I Introduction

Chapter 1

# Collaborative Reproductive Healthcare Model

## A Patient-Centered Approach to Medical and Psychosocial Care

**Sharon N. Covington and G. David Adamson**

## Introduction

There is nothing "typical" about the average patient who seeks fertility treatment today. Rapid advancement in technology and changes in societal views of reproductive rights have created choices and options for family building few could have imagined one generation ago. Heterosexual/opposite-sex couples, while still the norm, are being joined by a diverse group of adults who also long for children. Same-sex couples, transgender individuals, single men and women, older people beyond normal reproductive capacity, and those facing life-threatening medical circumstances or serious genetic conditions, have access to reproductive techniques that will allow them to have a child or children. In addition, are those who present wanting to preserve fertility options for the future through cryopreservation of their gametes, or even family members requesting sperm retrieval posthumously after a sudden, tragic death.

This chapter will lay the foundation for subsequent chapters in this book regarding the medical and psychosocial assessment and treatment of individuals and couples needing reproductive medical assistance. Optimal patient care involves the collaboration of numerous healthcare professionals (doctors, nurses, laboratory scientists, paraprofessionals, administrative staff, as well as mental health professionals) working together to provide reproductive medical services. Over the years, there has been a dramatic shift in the recognition of the psychological consequences of infertility and the role fertility counselors play as an integrated part of the treatment team. There is international consensus that the complex psychosocial issues of infertility patients' experience cannot be separated from the extraordinary reproductive technologies physicians use to treat these problems (i.e., "You can't separate what is being done to your body, from how you feel about what is being done to your body"), which necessitates a collaborative approach to care. The American Society for Reproductive Medicine (ASRM) and the European Society for Human Reproduction and Embryology (ESHRE), as well as numerous other professional organizations and governmental policies, recognize this multidisciplinary method [1,2]. In addition, there is recognition that, for patients seeking medically assisted reproduction (MAR), "optimal care" requires attention to patients' psychological well-being as well as the quality of their interactions with staff, clinicians and other personnel during treatment [3]. Negative intrapersonal psychological reactions to treatment and difficulties in interactions with others during treatment can create a psychological burden for patients, affecting compliance and their ability to make decisions about continuing with treatment. Thus, "best practice" in reproductive healthcare will include ways to minimize patients' emotional and psychological distress, while providing effective clinical care in a positive environment.

As clinicians and colleagues, the authors have spent their careers advocating for the medical and psychosocial integrative care proposed by Covington with the "collaborative reproductive healthcare model" [4] and by other authors as "patient-centered care" [5] or "integrated approach" [6]. This model has a biopsychosocial approach in which the diagnosis and treatment of impaired reproduction are considered in terms of a variety of aspects impacting an individual's/couple's experience with infertility: physiological, psychosocial, interpersonal, familial, spiritual, cultural and societal. A patient's overall health, functional status, emotional well-being, quality of life and resiliency are influential factors in how s/he can navigate the condition. This approach emphasizes the importance of healthcare professionals and patients as collaborators in diagnosis, treatment and health maintenance to achieve optimum results. This collaborative model integrates the best medical and psychosocial patient care, and is responsive to patient values and needs. The approach in this chapter will be to present this model through a medical and psychosocial overview of the evaluation and treatment of infertility.

The addenda referred to in this chapter are available for download at www.cambridge.org/covington-clinical-guide

## Overview of Infertility

In our modern world, most people think that getting pregnant is easy. They think this because a combination of sociologically driven delayed parenting, effective contraception and societal silence regarding infertility creates the perfect storm for disbelief when pregnancy does not occur almost immediately when they "try to get pregnant." Everyone is different, so some couples are highly fertile, others less so but still normal, some have sufficiently impaired fertility that they can be considered subfertile (although there is no agreed definition for this term) and some do not get pregnant within one year of having regular unprotected intercourse and, by the World Health Organization (WHO) definition, are considered infertile [7–9]. Since almost half of couples with no identifiable fertility problem will get pregnant in the second year of trying without any medical intervention, these couples often need and/or receive very little diagnosis and treatment [10]. Couples who fail to get pregnant after five years can be considered sterile, although very rarely pregnancies will occur without medical intervention even in these couples [11].

Importantly, in 2017 the International Glossary on Infertility and Fertility Care, led by the International Committee Monitoring Assisted Reproductive Technologies (ICMART) in partnership with most of the leading reproductive medicine societies in the world, recognized infertility also when due to an impairment of a person's capacity to reproduce either as an individual or with his/her partner, and confirmed again that infertility is a disease which generates disability as an impairment of function [8]. The WHO also published an Infertility Fact Sheet in 2020 that stated, "A wide variety of people, including heterosexual couples, same-sex partners, older persons, individuals who are not in sexual relationships and those with certain medical conditions, such as some HIV serodiscordant couples and cancer survivors, may require infertility management and fertility care services."

Infertility is now defined by the WHO, the American Medical Association and all the major reproductive medicine societies in the world as a "disease." Primary infertility means that the patient has never been pregnant. A woman experiencing infertility after having ever been pregnant, regardless of the outcome of that pregnancy, has secondary infertility. Recurrent miscarriage, historically defined as three spontaneous pregnancy losses, but now defined as the spontaneous loss of two or more clinical pregnancies and usually investigated at that time, is not considered to be infertility, but is a different disease classification [8] (please see the Glossary at the end of this book for other definitions of infertility and fertility care described in this chapter).

It is very difficult to determine the prevalence of infertility. However, studies that have been done suggest that about 7–9% of couples are infertile at any given time [12,13]. Traditionally, the causes of infertility in younger patients (<35) are ovulation problems in about 15% of cases, tubal/pelvic pathology in 35%, male factor in 35%, unexplained in 10% and other causes in the remaining 5% of cases (Figure 1.1). However, over the past two decades, as women and men have delayed attempts at pregnancy, ovulation and hormonal problems, along with decreased egg quality, affect about 40% of the couples, pelvic problems occur in about 30%, cervical/combined factor (e.g., vaginal/cervical abnormalities and failure to have sex) in about 5% and primarily male factor in about 25%. In addition, reduced sperm quality may affect an additional 25% of couples in which a female factor is the primary cause. Some, but not all, studies suggest that decreased ovarian reserve associated with the older age of women

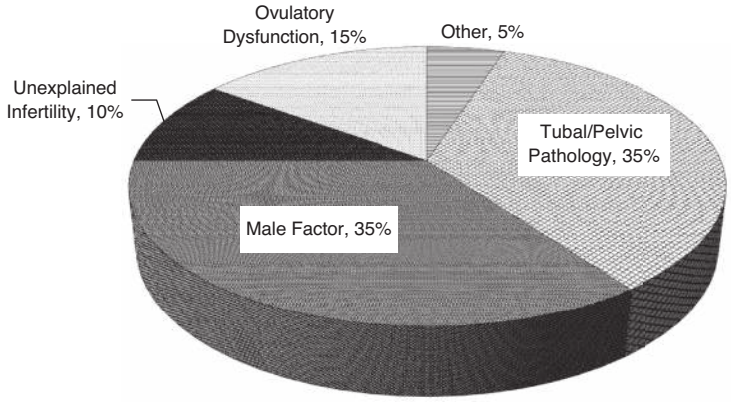


**Figure 1.1** Causes of infertility in couples.

attempting pregnancy is much more common in developed countries and pelvic factors, such as fallopian tube adhesions and occlusion, are more common in lower-to-middle income countries.

In developed countries a very common cause of difficulty getting pregnant is advanced age. The increased educational and economic opportunities for women have, understandably, resulted in many women delaying childbearing to pursue other life goals and interests. However, the female reproductive system has not changed. A baby girl is born with about 700,000 to one million eggs, the number of which continues to decrease over time. At puberty there are approximately 350,000–500,000 eggs (Figure 1.2) [14]. Women's fertility is at its peak from about age 23–31, and then begins to decrease because of a declining number of eggs and reduced percentage of eggs with a normal number of chromosomes (fewer euploid, i.e., normal number of chromosomes in the eggs and more aneuploid, i.e., abnormal number of chromosomes in the eggs). This results in a decreased pregnancy rate of approximately 3% per year from age 31–34, and 8% per year to age 39, so that at age 39 the average woman has about half the chance of getting pregnant than she did at age 31. From age 39–42 the chance of pregnancy is reduced about half again (Figure 1.3) [15]. Therefore, the chance that a woman in her mid-twenties will get pregnant is about 30% on the first

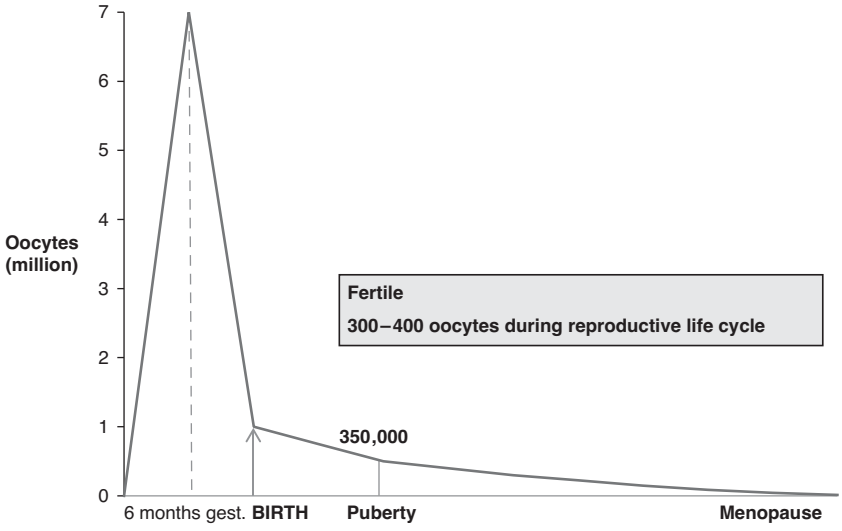


**Figure 1.2** Oocyte numbers over a lifetime (adapted from [14]).

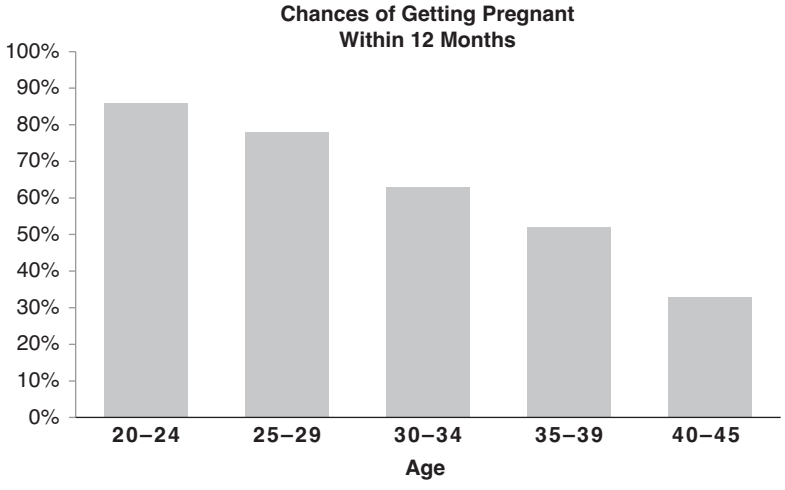


**Figure 1.3** A woman's chance of getting pregnant by age (adapted from [15]).

cycle without contraception, dropping gradually to about 10% on her sixth cycle and 3–5% by the twelfth cycle. Each of these numbers is approximately half as high for a 39-year-old woman and one-quarter as high for a 42-year-old woman [16]. While there is a wide range of ovarian reserve in women at any given age, age remains the most important predictor of the ability to get pregnant and deliver a healthy baby [17].

Male fertility is less well understood. Fertility decreases with age in men, but much less than in women, with a man in his fifties having about 70% the capability of creating a pregnancy that he had in his twenties. Additionally, rates of autism, schizophrenia and bipolar disorders and other problems may be higher in children born to older fathers [18]. Most of the time, when sperm quality is poor, a cause cannot be found. Situations that can cause male infertility include prior testicular surgery for cancer, chemotherapy or radiation treatment for cancer, serious testicular injury, undescended testicle(s), mumps after childhood, social and prescription drugs that interfere with spermatogenesis, sexually transmitted infections, obstruction of the vas deferens duct that transports sperm from the testicles to the penis, complications of hernia operations, exposure to environmental toxicants, possibly large varicocele and testicular exposure to high temperatures for prolonged periods of time.

General lifestyle and other factors can affect fertility. The commonest of these in developed and even many developing countries (now designated lower-to-middle income countries or LMIC) is obesity, which reduces fecundity through hormonal and ovulatory dysfunction in women and can also affect male sperm quality [19,20]. Excessive exercise and/or decreased weight for women can reduce fertility also. Other factors can include excessive use of alcohol, smoking, social drugs, certain prescription medications, exposure to environmental toxicants, radiation exposure, or excessive heat for men. It is important to emphasize good health habits with respect to diet, exercise and sleep. All reproductive-age women would benefit from taking a supplemental multivitamin, iron, folate, vitamin D and calcium [21].

Generally, women who are younger than 35 and don't get pregnant after one year of unprotected intercourse should seek professional assistance from their gynecologist or a reproductive endocrinologist. Because of the reduction in fertility that occurs with age, women aged 35–40 should see a physician after about 6 months of no contraception, and women 40 or older after 3 months. Of course, if a couple has a history of an issue that might contribute to fertility problems, they should see a fertility specialist when they start attempting or, even better, when they decide that they will want to have a family. Examples of such problems are prior chemotherapy or radiation, irregular menstrual cycles, known hormonal problems, history of pelvic surgery, endometriosis, ruptured appendix or surgery on the cervix and, for the male, history of penile, testicular or hernia operations, or exposure to heat, environmental toxicants, chemotherapy, radiation or other drugs that can affect sperm production.

The goal of fertility treatment is to optimize the number of healthy eggs that can potentially be fertilized in any given cycle and result in implantation of embryo and birth of a healthy singleton baby. Treatment of patients with low ovarian reserve can be done by using oral or injectable medications that increase the number of eggs ovulated. However, the quality of the eggs is not changed by these medications. Additionally, the risk of miscarriage and of having a baby with a birth defect increases with age. Fertility treatment can be used to overcome some, but not all, of these problems. Modern testing can help to identify babies with problems during pregnancy, and sometimes with in vitro fertilization (IVF) even before pregnancy, by testing embryos using preimplantation genetic testing (PGT), a rapidly evolving technology that raises important biological, societal, ethical and counseling issues that require expert interpretation and support (see Chapter 27 for further discussion).

When patients present to the physician with infertility, it is important to recognize the reason the patient is there. It is not to diagnose, not to treat, but rather to intervene to obtain the desired outcome – a healthy singleton baby. The barriers to achieving this patient goal are several: medical conditions in the female and/or male, the patient's age, financial barriers and psychological stress. Based on numerous clinicians' experience, approximately 50–60% of patients seen in a tertiary care center will have a baby [22]. About 10% will decide not to pursue treatment because the prognosis is very poor, while about 30% will not achieve their goal because of financial and/or psychological barriers: 10% financial reasons alone, 10% psychological reasons alone and 10% a combination of the two. Additionally, even the patients who do get pregnant will often experience significant financial and/or emotional challenges during their treatment. If the physician is to optimize intervention, these issues must be actively addressed. These challenges are even more severe in LMIC, where financial ruin and societal isolation are more common.

## Reproduction: Physiology and Pathophysiology

For pregnancy to occur, a healthy egg must be released from the ovary (ovulation) and be fertilized by a healthy sperm. Sperm are deposited at the cervix and make their way up through the endocervical canal and uterus to meet the egg, which has been picked up by a normally functioning fallopian tube from the ovarian surface or pelvis. The uterus must be functional and the endometrial lining must be able to respond to the estrogen and progesterone hormones secreted by the ovary so that the endometrium is prepared for implantation of the blastocyst. The blastocyst results from the fertilization of the egg and its development into a zygote and then an embryo and then the blastocyst by day 5 after fertilization (Figure 1.4).

The process of ovulation begins with the pulsatile release of gonadotropin releasing hormone (GnRH) from the hypothalamus at the base of the brain. This pulsatile release can be affected by weight, stress and other factors. The frequency of pulses changes during the menstrual cycle to cause the production of follicle stimulating hormone (FSH) by the pituitary gland, causing the follicles in the ovary to develop. The ovary must have follicles (the number of which become reduced with age) containing cells that make estrogen in the follicular phase (the first half of the menstrual cycle leading up to ovulation). During the follicular phase, approximately 10–20 follicles begin to grow, but eventually one exerts dominance over the others through a process of natural selection (the best one grows and the others stop growing). The rapidly increasing estrogen level from the cells in this enlarging follicle stimulates the release of luteinizing hormone (LH) by the pituitary gland, which causes the egg in the follicle to mature and to be released from the follicle (ovulation).

The egg is released into the pelvis and is picked up by the fallopian tube. The egg only lives about 12–24 hours, so it is important for sperm to be present when the egg is ovulated. The sperm, which have swum up from the cervix, fertilize the egg in the fallopian tube. Sperm will live 2–4 days in the female reproductive tract. The fertilized egg is called a zygote. The cells divide and at 3 days, the eight cells are called an embryo. The embryo continues to grow in the fallopian tube and enters the uterus at 5–6 days, comprises about 150–250 cells, and is called a blastocyst. The blastocyst floats in the uterus for about a day before implanting in the endometrium. The endometrium has been stimulated to grow by the estrogen from the follicle.

After ovulation, the follicle collapses on itself and becomes more vascularized and is called a corpus luteum ("body yellow"). This structure then makes progesterone under the influence of LH and some FSH that is produced by the pituitary gland. The progesterone is essential for the endometrium to develop properly so that implantation of the blastocyst can occur. If implantation and pregnancy occur, the trophoblast (early placenta) secretes human chorionic gonadotropin (hCG) which is the hormone tested for to detect pregnancy. The hCG stimulates the corpus luteum to continue producing progesterone until the placenta takes over with progesterone production at approximately 8–10 weeks of pregnancy. Progesterone is necessary to maintain the developing pregnancy.

Understanding the physiology of reproduction, it is no wonder there may be many things that impede,

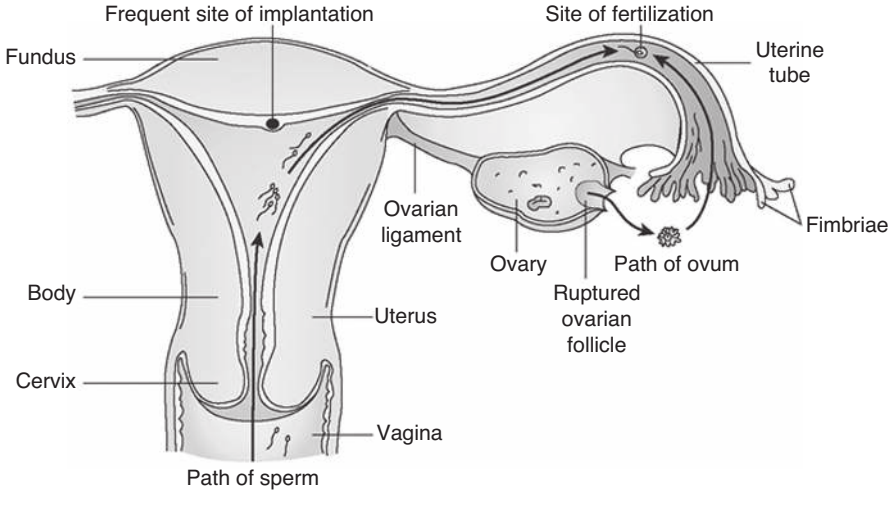


**Figure 1.4** Female reproductive anatomy and physiology.

diminish or get in the way of fertilization and implantation. While there are many specific causes of infertility, the general categories are simple:

1. *Female factors*:
   a. Egg and hormonal factors: decreased ovarian reserve based on age or other factors; ovulation abnormalities from hypothalamic/pituitary gland dysfunction, polycystic ovarian syndrome (PCOS – diagnosed by the presence of two or three of the following symptoms/signs: (1) irregular ovulation; (2) clinical or biochemical hyperandrogenism; or (3) antral follicle count equal to or greater than 20 in either ovary, or ovarian volume equal to or greater than 10 ml in either ovary), or abnormal weight; hormonal problems such as thyroid disease, hyperprolactinemia or renal gland disease; and endometrium problems affecting implantation.
   b. Pelvic/anatomic factors: uterine problems such as fibroids, adenomyosis, polyps, adhesions or congenital abnormalities; tubal problems such as adhesions, internal fibrosis or obstruction; pelvic peritoneal problems such as endometriosis or adhesions; cervical or vaginal abnormalities preventing deposition of sperm at the cervix and/or access of sperm into the uterus and fallopian tubes [23].
2. *Male factor:* azoospermia, oligospermia, decreased motility or morphology; genetic disorders (e.g., Klinefelter's); erectile dysfunction (ED), ejaculatory dysfunction or other problems affecting the delivery of sperm to the cervix at the appropriate time [24].
3. *Combined factor:* having intercourse at the wrong time with respect to timing of fertilization; using lubricants that harm sperm.
4. *Unexplained:* in about 10–20% of cases, a definitive cause of infertility is not identifiable and the diagnosis is "unexplained infertility." However, this diagnosis is commonly thought to represent an undiagnosable egg or sperm problem.

# Evaluation of Infertility: Collaborative Care

## Medical Management

Initial assessment of infertility includes a history and physical examination of both male and female partners [25]. The female history involves asking about menstrual history, prior pregnancies and attempts at prior pregnancy, fatigue, constipation and other symptoms of thyroid disease, breast secretions, acne and hirsutism. Use of exogenous hormones such as estrogen found in soy-based products and alternative medicine such as herbs or other supplements are potentially important because these bioactive compounds can interfere with the patient's own hormones. History of issues affecting pelvic factor, such as prior abdominal/pelvic operations, sexually transmitted infections (STI) and pelvic pain with menses, intercourse or bowel/bladder function, is also significant. Male factor should be assessed by history of prior pregnancies created and/or exposure to pregnancy, sexually transmitted infections, urethritis, prostatitis, reproductive injuries, accidents, operations or diseases, undescended testicle(s), environmental toxicants, excessive heat, erectile dysfunction, obesity, genetic causes, hormonal abnormalities and other reproductive problems [26]. Combined factor history includes cervical operations, frequency and timing of intercourse and use of lubricants. General questions regarding weight, diet, exercise, sleep, smoking, alcohol or drug use, exogenous hormones, alternative medicines, other medications, general health and prior fertility testing and treatment are important for both female and male patients.

### Female Testing

Physical examination includes general health, height and weight, blood pressure and respiratory rate. Visual examination of the external genitalia, vagina and cervix should be performed followed by bimanual examination of the uterus, ovaries and rectovaginal area. The thyroid should be examined, along with the breasts for galactorrhea (nipple secretions) and the skin for acne or hirsutism (abnormal facial hair, periareolar hair).

Initial testing for causes of infertility is fairly simple. Table 1.1 lists common blood work used to test for ovarian reserve and the normal levels [27]. In addition, hyperandrogenemia (increased male hormone levels) can be tested with testosterone and possibly other androgenic hormone levels in selected situations. The clomiphene citrate challenge test (CCCT) is a more sensitive test of ovarian reserve than cycle day 3 FSH alone and is occasionally helpful. Karyotype (chromosome testing) is occasionally indicated to rule out genetic problems. Endometrial biopsy to date the endometrial development is a traditional test that has been shown not to be helpful and is no longer performed. Newer tests such as the endometrial receptivity assay are sometimes performed but are yet to be validated to improve live birth rates.

**Table 1.1** Ovarian reserve testing [27]

| |
|---|
| **Blood levels** |
| Anti-mullerian hormone (AMH: normal ~ > 1 ng/ml);<br>follicle stimulating hormone (FSH: normal ~ <10 miU/ml)<br>Estradiol (E2: normal ~ < 80 pg/ml)<br>Thyroid stimulating hormone (TSH: normal < 2.5 miU/l);<br>prolactin levels (PRL: normal ~ 25 ng/ml). |
| **Ultrasound** |
| Antral follicle count (AFC: normal ~> 7) |

Pelvic factor is usually assessed initially with ultrasound to obtain information about the uterus (e.g., uterine myomas, which are benign muscle tumors of the uterine wall), congenital abnormalities (septate uterus may be associated with infertility, single and double uterine abnormalities with pregnancy complications) and endometrial thickness and characteristics; the ovaries (size, antral follicle count, ovarian cysts); the fallopian tubes (hydrosalpinx or complete distal obstruction of the fallopian tube), paratubal cysts and possibly endometriosis (only endometriomas which are ovarian cysts of endometriosis and deeply infiltrative endometriosis can be seen on ultrasound). A saline infusion sonogram (SIS, also known as a sonohysterogram or SHG) provides additional sensitivity (ability to detect a real abnormality) to identify intrauterine polyps, myomas or adhesions. After an ultrasound, the most common test of the pelvic organs is a hysterosalpingogram (HSG). The HSG is a radiological procedure that is better at documenting whether the uterine cavity is normal shape and whether the fallopian tubes are open and/or have intratubal damage or peritubal adhesions. Very occasionally magnetic resonance imaging (MRI) or computerized tomography (CT) may be used to help define abnormalities of the uterus or ovaries or other pelvic masses. Surgical procedures that can be used to further diagnose and then to treat problems that have been identified by imaging technology include hysteroscopy (passing a small telescope through the cervix to look into the uterine cavity) and laparoscopy (passing a small telescope through a sub-umbilical incision into the abdomino-pelvic cavity to look at the internal organs) with hydrotubation (injection of colored fluid through the fallopian tubes to check for patency), which are minor surgical procedures that usually require anesthesia.

## Male Testing

Male testing is almost always initiated with a semen analysis to measure volume of semen, pH, liquefaction, count, motility and morphology. Normal parameters by the World Health Organization Standard (6th edition) count are volume is 1.4 ml or more, count 16 million/ml or higher, total motility 42% or more, progressive motility 30% or more and strict morphology 4% or higher [28]. Morphology is especially difficult to assess and many men have slightly decreased morphology. Antisperm antibody and other male tests rarely add additional useful information except perhaps for men with prior vasectomy considering reversal [29].

Tests for combined factor generally involve sexually transmitted infection testing for HIV 1 and 2, HTLV (human T lymphotropic virus) I and II for men, hepatitis B and C, syphilis, chlamydia and gonorrhea. The traditional test for combined factor, the postcoital test, has been shown not to be helpful and is no longer performed [30].

General/systemic tests for hematology (blood, spleen), biochemistry (liver, kidneys, parathyroid), and blood sugar (pancreas) are generally indicated if not done within the past 1 to 2 years. Obese patients or those with family history of diabetes mellitus should be tested with fasting blood sugar (normal <100 mg/dl) and HgA1c (a measure of glucose metabolism, normally less than 5.7%).

Genetics testing has become much more common in the last several years. This can include preconception testing to identity single gene defects or translocations that can increase risk of morbidity and mortality and preimplantation genetic testing during IVF cycles to identify normal and abnormal embryos, the latter having decreased chance of pregnancy and a higher chance of poor maternal and fetal outcomes [31].

The purpose of testing is not to do tests or, in fact, to simply make a diagnosis. The purpose of testing is to determine the prognosis for the patient given the test results, and how that prognosis can be improved by: intervention with lifestyle or other general/systemic changes; hormonal treatment of specific ovulation or other hormone problems; controlled ovarian stimulation to increase the number of eggs ovulated in a given month; surgical intervention to improve the pelvic organs; male factor treatment with drugs or surgery; or combined factor treatment to get more, better sperm closer to the egg(s) at the right time. All diagnostic tests and medical or surgical interventions should be focused on improving the patient's quality of life by better disease management and, specifically, meeting the desired wish of delivering a healthy singleton baby.

At this planning visit, their physician may explain to a couple that infertility represents the fifth highest

burden of disease globally in reproductive-age individuals, and that learning one is infertile often carries an emotional impact equivalent to that of a diagnosis of HIV or cancer [32]. Additionally, this is a condition that often must be dealt with by the couple alone because it is generally not discussed socially, even while there can be significant pressures from other family members to have children. Infertility is often the first major challenge a young couple face together, so it is important to communicate clearly to each other how they feel and what they want to do. The husband/partner can be educated about the fact the woman (or female partner receiving treatment in a same-sex relationship) almost always experiences much more pressure and emotional stress, and so the partner must support her personally and socially; and she needs to express appreciation for these efforts, even though they cannot completely resolve her emotional burdens. The importance of obtaining the best available evidence, asking questions and making logical decisions can be emphasized. The value of emotional support through good nutrition, sleep and exercise as well as meditation, prayer, yoga, acupuncture, mindfulness, or other mind–body exercises and support groups is emphasized. The important role of individual, couple and/or group counseling during treatment is explained. They are provided with written materials on the medical and emotional aspects of infertility, support resources and information, and the psychological services available at the clinic (see Addendums for examples of support resource materials).

## Psychosocial Management

Despite the media attention often given to infertility, few people ever anticipate they will have problems getting pregnant or carrying a baby. There is mounting evidence that men and women frequently underestimate their reproductive time clock as well as lifestyle issues that can affect childbearing (e.g., smoking, body weight, alcohol, drug and caffeine consumption), and it is suggested that people should be encouraged to think about parenthood goals in a similar way as one does other important life goals, like education and careers [3]. In addition, advances in technology in cryopreservation of oocytes have opened a new area of counseling for women needing to preserve their fertility due to a medical problem, usually cancer treatment, or by choice to use in the future (see [33], pp. 212–235 on fertility preservation counseling). Hence, mental health professionals (MHP) in all types of practice settings can play an important role in helping their clients understand and consider preconception issues, fertility awareness and reproductive options.

The intention and planning of family creation is something that takes place psychologically long before it ever occurs physically. Individuals and couples begin thinking about having a child and being a parent often while still children themselves, as the imaginary journey towards parenthood begins. The longer one walks down this path, the stronger the attachment to the "wished-for" baby. If difficulties occur along the road, assistance may be needed to achieve the dream of a child. These difficulties may be caused by medical or genetic issues, which result in infertility, or by other life circumstance, such as not finding a partner or sexual orientation, whereby people are technically not "infertile" but nonetheless need medical assistance (now described as "fertility care") to have a child. No matter what the path is that has brought an individual or couple to seek MAR, every person brings a history that will impact how he or she experiences impaired reproduction (see Chapter 2 on reproductive psychology).

### Psychosocial Context

Reproduction is a basic human need, influenced by strong psychological, cultural and social drives. Griel and colleagues [34] describe infertility as a "socially constructed reality" rather than purely a medical condition with psychological consequences. Individuals and couples must embrace the role of parenthood as a desired social role or they would not seek medical assistance. For couples, it is a condition that affects them both, no matter who is identified as impaired, and is most evident as a state of "absence" (i.e., no child) rather than disease or symptoms. In addition, there are strong sociocultural influences in both developed and LMI countries that shape how an individual or couple experience infertility. In pronatalist cultures, childlessness is surrounded by shame and stigma, while in developed societies, not having a child may be viewed as a voluntary, viable choice. Griel et al. state, "The experience of infertility is shaped by the social context ... [and] best understood as ... a process whereby individuals come to define their ability to have children as a problem, to define the nature of that problem, and to construct an appropriate course of action" ([34], p. 141).

In a controversial revision of Maslow's hierarchy of needs theory, Kenrick and colleagues [35] renovated the pyramid by replacing "self-actualization" and putting "parenting" at the top, reflecting new findings from the fields of neuroscience, developmental and evolutionary

psychology. They contend that reproduction is not just about producing children, but also raising and parenting them so they, in turn, will reproduce. Therefore, all the effort that goes into parenting (e.g., caring, feeding, nurturing, educating children) is based in deep-rooted psychological urges that are a hallmark of being human and are passed down from generation to generation.

Thus, parenthood is not only a desired social role, but also a biologically driven need, creating the "perfect storm" for psychological distress when thwarted. It is well established in the literature (and throughout this text) that infertility is an inherently stressful experience that creates great emotional turbulence in the individual and/or couple the longer it goes on. So, whether by impairment or circumstance, patients presenting for MAR will need psychological support and assistance throughout the treatment process. While most couples presenting to clinics are emotionally well-adjusted and not fundamentally different from others, they are more likely to experience distress over time, affecting self-esteem and life satisfaction, because of infertility [34].

Men and women will experience infertility differently in both the way they feel and the way they cope. Most studies indicate that women experience greater infertility-related stress, reporting more symptoms of depression and anxiety than men. Men also experience infertility stress, but with less emotional affect and more indirectly, through the effect it has on their partner and concern about her [34]. The emotional context changes when infertility is gender-specific (i.e., female factor or male factor), with the diagnosed individual within a couple having a more negative response typically reflecting negative feelings surrounding diminished self-esteem, self-image and body-image [36]. Consequently, shame may become a defining force as an individual feels there is something inherently wrong or defective about themself. Feelings of grief and loss, well documented throughout the literature, are the emotional response and continue when treatment is unsuccessful and, finally, when moving on to third party reproduction.

Regarding coping strategies, women display higher levels of seeking social support (e.g., talking to friends and family), avoidant behavior of painful situations (e.g., baby showers, pregnant friends) and information-seeking. Men tend to use distancing from the pain of infertility and problem-solving [37]. Similar dynamics may occur in same-sex relationships. These different partner/gender-related coping strategies may give rise to additional stress within a couple's relationship, as women seek more ways to obtain emotional support, while men attempt to problem-solve and, when not effective, distance themselves out of frustration. This dynamic can be played out further in their sexual relationship, which is explained in the adage: "Women need to feel loved (i.e., emotionally supported, feeling truly understood) in order to have sex, and men need to have sex (i.e., take action, physical response) in order to feel loved." Thus, infertility can have a powerful effect on a couple's sexual relationship, not only due to the repeated, time-sensitive, performance demands of procreation, but also because of the differences in the ways men and women cope with distress (see also Chapter 4 on couples and Chapter 6 on sexual therapy).

## Assessment

Infertility is not experienced in a vacuum and needs to be understood within the context of the history a patient brings to it. Just as physicians would not begin to treat a patient without comprehensive history-taking and doing a thorough medical examination, fertility counselors also must take a similar approach. Tools are available to help gather information, as well as self-administered interventions for patients in need of additional emotional support.

There are several self-report, standard screening tools for depression and anxiety which are easily administered, readily available on the Internet, and in numerous languages. The Patient Health Questionnaire (PHQ-9) screens for the presence and severity of depression and takes less than 3 minutes to complete. The Generalized Anxiety Disorder (GAD-7) can be used for screening and severity measuring of anxiety. Research has shown that psychological distress is common during infertility treatment, yet most patients are not screened for, nor receive referrals to, mental health services [38]. It is also important for all healthcare professionals to routinely assess fertility patients' coping and distress as part of standard care (not in response to someone "falling apart") and provide support resources. All patients bring a psychosocial history into their reproductive experience, which has a profound effect on how they feel and deal with it. The psychological side effects of medications used during treatment, and considerations for patients with a psychiatric history and on psychotropic medication, can impact treatment as well as interactions with the treatment team (see Chapter 7 on the intersect between psychiatric disorders and infertility).

Besides standard instruments used in the screening of depression and anxiety, several infertility-specific screening tools have been developed that help clinicians identify how patients are doing and their level of distress. These tools are validated, self-administered instruments, quick

to take, and can be easily interpreted by clinicians. FertiQoL can be completed online by patients (http://sites.cardiff.ac.uk/fertiqol/download), is currently available in 46 languages, and takes about 10–15 minutes to complete [39]. It assesses the impact of fertility problems and its treatment on a patient's quality of life along domains of personal, social and relational life. SCREENIVF has been found to be highly predictive of those at risk for treatment distress, which helps in directing patients towards additional psychological support [40]. The Fertility Problem Inventory (FPI) is another validated tool that measures an individual's infertility-related stress as well as the impact on a couple's relationship [41]. Any of these screening tools will help the fertility counselor in the assessment of a patient's current functioning and need for support as treatment progresses.

## Anticipation, Prevention and Support

For patients entering treatment, it may feel like embarking on a journey and entering a strange land where you don't speak the language or know the terrain you must travel. In this sense, fertility counselors, along with other members of the treatment team, will serve as guides. Metaphors like this abound that relate to the struggles and issues faced by patients, from the "emotional rollercoaster" of treatment cycles, "road maps" of where one has been and is going, and "bridges" that need to be crossed to reach a goal or connect to divergent paths or views. Since both words and visualizations are used, metaphors can be a powerful tool to open ways of thinking, evoke emotions, help understanding and change perspective with infertility patients.

Preparatory counseling is seen as both helpful and a valuable service for new patients entering treatment [42]. Patients need to anticipate what is ahead and should be provided with information and reading materials which are racially and culturally sensitive to the diversity of patients entering a practice. Materials regarding medical conditions, treatment options, the emotional experience of infertility, support services and resources should be available in printed versions to share during a counseling session, as an electronic file that can be emailed to patients prior to meeting, and on the clinic website. These educational materials and resources become the fertility counselor's "tools of the trade" and having them readily available and organized is important. Being able to anticipate what is ahead emotionally, where and how difficulties may arise and what strategies might help, can prevent more serious problems. Helping patients understand that "an ounce of prevention is worth a pound of cure" may help them be more adaptive and resilient to the distress of infertility.

Support becomes a pivotal piece of care for all members of the treatment team. Patient-centered care is supportive and focuses on positive communication with staff – empathy, respect, sensitivity, trustworthiness and responsiveness. As all MHPs know, these interactions are the basis of forming a therapeutic relationship in counseling. While individual and couple counseling should be easily accessible for patients, the reality is that only a small minority will follow on their own and those given a referral for counseling during a "crisis" often deem it as another example of their inadequacy [38,43] (see also Chapters 3 and 4 on individual and couple fertility counseling).

Research has shown that the most effective psychosocial intervention is group counseling along with psychoeducation, normalizing the emotional response to infertility, teaching effective coping strategies and educating patients on various aspects related to treatment and family building [43]. These groups can consist of periodic (weekly/monthly), open-ended gatherings which are more emotion-focused on dealing with treatments (e.g., general infertility, recipients of donor gametes, intended parents or gestational surrogates, secondary infertility, etc.), skill-building (e.g., mind–body techniques, cognitive–behavioral strategies, etc.), or specific topics providing more psychoeducation (e.g., adoption discussion, disclosure assistance, etc.), yet all will be offering patient support [44]. Patient organizations, such as Resolve, continue to provide support, advocacy and information, while the Internet has dramatically changed the way patients access information, seek support (chat rooms, blogs, social media, etc.) and obtain education [45]. Furthermore, during COVID-19, virtual support groups via telehealth have provided a life-line to isolated fertility patients (see Chapter 5 on group counseling).

Spirituality is another form of support, often overlooked by clinicians, which should be considered by fertility counselors (see Chapter 8 on spirituality). Religion and spirituality usually occur within a cultural context of the patient going through treatment and may provide important information about how infertility is perceived. Patients with a strong spiritual foundation utilize this belief system to cope with the sense of loss of control, to help in decision-making and to find meaning and purpose from the experience. While many clinicians, both medical and psychological, are uncomfortable with addressing religion and spirituality, research continues to show this is a neglected area that fertility patients wish was discussed [46].