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Review article

The experience of infertility: a review of recent literature

Arthur L. Greil[1], Kathleen Slauson-Blevins[2] and Julia McQuillan[2]

[1]*Division of Social Sciences, Alfred University, New York, USA*
[2]*Department of Sociology, University of Nebraska, Lincoln, USA*

Abstract About 10 years ago Greil published a review and critique of the literature on the socio-psychological impact of infertility. He found at the time that most scholars treated infertility as a medical condition with psychological consequences rather than as a socially constructed reality. This article examines research published since the last review. More studies now place infertility within larger social contexts and social scientific frameworks although clinical emphases persist. Methodological problems remain but important improvements are also evident. We identify two vigorous research traditions in the social scientific study of infertility. One tradition uses primarily quantitative techniques to study clinic patients in order to improve service delivery and to assess the need for psychological counselling. The other tradition uses primarily qualitative research to capture the experiences of infertile people in a sociocultural context. We conclude that more attention is now being paid to the ways in which the experience of infertility is shaped by social context. We call for continued progress in the development of a distinctly sociological approach to infertility and for the continued integration of the two research traditions identified here.

Keywords: infertility, literature review, psychological distress, treatment, illness experience

Introduction

Most medical sociologists agree that health and illness are best understood, not as objectively measurable states, but as socially constructed categories negotiated by professionals, sufferers and others in a sociocultural context. Decisions as to what constitutes abnormality, how to define that abnormality and what steps, if any, should be taken to deal with its conditions are all made within a social context. How sufferers are seen by others and how they come to see themselves are both products of processes of social definition. Conrad and Schneider (1980) have used the term 'medicalisation' to denote the process by which certain behaviour comes to be understood as a question of health and illness, subject to the authority of medical institutions. One phenomenon that has become increasingly defined as a medical condition is infertility, usually defined in the biomedical context as the inability to conceive after 12 months of regular unprotected intercourse. The medicalisation of infertility began in

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earnest with the development of fertility drugs in the USA in the 1950s but it has proceeded even more rapidly since the development of such assisted reproductive technologies (ART) as in vitro fertilisation (IVF) and intra-cytoplasmic sperm injection. Thompson (2005) has recently described the complex ontological choreography involving precisely timed actions (for example, injections of hormones, ejaculation of sperm and cryopreservation of gametes) among an interrelated set of actors (for example, physicians, nurses and patients) to produce a baby in the modern ART clinic.

The social construction of health and illness is perhaps even more striking in the case of infertility than it is for other conditions. Firstly, 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. Secondly, while the biomedical model treats medical conditions as a phenomenon affecting the individual, infertility is often seen, especially in developed countries, 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, the larger social networks. Thirdly, the presence of infertility is signalled, not by the presence of pathological symptoms, but by the absence of a desired state. It is, in the words of Koropatnick *et al.* (1993: 163), a 'non-event transition'. Fourthly, 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, fostering or changing partners. Infertility is best understood as a socially constructed process whereby individuals come to define their ability to have children as a problem, to define the nature of that problem and to construct an appropriate course of action. The study of infertility has much to contribute to the sociology of health and illness by providing researchers with an ideal vantage point from which to study such features of medicalised healthcare as the tension between the voice of medicine and the voice of the lifeworld (Mishler 1984), the gendered nature of health and healthcare and the interplay between structure and agency.

Because it involves an inability to achieve a desired social role, infertility is often associated with psychological distress. About 10 years ago Greil (1997) published a review and critique of the literature on the socio-psychological impact of infertility. He noted that, while the descriptive literature on the psychological consequences of infertility presented infertility as a devastating experience, attempts to test the psychological consequences hypothesis had produced more equivocal results. Studies that looked for psychopathology did not find significant differences between infertile individuals and others, while studies that employed measures of stress and self-esteem did find significant differences. He found support for the conclusion that infertility is a fundamentally different experience for women than for men. Greil also noted that the psychological distress literature was characterised by a number of flaws, including non-representative samples, failure to study those who have not sought treatment, failure to study economically deprived and culturally distinct populations, use of cross-sectional designs and a failure to come up with a satisfactory solution to the problem of 'controls'. Most importantly, however, Greil argued that the psychological distress literature showed little regard for *the social construction of infertility,* treating infertility instead as a medical condition with psychological consequences.

Our goal here is to assess research published since the last review article to determine how it has changed, to discover new lines of research, to summarise generalisations about infertility experiences and to assess persistent limitations and progress in the methodological and theoretical dimensions of infertility research. We conclude that researchers are moving toward situating infertility in social contexts although the clinical focus of much earlier work persists. We also find that, while many methodological problems remain, important attempts to redress these problems are evident. We note further that there has been progress in certain lines of inquiry, including cross-cultural studies of infertility, the possible long-term consequences of childlessness, the relationship between infertility and stress and the importance of infertility in men's lives. Throughout, we try to demonstrate the importance of making use of non-clinic-based samples if we are to progress in our understanding of the experience of infertility.

We identify two distinct traditions of research in the study of the social and psychological consequences of infertility. One tradition is characterised by the quantitative analysis of patient populations – often focusing on patients being treated via ART – with the goals of improving service delivery and of assessing the need for psychological counselling procedures. These clinically oriented studies typically make use of the quantitative analysis of standardised psychological assessment instruments. The other tradition is based on the qualitative analysis of infertile women and men – both in developed and developing societies – outside the clinic context. Those being studied may or may not be patients in biomedical contexts but the focus of this research is not so much on improving care as on understanding the experience of infertility and the social context that shapes it. This second tradition has been more informed by developments in social scientific studies of illness experience, gender, the body and stigma.

There is little evidence that these two traditions 'speak' to each other; works in one tradition seldom cite works in the other. In the following review, we attempt to take a first step toward integrating these two research traditions. Because our emphasis here is on the experience of infertility and infertility treatment, we focus on studies published in the last 10 years that directly assess the responses to infertility of women, men, and couples. We exclude studies that focus exclusively on the institution of reproductive technology and its cultural and societal context. These are the subjects of a recent review by Inhorn and Birenbaum-Carmeli (2008). We also exclude studies for which the primary focus is on the incidence and prevalence of infertility.

Methodological Issues

Many methodological shortcomings in infertility research noted by Greil (1997) still persist. Pasch and Christensen (2000) enumerated the following shortcomings in social-scientific research on infertility: small sample sizes, poor sampling methods, use of non-standardised measures, lack of adequate control groups and studies being conducted in infertility treatment centres with which the researcher is affiliated. Henning *et al.* (2002) criticise the many studies that rely primarily on self-report data, those that do not allow the separation of the psychological consequences of infertility from the psychological consequences of the infertility treatment and reliance on cross-sectional data.

Clinic-based studies of treatment seekers still prevail in research on the consequences of infertility (Henning *et al.* 2002). The focus on people receiving treatment makes it difficult to generalise to those who do not seek treatment (Greil 1997). In the USA, for example, less than half of infertile women seek treatment (Greil and McQuillan 2004, Stephen and Chandra 2000). Clinic-based studies therefore provide no information about half of the infertile female population. Even in nations where access to infertility treatment is guaranteed by the state there are still many couples who do not seek treatment (Boivin *et al.* 2007). Without studies of non-treatment seekers it is impossible to determine what factors differentiate those who seek treatment from those who do not or why those who would like to receive infertility treatment do not have access to it. Even among treatment seekers, the emphasis has been on the most advanced treatments, limiting our ability to understand those who stop treatments after initial attempts. Without a non-clinic comparison group it is impossible to untangle the effects of infertility from the effects of infertility treatment on psychological outcomes.

Since 1997 there have been some important studies using non-clinic based samples. King (2003) used the National Survey of Family Growth, a nationally representative sample that included infertility status data for women in the USA to assess whether treatment seekers and non-treatment seekers are more likely to meet the criteria for anxiety. Malin *et al.* (2001) made use of a Finnish probability sample to determine the degree of satisfaction with treatment. Redshaw *et al.* (2007) used a nationally representative sample of women who had recently given birth in the UK to assess their reactions to infertility treatment. Sundby *et al.* (1998) and Leonard (2002a, 2002b) selected infertile respondents in The Gambia and in southern Chad using systematic sampling techniques in order to obtain a picture of the experience of infertility in those nations. McQuillan *et al.* (2003) studied a probability sample of 580 women in the mid-western USA with an oversample of minority women in order to determine the relationship between infertility and general distress. Greil, McQuillan, and their colleagues are now collecting data for the National Study of Fertility Barriers (NSFB), a prospective panel study based on a random sample of US women with an oversample of minorities and women who have not completed their childbearing.

Other studies have taken steps short of a population study to improve the generalisability of their findings. Epstein *et al.* (2002) and Bunting and Boivin (2007) used internet surveys to obtain respondents for a study on internet use for infertility support through an internet-based study and for study of treatment seeking, respectively. Jordan and Revenson (1999) conducted a meta-analysis of six studies using the Ways of Coping Checklist. Jordan and Ferguson (2006) found respondents, of whom 11.4 per cent had fertility problems, at family practice clinics.

As studies of infertility in developing societies have proliferated, ethnographic approaches have become more common. These studies inevitably raise questions of representativeness, but, unlike studies of infertility in developed countries, they have not been as frequently limited to studying people in western-style infertility centres. These studies cannot really deal with causality in a definitive way, but that is not their primary purpose. Instead, ethnographic studies provide rich detail and insight regarding the meaning of infertility in women's and men's own words and from their local perspective (Inhorn and Birenbaum-Carmeli 2008). The fact that there have now been qualitative community-based studies done in many different cultural settings means that we are beginning to develop a sense of the experience of infertility in developing countries.

Cross-sectional analysis, still the most common design in studies of the social and psychological consequences of infertility, makes it impossible to sort out cause and effect. There have been more longitudinal designs in recent years, but most employ a fairly narrow time frame. Several studies have assessed fluctuations in stress levels during a reproductive cycle (for example, Edelmann and Connolly 1998, Verhaak *et al.* 2005). Other studies have worked with a slightly longer time frame (Anderson *et al.* 2003, Hjelmstedt *et al.* 2004, Holter *et al.* 2006). Much can be learned from longitudinal studies with expanded time frames. The Copenhagen Multi-Centre Psychosocial Infertility (COMPI) study (Boivin and Schmidt 2005, Peronace *et al.* 2007, Schmidt *et al.* 2005a) measured Danish women at their initial visit to an infertility clinic and assessed treatment outcomes one year later. Schneider and Forthofer (2005) used data collected in 1988, 1989 and 1990 from the USA-based Study of Marriage, Family and Life Quality. The NSFB, now under way, involves re-interviews of a nationally representative sample of US women three years after the original interview.

Another methodological question has to do less with designing studies than with conceptualising infertile individuals. As long as the study of infertility is limited to the study of clinic patients, conceptualising who should be considered infertile seems straightforward. In most studies, infertile individuals 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 people becomes blurred (Greil and McQuillan forthcoming), and infertile individuals are seen to constitute a much more diverse group than was 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) and Jacob *et al.* (2007) have divided infertile women into the 'sub-fecund with intent' (women who say they tried to conceive for at least 12 months without conception) and the 'sub-fecund without intent' (women who report having had unprotected intercourse without conception but who do not say that they were consciously trying to conceive at the time) and have discovered that the two groups differ with regard to both distress levels and help-seeking behaviour.

Studying infertility in developing countries reveals that western biomedical definitions of infertility exclude a large portion of women in developing societies who think of themselves as infertile (Gerrits 1997). Sundby (2002) writes that in The Gambia and Zimbabwe infertility is experienced as anything that prevents women from realising their reproductive ambitions. Leonard (2002b) presents the narrative of Solkem, a Chadian woman who, because her husband left her and she no longer has regular intercourse, might not be classified as infertile according to the western biomedical definition but who is nonetheless preoccupied with the quest for conception.

Descriptive literature on the experience of infertility

Recent contributions to the descriptive literature on infertile women (for example, Becker 2000, Clarke *et al.* 2006, Earle and Letherby 2007, Johansson and Berg 2005, Redshaw *et al.* 2007) tend to confirm and elaborate upon previous characterisations of infertile individuals. Several characterisations of infertile women or couples have emerged from qualitative research. For example, Williams (1997) extracted 11 themes from interviews with infertile women: negative identity; a sense of worthlessness and inadequacy; a feeling of 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 a sense of isolation. Ulrich and Weatherall (2000) suggest that women experience infertility as an unanticipated life-course disruption. Martin-Matthews and Matthews (2001) focus on the sense among infertile women that time is slipping away and explore the interaction between familial and societal timetables, body timetables and treatment timetables (see also Earle and Letherby 2007). Parry and Shinew (2004) report that leisure satisfaction is impaired by the process of seeking treatment and by feelings of social isolation. Evidence suggests, however, that the characterisation of infertile woman as totally immersed in the process of trying to become pregnant describes only treatment seekers (Greil and McQuillan 2004 and forthcoming, Jacob *et al.* 2007, White *et al.* 2006).

The importance of sociocultural context

The social-scientific literature on infertility is increasingly emphasising the importance of the sociocultural context in shaping the lived experience of infertility. Kirkman and Rosenthal (1999) argue that the degree of availability of reproductive technology plays a major role in shaping perceptions of and responses to infertility. Letherby (2002) suggests that ambivalence toward motherhood may have been more socially acceptable before the advent of assisted reproductive technologies (ART). In a qualitative study of infertile individuals in South Africa, Sewpaul (1999) shows how differing religious traditions can shape the experience of infertility. According to Sundby (1997), while infertility is seen as a stigma in The Gambia, the existence of a strong fostering tradition means that 43 per cent of infertile couples have a foster child, a circumstance certain to have an impact on the experience of infertility. Feldman-Savelsberg (2002) argues that the experience of infertility is permeated by the political context in Cameroon, where infertile women feel that a weakening state cannot protect them as well from witches as it once did.

One characteristic of the sociocultural context that influences infertility is pro-natalism (Parry 2005, Ulrich and Weatherall 2000). While all societies are pro-natalist, some emphasise the centrality of motherhood to women's identity more than others. For example, Israel is an intensely pro-natalist 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). Bhatti *et al.* (1999) discuss the importance of fertility to the female role in squatter settlements in Pakistan. 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. Among the Yoruba the adult woman's role depends on motherhood because children are essential to the continuation of lineages (Pearce 1999). Pashigian (2002: 135) reports that in northern Vietnam womanhood and motherhood are conflated, asserting that trying to have a baby is an attempt 'to engage in normative identity formation'. 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 labelling themselves infertile (Barden-O'Fallon 2005).

The experience of infertility is shaped by patriarchy, but the degree of male dominance and the range of roles other than motherhood open to women vary from society to society. In Egypt women bear the burden of infertility even when they know there is a male cause (Inhorn 2003). 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. Several studies demonstrate that infertile women who experience rejection or pressure from husbands and family experience higher levels of distress (Gulseren *et al.* 2006, Guz *et al.* 2003*)*. Gerrits (1997) reports that the experience of infertility may be different in matrilineal societies. While patriarchy may be less striking in developed societies, it is by no means irrelevant to the experience of infertility in them. 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 (2004), by casting blame on their wives.

Two worlds of infertility

As the above comments suggest, salient differences exist between the experience of infertility in developed and developing societies. It may be justifiable to think in terms of two worlds of infertility. Developed and developing societies tend to differ in prevailing assumptions about childlessness. In developed societies voluntary childlessness is viewed as a more viable and legitimate option and women without children are often presumed to be voluntarily childfree. According to Riessman (2000: 113), however, voluntary childlessness is rare in Kerala, India, since 'bearing and rearing children are central to women's power and well-being'. Leonard (2002a) 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 childless only if they are infertile. Therefore in cultures in which voluntary childfree status is acknowledged, many women experience infertility as a 'secret stigma' (Greil 1991b: 22); 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.* 2005).

Policymakers and scholars are often more concerned about overpopulation than infertility in developing countries (Bos *et al.* 2005, Inhorn and Birenbaum-Carmeli 2008, Nachtigall 2005, van Balen and Gerrits 2001), yet the viewpoint of those who suffer from infertility is often quite different from that of those who make policy. From the point of view of national and international policy, overpopulation is the most important problem, but women in the Cameroon grasslands perceive infertility and population decline to be the chief threat (Feldman-Savelsberg 2002). Studies of infertility in developing societies are often quite sensitive to issues of sociocultural context; studies of infertility in developed societies more often treat infertility as a medical, ethical or psychological issue and pay less attention to the sociocultural context (Bos *et al.* 2005).

Another difference between infertility in developed and developing societies has to do with folk models for making sense of infertility. In developed societies, acceptance of the biomedical model is virtually hegemonic, while in other societies biomedical interpretations of infertility coexist and interact to a greater degree with traditional interpretations (Dyer *et al.* 2004, Feldman-Savelsberg 2002, Gerrits 1997, 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). In both developed and developing societies, folk explanations of infertility may be intertwined with biomedical interpretations (Kahn 2000, Sewpaul 1999, Yebei 2000). Among the Sara of southern Chad (Leonard 2002a, 2002b), whether one uses western medicine ('going to the hospital') or traditional solutions ('going to the village') depends on the interpretation of the problem.

Research on the psychology of infertility

Alongside the descriptive literature is a more quantitatively oriented literature focused on testing hypotheses about psychosocial aspects of infertility. Edelmann and Connolly (1998) found no evidence of psychopathology among British infertility patients and propose that differences between the findings of controlled research and findings based on clinical impressions stem from the fact that counsellors see the most distressed patients. They may, however, be responding to past arguments rather than to contemporary accounts in that most of the descriptive literature – as well as most reports based on clinical impressions – asserts not that infertile patients are fundamentally different from others in their psychological functioning but that the experience of infertility is a source of psychological distress (Greil 1997). In a literature review of studies of patients undergoing IVF, Eugster and Vingerhoets (1999) find that IVF couples are well-adjusted. Wischmann *et al.* (2001) suggest that, while most couples do not have a psychopathology there is a subgroup that needs psychological help.

While infertile women are not necessarily more likely to exhibit psychopathology they are more likely to experience higher levels of distress than comparison groups (Beutel *et al.* 1998, Fekkes *et al.* 2003, Monga *et al.* 2004, Oddens *et al.* 1999). Wischmann *et al.* (2001) found that women in a German clinic suffered slightly higher stress than norms and also scored lower than norms on a number of sub-scales of life satisfaction. Infertile women have higher distress scores on the Patient Health Questionnaire than do other women in family practice clinics (Jordan and Ferguson 2006). Women currently experiencing infertility problems display more depression and anxiety than counterparts who have eventually conceived naturally (Oddens *et al.* 1999). Several studies (Holter *et al.* 2006, Verhaak *et al.* 2005), however, have found that IVF women do not differ significantly from norms on general distress.

Studies of men also report mixed results. Baluch *et al.* (1998) found that Iranian men with infertility have higher scores for depression and trait anxiety, especially among those with male-factor infertility. Folkvord *et al.* (2005) report that one-third of infertile men in Zimbabwe showed signs of mild clinical depression. On the other hand, Monga *et al.* (2004) assert that men in infertile couples do not differ from controls on a scale of psychological wellbeing. On the basis of a longitudinal study in Denmark, Peronace *et al.* (2007) conclude that infertility is stressful for men regardless of the source of infertility. Younger Dutch IVF men but not older men exhibited more emotional problems than norms (Fekkes *et al.* 2003).

Much research on both fertility-specific distress and general distress has focused on gender differences in levels of distress. Literature reviews (Abbey 2000, Eugster and Vingerhoets 1999, Henning *et al.* 2002, Savitz-Smith 2003) report evidence that women experience more infertility stress than men. Edelmann and Connolly (1998) suggest that this finding may simply reflect the tendency for women generally to be more distressed than men. Despite this caution, most recent studies confirm earlier research that concludes that infertility is more distressing for women than it is for men (Anderson *et al.* 2003, Holter *et al.* 2006, Lee and Sun 2000, Monga *et al.* 2004, Schneider and Forthofer 2005, Slade *et al.* 2007*)*. Additionally, White and McQuillan (2006) found that relinquishing a strong intention to have a child is associated with elevated distress for women but not for men. Pasch and Christensen (2000) write that women invest more in having children and are more treatment-oriented than men. Women experience higher levels of stigma than men (Slade *et al.* 2007). On the other hand, Dyer *et al.* (2004) show that men in South Africa are very bothered by involuntary childlessness.

It is also important to explore *qualitative* differences in the ways that men and women are affected by infertility. Beutel *et al.* (1998) posit that while infertile wives experience infertility as having a greater impact on their daily lives and feel a need for more support, their husbands feel more responsible. Hjelmstedt *et al.* (1999) argue that both men and women report feelings of injustice but assert that women are more likely to admit to changes in mood, jealousy of those who are not infertile and a sense that their biological clocks are ticking away. Men are concerned about loss of control and are worried about their partner's reaction to infertility (Hjelmstedt *et al.* 1999). Much of the above is reminiscent of Greil's (1991a) argument that wives experience infertility as a direct blow to their self-identity, whereas husbands experience infertility indirectly through the effect that it has on their wives.

Most researchers who have investigated the relationship between infertility diagnosis and distress have reached the conclusion that the diagnosis does not exercise an influence over distress levels (Edelmann and Connolly 1998, Hjelmstedt *et al.* 1999, Holter *et al.* 2007, Verhaak *et al.* 2005, Wischmann *et al.* 2001: for an exception, see Dhaliwal *et al.* 2004). No studies have established the extent to which distress among infertile individuals may reflect infertility treatment rather than infertility itself. Based on a national probability sample of women in the USA, King (2003) concludes that the effects of sub-fecundity on general anxiety disorder are not moderated by treatment. Some studies show that the length of treatment is not related to the level of stress (Anderson *et al.* 2003), but several researchers have reported contradictory findings (Chiba *et al.* 1997, Nasseri 2000). One unanswered question is whether changes in distress over time are a response to treatment or whether they are a result of the duration of infertility. Studies of IVF women and men (Ardenti *et al.* 1999, Boivin *et al.* 1998) have documented that distress levels vary with the stage of treatment. Studies of IVF women have also provided evidence that it is the outcome of the treatment rather than its duration that gives rise to increased levels of distress (Lok *et al.* 2002, Sydsjö *et al.* 2005, Verhaak *et al.* 2007). Most women eventually adjusted to unsuccessful treatment but a significant minority showed signs of emotional problems (Beutel *et al.* 1998, Holter *et al.* 2006, Verhaak *et al.* 2001, 2005, 2007).

The sizable literature on the relationship between distress and coping strategies among infertile individuals (for example, Benyamini *et al.* 2008, Schmidt *et al.* 2005b, van den Akker 2004) has been reviewed by Abbey (2000). According to Gibson and Myers (2002), social coping resources, growth-fostering relationships, partner support and family support all contribute to lessened infertility stress among women. Hansell *et al.* (1998) report that women who responded to infertility as a 'challenge' were less distressed than women who responded to infertility as a 'loss'. Brothers and Maddux (2003) report that women who perceive a strong link between their future happiness and becoming a parent exhibit higher levels of psychological distress. The focus on gender differences is also evident in studies of coping strategies (Dhillon *et al.* 2000, Hjelmstedt *et al.* 1999). A meta-analysis of six studies using the Ways of Coping Checklist led Jordan and Revenson (1999) to conclude that women display higher levels of seeking social support, escape or avoidance, plan-oriented problem-solving and positive reappraisal. Some evidence suggests that distress levels are related to one's partners coping strategies as well as to one's own (Schmidt *et al.* 2005a). A fascinating discovery comes from Pasch *et al.* (2002), who say that husbands display more negative effects when wives want to talk. While infertility may lead to stress and communication problems between marital partners, Greil (1991a, 1997) claims that couples nonetheless report that they feel that infertility has brought them closer together. A literature review by Pasch and Christensen (2000) finds that infertility does not typically lead to relationship or sexual problems (see also Daniluk 2001, Hjelmstedt *et al.* 1999, Schmidt *et al.* 2005a, Sydsjö *et al.* 2005). Webb and Daniluk (1999) state that when men reported actually beginning to deal with their infertility they started talking to their partners, which ultimately resulted in a sense of infertility as a shared experience and in turn strengthened relationships. There are, however, some who claim that infertility does have a deleterious impact on marital relationships (Wirtberg *et al.* 2007). According to Sundby (1997), in The Gambia, where marital stability is already an issue, infertility is seen as a major threat to marital stability.

These studies suggest that the impact of infertility on marital relationships depends on the sociocultural context. For example, in settings where women's roles are more closely tied to having children, where producing children for one's family is considered an important obligation and where marriage is defined in terms of producing and raising children, infertility is likely to have a greater negative impact on couple relationships. This implies that infertility will have a greater impact on relationships in the developing world. Evidence for this claim comes from research showing that infertility is more strongly associated with psychopathology in Nigeria, a polygamous society (Aghanwa *et al.* 1999).

Researchers are conducting more systematic studies of the use and effectiveness of psychological interventions than was the case in the past (Domar *et al.* 2000, McQueeney *et al.* 1997, Pook *et al.* 2001). A literature review of studies of the effectiveness of psychosocial interventions concludes that the evidence does not yet support the conclusion that counselling is beneficial (Boivin 2003). More infertility patients express a need for counselling than actually seek it (Boivin *et al.* 1999). Guerra *et al.* (1998) present evidence suggesting that many infertility patients who could benefit from counselling are not referred. Many couples now use the internet for information and support (Kahlor and Mackert 2009, Porter and Bhattacharya 2008, Rawal and Haddad 2006). Wingert *et al.* (2005) argue that internet self-help in the form of online bulletin boards serves many of the same functions as support groups, but Epstein *et al.* (2002) present evidence that suggests that women who use the internet as their only outlet for infertility support are more depressed than those with multiple outlets. Cousineau *et al.* (2008) have found that a programme designed to provide patient support via the internet had positive effects.

Although most researchers have rejected the notion that psychopathology is an important causal factor in infertility (Brkovich and Fischer 1998), there is support for the cyclical argument (van Balen 2002) that infertility produces stress, and that stress in turn inhibits fertility (Henning *et al.* 2002, Pook *et al.* 2004). In a literature review on psychological distress and infertility, Wischmann (2003) argues that stress and anxiety are likely to be contributing causes but are rarely the sole cause of infertility and asserts that methodological improvements are necessary before definitive statements about the causal roles of stress and anxiety can be made. In another literature review, Eugster and Vingerhoets (1999) cite some evidence that psychological factors may influence IVF success rates. This is supported by research by a number of researchers (Boivin and Schmidt 2005, Boivin *et al.* 2006, Gulseren *et al.* 2006), but others (Anderheim *et al.* 2005, Salvatore *et al.* 2001) find no evidence for this. Strauss *et al.* (1998) report that psychological variables explain only a very small proportion of the variance in treatment outcomes. There is evidence that stress levels and coping strategies have an impact on sperm quality (Pook and Krause 2005, Pook *et al.* 1999).

Sociocultural environment of treatment

Alongside the literature on the experience of infertility exists another body of research that focuses on the experience of infertility *treatment* both in developed and developing societies. An important factor influencing the experience of infertility, even in developed societies, is access to care (Beckman and Harvey 2005). Ethnic minorities in the USA, the UK and The Netherlands have less access to care than non-Hispanic Whites (Becker *et al.* 2005, Bitler and Schmidt 2006, Culley and Hudson 2006, 2007, Henne and Bundorf 2008, Inhorn and Fakih 2005, Jain 2006, van Rooij *et al.* 2007, White *et al.* 2005). Even in Massachusetts, a US state with mandated ART coverage, Latino women, less educated women and poor women are underrepresented in ART clinics (Jain 2006). Feinberg *et al.* (2006, 2007) found that African Americans were not underrepresented at a military fertility clinic where everyone was guaranteed equal access but that Hispanics were underrepresented. In contrast to US women, Israeli women experience infertility in the context of state support of infertility treatment (Kahn 2000, Remennick 2000). In France, where ART is subsidised, socioeconomic status (SES) and occupation do not seem to affect the utilisation of ART but low SES women are overrepresented among early ART pioneers (Tain 2003). This suggests that, as new treatments become available, patterns of usage and, indeed, the experience of infertility, may change as well. For example, Miller (2004) observes that the intention to have children has risen faster among sub-fecund women than among fecund women and speculates that this trend may be a response to the increasing availability of ART.

Although rates of seeking help for infertility are comparable in developed and less developed societies (Boivin *et al.* 2007), access to care is much more severely limited in developing societies (Kielman 1998, Nachtigall 2005, Ombelet *et al.* 2008, van Balen and Gerrits 2001). Dyer *et al.* (2002) discovered that one-quarter of female South African clinic patients had been seeking care for over five 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 *et al.* 1998, Sundby and Jacobus 2001). Lack of coordination between care providers means that people may go through the same treatment several times. Affluent women in The Gambia, India and Egypt have access to sophisticated gynaecological facilities and ART but the needs of poor and middle-class women are not met (Sundby *et al.* 1998, Widge 2005).

A crucial difference between infertility treatment in developed and developing societies is the greater availability, acceptance and utilisation of alternative care systems in developing societies (Kielman 1998, Okonofua *et al.* 1997). Many clinic patients in both South Africa and Zimbabwe say that they went first to see a traditional healer (Dyer *et al.* 2004, 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, while the most common ‘treatment’ for men is remarriage. 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 biomedical treatment.

The delivery of infertility treatment appears to be shaped in many ways by its sociocultural 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 are no blood ties to the father and no maternal bond. 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, Meirow and Schenker 1997). Handwerker (2002) posits that the ideological importance in China of having sons fuels the Chinese ART industry. Inhorn (2000) 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.

Because only about half of infertile individuals worldwide seek treatment, the question of what factors influence help-seeking is an intriguing one. On the basis of a study of a population-based sample of infertile women, White *et al.* (2006) conclude that self-definition as infertile is key to seeking treatment. Because this was a cross-sectional study, it remains unclear 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 labelled infertile were less likely to seek treatment. Greil and McQuillan (2004) have found that infertile individuals with intent were more likely to seek treatment than infertile individuals without intent. It is apparent that not all US women who are infertile by the medical definition see themselves as infertile. Conversely, Gerrits (1997) notes that Macua women in Cameroon who sought both western and traditional treatment were not necessarily infertile by the biomedical definition.

Greil's early qualitative work (1991a) showed that wives were much more likely to initiate treatment than husbands. More recently, Daniluk (2001) has reported that, of the 65 infertile couples she interviewed, it was the woman who initiated treatment in all cases (see also Webb and Daniluk 1999, Throsby and Gill 2004). Although women are very treatment-oriented, they nonetheless find the experience of treatment highly stressful (Peddie *et al.* 2005, Schmidt 1998). Yebei (2000) discovered that Ghanaian women in The Netherlands found infertility treatment unpleasant and emotionally draining. Husbands, too, find treatment stressful (Schneider and Forthofer 2005), but men who perceive healthcare professionals as supportive report lower levels of stress and anxiety (Brucker and McKenry 2004). 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 biomedicine and by the technical aspects of infertility treatment, especially in situations where language barriers exist (Becker *et al.* 2005, Ulrich and Weatherall 2000, Wingert *et al.* 2005). The infertility treatment experience has been described as a situation that engulfs patients and dominates their daily routine (Daniluk 2001, Redshaw *et al.* 2007). Greil (2002) summarises the experience of treatment of infertile women in terms of three paradoxes: (i) their sense of loss of control leads them to treatment where they lose even more control; (ii) their feelings of loss of bodily integrity leads them to treatment where the body is invaded; and (iii) their sense of loss of identity leads to treatment where they feel they are not treated as whole people. Still Greil (2002) insists that infertile women in the USA should not be seen as passive victims (see also Letherby 2002, Parry 2005). Riessman (2000, 2002) and Todorova and Kotzeva (2003) make similar observations about women in southern India and Bulgaria, respectively.

Infertility patients want to receive patient-centred care (Schmidt *et al.* 2003) and more information than they currently receive (Souter *et al.* 1998). Redshaw *et al.* (2007) report that infertility patients complained about the lack of continuity of care, about the inconvenience of treatment and about its emotional and financial costs. Nonetheless, women expressed stoicism and saw the difficulties of treatment as the price they had to pay to have a child. Malin *et al.* (2001) found that Finnish women treated prior to 1990 were more dissatisfied than women who received treatment after that time. Patients expressed satisfaction if they perceived that care was individualised, supportive and friendly. Sources of dissatisfaction were the slow progress of treatment and poor relationship with healthcare providers. Women display variability in which aspects of treatment they find most stressful (Benyamini *et al.* 2005).

The difficulties patients have in putting a stop to treatment have also been discussed (Greil 1991a, Sandelowski 1991). According to Throsby and Gill (2004: 12), women find it especially difficult to stop treatment, but their husbands step in to exercise a 'rational veto' by bringing in considerations of the emotional and physical health of wives. Olivius *et al.* (2004) find that 26 per cent of women who voluntarily stop IVF treatment do so because of the psychological burden entailed. Although it is difficult to stop treatment, Verhaak *et al.* (2007) say that stopping treatment leads to reduced depression and anxiety among IVF women, even if they do not conceive. Unsuccessful IVF couples do not regret the IVF experience; instead they view it as their best chance to have conceived (Daniluk 2001, Johansson and Berg 2005, Throsby and Gill 2004). Women who have stopped IVF treatment often go through a period of self-reflection before coming to terms with their infertility (Peddie *et al.* 2005). A study of Scandinavian women two years after unsuccessful IVF found that the women refocus on other concerns but still retain hope for a child (Johansson and Berg 2005). Johansson and Berg (2005) describe women who, even after they discontinued treatment, do not relinquish hope, at least until they reach menopause. Small-sample studies of women who are not able to have biological children find that many restructure their definition of family to include adoption and childfree lifestyles (Parry 2005, Su and Chen 2006, Ulrich and Weatherall 2000).

Achieving pregnancy does not necessarily restore normalcy to the lives of infertile individuals. Eugster and Vingerhoets (1999) report in a literature review that pregnancy for people undergoing IVF is more stressful than for people without fertility problems (see also Bevilacqua *et al.* 2000), but Cox *et al.* (2005) find no evidence of lower self-esteem for those who became pregnant via IVF. Letherby (1999) states that infertile women who have given birth through ART report feelings of anxiety and guilt as well as an obligation to be perfect mothers. Conversely, Hjelmstedt *et al.* (2004) report that, six months postpartum, successful infertility patients felt they had left infertility behind them. Parents say infertility has led them to have stronger feelings for children, to have greater tolerance for the difficulties of parenting and to be more grateful. Men felt infertility had made them emotionally closer to their children than they would otherwise have been. The few empirical studies that have been done on the acquisition of maternal identity among infertile women show that infertile mothers have lower self-evaluations and take longer to embrace the motherhood identity (Gibson *et al.* 2000, McMahon 1999). There is, however, no evidence of problematic maternal behaviour, marital problems or psychological problems (Repokari *et al.* 2007). Ulrich and Weatherall (2000) state that infertile women who eventually give birth discover that motherhood presented more challenges than they had expected. Eugster and Vingerhoets (1999) find no differences in parenting between parents who have conceived through IVF and other parents.

Some researchers have addressed the long-term consequences of infertility. Wirtberg *et al.* (2007) conducted in-depth interviews with 14 Swedish women 20 years after unsuccessful tubal surgery. They found that the women still had vivid memories of their time as infertility patients although all but three were able to develop a satisfying childfree lifestyle. With peers beginning to have grandchildren, however, several felt as if they were experiencing infertility all over again. Qualitative interviews conducted by Zucker (1999) reveal that, compared to women with other reproductive problems, infertile women were more likely to recall feelings of failure and uncertainty. In a 10-year follow-up study of IVF women, Sundby *et al.* (2007) found that women remembered the period of infertility as a difficult time in their lives. Most of the IVF women in the Sundby *et al.* (2007) study became mothers. Regardless of the outcome, they all found ways to cope with their situation. There is evidence that the long-term negative consequences of infertility exist only among the involuntarily childless (see also Jacob *et al.* 2007, McQuillan *et al.* 2003, 2007). Distress levels for ever-infertile mothers, whether they have biological or adopted children, are not significantly different from those found among the fertile. In a study of women who adopted, used ART or pursued surrogacy, van den Akker (2004) found that women with children reported a higher quality of life than childless women, regardless of the process by which they obtained children.

Conclusions

The publication of scholarly research on the infertility experience has grown in the past 10 years. Scholars continue to explore the extent to which infertility is a source of psychological distress and to accumulate evidence about the importance of gender for the experience of infertility. Research continues to examine in detail the characteristics of IVF patients and many aspects of the experience of IVF treatment. New trends are evident as well. There has been an explosion of ethnographic research that places the experience of infertility in its sociocultural context. More attention is now being devoted to the investigation of the long-term consequences of infertility. It is also possible to discern some movement towards an increased emphasis on the study of the dialectical relationship between infertility and stress and on the assessment of the effectiveness of psychological interventions.

Some methodological weaknesses persist but there is also progress. There is increased recognition of the importance of studying couples and of learning more about the male experience of infertility. There is a growing recognition that reliance on small, non-representative, clinic-based samples of treatment seekers is a problem and researchers have begun to address these issues. While the underrepresentation of economically deprived and culturally distinct populations continues to be a problem in the study of infertility in developed societies, the publication of ethnographic studies of infertility in developing countries has drawn attention to the need for more of this work. Research and analyses are moving in the direction of placing the experience of infertility within its social context by bringing sociological and socio-psychological theories to bear on the experience of infertility.

There are now two vigorous research traditions in the social-scientific study of infertility. One tradition primarily uses quantitative techniques to study clinic patients with an eye to improving service delivery and to assessing the need for psychological counselling. The other tradition primarily uses qualitative research to capture the experiences of infertile individuals in their sociocultural context. In this article we have tried to interweave these two traditions in an effort to begin the process of integrating them. Much can be gained by combining the methodological rigour of the clinical literature with the sensitivity to the socially constructed nature of infertility evidenced by the cross-cultural literature. Gerrits' recent (2008) study of a Dutch fertility clinic provides us with an excellent example of a work that brings an ethnographic sensibility to the modern clinic setting. Sundby *et al.* (1998) and Leonard

(2002a, 2002b) have employed sophisticated sampling techniques in an effort to strengthen the generalisability of their ethnographic observations. Bunting and Boivin (2007) have recently applied quantitative techniques outside the clinic setting in order to observe infertility decision-making among women early in the process. The NSFB provides researchers with the opportunity to address questions of self-definition, social influence and other issues that have often been neglected in the quantitative literature. The COMPI research programme represents another notable effort to apply quantitative methodological strategies to questions revolving around the social construction of infertility.

It seems fairly clear that infertility researchers have begun to apply insights from the sociology of health and illness, the sociology of gender, the sociology of the body and the sociology of deviance to understanding the experience of infertility. It is less clear that these fields have been influenced by research on infertility, but the study of infertility has much to contribute to the wider discipline. The research on infertility reported upon here can tell sociologists a great deal about the role of power and social structure in the social construction of reproduction, nicely captured by the phrase 'stratified reproduction' (Ginsburg and Rapp 1995: 3). The research reported upon here also provides us with evidence that women are not merely passive victims of medicalisation and male reproductive control but are rather active agents in defining their own experience and in constructing meaningful moral worlds in situations not of their own choosing. The literature described here sends a clear message about the importance of self-identity in the medical help-seeking process and about the importance of the body for identity. The infertility literature can also serve to remind us that it is not only women who reproduce, who undergo medicalisation and who experience stigma, and that men need to be a part of research on gender and health.

Address for correspondence: Arthur L. Greil, Division of Social Sciences, Alfred University, 1 Saxon Drive, Alfred, New York 14802, USA
e-mail: fgreil@alfred.edu

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