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The Social Construction of Infertility

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Abstract

Health and illness are not objective states but socially constructed categories. We focus here on infertility, a phenomenon that has shifted from being seen as a private problem of couples to being seen as a medical condition. Studying infertility provides an ideal vantage point from which to study such features of health care as inter-societal and cross-cultural disparities in health care, the relationship between identity and health, gender roles, and social and cultural variations in the process of medicalization. Infertility is stratified, both globally and within Western societies. Access to care is extremely limited for many women in developing societies and also for marginalized women in some highly industrialized societies. We also discuss the ways in which responses to infertility are influenced by the process of self-definition. The experience of infertility is profoundly shaped by varying degrees of pronatalism and patriarchy. In advanced industrial societies, where voluntary childfree status is acknowledged, many women experience infertility as a “secret stigma”; in other cultures, where motherhood is normative for all women, infertility may be impossible to hide. In the West, acceptance of the medical model is virtually hegemonic, but in other societies medical interpretations of infertility coexist with traditional interpretations.

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Introduction

Medical sociologists argue that health and illness are best understood, not as objectively measurable states, but as socially constructed categories negotiated by professionals, sufferers, and others within a socio-cultural context. Decisions as to what constitutes “abnormality”, how abnormalities are defined, and what steps, if any, should be taken to deal with them are all made within a social and cultural context. Conrad and Schneider (1980) have used the term “medicalization” to denote the process by which certain behaviors come to be understood as questions of health and illness, and therefore subject to the authority of medical institutions. Medicalization has progressed much further in highly industrialized nations than it has in less industrialized societies (Conrad 2007). Within highly industrialized nations, the medicalization of woman’s lives has proceeded at a faster pace than the medicalization of men’s lives (Inhorn 2006).

We focus here on infertility, a phenomenon that has shifted from being seen as a private problem of couples to being seen as a medical condition that focuses primarily on women (Becker 2000; Bell 2009; Franklin 1997; Greil 1991a,b; Thompson 2005). Infertility, usually defined in the medical context as the inability to conceive after 12 months of regular unprotected intercourse, is quite common. Boivin et al. (2007) estimate the prevalence of infertility worldwide to be about 9 percent. Lifetime prevalence rates are considerably higher. The National Survey of Fertility Barriers data set we have collected in the United States reveals that 51.8 percent of women aged 25–45 report infertility *at some point in their lives*. The medicalization of infertility began in earnest with the development of fertility drugs in the United States in the 1950s, but it has proceeded even more rapidly since the development of such assisted reproductive technologies as in vitro fertilization (IVF) and intra-cytoplasmic sperm injection (ICSI).

The social construction of health and illness is perhaps even more striking in the case of infertility than for other health conditions. First, no matter how medical practitioners may define infertility, couples do not define themselves as infertile or present themselves for treatment unless they embrace parenthood as a desired social role. Second, while the medical model treats medical conditions as phenomena affecting the individual, infertility is often seen, especially in advanced

industrialized nations, as a condition that affects a couple regardless of which partner may have a functional impairment. Thus, defining oneself as infertile involves not simply negotiations between the individual and medical professionals but also negotiations within the couple and, possibly, larger social networks. Third, the presence of infertility is signaled, not by the presence of pathological symptoms, but by the absence of a desired state. Fourth, it is more obvious in the case of infertility than it is for other medical conditions that other possibilities exist rather than pursuing a “cure”. Possible alternatives to treatment include self-definition as voluntarily childfree, adoption, fosterage, or changing partners. Infertility is best understood as a socially constructed process whereby individuals come to regard their inability to have children as a problem, to define the nature of that problem, and to construct an appropriate course of action.

Studying infertility contributes to the sociology of health and illness by providing an ideal vantage point from which to study such features of health care as inter-societal and cross-cultural disparities in health care, the relationship between identity and health, gender roles, and social and cultural variations in the process of medicalization. Although infertility affects men and women, in this review we focus primarily on the voluminous research about women with infertility; our particular interest is women’s roles across cultures. Reviewing the research on couples and men would require a separate article. Ethnographic studies of infertility describe the feelings of distress that couples experience as they try unsuccessfully to achieve pregnancy (Becker 2000; Greil et al. 2010). Johansson and Berg (2005) extracted three themes from interviews with infertile women: the centrality of the infertility experience, social isolation, and grief. Williams (1997) culled 11 themes from interviews with infertile women: negative identity; worthlessness and inadequacy; lack of personal control; anger and resentment; grief and depression; anxiety and stress; lower life satisfaction; envy of other mothers; loss of the dream of co-creating; the “emotional roller coaster”; and isolation. The emotional consequences of infertility can persist even 20 years after discontinuing treatment (Wirtberg et al. 2007). And, as we shall see, infertility can have especially devastating consequences of infertility for many women in less-industrialized societies (Bharadwaj 2003; Handwerker 1995; Inhorn 1994, 1996; Inhorn and Bharadwaj 2008; Nahar 2007).

Stratified reproduction

Infertility is not only medicalized but stratified as well. Colen (1986) first used the phrase “stratified reproduction”, later popularized by Ginsburg and Rapp (1995), to describe how reproduction is structured across social and cultural boundaries, empowering privileged women and disempowering less privileged women to reproduce. When medicalization intersects with reproductive politics, some groups of women are encouraged to “choose” certain treatments and are discouraged from “choosing” others. Research on stratified reproduction has usually focused more on contraceptive practices such as abortion, sterilization, and birth control than on infertility.

From the point of view of many policy makers and of much media, the problem in underdeveloped countries is that they are overpopulated. Thus infertility is depicted as not being a serious problem in less industrialized societies (van Balen and Trudie Gerrits 2001; Bos et al. 2005; Inhorn and Daphne Birenbaum-Carmeli 2008; Nachtigall 2005). In fact, however, infertility is found throughout the world and is especially common in central Africa. Feldman-Savelsberg (2002) reports that the women she studied in the Cameroon grasslands perceive their chief threat to be, not overpopulation, but infertility and population decline.

In the United States, where we live, and in other highly industrialized societies, media often constructs the typical infertility patient as a middle-class White woman who delayed childbearing in order to pursue a career (Bell 2009, 2010; Sandelowski and de Lacey 2002). Conversely, poor and non-White women are often characterized by negative public images that depict them as hyper-fertile and sexually irresponsible (Roberts 1997; Solinger 2005). White women with higher incomes or education are directed away from sterilization and toward infertility treatment while women of color are more often encouraged to get sterilized and less often directed to infertility treatment. Recent state infertility mandates in the United States have focused on providing access to infertility services for people who can afford them, while Medicaid covers contraception but not infertility services (King and Meyer 1997). As Cussins (1998, 73) puts it, public characterizations in the United States divide women into “... those for whom contraception is available if only they’d use it and those for whom there are infertility treatments.”

Despite evidence that infertility is distressing, fewer than 50 percent of infertile women receive medical treatment (Boivin et al. 2007). Although rates of infertility help-seeking are comparable in developed and less developed societies, access to care is severely limited in developing societies (Ombelet et al. 2008). Dyer et al. (2002) discovered that one quarter of female South African clinic patients had been seeking care for over 5 years before their first appointment at an infertility clinic. Lack of access to primary care appeared to be a major barrier. Sundby (2002) writes that the formal medical systems in both The Gambia and Zimbabwe are unable to meet the need for services. That infertility is a major concern is evident from the high proportion of hospital admissions, but the care women receive is often inappropriate (Sundby and Jacobus 2001). Affluent women in The Gambia, India, and Egypt have access to sophisticated gynecological facilities and ART, but the needs of poor and middle-class women are not met (Inhorn 2000; Widge 2005).

Access to care is an issue for ethnic minorities and those with lower socio-economic status (SES) in many advanced industrial nations as well (Beckman and Harvey 2005; Culley et al. 2009). Degree of access varies from one society to the next. In both France (Tain 2003) and Israel (Kahn 2000; Remennick 2000), where there are state-subsidized infertility treatments, socioeconomic status does not seem to affect the utilization of ART. Access to treatment is especially limited in the United States because health care is based on a market model, infertility treatment is expensive, and most states do not mandate insurance coverage. Of 31,047 women interviewed between 1982 and 2002, 15.8 percent of White women reported ever having received treatment for infertility as compared to 10.7 percent of Black women and 12.2 percent of Hispanic women (Bitler and Schmidt 2006). Even in Massachusetts, a state with mandated ART coverage, Latino women, less educated women, and poor women are underrepresented in ART clinics (Jain 2006).

There is evidence that race disparities in infertility treatment in the United States are partially a reflection of disparities in economic resources, such as income and access to health insurance in infertility treatment (Bitler and Schmidt 2006; Jain 2006; Jain and Hornstein 2005; Staniec and Webb 2007). It is well documented that average earnings are lower, proportion unemployed is higher, and proportion in poverty is higher among women of color compared to White women. Staniec and Webb (2007) show that money does matter when it comes to

infertility services. Bell (2009, 2010), however, reminds us that SES matters in more subtle ways as well. For example, the sequencing and scheduling of appointments assumes a level of flexibility and autonomy at work that poorer women are unlikely to have. In addition, the lower- and working-class women Bell interviewed reported being steered away from infertility treatment by medical personnel who tried to talk them out of getting pregnant. Perhaps most importantly, lower-class women and women of color are aware of the social characterization of themselves as women not fit to reproduce. As one respondent told Bell (2009), infertility treatment is “way out of my league”.

But racial and class differences in infertility treatment may also stem from such social cues as encouragement or lack of encouragement from significant others to pursue treatment. White et al. (2006) argue that lower levels of infertility treatment among racial minorities could be accounted for by cultural aversion to technological solutions, distrust of the medical establishment, and fear of being rejected for treatment. One barrier to treatment for infertile Black women is lack of support for medical interventions from their husbands (Inhorn et al. 2009). There is also a well-earned distrust of medical institutions among many African-Americans (Dovidio et al. 2008). Because Black and Mexican American women often have a more holistic approach to health than White women, they may see treatment as non-spiritual and suspect (Inhorn et al. 2009; Jenkins 2002; Molock 1999). Molock (1999) suggested that a strong tradition of caring for other people's children often leads to many friends and family of Black women exerting less pressure toward treatment.

Infertility and identity

Access to medical care and socio-cultural attitudes toward medical treatment are not the only factors determining who receives treatment and who does not. A study of a cross-sectional population-based sample of infertile women revealed that self-definition as infertile is key to seeking treatment (White et al. 2006), but the study could not definitively determine whether defining oneself as infertile is a prerequisite to seeking treatment or whether it is treatment that leads individuals to define themselves as infertile. Bunting and Boivin (2007) found that women who were more concerned about being labeled

infertile were less likely to seek treatment. It is apparent that not all US women who are infertile by the medical definition identify as having a fertility problem. Conversely, Gerrits (1997) notes that Macua women in Cameroon who sought biomedical and traditional treatments sooner than 12 months of trying to conceive were not necessarily infertile by the medical definition but saw themselves as having a fertility problem.

Clinic-based studies of treatment seekers still prevail in research on the consequences of infertility (Henning et al. 2002). Studies of patients provide no information about half of the female infertile population (Greil et al. 2010). Infertility patients represent a subset of infertile women who have both a strong desire to become pregnant and the social and material resources that will allow them to do “whatever it takes” to have a child. The characterization of infertile women in the advanced industrialized nations as highly distressed and totally immersed in the process of trying to become pregnant describes only treatment seekers. Even among treatment seekers, the research emphasis has been on the most advanced treatments, to which less advantaged women have limited access.

As long as research on infertility is limited to the study of clinic patients, conceptualizing who should be considered infertile seems straightforward. In most studies, the infertile are implicitly and inadvertently defined operationally as “people who present themselves for infertility treatment”. Once we move beyond treatment seekers, we observe that the line between infertile and non-infertile becomes blurred (Greil and McQuillan 2010). Moving beyond treatment seekers reveals the infertile to be a much more diverse group than previously understood. How are we to classify a woman who would be considered infertile according to the medical definition but who does not see herself as having “tried” to conceive and who does not consider herself to be infertile? This is an important question, because such individuals are quite common. Greil and McQuillan (2004) have divided infertile women into the “subfecund with intent” (women who say they tried to conceive for at least 12 months without conception) and the “subfecund without intent” (women who report having had unprotected intercourse without conception but who do not say that they were explicitly trying to conceive at the time) and have discovered that the two groups differ with regard to both distress levels and help-seeking behavior.

Infertility in socio-cultural context

The social-scientific literature on infertility is increasingly emphasizing the importance of the socio-cultural context in shaping the lived experience of infertility. One characteristic of the socio-cultural context that influences infertility is pronatalism (Parry 2005). While all societies are pronatalist, some emphasize the centrality of motherhood to women's identity more than others. For example, Israel is an intensely pronatalist society with state subsidies for IVF and surrogacy (Birenbaum-Carmeli 2004; Kahn 2000). Remennick (2000) studied a small Israeli sample and concluded that none of the women she spoke to even believed that there was such a thing as voluntary childlessness. In developing societies especially, having children may be the key to women achieving adult status and gaining acceptance in the community (Hollos 2003). According to Sundby and Jacobus (2001), in southern Africa, the birth of children gives a woman the right to share in her husband's property and wealth. In Yoruba culture, the adult woman's role depends on motherhood because children are essential to the continuation of lineages (Pearce 1999). In Cameroon, infertility can be a source of poverty for women (Feldman-Savelsberg 2002). Because fertility is so central to women's identities in developing countries, women and men with fertility problems may resist labeling themselves infertile (Barden-O'Fallon 2005).

The experience of infertility is shaped by patriarchy. In Egypt, women bear the burden of infertility even when they know there is a male cause (Inhorn 2002). According to Nahar et al. (2000), in Bangladeshi slums the "treatment" for males is remarriage, as women are held responsible for infertility. Jenkins (2002) reports a case in Costa Rica where a woman, Silvia, had to resign herself to childlessness because her husband refused to be tested. Gerrits (1997) reports that the experience of infertility may be different in matrilineal societies. While patriarchy may be less striking in advanced industrial nations, it is by no means irrelevant to the experience of infertility. In a qualitative study of males who are infertile and have discontinued IVF, Throsby and Gill (2004) discuss what they see as the influence of hegemonic masculine culture on spousal relations. Husbands feel that infertility threatens their masculinity; while wives are pitied, husbands are teased. Men respond, according to Throsby and Gill, by casting blame on their wives.

“Two Worlds” of infertility

Although any simple dichotomy necessarily involves overgeneralization, it may make sense to think in terms of “two worlds” of infertility. Advanced industrial societies and developing societies tend to differ in prevailing assumptions about childlessness. In many advanced industrial societies, voluntary childlessness is viewed as more legitimate, and women without children are often presumed to be voluntarily childfree (Kerr 1999). According to Riessman (2000, 113), however, voluntary childlessness is rare in Kerala, India, because “bearing and rearing children are central to women’s power and wellbeing.” Leonard (2002) reports that in Chad, there is pressure to prove one’s fertility soon after marriage; menstruation is regarded as a “bad sickness”. Because motherhood is so tightly connected to marriage in many cultures, the presumption is that women are only childless if they are infertile. In cultures in which voluntary childfree status is acknowledged, many women experience infertility as a “secret stigma” (Greil 1991a,b); in cultures in which there is no concept of voluntary childfree status, it is impossible to hide infertility. The stigma and distress of infertility, therefore, is likely to be greater in developing countries (Dyer et al. 2002).

In many advanced industrial societies, acceptance of the medical model is virtually hegemonic, but in other societies medical interpretations of infertility coexist and interact to a greater degree with traditional interpretations (Dyer et al. 2002; Leonard 2002; Mariano 2004; Nahar 2007). Male infertility in Egypt is explained by the belief that the “worms” (sperm) are weak (Inhorn 2003). Among the Macua of Madagascar, infertility may be attributed to a husband’s and wife’s blood failing to mix, a woman’s marriage to a spirit, or pubic hair – buried during initiation rites – being dug up by a witch (Gerrits 1997).

The relatively few studies of infertility among marginalized racial groups in advanced industrial nations (see Becker et al. 2005; Culley et al. 2009) suggest that, while marginalized women generally experience similar levels of distress as White and middle-class women, distress may actually be heightened for women of color because of their own and others’ expectations of them as the kind of people who have babies rather than those who have trouble becoming pregnant. Ceballos (1999) titled her ethnographic account of the experiences of infertile Black women, “The Only Black Woman Walking the Face of the Earth

Who Cannot Have a Baby.” Szkupinski-Quiroga (2002) found that the infertile women of color she interviewed experienced infertility not only as a challenge to personal identity, but as a challenge to ethnic identity as well, because they saw having children as a fundamental aspect of being full-fledged members of their ethnic communities.

The socio-cultural environment of treatment

Another crucial difference between the experience of infertility in advanced industrial societies and in developing societies is the greater availability, acceptance, and utilization of alternative care systems in developing societies (Kielman 1998). Many clinic patients in both South Africa and in Zimbabwe say that they went first to see a traditional healer (Dyer et al. 2002; Folkvord et al. 2005). Nahar et al. (2000) comment that in Bangladeshi slums, the most common treatment for women involves the use of herbalists and healers. Yebei (2000) reports that, even after they had immigrated to the Netherlands, Ghanaian women often had to seek alternative practitioners, such as herbalists and spiritual healers, because of the high cost of medical treatment.

The delivery of infertility treatment appears to be influenced in many ways by the socio-cultural context. Treatment of infertility in India is shaped by the fact that “adoption is not an option” given the Indian ideology of marriage and the family. Inhorn (2000) writes that Islam prohibits adoption because there is no maternal bond and no blood ties to the father. In contrast, Jenkins (2002) describes the situation in Costa Rica, where adoption is a socially acceptable solution to the problem of infertility because unwed pregnancies are a problem and abortion is illegal. In countries influenced by Islam, religious leaders deem donor insemination unacceptable (Folkvord et al. 2005). Handwerker (2002) posits that the ideological importance in China of having sons fuels the Chinese ART industry. Inhorn (2000, 2002) has been especially eloquent in discussing the interplay between cultural understandings and reproductive technology in Egypt. Mitchell (2002) argues that increased marketing of reproductive technologies has led to couples seeking help earlier and may have resulted in unnecessary treatments.

Throughout the world, women find the treatment experience highly stressful (Peddie et al. 2005). Redshaw et al. (2007) find that patients report feeling that they have little control over treatment and that they are not being treated like people. Several studies have shown that patients are intimidated by the language of medicine and by the technical aspects of infertility treatment, especially in situations where language barriers exist (Becker et al. 2005; Culley et al. 2009; Ulrich and Weatherall 2000; Wingert et al. 2005). Greil (2002) summarizes the experience of treatment in terms of three paradoxes: (a) infertile women's sense of loss of control leads them to treatment where they lose even more control; (b) infertile women's feelings of loss of bodily integrity leads them to treatment where the body is invaded; and (c) infertile women's sense of loss of identity leads to treatment where they feel they are not treated as whole people. Still Greil insists that infertile women in the United States should not be seen as passive victims (see also Letherby 2002; Parry 2005). Riessman (2002) and Todorova and Kotzeva (2003) make similar observations about women in southern India and Bulgaria respectively.

Infertile women are not merely passive products of their socio-cultural environment, but the socio-cultural environment does profoundly shape the experience of infertility. This essay has shown that women's experiences of infertility are shaped by socio-cultural influences such as gender ideology, access to care, family structure, ethnic identity, and social class. Therefore, the study of differential experiences of infertility and access to infertility treatment provide insights into the social construction of infertility and a window into women's reproductive lives from a global sociological perspective.

The Authors

Arthur L. Greil received his BA from Syracuse University in 1971, his MA from Rutgers University in 1974, and his PhD from Rutgers University in 1979. He is currently Professor of Sociology at Alfred University in New York State. He has been at Alfred University since 1977. Dr Greil's main research interests are in the areas of reproductive health, adult socialization and identity change, and the sociology of religion. Dr Greil's book, *Not Yet Pregnant: Infertile Couples in Contemporary America*, was published in 1991 by Rutgers University Press and deals with the theme of gender and the experience of

infertility. He is the author of many articles on psychosocial aspects of infertility. He is currently at work analyzing data from the National Study of Fertility Barriers, a population-based survey of American women. His work in the sociology of religion has focused on conversion, quasi-religion, and religion and politics. He has edited books on quasi-religion and the definition of religion.

Kathleen Slauson-Blevins is a PhD candidate in the sociology department at the University of Nebraska-Lincoln. Her research focuses on health, reproduction, family, gender, and new technologies. Her dissertation explores how women with fertility barriers use the internet for social support and information about infertility.

Julia McQuillan's research brings social psychological approaches to questions of health and social inequality. She has co-authored articles in several Social Science and health journals on responses to infertility and fertility barriers. She is co-investigator on the National Survey of Fertility Barriers (NSFB), a National Institute of Child Health and Development funded two-wave public use data set. She is also co-Principal Investigator on the National Science Foundation funded ADVANCE project at the University of Nebraska. She is currently collaborating on studies of childlessness distress among women without children, changes in self identifying a fertility barrier over time, fertility intentions among lesbians, social marginalization among faculty and social location effects on health trajectories. Through her position as Director of the Bureau of Sociological Research (BOSR) she is collaborating with colleagues on several methodological studies assessing factors associated with retaining participants in longitudinal studies. McQuillan earned her BA, MA and PhD degrees in Sociology from the University of Connecticut.

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