientists as a universal biological entity that “falls naturally into the domain of the basic sciences and is therefore beyond the purview of social and cultural anthropology” (Lock 1993:134). Since the late 1970s, as Lock (1993) argues in her review of the body in anthropology, the universalistic perspective of the body has been shifted. Bodily practices and knowledge were put under the sociological gaze.<sup>2</sup> As Berthelot (1986) has remarked in regard to socioanthropological literature, “the body would now appear to be everywhere.” My anthropological take on the body follows the work of Foucault (1971, 1973, 1977, 1980), who placed the body in a political context and within processes of knowledge and power. This critical view was also developed by sociologists working in the Marxist and feminist traditions, who stressed the role of the body as a window to class and gender hierarchies. “Writing the body”

# Disability in Local and Global Worlds

*Edited by*

BENEDICTE INGSTAD

SUSAN REYNOLDS WHYTE

*University of California Press*

BERKELEY    LOS ANGELES    LONDON