COURSE #91522 — 5 CONTACT/CLOCK HOURS RELEASE DATE: 07/01/22 EXPIRATION DATE: 06/30/25

Couples with Infertility: Sociocultural Considerations

HOW TO RECEIVE CREDIT

- Read the enclosed course.
- Complete the questions at the end of the course.
- Return your completed Evaluation to NetCE by mail or fax, or complete online at www.NetCE.com. (If you are a behavioral health professional or Florida nurse, please return the included Answer Sheet/Evaluation.) Your postmark or facsimile date will be used as your completion date.
- Receive your Certificate(s) of Completion by mail, fax, or email.

Faculty
Alice Yick Flanagan, PhD, MSW, received her Master's in Social Work from Columbia University, School of Social Work. She has clinical experience in mental health in correctional settings, psychiatric hospitals, and community health centers. In 1997, she received her PhD from UCLA, School of Public Policy and Social Research. Dr. Yick Flanagan completed a year-long post-doctoral fellowship at Hunter College, School of Social Work in 1999. In that year she taught the course Research Methods and Violence Against Women to Masters degree students, as well as conducting qualitative research studies on death and dying in Chinese American families. (A complete biography appears at the end of this course.)

Faculty Disclosure
Contributing faculty, Alice Yick Flanagan, PhD, MSW, has disclosed no relevant financial relationship with any product manufacturer or service provider mentioned.

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Division Planner/Director Disclosure
The division planner and director have disclosed no relevant financial relationship with any product manufacturer or service provider mentioned.

Audience
This course is designed for social workers, therapists, mental health counselors, nurses, and other members of the interprofessional team who work with couples from diverse racial and ethnic minority groups who are experiencing infertility.

Accreditations & Approvals

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NetCE designates this continuing education activity for 5 ANCC contact hours.

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Social Workers participating in this intermediate to advanced course will receive 5 Clinical continuing education clock hours.

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The purpose of NetCE is to provide challenging curricula to assist healthcare professionals to raise their levels of expertise while fulfilling their continuing education requirements, thereby improving the quality of healthcare.

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Course Objective

Given the ever-increasing multicultural diversity in the landscape of the United States, the provision of culturally competent and sensitive practice is vital. The purpose of this course is to provide an overview of how culture influences how individuals view children, fertility, and the causes of infertility and how couples seek help and cope with the challenges of infertility. By increasing their knowledge in this area, practitioners can develop greater cultural sensitivity, promote rapport and trust among practitioners and clients, and reduce the possibility of early termination of services.

Learning Objectives

Upon completion of this course, you should be able to:

1. Define infertility and other terms associated with infertility.
2. Discuss the scope of infertility among women in the United States and worldwide.
3. Identify culture, race, and ethnicity, and outline demographic trends of different racial and ethnic groups in the United States.
4. Explain the medicalization of infertility.
5. Describe the cultural values of womanhood, family, and having children and how this affects the social construction of infertility.
6. Discuss how various cultural groups ascribe meaning to infertility and fertility.
7. Describe different help-seeking patterns in response to infertility.
8. Identify psychologic and social consequences of infertility and how culture influences coping patterns.
9. Evaluate racial and ethnic disparities in infertility treatment.
10. Discuss best practice guidelines for assessments and interventions for couples who are experiencing infertility.

Sections marked with this symbol include evidence-based practice recommendations. The level of evidence and/or strength of recommendation, as provided by the evidence-based source, are also included so you may determine the validity or relevance of the information. These sections may be used in conjunction with the course material for better application to your daily practice.

INTRODUCTION

The topic of infertility has increasingly evolved from being considered a private issue to a more public medical topic. All health conditions are socially constructed; however, infertility is an example of a highly socially constructed problem, influenced by layers of contextual factors, including culture, socioeconomic status, societal expectations, family, and individual factors [1]. Ultimately, infertility is a sensitive and difficult topic. Developing trust and rapport with clients who are facing barriers to getting pregnant is not without its challenges. This can be further exacerbated when working with clients from different cultural groups, because when communication styles, patterns, and differences are perceived to be irreconcilable, clients are more likely to terminate treatment prematurely. Disciplines such as nursing, social work, counseling, and mental health have called for more holistic assessment and interventions that encompass the physical, psychological, social, spiritual/religious, and emotional. Consequently, it is imperative to take into account the cultural background of clients when creating and/or implementing treatment plans for infertility [2].

This course will provide an overview of the cultural context of infertility. Intertwined in this will be discussion of how women and children are viewed by different cultures and the various cultural meanings of infertility. Regardless of the sociocultural background of a couple experiencing infertility, it can be emotionally draining and can add strain to the relationship. Many couples with infertility go through a grieving process as they wrestle with the loss of a dream to have a child, to be a parent, and/or to live their ideal future. Others experience significant stigma, what some have termed an "invisible shame" [3]. This course will also discuss the intersection of culture in coping and help-seeking patterns. Finally, culturally sensitive interprofessional practice and intervention guidelines are offered.

As a side note, this course will focus on infertility among heterosexual couples and individuals, particularly women. Infertility that arises in same-sex couples is associated with unique factors and impact on one's perceived identity and role in society, and addressing these factors is beyond the scope of this course. It is possible that some information will be applicable to both groups.

DEFINITIONS

It is important to define the terminology used to discuss infertility, as many variations in meaning exist and even the definition of infertility is complex. These variations may be influenced by the sociopolitical climate, technologic advances, and/or advances in reproductive health. Because of the varying definitions, prevalence estimates of infertility range from 1.8% to 47.7% [134]. Medically, infertility is defined as a woman's inability to become pregnant after 12 continuous months of attempting (i.e., unprotected sex with the same male partner) [4]. The World Health Organization defines infertility as a disease with associated disability and functional impairment [135]. It can be further classified as primary infertility, secondary infertility, impaired fecundity, or subfertility. Primary infertility refers to not having children and not being able to conceive after one year of unprotected sex; secondary infertility is the inability to conceive after at least one other pregnancy or live birth [5; 135]. When defining infertility in women, the term is sometimes also loosely applied to those unable to carry a pregnancy to full term; however, the term "impaired fecundity" (i.e., infertility and failure to carry to term combined) is more accurate [6]. It is estimated that 7.4 million women in the United States are affected by impaired fecundity [39]. Subfertility is defined as reduced fertility with an extended period of non-conception—usually longer than six months but less than one year. In some cases, two individuals with subfertility may result in an infertile couple [7]. Ultimately, to define a problem as the inability to produce a certain outcome is problematic because it places less

emphasis on the underlying risk factors, which can then cloud efforts to prevent or clinically manage the disorder [8].

Another perspective involves the couple's perception of themselves as infertile or not [1]. Implicit in the medical definition of infertility is the seeking of treatment, as these are individuals who acknowledge there is a problem and who are diagnosed [9]. The social construction of infertility also impacts the definition and will be explored in detail later in this course.

SCOPE OF THE PROBLEM

The World Health Organization has estimated that there are between 48 million and 186 million people who have experienced infertility issues worldwide [42]. Worldwide, estimates for infertility range between 8% and 12% [135]. In parts of Asia, Europe, Africa, and the Middle East, the prevalence is higher, up to 30% in some places [135]. In the United States, 12.1% of women between 15 and 44 years of age have an impaired ability to carry a pregnancy to full term (impaired fecundity) [10]. In addition, 19.4% of women 15 to 49 years of age are classified as infertile (defined as 12 consecutive months of unprotected sex without resulting in pregnancy without a history of surgical sterility) [4]. The likelihood of infertility/impaired fecundity increases with age in women. An estimated 26.2% of women 40 to 44 years of age are considered infertile, compared with 23% of women 35 to 39 years of age and 11% of women 30 to 34 years of age [10].

In a systematic review of population studies worldwide, the 12-month prevalence rate of infertility in developed countries ranged from 3.5% to 16.7%, compared with prevalence rates of 6.9% to 9.3% in developing nations [11]. Compared with other Hispanic subgroups, Mexican women tend to have higher fertility rates, with foreign-born women displaying higher fertility rates compared with those born in the United States [12]. According to the U.S. Census Bureau, Hispanic Americans (with the exception of Cuban Americans) tend to have a higher rate of recent fertility compared with non-Hispanic White Americans after controlling for poverty, education, age and marital status [136]. A separate study found that, compared to the general population, African American women had a 45% higher prevalence of infertility and Alaskan Indian women had a 37% higher prevalence of infertility. Black women also tend to undergo longer durations of infertility before seeking treatment compared with White women [13]. In general, Black and Hispanic women try conceiving an average of 18 months longer than White women before seeking medical help [14].

CULTURE, RACE, AND ETHNICITY

Culture has been conceptualized as a diversity domain, characterized by having different value systems, norms, and social and behavioral patterns [43]. Specifically, culture refers to the values and knowledge of groups in a society; it consists of approved behaviors, norms of conduct, and value systems [15; 16]. Culture involves attitudes and beliefs that are passed from generation to generation within a group. These patterns include language, religious beliefs, institutions, artistic expressions, ways of thinking, and patterns of social and interpersonal relations [17]. Culture can also represent worldviews—encompassing assumptions and perceptions about the world and how it works [18]. Culture has two components: the observable and the unobservable [52]. The observable include things such as language, customs, and specific practices, while the unobservable include beliefs, norms, and value systems. Culture helps to elucidate why groups of people act and respond to the environment as they do [19].

On the other hand, race is linked to biology. Race is partially defined by physical markers, such as skin or hair color [20]. It does not refer to cultural institutions or patterns, but it is generally utilized as a mechanism for classification. In modern history, skin color has been used to classify people and to imply that there are distinct biologic differences within populations [21]. Historically, the census in the United States defined race according to ancestry and blood quantum; today, it is based on self-classification. Racial characteristics are also assigned differential power and privilege, lending to different statuses among groups [22]. The American Anthropological Association defines race as "an ideology of human differences" which then "became a strategy for dividing, ranking, and controlling colonized people" [110].

Ethnicity is also a complex phenomenon and has been defined in many different ways. Alba identified four components of ethnicity [23]:

- Social class
- Political process
- Traditions
- Symbolic token

When ethnicity is viewed as social class, the individual's ethnicity is compared to or equated with their socioeconomic class (e.g., working class or lower class). This is most clear in ethnic enclaves, the residents of which have strong cultural and familial ties [24].

Ethnicity may also be associated with persecution, both political and social. Ethnic unity may serve as a tool for social change and political reform [24]. Several famous ethnic movements took place in the 1960s, such as the unification of farm workers headed by César Chávez. Ethnicity has also been viewed as a return to traditions, characterized by a renewed interest in ethnic foods, traditional religious practices, native language, and folklore [24]. Finally, ethnicity is also acknowledged as being a symbolic token, a way for individuals to maintain a nostalgic connection to their homeland [24].

The role of race, ethnicity, and culture in the development of health disparities is controversial. Although a discussion of the many causes of health disparities is beyond the scope of this course, it is important to know that it is a complex, multifaceted issue rooted in biologic vulnerabilities, differential access to resources, environmental conditions, and a range of social, cultural, and economic factors [25]. Some of these factors will arise when discussing help-seeking for infertility.

THE INCREASINGLY DIVERSE LANDSCAPE IN THE UNITED STATES

According to U.S. Census data, the minority population is growing each year. By 2060, the minority population is expected to increase to 241 million, with the Hispanic population growing by 142%, the Asian population by 116%, and African American population by 50% [26]. Hawaii, New Mexico, California, the District of Columbia, and Texas are regions in the United States that consist of a "majority-minority," meaning that more than half of the areas' populations consist of individuals who are an ethnicity other than non-Hispanic White [27]. In California, for example, 39% of the population is Latino while 35% are White [137]. With the increase of immigration and the slower birth rate in White families, it is anticipated that the United States is rapidly moving toward becoming a majority-minority [27]. According to 2020 U.S. Census data, 40% of Americans identify as multi-race (one or more racial/minority group) [160].

AFRICAN AMERICANS

"African American" is a classification that serves as a descriptor; it has sociopolitical and self-identification ramifications. The U.S. Census Bureau defines African Americans or Black persons as "having origins in any of the Black racial groups of Africa" [29].

According to the U.S. Census, African Americans number 48.2 million as of 2019 [30]. By 2060, it is projected they will comprise 17.9% of the U.S. population [30]. This group tends to be young; 30% of the African American population in the United States is younger than 18 years of age. In 2019, the median age for this group was 35 years [161]. In terms of educational attainment, in 2019, 87.9% of those 25 years of age and older have a high school diploma [30].

ASIAN AMERICANS

As of 2019, 22.9 million Americans identified as Asian [138]. California has the largest concentration of Asian residents (6.5 million) followed by New York (1.8 million) [138]. This group had the highest growth rate between 2000 and 2019 (81%) of any racial/ethnic group [162]. Chinese Americans represent the largest Asian subgroup in the United States, and it is projected that this population will grow to 35.7 million between 2015 and 2040 [32; 33]. They also have the highest educational attainment of any racial/ethnic group, with 54.6% of Asian Americans 25 years of age and older having a bachelor's degree or higher in 2019 [138].

"Asian" is a single term widely used to describe individuals who have kinship and identity ties to Asia, including the Far East, Southeast Asia, and the Indian subcontinent [34]. This encompasses countries such as China, Japan, Korea, Vietnam, Cambodia, Thailand, India, Pakistan, and the Philippines. Pacific Islander is often combined with Asian American in census data. The Pacific Islands include Hawaii, Guam, Samoa, Fiji, and many others [34]. There are more than 25 Asian/Pacific Islander groups, each with a different migration history and widely varying sociopolitical environments in their homelands [35].

Asian American groups have differing levels of acculturation, lengths of residency in the United States, languages, English-speaking proficiency, education attainment, socioeconomic statuses, and religions. For example, there are approximately 32 different languages spoken among Asian Americans, and within each Asian subgroup (e.g., Chinese), multiple dialects may be present [35; 36].

HISPANICS/LATINOS

The term "Hispanic" refers to individuals who self-identify as having origins in Spain or Spanish-speaking countries, such as Mexico, Guatemala, Peru, Ecuador, or the Dominican Republic [37]. In 2019, there were 60.6 million Hispanic persons in the United States [163]. The majority of the Hispanic population in the United States (63.3%) identify themselves as being of Mexican descent [38]. Approximately 27% of the U.S. Hispanic population identify as Puerto Rican, Cuban, Salvadoran, Dominican, Guatemalan, Colombian, Honduran, Ecuadorian, or Peruvian [38].

In 2010, Hispanic Americans represented 16% of the U.S. population; by 2019, this increased to 18% of the U.S. population [164]. It is estimated that Hispanics will comprise 31% of the U.S. population by 2060 [28]. In 2019, the three states (Texas, California, and Florida) with the largest Hispanic population also had the most growth [164].

NATIVE AMERICANS

The Native American population is extremely diverse. According to the U.S. Census, the terms "Native American," "American Indian," or "Alaskan Native" refer to individuals who identify themselves with tribal attachment to indigenous groups of North and South America [41]. In the United States, there are 574 federally recognized tribal governments [41].

In 2019, it was reported that there were 6.9 million Native Americans in the United States, which is approximately 2% of the U.S. population [41]. By 2060, this number is projected to increase to 10.2 million, or 2.4% of the total population [41].

In general, this group is young, with a median age of 31 years, compared with the general median age of 37.9 years. As of 2019, the 10 states with the greatest number of residents identifying as Native American are Arizona, California, New York, Alaska, Oklahoma, New Mexico, South Dakota, Texas, North Carolina, and Montana [U.S. Department of Health and Human Services, Office of Minority Health, 2022]. In 2019, this group had the highest poverty rate (24.1%) of any racial/ethnic group [41].

MEDICALIZATION OF INFERTILITY

Medicalization refers to the migration of social problems to the realm of biomedicine and the healthcare system. The problem is then considered a disease and authorized agents (e.g., physicians, nurses) are involved in diagnosing, treating, and monitoring the patient [9; 44; 139; 165].

Prior to the 1960s, infertility was viewed as a condition with moral and emotional connotations [139]. However, infertility became a medical condition in the 1960s and 1970s as the result of significant events in the medical landscape [45; 139]:

- The introduction of hormonal birth control and associated ability to control reproduction
- The rise of diagnostic laparoscopy and improved visualization of the female reproductive system
- The increase in the number of trained gynecologists and obstetricians
- The decline in fertility rates

Simultaneously, a series of social forces impacted the medicalization of infertility. More women entered the workforce and delayed having children. The rate of sexually transmitted infections increased as a result of expanded sexual freedom (i.e., the "sexual revolution") [45]. Advances in birth control gave individuals greater control over the timing of conception. Scritchfield asks: "What happens when pregnancy does not occur on schedule? How are believers in personal efficacy, planning, and the achievement ethic likely to respond? They look toward infertility as a medical condition, and they forget that biology is not always, or even usually, so amenable to human control and intent" [46].

Clinical terms have been developed to describe the physiologic factors underlying infertility, such as cervical insufficiency and low sperm count [9; 44; 45; 47]. With the medicalization of infertility came the increasingly feminized perspective of the "disease." Although male infertility has also been medicalized, infertility is typically framed as a woman's problem, and this course will primarily focus on infertility in women [46]. Clinical terms typically used often allude to failures or even violence in women's bodies, including "hostile cervical mucus," "blocked Fallopian tubes," "incompetent cervix," and "failure to conceive" [48]. Medicalizing infertility typically places the blame on a biological factor, which can move the attention away from the patient as being damaged [165].

The biomedical perspective dominates health practices in Western medicine, and it advocates the disease model, which focuses on biologic dysfunction and symptoms [49]. Within this model, the physician handles the care of the patient and legitimizes that the disease is present [49]. The Western biomedical model adheres to a reductionist and empirically based disease model, emphasizing the diagnosis and treatment of disease using immunizations, antimicrobial medications, and other medical interventions [50]. This model is considered objective and more scientific.

There are some benefits when conditions become medicalized. If a problem is considered a medical condition, it can raise the status of the "patient," particularly when the condition is ambiguous and impacts an individual's ability to conform to social and cultural norms [44]. Infertility is ambiguous in the sense that there are usually no specific symptoms (other than an inability to conceive), and it prevents individuals from adhering to cultural/societal norms regarding parenthood and family. A woman can point to the disease (rather than some essential flaw in herself) as the cause of the infertility [44]. This gives women permission to adopt the sick role, and the behaviors and feelings of the "sick" individual are legitimized [51].

SOCIAL CONSTRUCTION OF INFERTILITY, WOMANHOOD, AND FAMILY

Definitions of infertility and the perspectives surrounding its etiology and treatment are socially constructed and politically charged. In the case of infertility, its social construction is influenced by notions of femininity, womanhood, children, and family. This section will discuss the social construction of infertility in Western society, particularly the United States.

INFERTILITY

As noted, infertility is predominantly constructed as a women's disorder despite the fact that about half of all cases involving an inability to conceive are due to male factor infertility [166]. Because reproduction has been placed solely in women's realm, men are often excluded from discussions of infertility and reproductive care has been feminized [139]. In general, women who are childless are viewed as social anomalies in Western cultures; the same is generally not true for men [53].

A woman who is diagnosed with infertility is often viewed as flawed or tragically broken; women who voluntarily opt not to have children are often seen as selfish and uncaring [53]. In non-Western countries, hyperfertility is considered a more pressing issue, as policymakers are more concerned with rapidly growing population rates [54; 55]. When infertility in the non-Western context is discussed, it is conceptualized as "barrenness among plenty" [55]. In a similar vein, social class impacts this view of hyperfertility in Western cultures. In the United States, poor women tend to be viewed as overly fertile and irresponsible, while more economically advantaged women are depicted as not being able to have children due to medical reasons [51].

Social problems do not emerge within an objective vacuum [56]. Instead, people make assertions and shape their views about certain conditions by typifying or depicting the nature of the social problem (e.g., large and growing, the result of negligence) [56]. Sangster and Lawson conducted a content analysis of 157 news articles about infertility published in 2012 in Canada [47]. Half of the articles described infertility using alarm terminology, depicting it as a public health concern that warranted consternation [47]. In a study examining women's perceptions of the risk of infertility, women who read more articles about women who became pregnant in their late 30s overestimated the risk [57].

Another way social problems are characterized is by tracing the cause(s) of the problem and identifying solutions. Slightly more than 40% of the articles analyzed by Sangster and Lawson constructed infertility as the result of a choice to delay childbearing, and 46% of the articles portrayed in vitro fertilization as the recommended course of treatment [47]. In other countries, the media may link women's infertility to sexual promiscuity, abortion, or having children outside of marriage.

The language of infertility can also be a source of bias. Terms such as "barren" and "sterile" convey a level of inadequacy [48]. As discussed, Western societies tend to embrace the biomedical model of infertility. This in part stems from cultural values that emphasize individualism and personal responsibility. In general, Americans tend to believe that they will be able to overcome obstacles through will power and determination. In the case of infertility, technology and medicine are the main tools to "overcome" infertility [59].

How a condition is defined and the parties involved in creating that definition can give a glimpse of the underlying values. For example, in some states (e.g., Rhode Island) infertility is defined as the condition of being unable to get pregnant or to carry a pregnancy among a married couple [140]. This definition relies on heteronormativity, as women who are married in a heterosexual relationship fit more easily into the definition [140].

The process of diagnosing and treating infertility is largely private in the United States. As of 2019, 17 states require insurance coverage for infertility treatment [167]. However, in non-Western countries, infertility is considered a community tragedy, rather than an individual one, and it is experienced by all members of the community [60]. In some cultures, particularly in Asian families, not having children is an affront to filial piety and a disruption of the social security net [61].

WOMANHOOD, MOTHERHOOD, AND PRONATALISM

Notions of womanhood and motherhood are intertwined, despite the progress women have made in academic and professional spheres and the advancements in medical technology allowing for greater reproductive freedom. It remains expected for women in both Western and non-Western societies to move through life as daughters, then wives, and finally mothers. Motherhood is the socially respected identity for women [62]. An inability (or unwillingness) to meet the "motherhood mandate" upsets the social order and signifies defectiveness [63]. In some cases, these norms are closely linked to religious beliefs. For example, some religions focus on motherhood (or parenthood in general) as a mandate and fulfillment of God's ordinance [168].

It is important to note that this supports social heteronormativity and the idealization of marriage [140]. These gender role expectations are developed and reinforced through the performance of gender (i.e., behaving in a way that meets gender role expectations). In an interview study of 40 women experiencing infertility, the participants reported being unable to participate in typical interactions with other women, because conversations often centered around experiences raising children [63]. As a result, the women felt the infertility had removed their ability to be mothers but also threatened their identity as women by impeding their ability to bond with other women over shared gender roles. In general, the participants felt that their inability to make the transition to motherhood resulted in others treating them as somewhat less of a woman and less of an adult [63].

Not being able to have children (when motherhood is desired) ultimately makes a woman feel incomplete, and this appears to apply across cultures. In a study of Chinese couples with infertility in Hong Kong, the women reported experiencing shame and not being considered a complete woman [62]. Many Chinese women derive their identity and womanhood from being able to have children, particularly sons [141]. A study involving Latina immigrant women revealed the belief that being a complete woman involves having biological children because it demonstrates that a woman's body is socially and sexually useful, versus being selfish and/or broken [64]. This may be tied to the Hispanic cultural concept of *marianismo*, which venerates the ideal woman as being a pure and sacrificial mother [65]. In Nigeria and Cameroon, women with infertility are regarded as incomplete because they are not able to transition to full womanhood and adulthood [55; 66].

This theme of pronatalism is common in Western cultures. Pronatalist ideologies echo the "social, political, and moral values, attitudes, outlooks, and beliefs that shape society's interpretation of women's and men's social roles regarding parenthood" [67]. Specifically, these ideologies emphasize the inextricable link between a woman's identity and her ability to reproduce [67]. These values underlie the social structure and are also reinforced through governmental policies (e.g., income tax deductions) [45]. Despite common themes of choice and self-determination in Western society, the desire to have children is considered a natural instinct that every woman should have [51]. The belief that motherhood is a natural instinct has emerged in multiple studies [48]. The discourse on motherhood often depicts childless persons as selfish, materialistic, or child-hating [169]. An analysis of 327 Australian newspaper articles published between 2007 and 2011 found four categories of representations of childless women [170]. The first was "sympathy-worthy women," which included those women who were involuntarily childless and deserved pity. The second was "career women," or women who put their careers and ambitions first; women in this category were typically depicted

as selfish. The third category was "reprimanded women." Depictions in this category were closely connected to "career women" and were described as irresponsible and negligent. The final category was "artifact of feminism," which attributed the choice to remain childless as a result of feminist ideology. Childlessness is often considered an acceptable topic of conversation, despite it being painful for couples experiencing infertility [51]. Constant questions regarding reproductive plans reinforce individuals' feelings of failure and of being judged as selfish [67].

Tying a woman's worth to her reproductive capabilities also exists in non-Western countries. In South Africa, for example, "the bearing of children is seen as an essential part of being a woman and of achieving success as one" [68]. A woman bears a great responsibility in producing *izizukulwane*, which is a term that means "generations." Therefore, children represent a continuation of the family—genetically, socially, and culturally [60]. In many cultures, children serve as a social security mechanism, a way to ensure that religious rites are performed for the dead, and a means to guarantee social status for families [69; 70; 71]. In Ghana, motherhood is considered essential to a woman's identity. Those who are not mothers tend not to be accepted, which leads to social exclusion. One Ghanaian research participant stated that having children was more important than having a husband [171]. The importance of having children is so important in some developing countries that a woman with infertility may be ostracized from her community, abandoned by her husband, and forced to leave her home [72].

FAMILY

The social construction of infertility, womanhood, and motherhood is influenced by the social construction of family. Despite the diversity of family structures in today's society, the conceptualization of a family as consisting of a married heterosexual couple and their biological children persists [73]. In other words, the nuclear family system is the standard [172]. In the United States, the notion of the family is organized around marriage, law, procreation, co-residence, and biologic relatedness [74]. Pronatalism emphasizes women's reproduction of their own children and the assumption of biologic relatedness in the definition of family [73; 141]. The need for biological children in the family system is rooted in the perceived need to continue a genetic line. However, pronatalism does not appear to extend to racial and ethnic minority women, particularly those who are from low-income backgrounds [169].

SOCIOCULTURAL CONTEXT OF INFERTILITY

All individuals have cognitive representations or schemas of illness or health issues [75]. These schemas are used to make sense of one's control of the health problem, the symptoms that arise from the illness, the cause of the health problem, and the disease course (e.g., acute, chronic, or intermittent). These schemas are influenced by family, friends, social institutions (e.g., healthcare systems), and culture [75]. This section will review these schemas of infertility and how sociocultural forces impact individuals' representations of infertility.

TERMINOLOGY

The terminology used to describe any condition can have an impact on its perception. In English, the word "fertile" is defined as capable of producing, abundant, and prolific, while the term "infertile" means unfruitful, sterile, and unproductive. Although the term "barren" is not employed as often, it conveys negative images of starkness, sterileness, and emptiness [76]. Historically, women with infertility carry the stigma of some type of moral and spiritual failure [76]. In Nigeria, the term for infertility is *rashin haifuwa*, which translates as "lack of childbirth" [55]. This term is used regardless of whether a woman has had a child previously or not [55]. In Punjabi, the most widely spoken language in Pakistan, the term used to describe infertility (*baanjh*) literally translates to mean "barren" and is associated with negative connotations [77].

PERCEPTIONS OF THE CAUSES OF INFERTILITY

Medically, there are many potential causes of infertility. The three most prevalent categories are ovulatory disorders, fallopian tube patency problems, and problems with sperm and/or semen [78]. However, patients' perceptions as to the causes of infertility are often more complex and involve cultural and spiritual explanations. Lay perceptions about the causes of infertility can be generally organized into four categories: supernatural causes, fate/destiny, infections, social factors, and sexual practices and other environmental factors. Supernatural causes include evils spirits, witchcraft, black magic, and curses [55; 79; 80]. In one study, Kuwaiti women with lower literacy and educational attainment tended to blame their infertility on evil spirits and witchcraft, while their more educated counterparts cited biopsychosocial causes such as psychosexual factors, poor nutrition (i.e., inadequate vitamin intake), and marital problems [80]. In another study, 60% of the female participants from Saudi Arabia attributed infertility to an "evil eye" [142]. In a cross-sectional survey of adults from Pakistan, approximately 30% believed that evil spirits (*jinns*) were the cause of infertility and 40% attributed infertility to black magic [79]. In Indonesia, infertility is often attributed to supernatural causes, and polygamy is acceptable in cases of infertility [173]. In a study with 609 Lebanese participants, men were more likely to consider divorce, living separately, or a second marriage if their wife was infertile [174].

Religious and spiritual beliefs also play a role in lay persons' perceptions of the cause of infertility. In several studies, the most common lay explanation was that infertility was fate or part of God's will. In a study of women in Nigeria, many believed their infertility was rooted in God's plan [55; 143]. In Pakistan, women reported believing that children are a blessing from God, with infertility reflecting a lack of piety or unworthiness [79]. In some Asian cultures, the inability to conceive children is believed to be the result of displeasing ancestors and/or gods [175]. Analysis of online discussion forums devoted to infertility in Romania found that some participants attributed their infertility to divine causes, ultimately to test their faith and to build their character [144].

Hindu women may believe that their inability to have children is due to karma (i.e., the result of actions in a previous life) [60]. In other cultures, individuals may believe infertility is the result of not fulfilling certain cultural rituals and/or displeasing one's ancestors [60].

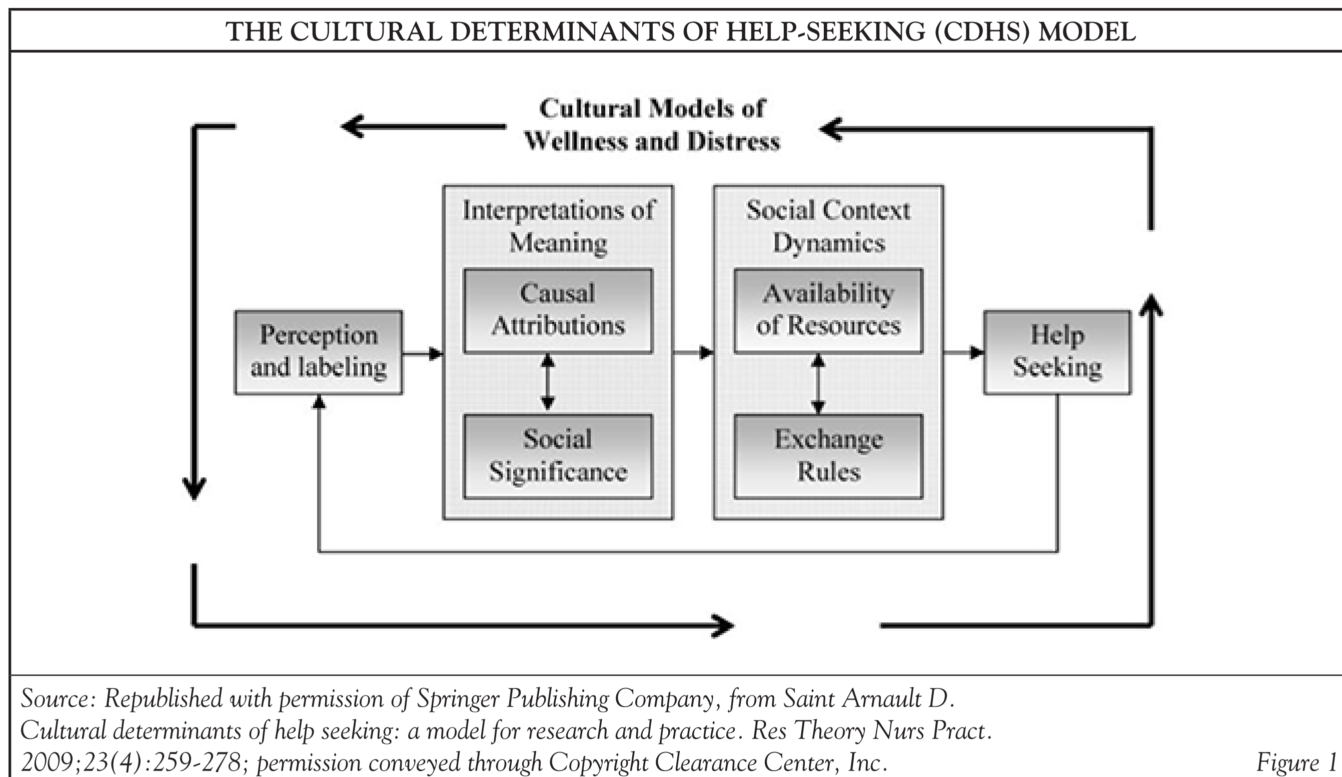
Infertility has also been attributed to infections or uncleanliness. Some Nigerian women reported believing their infertility was caused by infection or the introduction of dirt or other substances into their uterus [55]. Certain cultures consider infertility to be the result of the man's and woman's blood not blending well together [81]. Diet is also believed to play a role in some cultures [145]. Other social explanations include women's use of contraceptives, past abortions, masturbation, or perceived promiscuous behaviors [55; 145].

BURDEN OF BLAME

Unfortunately, women bear the brunt of the blame and assigned responsibility for infertility across cultures [70; 77; 79]. In some Middle Eastern cultures, many adhere to a "seed and soil" explanation of reproduction. According to this belief, the seed (semen) helps to create but the quality of soil (ovum, uterus) is responsible for conception, thus placing the responsibility for reproduction and infertility on women [176].

As a result, women who cannot conceive may be ostracized and stigmatized [55; 82; 146; 177]. Extended family members may also regard a woman's infertility as a breach in family loyalty [147]. Women with infertility may be excluded from certain cultural and social rituals [79]. In some cases, husbands are encouraged to divorce or take second wives [77; 82; 174]. A Bangladeshi proverb reflects this devaluing of women with infertility: "Even a fox or a dog does not eat the dead body of a childless woman" [83]. For men, infertility threatens their masculinity, and this may cause them to blame their partners. In many developing countries, the most viable "treatment option" for men is to obtain a new wife [84; 85].

THE CULTURAL DETERMINANTS OF HELP-SEEKING (CDHS) MODEL



Source: Republished with permission of Springer Publishing Company, from Saint Arnault D. Cultural determinants of help seeking: a model for research and practice. Res Theory Nurs Pract. 2009;23(4):259-278; permission conveyed through Copyright Clearance Center, Inc. *Figure 1*

HELP-SEEKING

Help-seeking involves a pathway or series of formal and informal contacts individuals use to request assistance. Individuals' help-seeking patterns provide a window to their attitudes toward infertility and its underlying causes and treatment [86]. Four main types of help-seeking patterns are [165]:

- Knowledge-seeking: Obtaining information to be better informed about the condition and solutions
- Socio-emotional support-seeking: Engaging active strategies to cope with a range of emotions and stressors
- Treatment-seeking: Initiating contact with and continuing to engage with health professionals
- Non-medical solution-seeking: Employing nonmedical strategies to address issues

The ways in which one seeks formal or informal assistance reflect culturally specific meanings and beliefs. The Cultural Determinants of Help-Seeking model posits that there are three major dimensions that influence how assistance is sought: perceptions and labeling, interpretations of meaning, and social context dynamics (***Figure 1***) [87].

Perceptions and Labeling

The first step in help-seeking is the perception by the individual that feelings, sensations, or outcomes are problematic and/or distressing [87]. This perception is sifted through cultural lenses. In the case of infertility, the major "symptom" experienced is an inability to conceive or remain pregnant. As discussed, in many cultures, impaired ability to conceive is primarily attributed to women. This then influences how help is sought and the treatment obtained.

Interpretations of Meaning

After an event or feeling is perceived as abnormal (i.e., a symptom), meaning is attributed. Two types of attributions can be made: attributions of social significance or causal attributions. A social significance attribution occurs when an individual attaches positive or negative social significance to the event. For example, a woman who has difficulty conceiving might believe this is reflective of a personal failure or character flaw [87].

A causal attribution involves an attempt to determine the source(s) of a symptom or event. The perceived cause may be related to physical, psychological/emotional, and/or environmental factors [88]. Often, the mode of help-seeking is partially influenced by the causal attribution. For example, those who believe that infertility is caused by supernatural disturbances tend to seek the assistance of religious leaders, spiritualists, and traditional healers [55]. The stigma associated with infertility in some cultures leads couples to seek assistance through traditional healers and alternative therapies before seeking more conventional treatment [69]. A study of British South Asian women who practiced Islam found that the women's first point of contact for help with infertility was usually religious leaders, who would offer prayers and suggest fasting and wearing amulets [77]. However, women exhibit varied responses to infertility. Even those who are committed to a medical perspective and solutions may seek a range of nonmedical interventions [165].

Social Context Dynamics

The individual's social context will also affect help-seeking. The availability of resources in one's personal social network system (e.g., family, friends), community, neighborhood, workplace, and institutional organizations will clearly guide the type and amount of help obtained. This is subject to social rules of exchange, which define who can partake in the resources, under what circumstances, and when they should be reciprocated. Knowing someone who used a resource (particularly successfully) can influence help-seeking [148]. Collectivistic cultures (e.g., China, Mexico) are more likely to provide assistance to members in their group, and it is expected that the individual will rely first on her or his family before seeking outside help [87]. However, because of the stigma associated with infertility and fear of ostracism, members of these cultures may seek help outside of their usual resources (e.g., family members and community) [69]. Meanwhile, individualistic cultures expect that individuals will use personal resources (internal and external) before seeking outside help. If others help, this favor is expected to be reciprocated in a short period of time [87]. In the United States, many women will start the process of seeking help with their gynecologist/obstetrician, which is often the healthcare provider with whom they have most frequent contact [178].

PSYCHOLOGICAL AND SOCIAL CONSEQUENCES OF INFERTILITY

This section provides a general snapshot of the consequences of infertility. However, it is important to remember that every couple and every individual will experience infertility differently [81]. Experiences should not be generalized and applied to all couples and individuals experiencing infertility. Much of the empirical literature on infertility is limited. In particular, studies tend not to include representative samples. For example, a majority of studies draw their samples from treatment seekers at infertility clinics. In addition, many empirical studies do not take into account how individuals construct meanings of their infertility experience and instead focus on psychopathology [81; 89]. Many couples are highly resilient and adapt positively, reporting their experiences have brought them closer together and strengthened their relationship [89].

GRIEF

Feelings of loss and grief are common among couples with infertility [149]. Four phases of the grief cycle have been identified: disbelief/denial, anxiety and loss of control, isolation and guilt, and resolution [90]. Some argue that women experiencing infertility undergo disenfranchised grief. The loss of a loved one is visible, openly acknowledged, and associated with clear rituals to facilitate the mourning process. However, women experiencing infertility typically cannot rely on social norms that guide mourning. As such, persons experiencing infertility often describe it as an invisible loss [179]. Even when persons experiencing infertility disclose their situation, they may not be met with the compassion and empathy that they deserve.

As discussed, many women feel they are to blame (a feeling that may be reinforced socially), and they struggle with the meanings of loss of motherhood and their identity as a woman. Women in West African cultures that highly value motherhood tend to experience greater sense of grief and psychological distress [150]. In qualitative interviews with women with infertility, the following themes emerged: sense of inadequacy, feelings of loss of personal control, anger and resentment, depression, loss of a dream of reproducing and being a mother, and grief [91]. The women also reported experiencing envy and jealousy upon seeing mothers with children [90; 91]. These feelings often led to social withdrawal and isolation [91]. In a study of 152 women undergoing infertility treatment, a significant association was found between maternal identity centrality and experiences of grief [92]. In one survey study, women who were undergoing fertility treatment who had overinvolved family members who accompanied them to treatment experienced greater grief if a treatment failed compared with those women whose family members were not aware of the situation [151].

Men also experience grief as a result of being unable to reproduce and may feel their identity or masculinity is threatened [89]. Men who believe they are the cause of the infertility experience higher levels of psychological distress and social withdrawal compared to women or male counterparts who do not believe they are the cause [93].

Unsuccessful in vitro fertilization (IVF) has also been shown to trigger grief responses and coping strategies in couples with infertility [94]. Studies of patients starting IVF have found the strongest predictors of psychological distress to be passive and active coping, self-criticism, and dependency and intrusiveness [95].

IMPACT ON MARITAL RELATIONSHIPS

Because they are not able to have children, couples may question the purpose of their marital relationship, which can result in marital distress [89]. Marital conflict and distress can be moderated by many variables, including the couples' educational level, length of marriage/relationship, age, and number of miscarriages [152]. Furthermore, the locus of control also plays a role in marital satisfaction. Couples who score higher on an internal locus control (e.g., the belief one has power to influence outcomes) tend to have higher marital satisfaction [152].

There has also been research indicating that the diagnosis of infertility can result in a marital benefit, defined as a strengthened and closer relationship [96]. It is important to enhance this effect, when possible. However, it is clear that a diagnosis of infertility and the subsequent stresses of treatment can result in marital discord, partially due to differences in coping and emotional adjustment. In a study of 48 married couples seeking fertility treatment, clear differences in husbands' and wives' approach to fertility treatment were evident [97]. The researchers found that women tended to be more invested and involved in the treatment process (e.g., more invested in having children, more interested in discussing the process, experienced greater loss of self-esteem) than men. The greater the husband's involvement and interest in the treatment process and the better the quality of marital communication, the more likely that the diagnosis and experience would result in a marital benefit [97]. The authors of this study concluded that couples in infertility treatment may benefit from counseling or therapy to increase husbands' involvement and interest in fertility treatment and improve communication within the marriage.

When couples have fertility problems, the National Collaborating Centre for Women's and Children's Health recommends both partners be informed that stress in the male and/or female partner can affect the couple's relationship and is likely to reduce libido and frequency of intercourse, which can contribute to the fertility problems.

(https://www.nice.org.uk/guidance/cg156. Last accessed June 10, 2022.)

Strength of Recommendation: Expert Opinion/ Consensus Statement

Impact on the marital relationship appears to occur across cultures. In a study of 250 couples in Iran, participants who were infertile exhibited low scores in areas of sexual satisfaction, marital satisfaction, and quality of life compared with their fertile counterparts [153]. In an Iranian study, researchers found a positive relationship between loneliness and emotional divorce (defined as feeling separated from each other), restlessness, and boredom [180]. Loneliness also predicted martial burnout. With emotional divorce, couples acknowledge there is a problem in the marriage, but continue with their marriage despite the fact the marriage is devoid of intimacy. This intensifies loneliness and marital burnout, perpetuating a cycle of blame and distrust [180]. In a study of couples in South Africa receiving infertility treatment, infertility-related stress was found to have an impact on the quality of communication, sexual satisfaction, intimacy, and overall dyadic adjustment [98]. The perceived cause (i.e., female or male factor) may also influence one or both partners' satisfaction in the marriage. In a study of Iranian couples seeking infertility treatment, female partners who attributed the infertility to a female factor experienced less marital satisfaction; in cases of male-factor infertility, wives reported lower sexual satisfaction [99]. Similar findings were reported by male partners. Coping strategies and perceived social acceptance play a part in perceived marital satisfaction, indicating that couples would benefit from psychotherapy, skills training, and support groups [100].

COPING PATTERNS

Coping is the psychological process of reducing stress from social, personal, familial, and interpersonal factors. Several coping styles or patterns have been identified [101]:

- Instrumental coping (problem-solving): Employing specific tools or strategies to help reduce the stress, including:
  - Planning (i.e., generating a plan of steps to move forward)
  - Suppression of competing activities
  - Seeking social support from friends, family, professionals, and para-professionals
- Emotion-focused coping: Specific strategies to manage one's emotional well-being during the challenging situation
- Active coping: Acknowledging the stress and attempting to mitigate the negative effects and outcomes
- Avoidant coping: Ignoring or denying the problem

A longitudinal study of 420 married couples with infertility examined common coping styles [102]. The researchers found that husbands tended to distance themselves from the infertility problem. This manifested as not taking the situation seriously, ignoring the problem in their lives, and refusing to discuss the issue—avoidant coping behaviors. This type of coping pattern was challenging for partners. In 20% of couples, the wives tended to use high levels of emotional and behavioral self-control while the husbands used low levels of emotional and behavioral self-control. Couples in this category reported experiencing significant infertility-related stress [102]. When both partners accepted responsibility for the infertility and associated treatment(s), there were high stress levels and low levels of marital adjustment. However, when both partners assumed little to no responsibility, stress levels were low and marital adjustment was high [102].

Studies have examined how coping style affects psychological and other psychosocial outcomes. In a survey study of 124 couples in Malaysia, couples who engaged in emotional coping experienced higher levels of depression [103]. No statistically significant relationships were found with problem-solving and avoidant coping strategies and psychological distress among men or women [103]. In an interview study with couples experiencing infertility, the couples discussed deliberate and conscious coping with the stressors associated with infertility [104]. Specific strategies included choosing not to dwell on the issue, completing treatment procedures, and engaging in activities for distraction.

It is important to recognize that relationship stress is dynamic; how one partner responds will affect the other partner. It is referred to as dyadic stress, and the coping patterns are referred to as dyadic coping [181]. In a study with 167 heterosexual couples undergoing fertility treatment, researchers found that when both partners engaged in positive dyadic coping styles (e.g., emotion- and problem-focused coping), the couples experienced greater marital adjustment [182].

Other coping strategies include normalizing and relying on religion or spirituality. Given that some individuals attribute infertility to an act of God or a higher being, religious/spiritual coping is common. In a study of Pakistani and British women receiving infertility treatment, several women identified religious coping as their main coping mechanism [154]. Persons from diverse minority and religious groups report relying on religious coping (e.g., prayer, meaning making, support from clergy) [183]. In a quantitative study with 186 Israeli women undergoing fertility treatment, seeking support from rabbis and from God correlated with reduced psychological distress [168].

INFERTILITY TREATMENT: ATTITUDES AND USE

ATTITUDES TOWARD INFERTILITY TREATMENT

Individuals' attitudes toward infertility treatment are linked to cultural norms and belief systems. In the United States, as in most Western developed countries, infertility treatment largely refers to artificial insemination and assisted reproductive technology (ART), while in developing countries, infertility treatment often consists (particularly initially) of alternative treatments, such as herbal remedies [81]. ART is an area of medical specialty serviced by reproductive endocrinologists. It can be useful for achieving pregnancy in women with tubal infertility or ovulatory infertility, particularly when pharmacologic fertility treatments and lifestyle modifications are not successful. Additionally, certain male factors necessitate the use of ART. Both donor eggs and donor sperm can be used for insemination and ART procedures. In this section, the focus is on ART for the treatment of infertility. The first child born through the use of ART in the United States was born in 1981 [184].

In studies with South Asian couples with infertility, many felt that using donated sperm and eggs was unacceptable [69; 105]. Donated sperm was perceived to be more problematic because the continuation of the male genetic line was highly valued [105]. Some ethnic/religious groups view sperm donation as analogous to adultery, and some believe it should be illegal [175]. In a study of 589 couples in Nigeria, about 7% reporting feeling that ART was "unnatural" [143]. In Islam, sperm donation may be likened to adultery, with the resultant child regarded as illegitimate [105]. Eggs donated by a family member (e.g., a sister) are often considered more acceptable [105]. The Christian commandment of "being fruitful and multiplying" has likely positively influenced the acceptability of ART among Christians [175].

DISPARITIES IN INFERTILITY TREATMENT

The use of ART has increased substantially in the United States, with the number of ART cycles and the number of resultant live births tripling between 1996 and 2015 [106]. In 2018, 203,119 ART procedures were performed in the United States [184].

Despite these trends, racial and ethnic disparities persist. A review of the National Survey of Family Growth found that of the women who had accessed fertility treatment between 2006 and 2010, the majority (67.3%) were White [107; 108]. Access to infertility services increases with higher education and socioeconomic status. In a 2020 study with 1,460 women seeking fertility treatment, 81.5% had an annual household income of more than $100,000 [185]. Racial and ethnic minority women also tend to wait longer to seek medical assistance for infertility compared with White women [13]. In the same 2020 study, African American and Hispanic women reported traveling twice as far on average for treatment compared with their White and Asian American counterparts [185]. Among racial and ethnic minority women, Asian American women are most likely to access ART while Native American Indian women are the least likely to access ART [155]. African American women are 20% less likely than White women to obtain fertility treatment [155].

Racial and ethnic disparities in access to fertility treatment are likely the result of several factors. One of the largest barriers to infertility services is the cost [109]. The average cost of an IVF cycle in the United States can range from $12,000 to $17,000 [156].

As of 2019, 17 states have passed insurance mandates to cover ART and other infertility treatments, and regardless of race and ethnicity, rates for ART usage are higher in states with insurance mandates compared with those without mandates [155; 156; 167]. However, there is evidence to suggest that these mandates have not ameliorated the differences in rates of infertility treatment by race or ethnicity and socioeconomic status [107]. For example, for African American and Hispanic women, rates for ART utilization remain lower than overall rates in states with insurance mandates [155]. Even with insurance, it is possible that some cannot afford co-payments or deductible costs [155]. Some studies looking at "equal-access" subpopulations, such as women in the military who have the same level and type of health insurance coverage, have found no disparities in use by race and Hispanic origin, particularly between non-Hispanic White and Black women, though Hispanic women still appear to use services at lower levels than non-Hispanic White women [107].

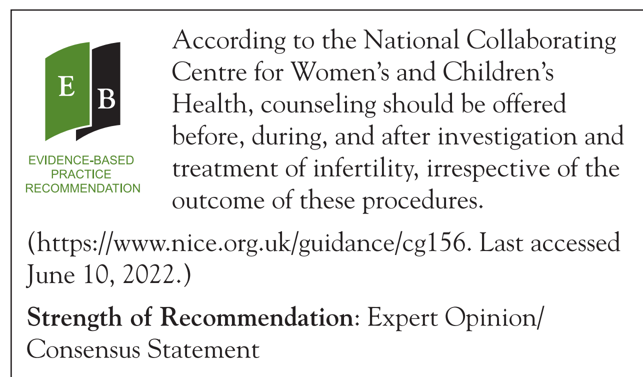
Another factor is the enduring stereotype of the hyperfertile racial minority woman. The myth that poor and minority women have too many children, for example, may impede racial/ethnic minority women from accessing infertility services due to the fear of being treated discriminatorily [111]. Related to this myth is the concept of "intensive mothering," which is the concept that the norm of motherhood is based on a White, middle-class, heterosexual standard. Those who deviate from this standard tend to experience negative treatment from service providers [109]. Some argue that the medicalization of infertility introduces a barrier that serves as a means of deciding who is "worthy" of becoming a parent [112].

Racial and ethnic minorities also tend to mistrust the medical establishment, resulting in lower usage of healthcare services, including infertility treatment [113; 186]. Because reproductive technologies are relatively new, some racial minority women and men may be hesitant to use them because they equate the procedures with experimentation. A history of unethical and damaging experimentation and forced or coerced sterilization in racial/ethnic minority populations have contributed to a general distrust of the healthcare system and specifically of procedures related to reproduction [7; 114].

BEST PRACTICES WHEN WORKING WITH INDIVIDUALS AND COUPLES WITH INFERTILITY

SELECTION OF COUNSELING SERVICES

Counseling services for individuals and couples with infertility may be categorized as patient-centered, supportive, or therapeutic. Determining the best type of counseling will help to define the role of the practitioner.



According to the National Collaborating Centre for Women's and Children's Health, counseling should be offered before, during, and after investigation and treatment of infertility, irrespective of the outcome of these procedures.

(https://www.nice.org.uk/guidance/cg156. Last accessed June 10, 2022.)

Strength of Recommendation: Expert Opinion/ Consensus Statement

Patient-Centered Counseling

Patient-centered counseling consists of providing information about common questions, different treatment options and specific procedures and assisting patients to understand the implications of their selected approach. As the couple or individual progresses through the decision-making process, the ethical, legal, social, and psychological ramifications should be explored [115; 116; 157]. Even though the dissemination of educational information is vital, women want to feel listened to and have their experiences validated. Patients want to be treated as the experts of their own bodies and not feel like their bodies are being treated as objects for medical treatment [178].

Supportive Counseling

Supportive counseling involves providing aid to the individual or couple. This encompasses both affective support and concrete support (e.g., referring the couple or individual to specific resources) [116]. This type of counseling can be provided during the diagnostic process, during fertility treatment, and even after conception. In a study of 32 couples receiving infertility treatment in Canada, participants reported having received inadequate information about the possible risks and side effects of treatment [117]. This speaks to the need for practitioners to be aware of various definitions of the types of infertility, risk factors, biopsychosocial responses to infertility treatment, and available evidence-based treatment options [158]. Couples seeking infertility treatment are generally not familiar with the biomedical and technical language, which can make them feel intimidated and anxious [158]. In addition, feelings of loneliness and isolation were common. Active listening and encouragement may help address these feelings. If a couple is open to talking with another couple going through a similar experience, referral to support groups or online support forums may be useful [117].

Therapeutic Counseling

Therapeutic counseling, or psychotherapy, may be short- or long-term, depending on the needs of the patient [115; 116]. Initially, crisis counseling may be necessary following the diagnosis of infertility [157]. However, in the longer term, therapeutic counseling may focus on a range of issues that may arise, such as impaired communication, intimacy problems, poor coping skills, setting goals that are not completely reliant on getting pregnant, and dealing with the possibility of not getting pregnant after all the infertility treatments [118; 157; 158]. Practitioners often attempt to normalize couples' feelings of anger or exclusion from family events [95].

ASSESSMENT

Assessment is an ongoing process, and practitioners should assess several areas at the initial phase of contact and throughout the counseling process, including emotional state, mental health issues, factors affecting emotional response, and views regarding family, parenthood, and children [7].

Emotional State

Individuals and couples with infertility experience a range of fluctuating emotions, and the level of intensity varies depending on the stage of grief and phase of the treatment process. Five emotional phases have been described for couples experiencing infertility [119]:

- Dawning: Becoming aware of the problem
- Mobilization: Seeking medical attention and confirming diagnosis
- Immersion: Uncertainty during intensive testing and treatment
- Resolution: Coming to terms with being unable to have a biological child, often with associated grief and mourning
- Legacy: The ongoing process of coming to terms with the legacy of infertility and its implications

Factors that Influence the Level and Intensity of Emotional Distress

As part of the assessment process, practitioners should evaluate individuals on the micro level. This entails assessing for pre-existing psychopathologies, coping strategies and problem-solving skills, and personality/temperament [115]. The practitioners should then assess the couple's social environment for factors that could potentially exacerbate or help to mitigate distress, including existing social support networks, current marital relationships, family dynamics, available resources, and other situational factors [115].

Treatment-related factors will also impact a couple's emotional state. As such, practitioners should assess for side effects from treatment, attitudes held toward infertility treatment, and current and past experiences with infertility treatment failure [115].

Views about Parenthood, Family, and Children

Practitioners should also evaluate the cultural and family messages each individual receives about definitions of family and parenthood; views of mother- and womanhood; the stigma of childlessness; perceptions of masculinity, femininity, and gender roles; and beliefs regarding sexuality and pregnancy [7; 158]. A genogram may be a helpful visual tool to obtain this information. The practitioner could draw a genogram or family tree and discuss how various family members define each of the topics.

Mental Health Issues

Because depression, anxiety, social isolation, and marital stress are common in persons experiencing infertility, these dimensions should be considered. A mental health assessment should be completed prior to initiating treatment of infertility. This assessment should include a complete patient history, with specific attention paid to histories of mood disorders and stress [120; 121]. Some patients may be reluctant to disclose past psychiatric issues due to a fear of being refused infertility treatment [120]. Therefore, healthcare professionals should ask direct questions about mood and anxiety symptoms. Patients who display current evidence of psychiatric disorders should be referred for further treatment.

POTENTIAL PRESENTING ISSUES RELATED TO INFERTILITY

Couples experiencing infertility may present with a variety of psychosocial issues, including [116]:

- Relationship issues
- Sex and sexuality issues
- Challenges related to religious and cultural beliefs about infertility and potential options
- Possible adoption avenue
- Ethical issues related to surrogacy, donation, and other technologies
- Past experiences and events triggered as a result of the current crisis

Other seemingly peripheral themes and topics may emerge over the course of caring for these patients. For example, family of origin concerns or topics related to the couple's history (e.g., gender roles, identity, communication, sex) may arise [95]. It is important to create a safe place for such discussions to take place [122].

Loss, disenfranchised grief, and mourning are also recurring themes. The role of anticipatory grief should be considered [123]. Anticipatory grief involves the mourning of a future loss, in this case, the impending loss of parenthood. As part of the mourning process, the couple is tasked with defining what this loss will mean. Because loss, grief, and mourning are experienced differently, each individual should be given the opportunity to articulate her or his loss [122]. Practitioners should validate that while the loss might be experienced differently, every experience is equally valid [122].

Feelings of blame and guilt often surface for couples with infertility [7]. As described, most cultures and societies place great importance on reproduction, with the responsibility largely falling to women to ensure parenthood occurs. Whether or not blame is explicitly or verbally assigned, the couple may internalize these feelings, which can have an adverse effect on communication and the marital relationship [7].

The extent to which the problem is a shared experience will be influenced by the extent blame is assigned and the emotional phases the couple progresses through. Some phases will not necessarily be negotiated by the couple as a team; they may be on different paths [124]. For example, one partner might want to continue to pursue treatment despite a history of failures, while the other partner wants to give up [124]. During this phase, one partner will unavoidably feel like he/she is going through the journey alone. Again, it is important to help each partner understand that while the path may be slightly different, each person's journey is equally important and authentic [3].

INTERVENTION STRATEGIES

Externalizing the Problem

Couples and individuals may require assistance externalizing their infertility. This technique involves exploring the problem separate from oneself [7]. Often, the couple may blame themselves for the infertility or place an extreme amount of energy and relational importance on it [7]. Patients may be asked to think about ways they can deal with the feelings of helplessness triggered by infertility [7]. Identifying activities they can do individually and as a couple that are separate from the problem can help couples distance themselves from it.

Cognitive-Behavioral Interventions

Cognitive-behavioral interventions focus on identifying negative or erroneous beliefs or cognitions that influence behaviors, and these approaches are commonly used in patients experiencing infertility [159]. Cognitive-behavioral interventions can assist couples to separate the negative thoughts of infertility from sex and feelings about their relationship [125]. Many couples undergoing infertility treatment feel that sex is no longer intimate or exciting but has become mechanical and procedural. Relaxation techniques, physical activity, skills to identify excessive ruminating and fatalistic thinking, expression of feelings, and educating couples about potential sexual problems that may occur can minimize this problem [3; 187].

Stress Management, Relaxation, and Guided Imagery Techniques

Relaxation and mindfulness interventions can be beneficial, as the phases of infertility can be emotional, taxing, and stressful. Individuals should be taught to recognize their own physical and emotional symptoms of stress [3]. Mind-body strategies can also help with psychological distress and depressive symptoms [31].

Good breathing takes discipline and deliberate practice, but the effects on self-awareness and coping can be considerable. Like breath work, imagery and meditation are also valuable, cost-effective

skills that can be used to increase coping and resilience, but they also take practice and discipline. A small study of women enrolled in group mind-body interventions found that they experienced greater relaxation, greater perceived social support, and fewer depressive symptoms than a control group that did not receive the interventions [40; 126].

Solutions-Focused Interventions

Many couples with infertility feel helpless and disempowered, and counselors should implement solutions-focused interventions that actively involve the couple so as to not exacerbate the already-existing feelings of passivity. For example, the couple may be advised to draw a road map and a satisfaction lifeline [95]. The road map can outline the available options and can be revisited and altered at any time. The satisfaction lifeline is a visual history of the relationship to the current time period. The couple places positive and negative events on the timeline, outlining their grades of satisfaction and how having or not having a child will affect their life satisfaction [95]. The goal is to assist the couple to see that not having a child does not necessarily mean their satisfaction with life and their marriage will be diminished.

Narrative Therapy

Narrative therapy entails working with the individual to develop new, richer stories, applying newly constructed meanings to life experiences. The therapist helps the individual to understand how cultural and societal scripts play a role in shaping the way the couple views their lives [58]. This may mean that infertility is deconstructed so it is not viewed as an unsolvable problem or as an issue inherent to the couple [125]. For example, the couple may identify the dominant cultural discourse(s) (e.g., views about parenthood and mother/fatherhood, meanings of having children) and deconstruct these cultural messages. This may lead to discussion of how these cultural messages have influenced the meaning ascribed to infertility [7; 109; 127]. As part of this process, each partner should be encouraged to verbalize and express anger and guilt [127]. The goal in narrative therapy is to help the individual or the couple experiencing infertility to view their lives in a way that recognizes there are many ways to attain fulfillment and generativity [58].

CULTURAL AND GENDER SENSITIVITY

Infertility can trigger a variety of emotions, and individuals may be sensitive to how others perceive and treat them. Consequently, the terms that practitioners use should be selected carefully. For example, the word "sterility" should generally be avoided because it implies a permanent failure rather than an issue that can be overcome [128].

When working with racial and ethnic minority clients, clinicians should be mindful that many of the interventions used to address psychosocial issues that arise in couples with infertility are based on Western cultural norms. In the United States, obtaining counseling or therapy is generally viewed positively as a mechanism to promote insight and personal growth. Counseling and therapy are rooted in the ideals of personal responsibility, whereby one takes control of destiny and the external environment. The notion of the "self" is at the heart of individualism; however, individuals from other cultural groups may be more collectivistic or group-oriented. In these cases, "talking therapies" will be culturally dissonant, and this is exacerbated by the fact that topics such as infertility, sexuality, and intimacy are typically considered private [7].

Communication with couples regarding lifestyle changes is a vital step in improving the chances of natural conception. When there is an obvious disconnect in the communication process between the practitioner and patient due to the patient's lack of proficiency in the English language, an interpreter should be utilized. Frequently, this may be easier said than done, as there may be institutional and/or patient barriers. A study of low-income, immigrant Latino couples with infertility found that communication was a major issue, with language and cultural barriers resulting in patients having difficulty both in understanding diagnoses and treatments and in communicating their questions, concerns, and experiences [129].

Reproductive care visits in which the patient and provider spoke different languages (and a staff interpreter was used) are significantly less likely to contain documentation of the provision of education and counseling services than visits with language-concordant providers [130].

Cultural generalizations should be avoided [131]. Even professionals attempting to incorporate cultural knowledge and sensitivity into their practice may unwittingly apply cultural generalizations. For example, in one study, when fertility topics were raised, practitioners used generalizations about the Asian family and how marriage was preferred in Asian cultures and automatically assumed that children were highly valued. Treating cultural/ethnic groups as a homogenous category perpetuates misunderstandings and miscommunications [131].

Gender sensitivity is equally crucial. Practitioners should be mindful that men and women with infertility experience a different set of dynamics. Men tend to be ambivalent in seeking psychosocial counseling and may have more difficulty identifying and verbalizing their infertility-related emotions [132]. Practitioners should address these issues and acknowledge the differences in stressors and experiences [132].

Both men and women with infertility frequently feel marginalized, reporting an "invisible shame" that cloaks their lives [3]. Many are fearful that discussing how distressed they are in not being able to have children will upset their partner and therefore suppress their feelings [3].

Many educational resources and psychosocial interventions specifically target women. When working with men regarding infertility, it is important to be sensitive to their unique needs and experiences [133]. Informational brochures that address the psychosocial issues triggered by infertility and through infertility treatment may be provided. Interaction with other men going through similar experiences (e.g., a support group) may be helpful. Professionals should take steps to make personal contact with men rather than going through their wives or partners. Educational information should be provided to men prior to treatment, as it increases the likelihood of men engaging in the process [3; 133].

INTERPROFESSIONAL COLLABORATION AND PRACTICE

Infertility has been described as a "matterpsychic" condition, whereby one cannot separate the medical, psychological, emotional, social, and cultural dimensions [188]. As such, interprofessional collaboration and practice is crucial to providing optimal care. Care plans should be synchronized and carefully coordinated among practitioners. In order to achieve this, a collaborative interprofessional team approach should be maintained, with every provider contributing their unique skills, competence, and knowledge. Physicians, nurses, psychologists, social workers, counselors/therapists, pharmacists, alternative and complementary practitioners, religious and spiritual advisors, and cultural experts all play a key role when working with women from diverse backgrounds experiencing infertility.

Interprofessional collaboration and practice is characterized as a process whereby multiple service providers representing different professional fields work together to provide comprehensive services to clients/patients in order to coordinate high-quality services across settings. It requires professionals to alter the way they practice—moving from working in a silo to working in a collaborative and trusting manner, sharing information, resources, and multiple perspectives to address the complex problems of clients and patients. Efficiency, cost containment, and measurable outcomes are key. The core features of interprofessional practice are sharing, interdependence, communication, and mutual trust and respect [189; 190].

When working with persons and families from diverse backgrounds, cultural sensitivity and competency are crucial, and there is much overlap between cultural competency and interprofessional collaboration [191; 192]. Both cultural competency and interprofessional collaborations require that professionals take time to critically reflect on the historical and sociopolitical factors that have impacted their professional relationships. By practicing cultural competency, interprofessional collaboration and communication can improve [192]. Both cultural competency and interprofessional practice foster sensitivity and awareness to alternative perspectives and value systems to challenge stereotypes and reduce prejudice [191]. Ensuring appreciation for various professional lenses can lead to improved patient outcomes and enhanced patient communication [191]. Those seeking fertility treatment require care and support not by a range of individuals (e.g., physician, nurse, psychologist), but a group of professionals who work collaboratively, bringing in supportive care and services in order to address the patient's biopsychosocial needs during and after assessment, diagnosis, and treatment [188; 193].

CONCLUSION

Societal messages reinforce the belief that adult development and identity is premised on having biological children, particularly for women. In many cases, women feel they are not treated as adults and are not able to participate in the performance of their gender because they have not had children. For many couples, a diagnosis of infertility is a crisis event requiring individuals to gather the psychological resources necessary to cope. In some cultures, this crisis can result in marginalization, family and community ostracism, shame, and even divorce. Infertility is largely defined culturally, and practitioners should take cultural context into account when planning interventions and education.

FACULTY BIOGRAPHY

Alice Yick Flanagan, PhD, MSW, received her Master's in Social Work from Columbia University, School of Social Work. She has clinical experience in mental health in correctional settings, psychiatric hospitals, and community health centers. In 1997, she received her PhD from UCLA, School of Public Policy and Social Research. Dr. Yick Flanagan completed a year-long post-doctoral fellowship at Hunter College, School of Social Work in 1999. In that year she taught the course Research Methods and Violence Against Women to Masters degree students, as well as conducting qualitative research studies on death and dying in Chinese American families. (A complete biography appears at the end of this course.)

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