

The clinical content of preconception care: preconception care for special populations

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Women with disabilities, immigrant and refugee women, and cancer survivors may have medical, psychosocial, and/or cultural issues. Appropriate preconception guidance and management of reproductive planning and preconception issues is essential to ensure that women in these groups can make informed reproductive decisions and achieve optimal reproductive outcomes.

Key words: cancer, disability, immigrant, preconception, refugee

Ongoing preconception risk assessment, guidance, and intervention, when integrated into primary and specialty care, can accomplish 3 goals. The first is to minimize risks for a woman, if she becomes pregnant, and risks to her offspring. The second is to optimize a woman's health in her reproductive years and beyond. The third is to assist a woman to proactively plan for her reproductive future. These goals are important to achieve for all women of reproductive age, but may be of particular importance among women who are at risk for poor reproductive health outcomes or who have special reproductive health needs.

Women with disabilities and immigrant and refugee women may experience physical, social, and/or cultural barriers to accessing and obtaining health care, including preconception care. They

may have also have to face and overcome a variety of personal obstacles, and these strengths should be acknowledged by care providers as they creatively strategize with these women so they may secure ongoing, viable health care and plan their reproductive futures to their best advantage.

There are increasing numbers of cancer survivors of reproductive age. Cancer survivors benefit from guidance about risks of treatment to their fertility and about fertility preservation options. They should be counseled about risks of past or current treatment to their current and future health and how these risks may impact pregnancy or the health of potential offspring. Ongoing screening is indicated for some survivors, and may uncover medical issues, such as impaired cardiac function, that are important to diagnose preconceptionally so that a woman can make fully informed reproductive decisions.

This article summarizes the value of preconception counseling and interventions specific to each of these groups of women and identifies clinical guidelines, where applicable.

Women with disabilities Burden of suffering

There are an estimated 54-60 million people with disabilities in the United States and more than half are women, many of reproductive age.¹ Individuals may be born with disabilities or may acquire them during the course of a lifetime. The impairment may be stable or progressive. Disabilities include those af-

fecting motor or sensory abilities, as well as developmental disabilities and mental illness. People with disabilities may experience a variety of barriers to care. Besides physical and administrative barriers, women with disabilities have identified attitudinal barriers to gynecologic care. They report that providers may assume that they are not sexually active or that they do not desire pregnancy.²⁻⁴ Preexisting medical issues can affect a woman's health in pregnancy and the pregnancy outcome.⁵ In a large sample of women with disabilities, those with functional limitations, of all ages, were more likely to report fair or poor health, current smoking, hypertension, overweight, and mental health problems than women without functional limitations.⁶ Studies report that women with physical disabilities experience the same rates of abuse as other women but experience a longer duration of abuse.^{7,8} Some disabilities, such as systemic lupus erythematosus (SLE), can worsen in pregnancy and some may be exacerbated postpartum, such as rheumatoid arthritis or multiple sclerosis. SLE is associated with an increased risk of fetal loss, fetal growth restriction, and preeclampsia.⁹ Conditions that are common in pregnancy may be more severe in women with disabilities. Examples are fatigue, fluid retention, bladder dysfunction, and problems with weight gain. There are certain complications that may develop or worsen during pregnancy because of a woman's disability.² Women with spinal cord injuries are at risk for autonomic dysreflexia, which can be precipitated by pelvic examinations or labor.

Those with limited mobility and those who use wheelchairs are at an increased risk for deep vein thrombosis. Among women with neurologic conditions, urinary tract infections, respiratory dysfunction, urinary incontinence, spasticity, constipation, or pressure ulcers may be issues in pregnancy. Women who

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have impaired balance, muscle weakness, or paralysis are at increased risk for falls during pregnancy.²⁻⁴

How detectable is the condition?

Disabilities are identified through history and physical examination and through indicated diagnostic tests and evaluation by specialists.

How effective are the current treatments?

Women with disabilities will have greater access to care and willingness to participate in care if physical, administrative, and attitudinal barriers are minimized. Preconception consultation with medical specialists, nursing, social services, and occupational and physical therapists can assist in planning and can potentially maximize pregnancy outcomes, although supporting data are lacking.

Genetic counseling is valuable for women with or at risk for genetic conditions, and their families, to give them the opportunity to make informed decisions about whether they will elect genetic testing, the risk of having an offspring given a particular heritable or genetic condition, and the options they will have based on the results.⁵

Impact of preconception care

Planning preconceptionally to maximize social and environmental supports for women with disabilities would seem advantageous considering the demands of parenting, and research has shown that disabled persons who have intact social support report a better quality of life than those who lack social support.¹⁰ Avoidance of teratogenic effects can only be successful if women taking teratogenic medications are counseled preconceptionally about the use of these medications and plan with their providers the best way to balance their medical treatment with a desire for a healthy pregnancy and infant. Women who discover they are at risk for a genetic condition preconceptionally, as opposed to during pregnancy, may use this information in weighing whether or not they desire to become pregnant and—depending on the condition—have more options to choose

from to avoid passing the condition to their offspring.

Recommendations by other groups

The American College of Obstetricians and Gynecologists,^{11,12} along with other groups,¹³ have made recommendations.

Recommendation. Providers should understand that women with disabilities can have healthy pregnancies and that disabilities can coexist with wellness. Providers should work to remove physical, administrative, and attitudinal barriers to the care of disabled women.

All women of reproductive age, including those with disabilities, should receive counseling about the potential effects of any medications they use on pregnancy-related outcomes and about options to alter dosage or switch to safer medications prior to conception. The medical, social, and psychological issues related to pregnancy and the disability should be assessed, and the woman and her family should be counseled on them. Health care providers should offer women with disabilities contraceptive choices that are practical and appropriate for the individual's medical and personal needs. Issues involving informed consent and guardianship need to be addressed when caring for women with developmental disabilities, in relation to contraception and pregnancy. Referral for genetic counseling, if appropriate, is indicated for all women preconceptionally; however, it may raise difficult psychosocial issues for women with disabilities and, therefore, counseling referrals should be handled sensitively. *Strength of recommendation: B; quality of evidence: III.*

Immigrant and refugee populations

Burden of suffering

There is ample research on the epidemiologic paradox showing that foreign-born women have better birth outcomes despite late access to prenatal care and probably less access to preconception care (healthy migrant effect) than US-born women. However, refugee women—who have often lived under extremely stressful conditions in their home country (war, persecution) and spent time in refugee camps—are a group

of immigrants who have worse birth outcomes when compared with US-born women. Immigrant women face social, language, and cultural barriers that may affect their preconception health. Immigrants from developing countries may have a lower level of overall health, if they have had limited or no access to health care in their countries of origin. However, foreign-born women may also display healthy behaviors that should be maintained after immigration to the United States and that are at risk of getting lost as a result of acculturation (eg, less likely to use tobacco and alcohol or drugs, less sedentary lifestyle). Preexisting medical issues can affect a woman's health in pregnancy and the pregnancy outcome.¹⁴ Immigrants from regions of the world where tuberculosis and hepatitis B are common may suffer from the effects of these untreated conditions.¹⁵ Immigrant women may experience psychological stresses related to the events that motivated their immigration, events occurring while immigrating, and events occurring in the United States. Separation from family, uncertain immigration status, social isolation, and occupational stresses may negatively impact their mental and physical health. Immigrant women face unique challenges in accessing health care. Of the estimated 16.6 million foreign-born women in the United States in 2003, more than half (59.2%) were noncitizens—a figure that includes documented and undocumented immigrants.¹⁶ Women who are noncitizens are far more likely than citizens to have no usual source of health care (26.1%) and no health insurance (45.5%), and almost 3 times more likely to have not seen a health professional in the past year compared with those born in the United States, according to the Health Resources and Services Administration.¹⁷ Immigrants who do not speak English may have difficulty finding health care. Immigrants' perceptions and beliefs surrounding health and illness and their attitudes toward health care providers vary widely depending on their cultures and the extent of their interactions with health care in the United States.¹⁸⁻²⁰

How detectable is the condition?

Pregnancy is the time at which immigrant women of reproductive age are most likely to receive health care services. Therefore, identification in the preconception or interconception period is difficult, especially identification of those who are undocumented and may be reluctant to seek care or to be able to afford it if they are ineligible for health coverage benefits.

How effective are the current treatments?

The effectiveness of preconception care for immigrant women is limited by the barriers described in this section. It seems reasonable that the preconception health of immigrant women could be improved by increasing culturally competent outreach efforts and improving access to care.^{21,22} It is difficult to support this assertion because there is a lack of published studies about outreach and approaches to the care of immigrant women.

Impact of preconception care

Preconception care can help reduce the incidence of perinatal complications through identification and management of clinical issues. For a woman to receive preconception care, she must have access to a source of primary care. Thus, access to primary care must be ensured before pregnancy occurs.

Recommendations by other groups

None identified.

Recommendation. Given the opportunistic fashion in which preconception care of immigrant and refugee women typically must occur, it is important to consider preconception concerns as part of all health care encounters with immigrant and refugee women of reproductive age. Referring such women to a source of ongoing primary care that is culturally and linguistically competent, and that will accept their insurance coverage or provide care free of charge or on a sliding fee basis, is important for immigrant and refugee women. Seek to identify and understand the needs of immigrant women and their families. Understand immigrants' potential for increased medical and social risks and

previously undetected medical problems. Deliver services and written materials in the preferred language of the population served. Ensure that interpretation and translation services comply with all relevant federal, state, and local mandates governing language access.

Integrate preconception care into refugee screening. Work with ethnic community-based organizations to provide preconception care messages in non-health care settings such as English as a second language classes. Screen immigrants at high risk for tuberculosis and refer for treatment as indicated. Screen immigrants born in Asia, the Pacific Islands, Africa, and other countries where hepatitis B is highly endemic, with the hepatitis B surface Antigen (HBsAg) test. Highly endemic means that > 8% of the population in that country has hepatitis B virus infection. Assess the immunization history, including the rubella status, of immigrant women and administer any needed vaccines, or refer for these services. Assess the mental health of immigrant women and refer for services as needed. *Strength of recommendation:* B; *quality of evidence:* III.

Cancer survivors

Burden of suffering

For many types of cancers, survival has increased in the past decades. In 1996, it was projected that the prevalence of cancer survivors 16-44 years of age would be 1 in every 900 persons in the United States by the year 2000.²³ Cancer survivors of reproductive age face the challenge of integrating the experience of cancer and its treatment into their future plans, including their plans for reproduction.

There are potential negative physical and psychological impacts of the cancer experience on pregnancy and child rearing, but positive psychosocial effects have been identified as well.^{24,25} Cancer survivors are at risk for permanent infertility or compromised fertility. Factors affecting male infertility include the type of cancer (eg, testicular) and effects of chemotherapy or radiation on sperm number, motility, morphology, and DNA integrity. In girls and women, fertility may be compromised by surgical, medical, or radiation treatments, which

may decrease the quantity of primordial follicles, affect hormonal balance, or interfere with reproductive organ function.^{23,26} Depression, chronic fatigue, cognitive changes, and neuropathies—all of which can make pregnancy and parenting more difficult—are not uncommon treatment side effects experienced by cancer survivors. A cancer survivor with a history of abdominal/pelvic radiation who becomes pregnant has an increased risk of having a low birth-weight infant, with an inverse association observed between higher doses of radiation and infant birth weight.

Studies of cancer survivors have not found them to have an increased risk for miscarriage or birth defects, and most types of chemotherapy are not linked to adverse pregnancy outcomes.^{27,28} Furthermore, there is no documented increase in risk of childhood cancer among the offspring of childhood cancer survivors, but longer follow-up is needed.²⁹ However, survivors of hereditary cancers, such as certain types of breast, ovarian, and colorectal cancers, who test positive for the genetic mutations associated with these cancers, risk passing on these mutations to their offspring.

Genetic testing for the BRCA1 and BRCA2 genetic mutations has been shown to be highly sensitive but the specificity is not well studied.³⁰ Women who have received anthracycline-based chemotherapy regimens or radiation in the area of the heart or surrounding tissues are at an increased risk for heart damage.³¹ This damage may manifest months or years later and, although rare, could worsen in pregnancy or the postpartum period.³² Childhood cancer survivors who received doxorubicin and who had resultant left ventricular dysfunction before pregnancy have been documented to have further declines in cardiovascular function after pregnancy.³³

How detectable is the condition?

Cancer survivors planning their reproductive futures may have had cancer as a child or as an adult. Their risk for infertility can be assessed, in part, by the history of their cancer and treatment. Records of cancer treatment can be very helpful. Permanent infertility or com-

promised fertility in survivors depends on their age, sex, and pretreatment fertility; the type of cancer; treatment type, dose, and intensity; size and location of radiation fields; and method of administration of chemotherapy. The older a woman is at the time of the cancer diagnosis, the higher her risk of premature ovarian failure (POF). The chemotherapeutic agents most likely to cause POF are the alkylating agents. Examples of commonly used alkylating agents are cyclophosphamide, nitrogen mustard, and procarbazine. The woman's age at the time of radiation treatment, the total dose, and the number of exposures affects the degree of damage to ovarian tissue. Women who receive pelvic or abdominal radiation, plus chemotherapy, have a higher risk for POF than those receiving only chemotherapy.³⁴

How effective are the current treatments?

Fertility preservation is very important to many cancer survivors. The 2 most successful methods are sperm cryopreservation for men and embryo freezing for women. Limited data show that fertility preservation techniques do not decrease the success of cancer therapy.²³ No clear guidelines exist regarding timing of conception postcancer diagnosis. Generally the advice is to wait until treatment is concluded. Breast cancer survivors comprise a large group of reproductive-aged women who may be planning or contemplating pregnancy. These women have typically been counseled to wait 2 years before conception to pass the period of highest risk for recurrence. However, for women with localized disease, survival has not been shown to be adversely affected when conception occurred within the 2 years after diagnosis.³⁵ Genetic counseling is valuable for women with a personal or family history of a cancer with a known associated genetic mutation so that the woman may explore her risk and the implications of testing herself and future offspring for the mutation.

Impact of preconception care

Cancer survivors have an increased risk of having a low birth-weight baby. Con-

trol of other risk factors for low birth weight, such as smoking cessation, has been shown to reduce the risk of having a low birth-weight infant.

Diagnosis of cardiac dysfunction prior to pregnancy permits the initiation of medication, if indicated, that may delay the progression of the dysfunction,³⁶ and makes it possible to counsel the woman about her risks for a further decline in function during or after pregnancy. If she elects to become pregnant, appropriate monitoring can be planned during pregnancy and delivery including anesthesia management for labor and birth.³⁰

Preconceptional genetic counseling is valuable for women with a known personal history of hereditary cancer, to give them the opportunity to make informed decisions about whether they will explore the option of preimplantation genetic testing.²⁵

Recommendations by other groups

The American Society of Clinical Oncologists²⁴ and the American Society for Reproductive Medicine²⁶ have published recommendations about fertility preservation in cancer patients. The Children's Oncology Group has published risk-based pediatric cancer survivor guidelines.³⁰

Recommendation. Newly diagnosed cancer survivors should be educated about fertility preservation options as soon as feasible and should be referred to reproductive specialists if these options are desired.²⁴ Cancer survivors considering pregnancy should be counseled about the potential reproductive effects of various cancer treatments on fertility and on pregnancy. Women who have received alkylating chemotherapeutic agents and/or pelvic or abdominal radiation should be counseled that they have an increased risk for POF. Women who have had pelvic or abdominal irradiation should be counseled that they are at risk for having a low birth-weight infant. When considering pregnancy, breast cancer survivors who are candidates for selective estrogen receptor modulators (SERMs) should be counseled that these agents are generally avoided during pregnancy because of case reports of animal and human birth defects.³⁷ A reli-

able nonhormonal contraceptive method should be used during treatment with a SERM. Genetic counseling and testing should be offered to survivors of cancers linked to genetic mutations to inform their decisions about future reproduction. Female cancer survivors who received anthracycline chemotherapy, radiation to the heart or surrounding tissues, or both should be evaluated by a cardiologist prior to conception. Annual breast screening for female childhood cancer survivors who received chest radiation is recommended beginning at age 25 years. *Strength of recommendation: A; quality of evidence: III.*

Conclusion

Women with disabilities, immigrant and refugee women, and cancer survivors all face the challenge of integrating their experiences into their reproductive decision making.

Providers who seek to understand both their challenges and their strengths can team with these women to help them achieve better health, including reproductive health.

Women in all 3 of these groups will benefit from discussion of their reproductive life plans. Providers who make no assumptions about what a given woman's reproductive plan might be and who initiate the discussion will aid women in making informed reproductive decisions. Preconception guidance and interventions that address physical, psychosocial, and/or cultural issues can produce better health for these groups of women and for their potential offspring. ■

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