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Responding to Infertility: Lessons from a Growing Body of Research and Suggested Guidelines for Practice

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Review

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Responding to Infertility: Lessons From a Growing Body of Research and Suggested Guidelines
for Practice

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Abstract

Infertility is a common, yet often misunderstood, experience. Infertility is an important topic for family scientists because of its effects on families; its relevance to research in related areas, such as fertility trends and reproductive health; and its implications for practitioners who work with individuals and couples experiencing infertility. In this review, we focus on common misperceptions in knowledge and treatment of infertility and highlight insights from recent research that includes men, couples, and people with infertility who are not in treatment. The meaning of parenthood, childlessness, awareness of a fertility problem, and access to resources are particularly relevant for treatment seeking and psychosocial outcomes. On the basis of insights from family science research, we provide specific guidelines for infertility practice within broader social contexts such as trends in health care, education, employment, and relationships. Guidelines are presented across three areas of application: infertility education for individuals, families, and practitioners; steps to support the emotional well-being of those

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3 affected by infertility; and understanding of treatment approaches and their implications for
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5 individuals and couples.
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10 *Key Words:* assisted reproductive technology, health disparities, identity, infertility, life course,
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12 parenthood
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17 Parenthood is generally a desired and anticipated role for most individuals (Becker, 2000;
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19 Matthews & Martin-Matthews, 1986; Tichenor, McQuillan, Greil, Contreras, & Shreffler, 2011).
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21 Although an increasing proportion of Americans do not have children, most still expect to have
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23 children (Thornton & Young-DeMarco, 2001) and assume they can become parents when they
24
25 are ready. Once ready, however, many couples may find that life course plans and expectations
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27 for parenthood are disrupted by infertility (Loftus & Andriot, 2012). For some women and
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29 couples, infertility can result in emotional distress, identity challenges, a sense of loss of control,
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31 feelings of stigmatization and isolation, and strain in relationships (for a review, see Greil,
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33 Slauson-Blevins, & McQuillan, 2010). There is much variation in the experiences and outcomes
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35 of infertility; the meanings and consequences of infertility are shaped by the context and
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37 accumulation of reproductive experiences, including fertility histories, attitudes, and intentions.
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44 The diversity of infertility experiences has direct implications for best practices among
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46 practitioners working with these individuals and couples. For example, practitioners should
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48 empower those they serve by providing nonprescriptive information and allowing the parameters
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50 of assistance and the goals of the decision-making process to be dictated by the individuals and
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52 couples experiencing infertility. This may entail initiating discussions intended to elucidate
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54 relevant values, such as the meaning attributed to parenthood, and how those values intersect
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3 with couples' desires to (a) have a biological child, (b) parent a nonbiological child, or (c) opt
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5 out of efforts to have a child. In these discussions, individuals or couples must also consider the
6
7 costs—direct and indirect, intrinsic and extrinsic, material and emotional costs—of infertility
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9 treatment, adoption, or opting out of parenthood. Practitioners working with those experiencing
10
11 infertility should also be prepared to provide unbiased empirical evidence that can help people
12
13 make informed decisions for themselves. Those experiencing infertility may also be relieved to
14
15 know that most infertile individuals who never give birth (regardless of parenthood status)
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17 ultimately do not suffer long-term negative psychological consequences (Bures, Koropecjy-
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19 Cox, & Loree, 2009).
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25 Given these considerations, we propose that basic family science research translates into
26
27 three key tasks for practitioners working with those experiencing infertility: (a) provide
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29 education and awareness about reproduction and infertility treatment, (b) outline the role that
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31 practitioners can have in the promotion of emotional well-being, and (c) identify how to support
32
33 the decision-making processes among individuals and couples treating infertility. In this article,
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35 we elaborate ways that evidence-based tasks related to fertility have evolved. We also translate
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37 family science findings to help family practitioners move toward the preceding three goals:
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39 educate, provide emotional support, and help couples and individuals with decision-making in
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41 the context of infertility.
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46 Because of the diversity of reproductive attitudes, experiences, and consequences
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48 documented in the research literature on infertility (Greil, Shreffler, Schmidt, & McQuillan,
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50 2011), the one certainty is that no assumptions can be made with regard to the decisions people
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52 experiencing or anticipating infertility will make for themselves. Thus, family practitioners can
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3 be helpful to individuals and couples with infertility by asking essential questions and providing
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5 information about options with a focus on sensitivity to this diversity of experience.
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8 On the point of sensitivity, especially as it relates to emotional well-being, sensitivity to
9
10 each individual and couple is essential. For example, the terms used with regard to infertility can
11
12 be hurtful; viewing pregnancy or birth as a success can imply that continued infertility represents
13
14 failure. Even the term *family* can be awkward for those without children. Bulcroft and Teachman
15
16 (2003) outlined several problems associated with defining and categorizing childless/childfree
17
18 women. As they pointed out, the language either problematizes (childless) or glorifies (childfree)
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20 the absence of children, each term conveying information about normative categories, social
21
22 expectations, and the value of children and parenthood. The most descriptive phrase, people
23
24 without children, is awkward and still implies a lack of children. Moreover, not all individuals
25
26 and couples with infertility describe themselves as infertile or even as having a fertility problem.
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28 Practitioners should, therefore, inquire and take cues from those whom they serve with regard to
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30 the terms and characterization they prefer in reference to their reproductive circumstances.
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EDUCATION AND AWARENESS OF REPRODUCTION AND INFERTILITY TREATMENT

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37 Translating discovery science to guidelines for practice-based family scientists working with
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39 individuals and couples around issues of conception and childrearing emphasizes helping
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41 families better understand infertility. A recent Centers of Disease Control and Prevention (CDC;
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43 2014) report suggests that a public health approach is needed for infertility prevention, detection,
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45 and management (see also Macaluso et al., 2010). Following this suggestion, education targeting
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47 awareness, prevention, and detection of infertility is an important aspect of guidelines for
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49 practitioners. Areas of particular importance are addressed in what follows and include
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51 understanding of the following:
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- Definitions of infertility, primary infertility, and secondary infertility
- Importance of pregnancy intent when diagnosing infertility
- Patterns and potential risks and solutions for women and men, including age-related fertility decline; behaviors associated with fertility (e.g., maintain a healthy weight, stop smoking); and environmental and occupational environments that help maintain fertility
- Detection of health conditions, such as sexually transmitted infections, that lead to infertility
- Experiences of and responses to infertility

Definitions of Infertility

The accepted medical criterion for infertility is 1 year of regular, unprotected heterosexual intercourse without conception (American Society for Reproductive Medicine, 2008). From 2006 to 2010, a 12-month period of infertility affected approximately 6% of married women and 9% of all U.S. men aged 15 to 44 years (Chandra, Copen, & Stephen, 2013), but about 44% of U.S. women meet the definition of infertility at some point during their reproductive years (Johnson, McQuillan, Greil, & Shreffler, 2014). Therefore, infertility is quite a common experience for women, men, and couples in the United States.

A common misperception about infertility is that all infertile individuals are childless. Many women and couples who are classified as infertile using the standard medical definition actually have children. Medical professionals classify women as having either primary or secondary infertility. Health care providers use the term “primary infertility” to describe those who have never had a pregnancy and “secondary infertility” to describe those who have previously been pregnant (American Society for Reproductive Medicine, 2008). Secondary infertility was about twice as common until recently, when primary infertility rates increased due

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3 to childbearing postponement (Chandra et al., 2013). Given the challenges of measuring
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5 infertility at the population level, trends in infertility rates and changes over time and across
6
7 countries are difficult to measure accurately (Guzick & Swan, 2006). Yet there is strong
8
9 evidence that involuntary childlessness and having fewer children than many people desire have
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11 become more prevalent in the United States and other industrialized countries (Schmidt,
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13 Sobotka, Bentzen, & Andersen, 2012).
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17 The definition of infertility presumes that not using contraception indicates trying to have
18
19 a baby. This presumption, however, is inconsistent with evidence that a substantial portion of
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21 women are ambivalent and “okay either way” about pregnancy (McQuillan, Greil, & Shreffler,
22
23 2011). In addition, about half of the women identified as meeting criteria for infertility in a
24
25 probability-based sample did not self-identify as infertile because they were not trying to
26
27 conceive; these women can be considered hidden with regard to infertility because they neither
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29 desire pregnancy nor seek treatment and are thus absent from infertility clinics (Greil,
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31 McQuillan, Johnson, Slauson-Blevins, & Shreffler, 2010).
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37 Much of what is known about the experience of infertility has come from small clinic-
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39 based samples or other nonrepresentative samples (Greil, Slauson-Blevins, & McQuillan, 2010).
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41 Reliance on clinic samples of women and couples seeking treatment means that considerably less
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43 is known about the infertile individuals who have not sought treatment—approximately half of
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45 those who are infertile and are trying to conceive (Greil, McQuillan, et al., 2010). The study of
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47 infertility was initially primarily limited to the study of clinic patients, but once research moved
48
49 beyond treatment seekers to include a focus on women with infertility who were not seeking
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51 treatment, it became clear that there is considerable diversity among those who meet the criteria
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53 for infertility. The diversity of experiences with infertility, particularly among those not seeking
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3 medical treatment, raises important questions about the social dimensions of the experience of
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5 infertility, the process of self-identifying as infertile, and the challenges involved in estimating
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7 the unmet need for infertility counseling and treatment (Greil, Slauson-Blevins, Tiemeyer,
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9 McQuillan, & Shreffler, 2016).

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13 Furthermore, reliance on studies of treatment seekers made it difficult to distinguish
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15 between the psychological effects of infertility and the psychological effects of infertility
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17 *treatment*. In recent years, more efforts have been made to advance understanding of various
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19 factors (individual, familial, economic, medical, and cultural) that affect responses to infertility.
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21 For example, the National Institute of Child Health and Human Development funded a national
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23 study resulting in the National Survey of Fertility Barriers. This probability-based study of 4,712
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25 U.S. women of reproductive age and 932 of their partners followed participants over 3 years in
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27 two waves of data. This study included an oversample of racial and ethnic minority women as
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29 well as women who were deemed to be at-risk for infertility (based on criteria such as age,
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31 sterilization status, number of children, heterosexual relationship status, desire for children, prior
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33 miscarriages, and episodes of unprotected heterosexual intercourse for a year or more without
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35 conception). Additionally, the CDC recently intensified efforts to address infertility from a
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37 public health approach by identifying targeted priorities to address infertility prevention,
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39 detection, and management (CDC, 2014; Macaluso et al., 2010). The resulting discoveries about
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41 the causes and consequences of infertility and infertility treatment, as well as priorities
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43 determined by the CDC, contribute to the development of guidelines for practitioners working
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45 with individuals and couples experiencing infertility.
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53 Thus, only recently have researchers begun to examine the meaning of infertility and its
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55 consequences for nonclinical samples of women, including lower status women such as racial
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and ethnic minority women (Bell, 2014) and those in underrepresented sexual minority groups (Kazyak, Park, McQuillan, & Greil, 2016). The experiences of men have also been underresearched (Culley, Hudson, & Lohan, 2013). These considerations and their implications for practitioners and education are addressed in the following sections.

Patterns, Risks, and Solutions for Women and Men

Although much of the literature highlighted here reflects the greater body of literature on infertility in its focus primarily on women's experiences with infertility (Culley et al., 2013), men also experience infertility. Approximately 50% of infertility cases among heterosexual couples are attributable to female factors, 20% to male factors, and 30% to combined female and male factors or to unknown factors (Thonneau et al., 1991). The most common causes of male infertility are low quantities or poor quality of sperm (Greil et al., 2016). Environmental and occupational hazards are suspected causes of declining human sperm quality in industrialized countries (Swan, Elkin, & Fenster, 2000). Many of the risk factors for male infertility, such as age, health status, and obesity, are similar to those for women (Ramlau-Hansen et al., 2007).

Infertility in women is often caused by problems with ovulation, the cervix or uterus, or the fallopian tubes (Greil, Schmidt, & Peterson, 2016). Perhaps the most important risk factor for female infertility is age. Women's ability to get pregnant declines with age; female fertility declines gradually starting around 35 years of age then declines more dramatically after 40 years of age (Practice Committee, 2016; Reproductive Endocrinology and Infertility Committee, 2012). Because more women and couples in the United States are postponing childbearing, more women experience infertility before they have had their desired number of biological children; even if the incidence and prevalence of infertility and the desired number of children were to remain the same in the future, infertility is likely to have an increasing impact on future

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3 childbearing patterns and number of births per woman due to age-related infertility (Greil,
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5 Schmidt, & Peterson, 2016).

Detection of Health Conditions Leading to Infertility

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10 Other bio-behavioral factors associated with female infertility include obesity, smoking, and
11
12 sexually transmitted diseases. Obesity, for example, is associated with ovulation problems due to
13
14 hormonal imbalances, and irregular ovulation is one of the most common reasons for infertility
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16 (Ramlau-Hansen et al., 2007). Increasing obesity rates in many countries (Gordon-Larsen, The,
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18 & Adair, 2010) may lead to increases in future infertility rates. Both amount and duration of
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20 smoking increase risk for infertility among women (Laurent, Thompson, Addy, Garrison, &
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22 Moore, 1992). Infertility also occurs as the result of treatment for other health problems; cancer
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24 treatments, for example, often lead to infertility (Carter et al., 2010), and sexually transmitted
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26 diseases, such as chlamydia, can cause infertility due to tubal scarring (Scholes et al., 1996).

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32 These known causes of infertility aside, many of the risks and pathways leading to female
33
34 and male infertility remain unexplained. The CDC's (2014) National Public Health Action Plan
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36 highlighted a need for additional research on the causes of infertility and the biological
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38 mechanisms that precede infertility, including a better understanding of reproductive aging,
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40 impacts of environmental hazards on fertility during key developmental stages, the role of
41
42 infectious disease in infertility, chronic endocrine and metabolic conditions, behavioral factors,
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44 occupational hazards, and genetic influences.

Experiences of and Responses to Infertility

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49 Infertility is often incorrectly viewed as a problem primarily for White middle-class women
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51 (Bell, 2014). Yet women from racial and ethnic minority groups and those in lower social classes
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53 are more likely to experience adverse reproductive events than White and middle- or upper-class
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3 women, respectively. Adverse reproductive events include, but are not limited to, higher rates of
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5 recurring pregnancy loss (Price, 2006), infertility (Greil, Shreffler, Schmidt, & McQuillan,
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8 2011), unintended pregnancies (Musick, England, Edgington, & Kangas, 2009) and
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10 noncontraceptive (e.g., due to health problems or other reasons) sterilization surgeries (Shreffler,
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12 McQuillan, Greil, & Johnson, 2015). Many people with fertility barriers who are from racial and
13
14 ethnic minority groups and those in lower social classes experience distress associated with
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16 infertility (Greil, McQuillan, & Sanchez, 2016). Some recent work (Shreffler, Greil, &
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18 McQuillan, 2011; Shreffler, Hill, & Cacciatore, 2012; Shreffler et al., 2015; Wildsmith, Guzzo,
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20 & Hayford, 2010) highlights the importance of repeat adverse or stigmatized reproductive
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22 experiences (e.g., repeat pregnancy losses, abortions, or unintended pregnancies) and multiple
23
24 adverse reproductive events (e.g., infertility combined with a history of pregnancy losses) for
25
26 various outcomes including birth likelihood, psychological distress, and elevated risk of divorce.
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28 Because most infertility clinic patients are White and middle class, much of what we know of
29
30 infertility causes and consequences has been shaped by samples of White, middle-class people
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32 with infertility (Bell, 2014). Population data provide evidence that both infertility prevalence and
33
34 infertility treatment in the United States are stratified by socioeconomic status and race/ethnicity:
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36 Those with higher incomes, private insurance, and who are White have more support and access
37
38 to treatment than others (Greil, Slauson-Blevins, et al., 2016). Yet regardless of socioeconomic
39
40 status and race/ethnicity, women who experience infertility report greater desire to have children
41
42 and want more children than women who have not experienced infertility (Shreffler et al., 2016).
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PRACTITIONERS' ROLE IN THE PROMOTION OF EMOTIONAL WELL-BEING

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52 Several reviews of research literature and meta-analyses summarize findings regarding the
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54 psychosocial impacts of infertility for individuals and families (Greil, 1997; Greil, Schmidt, &
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Peterson, 2016; Greil, Slauson-Blevins, & McQuillan, 2010). Generally, conclusions from these reviews indicate that although infertility does not cause psychopathology, infertility is a source of psychological distress, particularly for women. Infertility treatment can be an additional stressor. The consequences of both infertility and treatment for couples are mixed; although communication and feelings of closeness often increase in the short term, infertility can also lead to greater relationship strain and communication problems (Greil, Schmidt, & Peterson, 2016; Greil, Slauson-Blevins, & McQuillan, 2010). The following guidelines may be helpful for supporting individuals and couples experiencing infertility:

- Recognize that emotional responses to infertility may vary.
- Recognize that infertility affects the couple even when only one partner is undergoing treatment.
- Reassure those experiencing infertility that many people struggle with similar challenges.

Emotional Responses to Infertility May Vary

There is substantial descriptive research, primarily qualitative, that attempts to characterize the psychosocial experience of infertility (Becker, 2000; Inhorn, 2015; Wirtberg, Moller, Hogström, Tronstad, & Lalos, 2007). Taken as a whole, qualitative studies present a picture of infertility that suggests it is an emotionally devastating experience, especially for women, in large part because it threatens identity, which leads to feelings of failure, defectiveness, and reduced competence; feelings of isolation and alienation from the those who are fertile; a profound sense of stigma; and a strong commitment to treatment (Becker, 2000; Greil, 1991; Inhorn, 2015; Wirtberg et al., 2007).

Descriptive research on infertility shows how social context and gender, family structure and couple relationships, medical institutions, and reproductive technology (Becker, 2000; Bell,

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1
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3 2014; Inhorn, 2015) shape the experience of infertility. In some cultures, for example,
4
5 motherhood is central to women's status and infertility can be a greater source of stigma and
6
7 shame than for women in societies where voluntary childlessness is acceptable (Greil, Schmidt,
8
9 & Peterson, 2016). For many people, the treatment experience is stressful. People undergoing
10
11 treatment often report feeling they have little control over treatments (Redshaw, Hockey, &
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13 Davidson, 2007), are intimidated by the language of biomedicine and the technical aspects of
14
15 infertility treatment (Becker, Castrillo, Jackson, & Nachtigall, 2005), or have difficulty accepting
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17 unresolved infertility after treatment that does not lead to a birth (Peddie, van Teijlingen, &
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19 Bhattacharya, 2005).

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25 These may be reasonable outcomes due to the complexities associated with approaches to
26
27 address infertility. Because there are numerous contemporary medical technologies for infertility,
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29 few couples are told that they may never be parents (Greil, 1991; van den Broeck et al., 2009). In
30
31 addition, couples who stop infertility treatments tend to stop for financial and psychological
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33 reasons even when more treatment options are available (Boivin et al., 2012). Contemporary
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35 infertility may be characterized, therefore, by a state of statuslessness and ambiguity (Allan,
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37 2007) in which couples can either achieve a desired goal or give up on that goal and chart a new
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39 life course.
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44 With a few exceptions (e.g., Bell, 2014; Wilson, 2014), extant research on experiences of
45
46 infertility has focused on those who are seeking treatment. Thus, the characterization of women
47
48 with infertility as struggling with identity and as immersed in the process of trying to become
49
50 pregnant often fails to acknowledge that these are the experiences of treatment seekers, and
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52 therefore may not characterize the experiences of those not seeking treatment (Greil &
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54 McQuillan, 2004; White, McQuillan, Greil, & Johnson, 2006).
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Contrary to these qualitative studies, quantitative studies do not always support the insights from the mostly clinic-based studies described. Several studies converged on a consensus that most women and men with infertility do not meet criteria for clinically significant psychopathology (Thorn, 2009; Wischmann, Stammer, Scherg, Gerhard, & Verres, 2001). Although the literature does not suggest that infertile women are fundamentally different from others in their psychological functioning, the experience of infertility does seem to be a source of psychological distress (Greil, Schmidt, & Peterson, 2016). Indeed, the majority of quantitative studies have found that people with infertility have more symptoms of distress than fertile control samples (Fekkes et al., 2003, Holter, Anderheim, Bergh, & Moller, 2006; Jordan & Ferguson, 2006).

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There is evidence that many of the long-term negative consequences of infertility may exist only among those who are involuntarily childless (Jacob, McQuillan, & Greil, 2007; McQuillan, Greil, White, & Jacob, 2003; McQuillan, Stone, & Greil, 2007; Schwerdtfeger & Shreffler, 2009). The aggregate distress level for mothers with adopted or biological children who have ever been infertile is not statistically higher than the aggregate distress level found among their counterparts who have never experienced known infertility. That said, there is considerable variation in distress among women with infertility (Greil, Shreffler, Schmidt, & McQuillan, 2011; McQuillan et al., 2003, 2007). Working within the current categories associated with infertility, those who would be defined as experiencing primary infertility, have not adopted a child, think of themselves as trying to become pregnant, are older, place a higher value on motherhood, or report lower levels of social support experience more distress than their respective counterparts (Greil et al., 2012). Notably, however, in a model using control variables

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3 among a probability-based sample of women with infertility, infertility-specific distress did not
4 vary across racial or ethnic identities (Greil, McQuillan, & Sanchez, 2016).
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Recognize That Infertility Often Involves the Couple

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10 The vast majority of infertility research has focused on women's infertility, treatment, and
11 distress (cf. Barnes, 2014). This may be justified because data that do exist on men's experiences
12 (e.g., Eugster & Vingerhoets, 1999; Greil, Slauson-Blevins, & McQuillan, 2010; Henning,
13 Strauss, & Strauss, 2002) indicate that women experience more infertility stress than men.
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17 Nonetheless, men are also affected by infertility, whether their own or a partner's infertility.
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20 More research examining men's experience of infertility is needed to better understand how men
21 and women's experiences differ to inform guidelines for helping people with infertility. For
22 example, the experience of infertility may be detrimental to women's self-identity, whereas
23 men's most salient experience stemming from infertility may be indirect through the effect it has
24 on their partners (Greil, 1991).
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Provide Reassurance by Educating About Common Experiences

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36 Studies indicate that infertility can have both desirable and undesirable outcomes (Greil,
37 Slauson-Blevins, & McQuillan, 2010; Verhaak et al., 2007). For example, among the deleterious
38 effects of infertility on relationships, sex can lose its spontaneity and become more chore-like
39 rather than a source of pleasure or expression of intimacy within the relationship (Piva, Lo
40 Monte, Graziano, & Marci, 2014; see also Glover, McLellan, & Weaver, 2009; Ozkan, Orhan,
41 Aktas, & Coskuner, 2016). Conversely, infertility can lead to stronger couple relationships
42 (Peterson, Pirritano, Block, & Schmidt, 2011; Wagner, Wrzus, Neyer, & Lang, 2015), especially
43 among partners who approach infertility as a shared problem (Greil, 1991).
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3 Practitioners who focus on the emotional well-being of infertile individuals and couples
4 have several responsibilities, including helping their clients make decisions about how far to
5 proceed with infertility treatments, helping them to communicate better as a couple about issues
6 surrounding infertility, and helping them to cope with potentially traumatic experiences such as
7 pregnancy loss and treatments that do not result in a live birth (Norre & Wischmann, 2011).
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SUPPORTING THE DECISION-MAKING PROCESS

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17 There are many possible responses to infertility. Guidelines for helping families make decisions
18 about how to proceed include the following:
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21 • Inform couples with infertility about what treatment entails, including risks, benefits, and
22 rates of live births.
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- 24 • Identify barriers to treatment, promote equal access to treatment, and eliminate disparities
25 in infertility treatment.
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- 27 • Inform couples about alternatives to infertility treatment, such as adoption and childfree
28 living.
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Treatment Risks, Benefits, and Rates of Live Births

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37 For those who pursue medical treatment, testing for infertility generally includes semen analysis,
38 ovulation testing, hysterosalpingography (visualization of the uterine tubes), hormone testing,
39 and laparoscopy (visualization of the pelvic area). Treatments for infertility include ovulation
40 induction; insemination with semen; and assisted reproductive technology (ART), such as in
41 vitro fertilization (IVF; Zegers-Hochschild et al., 2009). Among women who seek treatment,
42 ovulation drug therapy is the most common type of infertility treatment (86%), followed by
43 artificial insemination (30%), surgery to correct blockages in the uterine tubes (20%), and IVF
44 (13%; Kessler, Craig, Plosker, Reed, & Quinn, 2013). Most infertility treatments are invasive,
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3 time-consuming, and often prohibitively expensive where these procedures are not covered by
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5 health insurance. On this latter point, in the United States there are higher rates of infertility
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7 treatment in the 15 states with mandated insurance coverage for infertility treatments than in
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9 states without mandated coverage, particularly among older and more educated women (i.e.,
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11 those who are more likely to have health insurance; Bitler & Schmidt, 2012).
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15 Rates of live births after infertility treatment vary from study to study, likely due to
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17 differences among couples seeking (or accepted for) treatment, types of treatments reported, and
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19 cultural or societal differences affecting health care policies and practices. A study of couples
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21 from a fertility clinic in Denmark—a country with a tax-financed public health care system that
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23 includes access to ART treatments—found that 75% of women under 35 years of age reported a
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25 live birth within 5 years of beginning treatment (Pinborg, Hougaard, Nyboe Andersen, Molbo, &
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27 Schmidt, 2009). However, only 52% of women who were 35 years of age or older when
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29 treatment was initiated reported a subsequent live birth. A Dutch study found that 72% of
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31 patients at a fertility clinic reported a live birth but that only about half of these births could be
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33 attributed to treatment (Brandes, Hamilton, Bruin, & Kremer, 2010). A Swedish study found that
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35 57% of fertility clinic patients experienced a live birth and that three quarters of these births
36
37 could be attributed to treatment (Aanesen & Westerbotn, 2014). Estimates indicate that IVF
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39 results in live births in 38% of cases in the United States and 28% of cases in Europe (Baker et
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41 al., 2010). Collins and Van Steirteghem (2004) pooled data from a large number of published
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43 studies and reported a success rate of 37% for treatments that did not involve ART. Notably,
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45 these studies are based on fertility clinic samples; the live-birth rate for infertile individuals who
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47 are not treated at fertility clinics is unknown because most studies of treatment outcomes have
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49 used data from specialized fertility clinics.
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RESPONDING TO INFERTILITY

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Although many individuals and couples who seek fertility treatments ultimately experience a live birth, pregnancy may not restore normalcy to the lives of infertile individuals. Treatment for infertility is linked to distress over and above that caused by infertility itself (Greil, Lowry, McQuillan, & Shreffler, 2011), and pregnancy is more stressful than for people undergoing IVF than people without fertility problems (Eugster & Vingerhoets, 1999). Women with infertility who have given birth through ART have reported that they perceive themselves to be less-than-ideal mothers because they achieved motherhood in an unusual way (Letherby, 1999). In addition, women who transition to parenthood after experiencing infertility treatments tend to have lower evaluations of themselves and embrace a motherhood identity slower than women who have not experienced infertility (Gibson, Ungerer, Tennant, & Saunders, 2000). Conversely, Hjelmstedt, Widström, Wramsby, and Collins (2004) reported that at 6 months postpartum, those who had infertility treatment and a live birth tended to feel that infertility was behind them and that their experience with infertility had strengthened their feelings for and emotional closeness to their children, provided greater tolerance for parenting difficulties, and had left them more grateful for their children. Although many studies have identified differences between parents who experienced infertility and their counterparts who did not, Eugster and Vingerhoets (1999) found no differences in parenting between parents who have conceived through IVF and other parents. Importantly too, there is no evidence of problematic maternal behavior, marital problems, or psychological problems for couples after resolved infertility (Repokari et al., 2007).

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More research is needed on the long-term effects of infertility treatment for women and their children (Van Voorhis, 2006), although several small-sample studies have been conducted from which tentative conclusions can be drawn. Wirtberg et al. (2007) found that, 20 years later,

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3 women who had undergone tubal surgery that did not help them have a live birth still had vivid
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5 memories of their time as infertility patients, and nearly all reported long-term effects on their
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7 sexual lives and relationships. In addition, many indicated that they felt as if they were
8
9 experiencing infertility again as their peers were transitioning to grandparenthood. In a 10-year
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11 follow-up study of IVF women, Sundby, Schmidt, Heldaas, Bugge, and Tanbo (2007) found that
12
13 women remembered the period of infertility as a difficult time in their lives, even though most of
14
15 the women in the study eventually became mothers. Regardless of the outcome, they all found
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17 ways to cope with their situation. As noted earlier, there is evidence that the long-term negative
18
19 consequences of infertility primarily occur among those who remain involuntarily childless
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21 (Jacob et al., 2007; McQuillan et al., 2003, 2007; Schwerdtfeger & Shreffler, 2010). In a study of
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23 women who adopted, used ART, or pursued surrogacy, van den Akker (2004) found that mothers
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25 reported a higher quality of life than nonmothers, regardless of the process by which the mothers
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27 became parents.
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34 Practitioners working with people in the process of getting medical help for infertility can
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36 help with realistic expectations for the odds of a live birth, recognition of the stresses associated
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38 with treatment processes, and evidence that people who become parents through various avenues
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40 tend to report a higher quality of life than those who do not become parents. Helping people
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42 understand the physiology of pregnancy and the extra challenges of conception after 35 years of
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44 age could lead some individuals and couples with a low probability of experiencing a live birth
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46 from treatment to find a nontreatment approach to parenthood or to lower expectations of a live
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48 birth.
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53 *Barriers, Equal Access, and Disparities*
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RESPONDING TO INFERTILITY

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3 Several studies of medical help-seeking for infertility have focused on barriers to treatment
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5 (Adashi & Dean, 2016). Infertility help-seeking varies by race and ethnicity. For example, racial
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7 and ethnic minority group members, particularly African American individuals and couples, are
8
9 less likely than Whites to seek treatment, in part because their friends and family are less likely
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11 to encourage doing so, they tend to be more distrustful of medical institutions and have more
12
13 ethical concerns with fertility treatments, and they exhibit less planning or intentionality about
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15 pregnancy (Dovidio et al., 2008; Greil, McQuillan, Shreffler, Johnson, & Slauson-Blevins, 2013;
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17 White, McQuillan, & Greil, 2005). Women and couples of lower socioeconomic status in all
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19 racial groups also tend to encounter financial barriers to treatment (Bell, 2014; Greil, McQuillan,
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21 Shreffler, Johnson, & Slauson-Blevins, 2011). Gay men and lesbians, as well as unpartnered
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23 individuals, are not permitted to receive ART in some jurisdictions and fertility clinics,
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25 regardless of infertility status (Ethics Committee of the ASRM, 2009). Some delay or avoid
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27 treatment by their own choice because they perceive infertility to be a stigmatized condition
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29 (Bunting & Boivin, 2007) or because they have ethical concerns about infertility treatments—for
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31 example, they are opposed to selective reduction of multiple-embryo pregnancies to reduce risk
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33 to the mother or to treatments that result in a child who is not biologically related to either parent
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35 (Shreffler, Johnson, & Scheuble, 2010). However, ethical concerns about ART are declining
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37 over time, and they are declining fastest for women, who initially had the greatest concerns
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39 (Greil et al., 2017).
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48 Social cues from partners, parents, family, friends, and others who have children or have
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50 undergone treatment can also influence decisions about whether to pursue medical solutions for
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52 infertility (Bunting & Boivin, 2007; Greil, McQuillan, et al., 2011; Greil, McQuillan, Shreffler,
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54 Johnson, & Slauson-Blevins, 2013). Other factors that are associated with a higher likelihood of
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3 seeking medical treatment include having primary infertility, being older, and self-identifying as
4 someone with a fertility problem (Greil & McQuillan, 2004; Greil et al., 2013; Greil, McQuillan,
5 et al., 2011). For women in the United States, there is no direct association between religiosity
6 and propensity to seek help for infertility; rather, the association is mediated by the degree to
7 which women value motherhood and have ethical concerns about infertility (Greil, Slauson-
8 Blevins, & McQuillan, 2010).

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Practitioners can help individuals and couples with infertility sort out the ethical, religious, and social dimensions of treatment versus other responses to infertility. Practitioners can also play a subtle role in reducing the barriers that some groups of people experience by, for example, ensuring that the images on promotional material depict the diversity of the infertile population. Talking to people with infertility about their desires and concerns, as well as working to lower costs and increase access to the array of options available for those experiencing infertility, will also help to ensure that people make choices that are both informed and a good fit for their situation.

Alternatives to Infertility Treatment

Individuals and couples experiencing infertility have a range of options other than treatment, including accepting childlessness or choosing to have no children, becoming a foster parent, adopting, praying for change in fertility status, seeking counseling, joining a support group, seeking various forms of complementary and alternative medicine, and seeking surrogacy (Greil, Lowry, Johnson, Simon, & Slauson-Blevins, 2012). Most people experiencing infertility explore multiple options at the same time. One of the more common nonmedical response options to infertility is adoption. Although more than 40% of (fertile and infertile) women have considered or are currently considering adoption, only half actually take steps in pursuit of adoption (Park &

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3 Wonch Hill, 2014). Those who place greater importance on motherhood and had prior infertility
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5 treatments are more likely to pursue adoption (Park & Wonch Hill, 2014). Conversely, the costs
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7 associated with adoption, the difficult application and intake process, and situational factors
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9 (e.g., not in a stable relationship, waiting to try for a biological child first, and work conflicts)
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11 serve as barriers to adoption (Slauson-Blevins & Park, 2016). Although more than 90% of a
12
13 sample of college students said they would be willing to adopt a child if they could not have a
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15 biological child (Whatley, Jahangardi, Ross, & Knox, 2003), there is evidence that most
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17 Americans regard adoption as a second-best option that is not nearly as desirable as having a
18
19 biological child (Fisher, 2002). Historically, negative attitudes toward adoption were due to the
20
21 “twin stigmata of infertility and illegitimacy” (Haines & Timms, 1985, p. 77), but even if less
22
23 adoption stigma exists today, there are lingering concerns that it might be more difficult to
24
25 develop the same feelings for adopted children that are assumed to be innate for biological
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27 children, and many women considering adoption therefore view it as a last option after trying to
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29 conceive a biological child and undergoing expensive treatments (Slauson-Blevins & Park,
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31 2016).

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39 Helping women and couples think about several possible responses to infertility,
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41 particularly involuntary childlessness, may be a useful process. Women and couples, particularly
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43 those at the upper end of the fertility window in terms of age, have limited time to make a
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45 decision to seek medical help if they want to pursue a live birth. They need accurate information
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47 about what is involved in the array of responses (fostering, adopting, treatment), including the
48
49 time limit on each option. Guiding without directing is important because income, race/ethnicity,
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51 religiosity, ethics, education, wealth, relationship quality, and health shape people’s viable
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RESPONDING TO INFERTILITY

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3 responses to infertility; assuming that medical technology is the obvious or most desirable option
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5 ignores the constraints that financial and social identity place on access to treatment.
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CONCLUSION

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10 The state of current knowledge and practice concerning infertility has important implications for
11
12 future research, public awareness, and social policy. Although much is known about risk factors
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14 for infertility from aggregated national data, additional research to identify potential markers of
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16 fertility decline could help couples with their decision-making regarding childbearing (CDC,
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18 2014). Americans tend to be more optimistic about their ability to conceive than statistics
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20 indicate that they should be, and many couples plan to wait until their mid-30s to begin trying to
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22 conceive (Reproductive Medicine Associates of New Jersey, 2015). There is a lack of fertility
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24 knowledge in the general population that could help couples when they try to conceive, including
25
26 lack of awareness about the most fertile time of the month, overestimating chances of pregnancy
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28 during ovulation, and uncertainty about factors that might increase risk of infertility (Bunting &
29
30 Boivin, 2008). Although many people are aware that treatments for infertility exist, they often do
31
32 not know the extent of age-related fertility decline and tend to overestimate treatment success
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34 rates (Peterson, Pirritano, Tucker, & Lampic, 2012). Treatments can also be quite expensive;
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36 Katz et al. (2011) found that median per-person costs ranged from \$1,182 for medications only,
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38 to \$38,015 for IVF donor eggs; those who had “successful” outcomes (e.g., IVF treatments
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40 resulting in a live birth) were even more costly, at a mean cost of \$61,377. Further, as
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42 highlighted earlier, treatment adds to the stress that those experiencing infertility often feel.
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50 Therefore, greater awareness about human reproduction among the general public is needed to
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52 potentially reduce the need for infertility treatment. Finally, social policies regarding those who
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54 are experiencing infertility may be warranted. There are many disparities in the receipt of
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3 services for infertility and there is a large unmet need for treatment in the United States. The
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5 existence and continuation of such disparities highlight the importance of formulating social
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7 policies that will overcome barriers to the receipt of services for those who desire them to
8
9 improve maternal and infant outcomes (Macaluso et al., 2010). In addition to infertility
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11 treatment, mechanisms for covering the costs of adoption and other methods of family formation
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13 should be considered.
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REFERENCES

- 30
31
32 Aanesen, A., & Westerbotn, M. (2014). Prospective study of a Swedish infertile cohort 2005–08:
33
34 Population characteristics, treatments and pregnancy rates. *Family Practice, 31*, 290–297.
35
36 doi:10.1093/fampra/cmu003
37
38
39 Adashi, E., & Dean, L. A. (2016). Access to and use of infertility services in the United States:
40
41 Framing the challenges. *Fertility & Sterility, 105*, 1113–1118.
42
43 doi:10.1016/j.fertnstert.2016.01.017
44
45
46 Allan, H. (2007). Experiences of infertility: Liminality and the role of the fertility clinic. *Nursing*
47
48 *Inquiry, 14*, 132–139. doi:10.1111/j.1440-1800.2007.00362.x
49
50
51 American Society for Reproductive Medicine. (2008). Definitions of infertility and recurrent
52
53 pregnancy loss. *Fertility and Sterility, 90*(Suppl. 5), S60.
54
55
56 doi:10.1016/j.fertnstert.2012.09.023
57
58
59
60

RESPONDING TO INFERTILITY

24

- 1
2
3
4 Baker, V. L., Jones, C. E., Cometti, B., Hoehler, F., Salle, B., & Soules, M. R. (2010). Factors
5 affecting success rates in two concurrent clinical IVF trials: An examination of potential
6 explanations for the difference in pregnancy rates between the United States and Europe.
7
8 *Fertility and Sterility*, 94, 1287–1291. doi:10.1016/j.fertnstert.2009.07.1673
9
10
11
12 Barnes, L. W. (2014). *Conceiving masculinity: Male infertility, medicine, and identity*.
13 Philadelphia, PA: Temple University Press.
14
15
16
17
18 Becker, G. (2000) *The elusive embryo: How women and men approach new reproductive*
19 *technologies*. Berkeley, CA: University of California Press.
20
21
22
23 Becker, G., Castrillo, M., Jackson, R., & Nachtigall, R. D. (2005). Infertility among low-income
24 Latinos. *Fertility and Sterility*, 85, 882–887. doi:10.1016/j.fertnstert.2005.09.052
25
26
27
28 Bell, A. V. (2014). *Misconception: Social class and infertility in America*. New Brunswick, NJ:
29 Rutgers University Press.
30
31
32
33 Bitler, M. P., & Schmidt, L. (2012). Utilization of infertility treatments: The effects of insurance
34 mandates. *Demography*, 49, 125–149. doi:10.1007/s13524-011-0078-4
35
36
37
38 Boivin, J., Domar, A. D., Shapiro, D. B., Wischmann, T. H., Fauser, B. C. J. M., & Verhaak, C.
39 (2012). Tackling burden in ART: An integrated approach for medical staff. *Human*
40 *Reproduction*, 27, 941–950. doi:10.1093/humrep/der467
41
42
43
44 Brandes, M., Hamilton, C. J. C. M., Bruin, J. P., & Kremer, (2010). The relative contribution of
45 IVF to the total ongoing pregnancy rate in a subfertile cohort. *Human Reproduction*, 25,
46 118–126. doi:10.1093/humrep/dep341
47
48
49
50
51
52
53
54
55
56
57
58
59
60

RESPONDING TO INFERTILITY

25

1
2
3 Bunting, L., & Boivin, J. (2007). Decision-making about seeking medical advice in an Internet
4 sample of women trying to get pregnant. *Human Reproduction*, *22*, 1662–1668.

5
6
7 doi:10.1093/humrep/dem057

8
9
10 Bunting, L., & Boivin, J. (2008). Knowledge about infertility risk factors, fertility myths and
11 illusory benefits of healthy habits in young people. *Human Reproduction*, *23*, 1858–1864.

12
13
14
15 doi:10.1093/humrep/den168

16
17 Bures, R. M., Koropecykj-Cox, T., & Loree, M. (2009). Childlessness, parenthood, and
18 depressive symptoms among middle-aged and older adults. *Journal of Family Issues*, *30*,

19
20
21
22
23 670–687. doi:10.1177/0192513X08331114

24
25 Carter, C., Raviv, L., Applegarth, L., Ford, J. S., Josephs, L., Grill, E., & Baraka, R. R. (2010). A
26 cross-sectional study of the psychosexual impact of cancer-related infertility in women:

27
28
29
30
31
32
33 Third-party reproductive assistance. *Journal of Cancer Survivorship*, *4*, 236–246.

34
35
36
37
38
39
40
41
42
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47
48
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50
51
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53
54
55
56
57
58
59
60
doi:10.1007/s11764-010-0121-2

Centers for Disease Control and Prevention. (2014). *National public health action plan for the
detection, prevention, and management of infertility*. Atlanta, GA: Author.

Chandra, A., Copen, C. E., & Stephen E. H. (2013, August 14). Infertility and impaired fecundity
in the United States, 1982–2010: Data from the National Survey of Family Growth.

National Health Statistics Reports (no. 67). Hyattsville, MD: National Center for Health
Statistics.

Chandra, A., Copen, C. E., & Stephen E. H. (2014, August 14). Infertility service use in the
United States: Data from the National Survey of Family Growth, 1982–2010. *National*

Health Statistics Reports (no. 73). Hyattsville, MD: National Center for Health Statistics.

RESPONDING TO INFERTILITY

26

- 1
2
3 Collins, J. A., & Van Steirteghem, A. (2004, January 22). Overall prognosis with current
4 treatment of infertility. *Human Reproduction Update*, *10*, 309–316.
5
6 doi:10.1093/humupd/dmh029
7
8
9
10 Culley, L., Hudson, N., & Lohan, M. (2013). Where are all the men? The marginalization of men
11 in social scientific research on infertility. *Reproductive Biomedicine Online*, *27*, 225–235.
12
13 doi:10.1016/j.rbmo.2013.06.009
14
15
16
17 Dovidio, J. F., Penner, L. A., Albrecht, T. L., Norton, W. E., Gaertner, S. L., S., & Shelton, N. J.
18 (2008). Disparities and distrust: The implications of psychological processes for
19 understanding racial disparities in health and health care. *Social Science and Medicine*,
20 *67*, 478–486. doi:10.1016/j.socscimed.2008.03.019
21
22
23
24
25
26
27 Ethics Committee of the American Society for Reproductive Medicine. (2009). Access to
28 fertility treatment by gays, lesbians, and unmarried persons. *Fertility and Sterility*, *92*,
29 1190–1193. doi:10.1016/j.fertnstert.2009.07.977
30
31
32
33
34 Eugster, A., & Vingerhoets, A. J. (1999). Psychological aspects of in vitro fertilization: A
35 review. *Social Science & Medicine*, *48*, 575–589. doi:10.1016/S0277-9536(98)00386-4
36
37
38
39 Fekkes, M., Buitendijk, S. E., Verrips, G. H. W., Braat, D. D. M., Brewaeys, A. M. A., Dolfing,
40 J. G. . . . Macklon, N. S. (2003). Health-related quality of life in relation to gender and
41 age in couples planning IVF treatment, *Human Reproduction*, *18*, 1536–1543.
42
43
44
45
46
47
48
49 Fisher, A. P. (2003). Still “not quite as good as having your own”? Toward a sociology of
50 adoption. *Annual Review of Sociology*, *29*, 335–361.
51
52
53
54
55
56
57
58
59
60

RESPONDING TO INFERTILITY

27

1
2
3 Gibson, F. L., Ungerer, J. A., Tennant, C. C., & Saunders, D. M. (2000). Parental adjustment and
4 attitudes to parenting after in vitro fertilization. *Fertility and Sterility*, *73*, 565–574.

5
6
7
8 doi:10.1016/S0015-0282(99)00583-X
9

10 Glover, L., McLellan, A., & Weaver, S. M. (2009). What does having a fertility problem mean to
11 couples? *Journal of Reproductive and Infant Psychology*, *27*, 401–418.

12
13
14
15 doi:10.1080/02646830903190896
16

17 Gordon-Larsen, P., The, N. S., & Adair, L. S. (2010). Longitudinal trends in obesity in the
18 United States from adolescence to the third decade of life. *Obesity*, *9*, 1801–1804.

19
20
21
22 doi:10.1038/oby.2009.451
23

24 Greil, A. L. (1991). *Not yet pregnant: Infertile couples in contemporary America*. New
25 Brunswick, NJ: Rutgers University Press.
26

27
28 Greil, A. L. (1997). Infertility and psychological distress: A critical review of the literature.
29

30
31
32 *Social Science and Medicine*, *45*, 1679–1704. doi:10.1016/S0277-9536(97)00102-0
33

34 Greil, A. L., Lowry, M., Johnson, K. M., Simon, R. M., & Slauson-Blevins, K. S. (2012,
35 August). *Pursuing pregnancy: Medical and non-medical responses to infertility*. Paper
36 presented at the Annual Meeting of the American Sociological Association, Denver, CO.
37
38

39 Greil, A. L., McQuillan, J., Lowry, M., & Shreffler, K. M. (2011). Infertility treatment and
40 fertility-specific distress: A longitudinal analysis of a population-based sample of U.S.
41 women. *Social Science & Medicine*, *73*, 87–94. doi:10.1016/j.socscimed.2011.04.023
42
43
44
45

46 Greil, A. L., & McQuillan, J. (2004). Help-seeking patterns among subfecund women. *The*
47
48
49
50
51
52 *Journal of Reproductive and Infant Psychology*, *22*, 305–319.

53
54
55
56
57
58
59
60 doi:10.1080/02646830412331298332

RESPONDING TO INFERTILITY

28

- 1
2
3 Greil, A. L., McQuillan, J., Johnson, K. M., Slauson-Blevins, K. S., & Shreffler, K. M. (2010).
4
5 The hidden infertile: Infertile women without pregnancy intent in the United States.
6
7
8 *Fertility and Sterility*, 93, 2080–2083. doi:10.1016/j.fertnstert.2009.08.024
9
- 10 Greil, A. L., McQuillan, J., & Sanchez, D. (2016). Does fertility-specific distress vary by race
11
12 among a probability sample of women in the United States? *Journal of Health*
13
14 *Psychology*, 21, 183–192. doi:10.1177/1359105314524970.
15
16
- 17 Greil, A. L., McQuillan, J., Shreffler, K. M., Johnson, K. M., & Slauson-Blevins, K. S. (2011).
18
19 Race-ethnicity and medical services for infertility: Stratified reproduction in a
20
21 population-based sample of U.S. women. *Journal of Health and Social Behavior*, 52,
22
23 493–509. doi:10.1177/0022146511418236
24
25
26
- 27 Greil, A. L., McQuillan, J., Shreffler, K., Johnson, K. M., & Slauson-Blevins, K. (2013). The
28
29 importance of social cues for medical helpseeking: The example of infertility.
30
31
32 *Sociological Inquiry*, 8, 209–237. doi:10.1111/soin.12000
33
- 34 Greil, A. L., Schmidt, L., & Peterson, B. D. (2016). Psychosocial and biological approaches to
35
36 understanding and treating adjustment to infertility. In A. Wenzel (Ed.), *Oxford*
37
38 *handbook of perinatal psychology* (pp. 524–547). New York, NY: Oxford University
39
40 Press.
41
42
- 43 Greil, A. L., Shreffler, K. M., Schmidt, L., & McQuillan, J. (2011). Variation in distress among
44
45 women with infertility: Evidence from a population-based sample. *Human Reproduction*,
46
47 26, 2101–2112. doi:10.1093/humrep/der148.
48
49
- 50 Greil, A. L., Slauson-Blevins, K., & McQuillan, J. (2010). The experience of infertility: A
51
52 review of recent literature. *Sociology of Health & Illness*, 32, 140–162.
53
54
55
56
57
58
59
60

RESPONDING TO INFERTILITY

29

- 1
2
3 Greil A. L., Slauson-Blevins, K. S., Shreffler, K. M., Johnson, K. M., Lowry, M. H., Burch, A.
4
5 R., & McQuillan, J. (2017). Decline in ethical concerns about reproductive technologies
6
7 among a representative sample of US women. *Public Understanding of Science*, *26*, 789–
8
9 805. doi:10.1177/0963662515625402
10
11
12 Greil A. L., Slauson-Blevins, K., Tiemeyer, S., McQuillan, S., & Shreffler, K. M. (2016). A new
13
14 way to estimate the potential unmet need for infertility services among women in the
15
16 United States. *Journal of Women's Health*, *25*, 133–138. doi:10.1089/jwh.2015.5390
17
18
19 Guzick, D., & Swan, S. (2006). The decline in infertility: Apparent or real? *Fertility and*
20
21 *Sterility*, *86*, 524–526. doi:10.1016/j.fertnstert.2006.05.027
22
23
24 Haimes, E., & Timms, N. (1985). *Adoption, identity and social policy: The search for distant*
25
26 *relatives*. Aldershot, England: Gover.
27
28
29 Henning, K., Strauss, B., & Strauss, B. (2002). *Psychological and psychosomatic aspects of*
30
31 *involuntary childlessness: State of research at the end of the 1990's*. Ashland, OH:
32
33 Hogrefe & Huber.
34
35
36 Hjelmstedt, A., Widström, A. M., Wramsby, H., & Collins, A. (2004). Emotional adaptation
37
38 following successful in vitro fertilization. *Fertility and Sterility*, *81*, 1254–1264.
39
40
41 doi:10.1016/j.fertnstert.2003.09.061
42
43
44 Holter, H., Anderheim, L., Bergh, C., & Moller, A. (2006). First IVF treatment—short-term
45
46 impact on psychological well-being and the marital relationship, *Human Reproduction*,
47
48 *21*, 3295–3302. doi:10.1093/humrep/del288
49
50
51 Inhorn, M. C. (2015). *Cosmopolitan conceptions: IVF sojourns in global Dubai*. Durham, NC:
52
53 Duke University Press.
54
55
56
57
58
59
60

RESPONDING TO INFERTILITY

30

- 1
2
3
4
5
6
7
8
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40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
- Jacob, M. C., McQuillan, J., & Greil, A. L. (2007). Psychological distress by type of fertility barrier. *Human Reproduction*, *22*, 885–894. doi:10.1093/humrep/del452
- Johnson, K. M., McQuillan, J., Greil, A. L., & Shreffler, K. M. (2014). Towards a more inclusive framework for understanding fertility barriers. In M. Nash (Ed.), *Reframing reproduction* (pp. 23–38). London, England: Palgrave Macmillan.
- Jordan, C. B., & Ferguson, R. J. (2006). Infertility-related concerns in two family practice sites. *Families, Systems and Health*, *24*, 1, 28–32. doi:10.1037/1091-7527.24.1.28
- Katz, P., Showstack, J., Smith, J. F., Nachtigall, R. D., Millstein, S. G., Wing, H. . . . Adler, N. (2011). Costs of infertility treatment: Results from an 18-month prospective cohort study. *Fertility and Sterility*, *95*, 915–921. doi:10.1016/j.fertnstert.2010.11.026
- Kazyak, E., Park, N., McQuillan, J., & Greil, A. L. (2016). Attitudes toward motherhood among U.S. sexual minority women. *Journal of Family Issues*, *37*, 1771–1796. doi:10.1177/0192513X14554396
- Kessler, L. M., Craig, B. M., Plosker, S. M., Reed, D. R., Quin, G. P. (2013). Infertility evaluation and treatment among women in the United States. *Fertility and Sterility*, *100*, 1025–1032. doi:10.1016/j.fertnstert.2013.05.040
- Laurent, S. L., Thompson, S. J., Addy, C., Garrison, C. Z., & Moore, E. E. (1992). An epidemiologic study of smoking and primary infertility in women. *Fertility and Sterility*, *57*, 565–72. doi:10.1016/S0015-0282(16)54901-2
- Letherby, G. (1999). Other than mother and mothers as others: The experience of motherhood and non-motherhood in relation to “infertility” and “involuntary childlessness.” *Women’s Studies International Forum*, *22*, 359–372. doi:10.1016/S0277-5395(99)00028-X

RESPONDING TO INFERTILITY

31

- 1
2
3 Loftus, J., & Andriot, A. L. (2012). "That's what makes a woman": Infertility and coping with a
4 failed life course transition. *Sociological Spectrum*, *32*, 226–243.
5
6 doi:10.1080/02732173.2012.663711
7
8
9
10 Macaluso, M., Wright-Schnapp, T. J., Chandra, A., Johnson, R., Satterwhite, C. L., Pulver, A.
11 . . . Pollack, L. A. (2010). A public health focus on infertility prevention, detection, and
12 management. *Fertility and Sterility*, *93*, e1–e16. doi:10.1016/j.fertnstert.2008.09.046
13
14
15
16
17 Matthews, R., & Matthews, A. M. (1986). Infertility and involuntary childlessness: The
18 transition to nonparenthood. *Journal of Marriage and the Family*, 641–649.
19
20 doi:10.2307/352050
21
22
23
24 McQuillan, J., Greil, A. L., & Shreffler, K. M. (2011). Pregnancy intentions among women who
25 do not try: Focusing on women who are okay either way. *Maternal and Child Health*
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
- McQuillan, J., Greil, A. L., Shreffler, K. M., & Tichenor, V. (2008). The importance of
motherhood among women in the contemporary United States. *Gender & Society*, *22*,
477–496. doi:10.1177/0891243208319359
- McQuillan, J., Greil, A. L., White, L., & Jacob, M. C. (2003). Frustrated fertility: Infertility and
psychological distress among women. *Journal of Marriage & Family*, *65*, 1007–1018.
- McQuillan, J., Stone, R. A. T., & Greil, A. L. (2007). Infertility and life satisfaction among
women. *Journal of Family Issues*, *28*, 955–981. doi:10.1177/0192513X07300710
- Musick, K., England, P., Edgington, S., & Kangas, N. (2009). Education differences in intended
and unintended fertility. *Social Forces*, *88*, 543–572. doi:10.1353/sof.0.0278
- Norre, J., & Wischmann, T. (2011). The position of the fertility counsellor in a fertility team: A
critical appraisal. *Human Fertility*, *14*, 154–159. doi:10.3109/14647273.2011.580824

RESPONDING TO INFERTILITY

32

- 1
2
3 Ozkan, B., Orhan, E., Aktas, N., & Coskuner, E. R. (2016). Sexual dysfunction and depression
4 among Turkish women with infertile husbands: The invisible part of the iceberg.
5
6 *International Urology and Nephrology*, 48, 31–36. doi:10.1016/j.urology.2015.03.005
7
8
9
10 Park, N. K., & Wonch Hill, P. (2014). Is adoption an option? The role of importance of
11 motherhood and fertility help-seeking in considering adoption. *Journal of Family Issues*,
12
13 35, 601–626. doi:10.1177/0192513X13493277
14
15
16
17 Peddie, V. L., van Teijlingen, E., & Bhattacharya, S. (2005). A qualitative study of women's
18 decision-making at the end of IVF treatment. *Human Reproduction*, 20, 1944–1051.
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
- Peterson, B. D., Pirritano, M., Block, J. M., & Schmidt, L. (2011). Marital benefit and coping strategies in men and women undergoing unsuccessful fertility treatments over a 5-year period. *Fertility and Sterility*, 95, 1759–1763. doi:10.1016/j.fertnstert.2011.01.125
- Peterson, B. D., Pirritano, M., Tucker, L., & Lampic, C. (2012). Fertility awareness and parenting attitudes among American male and female undergraduate university students. *Human Reproduction*, 27, 1375–1382. doi:10.1093/humrep/des011
- Pinborg, A., Hougaard, C. O., Nyboe Andersen, A., Molbo, D., & Schmidt, L. (2009). Prospective longitudinal cohort study in cumulative 5-year delivery and adoption rates among 1338 couples initiating infertility treatment. *Human Reproduction*, 24, 991–999. doi:10.1093/humrep/den463
- Piva, I., Lo Monte, G., Graziano, A., & Marci, R. (2014). A literature review on the relationship between infertility and sexual dysfunction: Does fun end with baby making? *The European Journal of Contraception and Reproductive Health Care*, 19, 231–237. doi:10.3109/13625187.2014.919379

RESPONDING TO INFERTILITY

33

Practice Committee of the American Society for Reproductive Medicine. (2016). Aging and infertility in women. *Fertility & Sterility*, *86*, S248–S252.

doi:10.1016/j.fertnstert.2006.08.02

Price, S. K. (2006). Prevalence and correlates of pregnancy loss history in a national sample of children and families. *Maternal and Child Health Journal*, *10*, 489–500.

doi:10.1371/journal.pone.0095708

Ramlau-Hansen, C. H., Thulstrup, A. M., Nohr, E. A., Bonde, J. P., Soerensen, T. I., & Olsen, J. (2007). Subfecundity in overweight and obese couples. *Human Reproduction*, *22*, 1634–

1637. doi:10.1093/humrep/dem035

Redshaw, M., Hockley, C., & Davidson, L. L. (2007). A qualitative study of the experience of treatment for infertility among women who successfully became pregnant. *Human*

Reproduction, *22*, 295–304. doi:10.1093/humrep/del344

Repokari, L., Punamäki, R. L., Unkila-Kallio, L., Vilska, S., Poikkeus, P., Sinkkonen, J. . . .

Tulppala, M. (2007). Infertility treatment and marital relationships: A 1-year prospective study among successfully treated ART couples and their controls, *Human Reproduction*, *22*, 1481–1491. doi:10.1093/humrep/dem013

Reproductive Endocrinology and Infertility Committee. (2012). Advanced reproductive age and fertility. *International Journal of Gynecology and Obstetrics*, *117*, 95–102.

doi:10.1016/j.ijgo.2011.11.002

Reproductive Medicine Associates of New Jersey. (2015). *Infertility in America: 2015 survey and report*. Basking Ridge, NJ: Reproductive Medicine Associates. Retrieved from

<http://www.rmanj.com/2015/04/infertility-in-america-2015-survey-report>

RESPONDING TO INFERTILITY

34

- 1
2
3 Schmidt, L., Sobotka, T., Bentzen, J. G., & Andersen, A. N. (2012). Demographic and medical
4
5 consequences of the postponement of parenthood. *Human Reproduction Update*, 18, 29–
6
7 43. doi:10.1093/humupd/dmr040
8
9
- 10 Scholes, D., Stergachis, A., Heidrich, F. E., Andrilla, H., Homes, K. K., & Stamm, W. E. (1996).
11
12 Prevention of pelvic inflammatory disease by screening for cervical chlamydial infection.
13
14 *New England Journal of Medicine*, 334, 1362–1366.
15
16 doi:10.1056/NEJM199605233342103
17
18
- 19 Schwerdtfeger, K. L., & Shreffler, K. M. (2009). Trauma of pregnancy loss and infertility for
20
21 mothers and involuntarily childless women in the contemporary United States. *Journal of*
22
23 *Loss and Trauma*, 14, 211–227. doi:10.1080/15325020802537468
24
25
- 26 Shreffler, K. M., Greil, A. L., & McQuillan, J. (2011). Pregnancy loss and distress among U.S.
27
28 women. *Family Relations*, 60, 342–355. doi:10.1111/j.1741-3729.2011.00647.x
29
30
- 31 Shreffler, K. M., Hill, P. W., & Cacciatore, J. (2012). Explaining increased odds of divorce
32
33 following miscarriage or stillbirth. *Journal of Divorce and Remarriage*, 53, 91–107.
34
35 doi:10.1080/10502556.2012.651963
36
37
- 38 Shreffler, K. M., Johnson, D. R., & Scheuble, L. K. (2010). Ethical problems with infertility
39
40 treatments: Attitudes and explanations. *The Social Science Journal*, 47, 731–746.
41
42 doi:10.1016/j.soscij.2010.07.012
43
44
- 45 Shreffler, K. M., McQuillan, J., Greil, A. L., & Johnson, D. R. (2015). Surgical sterilization,
46
47 regret, and race: Contemporary patterns. *Social Science Research*, 50, 31–45.
48
49 doi:10.1016/j.ssresearch.2014.10.010
50
51
52
53
54
55
56
57
58
59
60

RESPONDING TO INFERTILITY

- 1
2
3 Shreffler, K. M., Tiemeyer, S., Dorius, C., Greil, A. L., McQuillan, J., & Spierling, T. (2016).
4
5 Infertility and fertility intentions, desires, and outcomes among U.S. women.
6
7
8 *Demographic Research*, 35, 1149–1168. doi:10.4054/DemRes.2016.35.39
9
- 10 Slauson-Blevins, K. S., & Park, N. K. (2016). Deciding not to adopt: The role of normative
11
12 family ideologies in adoption consideration. *Adoption Quarterly*, 19, 237–260.
13
14
15 doi:10.1080/10926755.2015.1121185
16
- 17 Sundby, J., Schmidt, L., Heldaas, K., Bugge, S., & Tanbo, T. (2007). Consequences of IVF
18
19 among women: 10 years post-treatment. *Journal of Psychosomatic Obstetrics &*
20
21
22 *Gynecology*, 28, 115–120. doi:10.1080/01674820701447447
23
- 24 Swan, S. H., Elkin, E. P., & Fenster, L. (2000). The question of declining sperm density
25
26 revisited: An analysis of 101 studies published 1934–1996. *Environmental Health*
27
28
29 *Perspectives*, 108, 961–966.
30
- 31 Thonneau, P., Marchand, S., Tallec, A., Ferial, M. L., Ducot, B., Lansac, J. . . . Spira, A. (1991).
32
33 Incidence and main causes of infertility in a resident population (1,850,000) of three
34
35 French regions (1988–1989). *Human Reproduction*, 6, 811–816.
36
37
- 38 Thorn, P. (2009). Understanding infertility: Psychological and social considerations from a
39
40 counselling perspective. *International Journal of Fertility and Sterility*, 3(2), 48–51.
41
42
- 43 Thornton, A., & Young-DeMarco, L. (2001). Four decades of trends in attitudes toward family
44
45 issues in the United States: The 1960s through the 1990s. *Journal of Marriage and*
46
47
48 *Family*, 63, 1009–1037. doi:10.1111/j.1741-3737.2001.01009.x
49
- 50 Tichenor, V., McQuillan, J., Greil, A. L., Contreras, R., & Shreffler, K. M. (2011). The
51
52 importance of fatherhood to US married and cohabiting men. *Fathering*, 9, 232–251.
53
54
55
56
57
58
59
60

RESPONDING TO INFERTILITY

36

- 1
2
3 van den Akker, O. (2004). Coping, quality of life and psychological symptoms in three groups of
4
5 sub-fertile women. *Patient Education and Counseling*, *57*, 183–189.
6
7 doi:10.1016/j.pec.2004.05.012
8
9
- 10 Van den Broeck, U., Holvoet, L., Enzlin, P., Bakelants, E., Demyttenaere, K., & D'Hooghe, T.
11
12 (2009). Reasons for dropout in infertility treatment. *Gynecologic and Obstetric*
13
14 *Investigation*, *68*, 58–64. doi:10.1159/000214839
15
16
- 17 Van Voorhis, B. J. (2006). Outcomes from assisted reproductive technology. *Obstetrics and*
18
19 *Gynecology*, *107*, 183–200. doi:10.1097/01.AOG.0000194207.06554.5b
20
21
- 22 Verhaak, C. M., Smeenk, J. M. J., Evers, A. W. M., Kremer, J. A. M., Kraaimaat, F. W., &
23
24 Braat, D. D. M. (2007). Women's emotional adjustment to IVF: A systematic review of
25
26 25 years of research. *Human Reproduction Update*, *13*, 27–36.
27
28 doi:10.1093/humupd/dml040
29
30
- 31 Wagner, J., Wrzus, C., Neyer, F. J., & Lang, F. R. (2015). Social network characteristics of early
32
33 midlife voluntarily and involuntarily childless couples. *Journal of Family Issues*, *36*, 87–
34
35 110. doi:10.1177/0192513X13490931
36
37
- 38 Whatley, M., Jahangardi, J. N., Ross, R. & Knox, D. (2003). College students' attitudes toward
39
40 transracial adoption. *College Student Journal*, *37*, 323–326. Retrieved from
41
42 http://projectinnovation.biz/csj_2006.html
43
44
- 45 White, L., McQuillan, J., & Greil, A. L. (2005). Explaining disparities in treatment seeking: The
46
47 case of infertility. *Fertility and Sterility*, *85*, 853–857.
48
49 doi:10.1016/j.fertnstert.2005.11.039
50
51
- 52 White, L., McQuillan, J., Greil A. L., & Johnson, D. R. (2006). Infertility: Testing a helpseeking
53
54 model. *Social Science & Medicine*, *62*, 1031–1041. doi:10.1016/j.socscimed.2005.11.012
55
56
57
58
59
60

RESPONDING TO INFERTILITY

37

- 1
2
3 Wildsmith, E., Guzzo, K. B., Hayford, S. R. (2010). Repeat unintended, unwanted, and seriously
4
5 mistimed childbearing in the United States. *Perspectives on Sexual and Reproductive*
6
7 *Health, 42*, 14–22. doi:10.1363/4201410
8
9
- 10 Wilson, K. J. (2014). *Not trying: Infertility, childlessness, and ambivalence*. Nashville, TN:
11
12 Vanderbilt University Press.
13
14
- 15 Wirtberg, I., Moller, A., Hogström, L., Tronstad, S. E., & Lalos, A. (2007). Life 20 years after
16
17 unsuccessful infertility treatment. *Human Reproduction, 22*, 598–604.
18
19 doi:10.1093/humrep/del401
20
21
- 22 Wischmann, T., Stammer, H., Scherg, H., Gerhard, I., & Verres, R. (2001). Psychosocial
23
24 characteristics of infertile couples: A study by the “Heidelberg fertility consultation
25
26 service.” *Human Reproduction, 16*, 1753–1761. doi:10.1093/humrep/16.8.1753
27
28
- 29 Zegers-Hochschild, F., Adamson, G. G., de Mouzon, J., Ishihara, O., Mansour, R., Nygren, K.
30
31 . . . van der Poel, S. (2009). The International Committee for Monitoring Assisted
32
33 Reproductive Technology (ICMART) and the World Health Organization (WHO)
34
35 revised glossary in ART terminology, 2009. *Human Reproduction, 24*, 2683–2687.
36
37
38
39 doi:10.1016/j.fertnstert.2009.09.009
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
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