

A PROVIDER'S HANDBOOK  
ON  
CULTURALLY  
COMPETENT  
CARE



WOMEN'S HEALTH  
1<sup>ST</sup> EDITION

*Kaiser Permanente National Diversity Council  
and the Kaiser Permanente National Diversity Office*



KAISER PERMANENTE®



*Femme*  
*quilt*  
*An original hand painted art*  
*quilt that celebrates the beauty*  
*and diversity of women.*

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of the Colorado Permanente  
Medical Group.

women's health

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# INTRODUCTION

Kaiser Permanente is committed to providing linguistically and culturally competent care to its increasingly diverse membership. Meeting the needs of its membership and addressing the urgent national problem of disparities in health status and health care delivery require interventions that are respectful, patient-centered, and culturally skilled. One such intervention is the Provider Handbooks. The goal of the Provider Handbooks is to provide Kaiser Permanente clinicians with an overview of the cultural and epidemiological differences that characterize major cultural groups represented within our membership. In no way is our intention to stereotype patients by groups. The Handbooks focus on common characteristics of each group that may have implications for health care organizations and practitioners.

It is a pleasure for the Kaiser Permanente National Diversity Council and the National Diversity Office in collaboration with Drs. Calvin Wheeler, Physician-in-Chief, David Newhouse, Assistant Physician-in-Chief, and the Center of Excellence for Women's Health in the Fremont/Hayward Service Area to present the latest in the series of Provider Handbooks on Culturally Competent Care. The Women's Health Handbook presents health care research, information and tools and explores issues of culture, race and ethnicity with the intent to make an important contribution to positive health outcomes within Kaiser Permanente's membership and reduce racial and ethnic health disparities.

In keeping with the Kaiser Permanente philosophy of total health (considering the mind, body and spirit), the authors were asked to speak to their areas of expertise as they reflected on the spirit behind their work and their passion for improving health care for women. The voice of the authors in this Handbook is clear and compelling. Some of the chapters in this Handbook are personal and rely more on a story-telling approach, while others use facts and data to make their point. Some authors have graciously demonstrated their passion for Women's Health through their artwork.

The choice of color of the Women's Health Handbook – Gold – was deliberate. Several ancient healing traditions used gold to heal and restore balance of mind and body, and women were often the healers in these traditions. Creating a healing environment is both a science and an art and not only nourishes the spirit of the patient, but that of the provider.

Our hope is that the spirit and passion brought to this writing and this Handbook will be a reminder to all providers in health care of the precious and unique nature of every patient encounter.

# DEMOGRAPHICS

Maria Servin

## AUTHOR FOREWORD

This chapter provides a snapshot of women's health in the United States across diverse cultural, racial, and ethnic groups. It contextualizes the data presented throughout the Women's Health Handbook, highlighting demographic trends that may indicate changing health risks among women. Much of the information, presented here as an overview, will be covered in more detail in subsequent chapters.

National surveys and data collected on health and health behaviors by gender, age, race, and ethnicity offer demographic data that increasingly reflect the diversity of the more than one-third of adult women in the United States who are racial and ethnic minorities. However, research and data for specific sub-populations of women by race and ethnicity remains limited making it difficult for health care providers to access accurate information to address the health needs of all women. Gaps in data collection highlight the need for health organizations to collect race, ethnicity, and language data at a granular level and not just reflect the standard racial and ethnic categories as identified by the Federal Office of Management and Budget.

In this chapter, I hope to provide information that helps identify health risk factors for women of diverse cultural, racial, and ethnic groups by demographic trends. I hope this information adds to the knowledge you obtain from a medical examination, and enables you to offer patients respectful, culturally skilled, quality care.

## INTRODUCTION

A woman's membership in groups defined by race and ethnicity, age, income, education, employment, and sexual orientation influence her health status, and her access to and utilization of health care. Gender further influences the social and economic determinants of health, such as social status, the lived experience of racism and discrimination, access to nutrition, housing, physical activity, transportation, working conditions, sexual harassment, gender discrimination and safe neighborhoods. This chapter presents demographic data to describe women in the United States as both a specific and a diverse group, and highlights some of the health challenges facing women of diverse cultures, races, and ethnicities.

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*We are women from all kinds of childhood streets: the farms of Puerto Rico, the downtown streets of Chinatown, the barrio, city-Bronx streets, quiet suburban sidewalks, the plains, and the reservation.<sup>1</sup>*

—This Bridge Called My Back: Writings by Political Women of Color

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Maria Servin is the service director of Marketing and Diversity for the Kaiser Permanente Fremont/Hayward Medical Centers in Northern California. Maria is currently the president of the Northern California Kaiser Permanente Latino Association and a proud past recipient of the KPLA Visionary Leadership Award (2003) and the Kaiser Permanente R.J Erickson Award (2002). Maria is most proud of having raised two beautiful young adults and enjoys spending time with them and her husband of over 20 years.

## AGE

In 2005, 150.4 million girls and women lived in the United States.<sup>2</sup> A large number of these women were between 15-44 years old and considered to be of reproductive age. Pre-conception health and reproductive health needs are important health services for women in this age group. (See the Reproductive Health chapter for information on pre-conception care).

Over the next 50 years, however, this distribution will shift toward an increasingly older female population in the United States. By July 2020, the U.S. Census Bureau estimates that the number of women 65 or older will exceed 29 million and represent close to one-fifth of the total female population. This rise is due, at least in part, to an increase in life expectancy for women, but primarily results from the aging of the baby boom population born between 1946-1964.<sup>3</sup>

## LIFE EXPECTANCY

Women comprise about 51.1% of the U.S. population<sup>4</sup> and live, on average, to be 80.2 years old, about five years longer than men.<sup>5</sup> As a result, the gender ratio for the U.S. population over 65 years is about 70 men for every 100 women, and about 41 men for every 100 women 85 years and over.<sup>6</sup> Older women who live alone may have limited social support and networks to take care of their health needs. In addition, the aging of the female population is likely to result in increasing numbers of women living longer but with more chronic illnesses and functional disabilities. With the aging female population, it is important for providers to understand the issues at the end of life that women may face and to provide care in a manner that is respectful and culturally skilled. (See the Spiritual Care: Death and Dying chapter for more information on end of life issues).

## RACE AND ETHNICITY

Women in the United States, specifically younger women, are racially and ethnically diverse. In 2004, 9% of women 65 years and older were black and 6% were Hispanic; however, among women younger than 24, 15% were black and 17% were Hispanic.<sup>7</sup> Similarly, non-Hispanic white women were 82% of women 65 years and older, but only 62.7% of women younger than 24.<sup>7</sup> In 2006, the U.S. population (male and female) divided by race and ethnicity is as follows:<sup>8</sup>

- 66.4% white (non-Hispanic)
- 14.8% Hispanic
- 12.8% African American
- 4.4% Asian American
- 1.0% American Indians/Alaska Natives
- 0.2% Native Hawaiians/Pacific Islanders

Providers must consider the influence and interaction of race, ethnicity, and culture on a woman's health experiences, status, and outcomes when she presents with a health condition.

## LANGUAGE

According to the 2000 U.S. Census, 18% of the population 5 and over speaks a language other than English, a significant increase from 1990 (14%) and 1980 (11%),<sup>9</sup> and 8.1% of the population noted that they speak English "less than very well." The most common non-English language spoken at home is Spanish (28.1 million speakers) followed by Chinese (2.0 million speakers).<sup>9</sup> For many women who speak a language other than English, language barriers may complicate their access to care and hinder effective communication with their providers, affecting the quality of care received and patients' satisfaction with that care. Important considerations for the provider and the health care system in meeting diverse language needs of patients include the availability of bilingual and multilingual providers to ensure language concordance between providers and their patients, easily accessible interpreter services and written health information, and health education classes in non-English languages (taking into account the aspect of health literacy) for limited English proficient populations.

## FAMILY STRUCTURE

In 2005, 12.6% of all households were run by a female householder with no husband present, compared to only 4.6% run by male householders with no wife present (about 2.7 times less).<sup>10</sup> Over the past ten years, the number of reported same-sex households has grown significantly. Of all households, 0.7% self-identify as unmarried same sex partners, and a little under half are female (0.3%).<sup>11</sup> Inter-racial families are also growing in numbers. It is important for providers to understand a woman's family structure to assess her network of social supports and potential stressors that may affect her health. For example women in same sex households may face discrimination and stigma that can negatively impact their health. (See the Lesbian Health chapter for more information on lesbian health).

## CAREGIVERS

Care-giving tasks may include housework, transportation, and financial decision-making. It is estimated that there are 44.4 million American caregivers age 18 and older that provide unpaid care to another adult. The majority of caregivers (83%) are helping relatives.<sup>12</sup> Many caregivers contend with their own unmet needs and challenges to their health including finding time for themselves, managing emotional and physical stress, and balancing work and family responsibilities. Eight out of ten mothers/guardians take primary responsibility for choosing their children's doctors, taking their children to appointments, and ensuring that they receive follow-up care.<sup>13</sup> It is important to understand a woman's caregiving responsibilities and its effect on her physical and emotional health and well being. Providers can ask patients about their caregiving responsibilities and offer resources and suggestions to help them build and/or strengthen their social support networks (See the Health Beliefs and Patterns of Care chapter for more information about caregivers).

## EDUCATION

Education is an important determinant of health, and women are graduating from high school and colleges at greater rates than men.<sup>14</sup> Asians have the highest rate of college graduation, followed by non-Hispanic whites, blacks, and Hispanics.<sup>15</sup> Non-Hispanic white and Asian men are more likely to graduate from high school or college than Non-Hispanic white and Asian women respectively, while black and Hispanic women are slightly more likely to graduate than men of the same race and ethnicity.<sup>15</sup>

Educational attainment has implications for health behaviors. According to an analysis of the 2005 Kaiser Permanente Member Health Survey, educational attainment appeared to have a stronger influence on behavioral health risks (i.e., obesity, smoking) and health status for women than for men.<sup>16</sup> In addition, the 2005 survey found a positive correlation between educational attainment and obtaining health information from multiple sources, including the Internet. Even so, significant disparities in health risks remain among education levels and across race and ethnicity. In the same Kaiser Permanente Member Health Survey, for instance, college-educated Asian Americans and Latinos were much less likely to eat at least 3 servings of fruits and vegetables each day than college-educated Non-Hispanic whites.

## INCOME AND POVERTY

Income represents one dimension of social class that is influenced by gender, and it has profound effects on health. Across racial and ethnic groups, women are more likely than men to live in poverty. Despite women's increased participation in the labor force, they continue to earn less than men. In 2005, the female to male earnings ratio was .77.<sup>17</sup> Median income also varies by race and ethnicity. The median incomes for white non-Hispanic and Asian households were above average (\$50,784 and \$61,094 respectively), while the median incomes for Hispanic and black households were below average (\$35,967 and \$30,858 respectively).<sup>18</sup>

Single female householders as a group tend to encounter higher rates of financial difficulty than single male householders or women in married couples. In 2005, families with a female householder and no husband present experienced far higher rates of poverty (28.7%) than married-couple families (5.1%) or families with a male householder and no wife present (13.0%).<sup>18</sup> Women who live in poverty may lack health insurance and access to preventive health services.

## IMMIGRANT HEALTH

Immigrants are the fastest growing segment of the U.S. population. As a percentage of the total population, the foreign-born population increased from 4.7% in 1970 to 11.5% in 2002.<sup>19</sup> Currently, over one-half of the immigrants to the United States are from Latin America, 25% are from Asia, 14% are from Europe, and 8% are from other regions.<sup>19</sup>

Immigrants underutilize health care services in the United States for a variety of reasons, including a lack of understanding of how the health care system works, limited English proficiency, the cost of care and lack of financial resources, the “inappropriateness” of services for culturally diverse populations, social stigma related to accessing specific services such as mental health services, potential preference for folk healers, concepts about health that differ from those of the dominant biomedical culture, and – for illegal immigrants – the fear of being sent back to their country of origin.<sup>20</sup> In addition to substantial linguistic, cultural, legal, and financial barriers, physicians are faced with medical conditions that they may not have seen before, including unusual infectious diseases and complex mental health and social issues.

Studies of the health outcomes of immigrant populations have documented disparities in health and access to care compared with their native-born counterparts while also reporting some health measures (self-assessed health, bed disability days, functional limitations, chronic conditions) that show that generally, new immigrants from various countries fare better than their native-born counterparts.<sup>19</sup> In spite of having limited access to health care and being uninsured, Hispanic immigrant adults had significantly better health than their U.S.-born counterparts. The health that Hispanic immigrants enjoy despite adverse sociodemographic characteristics and access to care factors, is often referred to as the “Latino paradox.”<sup>19</sup> Similar to immigrant Latino adults, the CDC reports that immigrant Asian adults are also healthier than their U.S.-born counterparts with less obesity, lower hypertension rates, and fewer risk factors for cardiovascular disease.<sup>19</sup>

## HEALTH CARE INSURANCE

Data from the Centers for Disease Control & Prevention (CDC)<sup>21</sup> indicate that women of all ages are slightly more likely to be insured than men and more likely to have a publicly funded source of health insurance (i.e., Medicaid, Medicare). This reflects the relative number of women, in comparison to men, who live below the poverty level in the United States. In 2005, the source of health coverage for women 18-64 was distributed as follows:<sup>22</sup>

- 61% received health insurance coverage from their own, or their spouse’s, employer
- 6% were covered by private insurance
- 10% were insured by Medicaid
- 3% obtained coverage through other government programs
- 20% were uninsured

Foreign-born adults were more likely to be uninsured than their native-born counterparts (26% compared with 11%).<sup>19</sup> As women are more likely to work part-time, have lower incomes, and rely on spousal coverage, these trends can make a woman more vulnerable to losing her coverage if she becomes divorced or widowed, if her spouse becomes unemployed, or if her spouse’s employer drops family coverage or increases insurance premiums and out-of-pocket costs to unaffordable levels. In addition, for many women, access to health care is complicated by health plan coverage policies, affordability, and logistical barriers, such as transportation. A substantial proportion of women change doctors due to dissatisfaction with quality of care, resulting in care that is fragmented.<sup>3</sup>

## HEALTH STATUS – AN OVERVIEW

Many women have health conditions that necessitate ongoing treatment. (See the Major Diseases chapter for more information on the prevalence and incidence of major diseases among women). According to a survey conducted by the Kaiser Family Foundation:<sup>13</sup>

- Over one in 10 women (13%) had a health problem that limited their ability to participate in everyday activities.
- Compared to women 18–44, women 45–64 were three times as likely to have cancer or heart disease and four times as likely to have arthritis or hypertension.
- Low-income women were twice as likely as those with higher incomes to have fair or poor health status (23% and 10%, respectively) and conditions that limit activity (19% and 9% respectively).
- Women were at considerably higher risk for experiencing health problems in their older years, when the combination of increasing age and economic hardship takes its toll.
- Among low-income women 45–64, 49% reported arthritis, 41% had hypertension, and 32% had mental health concerns such as anxiety or depression.
- Latinas were the most likely to report fair or poor health (29%), and African American women were the most likely to report a health condition that limited their activity (16%).
- Among African-American women 45–64, over half (57%) reported hypertension and 40% had arthritis.
- One in six Latinas and African-American women 45–64 were diagnosed with diabetes in the past five years.

## RACIAL AND ETHNIC HEALTH DISPARITIES

On many measures of health status and access to care, communities of color fare worse than white communities. Disparities are evident across several areas including health status, health insurance coverage rates, access to physicians, coping with health care costs, transportation, childcare availability, use of preventive services, and perceptions of quality of care.<sup>13</sup> The 2004 Kaiser Women’s Health Survey indicated that Latina women were less likely to have a doctor than women of any other race or ethnicity,<sup>13</sup> and one in three Latina women reported delaying or going without care that year because the cost was too high.

African Americans in the United States experience a higher rate of poverty than non-Hispanic whites (24.3% vs. 8.2% respectively in 2006).<sup>23</sup> A significantly higher rate of African-American women 45 and older report having fair to poor health, including arthritis and diabetes, when compared to white women.

Over one third of all American Indians live in poverty<sup>24</sup> and as a result suffer from higher rates of malnutrition, tuberculosis, diabetes, and high maternal and infant mortality rates. Furthermore, they experience significantly higher rates of alcoholism and mental health disorders than do other racial and ethnic groups and may be at greater risk for abuse in a relationship, sexual assault, fetal alcohol syndrome, and depression.

In addition, women with physical or cognitive disabilities face an increased risk of intimate partner abuse and an increased risk of inadequate nutrition, among other disparities in health status.<sup>25</sup> Provider assumptions about women with disabilities, such as they are not sexually active, can be harmful to their health. In order to provide women with adequate reproductive health care and preventive screening, physicians need to take a sexual history with all patients. (See the chapter on Sexuality for more information on sex and sexuality among women of diverse cultures).

Systemic heterosexual bias can affect the health coverage of lesbian, gay, bisexual, and transgender (LGBT) individuals in relationships when employers, insurance companies or legal barriers deny health care coverage to LGBT partners. Furthermore, many LGBT individuals experience fear of discrimination and stigma and limited access to care, even when they do have insurance. It is important for providers to understand the health issues that face this group and the importance of obtaining a comprehensive personal history. (See the chapter on Lesbian health for more information on lesbian health).

## CONCLUSION

The intent of this chapter, as an overview to other chapters in the Women’s Health Handbook, is to provide health care providers with information that considers the social and cultural determinants and influences on a woman’s health beyond just the information obtained from a medical examination. As part of providing

culturally-skilled quality care, it is important to obtain information about how the patient views herself, her health, her family and community and the supports and stressors in her life by using cross-cultural interaction techniques, nonverbal cues and open-ended questions.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- Be sensitive to health concerns that particularly affect specific racial and ethnic groups and offer health education services to all female patients.
- Women face challenges regarding access to health care, especially in an environment of rising health care costs. Families with single mothers are more likely to experience financial difficulty than families with married couples, or single fathers.
- Encourage female patients to obtain mammograms, Pap smears, blood pressure checks, and other routine screenings.
- Do not assume that disabled women are not sexually active. Administer the same screening, education, and treatment for STDs that is provided for able-bodied women.
- When implementing new technology such as Kaiser Permanente's HealthConnect™, include high quality interpretation and translation services as an integral part of the infrastructure and planning of such tools.

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# RISK FACTORS

Mala Seshagiri and Katherine Brown-Favrot

## AUTHOR FOREWORD

Women throughout the world are exposed to behavioral, social, environmental, and economic risks that profoundly affect their health and wellness. Research continues to document the effect that these risk factors have on health outcomes for women and their families throughout the world. While writing this chapter I often reflected on the different risks that women in my life have been exposed to: cooking in pots or storing water in clay jugs that may leach lead, inadvertent exposure to toxic chemicals in their neighborhoods, and limited access to diagnostic screening exams. I dedicate this chapter to my soft-spoken, wise, and sweet mother, and my sister who is a cancer survivor. — *Mala Seshagiri*

At a time when there were only three antiretroviral medications available and almost everyone died of AIDS soon after diagnosis, Nicole was one of my first HIV patients. Nicole was a male-to-female transgender woman, tall and slender, with long, curly red hair. As her CD4 cells dropped, she grew thin and more fatigued and the last time I saw her, she was too exhausted to carry on a conversation. Nicole disappeared from care after that visit and I never had the chance to tell her that she was the bravest woman I knew. I dedicate this chapter to the memory of Nicole in the hope that we may honor her womanhood by caring for women with compassion, dignity, and grace. — *Katherine Brown-Favrot*

## INTRODUCTION

In the 2002 World Health Report: Reducing Risks, Promoting Healthy Life, the World Health Organization (WHO) identified global risk factors that account for over 40% of the 57 million deaths worldwide each year. WHO defined “risk” as “a probability of an adverse outcome, or a factor that raises this probability.” Some of the top preventable risk factors studied in the report were unsafe sex, high blood pressure, tobacco, alcohol, unsafe water, sanitation and hygiene, high cholesterol, indoor smoke from solid fuels, iron deficiency, and overweight/obesity. Together, these account for more than one-third of all deaths worldwide.<sup>1</sup> This chapter details some of the more important risk factors that affect the mental, physical,



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Katherine Brown-Favrot, MA RN MBA MFA grew up in Berkeley, California. As a nurse she has worked in the areas of neurological intensive care, emergency care, spinal cord injury, traumatic brain injury, and HIV/AIDS. She writes fiction, poetry, and journalism; several of her short stories have won awards. She lives with her husband, a Great Dane, a Labrador Retriever, two cats, and a tarantula (who makes her home in a terrarium). *My co-author, Mala Seshagiri, and I are grateful for the help and support of my husband, David Favrot. He never begrudged the time I spent working on the chapter and he was gracious and generous, readily sharing his expertise as a professional editor. Thank you, David.*

and spiritual health of women from diverse cultural backgrounds and a wide range of lived experiences in the United States.

## SOCIOECONOMIC RISK FACTORS THAT AFFECT WOMEN'S HEALTH

The 2002 WHO report argued that, “while much scientific effort and most health resources today are directed towards treating disease rather than preventing it, focusing on risks to health is the key to prevention.”<sup>1</sup> The following examples illustrate some of the socioeconomic risk factors that may affect women's health in the United States.

**Neighborhoods:** The neighborhood in which a woman lives affects her health status and access to health care. Studies have shown that living in a disadvantaged neighborhood leads to an increase in risk for heart disease.<sup>2</sup> In 2003, study results<sup>3</sup> examining the influence of economic factors on mortality among black, Mexican-American, and white women and men in the United States demonstrated that those who live in lower-income neighborhoods face numerous challenges in adopting and maintaining healthy lifestyles. Low-income neighborhoods in the study had few grocery stores with affordable fresh produce, few safe places to exercise, inadequate public transportation, and poor availability of health care services, including pharmacies. In addition, residents in these neighborhoods had a high exposure to crime, toxic chemicals, and poor quality air and water. Providers must consider a woman's access to affordable healthy food and safe exercise options in her neighborhood before making recommendations regarding diet and exercise.

**Income Inequality and Pay Differential:** In the United States at the end of 2001, 10% of the population owned 71% of the wealth and the top 1% controlled 38%. The bottom 40% owned less than 1% of the nation's wealth.<sup>4</sup> Social class shapes opportunities for good health: “those on the top have the most access to power, resources and opportunity — and thus the best health. Those on the bottom face more stressors — unpaid bills, jobs that don't pay enough, unsafe living conditions, exposure to environmental hazards, lack of control over work and schedule, worries over children — and the fewest resources available to help them cope. The net effect is a health-wealth gradient, in which every descending rung of the socioeconomic ladder corresponds to worse health.”<sup>5</sup>

Significant pay differences between men and women in the United States create a gender earnings gap. Women earn less than men, are less likely to own their own business, and more likely to live in poverty. According to 2008 data from the Institute for Women's Policy Research, among workers 15 years of age and older, women continue to earn only 76.9% of what men earn. White and Asian-American women are more likely to earn more each year than black, Native American and Hispanic women.<sup>6</sup> Earning potential is closely tied to health outcomes as well as the ability to secure adequate health insurance. Uninsured women are least likely to have had a provider visit in the past year and report lower rates of screening tests for many conditions.<sup>7</sup>

**Educational Levels:** Inequities in levels of educational attainment for women vary by income levels, race, and ethnicity. For example, Latinos, a disproportionately low-income population, lag markedly behind: the average Latino 25 years of age or older had 11 years of schooling in 2005, which is the lowest in the country, compared to 13.8 years among whites, 13 years among blacks, and 14.2 years among Asians.<sup>8</sup> It is important that providers do not make assumptions as to the causes of these discrepancies between groups. These studies demonstrate the current landscape, but they do not lend insight as to how or why these trends have developed over time. Issues of one's immigration status, family circumstances, cost of education, and other factors influence the number of years of schooling a woman may have.

Unfortunately, regardless of the cause, lack of education puts women at a disadvantage in the labor market and has long-term consequences for health outcomes for both women and their families. In the 2001 National Health Interview Survey, “the better educated a person was, the more likely that person was to report being in ‘excellent’ or ‘very good’ health.”<sup>9</sup> In general, low levels of education are associated with

Will you ever bring a better gift  
for the world  
than the breathing respect that  
you carry  
wherever you go right now? Are  
you waiting  
for time to show you some  
thoughts?

– William Stafford

poorer psychological function, less optimal health behaviors, and poorer biological conditions.<sup>10</sup> Education improves earning power and consequently, the ability to make healthy lifestyle choices, as access to healthy foods and safe places to exercise may be more readily available to individuals with more earning power. In addition, the occupations of people with lower levels of education may expose workers to greater health hazards such as heavy machinery, chemical exposure, or work shifts that disrupt sleep cycles.<sup>11</sup>

**Occupation:** Occupational risk factors also significantly affect women's health. Violence in the workplace is a significant risk factor for woman. According to recent data from the National Institute for Occupational Safety and Health (NIOSH), homicide is the leading cause of death for women in the workplace, accounting for 40% of all workplace deaths among female workers. These homicides appear primarily in workplaces such as grocery stores, eating establishments, and gasoline stations, and are often the result of a robbery.<sup>12</sup> Female workers are also at risk for non-fatal violence. Women were victims of two-thirds of the injuries resulting from workplace assaults, most occurring to those working in service occupations such as health care.<sup>12</sup>

Women who work in jobs that have been historically held by men, such as in the construction industry, may face health and safety risks due to inadequate or ill fitting equipment and clothing available to them. Personal protective equipment (PPE) and clothing (PPC) are often designed for average-sized men. The protective functions of PPE/PPC such as respirators, work gloves, and work boots are reduced when they do not fit female workers properly.<sup>12</sup> Furthermore, women who work as manicurists, housecleaners, and factory workers handle toxic chemicals on a daily basis.<sup>13</sup>

## INTERPERSONAL RISK FACTORS THAT AFFECT WOMEN'S HEALTH

**Caregiving:** Women caregivers may face many stresses and unmet needs, such as finding time for themselves, managing emotional and physical stress, and balancing work and family responsibilities. When assessing factors that affect stress, providers can ask women about their caregiving responsibilities: "Who do you take care of in your daily life?" Providers should also help caregivers identify those people or resources they can turn to for support. (See the Health Beliefs and Patterns of Care chapter for information on caregiving and its effect on health).

**Intimate Partner Violence:** Intimate partner violence (IPV) is a public health problem with serious medical and social consequences. Abused women are found among every racial and ethnic group and in every region and socioeconomic class; however, women who are physically abused are more likely to be relatively young, unmarried, nonwhite, less educated, and with low household incomes.<sup>14,15</sup> Health problems among physically and sexually abused women are not limited to physical injuries; the acute consequences of abuse include a wide range of long-term health complaints including heart problems, physical functioning limitations, increased health care utilization, more diagnostic tests, and frequent surgeries.<sup>16</sup> Violence may also put women at a higher risk for poor reproductive health behavior including unintended pregnancy, STD and HIV transmission, or increased stress related to trauma.<sup>17</sup> Furthermore, abuse during pregnancy may be a significant risk for low birth weight, low maternal weight gain, infections, anemia, smoking, and alcohol and drug use.<sup>18</sup> A recent meta-analysis of more than 40 studies of the mental health effects of domestic violence concluded that intimate partner violence has a considerable effect on mental health, leading to elevated levels of depression, suicide ideation and actions, anxiety, and posttraumatic stress disorder (PTSD).<sup>19</sup> It is important for providers to ask about both physical and psychological abuse and make referrals to the appropriate agencies.<sup>20</sup> (See the chapter on Intimate Partner Violence for more information on intimate partner violence and its effects on health).

## BEHAVIORAL RISK FACTORS THAT AFFECT WOMEN'S HEALTH

**Lack of Physical Activity:** Lack of regular physical activity can lead to increased risk for many chronic conditions such as obesity, heart disease, hypertension, diabetes, and osteoporosis. According to the 2001 and 2005 Behavioral Risk Factor Surveillance System (BRFSS) data, 49.6% of white women over 18 report exercising regularly compared with 36.1% of black women and 40.5% of Hispanic women. However, between 2001 and 2005, women of color had increased their exercise levels compared to white women.<sup>21</sup>



Providers can ask women about the range of activities they may engage in and help them to identify strategies for being more physically active that take into consideration neighborhood safety, work schedules and a busy life.

**Smoking:** Smoking and/or exposure to secondhand smoke continues to be one of the leading causes of preventable morbidity and mortality in the United States. Furthermore, women of reproductive age who smoke are at increased risk for multiple adverse pregnancy-related health outcomes, including difficulty conceiving, infertility, spontaneous abortion, premature rupture of membranes, low birth weight, neonatal mortality, stillbirth, preterm delivery, and sudden infant death syndrome (SIDS). According to 2006 CDC data, among women of reproductive age (18-44), smoking prevalence is highest among non-Hispanic white women (24.5%) and lower among black (16.3%) and Hispanic women (10.5%). Women with less than a high school diploma (28.3%) and divorced, widowed, or separated women (34.7%) have the highest smoking rates.<sup>22</sup> Women with disabilities are at higher risk for alcohol, drug abuse, and domestic violence.<sup>23,24,25</sup>

**Diet and Nutrition:** Diet and nutrition have a profound effect on a woman's health. According to 2005 BRFSS data, only 12.6% of non-Hispanic black and 14.8% of Hispanic women consumed five or more servings of fruits and vegetables a day and regularly exercised, compared to 17.4% of non-Hispanic white women. Cultural, religious, social, and environmental factors affect dietary patterns of a family,<sup>26</sup> as does the family's financial situation. Vegetarianism, prohibition of certain foods, fasting, or other eating restrictions may be integrated into the family lifestyle. Beliefs that particular dishes warm or cool the body, can cause disease, or affect healing may additionally determine what foods are prepared. Women have specific nutritional needs and vulnerabilities and in a male-dominated home environment may not have their nutritional needs met.

**Eating Disorders:** Eating disorders are closely linked to a woman's health. A study<sup>27</sup> of pre-and early perimenopausal black, Hispanic, and white women demonstrated that predictors of eating disorder symptoms in older women included a history of depression and depressive symptoms, childhood victimization, lifetime substance dependence, and obesity. (See the chapter on Health Beliefs and Patterns of Care for more information on eating disorders).

**Sexual Behavior:** Unsafe sexual behavior is a risk factor for sexually transmitted diseases (STDs) and HIV. Ignorance about a partner's sexual activities, HIV status, and intravenous drug use, stigmatization against men who have sex with men, rigid gender roles, and abusive relationships in which women are unable to negotiate safer sex and condom use may contribute to the rising incidence of STDs and HIV among women of color. (See the Major Diseases and Reproductive Health chapter for more information on STDs and HIV).

Women with disabilities may not be able to detect signs and symptoms of STDs. Providers may assume that a woman with a disability is not sexually active and therefore fail to screen for STDs.

Rosemary Basson describes the following myths<sup>28</sup> contributing to the lack of attention paid to the sexual health of women with disabilities:

- Disabled women are asexual.
- Disabled women who are single are celibate.
- Disabled women cannot be mothers.
- All disabled women are heterosexual.
- Disabled women should be grateful for sexual relationships.

The presence of an STD in a woman with a disability could also be a sign of sexual abuse. Sexual abuse and sexual harassment are more commonly experienced by women with disabilities than other women, and economic dependence and social isolation may be contributing factors.<sup>28</sup>

**Alcohol Use:** Alcohol use greater than one glass of wine per day increases a woman's chances for high blood pressure, stroke, some types of cancer, injury (e.g., motor vehicle crashes, violence), and suicide. Drinking alcohol during pregnancy can cause birth defects and developmental disabilities, known as fetal alcohol spectrum disorders. Providers can encourage women of childbearing age (18–24) and pregnant women to avoid alcohol and tobacco use. Other efforts might include broad-based screening and brief intervention for alcohol misuse in primary and women's health care settings.

## HEALTH CARE RISK FACTORS THAT AFFECT WOMEN'S HEALTH

**Lack of health insurance and limited access:** More than 17 million women in the United States are without health insurance. Uninsured women are more likely to postpone care and forego filling prescriptions than their insured counterparts and often delay or do not receive mammograms, Pap tests, or other forms of preventive care. In addition, limited access to preventive health and health screenings can contribute to delayed diagnosis and treatment for disease, leading to an increase in health disparities in the United States. (See the Demographics chapter for information on health disparities in women).

**Use of Complementary and Alternative Medicine:** While the use of Complementary and Alternative Medicine (CAM) is not in itself a risk factor, in some situations it may present a contraindication to Western allopathic medical practice. According to a 2002 Survey conducted by the National Center for Complementary and Alternative Medicine division of the National Institutes of Health (NIH), 36% of adults use "some form of CAM. When megavitamin therapy and prayer specifically for health reasons are included in the definition of CAM that number rises to 62%."<sup>29</sup> What constitutes CAM covers a wide range of health and wellness behaviors, and may include herbal remedies, massage, prayer, and meditation specifically for health reasons.<sup>30</sup>

Pain – has an Element of Blank –  
It cannot recollect  
When it began – or if there were  
A time when it was not –  
It has no Future – but itself –  
Its Infinite realms contain  
Its Past – enlightened to perceive  
New periods – of Pain.

– Emily Dickinson

Many women who are new immigrants to the United States or from cultures with strong healing traditions are also likely to use CAM, as each woman brings not only her lived experience but also her catalogue of cultural knowledge and health-related experience on entering the United States and the biomedical system. However, this reality demands a high degree of vigilance from providers, as there are contraindications to the use of herbal products with many standard medications.<sup>31</sup> Symptoms in some patients may be the result of an herbal medication used together with a conventional Western medication. For example, kava and comfrey have been linked to liver damage, and St. John's Wort has many interactions with conventional drugs. It is crucial that a provider develop a sensitive way of inquiring about the use of CAM.

**Pain Management:** Women may face discrimination in pain management due to the great variations in expression of pain among women of different racial and ethnic groups.<sup>32,33</sup> An article in the Journal of the National Medical Association<sup>34</sup> reports that women are more likely to suffer from chronic pain than men, but their pain complaints receive less attention than those made by men. "Women's self-reports of pain may often be discounted at least until there is objective evidence for the pain's cause. Medicine's focus on objective factors and its cultural stereotypes of women combine insidiously, leaving women at greater risk for inadequate pain relief and continued suffering."<sup>35</sup> In addition to bias based on gender, black women are more likely to report disability due to pain and more psychological distress than white women.<sup>36</sup>

**Caesarean Delivery:** Caesarean delivery, a major surgery once reserved for women experiencing clinical indications that put herself or her baby at risk, has, in some parts of the world, become commonplace and "elective." Given its risk, expense, and effect on health care delivery systems, the WHO has stated that the Caesarean rate should not exceed 15% of all births.<sup>37</sup> Caesarean surgery raises maternal and neonatal health risks in the short- and long-term, and each subsequent Caesarean exponentially increases a woman's risk for significant complications associated with the procedure, such as hemorrhaging, requiring blood transfusions, peripartum hysterectomy, and death associated with abnormal placental attachment such as placenta previa and accreta.<sup>38</sup> (See the Pregnancy chapter for more information on Caesarean delivery).



**Female Genital Mutilation:** Female genital mutilation (FGM) places a woman at greater risk for health complications throughout her lifetime. The WHO and the International Federation of Gynecology and Obstetrics have called for the cessation of FGM. Infection, scarring, painful sexual intercourse and difficulties during childbirth are all commonplace complications of this practice.<sup>39</sup> Providers who see women from countries where FGM is common should be familiar with the complications that may arise due to this procedure.

Women also face clear risks to their health from certain chronic conditions, some of which are highlighted below:

**Obesity:** Obesity is a growing public health issue in the United States with 30% of all adults in the United States falling in the obese category (BMI over 30) and 65% overweight (BMI greater than 25), according to data from the 1999–2002 National Health and Nutrition Examination Survey (NHANES III).<sup>40</sup> Obesity prevalence is highest among African-American women. More than half of non-Hispanic black women aged 40 years or older are obese and more than 80% are overweight.<sup>41</sup> Risks associated with overweight and obesity are hypertension, dyslipidemia (high total cholesterol or high triglyceride levels), type 2 diabetes, coronary artery disease, stroke, gallbladder disease, osteoarthritis, sleep apnea, respiratory problems, and some cancers such as those of the endometrium, breast, and colon. Further, data analysis associated with the Framingham Heart Study found that the chance of becoming obese increases if a friend, sibling, or spouse is also obese.<sup>42</sup> Culturally sensitive modifications that include family members, address attitudes about exercise, and include culturally specific recipes can lead to significant improvements.<sup>43</sup>

**Coronary Heart Disease:** “In the United States, coronary heart disease (CHD) is the primary cause of death in women. Although onset lags ten years behind that of men, 38% of women die within one year of their first myocardial infarction (MI) compared with 25% of men...”<sup>44</sup> The signs and symptoms of a heart attack associated with cardiovascular disease may manifest differently in women than in men. For instance, women may experience shortness of breath, dizziness and nausea rather than crushing chest pain. (See the Major Diseases chapter for more information on coronary heart disease and women).

**Diabetes:** The American Diabetic Association reports that the prevalence of diabetes is 2–4 times higher in black, Hispanic, Native American, and Pacific Islander women than white women. Diabetes and hypertriglyceridemia may be important risk factors for heart attacks in women and require treatment. A recent decline in CHD mortality of 36% and 27% was reported among non-diabetic men and women respectively. However, a decline of only 13% was observed in men with diabetes, and, more alarmingly, an increase of 23% was observed in women with diabetes.<sup>45</sup>

Do you see me?

Do you see me? Inside the hippo-  
elephant

with a human face,

I am here...

I try to tell you I am not a hippo-elephant  
woman,

my inner life is thin.

When you cannot hear, I cry inside  
and eat more,

adding layer on layer of fat

to make my diminished spirit feel  
big and loved.

– Katherine Brown-Favrot

## ENVIRONMENTAL RISK FACTORS THAT AFFECT WOMEN’S HEALTH

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*We don’t all bear equal risks when contaminants are allowed to circulate  
in our environment and our bodies. People aren’t uniformly vulnerable.  
Women and children are disproportionately affected...and our future  
generations will be affected.*<sup>46</sup>

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According to a report from The Women’s Foundation of California, “...women have traditionally borne the consequences of environmental contamination...through diminished fertility, abnormal fetal development, increased rates of cancer and other forms of environmental illnesses.” According to this report, the estimated health care costs of diseases affecting women that have a “strong environmental association” total \$12.2 billion.<sup>47</sup>

**Recombinant Bovine Growth Hormone:** Recombinant Bovine Growth Hormone (rBGH) is used to increase a cow's milk production and has been shown to increase Insulin-like growth factor-L (IGF-L) compared to untreated milk. IGF-L has been implicated in increased risk for several types of cancer including prostate and pre-menopausal breast cancer. Blood samples from women participating in the Nurse's Health Study showed a positive association between dairy intake and circulating IGF-L concentrations in pre-menopausal women. Providers must encourage women patients to educate themselves as consumers to make informed choices.

**Mercury:** Mercury poisoning, often the cumulative result of eating fish with high levels of mercury in their flesh, such as shark, swordfish, king mackerel, or tilefish, is a concern for women of childbearing years, pregnant women, nursing mothers and young children. Skin whitening creams, commonly used by women from Southeast Asia, are another source of mercury poisoning, often containing amounts 2,000 times above what is allowable by law.<sup>48</sup>

**Bisphenol A:** Bisphenol A (BPA) is a chemical used in the manufacture of polycarbonate plastics and epoxy resins. The 2003-2004 National Health and Nutrition Examination Survey (NHANES III) conducted by the CDC found detectable levels of BPA in 93% of 2517 urine samples from people six years and older. According to the National Toxicology Program (NTP), an interagency NIH program, there are concerns of neural and behavioral effects in fetuses, infants, and children exposed to BPA. Providers may caution patients to avoid microwaving polycarbonate plastic food containers.

**Lead Exposure:** Lead exposure affects health causing developmental neurotoxicity, reproductive dysfunction, and toxicity to the kidneys, blood, and endocrine systems. Pregnant women and children under the age of six have the highest risk of absorbing lead in the largest quantities.<sup>49</sup> According to the California Poison Control System,<sup>50</sup> high lead levels are found in water boiled in leaded pots and pans, foreign cosmetics such as Kohl (eye liners commonly used in South Asia) and foreign cold medicines. In a 2004 study,<sup>51</sup> one in five Ayurvedic herbal medical products produced in South Asia, and available in Boston South Asian grocery stores, contained potentially harmful levels of lead, mercury, and/or arsenic. To avoid or minimize lead poisoning, the following safety guidelines are recommended.<sup>52,53</sup>

- Pottery made in the United States must meet safety guidelines for lead. Food should not be prepared, served or stored in imported pottery or pots unless the label or tag on the item indicates "Safe for food use." Recommendations such as "Not for food use," "Plate may poison food," or "For decorative purposes only" must be taken seriously. Also warning labels may have been erased or painted over.
- Hair dyes manufactured outside the United States may contain toxic chemicals.
- Tamarindo jam or candy (packaged in white, dark brown, and green glazed ceramic jars) is unsafe for consumption, as lead may leach from the pottery into the product.

## CONCLUSION

What do we want you to remember?<sup>54</sup>

Our pain

Our struggles

Our fear

Our anger

Our hope

The times we were too sick to care

The times we cried so much we almost didn't stop

The times we laughed with relief



What do we want?  
To hear you speak honestly and gently  
To explain, no matter the difficulty  
To end each visit with a touch  
Even when you don't want to.

Remember us.  
We are human  
Like you, the same, different,  
Full of mystery,  
And alive.

– Katherine Brown-Favrot.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS:

- The information in this chapter about risk factors for different populations are only measurements of existing realities rather than indicative of relevant causes. Balance the knowledge of risk factors with the understanding that each patient's experience is unique, and may differ from the cultural groups (by age, ethnicity, socioeconomic status, sexual orientation, or disability) with which she may identify.
- The disease model at a cellular level is not sufficient to explain the complexity of a disease. Look at the whole person and the context in which a woman patient lives.
- Provider bias is a risk factor for women's health as it compromises quality patient care. Harvard University has developed an on-line tool for evaluating and uncovering one's own hidden medical biases. It can be viewed at <http://implicit.harvard.edu>.
- A non-judgmental attitude about CAM may encourage patients to share information about their own practices. Treatment plans may be jeopardized if CAM is not taken into consideration as CAM may have interactions with commonly prescribed medications.
- People use the categories and rules of their specific cultures and ethnic groups to frame what they consider to be acceptable foods. Providers must use this information to develop culturally appropriate weight loss menus with each patient.
- A reference on performing pelvic and breast exams on women with disabilities called Table Manners and Beyond is available on line at <http://www.bhawd.org/sitefiles/TblMrs/cover.html>.

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# HEALTH BELIEFS AND PATTERNS OF CARE

Jandel Allen-Davis

## AUTHOR FOREWORD

I recall a young patient who was being molested by her stepfather. Exhausted at the end of the day, I was tempted to rush the “walk-in” exam and treat her for an apparent urinary tract infection. However, I slowed down, took a good history and, after examining her, diagnosed a primary genital Herpes simplex virus infection. What “health belief” did my young patient bring with her to the exam? It became evident at the criminal trial, when the District Attorney handed me a letter and asked if I had seen it before. The letter was an impassioned plea for help written by an isolated and scared 13-year-old.

*“Please help me, Doctor,”* the letter began. *“My stepfather touches me down there and he is not clean.”* I never saw the letter, but I didn’t have to. I had created the opportunity for the real story to unfold during her exam. The belief she brought into that exam was that it would not be safe for her to actually tell her story; rather, she would have to advocate for herself, by passing a note and avoiding the shame of having to speak the words aloud.

She is now a young adult woman, and she and her mother remain eternally grateful for my help. This is a dramatic example to illustrate that the life experiences and beliefs patients bring to the clinical encounter can inform the care experience. This chapter is an exploration of women’s cultural beliefs and the unspoken, and sometimes spoken, factors that providers should consider in women’s care. By understanding the role of health beliefs in women’s wellness, illness, and patterns of care, we possess the ability to transform a life and affect patient outcomes. It is in this spirit that I give you this chapter.

## INTRODUCTION

It is difficult to analyze the health beliefs of women as a group without an exploration of the health beliefs of many demographic sectors, including race, ethnicity, geographic location, and socioeconomic status. From a global context, women as a group cross all geographic boundaries, cultures, ethnicities, races, and religions.<sup>1</sup> Women’s diversity reflects the *world’s* diversity. With this cautionary introduction, this chapter discusses women’s health beliefs in the context of their sociocultural origins, and how those beliefs affect patterns of care.

## PATTERNS OF CARE

While women are more likely than men to report a visit to a physician’s office within the last year, there are many barriers to care that persist on a chronic level. These include caretaking responsibilities, lack of



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health care coverage, and status as women within a given community. The following are factors that shape patterns of care and influence access to care for women.

**Caretaking Responsibilities:** Women’s family roles and responsibilities often hamper attention to personal health needs. In addition to acting as primary caretaker for immediate family members, 10% of women report caring for an elderly or ill relative.<sup>2</sup> The most frequently identified reasons for delays in seeking care are lack of insurance and time constraints.<sup>2</sup> This is largely due to competing commitments that don’t allow women to prioritize their health care needs. These competing commitments include care of their children and elder relatives or ailing partners, balancing work and family priorities, and assessing how to allocate limited financial resources across a variety of needs.

**Gender Roles:** The status of women within some cultures can make it difficult for women to access needed services. In some cultures, such as the Asian and Pacific Islander community, women may be less likely to make independent decisions regarding their own health, and may neglect their personal health, due to their cultural role in keeping their families whole and intact.<sup>3</sup>

**Competing Demands and Time Famine:** An important consideration for the provider when determining how a woman perceives and engages in self-care when ill is to consider her care in the context of demands placed on her time by home and work. Providers may see some interesting adaptations in self-care and medication that enable women in the United States to keep pace with all of the competing demands on their time in a given day. In a small study aimed at patterns of self-care and self-medication, researchers found that in an effort to keep up, women may take “short cuts” to shorten the course of illness, to avoid medical office visits, and to treat symptoms that could interfere with the performance of work and domestic activities:<sup>4</sup>

“Time famine” is used to describe the chronic shortage of time that plagues individuals; women are particularly affected by this time crunch, as they may often still have primary responsibility for domestic activities while working outside of the home.

- “I don’t have time to be sick” is a common refrain. Women will continue their activities until, and unless, they have no choice but to rest or are too sick to work.
- Self-medicating occurs more often and sooner in minor and major illness based on the amount of work and activity required of them. Commonly used medications include antihistamines, pain relievers, antacids and antidiarrheals. Medications that achieve multiple aims (e.g., pain relievers and decongestants) are valued for their efficiency.
- Sleep products are used to increase sleep efficiency, as insomnia is a barrier to effective functioning.

Providers must consider this concept when women present in the course of an illness seeking treatment. Asking about work/life stress and balance, and working with patients to explore alternatives to continuing to work sick (or less than at full capacity) is an important task for the provider.

**Health Coverage:** Men are more likely to carry insurance through their employer (that is, to be the primary insured party), while women are more likely to have insurance as a dependent (i.e., carried on their spouse’s or partner’s insurance policy through work).<sup>3</sup> This leaves women more vulnerable to changes in spousal employment status, marital status, and employer-based changes in the amount of health insurance coverage afforded employees. This can in turn influence her health behaviors and affect her ability to access care. Women can also be left with financial and familial burdens following the death of a spouse, which can also directly and indirectly affect their health.

## BELIEFS ABOUT HEALTH, WELLNESS, AND ILLNESS

One relatively understudied area of social science research in women’s health is the influence of health beliefs on health behaviors and outcomes. Providers who consider the socioeconomic context of the woman coupled with an appreciation for her culturally-shaped health beliefs and how that influences health behaviors and attitudes might enhance care and improve health outcomes of women.



**Social Context:** Women’s social contexts are important determinants of their sense of health and wellness. Providers should consider the following contexts when discussing illness, prevention, and wellness with women, especially if the providers are attempting to help shape behavior and promote health:

- The woman’s connection to her community, and her community or culture’s perceptions of wellness, illness, and beauty or goodness.
- The extent to which she feels in harmony with her physical, spiritual, and social surroundings.
- The importance she places on remaining healthy enough to function in the home and community at a high level (i.e., her roles and responsibilities in the family and community).

Women often make the connection between life circumstances and illness and will frequently express observations regarding imbalance and its effects on health. Providers can probe women about this by asking, “How has your condition affected your day-to-day life, and how has your day-to-day life affected your illness?” or “Is there anything happening in your life right now that you think has made this illness more difficult to handle?”

The following are sample questions that providers might ask to better understand the influence of the social context in a woman’s life.

- Are you involved in any volunteer activities? Do you enjoy them and why?
- What factors do you consider in deciding if you are well or ill, aside from physical symptoms?
- If you were to become ill enough to require a hospital stay, what would be the effects on your family? Your work? Your community?

It is clear that providers need to understand a woman’s orientation to health and health beliefs and how to assess that orientation if they are to connect with patients and affect their health. Whether health beliefs play out differently based on gender is unknown. However, women may discuss their beliefs, if asked. This could provide an important inroad to behavioral change.

**Cross-Cultural Perspectives:** Perceptions of illness and wellness vary across cultures. One of the more impressive examples of this is vividly outlined in the book, *The Spirit Catches You and You Fall Down*.<sup>5</sup> This work chronicles the diagnosis and treatment of a Hmong child with what biomedicine terms a seizure disorder, and highlights the differences between the Hmong parents’ perception of the child’s illness and that of her American doctors. The ability of the American health care system to care for the child is limited not only by language barriers, but also by a failure to recognize the cultural significance of *qaug dab peg*, the Hmong term that pairs the child’s symptoms with the parents’ beliefs in spiritual rather than biological causes of the illness. This failure of transcultural communication demonstrates the importance of understanding how illness and wellness are perceived across cultures.

The connection between the natural world, relationships, and illness is an important concept for providers to understand. Taoism, Buddhism, Confucianism, Animism, Ayurvedism, and Naturalism are all loosely based on the belief that when one is in harmony with nature, one is well and thriving. Illness indicates imbalance in these systems. It is believed that restoring this balance by tending to relationships and being gentle with nature will return the system to wellness.

There are a number of health beliefs that are culturally based and can be found in other chapters throughout the *Women’s Health Handbook*. Following is an exploration of the specific issues of body image and weight, and reproduction and childbearing where health beliefs may influence women’s health behaviors and patterns of care.

**Body Image and Weight:** Women’s body size and shape carry different values in the many cultures within the United States. Dissatisfaction with body image is linked to depression, sexual dysfunction, and eating disorders, particularly in Western countries.<sup>6</sup> Eating disorders and excessive physical activity can be avenues to maintain the oft unattainable image of beauty as portrayed in the media.

The *self-objectification theory* is one theory used to explain the relationship between body image and dissatisfaction. This theory purports that over time, women begin to view their physical appearance as they think others see them, hence objectifying themselves. This results in body dissatisfaction and subsequent deleterious effects on health including obesity, eating disorders, and unnecessary and risky surgery. Obesity is emerging as a major public health issue in our nation and affects all ethnic groups. As society as a whole has continued to gain weight over the last 20 years, the prevailing definition of overweight has shifted among white and black women; being overweight is relatively more socially acceptable, and yet a preoccupation with being overweight remains among many women.<sup>6</sup>

While the influence of Western popular culture and media on women's sense of beauty is subtle, pervasive, and in some cases destructive, there are some cultures such as Samoan and Hawaiian cultures where overweight is considered and accepted as the norm. This perception presents challenges when discussing weight loss with many women. To address issues of weight loss and obesity, providers require an understanding of the connection between perceptions of beauty and weight within different cultures, and how those perceptions are influenced by the overlay of socioeconomic status. One tool used to assess satisfaction with body image is the Stunkard Figure Rating Scale which consists of 9 silhouettes of men and women ranging from extremely thin to extremely obese. A difference between self-perceived body size and ideal body size implies dissatisfaction with body image.

In a study of 276 Mexican-American women,<sup>7</sup> participants were asked to view 9 silhouettes of female figures ranging from severely obese to severely thin and rank their self-perceived body shape and their ideal shape. In all age categories, women thought men would find a heavier woman more attractive. The more acculturated Mexican-American women tended to rank thinner women as the ideal compared to less acculturated women. Heavier women tended to rank the heavier figures as acceptable or ideal.

In a survey of 3,913 men and women participants in the Coronary Artery Risk Development in Young Adults study,<sup>8</sup> using the same figure rating scale, a statistically significant discrepancy was observed between self-perceived and ideal body weight for Caucasian and African-American men and women. The difference was greater between women. African-American women had a lower discrepancy between the self-perceived and ideal body weights than Caucasians, even though their Body Mass Index (BMI) was higher than Caucasian women. Moreover, ideal body weight appeared to be more heavily influenced by socioeconomic status, while self-perceived weight appeared to be more heavily influenced by ethnicity. African-American women of lower socioeconomic status appeared to be the most satisfied with their body size, even when that size was overweight.

Motivations for weight loss are influenced by the complex interplay of culture, ethnicity, and socioeconomic status. Higher body size satisfaction can make weight loss motivation more difficult. Therefore, strategies to assist women in weight loss must include a consideration of factors that affect perceptions of real and idealized weight.

**Reproduction and Childbearing:** Health beliefs surrounding women and reproduction are woven throughout all cultures.

**Menstruation:** Menstruating women have historically been viewed as impure in some cultures and were often isolated during their cycle.<sup>9</sup> Some African-American women may believe that menstruation is a cleansing process and may raise concern and resistance to treatments that control or stop menstrual flow. Other beliefs about menstruation include a ritual bath in turmeric and vermilion as a pubertal rite in some Hindu cultures<sup>9</sup>, and not touching sacred objects, people, or things during the menstrual period among Hindus.

**Pregnancy and Childbirth:** Beliefs and behaviors related to pregnancy and childbirth also abound in many cultures.

Some of the beliefs and behaviors are:

- Raising arms above the head will cause nuchal cords and fetal “strangulation.”
- The sex of the baby can be determined using various “tests,” such as floating a needle suspended by a



thread about the pregnant abdomen and observing the directional rotation, or mixing Drano® and the pregnant woman's urine and watching for specific color changes, which vary based on fetal sex.

- Having intercourse at specific times will increase the likelihood of having a child of one sex or the other.
- Certain routine activities can increase the chance of spontaneous abortion, for example, carrying or lifting heavy objects or jumping across ditches in some Hindu cultures.
- Psychological stress may increase the risk of spontaneous abortion.
- Eating spicy foods is believed to induce labor.

**Surgical Procedures:** Another important issue for clinicians to consider is the effect of hysterectomy and mastectomy on a woman's identity and sense of sexual self. While women may not discuss their concerns regarding sexual functioning after hysterectomy openly with providers, many women may worry about a decrease in attractiveness to themselves and their partners. Some women believe that after hysterectomy, sex is no longer possible, as they misperceive that the vagina is removed as well, or that their cognitive and emotional functioning will be impaired postoperatively.

Much attention has been given to the overuse of hysterectomy to correct real and perceived reproductive health concerns in women. Hysterectomy is the second most frequently performed procedure in the United States.<sup>10</sup> There are significant racial and ethnic differences with respect to how often this procedure is performed and African-American women are more likely to have a hysterectomy than any other racial and ethnic group.<sup>10</sup> Further careful and respectful research is necessary to fully understand the basis of the differential rates of hysterectomy among women from different racial and ethnic backgrounds. Providers must furnish women with full information about the medical advantages and disadvantages of a hysterectomy and understand that her decision is influenced by the complex interplay of her socioeconomic status, cultural views and access to care among other issues.

## RELIGION, SPIRITUALITY, AND FAITH

Spirituality and religion play an important role in the lives of people of all cultures. In addition to serving as an invaluable point of social connection, there is a body of literature examining the role of faith and spirituality in health, including its role in coping with birth, life, death, and dying.<sup>11</sup> In this context, spirituality is recognized as a factor that contributes to health for some women.

Spirituality may be important to patients dealing with end-of-life issues<sup>12, 13</sup> and critical care.<sup>12</sup> Severe and/or terminal illness offers the opportunity for the healing of relationships, gaining inner peace, and reconnecting to the spiritual.<sup>12</sup> (See the Spirituality: Death and Dying chapter for more information on end of life issues across cultures).

There is less literature that specifically addresses women and the role of religion or spirituality in their health care and health beliefs. In a study examining the experience of 34 Asian American women (Chinese-American and Korean-American) with breast cancer, spiritual beliefs were cited as a major source of support.<sup>14</sup> Further, women's attitudes toward abortion may also be greatly influenced by spirituality. In one survey, those who expressed stronger spirituality and fatalism were less likely to support pregnancy termination.<sup>15</sup>

## GENERATIONAL ISSUES

The effects of generation on health care patterns and beliefs are a relatively new area of study and therefore the data are limited. It is intuitive, however, that generational issues should affect patterns of care and health beliefs. Health priorities and perceptions of health change as people age. Cognitive development in adolescence progresses from concrete (ages 11-13) to abstract thinking (ages 18-21). At the same time, the health status of teens is generally viewed as excellent when traditional medical conditions including chronic disease are the parameter. These two factors are thought to account for much of the risk-taking behavior seen in these age groups.

Health beliefs in older women shift to concerns about aging, dying, and retaining functional status. In a survey of Canadian women aged 55-93, women become more concerned with preventing disability,

specifically related to memory loss, preserving mobility and function and treating urinary incontinence as they aged.<sup>16</sup> In an essay exploring age and health-related quality of life, Blieszner asserts that in order for older women to cope well, they require a sense of acceptance of life outcomes, satisfying close relationships, meaningful use of time, and spiritual beliefs and values.<sup>17</sup> Providers can assist in this by making time for women to talk about significant changes in their lives in a supportive way. Doing so may provide an entry into discussing active and participative management of chronic illnesses.

## SELF-CARE

**The role of the Internet:** With increasing access to medical information over the Internet, women will frequently come to the clinical setting with questions about symptoms or conditions based on their own research. Women also access the Internet for information and support related to certain health issues, such as anorexia, bulimia, breast cancer, and breastfeeding, as sources of information and support.

In a study of melanoma patients who were asked about the use of the Internet in researching their condition, 35% of women reported accessing the Internet for information about their condition, compared to 23% of men.<sup>18</sup> In the same study, significantly more of the study population was under age 40. There is widespread concern about the quality of the many forms of information available via this powerful communication tool. Providers have a responsibility to help their patients to tease out fact from fiction, and possibly re-direct patients to reliable Internet sites.

A 2005 Pew Internet Survey found that, while men outpace women in Internet use, women are catching up. One significant difference between men and women is that while men use the Internet to procure information, women view it as a way to connect to others and to access health information.<sup>19</sup> One survey found that there are no major differences between the sexes regarding why the Internet is used, although both groups state that the use of the Internet enhances the doctor patient relationship, presumably by providing an alternate source of confirmatory information and thereby increasing trust.<sup>20</sup>

**Role of Literacy:** In a 2003 survey of adult women aged 18-64 years, women of color were significantly less likely to use the print media, including the Internet, for health information in comparison to white women.<sup>21</sup> This might point to socioeconomic factors including access to computer technology, low English proficiency, and low literacy levels. Low English proficiency and low literacy levels may lead to poor access to care, poor compliance with treatment regimens, and poor health outcomes. It is important for the U.S. health care system to provide health information to patients in a linguistically sensitive manner, regardless of gender.<sup>21</sup> A failure to communicate information in a way that is understandable and that considers language and literacy levels puts minority women at risk for poorer health outcomes. In assuring that women understand what is being communicated, providers can ask patients to repeat care plans *in their own* words based on what the provider has said. This allows for clarification of management plans, or reinforcement and encouragement when the patient understands the plans accurately.

**The Role of Complementary Medicine:** Examples of Complementary and alternative medicine (CAM) include acupuncture, massage therapy, herbal and multivitamin supplements, relaxation techniques, Ayurvedic, traditional Chinese medicine, and chiropractic care. The 1999 National Health Interview Survey demonstrated that women utilize CAM more than men, and of the available techniques, spiritual healing practices are utilized most often. There is growing and sound evidence for the use of some herbal supplements in the treatment of vasomotor instability.<sup>22</sup>

There is no data regarding the extent to which alternative sources of medical information, such as complementary medicine and the Internet, modify behavior. A failure to recognize all sources of health care information and healing, including the use of herbal medicines, traditional healers, and other treatment modalities has the potential to cause harm to patients. It is important for providers to recognize that patients may be accessing other modalities for health information and care and that they are often reluctant to talk about it for fear of judgment and rejection by their care providers. One way to inquire about the use of alternative forms of healing is for providers to ask, "Are there other forms of medicine that we haven't talked about that you believe are or would be helpful in caring for you?"



## THE HEALTH CARE ENCOUNTER: NON-MEDICAL FACTORS AND THEIR ROLES IN OPTIMAL HEALTH OUTCOMES

If there is one unifying cross cultural concept that defines women's health beliefs and informs their interactions with the health care delivery system that concept is one's relationship with one's health care provider. Good working relationships with health care providers are strong determinants of compliance with treatment, adherence to preventive care, satisfaction with health care, and overall quality of care.<sup>23</sup>

Many patients are interested in their providers as people, not just clinicians. Women, in particular, show interest in providers who connect with them personally, and are more likely to inquire about their provider's family and personal interests. Answering these questions in a transparent way that does not detract from the business of caring for the patient goes a long way toward building trust and rapport. While this sort of transparency on the part of the provider can have a positive effect on health outcomes, it is important to maintain a balance between personal sharing and the professional provider-patient relationship (i.e., the effects of transference and counter-transference).

Women of color are more likely to feel disconnected from and unwelcome in the health care system, especially when verbal and non-verbal cues during health care encounters are perceived as negative, disrespectful, or non-supportive. While connections between the patient and provider can and do occur independent of the race of the provider, studies indicate that race-concordant visits are viewed more favorably, independent of the patient-centered communication.<sup>24</sup> The dearth of African-American, Latino and Native American physicians relative to the proportion of these population groups in the U.S. is a public health challenge in the United States.

According to the American Medical Association, approximately 26% of the U.S. doctors, in 2004, were female. Physician gender preference has been examined by a number of researchers. Most, but not all studies support the contention that women prefer female physicians for gynecologic examinations. This gender concordance does not appear to be as strong for primary care visits.<sup>1</sup> Among Arab-Americans and Muslims, female providers are preferred and may be insisted upon, except in extreme emergencies. When this accommodation is not possible, providers should work with families to help them feel as comfortable as possible in these cross-gender encounters.<sup>25</sup>

Gender and race concordance is positively associated with patient satisfaction. Important factors in this satisfaction include:<sup>23,26</sup>

- Participatory decision-making styles
- Complete explanations of clinical findings
- Longer office visits
- Respectful interactions
- Accessibility
- Patient-centered communication

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- Health beliefs are shaped by one's social context. Consider factors other than physical symptoms when assessing women patients and ask about issues related to children, work, partnership, marriage, and socioeconomic stressors.
- As the United States becomes more racially and ethnically diverse, many of the health beliefs ascribed to a particular group begin to blend. Assumptions regarding women's health beliefs based strictly on demographic factors may not be true. There is a need to be cognizant about not assigning generalizations about women as members from diverse population groups.
- Women of color may not feel connected to the U.S. health care system, with potentially negative effects on health. Investing in the beginning of the encounter by demonstrating respect and interest in the patient, eliciting her perspectives on what might be contributing to her illness, providing reassurance, and being accessible enhances the feeling of connectedness.

- While gender- and race-concordant encounters seem to have more positive outcomes in terms of physical health and patient satisfaction, given physician demographics, it is currently not practical. All providers possess the ability to demonstrate empathy and interest in patients and are encouraged to continually develop those skills in working with women.
- Unspoken and unseen health beliefs are large influencers to compliance with treatment regimens. Creating an environment where these beliefs can be explored in non-judgmental ways, are integrated into care plans, and are part of overall counseling and guidance improves satisfaction and health outcomes.
- Women can be viewed as a separate demographic group and do have some distinct orientations with respect to relationship and community. However, many of their beliefs are grounded in ethnic, racial, and religious customs. Many, but not all of these beliefs and practices are also influenced by the level of educational attainment. It is important to be aware of what is unspoken and unseen in the clinical encounter and respectfully ask what particular illnesses may mean to the patient.
- While many women may choose their providers based on gender (preferring females), there is evidence that communication styles matter as much as gender, and an open supportive communication style may be more important in patient satisfaction. Yet, in some cultures and in some age groups, women prefer female providers regardless.
- Immigration and acculturation play significant roles in the clinical setting. Providers may see cultural differences between women from the same ethnic group who have lived in the United States for a long period of time as compared to recent immigrants to the United States.
- As younger women “age-in” to health care, to address their desire and orientation of alternative ways to access physicians, consider developing alternative means of communicating and establishing relationships with patients, including use of internet websites, chat rooms, and on-line meeting groups.

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# INTIMATE PARTNER VIOLENCE

Brigid McCaw

## AUTHOR FOREWORD

In 1981, I was in medical school learning how to save lives. I was working hard studying anatomy, pathology, and pharmacology. What I didn't know at the time was that my younger sister was working much harder trying to save her own life and her daughter's in a physically and emotionally violent relationship. I didn't have a clue about the scope of the problem, what she was facing, and how it felt to live in an atmosphere of physical, sexual, and psychological abuse. In 1981, 28 years ago, no one asked my sister about what was going on – not even her doctor, who couldn't have missed the bruises on her pregnant abdomen.

Today, my sister is alive, well, and making the world a better place for all of us (especially her students — she is an elementary school teacher). She is a survivor. And her daughter, my niece, is a lovely young woman who teaches children with special needs.

I wrote this chapter because of these facts: 44% of adult women have experienced domestic violence, 1 in 6 have been raped, and 1 in 5 were victims of sexual abuse as a child. I wrote this chapter to help other clinicians like myself, who may not be aware of the scope of this problem, and that their role can be simple, straightforward, and absolutely life-saving.

I dedicate this chapter to our sisters, especially my own.

## OVERVIEW

Violence against women is a common and alarming public health problem in the United States and throughout the world. All health care providers will encounter women who are victims of violence. The majority of women will have experienced this violence from an intimate partner or family member. The problem is staggering, as are the costs and physical and mental health conditions that are associated with this kind of violence. The financial toll of Intimate Partner Violence (IPV) on direct medical and mental health care is \$4 billion per year. Women experiencing IPV have about twice the number of clinic visits and care utilization compared to women not experiencing IPV.<sup>1-3</sup>

The primary focus of this chapter is IPV, which is one type of domestic violence (DV). Domestic violence is a broad term which can include other types of family violence, such as child and elder abuse. Although extremely important, detailed discussion of these forms of abuse as well as the topics of sexual assault, human trafficking, genital mutilation, or violence related to war and torture is beyond the scope of this chapter. These topics are included in the books selected as clinician references.<sup>2, 4-6</sup>



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Intimate Partner Violence is a more specific term than domestic violence and is used in this chapter. IPV is a pattern of physical violence or threats of violence, verbal or emotional abuse, sexual coercion, rape, and stalking which is perpetrated by an intimate partner or ex-partner. Coercive control underlies the expression of IPV in most situations. It can include isolation, economic abuse, and sabotage of a patient's attempts to obtain medical care. Between 25-50% of women will experience violence from an intimate partner during their lifetime, 33% will have experienced physical or sexual abuse as a child. One woman in six will have been a victim of rape.<sup>4</sup>

IPV occurs across all ages, religions, ethnic and racial groups, socioeconomic levels, educational backgrounds, sexual orientation, and physical abilities. Young women (18-24 years old) and poor women are at higher risk. Assessing ethnicity or race as an independent risk factor has been problematic because of confounding risks such as poverty.<sup>4,7</sup>

The health consequences of IPV include death, physical injuries, mental health problems (depression, post traumatic stress disorder, suicide), sexually transmitted infections, unintended pregnancy, chronic pain, and symptoms such as fatigue, headaches, gastrointestinal and pelvic symptoms. Current or past history of abuse should always be included in the differential diagnosis for patients who present with these conditions. Women who have experienced IPV are at a higher risk for having chronic medical problems such as asthma, coronary artery disease, and stroke. Like other conditions associated with social stigma or shame, a woman may not disclose abuse when first asked.<sup>4, 8-10</sup>

IPV not only directly affects the victim, it also impacts the health and well-being of children in the home. In 30-60% of families affected by IPV, the children are also directly abused. Regardless of direct abuse, children who witness IPV as a child have an increased risk of health consequences which include emotional, behavioral, physical, and developmental problems as well as an increased risk for being a victim or perpetrator of IPV as an adult. Studies indicate that when women learn about the possible affects on their children it is often a strong incentive for seeking help.<sup>2, 6</sup>

## KEY CONCEPTS ABOUT IPV FOR A CLINICIAN

**A Pattern of Coercive Control Underlies the Dynamics of IPV:** Examples of specific tactics used by perpetrators include emotional abuse, isolation (limiting contact with friends and family), threats of or actual abuse of children or pets, economic abuse (limiting access to money), sexual abuse, stalking (monitoring activities, harassing phone calls, cyber-stalking), threats of physical abuse, threats of suicide, and physical abuse (punching, pushing, slapping, choking).<sup>4</sup>

**Emotional Abuse is Particularly Damaging:** Emotional abuse is an important form of aggression that is often overlooked. Threats, demeaning names, humiliation, and intimidation can be part of a pattern that is used by a batterer to control the partner. Survivors of IPV consistently report that the emotional abuse by their partner was even more debilitating than the physical injuries. They report that the insidious and continuing loss of self esteem made it difficult to feel they even deserved help.<sup>4</sup>

**Barriers to Ending Abuse:** Although, most women do end abusive relationships by separating from the abuser, this may not be the goal for every patient. This is particularly true for women from cultures where intact families are highly valued. As one Hispanic member of a domestic violence support group said, "I don't want the relationship to end, I just want the hitting to stop." Providers should focus on a woman's safety and recognize that leaving an abuser is a time of increased risk of homicide and injury for the victim, and needs to be done with careful thought and understanding of risk. Safety planning is an important intervention that can be started in the health care setting. Attention to confidentiality (screening in private, assuring safe phone number for callbacks) is another aspect of ensuring patient safety.<sup>5</sup>

It can be difficult for providers to understand the complex barriers to ending abuse that many victims face. These may include threats by the perpetrator to hurt or kill her, her children, or her family. Lack of transportation or a safe place to go are both impediments. Lack of financial resources and/or fear of losing a job are cited by women as a primary consideration in leaving an abusive relationship. Other obstacles include fear or ambivalence about using resources such as law enforcement, criminal justice, or

social service agencies. Victims may have difficulty considering shelters, support groups, or other services provided by an advocacy organization. Concerns about custody of children are common.<sup>2, 4, 5, 11</sup>

Beliefs that slapping and hitting are acceptable under certain circumstances or that physical abuse is a normal part of marriage or that IPV is a “family issue” and not a criminal justice problem may limit a victim’s assessment of her situation. Most women feel embarrassed about the violence they experience, and for some, revealing the violence or contemplating separation or divorce might cause shame and stigma for her and other members of her family resulting in further isolation.

## CLINICIAN INTERVENTIONS MAKE A DIFFERENCE

Despite these barriers, the majority of women end abusive relationships. On average, they are in abusive relationships for less than five years, typically leaving three to five times before the relationship ends. This information is contrary to the impression many clinicians have that most women dealing with IPV will not be successful in improving their safety.<sup>12</sup>

A “turning point” often cited by survivors is the realization that the abuse is a matter of life and death, or when someone else, particularly a child, is at risk. Studies show that women given resource information in the health care setting are much more likely to use safety promoting behaviors.

Although the majority of women do not enter into another abusive relationship, about 10-20% of women are abused by more than one partner. These women may have other co-existing mental health problems and/or a history that includes childhood or sexual abuse, which may impair their ability to seek help or envision healthy family relationships.<sup>12</sup>

Clinicians can use the conceptual model of “Stages of Change” in their interventions with women in abusive relationships. This model, which identifies the steps used in changing other behaviors such as smoking, can be useful for tailoring messages and interventions. For instance, if a woman is just beginning to identify that the relationship is abusive, educational materials about abuse and community resources are more likely to be helpful than information about how to obtain a restraining order.<sup>13-15</sup>

## CONSIDERATIONS OF IPV AMONG CULTURAL AND DEMOGRAPHIC GROUPS

This section highlights particular issues clinicians should be aware of that may affect a patient’s experience of IPV and the resources that are available to her. Some women will be dealing with more than one of these issues.

**Immigration:** In addition to IPV, immigrants to the United States may have a history of other traumatic experiences, limited social support systems, language barriers, financial problems, and limited knowledge of U.S. resources. They may be uncertain and fearful about their residency status and hesitant to seek help from police. Immigrants may not be aware that assault by a family member is a crime in the U.S. It is important to be aware that some of these women may have experienced political torture, rape, or sex trafficking that are also affecting their physical and mental health.<sup>4, 11</sup>

Sensitive issues like IPV pose additional problems for those with limited English language proficiency. It is not appropriate to ask children or other family members to provide interpretation, and this is particularly true in regard to questions about IPV.<sup>11</sup>

**Religious Beliefs:** Religious beliefs about the sanctity of marriage and a woman’s role in the family can create confusion and guilt in the situation of IPV. Although no religion condones abuse (physical, sexual, or emotional), there are traditional customs and scriptures which have been used to justify or excuse spousal abuse and violence. Providers should not overlook the important role that religious beliefs and the faith community may have in making it more difficult for someone to consider ending an abusive relationship. On the other hand, for some survivors, their faith community has been essential in providing the necessary support and resources to help them leave a violent situation.<sup>11, 16</sup>

**Individuals with Disabilities:** Individuals with disabilities have a higher risk of abuse, both from caretakers and intimate partners. In one study of women with disabilities, 62% reported some type of



emotional, physical, or sexual abuse. A woman with a disability may face the double vulnerability of isolation and dependency and the dilemma of having to choose between putting up with abuse or having no one else to meet specific needs related to her disability.<sup>4</sup>

**Teens and Young Adults:** Eighteen to twenty-five percent of high school girls and 25-36% of college women experience some form of dating violence. Many teens and young adults may confuse jealousy and controlling behaviors with love and may not recognize they are experiencing abuse. In addition to risk of injury, victims of dating violence are more likely to engage in risky sexual behavior, unhealthy dieting, substance abuse, and make suicide attempts. Unintended pregnancy is associated with IPV and can result from forced sex or a partner who prevents the use of contraception. Teens exposed to dating violence are at a higher risk for intimate partner violence later in adulthood.<sup>2, 17-19, 20</sup>

**Women Who Are Pregnant:** Most studies show that 7-20% of pregnant women experience physical abuse during pregnancy. Among pregnant teens the prevalence of abuse is even higher, at 20-30%. IPV during pregnancy is more common than some conditions for which pregnant women are routinely screened such as gestational diabetes, neural tube defects, and pre-eclampsia. Prenatal care can be an important point of contact for screening for IPV and assisting with appropriate intervention. Pregnancy is often a window of opportunity, as victims may be motivated by a desire to be a good parent.<sup>4</sup>

Pregnancy complications, including anemia, infection, first and second trimester bleeding, preterm labor, and delivery are significantly higher for abused women. IPV in pregnancy is also associated with late entry to prenatal care or sporadic prenatal care and increased complications such as inadequate maternal weight gain and abdominal trauma. Low birth weight and decreased breast feeding is also more prevalent. Maternal rates of depression, suicide attempts, and substance abuse are higher among women experiencing IPV. A recent systematic review demonstrates that homicide is one of the leading causes of pregnancy-associated death.<sup>4, 21</sup>

**Women with Mental Health Conditions:** Current IPV and history of abuse is associated with an increased risk of depression, anxiety, post traumatic stress disorder (PTSD), and suicidal ideation. IPV should be considered in any woman who presents with postpartum depression. Women experiencing IPV are 2-3 times more likely to be depressed compared to non-abused women.<sup>9, 22-24, 25, 26</sup> Intervention efforts aimed at reducing depression among women must also consider IPV.

**Substance Abuse:** The interplay of DV and substance abuse is complex. For some women, substance abuse increases their vulnerability to IPV, for others the substance abuse may be an attempt to self-medicate. Any patient identified with a substance abuse problem should also be asked about current and past IPV. This information should be included in their recovery plan. A mental health consultation can be recommended for most victims of IPV and any patient with a mental health diagnosis should be evaluated for current or past history of abuse.<sup>4, 6, 9, 24</sup>

**Older Women or Women with Chronic Diseases:** Older women or women with chronic diseases who are being abused face additional problems such as economic vulnerability, difficulties with transportation, and access to care. Partners can sabotage the ability of patients to keep appointments, obtain medications, and adhere to treatment recommendations. For women who want to leave the relationship, it is often difficult to locate a shelter that can accept a woman with significant medical problems. IPV should be a consideration whenever elder abuse by a spouse or partner is suspected as this may reflect a continuation of previously existing IPV that is now becoming evident.<sup>2, 4, 5, 27</sup>

**Sexual Orientation:** IPV (physical, emotional, and sexual) appears to be as prevalent in lesbian relationships as in heterosexual relationships and usually involves a primary aggressor and victim. A control tactic specific to homosexual relationships is the threat of “outing” (revealing sexual orientation at work, or to family and social contacts). In addition to social stigma and discrimination, it can be difficult for lesbian women to find local resources for support.<sup>2, 4, 11, 28</sup>

**Ethnic Background:** Ethnic background may be associated with some distinct issues providers should be aware of that may affect a woman’s perception of her situation and her options. A few examples are highlighted below.<sup>5</sup>

The centrality of family and distinct gender roles can affect the choices that Latina victims of IPV see for themselves. Concerns about financial security and fulfilling family and societal expectations about being a “good” mother and wife may lead her to remain in an abusive marriage. On the other hand, her concern about the effect on the children of witnessing abuse or being victims of abuse may be a very powerful motivation for seeking help. With increasing acculturation, many Latino families are undergoing changes in family roles and expectations for males and females. In some cases this can increase the risk for IPV.<sup>5, 11, 29</sup>

The negative experience of many African-American communities with the criminal justice system and social agencies may create hesitancy for a victim to report abuse and concern that it might be seen as a “betrayal” of community. Some women feel it is their responsibility to maintain the family regardless of the high physical and mental cost to themselves. Some African-American women are more likely to seek support and information from relatives, church, or health care than from social services or advocacy organizations.<sup>5, 11, 30, 31</sup>

Depending on place of birth and family, Arab Americans represent many different cultures and belong to many religions. Worldwide, most Arabs are Muslim, while in the U.S., most Arab Americans follow Christianity. The close-knit Arab-American community and emphasis on family ties and religion often means that victims of IPV turn to families and religious leaders for support.<sup>11, 32</sup>

Most of the Muslims living in the U.S. are immigrants and represent diverse parts of the world such as Indonesia, Philippines, South Asia, the Middle East, and Africa. Among this group are more traditional women who may be accompanied by their husbands to the clinical setting, and whose modesty may limit physical evaluation; in this situation, the identification of IPV can be particularly difficult. Requesting a period of privacy with the patient during examination is one way that a provider can respect traditional practices but also ask about sensitive subjects such as IPV. Muslim women dealing with IPV face multiple challenges including language differences and difficulty with locating culturally and religiously appropriate shelters.<sup>11, 16, 33</sup>

For some Asian-American patients, shame about IPV and the concern about “losing face” can present obstacles to disclosing abuse. Sometimes a woman will endure abuse because of the value of family harmony. Certain kinds of IPV related injuries (burning, scalding) are more common among victims of South Asian background. Separation and divorce may be very difficult because it can be a source of shame not just to the victim, but to parents and other family members.<sup>5, 16</sup>

**Past history of IPV:** The high prevalence and associated health effects of a past history of IPV, sexual assault, or child abuse/sexual molestation are well documented. These experiences increase the risk for current IPV. For some patients these past experiences affect their ability to receive medical care, examinations, diagnostic tests, and treatments. In addition, patients may have difficulties with trust that impair their relationships with medical providers and the health care system.<sup>4, 6</sup>

Although surveys demonstrate that the lifetime prevalence of rape is common among U.S. women (1 in 6), most sexual assaults are not reported and most clinicians do not routinely ask about it. Rape is associated with immediate injury and trauma, sexually transmitted infections including HIV, and pregnancy. In addition, depression and PTSD are common sequelae and may affect the patient’s willingness to obtain a routine pelvic exam. Other health conditions such as chronic pain and bladder conditions are also more common in women with a history of child and adult sexual assault.<sup>4</sup>

Unfortunately, most clinicians have received limited education about abuse in their medical training. Clinicians should have a heightened awareness of possible past history of trauma in patients who are easily startled, exhibit physical reactions like rapid heart rate, shallow breathing, tremulousness, or appear to have an inability to focus, or become very anxious about procedures and examinations. Possible history of trauma should be considered when a patient ignores repeated recommendations for mammograms and cervical cancer screening.<sup>4</sup>

## ADVERSE CHILDHOOD EXPERIENCES (ACE) STUDY

The Adverse Childhood Experiences (ACE) Study, a CDC-sponsored investigation of 17,000 adult Kaiser Permanente San Diego health plan members, provides compelling information that has significant



implications for health professionals. ACE include direct abuse and neglect, household dysfunction including mental illness, battered mother, parental loss or incarceration. In addition to the immediate neurodevelopmental affects of ACE on a child's physical and mental health, there are long-term adult health care consequences including increased risk of chronic conditions such as depression, chronic obstructive pulmonary disease, ischemic heart disease, and liver disease. There is also a strong relationship to health-related behaviors such as early initiation of smoking, sexual activity, and illicit drug use, adolescent and unintended pregnancies, and suicide attempts. To learn more about this ground-breaking study, go to: <http://www.cdc.gov/nccdphp/ACE/>.<sup>34, 35, 36</sup>

The long term health impact and significant prevalence of these experiences in the general population makes it essential that clinicians begin incorporating this information into their clinical practice and develop the skills to ask about and respond empathetically and effectively to their patients who disclose these experiences.

## A RECOMMENDED APPROACH FOR CLINICIANS

### Patients with a Current or Recent History of IPV:

The job of the clinician is to **Ask, Affirm, Assess, Document, and Refer**. The goal of intervention for IPV is to assist the patient in taking steps to be safer. This may not necessarily mean that the patient will leave or end the relationship.<sup>15</sup>

**Ask:** Routinely ask about IPV. This must be done in private (only the provider and patient and interpreter, if appropriate). A departmental policy that all patients will be seen privately for some part of the visit is recommended. Have a heightened awareness of possible IPV when a patient presents with “red flag” conditions such as chronic pain, fatigue, headache, gastrointestinal symptoms, pelvic pain, depression, anxiety, or injuries. Like other sensitive health issues, an inquiry about IPV may need to occur on several occasions before the patient feels safe enough and/or is ready to acknowledge and discuss it.

Ensure that information and materials about IPV are easily available in the exam room. This communicates that IPV is a health issue and enables a patient to obtain information even if she isn't ready to disclose IPV. Materials for exam rooms can be ordered from Health Education.

Here are some ways that clinicians can introduce questions about IPV:

- “Who do you live with at home? How are things?”
- “Because violence is so common, I ask all my patients if they have been hurt by people close to them.”
- “Do you ever feel emotionally or physically threatened or hurt by your partner?”

The following are direct and more specific questions and are available in HealthConnect.

- “Have you been hit, kicked, choked, punched, or otherwise hurt by a partner in the past year?”
- “Has anyone forced you to do sexual things you didn't want to do in the past year?”
- “Are you afraid of your partner?”

The following are some ways to inquire about IPV for teens or young adults:<sup>37</sup>

- “Because teen dating violence is so common, I have begun to ask all my teen/young adult patients about violence in their relationships. Has your partner ever hit you or hurt you in any way?”
- “Unfortunately, many teens experience threats, name calling, uninvited touching, sex, or violence, so I ask all my teen patients about it. May I ask you a few questions?”
- “Have you ever been forced to have sex or do something sexual that you didn't want to do? Does your partner ever refuse to practice safe sex?”
- “Has your partner ever tried to restrict your freedom or keep you from doing things that were important to you (like seeing your friends or spending time with your family)?”

If the patient says “no” to these questions, use this as an opportunity to say “I just want you to know that if something like this does happen, you can talk to me about it.” If a patient is experiencing abuse, this discussion may make it possible for her to disclose it in the future. Disclosure is not the primary goal — this kind of conversation may start the process of contemplation and assessment of the situation for the patient or provide the opportunity for prevention.

Why patients might not disclose IPV:

- Embarrassment/shame
- Hope that the abuser will change
- Threats from abuser to harm patient, her children, extended family, friends or pets
- Religious/cultural/family pressure to “make it work” or not discuss the issue outside the extended family
- Low self esteem or fear that she won’t be believed
- Lack of belief that anyone can help
- Financial or immigration issues

**Affirm:** If the patient discloses that she is currently dealing with IPV, provide a supportive response and affirm the patient. This by itself is an important intervention. Survivors of IPV state that a supportive message from a medical clinician was one of the most important things that led to their taking steps to be safer and seeking further assistance.

Helpful statements include:

- “No one deserves to be hit.”
- “This is a common problem, we can help.”
- “I am glad you told me about this.”
- “I am sorry this has happened to you.”

**Assess:** Ask the patient if it is safe for her to go home today, encourage safety planning, and provide resource information (pamphlet, crisis hot-line number). Providers should focus on a woman’s safety, recognizing that leaving an abuser is a time of increased risk of homicide and injury for the victim and needs to be done with careful thought and understanding of risk. Safety planning is an important intervention that can be started in the health care setting. Attention to confidentiality (screening in private, assuring a safe phone number for callbacks) is another aspect of ensuring patient safety. The Danger Assessment is a tool that can be used to help the patient identify risk factors that increase the danger of her situation.

Brief Danger Assessment:

Ask the patient if there is...

- Increase in severity/frequency of abuse?
- Threats of homicide or suicide?
- Gun or other weapon in the home?
- History of choking or attempted strangulation?

The higher the number of “yes” responses, the greater the risk of homicide to the patient.

HealthConnect contains smart phrases that can be used for progress notes and include an abbreviated danger assessment (.dvwithinjury or .dvwithoutinjury).

**Document:** Provide documentation in the medical record of what the patient has said. Use patient’s own words for duration, frequency, severity of abuse, including threats. If a current injury is present, the patient’s statements regarding how it occurred is important. Photographs of injuries can be particularly helpful and many clinics have a camera available for this purpose.



Diagnostic codes for domestic violence

- Domestic violence (995.81A)

If you would like to be more specific about the type of abuse, use:

- Abuse/violence, physical, domestic (995.81B), and/or
- Adult emotional abuse (995.82A), and/or
- Abuse/violence, sexual, domestic (995.83B)

If you are using HealthConnect, you can type in “domestic violence” or “adult abuse” to find these diagnostic codes.

**Understand Reporting Requirements Related to Intimate Partner Violence:** If the patient reports a history of IPV, but is not being treated for a current injury, the clinician is not required to make a report to law enforcement. This differs from elder and child abuse in which the suspicion or knowledge of abuse must be reported to Child Protective Services or Adult Protective Services. Most states require health care professionals to report specified acts of violence to law enforcement when a patient has an injury caused by a weapon, a violent assault, or domestic violence. Information about these laws can be found at [www.endabuse.org/health](http://www.endabuse.org/health)<sup>15</sup>

**Refer:** Refer the patient to a mental health clinician (social services, behavioral medicine specialist, psychiatry/chemical dependency) for further evaluation and follow up.

The role of the mental health clinician is to:

- Identify any co-existing mental health conditions (such as depression, PTSD, substance abuse) that may need further evaluation and treatment.
- Provide a danger assessment.
- Assist with safety planning.
- Provide the National Domestic Violence Hotline phone number and community resource information.

In most cases of IPV, couple counseling is not recommended because the dynamics of coercion and control undermine honest communication and problem solving.

### Patients with a Past History of IPV, Sexual Assault, Childhood Physical, Emotional, or Sexual Abuse:

Unfortunately, these experiences are very common.<sup>4, 6, 34, 35</sup> In addition to increasing the risk for experiencing IPV as an adult, these experiences can also have other long term health effects. The goal of inquiry about past history of abuse is to identify important information that may inform clinical evaluation and improve treatment recommendations. The role of the clinician is similar to that for current IPV: ask, affirm, assess, document, and provide appropriate referral and resources.<sup>4, 6, 35</sup>

**Ask:** Some ways to introduce and ask questions about history of abuse in a patient with a “red flag” condition (such as chronic pain, headaches, pelvic or gastrointestinal disorders, insomnia, depression, unintended pregnancy), include:

- “Many types of trauma — including childhood abuse, loss of a parent, accidents, or serious illnesses — are common and can be related to health problems, like chronic pain. I have begun asking my patients about this.”
- “When I see problems like these in my patients, often they were hurt as children, either through harsh physical punishment or by being forced to be sexual with a grown up or family member. Could this have happened to you?”
- “Often when I see a woman with this kind of problem, it is because someone has hurt her. Has that happened to you?”

Two brief screening questions for childhood abuse:<sup>38</sup>

- “When you were growing up, did people in your family hit you so hard that it left you with bruises or marks?”
- “When you were growing up, did someone try to touch you in a sexual way or try to make you touch them?”

**Affirm:** Overall, the most important step to accomplish is for the patient to feel acknowledged, and that they can “tell the worst secret” to another person, particularly one with the social power of a physician, and still feel accepted as a human being. These are samples of supportive responses a provider can offer when a patient discloses history of IPV, sexual assault, or history of child abuse:

- “I am sorry that happened to you.”
- “We know that at least 1 in 3 to 5 women are survivors of childhood sexual abuse. It is a terrible thing that so many children have suffered in this way.”
- “I know it took courage to tell me about this.”

**Assess:** Some sample questions include:

- “How do you think this experience has affected your health?”
- “Please tell me how this has affected you later in life?”

**Document:** Factual phrases such as “patient reports childhood sexual abuse” can be included in the progress note where appropriate. The following codes can be used for diagnosis if, in your clinical judgment, the history of abuse may be affecting the patient’s current health:

**Past History of Abuse During Adulthood:** past history of physical abuse during adulthood V15.41A; past history of emotional abuse during adulthood V15.42A; past history of sexual abuse during adulthood V15.41B

**Past History of Abuse During Childhood:** past history of childhood physical abuse V61.21D; past history of childhood emotional abuse V61.21G; past history of childhood sexual abuse V61.21B

**Refer:** Ask the patient if she would like some information on referral resources. A follow-up visit with a mental health provider can be helpful in identifying co-existing conditions like PTSD and providing an opportunity to learn about and discuss treatment options for trauma. These can include support groups, therapeutic writing, and counseling.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- Because IPV is very common and associated with many health issues, clinicians need to routinely inquire about IPV, have patient information readily available, and be familiar with the referral process in their facility.
- The goal of inquiry and intervention is to help a patient connect to resources that will improve her safety, regardless of whether she discloses abuse or is ready to leave an abusive relationship.
- Interventions in the health care setting can play a significant role in helping patients with current IPV and a past history of abuse.
- It is crucial for health care providers to be aware of the risks and constraints facing women in abusive situations and the cultural factors that influence their choices.
- Past history of IPV, sexual assault, or child abuse can affect patients’ ability to receive medical care. There are patient behaviors and medical conditions which can suggest a history of abuse. There are ways that clinicians can ask and respond that are helpful.

## RESOURCES TO OFFER PATIENTS:

- National Domestic Violence Hotline, 1-800-799-SAFE (7233) or 1-800-787-3224 (TTY) [www.ndvh.org](http://www.ndvh.org)
- National Teen Hotline, 1-866-331-9474 or 1-866-331-8453 (TTY) <http://loveisrespect.org/>



- [www.kp.org/domesticviolence](http://www.kp.org/domesticviolence) Domestic violence resources for anyone: includes IPV information, emergency hotlines, videos, stories of survivors and information about the Kaiser Permanente Family Violence Prevention Program.
- Weiss, E. Family and Friends' Guide to Domestic Violence. How to Listen, Talk and Take Action When Someone You Care About is Being Abused. Volcano, CA: Volcano Press, Inc.: 2003. [www.volcanopress.com](http://www.volcanopress.com)

## CLINICIAN TRAINING AND RESOURCES:

- “Domestic violence: How to ask, respond and use HealthConnect tools” TPMG (2008) 14 min training for clinicians. Go to: <http://kpnet.kp.org/violenceprevention/facility/training.html>
- Resources for improving the healthcare response to intimate partner violence: <http://kpnet.kp.org/violenceprevention/index.html>
- “Screen to End Abuse” Family Violence Prevention Fund, 30 min training video for health care providers. 2003 Order a free copy from: <http://fvpfstore.stores.yahoo.net/screentoenda.html>
- Surprenant, Z. and Taliaferro, E. Respond to Intimate Partner Violence – 10 action steps you can take to help your patients and your practice. Tucson, AZ, Medical Directions, Inc.: 2006. Can be purchased online at [www.amazon.com](http://www.amazon.com). Includes free access to [www.RespondtoDV.org](http://www.RespondtoDV.org), an online interactive case based course offering up to 16 CME units.
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# DECREASING DISPARITIES IN LESBIAN HEALTH CARE: ASSISTING MEDICAL PROVIDERS

Nancy Goler

## AUTHOR FOREWORD

The first time my partner saw a gynecologist was for a pap smear while she was in college. She filled out the questionnaire that the nurse gave her marking “Yes” to sexually active and then “None” to birth control. The doctor reaffirmed that she was sexually active and then told her to use birth control if she did not want to get pregnant. She told him that she didn’t need it, but instead of following up with her further on this statement, he advised her that she had “been lucky” and needed to start taking the pill. The message she picked up from him was loud and clear: he was not open to her coming out. He gave her a prescription for the pill, which she took. She did not feel she had a choice about whether or not to take the prescription, especially if she needed to return to the doctor for care. She did not want to have to deal with this line of questioning again. It made her feel like being a lesbian was unacceptable.

Her story, sadly, is not unique. Many of my lesbian friends and patients have had similar experiences. The results are all the same: they felt that their needs were not addressed by the health care system; they did not trust the doctors and believed they would receive compromised care if they revealed their sexual orientation. I, too, had these experiences. I fear that my lesbian friends who do not trust the medical community will miss preventative health check-ups resulting in delayed diagnoses. As a lesbian and a member of the medical community, I am committed to helping my peers in the medical field understand and accept their lesbian patients. I hope to assist the readers of this chapter to better understand this subset of women to whom you provide care.

## INTRODUCTION AND BACKGROUND

This is an exercise that I often facilitate during my speaking engagements. I recommend that you try this exercise prior to reading the chapter. Consider the implications for your patients. Write down the top 3 descriptors of yourself that are apparent to the general public, your family or friends such as: *Mother*, *White*, and *Pharmacist*

Next, I ask the audience three questions:

- How many heterosexuals wrote “straight” or “heterosexual” in their top three?
- How many gays or lesbians wrote “gay,” “lesbian,” or “homosexual” in their top three?
- How many gays or lesbians did not write their sexual orientation in their top three?

What did you write? What do you suppose happens each and every time?



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Invariably, heterosexual individuals do not have their sexual orientation as a top descriptor. In contrast, any individual in the room willing to be identified as a homosexual included their sexual orientation among the top three. Very often, it is the first descriptor they wrote. The intent of this exercise is for the audience to understand, that for the lesbian, gay, bisexual and transgender (LGBT) population, their sexual orientation may be one of the most important aspects of their lives. It often drives their decisions about where to live, who to befriend, and where to work including whether or not to come out to family, friends, health care providers etc.

The ability to correctly ascertain a woman's sexual orientation is more complicated than one would think. Sexual orientation is both behavioral and cognitive, and for some lesbians, these do not always coincide. To whom a woman is sexually attracted may not match her self-identified image or the image that she wants to portray in society. Although for many women there is a synchronous overlapping of desires, behavior, and identity, for some lesbians, desire may be present without the behavior or identity, while others may have a sexual relationship with another woman yet do not identify as lesbians.<sup>1</sup> There are no clear identifying markers for lesbians. They may be of any age, race, class or ethnicity. They may be mothers with toddlers or grown children, divorced, disabled, executives, or seniors with or without grandchildren.

Women who have sex with women (WSW) may self identify as heterosexual or bisexual. On the other hand, a woman who identifies as a lesbian may never have had sex with a woman. Sexuality does not exist in a static state; depending on how a patient is asked, a provider may get misinformation. For example, a woman may only identify as a lesbian when she is actually in a relationship. In addition, the younger generation of women who have sex with women may not use the term lesbian or homosexual and may prefer terminology with which providers may not be familiar.

#### What Else We May Call Ourselves:<sup>2</sup>

- **Heteroflexible:** A straight person with a queer mind-set
- **Pansexual:** A person who is attracted to people of multiple genders
- **Genderqueer:** A person who sees gender options as more than just male and female or does not fit into the binary male-female system
- **Trannydyke:** A transgender person who is attracted to people with a more feminine gender
- **Boi:** A boyish gay guy or a biological female with a male presentation
- **Half-dyke:** A bisexual woman who leans more toward women than men

Lesbians may not choose to identify as such due to social stigmatization, fear of decreased services or prior negative experiences with the health care community. Moreover, women who already identify with a minority group based on race, religion, or disability may hesitate to divulge a second “minority” status. Given the multiple levels of discrimination a woman may face if identified as a lesbian, she may hide her sexuality even in what appears to be a “confidential” or “anonymous” survey. Providers need to ask women open-ended questions about their sexuality such as: Are you currently sexually active? If so, with men, women, or both? If not, which is your preference? If a woman answers that she is sexually active with women, the providers must avoid the assumption that she has not been sexually active with men in the past or will not be in the future. A complete sexual and pregnancy history is important to assess the possible risk factors that may impact her health status and well-being. In addition, just as with heterosexual-identified women, a discussion of safer sex behaviors and health risks is warranted. The “labels” a woman uses to identify herself are of little consequence; ultimately, understanding her behaviors and risk factors is the health care provider's goal.

## PREVALENCE AND DEMOGRAPHICS

Given the level of discrimination, persecution and familial ostracism historically faced by the gay and lesbian community, it has been difficult to identify lesbians, leading to a scarcity in demographic research and an unclear understanding of the extent of social and health disparities in this population. Worldwide, there is little, if any, information on the percent of individuals who identify as gay or lesbian; in the United States, the information has been inconsistently collected.



The leading, and first look, at this issue was the Kinsey Report in 1948.<sup>3</sup> However, in Kinsey's first and most famous research, he looked exclusively at the male population in order to discern prevalence of same-sex behavior. In his research, he reported that 10% of males have had more or less exclusively homosexual behavior in the last 3 years.<sup>3</sup> This data was then extrapolated to the general population, and interpreted to mean that 10% of Americans, both male and female were homosexual. However, this logic is false: it only relates to sexual behavior in the last three years and not sexual identity. The dictum that approximately 10% of the population is homosexual has stayed strong, though unproven, through the years and continues to be used today.

In 1990, the U.S. Census Bureau made its first attempt at collecting data on same-sex households by identifying "Households with Same-Sex & Unmarried Partners." In the 1990 and 2000 census, information about unmarried partner households by sex of partner was available at the national, state, metropolitan, city, and county level.<sup>4,5,6</sup> However, a comparison cannot be made between the 1990 and 2000 census because both data sets were analyzed differently. This has limited the usefulness of comparisons of the number of same-sex unmarried partners between these two census data sets. Despite this limitation, the 2000 U.S. Census Bureau data reports that approximately 1 in 9 (11%) of unmarried partner households were of the same sex, with similar numbers for same-sex females and males living together. Across the nation, these numbers varied significantly with a much higher percentage reported in metropolitan areas and the highest percentage reported in California compared to other states.<sup>5,6</sup>

In Edward O. Laumann, et al.'s *The Social Organization of Sexuality: Sexual Practices in the United States*,<sup>1</sup> Laumann interviewed 3432 Americans, ages 18-59. From these interviews, Laumann found that 7.7% of men and 7.5% of women reported homosexual desires and 2.8% of men and 1.4% of women self-identify as gay or lesbian.<sup>1</sup> His data, however, only looked at a current point in time, and sexuality is a changing dynamic process for individuals in their lifetime. In addition his small sample size lends itself to sampling error making it difficult to extrapolate to society at large. Furthermore, in looking at the census data, it is clear that the rates of same-sex unmarried households vary by geographic area; in light of this, Laumann's probability sample is skewed.

Given the difficulty of identification and limited research, a common understanding for the usage of the term lesbian is needed for this chapter. For the purposes of understanding the information below, lesbian is used broadly to include women who have previously had sex with women, desire to have sex with women, currently have sex with women, or self-identify as lesbians. In this light, providers can also assist bisexual and transgender women, who also choose to have sex with women, with their health and psychosocial concerns. The specific topics of bisexuality and transgender are beyond the scope of the chapter. However, the needs of these communities also warrant sensitive and open-minded professionals to deliver their care.

## BARRIERS TO CARE

There are unique challenges for lesbians within health care. Many providers are not educated about lesbian health and may be uncomfortable with the topic. Until 1973, the American Psychiatric Association classified homosexuality as an illness or pathological condition. Most medical school training does not cover lesbian, gay, bisexual, or transgender (LGBT) issues, and only 11-37% of primary care providers take a social history.<sup>7</sup> In a 1996 study in New Mexico, 4.3% of physicians stated that they would deny medical service to homosexuals and 10.1% did not believe that homosexuals should be Ob/Gyns.<sup>8</sup> Sadly, there is no reason to believe that these physicians are unique in their beliefs, and, in some parts of the United States, more physicians may feel this way. Similar findings were cited in a nursing study in 1998, in which 8-12% of nurses reported despising LGBT people, 5-12% found LGBT individuals disgusting, and over 40%

Although there is no single health risk for lesbians currently understood to be related to a women's sexual orientation, lesbians as a group may have some risk factors based on lifestyle choices which carry a greater propensity for some diseases.

– Nancy Goler, MD

believed that LGBT people should keep their sexuality private.<sup>9</sup> Lesbians are perhaps justified in their fear of discrimination and negative reactions to their sexual orientation from the medical community.

As many lesbians do not divulge their sexuality to their medical providers, they often do not have their questions answered and risk factors for diseases fully assessed. In my experience as a health care provider, one of the most common reasons why lesbians do not seek health care is because of past negative health care experiences. Lesbians may not access health care because of lack of insurance with domestic partners, fear of discrimination, and misinformation from previous providers and the lesbian community regarding the risks of sexually transmitted diseases (STDs), and cancers.

Fundamentally, lesbians need access to high quality health screening, preventive care, and treatment, as do all women in general. This includes cervical and breast cancer screening, STDs and HIV risk assessment, assessment of mental health, diagnosis and treatment of substance abuse, pregnancy and parenting support, and assessment of domestic/intimate partner violence.

## HEALTH BEHAVIORS

Many lesbians face increased psychosocial pressures including acceptance of their own sexual orientation/coming out, discrimination, stigmatization and loss of support of family and friends. Lesbians have less protection under the law than heterosexual women, with many states and employers lacking discrimination clauses for sexual orientation. Also, without the advantages of marriage, lesbians are unable to make decisions for the health of loved ones, to keep custody of children of whom they are not the birth mother in the event of the death of their partner, or divorce, or to have access to pensions and social security when their partners die. These types of stressors often lead to unhealthy behaviors. The Women's Health Initiative Trial demonstrated that lesbians were twice as likely to be smokers and studies have reported higher rates of alcohol problems in lesbians as compared with heterosexual women. Lesbians also have increased rates of obesity, which increase their health risks.<sup>11</sup>

## SCREENING AND PREVENTATIVE CARE

Recommendations for preventative health screening including cervical cancer and breast cancer screening for lesbian women are the same as those for heterosexual women. Lesbians also need to have the same screening as the general community for colorectal cancer and heart disease. Over the past decade, research has borne out that cervical cancer is directly related to exposure to the human papilloma virus (HPV), and hence, is a sexually transmitted disease. Nonetheless, many women are unaware that the virus lives in the skin in the labia, groin, mons pubis, and thighs. Essentially, if a lesbian is sexually active while naked with another individual who has HPV, the transmission of HPV cannot be prevented.<sup>12,13</sup> Unlike other STDs, the virus is not carried in the secretions of the vagina, and thus, transmission is not prevented by protection from the vaginal secretions. For the majority of women, the exposure to HPV is unnoticed and does not have any sequelae. Nonetheless, some women will present with vaginal warts, or changes in their pap smear that may indicate a precancerous or cancerous condition.

As a group, lesbians are less likely to have had a child before age 30 or breastfed a child, both of which decrease the risk factors for breast cancer.<sup>10,14</sup> Despite this, the screening procedures for breast cancer are no different for lesbians as they are for the general population of women, unless the patient has a first degree relative with breast cancer.

## INFECTIONS AND SEXUALLY TRANSMITTED DISEASES

Lesbians need to be screened for sexually transmitted diseases (STDs), as well as vaginitis, because these have been shown to pass between women. The following is a brief description of STDs (except HPV, as it is discussed above), vaginitis, and possible transmission issues.<sup>14,15, 16,17,18</sup>

**Bacterial Vaginitis (BV):** BV occurs when there is an imbalance of the natural flora of the vagina. Its symptoms include a fishy odor and thin white, yellow, grey discharge. Although BV is not considered an STD, it is more common in lesbian and bisexual women than heterosexual women, often occurring in both the lesbian partners. It is easily treated with antibiotics (orally or intravaginally). If one lesbian in a couple has recurrent BV, it is prudent to treat both women.



**Candida Vaginitis:** Candida vaginitis, more commonly known as a yeast infection, is marked by a white, thick discharge and itching and/or burning. Although this is also not considered a sexually transmitted disease, it may be seen passed between lesbians in a couple and if recurrent, treatment of both partners may be helpful.

**Trichomonas Vaginitis (Trich):** Trichomonas is a single-celled parasite that is transmitted through sexual contact. Symptoms include a yellow, green, or grey vaginal discharge (often foamy) with a strong odor. Patients may also experience discomfort during sex and when urinating. It is treated with antibiotics and partners need to be treated as well.

**Gonorrhea:** Gonorrhea is a bacterium that causes an inflammation of the cervix and if left untreated can proceed to an infection in the uterus and fallopian tubes, known as pelvic inflammatory disease (PID). There may be no noticeable symptoms, but if there are, they include: A yellow, purulent discharge, burning with urination or abnormal bleeding or spotting. It is transmissible through vaginal secretions and is treated with antibiotics for the patient and her partner.

**Chlamydia:** Chlamydia is also sexually transmitted and like gonorrhea, may be asymptomatic. Symptoms are similar to those of gonorrhea, and if left untreated can proceed to PID. Treatment is with antibiotics for the patient and her partner. It is transmissible through vaginal secretions.

**Herpes:** Herpetic lesions are painful, ulcerative sores that occur, in general, at the junction of mucus membranes and skin, for example, the lips and labia. They are caused by a virus which, after an outbreak, lays dormant in the nerve root, such that future outbreaks tend to recur in the same area. There are two types, HSV 1 and HSV 2. In general, oral herpes is caused by HSV 1 and genital herpes is caused by HSV 2; however, approximately 15% of each type occurs in the opposite location. Generally, HSV is only transmitted when there is a current lesion, but asymptomatic shedding can occur, so it is always important to practice safer sex. There is no cure for herpes; however, there are anti-virals, which can limit the duration of the course and the frequency of outbreaks. There are also ointments that can decrease the pain.

**Syphilis:** Syphilis is an STD caused by bacteria and is marked by a non-painful ulcer in the genital or buttock area. Although rare in lesbians, if a lesbian has a non-painful ulcer, she should consult her physician. It is passed through direct contact with a syphilis sore during vaginal, anal, or oral sex. If untreated, syphilis can infect other parts of the body including the nervous system and heart. It is treated with antibiotics.

**Hepatitis:** Hepatitis is a viral infection that affects the liver. There are two types that can be sexually transmitted: Hepatitis B and Hepatitis C. Both are carried in the vaginal secretions and in blood, making them especially contagious in lesbians who are infected and have unsafe sex on their menses. There is a vaccine for Hepatitis B, but none for Hepatitis C. It is extremely important to practice safe sex, especially if either one of the women in the relationship is positive.

**HIV/AIDS:** HIV is the virus which causes the disease AIDS. It can take up to ten years without treatment for a woman who is HIV positive to develop AIDS, and longer if she receives medications. It is extremely important for all women to be tested and to practice safe sex. There is currently no cure for AIDS and no vaccine for prevention. Although transmission between lesbians has been infrequently reported, there are certain behaviors that increase the transmission of HIV, especially sexual behavior while on the menses or with the usage of sex toys.

## SAFER SEX PRACTICES

Given the information above, it is clearly essential that all lesbians understand and practice safer sex. I define safer sex as avoiding exposure to another person's bodily fluids without decreasing the sexual gratification of either partner. Safer sex behaviors include: kissing, hugging, mutual masturbation and touching/kissing partner's breasts as long as there are no lesions, blood, or breast milk. Other than HPV, all the infections described above are transmitted via direct contact with the lesion or through bodily secretions, which include vaginal secretions and blood. Lesbians may not realize that as menstruating women, they have increased risks for transmission during the menses. WSW need to protect themselves

from exposure to their partner's bodily fluids. Sex between women includes digital (finger/hand) to genital exposure, oral to genital exposure, and genital to genital exposure. Thus, a woman can protect herself from her partner's bodily fluids during digital to genital contact by using latex gloves or latex finger cots. For oral to genital protection, women can use a latex dental dam, double layered plastic wrap, or the *Reality* female condom to cover the genital area. Women must not partake in oral to genital contact if either person has a lesion on the mouth or labia. As oil-based lubricants can breakdown the latex, only water-based lubricants must be used. Also, if women use sex toys, such as vibrators or dildos, it should be covered with latex condoms or gloves and rinsed with a diluted (1 to 10) bleach/soapy water solution between usage.

## HEALTH RISKS

**Cancers:** As most cancer registries do not gather information on sexual orientation, it is unknown whether or not lesbians are at increased risk for various forms of cancer. However, as mentioned earlier, individual lifestyle choices of a lesbian may increase her risk for breast cancer. The Women's Health Initiative, the first national population-based research to include sexual orientation, has shown that lesbians more often used alcohol and cigarettes, thus increasing their risk for liver disease, lung cancer, and cardiovascular disease. Lesbians also displayed other risk factors that may increase their risk for reproductive cancers.<sup>11</sup> These risk factors include traditionally less childbearing and ensuing breast-feeding, which decrease the risks of breast, ovarian, and uterine cancer. The lesbian community also has less usage of oral contraceptives. Given that oral contraceptives decrease the risks of ovarian and uterine cancer, the majority of the lesbian community has not had the benefit of this protective effect.<sup>19,20</sup> Certainly, heterosexual women who have not had children or used oral contraceptives may have the same underlying risk factor, but lesbians face many barriers to quality health care that can prevent or delay diagnosis.

**Obesity:** The Women's Health Initiative also suggests that a greater proportion of lesbians are above the overweight threshold when Body Mass Index (BMI= 27) is calculated (52.3% of lifetime lesbians compared to 45.8% of heterosexual women).<sup>11</sup> Higher BMIs increase the risk for cardiovascular disease, joint problems, gallstones, and diabetes.

**Chronic Stress:** Lesbians may experience chronic stress from homophobic discrimination. The process of "coming out" is complicated and stressful for many lesbians. There is the fear of losing family, friends, and employment. There is also the fear for one's safety. This stress can lead to use of alcohol and cigarettes, which are behaviors more prominent among lesbians. Chronic stress can lead to medical problems such as depression. Screening for support networks may help to assess a patient's level of coping skills and resources. (See the Mental Health chapter for more information on assessment of support networks and resources).

**Intimate Partner Violence:** Preconceived stereotypes of violence within lesbian relationships may lead to decreased screening and lack of support for lesbians who are experiencing same-sex intimate partner violence (IPV). Even within the lesbian community there is denial about the prevalence of IPV, as there is often a sense of pride in the ability to maintain equal partnerships and a fear of further stigmatization if this information is shared in heterosexual society. The similar sizes of the same-sex partners in many cases often makes health care providers and law enforcement doubt the truth of the violence, as it conflicts with generally held notions of an aggressor being of a greater size than the partner.

Studies on same-sex IPV are limited by sample size but have borne out that IPV does occur in same-sex relationships both with lesbians and gay men. Most studies have shown that 30-40% of lesbians report at least one relationship with a same-sex partner in which she experienced an episode of IPV. These episodes ranged from slapping, shoving, and pushing, to beatings and assaults with weapons.<sup>21,22</sup> Lesbians may not only be in a current relationship with IPV, but may also have been a victim of IPV in previous relationships. According to the National Violence Against Women Survey published in July 2000, among women in current same-sex cohabitation relationships, 39.2% reported a history of IPV at some point in their lives as compared with 20.3% of women in current opposite-sex cohabitation.<sup>23</sup> Of the women in same-sex relationships who were victims of IPV in the past, 30.4% had been victimized by men while 11.4% had been victimized by women. As with heterosexual women, a lesbian in an abusive situation with a partner may face discrimination, a loss of personal safety, and potential loss of income and children. Domestic violence agencies serve both heterosexual and lesbian women; however, there may be programs at LGBT community-based agencies



designed to specifically meet the needs of both abused and abusive lesbian women. Providers need to be knowledgeable about local community resources and the services available. (See the Intimate Partner Violence chapter for more information about assessing for intimate partner violence).

**Mental Health Disorders:** Studies have shown that gay and lesbian youth have more risk factors for suicide, including feelings of hopelessness and increased rates of alcohol and substance abuse. Adolescents with same-sex orientation are twice as likely to attempt suicide as their heterosexual peers.<sup>24</sup>

## FAMILY PLANNING

There are many lesbian couples who may desire to start their family together. Along with adoption, reproductive options including intrauterine inseminations and in vitro fertilization have expanded. The first decision a lesbian couple generally makes is who the birth mother will be. If both women want to bear children, it is helpful to discuss which woman may be a preferable first choice, looking at risk factors including age and medical problems. Preconception counseling is important. The next step is for the couple to decide on a sperm donor. Some lesbian couples may choose to use a known donor and have a family with involvement of the biological father, while other couples may prefer to use an unknown donor who would not be involved in the parenting of the child. Prospective mothers should seek legal counsel since state laws for same-sex adoptions vary.

The birth mother will be exposed to the bodily fluids of the sperm donor, and as such, he needs to be tested for STDs including HIV, hepatitis, gonorrhea, chlamydia, and syphilis. Ideally, sperm is collected and frozen for later use, and the donor is tested at baseline and in three months. However, if the couple is using fresh sperm, then it is important that the donor is practicing safer sex and that he is tested at baseline and then again at three months when he donates the specimen. There are many reputable sperm banks throughout the nation that can provide tested specimens. When using a sperm bank, the donor has the option of having his name released to the child when the child reaches age 18. This can be a very difficult decision for women to make, and it is important to discuss whether or not they will want the offspring to know the name of the donor in the future. Sperm banks often will only release the sperm to a physician's office for insemination. The success of insemination using frozen sperm is markedly increased if coupled with intrauterine insemination by a skilled provider.

Some lesbian couples must also confront issues of infertility; however, the evaluation of fertility is too large and variable to be covered in this chapter. Fertility specialists can provide services that range from blood tests, surgical procedures, inseminations, medications for ovulation, and in vitro fertilization using the eggs of either woman or donor eggs.

Lesbian couples have many options to proceed with a safe and healthy pregnancy. It is important for providers to offer a supportive environment to encourage women to discuss these issues and obtain information.

## CONCLUSION

In summary, providers need to provide a safe environment in which all women feel supported and free to discuss issues impacting their health care needs, including sexual orientation. Lesbians need the same preventative health screening, STD checks, and safer sex discussions as heterosexual women. In addition, they need to be assessed for smoking and alcohol use as these risk factors are increased in the lesbian community. It is also important for providers to ascertain if their lesbian patients are living in a safe environment and have a supportive network of friends and/or family. In a greater context, more research and population statistics are needed. Not until we have data that clearly outlines the health disparities faced by lesbians and a society that unreservedly supports the lesbian, gay, bisexual, and transgender communities and their needs, including health care benefits for domestic partners and laws that prevent discrimination based on sexual orientation, will providers have all the information and tools they need to provide the best care possible to the lesbian community.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- There are no formal statistics of the demographics of lesbians in the United States or worldwide, only estimates.
- Lesbians cannot be identified by age, race, previous marriages, children or appearance.
- Many lesbians have had sexual encounters with men.
- Lesbians who are not comfortable sharing their sexuality with their provider may not share other pertinent medical information. Create a non-judgmental space for lesbian, bisexual, and transgender women by educating all staff on lesbian health issues.
- Use gender neutral language (e.g., “your partner”) and use forms that allow for same-sex responses.
- Lesbians may have some increased health risks due to increased rates of obesity, smoking, and alcohol abuse and decreased rates of oral contraceptive usage and breast-feeding.
- Lesbians are more likely to have experienced intimate partner violence at some point in their lives, and may currently be in a violent relationship. They require the same standard of screening as heterosexual women.
- Lesbians can transmit sexually transmitted diseases and need the same level of screening as heterosexual women.
- Advocate for data collection for lesbians in the United States and specific health research.

## RESOURCES

Gay and Lesbian Medical Association (GLMA). <http://www.glma.org>

Lesbian Health Research Center, Institute for Health and Aging, UCSF. <http://www.lesbianhealthinfo.org>

Lesbian STD Web Site, University of Washington. <http://depts.washington.edu/wswstd/>

National Center for Lesbian Rights. <http://www.nclrights.org>

The Mautner Project. <http://www.mautnerproject.org>

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# MAJOR DISEASES

Juanita L. Watts

## AUTHOR FOREWORD

Chronic diseases and health disparities in women by ethnicity, socioeconomic level, and age have increased over the past years. Advanced gender-specific research is resulting in new prevention strategies, more effective diagnostic tools and promising medications and treatments that promote an integrated, comprehensive approach to women's health. Increasing one's own knowledge of the unique impact of gender, ethnicity and race in major diseases will provide opportunities for healthcare providers to engage women in reducing risk behaviors and seeking appropriate preventive screenings. This chapter is dedicated to all providers who are committed to providing the highest quality of health care to women from diverse cultures.

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## CARDIOVASCULAR DISEASES

Juanita Watts, MD

Cardiovascular disease (CVD) includes heart attack, angina pectoris, stroke, high blood pressure, congestive heart failure, and congenital cardiovascular defects. Emerging data has displayed important sex-based differences in CVD, its pathophysiology, clinical presentation, diagnostic strategies, response to therapies, and adverse outcomes. While some women may perceive breast cancer as the greatest danger to their health, many do not realize that cardiovascular disease kills 10 times more women annually than breast cancer. Coronary heart disease is the leading cause of death for American women, and 1 in 5 women have some form of heart or blood vessel disease. According to the American Heart Association (AHA), in 2004, 35% of white women, 49% of African-American women, and 34.4% of Mexican-American women over age



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20 were diagnosed with CVD. With the exception of white women, the prevalence of CVD is higher for African-American and Mexican-American women than their male counterparts.

Given the high incidence of CVD in women and the societal tendency to associate men rather than women with CVD, better cardiovascular education of women during office visits and earlier and more aggressive control of coronary risk factors is required. The burden of heart disease and stroke could be reduced by addressing the major risk factors of high blood pressure, high blood cholesterol, smoking/tobacco use, diabetes, and physical inactivity.

## CORONARY HEART DISEASE

Juanita Watts, MD

Coronary heart disease (CHD) is the leading cause of death in the United States for men and women. According to the American Heart Association (AHA), someone in the United States has a CHD-related event about every 29 seconds. There are many factors that increase the risk for CHD.

Risk factors include

- Family history of coronary heart disease (especially before the age of 50)
- Age (65 and older)
- Tobacco use
- High blood pressure
- Diabetes
- High cholesterol levels (specifically, high LDL cholesterol and low HDL cholesterol)
- Lack of physical activity or exercise
- Obesity
- Higher-than-normal markers of inflammation, high blood homocysteine levels
- Menopause

For women, symptoms can include gastrointestinal symptoms, fatigue, arm pain and atypical chest pain in the left chest, abdomen, back, neck, jaw or arm that is often fleeting or sharp. This atypical chest pain is unrelated to exercise and is not relieved by rest or nitroglycerin. Women are more likely to have subtle symptoms of myocardial infarction (MI) such as nausea, vomiting, fatigue, shortness of breath, dizziness, abdominal or mid-back pain, and indigestion. Unfortunately, because these symptoms differ from those typically reported by men, women may not receive appropriate and aggressive treatment.

The treatment for CHD involves lifestyle changes, medications, and surgical interventions. Lifestyle changes may include:

- Maintaining a healthy body weight
- Eating a heart-healthy diet, which avoids saturated fats, cholesterol, and trans fat
- Reducing sodium to less than 2,300mg/day to keep high blood pressure under control
- Regular exercise – recommended 30 minutes/day, at least 5 days of the week
- Strict control of diabetes – Hemoglobin A1C less than 7.0
- Smoking cessation

Lipid-modifying drugs offer benefits to women comparable to those seen in men. Low-density lipoprotein cholesterol (LDL-C) is the primary target of lipid-modifying therapy for the reduction of coronary risk. However, there are differences between the sexes in the lipid profile that may have clinical implications. In women, changes in high-density lipoprotein cholesterol (HDL-C) and triglyceride levels are better predictors of coronary risk than LDL-C or total cholesterol. Thus, treatment beyond LDL-C may be of greater importance in women than in men. Furthermore, treatment options that provide improvement in all aspects

of the lipid profile should be considered. With regard to aspirin therapy, studies have shown that women over 65 benefited more from aspirin therapy than women under 65.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- It is imperative for clinicians to increase their awareness of sex-based differences in risk factors, lipid profiles, and treatment response to effectively refocus cardiovascular care in women.
- Few women appreciate that cardiovascular disease is a major health problem for women as well as men. This gap between fact and perception highlights the need to increase women's awareness about their vulnerability to CHD.
- The fact that coronary risk factors are reliable predictors of sudden cardiac death provides further rationale for coronary risk stratification and reduction for women. Cardiovascular risk factors should be assessed in women starting much earlier than menopause and should be treated as aggressively in women as in men.
- In light of evidence suggesting that HDL-C and triglyceride levels may be more important predictors of cardiovascular risk than total cholesterol or LDL-C, optimal treatment of women with dyslipidemia should start with LDL-C but not end there; triglycerides, HDL-C and, when appropriate, other markers of risk should be measured and abnormalities addressed.
- There is a need to refocus patterns of clinical practice to address the unique diagnostic and management needs of women with CHD.
- Clinicians should follow the new Food and Drug Administration labeling requirements for all estrogen and estrogen/progestin products. These products are not approved for heart disease prevention.
- Healthcare providers must discuss other approaches with their patients to reduce heart disease risk factors—e.g., diet, exercise, weight control, smoking cessation, lipid management and blood pressure control.

## HYPERTENSION

Juanita Watts, MD

Hypertension is a “silent” disease. Its symptoms may remain undetected for months, years, or even decades. Untreated hypertension is the leading cause of stroke in the United States, killing 100,000 women each year and disabling many more. It can also lead to kidney disease, blindness, and dementia.

## HIGHLIGHTS

- Women have lower rates of hypertension control than men. Controlling hypertension to high-normal levels could prevent one third of CAD events in women.
- After age 55, hypertension is more prevalent in women than in men.
- The risk of CVD doubles for each blood pressure elevation of 20 mm Hg systolic or 10 mm Hg diastolic.
- Essential (idiopathic) hypertension accounts for more than 90% of hypertension cases.
- Causes of hypertension are complex and usually involve age-related changes in renal, hemodynamic, and cardiovascular factors.
- The prevalence rises with age, approaching 80% to 90% in women over 70 years of age if subjects with isolated systolic hypertension are included.
- Women with chronic hypertension during pregnancy have a slight risk of adverse maternal and fetal outcomes.
- Pregnancy-specific hypertensive disorders (predominantly pre-eclampsia) account for 15% of maternal deaths.

There are several important gender-related differences: the incidence of hypertensive complications is significantly lower in women than in men, particularly in premenopausal women. Left ventricular hypertrophy is less common in women than in men with similar degrees of hypertension. A greater blood pressure load seems to be required to produce cardiovascular injury in women. This difference is taken



into account in a report from New Zealand that recommends that therapy be given only to those patients with an estimated overall 10-year risk for cardiovascular complications of at least 20%. At equal degrees of hypertension, women were at lower risk than men in all age groups from 40-70 years. The reasons for these differences are not clear, but hypertensive women have somewhat different hemodynamic findings from men matched for blood pressure, race, age, and body surface area. Women tend to have a 10% higher cardiac output and a 10% lower systemic vascular resistance (SVR). Women also tend to have a wider pulse pressure, related to shorter stature. This results in a more rapid return of the pulse wave to augment the peak pressure, increase the heart rate and induce a short diastolic period. Women also have only two-thirds as great a rise in blood pressure with exercise. Premenopausal women have less effective baroreflex buffering of blood pressure than men of similar age, which may explain less effective blood pressure regulation in women in response to vasoactive drugs and acute stress. It is possible that the lower SVR in some way minimizes vascular injury, thereby decreasing the incidence of coronary disease, heart failure, and stroke. The pathophysiologic mechanisms responsible for the hemodynamic differences are not known, but estrogens may play an important role.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- Recommended lifestyle changes to help manage blood pressure include weight control, increased physical activity, alcohol moderation, sodium restriction, and an emphasis on eating fresh fruits, vegetables, and low-fat dairy products.
- Women must be encouraged to reduce saturated fats intake to less than 7% of calories, if possible.
- Specific guidance on omega-3 fatty acid intake and supplementation recommends eating oily fish at least twice a week and taking a capsule supplement of 850-1000 mg of EPA (eicosapentaenoic acid) and DHA (docosahexaenoic acid) in women with heart disease, and 2000-4000 mg for women with high triglycerides.
- Hormone replacement therapy and selective estrogen receptor modulators (SERMs) are not recommended to prevent heart disease in women.
- Antioxidant supplements (such as vitamins E, C, and beta-carotene) should not be used for primary or secondary prevention of CVD.
- Folic acid should not be used to prevent CVD - a change from the 2004 guidelines that did recommend the consideration for its use in certain high-risk women.
- Routine low-dose aspirin therapy may be considered in women age 65 or older regardless of CVD risk status, if benefits are likely to outweigh other risks.

## DIABETES

Juanita Watts, MD

According to the CDC, from 1980 to 2004, the age-adjusted prevalence of diagnosed diabetes increased 59% for women. Data show that minority populations are disproportionately affected by diabetes. The age-adjusted prevalence of diagnosed diabetes during this time was higher among African-Americans and Hispanics than whites and highest among African-American females. A 7-year longitudinal study found that the greatest increase in diabetes prevalence was among Asians (68.0%) as compared to whites, African-Americans, and Hispanics. In general, regardless of race and ethnicity and sex, prevalence tended to be highest among persons aged 65 years or older and lowest among persons less than 45 years of age.

According to a CDC report on Women and Diabetes, as a group, American women are aging and growing more obese and less physically active; each of these factors increases the risk for type 2 diabetes.

Risk factors associated with diabetes include

- Old age
- Obesity
- Family history of diabetes

- Chronic steroid use
- History of gestational diabetes
- Impaired glucose metabolism
- Physical inactivity
- Race and ethnicity

Diabetes was the sixth leading cause of death listed on U.S. death certificates in 2002. It is believed that diabetic deaths are under-reported due to the many complications diabetes causes. Overall, the risk for death among people with diabetes is about twice that of people without diabetes of similar age. Screening for type 2 diabetes in patients with hyperlipidemia (LDL > 130) and hypertension (defined as a blood pressure  $\geq$  130/90 mmHg) is recommended regardless of age. Some of the complications associated with diabetes are high blood pressure, blindness, kidney disease, nervous system disease, amputations, dental disease and complications of pregnancy.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- Providers must encourage patients to manage their weight, nutrition, and exercise.
- There is a correlation between diabetes and cardiovascular diseases.
- Aggressive diabetic management decreases long-term effects of the disease.
- Hemoglobin A1C is best kept under 7 for patients under the age of 65.
- Providers must document all screening tests such as retinal exams and foot exams.

## OSTEOPOROSIS

Brenda Thomason, MSW and Nora Strick, MD

Osteoporosis is a progressive disease characterized by loss of bone mass and structure, which ultimately leads to fragility and increased risk of fracture. According to the National Osteoporosis Foundation, 80% of individuals affected by osteoporosis are women. Currently, eight million American women are estimated to have osteoporosis, and one in two women over the age of 50 will have an osteoporosis related fracture in her lifetime. Women are two to three times more likely to have a hip fracture than men, and the risk of a hip fracture for a woman is higher than the risk of breast, uterine, and ovarian cancer combined. Osteoporosis affects 20% of Caucasian and Asian women, 10% of Hispanic women and 5% of African-American women.

Even greater numbers of women are estimated to have Osteopenia, or low bone mass. Osteopenia is seen in 52% of Caucasian and Asian women, 49% of Hispanic women and 35% of African-American women. According to the National Osteoporosis Foundation, osteoporosis is under-recognized and under-treated in both Caucasian and African-American women. Osteoporosis may be asymptomatic until a patient has a fracture. This creates a challenge regarding awareness of the problem for both the patient and the provider. This disease is a major public health threat and it is important that screening and prevention become a regular part of medical practice.

Risk factors for osteoporosis include

- The aging population.
- Prior fragility fracture
- Low bone mineral density
- Family history of hip, wrist, or vertebral fracture after age 50 in a first-degree relative
- Being thin or small boned (<125 pounds in women)
- Current cigarette smoking



- Prolonged use of glucocorticoids
- Chronic eating disorders
- Depo-Provera use for more than 3 years
- Post menopausal

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- Identify patients at risk based on age, ethnicity, family history, past medical problems, and increase in steroid use.
- Promote weight bearing exercises, along with early increased calcium intake.

## BREAST CANCER

Joanne Schottinger, MD

Breast cancer is the most common cancer diagnosed in women in the United States and the second leading cause of cancer death in women. The vast majority (about 70%) of women diagnosed with breast cancer will have no family history and/or no identifiable risk factors. White women have a higher incidence of breast cancer than African-American women after age 35. In contrast, African-American women have a slightly higher incidence rate before age 35 and are more likely to die from breast cancer at every age according to the American Cancer Society (ACS) statistics. In the past, the rates of breast cancer in Asian women were significantly lower than white women. Much of this has been linked to differences in lifestyle factors such as diet, exercise, body weight, and choosing to have children later in life (or not at all). However, in recent years, the rates of breast cancer has risen sharply in some Asian populations. This is thought to be a result of “Westernization” of lifestyles.

Risk factors for the development of breast cancer include

- Advancing age
- Family history - first degree relative (i.e., mother, sister, daughter) with breast cancer under the age of 50
- Genetic risks (BRCA1 and BRCA 2 genes anomalies)
- Hormonal replacement therapy
- Abnormal breast lump biopsy results
- Chest wall irradiation
- Physical inactivity

Breast self-awareness is a way to encourage women to observe changes of the breast such as discoloration, configuration, tenderness, and nipple discharge over time. Screening for breast cancer with a mammogram can detect lumps and cancers so small that they cannot be felt yet; however mammographies will not detect all breast cancers. Most lumps will be benign, but it is important that all lumps be evaluated by a health care professional. Currently, use of MRI to screen for breast cancer is not recommended for most routine screenings.

Mammogram Screening Schedule – Women 50 to 69 are strongly recommended to have a mammogram at least every two years. Women who have a higher risk for breast cancer because of a positive family history of breast cancer, a previous abnormal biopsy, a personal history of breast cancer, or a family member with an alteration in the BRCA genes should be screened every year. Annual screening should start at the time of the diagnosis of a genetic abnormality or abnormal biopsy, at age 40 if the family member with breast cancer was diagnosed at an age over 50 and at age 35 if the family member with breast cancer was diagnosed at an age under 50. The benefits of screening mammography for women 40-49 and over the age of 70 are not as clear.

White women have higher compliance rates of adequate screening mammography than African-American, Asian, Hispanic, and American-Indian women. Efforts to decrease disparities in screening mammography

need to result in reduced breast cancer morbidity and mortality. Despite improvements in screening rates, it is disconcerting to note that disparities in breast cancer mortality persist among underserved populations such as African Americans, Hispanics, Native Americans, Vietnamese, and Native Hawaiians.

Mortality Differences – African-American women were more likely to have poor-prognosis tumors than white women. Their tumors were more often estrogen receptor-negative (a marker associated with poor clinical outcome), larger, and at a more advanced stage. African-American women with breast cancer were nearly five times likelier than white women to have these three unfavorable characteristics. Some studies point to genetic factors as a potential influence on the breast-cancer characteristics in African Americans.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- Early detection is key as the best survival rates are with early diagnosis of stage 0 and 1.
- Providers must encourage women between 40 and 69 to get mammograms done.
- Newer technology, including digital mammography and MRI, will help determine surgical interventions and treatment in a specific population of women.
- Genetic counseling is recommended for high-risk families with multiple first-degree relatives with breast cancers.

## LUNG CANCER

Martha Marshall, RN and Juanita Watts, MD

Lung cancer is the leading cause of cancer deaths in women. According to the ACS, nearly 70% of people diagnosed with lung cancer are older than 65; fewer than 3% of all cases are found in people under the age of 45. Lung cancer incidence rates among African-American women are equal to that of white women, although the prevalence of smoking in African-American females is much lower. The lung cancer survival rate is only 13% for African-Americans, while it is 16% for whites. Lung cancer is one of the most common types of cancer found in Hispanic men and women. Lung cancer is the leading cause of cancer death among American Indians and Alaska Natives. The general prognosis of lung cancer is poor, with overall survival rates of about 15% at 5 years. Early detection of lung cancer is critical.

The risk factors for lung cancer include:

Smoking – Smoking is the number one risk factor for lung cancer. The risk for dying of lung cancer is 20 times higher among women who smoke two or more packs of cigarettes per day than among women who do not smoke. Lung cancer risk increases with the number of years of smoking. This increase is independent of the number of cigarettes smoked per day. Quitting smoking decreases a woman's risk even if she has smoked for years. Complications of smoking increase the risk for cardiovascular disease and diabetes in women.

An estimated 18.1% of adult U.S. women 18 years or older are current cigarette smokers. Prevalence of cigarette smoking is highest among women who are American Indians or Alaska Natives (26.8%), followed by whites (20%), African-Americans (17.3%), Hispanics (11.1%), and Asians [excluding Native Hawaiians and other Pacific Islanders] (6.1%). Cigarette smoking estimates are highest for women with a General Educational Development (GED) diploma (38.8%) and lowest for women with an undergraduate college degree (9.6%) or a graduate college degree (7.4%). Smoking prevalence is higher among women living below the poverty level (26.9%) compared with women living at or above the poverty level (17.6%). An estimated 18% of pregnant women 15-44 years smoke cigarettes, compared with 30% of non-pregnant women of the same age. Non-smoking women are more likely to get lung cancer than non-smoking men.

Secondhand smoke – Nonsmokers who are exposed to secondhand smoke are inhaling many of the same cancer-causing substances as smokers. Even brief secondhand smoke exposure can damage cells in ways that set the cancer process in motion. As with active smoking, there is a dose-response relationship between secondhand smoke exposure and lung cancer - the longer the duration and the higher the level of exposure, the greater the risk of developing lung cancer. There is no risk-free level of exposure to secondhand smoke.



## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- Smoking cessation is the most important measure that can prevent lung cancer. No matter how long a patient smoked, quitting smoking will always decrease the risk for lung cancer.
- Women who are non-smokers but are exposed to second-hand smoking may be at risk for lung cancer
- Providers should encourage patients not to smoke during pregnancy.

## COLORECTAL CANCER

Monica Alvarado, MS CGC

Colorectal cancer (CRC) is the third most common cancer diagnosed in women in the United States, and the third most common cause of cancer death. The lifetime risk for CRC is approximately 5% for women. When CRC is detected early, the 5-year survival rates exceed 90%. Survival rates are almost identical in men and women in all ethnic groups. Only 39% of patients are diagnosed with localized disease, emphasizing the importance of screening and early detection. The 5-year survival rate decreases as the disease is diagnosed at a more advanced stage. African Americans, Hispanics, and Native Americans are more likely to be diagnosed at a more advanced stage than Non-Hispanic whites or Asian Americans.

Incidence of CRC is about 15% higher and mortality is about 40% higher in African-Americans than in whites. Incidence and mortality rates in Asian Americans, Hispanics, and Native Americans tend to be slightly lower than in Non-Hispanic whites.

Some of the risk factors for CRC include

- Age – over 90% of cases and deaths occur in people over the age of 50 years.
- A family history of CRC – CRC risk is two-to four-fold higher in those with an affected first degree relative (parent, sibling, or child). The risk is even higher if the relative was diagnosed before the age of 50. Approximately 5-10% of CRCs are hereditary. Any patient who has a suspicious family history of CRC may benefit from genetic risk assessment.
- High intake of red meat and low intake of vegetable fiber in the diet may lead to increased risk for CRC.
- Women who have Inflammatory Bowel Syndrome (Crohn's or Ulcerative Colitis), IBS for 10 years or longer, a past history of CRC, or adenomas have a significantly increased risk of CRC. They should be monitored for CRC through regular colonoscopies.
- Women who have had endometrial cancer before age 50 may be at risk for Hereditary Non-polyposis Colorectal Cancer (aka Lynch syndrome), especially if they have a positive family history of CRC.

CRC screening is recommended to begin at age 50 (Refer to KP clinical guidelines for appropriate screening tests). Those who have higher risks may need to start screening earlier than age 50. Despite the possibility of preventing CRC through screening, the percentage of people over 50 who actually undergo screening is low for both genders and all ethnic groups throughout the United States.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- Providers need to engage in an open discussion of CRC risks, screening recommendations, benefits and limitations of colorectal cancer screening with their patients.
- Women may feel more fearful or embarrassed to discuss CRC screening than men; this may prevent them from undergoing screening. Women who do not comply with mammography or pap smear recommendations may be less likely to undergo CRC screening.
- Providers must encourage regular screening for women over age 50 and those with a family history of CRC. Colonoscopy and polyp removal can actually prevent CRC.
- Providers must encourage their patients to have a diet that includes a variety of healthy foods including fruits and vegetables, low fat meats, and limited amounts of red meat.

- Providers are encouraged to discuss specific screening recommendations based on their patients' CRC risk profile.
- Patients must be offered genetics referral if the family or personal history is suspicious for hereditary colorectal cancer.
- Minorities, particularly African Americans and Hispanics, are more likely to be diagnosed with colorectal cancer in advanced stages.
- Providers must ensure that smoking-cessation counseling is documented.

## CERVICAL CANCER

Karen Lam, MHA and Juanita Watts, MD

Cervical Cancer is preventable and highly curable when detected early. Between 1955 and 1992, the number of cervical cancer deaths in the United States dropped by 74% due to implementation of widespread screening programs. According to the last published data from ACS, in the United States between the years 1999-2003, the incidence rates of cervical cancer (per 100,000) are 8.6 (white), 13.0 (African-American), 9.3 (Asian American), 7.2 (American Indian), and 14.7 (Latino). It is one of the few cancers that have a reliable screening tool available—the Papanicolaou (Pap) smear. Recently, researchers have identified the Human papillomavirus (HPV), as the main cause of cervical cancer. Currently, at Kaiser Permanente, the HPV test is co-collected with the Pap test.

The following factors may impact risk for cervical cancer

- Smoking – Women who smoke are about twice as likely to get cervical cancer as those who don't. Tobacco smoke can produce chemicals that may damage the DNA in cells of the cervix and make cancer more likely to occur.
- HIV positive – Being HIV positive makes a woman's immune system less able to fight both HPV and early cancers.
- Some studies suggest that women who have Chlamydia or have had it in the past are at greater risk for cancer of the cervix. Further studies are needed to find out if this is true.
- Diets low in fruits and vegetables are linked to an increased risk of cervical and other cancers.
- Being overweight.
- Long-term use of birth control pills increases the risk of this cancer. Some studies show a higher risk after 5 or more years of use.
- Women who have had multiple full-term pregnancies.
- Poor women or those with limited access to affordable healthcare or screening Pap tests.
- The daughters of women who took the drug DES (diethylstilbestrol) have a slightly higher risk of cancer of the vagina and cervix. This drug is a hormone that was used between 1940 and 1971 for some women who were in danger of miscarriages.
- Recent studies suggest that women whose mother or sisters have had cervical cancer are more likely to get the disease themselves.
- HPV – Human papillomavirus (HPV) infection is the single most important risk factor for cervical cancer. Studies have shown that within 2 years of becoming sexually active, about 75% of women have been exposed to some form of HPV. Cervical cancer tends to occur in midlife with half of women diagnosed with this cancer between 35-55 years of age. It is important for older women to continue having regular Pap tests at least until age 70, and possibly longer. Over a woman's lifetime, there is a 1 in 135 chance of developing cervical cancer. It is important to understand the correlation of HPV infections and cervical cancer. HPV can develop into genital warts, precancerous lesions, or cervical cancer, depending on the type of HPV. HPV is a very prevalent sexually transmitted disease.



HPV Vaccine: In June 2006, FDA approved the first vaccine for HPV. The HPV vaccine (Gardasil) is a series of 3 shots taken over a 6 month period and is fully protective for at least 5 years. Gardasil is very effective in preventing four types of HPV (Types 6,11,16,18) that cause 70% of all cervical cancer and 90% of genital warts. The vaccine will NOT treat HPV infection that is already present or its complications. The vaccine does not protect against all types of HPV. The Advisory Committee on Immunization Practices has recommended routine vaccination for girls 11-12 years of age. It also allows for vaccination of all girls and women between 9 and 26 years of age. It is preferred that all three doses of the vaccine be given before girls become sexually active.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- If a woman has not been screened for PAP/HPV in the last 2 years, it is imperative that she be screened.
- Once a woman at high risk is identified, she must be monitored to ensure that a possible change in her condition is detected early.
- Providers must ensure that females 11-26 years of age including those who are not sexually active get the HPV vaccination.
- Providers must discuss contraception, STD prevention, and safe-sex practices with sexually active women and educate women on correct screening frequencies of PAP/HPV tests based on a patient's risk factors.
- Women who have had a hysterectomy but still have an intact cervix will need to be screened for cervical cancer.

## OVARIAN CANCER

Karen Lam, MHA and Juanita Watts, MD

Ovarian cancer accounts for more deaths than any other cancer of the female reproductive system. Ovarian cancer is most common in women over 50. According to the National Cancer Institute from 1996-2000, the age-adjusted ovarian cancer incidence rate for white women (17.9 cancers per 100,000 women) was higher than the corresponding rates for Hispanics (14.0), Asians/Pacific Islanders (12.2), African-Americans (11.9) and American Indians/Alaska Natives (10.7).

It is extremely challenging to diagnose ovarian cancers since the symptoms are often vague and easily confused with other disease modalities. Often, complaints such as indigestion, bloating, and weight loss are the chief symptoms. The only definitive way to diagnose ovarian cancer is through a biopsy. There is no known screening test for ovarian cancer. Treatment for ovarian cancer may involve surgery, chemotherapy or radiation therapy, or a combination of these.

Risk factors for ovarian cancer may include

- Age – most ovarian cancers develop after menopause.
- Obesity – the death rate from ovarian cancer is 50% in obese women.
- Reproductive history – Women who started menstruating at an early age (before age 12), had no children or had their first child after age 30, and/or experienced menopause after age 50 may have an increased risk of ovarian cancer. There seems to be a relationship between the number of menstrual cycles in a woman's lifetime and her risk of developing ovarian cancer.
- Fertility drugs – Prolonged use of the fertility drug clomid, especially without achieving pregnancy, may increase the risk for developing ovarian tumors. However, infertility also increases the risk of ovarian cancer, even without the use of fertility drugs.
- Family history of ovarian cancer, breast cancer, or colorectal cancer in a first-degree relative.
- Personal history of breast cancer – If there is a history of breast cancer, there is an increased risk of developing ovarian cancer. Some of the reproductive risk factors for ovarian cancer may also increase breast cancer risk. Also, if there is a family history of breast cancer, there may be an inherited mutation of the BRCA1 or BRCA2 gene.

- Talcum powder – It has been suggested that talcum powder applied directly to the genital area or on sanitary napkins may be carcinogenic to the ovaries. Most, but not all, studies suggest an increased risk of ovarian cancer in women who used talc on the genital area. In the past, talcum powder was sometimes contaminated with asbestos, a known carcinogen. This may explain the association with ovarian cancer in some studies.
- Estrogen replacement therapy and hormone replacement therapy – Some studies suggest women using estrogens alone after menopause have an increased risk of developing ovarian cancer, but other studies have not found any effect on ovarian cancer risk.

Several factors have also been identified that decrease a woman’s ovarian cancer risk.

- Childbearing.
- The use of oral contraceptives.
- Women who have undergone tubal ligation or hysterectomy.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- Ovarian cancer should be considered if a post-menopausal woman presents with GI complaints.
- Women who are diagnosed with other female reproductive cancers are also at risk for ovarian cancer. Conversely, a woman with ovarian cancer must also be screened for breast and other cancers.
- Genetic counseling must be considered for women who have a family history of ovarian cancer.

## HIV/AIDS

Debra Washington, RN, MS and Juanita Watts, MD

According to the CDC in 2005, HIV infection was the 5th leading cause of death among all women aged 25-44 and the 3rd leading cause of death in African American women aged 25-44. In 2006, the incidence of AIDS for black women was approximately 21 times the rate for white women and the incidence for Latinas was 4 times the rate for white women.

Almost two-thirds (63%) of new HIV infections diagnosed in women in 2006 were in those aged 13 to 39. Older women are also at increasing risk for HIV/AIDS and other STDs, especially with the availability of Viagra and other erectile dysfunction drugs for men. The perception that older adults are asexual and not at risk for HIV/AIDS may lead to under screening. Women are most at risk of HIV through heterosexual contact, unsafe sexual practices, and the lack of awareness of male partner risks, such as unprotected sex with other partners, sex with men, HIV status, or intravenous drug use. The presence of another STD greatly increases the likelihood of acquiring or transmitting HIV infection. In some cases, exposure to HIV occurs due to occupational hazards such as a needlestick or blood exposure.

Some women do not perceive themselves as being at risk for HIV and do not recognize warning signs. Symptoms such as thrush, pneumonia, unexplained fever, herpes zoster, seborrhea dermatitis, night sweats, or weight loss, should alert health care providers to offer HIV testing. Early diagnosis of HIV infection allows women to take advantage of early treatment, avoid opportunistic infections, and make informed reproductive choices.

The term “down low,” or “DL,” is sometimes used to describe the behavior of men who have sex with other men as well as women and who do not identify as gay or bisexual. These men may refer to themselves as being “on the down low,” “on the DL,” or “on the low low.” The term has most often been associated with African-American men. Although the term originated in the African American community, the behaviors associated with the term are not new and not specific to African-American men who have sex with men.

In 2006, the CDC released the Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings, recommending routine testing for all adults aged 13 to 64 and repeat screening at least annually for those at high risk. Information about these recommendations can be



found at [www.cdc.gov](http://www.cdc.gov). In 2008, California law (AB 682) no longer required written consent for HIV testing. Instead providers must inform patients that they are ordering an HIV test and that the patient has the right to decline. Declinations must be charted (smart phrase .decline).

Kaiser Permanente has endorsed an HIV specialty model of care. In California, all HIV positive health plan members have the right to self-refer to, and receive care from, a certified HIV Specialist (Calif. H&S Code Sec 1344/1374.16 and amendment to the Codes, AB 2168). The criteria for an HIV specialist include providing continuing care to a minimum requisite number of HIV patients, completing a set number of HIV specific CMEs annually, and/or completing a certification exam. Specific steps to becoming an HIV Specialist can be found at the Websites for the American Academy of HIV Medicine (AAHIVM) and the HIV Medical Association (HIVMA) – [www.aahivm.org](http://www.aahivm.org).

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- All women, particularly women of color, are at risk of HIV infections.
- Any woman age 12 or older can consent to HIV, STD or pregnancy testing and care.
- Some menopausal woman may have vaginal dryness and thinning of the vaginal walls that make them vulnerable to small tears and abrasions that can increase the risk of HIV infection during unprotected sex.
- Providers need to be mindful of the fluidity of sexual behavior and that sexual behavior may not be synonymous with sexual orientation. For example, a woman may state that she is a lesbian, but may engage in occasional sex with men.
- Teens and younger women are at increased risk if exposed to an STD or HIV as their cervix is more fragile and prone to infection.
- Whenever possible and appropriate, providers should discuss sexual-risk behaviors and risk-reduction strategies for all STDs. HIV screening and safe-sex counseling is recommended for all persons who seek evaluation and treatment for STDs.
- Providers should refer all newly diagnosed HIV-positive patients to HIV specialty clinics to optimize treatment and outcomes.
- Universal safety precautions should be used with all patients whenever handling blood or body fluids.
- Providers must maintain confidentiality of all HIV information, including HIV medications, which must not be disclosed to the partner, family, or visitors.
- Positive screening tests for HIV antibodies must be confirmed by supplemental testing (e.g., WB or IFA) before being considered diagnostic of HIV infection.
- Providers should be alert to the possibility of acute retroviral syndrome and should order an HIV viral load test in addition to the HIV antibody test, if indicated. Patients suspected of having recently acquired HIV infection should be referred for immediate consultation with a specialist.

For pre-natal patients:

- All prenatal patients must be advised that they have the right to decline a HIV test (opt-out screening).
- Prenatal patients who decline HIV testing must sign the Prenatal Informed Refusal For the HIV Blood Test (form 04084-004) and declination must be documented. HIV testing must be offered again at the next appointment. Patients who decline prenatal testing may be at high risk for HIV. Fear of stigma, partner abandonment, or partner abuse are common concerns for many women who decline testing.
- Rapid HIV testing must be offered to all Labor and Delivery (L&D) patients who have not tested for HIV during the current pregnancy or are at risk of recent infection. A positive rapid HIV test result is a “preliminary positive” and a confirmatory Western Blot test is automatically sent to the Regional Laboratory. Treatment is initiated for mother in L&D and the perinatologist and HIV Specialist must be notified. Breastfeeding is contraindicated but mother can express and save breastmilk while waiting for the results of the confirmatory test.

- Babies born to HIV infected mothers will require increased surveillance for changes in HIV status and health conditions.
- Babies born to HIV infected mothers will start treatment shortly after birth and require special blood testing including an HIV DNA PCR test. An HIV Antibody Test is NOT ordered on the baby at this time as it will be positive due to maternal antibodies for about 18 months.

## SEXUALLY TRANSMITTED DISEASES

Karen Lam, MHA and Juanita Watts, MD

As reported in the CDC's Trends in Reportable Sexually Transmitted Diseases in the United States, 2004 report, it is estimated that 19 million new STD infections occur each year, almost half of them among young people 15 to 24 years. Direct medical costs associated with STDs in the United States are estimated at \$13 billion annually. Most STD infections will also make an individual more vulnerable to HIV infection and other STD infections if subsequently exposed.

Women bear the greatest burden of STDs, suffering more frequently and more serious complications than men. Pelvic inflammatory disease, chronic pelvic pain, infertility and ectopic pregnancies are all potential effects of STDs. (See the Reproductive Health chapter for more information on STDs).

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- Regardless of age or risk of pregnancy, women must be encouraged to use a condom to avoid exposure to STDs.
- STD testing including HIV testing should be offered to all women regardless of their age or perceived risk behavior.
- All STDs are reportable to the Public Health Department. It is the responsibility of the provider to report all new cases and to work with the patient to notify and test partners.

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# HOT FLASHES, HORMONES AND HEALTH: MENOPAUSE ACROSS CULTURES

Lorinda Hartwell

## AUTHOR FOREWORD

Menopause is a naturally occurring “equal opportunity” event that every woman who lives beyond the age of approximately 52 years will experience. Global population projections predict a marked increase in the number of postmenopausal women from 467 million in 1990 to 1,200 million in 2030. During the next 20 years, approximately 3.5 million African-American women, 2 million Latinas, and 1 million Asian-American women will enter menopause. Racial and ethnic differences exist with respect to how a woman approaches the menopausal transition, including the reporting of menopausal symptoms. Understanding these differences can help to decrease the incidence and/or severity of symptoms and increase the quality of life for millions of women. In addition to culture, race, and ethnicity, this chapter addresses the multiple issues that providers need to consider while interacting with a woman during the midlife transition.

## INTRODUCTION

In recent years, the aging of the female population, together with the availability of “replacement” hormones, has led to numerous studies of the menopause. Most of these studies were of middle-class white women living in the United States and Western Europe, with results that are not relevant to all women. How a woman approaches the menopausal transition depends on a number of factors including culture, race, and ethnicity, educational level, socioeconomic status and health-related factors such as stress. This chapter will cover the definitions, meaning, and key symptoms and treatments for menopause as they vary due to culture, race, and ethnicity.

Results from recent clinical trials such as the Women’s Health Initiative (WHI), studying the benefits and risks of hormone replacement therapy (HRT) and the Study of Women’s Health across the Nation (SWAN) have influenced thinking about the best clinical management for the menopausal woman. SWAN is among the largest trials to date on the menopausal transition.<sup>1</sup> This observational cohort study was among the first to enhance understanding of factors that can influence the health of women of diverse races and ethnicities and has added much to the understanding of cultural differences for women at midlife.

## DEFINITIONS OF MENOPAUSE

The menopause transition is defined as the time from the end of premenopause (when a woman’s periods are similar to what they have always been) through perimenopause (when periods are changing in length, bleeding characteristics and/or frequency), to post menopause (twelve months or more with no period, without an explanation like pregnancy or medication use).

The changes associated with aging and menopause vary historically and across cultures.<sup>2</sup> A medical model of menopause that emerged in the mid-20th century perceived menopause as an undesirable sign of aging — a



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life stage that needed medication for women to stay young and sexually appealing. Now, most women do not see menopause as a problem. Rather than being defined by a single event — the last menses — the menopausal transition is best understood as a social and biological process, part of the phenomenon of aging.<sup>2</sup> For the provider, this most often means a stance of inquiry and sensitivity during a period of several years that will help the patient evolve into a new stage in her life.

Culture, in the form of lifestyle choices (e.g., diet, reproductive behavior, and smoking) can also modify the underlying biology of the menopausal experience. It is important for the provider to consider how culture affects the body across the entire lifespan and not simply focus on the brief time around the end of menstruation. Interactions among genetics, environment, culture, and aspects of everyday life, including parity, socio-economic status, education, reproductive hormones and history, smoking, BMI and exercise, contribute over the lifespan to the development of women's bodies that eventually become menopausal with significant differences among them.<sup>4,5,6</sup>

Robert Wilson, a Brooklyn gynecologist whose 1966 book *Feminine Forever* catalogued the horrors of menopause as a “deficiency disease,” promoted life-long estrogen replacement therapy as a strategy for keeping women “fully sexed throughout their lives.”<sup>3</sup>

## AGE AT MENOPAUSE

About 1% of women have their final menstrual period before 40. This early menopause does not include women who stopped menstruating due to hysterectomy or medication. Overall, median age at natural menopause is 51.4 years, after adjustment for smoking, education, marital status, history of heart disease, parity, race and ethnicity, employment, and prior use of oral contraceptives. Current smoking, lower educational attainment, being separated/widowed/divorced, unemployment, and history of heart disease are independently associated with earlier menopause, while parity, prior use of oral contraceptives, and Japanese race and ethnicity are associated with later age at menopause.<sup>7</sup>

One of the most important factors influencing the age at menopause is smoking; women who are current smokers have an earlier menopause (by 1–2 years) than other women do.<sup>8</sup> African-American and Hispanic women are more likely to experience an early menopause than Caucasians. On the other hand, Chinese and Japanese women are very unlikely to have an early menopause. The lower estrogen levels of Asian women together with their lower fat levels as compared to African-American and Hispanic women may explain this difference.<sup>4</sup>

## ATTITUDES TOWARD MENOPAUSE AND AGING

The end of menstruation is an event of considerable significance for some women, and a tendency exists to attribute physical and psychological symptoms of all kinds to this experience.<sup>9</sup> Findings show that people throughout the world attach both positive and negative meanings to the end of menstruation, although few studies inquire about its positive aspects.<sup>10</sup> Qualitative research makes clear the ambivalence so often associated with the end of reproductive life. Much of this ambivalence may be dependent upon cultural attitudes toward aging, older women, and the role of older women in society. For example, cultures that value aging and revere life experience may tend to have a more positive view of menopause. Cultures that place a greater value on youth may result in women who fear aging and loss of reproductive ability. In a heterogeneous society like the United States, where many cultures interact, there are a wide variety of reactions to the menopausal transition.

Ideas associated with menopause, such as whether it is natural and normal or an illness, previous symptoms, and prior health conditions all shape the meaning of menopause. In addition, past or current reproductive health, mother's experience of menopause (e.g., hot flashes), attitudes toward childrearing and women's roles, marital status, relationships with husbands and partners and their attitudes toward symptoms of menopause, social support and the extended family, social status, socio-economic status, education, career and religious beliefs may also contribute to the meaning of menopause.

Many women may not seek medical assistance because they believe that menopause, like puberty, involves natural changes that are part of development and aging. Others, who see it as a problem or a

medical condition, may visit their doctor's office often. Providers, who reassure their women patients that menopause is a normal part of a woman's development, may help them to take the transition in stride. Research findings indicate that the majority of women pass through the menopausal transition with relatively little or no discomfort.<sup>1</sup> In a review, Obermeyer notes that while few women report major, long-lasting discomfort, in virtually all societies that have been investigated the overall image of menopause is associated with unpleasant symptoms.<sup>11</sup>

With the support of healthy lifestyles and the social support of friends and family, symptoms are often manageable and medical intervention may not be necessary.<sup>12</sup> For example, in a small study of 33 African-American and 35 Caucasian women, African-American women had a more positive attitude on questions that addressed sexuality, physical changes, and well-being. In addition, African-American women had significantly more positive attitudes toward menopause and were more likely to rely on family for information about the menopause transition.<sup>13</sup> Caucasian women, on the other hand, perceived menopause to be a medical problem for which they should seek prescription therapy and written resources.

Both groups rated psychosocial stressors as having a greater impact on well-being than did physical symptoms, and both were reluctant to use their physicians as primary resources for hormone replacement therapy (HRT).<sup>4</sup> In addition, African American women reported a more positive attitude toward menopause overall when compared with Hispanic, white, Japanese, or Chinese women.<sup>11,12</sup>

## MENOPAUSE SYMPTOM REPORTING

It is important for researchers and public health policymakers to identify the symptoms that are most bothersome and troublesome to women during the menopausal transition. Not all symptoms that occur during the menopause transition are due to hormonal changes. Therefore providers can help women distinguish between those that are due to hormonal changes and those that are simply due to aging. For example, vasomotor, sleep, and some vaginal symptoms have shown more relief with hormone replacement therapy (HRT) than with a placebo, thus indicating that these symptoms are related to changing hormone levels and menopause. However, at least 25% of women in clinical trials report significant improvement in their vasomotor symptoms when taking a placebo. Convincing evidence of treatment benefit requires placebo-controlled clinical trials.<sup>16</sup>

It is a new beginning, better sex, a blossoming. I am enjoying it while it lasts.<sup>15</sup>

Menopause is a period of celebration. The children are grown and I find menopause to be a period of personal growth—feeling comfortable to say what is on my mind, and be more outspoken, not being so worried about what people think of me. I have earned that at 50ish.<sup>15</sup>

– African-American Women in Focus Groups, April 2003

During menopause, vasomotor, urogenital, depressive-type, somatic symptoms, and a perceived decline in cognitive functioning affect greater than 50% of women.<sup>17,18</sup> Investigators are now seeking to determine whether modification of lifestyle factors such as obesity, smoking, alcohol consumption, and dietary fat intake can reduce or prevent the occurrence of these symptoms. Researchers also want to determine whether these symptoms are influenced by race or ethnicity.<sup>19,20</sup> Women may visit the physician because they have symptoms they suspect to be related to menopause or simply because they want information about menopause. In either case, providers can use the assessment for menopause symptoms as an opportunity to discuss issues related to aging that otherwise may not be addressed. Most of the usual symptoms associated with the menopause transition are discussed below.

**Vasomotor Symptoms:** Vasomotor symptoms or “hot flashes” are the most common symptom of menopause and research has shown that race and ethnicity have an effect on the frequency of occurrence of vasomotor symptoms such as hot flashes and night sweats. Hot flashes are not limited to women in the menopause transition. Some 20% of premenopausal women experience hot flashes and night sweats. However, the proportion of women who have hot flashes and night sweats increases dramatically in the perimenopause phase, and remains almost 50% in the post



menopause, at least until age 55. In the earlier phase, more African-American, Caucasian, and Hispanic women report having hot flashes and night sweats than Chinese and Japanese women. Black women have a greater risk for an earlier menopause—even greater than those of other races and ethnicities with currently irregular menstrual cycles<sup>21</sup>—and have 1.5 times the risk of white women for experiencing hot flashes.<sup>22</sup>

Results from SWAN suggest that Japanese and Chinese women report fewer vasomotor symptoms because of their low fat intake and decrease in estrogen variability. Among the women in SWAN, an increase in vasomotor symptoms has been attributed to higher body mass index (BMI), history of premenstrual symptoms, and passive smoke exposure, whereas current smoking or intake of phytoestrogen, dietary fiber, total calories, or antioxidants were not found to have an effect.<sup>5</sup>

- **Educational Attainment and Vasomotor Symptoms:** Fewer women with postgraduate education reported vasomotor symptoms. In contrast, women with lower incomes, women who smoked, and women who reported less physical activity experienced more vasomotor symptoms.<sup>18</sup>
- **Dietary Factors and Vasomotor Symptoms:** Consumption of the soy isoflavone, genistein, was not associated with vasomotor symptoms in any ethnic group,<sup>18</sup> however, median intake was 4-fold lower among U.S. Japanese-Americans than the average intake of 23.2 mg/day among Japanese living in Japan.<sup>23</sup>
- **BMI and Vasomotor Symptoms:** Vasomotor and other symptoms were positively associated with BMI, difficulty paying for basic needs, and smoking, and negatively associated with physical activity. These results suggest that lifestyle, race and ethnicity, and socio-economic status affect symptoms in the midlife age group.<sup>21</sup>
- **Physical Activity and Vasomotor Symptoms:** Evidence is mixed as to whether increased physical activity decreases vasomotor symptoms. However, physical activity may decrease perceived severity of symptoms and increase overall quality of life.<sup>24</sup> The SWAN study observed that daily exercise is associated with an overall decrease in the incidence of hot flashes.

**Memory Loss and Cognitive Decline:** It is common for women in Europe and North America to believe that they will suffer memory loss at menopause. While estrogen is essential to neurological functioning, it has not been substantiated that memory loss is directly associated with lowered estrogen levels at the end of menstruation.<sup>25</sup> Moreover, both men and women experience memory impairment as they age. Cognitive decline, however, was not observed among a subset of black and white women enrolled in SWAN; in fact, scores for both measures improved slightly over time for women in premenopause and early perimenopause.<sup>26</sup>

**Headaches:** Changing hormone levels are the reason most frequently given for headaches at the time of menopause. After menopause, most women's migraine related symptoms lessen. However, headaches can be a substantial problem at menopause and in HRT users. It is difficult to predict which women will develop worse headaches at menopause but a history of migraine and reduced coping with stress were significant factors in this group.<sup>27</sup>

**Cardiac Symptoms:** Many women complain of palpitations during the menopause transition. These palpitations are often related to vasomotor symptoms and do not necessarily indicate signs of cardiac disease. However, women with high blood pressure before menopause may have an increased risk for cardiac disease after menopause.<sup>28</sup> Another study suggested that cardiovascular risk factors determine the age at menopause, possibly by inducing ischemic damage in the ovaries or through direct effects on the endocrine system.<sup>29</sup>

**Shoulder Stiffness:** In Japan, the symptom reported more than any other during the perimenopause is shoulder stiffness,<sup>1,30</sup> but this symptom is also reported by a similar percentage of men and younger people.<sup>31</sup>

**Bone Strength:** It has been widely believed that Asian women have lower bone density than Caucasian women, but that is not correct. SWAN has shown that when differences in body size are considered, bone

density in Asian women is actually higher than in Caucasian women. Ignoring differences in bone size makes the bones of Asian women appear less strong than those of Caucasians. This discrepancy may explain why Asian women actually suffer fewer fractures than Caucasian women.<sup>32</sup> African-American women have higher bone density than Caucasians.

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*The doctor said I should take hormones because it helps my bones. I thought it was nice that they were thinking about me and I didn't have to bring up the topic—that they spoke about it first.*<sup>33</sup>  
— Chinese women in focus group, 2003

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SWAN has shown that greater physical activity at home (childcare, meal preparation, chores, etc.) is linked to higher bone density. It is crucial to measure all aspects of women's physical activity (not just sports activity) to understand the relationship between physical activity and bone strength.<sup>34</sup> In Japanese women, diets high in soy foods are linked to stronger bones than diets with less soy. Surprisingly, Chinese women who consume a diet high in soy do not have higher bone density than Chinese women consuming less soy, perhaps because Chinese and Japanese diets contain different kinds of soy foods. This suggests that not all soy foods improve bone strength.<sup>35</sup>

**Physical Activity:** Physical activity is another important factor in creating and maintaining a healthy lifestyle. Even if a woman only begins an exercise program after she has reached menopause, there are still enormous advantages.<sup>36</sup> The SWAN study considered various lifestyle factors that may influence differences in symptom reporting. No significant differences were found between the SWAN ethnic groups in relation to physical activity. Prior to the SWAN study, research had shown that African-American and Hispanic women reported low levels of recreational physical activity.<sup>37</sup>

**Urogenital Symptoms:** Many postmenopausal women report urogenital symptoms, especially an increase in vaginal dryness and incontinence. In the WHI, an elevated prevalence of urogenital symptoms was found to occur among women who were Hispanic, who were obese, and/or who had diabetes mellitus.<sup>38</sup> Hispanic women were also 2.1 to 3.1 times more likely to have each of four symptoms at the worst level of severity (discharge, irritation or itching, dryness, and dysuria) than were white women. These results confirm earlier findings that premenopausal, perimenopausal, and postmenopausal Hispanic women 40–55 have nearly twice the risk for vaginal dryness than white women.<sup>21</sup>

The WHI investigators were unable to explain the differences for Hispanic women after exploring hypotheses such as recent immigration, perceived quality of life (QOL), or language of the survey instrument. In the WHI study, African-American women had an increased risk of moderate or severe vaginal discharge compared with white women; however, whether vaginal ecology varies between races is unknown.<sup>37</sup>

**Depressive Symptoms:** Major depression, even before menopause, predicts cardiovascular risk. Mid-life women (Caucasian and African-American were the only two ethnicities studied) who have a history of two or more major depressive episodes are twice as likely to have a risk factor of heart disease (like cardiovascular plaque) before menopause than women who have no history of depression or only one episode of depression.<sup>18</sup>

In a study of black and white women 35–47, an increased likelihood of depressive symptoms during transition to menopause was significantly associated with increasing estradiol levels. This likelihood decreased in those with a rapidly increasing follicle-stimulating hormone (FSH) level and age compared with premenopausal women. After adjusting for employment, menopausal status, history of depression, premenstrual syndrome, poor sleep, hot flashes, and FSH level, black women were nearly twice as likely as were white women to report depressive symptoms. This was true both among the general population on the Center for Epidemiologic Studies Depression Scale (CES-D)—one of the most common screening tests for helping an individual to determine his or her level of depression—and among a subgroup with a diagnosis of major depressive disorder.<sup>39</sup>



## USE OF HORMONE THERAPY AND COMPLEMENTARY AND ALTERNATIVE MEDICINES

Study findings suggest that race and ethnicity do play a role with regard to awareness<sup>40</sup> and use of hormone replacement therapy (HRT).<sup>41</sup> In addition, these factors can influence whether menopausal symptoms are discussed and health care providers offer HRT.<sup>11</sup> Alexander and associates examined why, despite black women having more severe menopausal symptoms, they used HRT much less frequently than did white women. Although most of the black women had discussed HRT with their clinicians, few opted for this treatment because it was unnatural, had too many side effects, or required “taking pills”. Instead, they managed their symptoms with lifestyle changes, alternative therapies, and stress reduction.<sup>42</sup>

In another study of 35 white and 33 black perimenopausal women who had similar serum hormone levels and symptoms, 68.8% of white women had discussed their symptoms with a physician compared with 36.9% of black women. Physicians had asked 51.4% of white women about their symptoms and offered 25% of them HRT; this rate decreased to 21.2% for black women, none of whom were offered HRT. Although of small sample size, this study suggests that women of different ethnicities who report a similar prevalence of symptoms as white women may or may not be offered HRT.<sup>17</sup>

Data from the National Health and Nutrition Examination Survey III (NHANES III) found that overall, 36.7% of American women more than 60 years of age reported using HRT: 31.2% used pills, 10.2% used cream, and 1.9% used estrogen patches. In this first study to compare HRT use among racial groups by means of nationally representative data, 40% of non-Hispanic white women, 20% of non-Hispanic black women, and 24% of Mexican-American women reported HRT use. Those with the lowest use had less than 12 years of education or had an annual family income of less than \$20,000.<sup>10</sup>

Among African-American women from diverse socioeconomic levels, most were knowledgeable about the process of menopause; however, there were significant differences in the use of HRT and health promotion behaviors: 58% used HRT or would consider using it. Nearly half of the women (48.5%) sought information about HRT from printed materials, via the media, and in places where women may gather (e.g., churches, beauty parlors, and community centers).<sup>42</sup>

The majority of complementary and alternative remedies (CAM) for menopausal symptoms do not have proven effectiveness. Most herbal remedies are classified as food or dietary supplements, not drugs. Whether race or ethnicity affect how a woman views treatment of menopausal symptoms, including CAM, has not been widely studied. The 1998 Complementary and Alternative Menopausal Practices Survey found that Caucasian women are more likely to use both conventional medicine and CAM, and to use them more consistently than either African-American or Hispanic women.<sup>15,43</sup>

## CONCLUSION

Racial and ethnic differences exist with respect to how a woman approaches the menopausal transition, including reporting of menopausal symptoms. An understanding of these differences can help promote lifestyles that may decrease the incidence and/or severity of symptoms, and increase quality of life. However, although ethnicity, like social class, can function as useful shorthand to reflect variations in health patterns and outcomes, there is always the risk of over interpretation or oversimplification. There is a thin line between discovery of the uniqueness of the menopause process and its consequence for women of color and the attribution of all of these effects to race. Sensitivity and individuality are the keys.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

Today’s health care provider has to consider a bewildering array of changing “facts” and sees increasingly informed patients with strong personal convictions about menopause and their need for medication. Providers must be prepared to discuss a variety of menopause or age-related topics and decide what to recommend for a specific woman—often in less time than ever before. Recommendations should be individualized to each woman and her background. When asking about symptoms, evidence shows that the physician or other health care professional should be sensitive to each woman’s:<sup>44</sup>

- beliefs and attitudes about menopause, including her medical vs. non-medical treatment preferences, anxieties, and coping style
- socio-cultural and ethnic background that may affect her concerns and choices
- economic and insurance status
- work situation, job satisfaction, and stress
- other life stressors, particularly with personal relationships
- social supports
- overall quality of life
- current use of nonprescription herbal, nutraceutical (a nutritional supplement designed for a specific clinical purpose), or phytoestrogen remedies

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# MENTAL HEALTH

Jean Milofsky

## AUTHOR FOREWORD

Mental health services are critical to the delivery of all other health services and play a pivotal role in a woman's health and health care. The intent of this chapter is to encourage close collaboration between mental health and primary care providers within the integrated care delivery system that is unique to Kaiser Permanente. This chapter is composed of many complementary voices of women that reflect the perspectives on mental health and illnesses, strengths and stresses and risks and resiliencies of women across diverse cultures, races, and ethnicities in the United States. As Maxine Hong Kingston advises, read this with your "beginners mind" and "make your mind large, like the universe is large, so there is room for paradoxes."<sup>1</sup>

The Institute for Culturally Competent Care acknowledges and thanks two primary contributors to this chapter:

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## INTRODUCTION

According to the U.S. Surgeon General's 1999 Report on Mental Health, "Mental illness, no less than mental health, is influenced by age, gender, race, culture, and additional facets of diversity that can be found within all of these population groups – for example, physical disability or a person's sexual orientation."<sup>2</sup> Mental, physical, and social health and well-being can only be understood within each individual woman's particular social, cultural, economic, biological, and personal context. This chapter will explore the issues of mental health and perceptions of mental health and wellness among women from diverse cultures, races and ethnicities and elucidates specific life events in a woman's life that may impact her mental health and well being.

## UNDERSTANDING CULTURALLY COMPETENT CARE IN A MENTAL HEALTH SETTING

"To be effective, the diagnosis and treatment of mental illness must be tailored to all characteristics that shape a person's image and identity."<sup>2</sup> Services that are culturally competent incorporate an understanding



Dr. Jean Milofsky has been a practicing psychiatrist since 1982. She has been the Psychiatry and Mental Health department chair for the last five years and chaired the Colorado Permanente Medical Group Board of Directors in 2006. Her avocation is jazz piano and she plays chess to stave off the loss of precious brain cells. She has raised three self-sufficient and interesting young people now in their 20s, who she declines to call adults – but who are getting there...adulthood takes a lifetime to achieve.

*Dr. Milofsky acknowledges her friend Joan Sarnat, Ph.D for being a support and inspiration throughout her career in mental health. Dr. Sarnat is a psychologist/psychoanalyst who practices in Berkeley, California and teaches at the Psychoanalytic Institute of Northern California.*



of the impact of culture, race, and ethnicity on mental health and illness status, on interpretations of what it means to be mentally healthy and what constitutes appropriate interventions. Therefore, mental health services must be designed and delivered in a manner that is sensitive to the perspectives and needs of women from different cultures, ages, socioeconomic circumstances, and experiences.

## MENTAL HEALTH IN THE UNITED STATES – PAST AND PRESENT

Freud's famous query, "What does the woman want?" ["Was will das Weib?"]<sup>3</sup> alluded to the fact that women are distinct in their make-up from men. Freud based his theory of the Oedipus Complex on male psychology, and when challenged to include the experiences of girls and women, he belatedly created the Electra Complex. The work in the mental health field today derives, at least in part, from Freud's theories and observations. Increasingly, psychiatric approaches are becoming more responsive to the unique cultural and ethnic backgrounds of a diverse community of women.

Epidemiologic surveys indicate that about 1 in 5 Americans experience a mental disorder in the course of a year.<sup>2</sup> Some researchers assert that mental disorders such as depression, alcohol dependency, and schizophrenia are seriously underestimated by traditional epidemiologic approaches, which are mostly focused on mortality.<sup>4</sup> More than two-thirds (69.8%) of people with mental disorders have a disability. The relative importance of mental illness as a cause of activity limitation varies among different age groups. For younger adults, 18-44, mental illness was the second most frequently mentioned cause of activity limitation (10.4 per 1,000 people). For mid-life adults 45-64 years, mental illness ranked as the third most frequently mentioned cause of activity limitation (18.6 per 1,000). Relative to other conditions, mental illness was less frequently a cause of activity limitation for seniors, 65-74 years (11.4 per 1,000).<sup>5</sup> As the life expectancy of Americans continues to extend, the sheer number – although not necessarily the proportion – of persons experiencing mental disorders of late life (dementia, depression, and schizophrenia, among other conditions) will expand. According to the U.S. Surgeon General Dr. David Satcher, "Even more than other areas of health and medicine, the mental health field is plagued by disparities in the availability of and access to its services. These disparities are viewed readily through the lenses of racial and cultural diversity, age, and gender."<sup>2</sup>

## CONSIDERATION OF WOMEN'S MENTAL HEALTH AND WELLNESS

The social, cultural, economic and personal context in which a woman lives determines her vulnerability to mental or emotional distress at least as much as lived experience and inherited biological vulnerability. According to the World Health Organization (WHO):

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*Depression, anxiety, psychological distress, sexual violence, domestic violence, and escalating rates of substance use affect women to a greater extent than men across different countries and different settings. Pressures created by their multiple roles, gender discrimination and associated factors of poverty, hunger, malnutrition, overwork, domestic violence and sexual abuse, combine to account for women's poor mental health. There is a positive relationship between the frequency and severity of such social factors and the frequency and severity of mental health problems in women.*<sup>6</sup>

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Gender differences occur particularly in the rates of common mental disorders, especially depression, anxiety, and somatic complaints. Unipolar depression, predicted to be the second leading cause of global disability burden by 2020, is twice as common among women compared to men.<sup>7</sup> However, there are no significant gender differences in the rates of severe mental disorders like schizophrenia and bipolar disorder that affect less than 2% of the population.<sup>7</sup>

Kathie Weston, a Nurse Practitioner who has worked at Kaiser Permanente in Psychiatry and Behavioral Medicine for over 30 years says:

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*Women are more likely to be mental health consumers. Why is this? Women have social permission and acculturation to be more in touch with their*

*emotions and feelings... and may have less shame about these feelings than men. Men who are struggling with what may be mental health issues often enter care through the door of the medical doctor with physical symptoms such as "I have headaches" or "I can't sleep." Women will more easily call what is going on with them "anxiety" or "depression."*

Throughout their lifetime, women are exposed to mental health risks at differing rates depending on the influence of social and economic determinants of health such as poverty, income inequality, access to nutrition, housing, physical activity, transportation, working conditions, racism, sexual abuse and harassment or gender discrimination. Any one, or a combination of, the following issues may impact a woman's mental health and illness status at any one time:

**Child Sexual Abuse:** Child Sexual Abuse (CSA) is defined as non-consensual sexual activity experienced by someone under the age of 18 that negatively affects that person's psychological, physical, emotional, social and spiritual self. Approximately 1 in 3 women (30–45 %) and 1 in 6 men (13–16 %) report being sexually abused as children.<sup>8</sup> In the United States, an estimated 20 million people survive CSA and are living with its often devastating consequences for health and well-being.<sup>8</sup> Dr. James Mercy at the Center for Disease Control addressed the public health consequences of child sexual abuse (CSA):

*Imagine a...disease that affects one in five girls and one in seven boys before they reach 18; a disease that can cause...severe misconduct disorders among those exposed...can have profound implications for...future health by increasing the risk of problems such as substance abuse, sexually transmitted diseases and suicidal behavior;... Such a disease does exist—it's called child sexual abuse.<sup>9</sup>*

Extensive research lays out the broad health and social effects of child sexual abuse—harmful substance use, physical and mental illness, subsequent abusive sexual and intimate relationships, and increased risk for imprisonment and sex work.<sup>10</sup> (See the chapter on Intimate Partner Violence for more information on the effects of CSA on children).

**Eating Disorders:** Eating disorders affect girls and women of all racial and ethnic groups. Studies indicate that eating disorders are often undetected mental health disorders. A prevalent stereotype is that eating disorders predominantly affect white, middle class girls and women. However, the real picture is more complex. Among girls grades 9 -12 in the United States, Latinas have the highest rates of vomiting and laxative abuse.<sup>11</sup> The morbidity from eating disorders is hard to estimate as it is characterized by denial and lack of treatment. However, the National Eating Disorders Association estimates that there are over 10 million girls and women and 1 million boys and men with eating disorders in the United States.<sup>11</sup> (See the chapter on Health Beliefs and Patterns of Care for more information on eating disorders).

**Immigration:** Immigration may pose specific post-immigration stressors that may affect a woman's mental health. These stressors may include low social support, racism, discrimination, lack of an economic safety net, downward social mobility, and barriers in accessing health care such as language barriers, preference for traditional healers, concepts of health and wellness that differ from the Western style of medicine, lack of understanding of how the health care system works, as well as changes in food, lifestyle, and climate. Immigrant women who are parents may also experience conflict with their children due to the cultural and generational differences of acculturation. They often speak a language different from their children or grandchildren and have differing levels of formal education.

**Chronic health conditions:** Women with a chronic or terminal health diagnosis may face physical and mental health challenges. Serious diagnoses can threaten their autonomy and potential to care for themselves and their families as women are often the primary caretakers. A diagnosis that involves her identity as a woman (such as breast or ovarian cancer) can additionally threaten a woman's sense of herself as sexually whole, capable of intimacy, fertility, motherhood, or grandparenthood. The loss of a breast through mastectomy or hair from chemotherapy can be devastating. One study found a strong



association between the loss of fertility (i.e., hysterectomy) and psychological distress especially among younger, nulliparous women.<sup>12</sup> There are no formulas for how best to approach a patient in these moments; compassion and sincerity are fundamental attitudes on the part of the provider and may facilitate the patient's ability to deal with this challenge.

**Pregnancy:** Many common psychiatric conditions experienced by women cluster around events related to the reproductive life span such as pregnancy. It is important for providers to understand the significance of a woman's pregnancy to her. For some women, mood disorders worsen during pregnancy. The risk for antenatal depressive symptoms appears to increase with an unwanted pregnancy and a prior history of depression.<sup>13</sup> Pregnant women with mood or anxiety disorders may choose to discontinue anti-depressants during pregnancy or breastfeeding due to theoretical or actual harm to the fetus. These deeply personal decisions are complex and require provider sensitivity and respect.

**Post Partum Depression:** The “baby blues” are a very common event and may involve hypersensitivity, crying, or other emotional outbursts, and mild depressive symptoms such as poor appetite or lack of motivation. The baby blues may occur 2-4 weeks post-delivery and usually resolve within days to weeks. Postpartum depression does not differ from major depression as described in the DSM-IV. The difference is that this depression occurs in the postpartum period, with onset in the 4 weeks to 1 year after delivery. Postpartum depression can have serious effects for mothers, infants, and families. If the mother-child bond is fragile or nonexistent, mild deficiencies in infant cognitive performance can develop. Infants can experience failure to thrive and lifelong issues with self-esteem and security can develop for the infant. Data about postpartum depression among different ethnic groups are difficult to interpret, and some studies indicate that maternal race and ethnicity does not by itself predict risk of postpartum depression.<sup>13</sup> While large supportive families are protective, lower socioeconomic status can increase a woman's vulnerability to depression.<sup>13</sup>

**Postpartum psychosis:** Although it is very rare, postpartum psychosis is a true psychiatric emergency involving hallucinations and/or delusional thinking and can be potentially endangering to the life of the mother and/or the infant if not treated. Postpartum psychosis is overwhelmingly associated with bipolar disorder and can be influenced by a rapid decline in reproductive hormones, stressful life events (e.g., marital discord, unwanted pregnancy, inability to care for another child, financial stressors), history of depression and family history.

**Menopause:** Midlife and menopause may hold different meanings to women based on their culture, family history, their lived experiences, and their own social support systems. In this excerpt by Bell Hooks, she provides some clues for approaching this time of transition:

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*In the exciting world of women I was raised in—I learned early that aging would be filled with delight. Oh, how I was filled with delight when I heard Mama and her friends carry on about the joys of “the change of life.” They never used the word “menopause.” How intuitively sensible! Had they taken to heart medical ways of defining shifts in midlife, they might have been forced to take on board the negative implications this word would bring—the heavy weight of loss it evokes. Instead they had their own special language.<sup>14</sup>*

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Providers must consider the language used by women while referring to menopause. By listening to the language and values of women patients, providers can learn about how a woman views this time in her life from her own cultural or personal perspective. A sample question to use may be, “What do you call this transition?” In addition, a provider might ask, “What are some of the changes you see happening in your life at this time?” in order to encourage a discussion of challenging or stressful areas in her life, while also identifying the resources she may have to address those areas. (See the Menopause chapter for more information on menopause).

## THE IMPORTANCE OF SOCIAL SUPPORT AND NETWORKS IN WOMEN'S MENTAL HEALTH

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*People who feel lonely, depressed and isolated are 3 to 7 times more likely to get sick and die prematurely than those who have a sense of love, community and connection in their lives.<sup>15</sup>*

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Family, kinship, and friendship networks are important for a woman's emotional and physical well-being and can be a source of identity, empowerment, creativity, sustenance, and survival. These networks can provide women with different types of social support, such as emotional support (empathy, love, trust, and caring), instrumental support (tangible aid and services that offer direct assistance), informational support (advice, suggestions, and information to address a specific problem), and appraisal support (constructive feedback, affirmation, and social comparison).<sup>16</sup> Social support is essential to helping people cope with adversity. Unfortunately, however, family and community can also be environments fraught with physical and emotional violence and negative interpersonal interactions. (See the Intimate Partner Violence chapter for information about the mental health impact of interpersonal violence).

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*...There is increasing evidence that negative interpersonal interactions, such as those characterized by mistrust, hassles, criticism, too many demands, and domination, are more related to... risky health behaviors such as cigarette smoking, and susceptibility to infectious disease than is lack of social support.<sup>16</sup>*

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Providers need to assess a woman's social supports, the importance and meaning it holds in her life, and facilitate referrals to community resources as available.

## MENTAL HEALTH AND STIGMA

In 1999, the first ever Report of the Surgeon General on Mental Health identified stigmas surrounding both mental illness and treatment as a primary barrier to receiving care. Stigma assumes many forms, both subtle and overt. It appears as prejudice and discrimination, fear, distrust, and stereotyping. Stigmas against individuals with a mental illness can lead to many kinds of injustice, including discriminatory decisions regarding housing, employment, and education. Stigma prevents people from acknowledging their own mental health problems, much less disclosing them to others, and makes them reluctant to seek treatment for fear that the confidentiality of their diagnosis or treatment will be breached. In fact, epidemiological studies in the United States suggest that 50–60% of persons with mental distress do not seek treatment because of the stigma associated with mental health illness and disorders.<sup>17</sup> According to the 1999 Report of the U.S. Surgeon General on Mental Health:

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*Stigma erodes confidence that mental disorders are valid, treatable health conditions. It leads people to avoid socializing, employing or working with, or renting to or living near persons who have a mental disorder, especially a severe disorder like schizophrenia. Stigma deters the public from wanting to pay for care and, thus, reduces consumers' access to resources and opportunities for treatment and social services. A consequent inability or failure to obtain treatment reinforces destructive patterns of low self-esteem, isolation, and hopelessness. Stigma tragically deprives people of their dignity and interferes with their full participation in society.<sup>2</sup>*

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While stigma is a significant factor affecting utilization of mental health services, it can be influenced by experiences with or perceptions of the mental health system, particularly among communities of color. A history of racism, misdiagnosis, and mistreatment among communities of color may lead to mistrust or even fear of mental health treatment. Cultural values and personal beliefs also color the perception of mental illness, which may be viewed as a personal weakness, lack of self-discipline, or a moral failing.



Providing accurate information is one way to reduce the stigma of mental illness. Culturally competent care provided by bilingual and bicultural staff reduces shame and discomfort among those who seek mental health services. Such care helps individuals understand that mental disorders are not character flaws and legitimizes the experience of treatment as it would for any medical disorder.

Family and social support can help reduce stigma and facilitate use of more formalized care and treatment options. Studies from largely non-Hispanic samples have found family blame and criticism to be associated with relapse in patients with schizophrenia.<sup>18</sup> A 1996 survey found that people identified informal social supports such as self-help and peer support groups as an acceptable form of “treatment” and were more likely to cope with mental illness than avoid it if these support groups were available to them.<sup>2</sup> Services provided by bilingual and bicultural staff and other skilled providers who demonstrate an awareness and understanding of their client’s sociocultural context and cultural values can also help to reduce stigma.

## LABELING WOMEN WITH MENTAL DISORDERS

In the United States, as elsewhere, people in socially and politically dominant groups had the institutional power to define who was “normal,” “insane,” “mentally ill,” or “crazy.” As Sara Murray Jordan, a gastroenterologist, wrote, “in medicine... words are sometimes the most powerful drugs we can use.”<sup>19</sup> Women’s mental health has been historically defined in relation to an assumed “norm” of white, wealthy, male, heterosexual, U.S.-born, of Western-European Christian heritage, with no known physical or mental disabilities. For example, homosexuality historically portrayed as a religious “sin,” a legal “crime,” and a medical “sickness,” was presented as a disease in most Western medical texts in the 19th century. Not until 1973, after intense debate in the American Psychiatric Association, was homosexuality changed in the DSM-III from a “sexual deviation” to “sexual orientation disturbance.”<sup>20</sup>

Much madness is divinest sense  
To a discerning eye;  
Much sense the starkest madness.  
'Tis the majority,  
In this, as all, prevails.  
Assent, and you are sane,  
Demur, — you’re straightway dangerous,  
And handled with a chain.

—Emily Dickinson

The following insights from “Words Matter,” a training exercise by Harold Maio and Sylvia Caras<sup>21</sup> can help providers recognize the power in language and how words can be used respectfully with patients.

- Providers can consider saying “she *has* depression” rather than she “*suffers from,*” “*is burdened by,*” “*is afflicted with,*” “*struggling with,*” or is a “*victim of*” depression.
- To reflect the perspective that the mental illness is a part of a woman’s experience and not all of who she is, say that a woman “*has* schizophrenia” (vs. “*is* schizophrenic”).
- To reflect that people with mental illnesses are not homogeneous, refer to people diagnosed with mental disorders as “people with psychiatric disabilities” rather than “*the* mentally ill.”
- The person should be emphasized first before any descriptor such as, “a woman diagnosed with schizophrenia (vs. schizophrenic).”

When the subtext of much of the language used within mental health is examined, a prevalence of words like “victim,” “suffer,” “burdened,” and “afflicted” is used. While women may perceive or experience their lives and circumstances as being *victimizing* and *traumatizing*, they also have inner and outer resources they can draw upon to support their wellness. Lea Arellano, an Oakland-based organizational development and diversity trainer says to health care providers:

*Please don't be fascinated with our victim-hood. Be fascinated with our resilience, our resourcefulness, and the truth that we have survived all of these things, and that we are here... Here are some of the things I have done to get myself back from oppression. I've been in recovery for 28 years from alcohol addiction, 22 years from alcohol and substances. And I got sober in a community of sober people of color and sober lesbians. I utilized and use*

*12 steps, spiritual practice, co-counseling, along with nutrition, vitamins, and supplements. I (called on) the love of my communities and family, social justice work, good water, dance, movement, exercise and music.<sup>22</sup>*

## WOMEN, WELLNESS, AND WHOLENESS

*Even today, everyday language encourages a misperception that mental health or mental illness is unrelated to physical health or physical illness. In fact, the two are inseparable.<sup>2</sup>*

A woman's social and cultural identity and experience affect her interpretation and perception of mental health, illness and potential interventions. A woman's mental health must always be considered in the context of her life experiences. Taking a "strengths-based approach" to women's wellness rather than focusing on deficits and illnesses can help women access their resilience.<sup>18</sup> Resilience can be defined as "the capacity to bounce back from adversity"<sup>18</sup> Women can access and cultivate their resilience in a myriad of ways. Women can find strength and empowerment by helping others, by making greater meaning from their traumatic experiences, and by building and maintaining relationships.<sup>23</sup> The performer Pippa Fleming tells women:

*Don't be afraid to stand in front of the mirror and examine your life's wounds... Don't be afraid of breaking down, because that's what is needed if you want to thrive, rather than just survive. Don't be afraid of the truth... Take time to be with yourself... Heal through action, practice and ritual... Regard your health as a number one priority.<sup>24</sup>*

Providers must always remember to approach all women with empathy and mutual respect. When Lea Arellano was asked about what she wants Kaiser Permanente providers to know, she says:

*Listen deeply to my experience, my perceptions, and my knowingness about my health, my body, my spirit, my life. I can tell if (my health providers) are present or not. I can tell if they are listening or not. I ask them to be honest and authentic with me. I ask them not to assume that I am ignorant about my health and my body.<sup>22</sup>*

## ROLE OF KAISER PERMANENTE HEALTHCONNECT™

The KP HealthConnect technology gives Kaiser Permanente providers a unique tool for addressing mental health disorders and wellness at the interface of primary care, Ob/Gyn, and psychiatry. KP HealthConnect makes provider communication more efficient and aids common screening procedures. For example, the PHQ9 is a simple nine-item depression survey available on KP HealthConnect that can be used by primary care physicians in the diagnosis of depression.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- Understand what a woman's mental health means to her.
- Assess the availability of social supports in a woman's life and ask how the supports impact her health outcomes.
- Recognize that mental health and wellness are often connected to past or current life events, experiences and periods of transition.
- Understand the difference between baby blues and postpartum depression.
- There is a high incidence of more serious psychopathology in postpartum depression, primarily bipolar disorder, so psychiatric referral is necessary.



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# HONORING THE JOURNEY: CULTURALLY COMPETENT CARE OF THE CHILDBEARING FAMILY

Sylvia Berman

## AUTHOR FOREWORD

Pregnancy and childbirth is a shared transformational experience for the patient, her family, and the provider — one that exists across time and culture. As health care providers, we have the opportunity to create a childbirth experience for our patients that honors who they are as cultural beings. As a certified nurse midwife, I work with a culturally diverse population, many of whom are medically underserved. The United States has some of the most disparate maternal child health outcomes of any industrialized nation. This chapter addresses two important aspects of my work — cultural competence and health care disparities. I hope the information that follows on pregnancy, labor, and breastfeeding gives you new tools and knowledge to use in interacting with and guiding families through the every-day miracle of childbirth.

## INTRODUCTION

Pregnancy is an experience rich in cultural beliefs and practices. It is also a time when many women intensively utilize the health care system, often for the first time. Pregnancy therefore provides a perfect opportunity to realize the benefits of culturally competent care. Culturally competent prenatal care allows for an informed discussion between the patient and provider about choices and recommendations in pregnancy. It gives the health care provider the opportunity to affirm healthy or empowering traditional cultural practices. Establishing a context of mutual cultural respect provides a framework within which to discuss the rationale for medical recommendations that might contradict certain traditional practices – for example, refraining from ingesting some Ayurvedic or Chinese medicines that contain teratogenic substances such as lead. Perhaps the most important mandate of culturally competent care for providers is to obtain the information needed to reduce disparities in pregnancy and childbirth outcomes between various populations. Cultural competence improves our ability to care for all women, considering their cultural, racial, ethnic, and social identities. To the extent that a woman finds her prenatal care to be empathic and relevant, she is more likely to access health care for herself and her family in the future.

## PREGNANCY

**Prenatal Care:** Early initiation of prenatal care is important for assuring positive maternal and infant health outcomes. The goal for Healthy People 2010 is 90% initiation of prenatal care in the first trimester. However, according to the Centers for Disease Control and Prevention (CDC), no ethnic group had met that goal as of 2002.<sup>1</sup> According to the CDC, groups more likely to have delayed or no prenatal care include African Americans, Latinas, women less than 20 years of age, women with less than twelve years education, and multiparous women.<sup>1</sup> Reasons women may delay seeking prenatal care may include limited access to health insurance or inadequate insurance coverage, unintended pregnancy, intimate partner violence (IPV), fear of accessing the health care system due to a lack of a legal immigration status, lack of maternity care



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providers, and lack of language and racial concordance between provider and patient.<sup>1</sup> In some cultures (such as some Latin American cultures), pregnancy is viewed as a “normal” state of being, and women from these cultures may not view early initiation into prenatal care as a priority.<sup>2</sup> Community outreach strategies such as home visitation and telephone contact are the most effective tools for recruiting women of color, young women, and others at risk for delayed prenatal care, into early prenatal care.<sup>3</sup>

**The Cultural Assessment:** Cultural beliefs that influence behavior in pregnancy include the role of traditional medicine, beliefs about fetal development, and work and activity during pregnancy, the cultural value placed on prenatal care, and the role of the extended family. By completing a cultural assessment early in prenatal care, providers can elicit important information about the patient’s health beliefs, practices, and social support available to her during pregnancy and childbirth. An example from the University of Michigan, Program for Multicultural Health<sup>4</sup> is shown below.

## CULTURAL ASSESSMENT

- Can you tell me what languages are spoken in your home and the languages you speak and understand? In what language do you prefer to speak? In what language do you prefer to read or write?
- Describe your usual diet. Do you plan to change your diet during pregnancy, and if so, how?
- Can you tell me about your family and culture’s beliefs and practices surrounding birth?
- What are the cultural beliefs and traditions practiced in your country of origin and community? What kind of prenatal care do women receive in your country of origin and community?
- Do you use any traditional health remedies to improve your health?
- Who in your family or community gives you advice and emotional support during pregnancy?
- Are there any health care procedures or tests that your culture prohibits?
- Are there other cultural beliefs or considerations that would help me in caring for you during pregnancy?

*Used with permission from the University of Michigan, Program for Multicultural Health*

**Cultural Beliefs and Practices:** Each patient’s synthesis of modern Western obstetrics, complementary medicine, traditional wisdom, and personal health beliefs is unique. A common theme in traditional medicine is the humoral theory of disease. This includes, for example, the description of illness as an imbalance of “heat” and “cold.” In traditional Latin American cultures, for example, pregnancy is a “hot state.”<sup>5</sup> During pregnancy, women avoid foods, such as onions, chiles, and goat’s milk, and medicines, such as penicillin, that are classified as “hot.” On the other hand, in Chinese traditional medicine, pregnancy is a “cold state” which is balanced by taking “hot” foods such as ginger, beef, and chicken. Most Western medicines are considered hot. Chinese medicines may be hot or cold.<sup>6</sup> Many traditional pregnancy remedies such as the use of chamomile or yerba buena tea for gastrointestinal (GI) upset in Latino culture or cumin tea to stimulate labor are safe. However, certain traditional medicines from the Middle East and China, some Ayurvedic medicines used by the East Indian community and *greta*, and *azarcon* (used by the Latino community for GI upset) contain lead or other toxic or teratogenic substances which can cause maternal and fetal morbidity.<sup>7</sup>

**Fetal Development:** There are many cross-cultural similarities in beliefs about maternal influences on fetal development. In Latino, Arab, and Asian cultures, food cravings of the pregnant woman should be satisfied. If a woman does not satisfy a craving for a certain food, the baby may be born with characteristics of that food such as a birthmark in the shape of the food.<sup>8</sup> In the context of limited food availability, this belief may lead to preferential access to food for women during pregnancy and thus improve pregnancy outcomes.

Geophagia, the consumption of soil, clay, or chalk is common in parts of Africa, India, aboriginal Australia, and in African-American communities in the Southern United States. This craving is considered a fetal craving that needs to be satisfied. Geophagia, however, can cause nausea and diarrhea, hyperkalemia, and blockage of the large intestines. Lead and other toxic substances in the soil can cause miscarriage, stillbirth, and maternal illness.<sup>9</sup>

In many cultures, people believe that the pregnant woman’s emotional state and intellectual pursuits influence the pregnancy outcome or personal attributes of the developing child. In Korean cultures,

listening to music, praying, keeping “peace of mind,” talking to the fetus, and eating perfectly shaped or nicely decorated foods are practices that are considered to benefit the fetus. In traditional Chinese culture, the pregnant woman listens to classical music so that her child learns patience, wisdom, and artistic sensitivity. Some cultures believe that the moral disposition of the child is affected by the mother’s actions during pregnancy. The pregnant woman performs charitable deeds, avoids contact with dishonest people, and avoids complaining or having negative emotions.<sup>8</sup> In Mexican cultures, strong negative emotions during pregnancy are believed to put the pregnancy at risk for miscarriage, preterm delivery, or knots in the umbilical cord.<sup>10</sup>

While some of these beliefs may increase emotional and social support for women during pregnancy, stress, anger, and conflict are a part of life. A pregnant woman with this belief system absorbs not only the stressors of her life, but also assumes a burden of guilt due to a cultural belief that stress and negative emotions may harm her developing child. When these issues arise, providers must offer patients access to interventions for addressing emotional difficulties such as counseling and suggest stress reduction tools such as yoga and meditation. It is important to help the patient identify sources of support in her social network.

**Work and Activity During Pregnancy:** In most cultures, women are encouraged to remain active throughout pregnancy. Among traditional Latino cultures, prolonged inactivity in pregnancy is thought to increase the risk of the fetus becoming “stuck” to the uterus, thus causing a long and painful labor.<sup>10</sup> In Southeast Asia and East Africa, women work until labor begins. Among women who believe that normal activity improves pregnancy outcomes, those who have strenuous jobs may need more education about the importance of limiting activity under certain circumstances such as threatened preterm labor or gestational hypertension.

**Role of the Extended Family During Pregnancy:** Perhaps the most important influence of traditional culture on maternal well being during the childbearing year is the role of the extended family in support and decision-making. In one study, the women identified mothers, grandmothers, and aunts as the ones who “tell me what to do,” “go with me to the hospital,” and “take care of me.”<sup>10</sup> In traditional East Asian societies the sense of self, as rooted in Confucianism, exists in relationship to others in the extended family. A woman is primarily a daughter, sister, wife, and mother, and secondarily herself.<sup>11</sup> East Indian couples often defer to their parents’ wishes when making decisions about health care. Among African Americans, the traditional concept of family may be characterized by “group orientation, collective responsibility, cooperation and interdependence.”<sup>12</sup> In this framework, basic health care tenets such as self-actualization, patient autonomy and patient confidentiality are sometimes difficult to interpret. In order to honor the patient both as an individual and in relation to her family, providers can use a cultural assessment to assist in determining the role of the family in the patient’s prenatal care and decision-making process.

**Health Issues Related to Pregnancy:** In Healthy People 2010, a set of health objectives for the nation to achieve over the first decade of the new century, eliminating health disparities has been identified as one of the major goals.<sup>13</sup> Racial, ethnic, and economic inequities in health outcomes exist within many of the complications of pregnancy as elaborated below.

## RISK FACTORS AND OUTCOME DISPARITIES

**Ectopic Pregnancy:** Ectopic pregnancy (EP) is the primary cause of maternal death in the first trimester. The two major risk factors for EP are a history of sexually transmitted disease, specifically Chlamydia trachomatis, and a history of previous EP. Rates are highest for African-American women, especially between 35 to 44 years. The magnitude of disparity between African-American women and women of other ethnic groups remains large and disparities exist within ethnic groups. For example, while the Latino population in California is mostly from Mexico, in New York, where the Latino population is predominantly Puerto Rican, the EP rates among Latinas are comparable to those of African-Americans.<sup>14</sup>

**Gestational Diabetes Mellitus:** Gestational Diabetes Mellitus (GDM) is the most common medical complication of pregnancy. Factors which increase the risk for GDM include a maternal age of greater than 25 years, obesity, history of abnormal glucose metabolism, a first-degree relative with diabetes, and a history of infertility.<sup>15</sup> In a study of pregnancies screened for GDM in San Francisco between 1988 and



2001, the prevalence of GDM by race and ethnicity was 4.1% in whites, 4.3% in blacks, 7.0% in Latinas, and 9.7% in Asians.<sup>16</sup> While both Asian and Latina women may experience an increased risk of gestational diabetes, the prevalence of GDM appears to be increasing in all ethnic groups and seems to mirror the overall increase in diabetes mellitus in the United States, which may be caused by an increase in obesity in all populations.

**Preterm Birth:** Preterm birth (PTB) is the leading cause of neonatal morbidity and mortality and African-American infant mortality in the United States.<sup>17</sup> The rate of PTB for all births in the United States was 12.3% in 2003. PTB is divided into two categories – moderately PTB (32 -36 weeks gestation) and very PTB (less than 32 weeks completed gestation). While the rate of moderate PTB has continued to rise, the rate of very PTB has remained stable at about 2%.<sup>18</sup> A history of prior PTB, genital tract infections, uterine, cervical, or placental abnormalities, race and ethnicity, maternal medical conditions, oral health, obesity, and tobacco, cocaine or marijuana use appear to be maternal risk factors for PTB in singleton pregnancies.<sup>19</sup> The disparity between PTB rates of non-Hispanic whites and African Americans remains large. In 2002 the preterm birth rates in the United States by ethnicity were 11% in Caucasians, 17.5% in African Americans, 13.1% in American Indians, 7.7% in Chinese, 9.2% in Japanese, 13.5% in Hawaiian and 12.7% in Filipino.<sup>18</sup>

Not seeking prenatal care increases the risk of PTB even though no specific aspect of prenatal care itself has been demonstrated to reduce PTB.<sup>20</sup> Preterm birth prevention remains an enigma. A preterm birth has been described as an endpoint of a long term, sometimes lifelong, cycle of environmental, psychological, and emotional stressors.<sup>17</sup> A growing body of research examines the contribution of racism and the impact of the lived experience of racism on racial and ethnic health disparities. Several studies indicate an association between African-American women's experience of racial discrimination and poor birth outcomes including low birth weight, preterm birth, and infant mortality. Some researchers believe that for many women of color, racism across the life course, not just during the nine months of pregnancy, increases the risk of preterm delivery.<sup>17,19</sup> The stresses of racism experienced by women of color can affect health in many different ways, creating chronic wear and tear on physiological systems, impacting the pregnancy physiology of the mother and the developmental physiology of the child. Providers should address the conditions that affect women's health not just during pregnancy but from childhood, adolescence, and into adulthood.

Risk assessment, accurate and early diagnosis, prompt intervention, and delivery with an appropriate level of neonatal intensive care are tools available to providers to improve perinatal outcomes.

**Low Birth Weight Infants:** Low birth weight (LBW) is defined as a newborn with a weight of less than 2500 grams regardless of gestational age. Very low birth weight (VLBW) is a newborn weight of less than 1500 grams.<sup>13</sup> The United States has one of the highest rates of LBW in the industrialized world. In 2007, a UNICEF study found that the United States had the fourth highest rate of LBW infants out of 25 industrialized nations.<sup>21</sup> According to the National Vital Statistics report, black women had the highest rate of LBW infants (17.5%), followed by American Indians (13.1%), Hawaiians and Filipinos (12.7–13.5%), and whites (11.1%).<sup>18</sup>

VLBW is largely a result of preterm birth. Intrauterine growth retardation resulting from smoking accounts for 20–30% of all LBW infants born in the United States. Groups at risk of delivering a LBW infant include African-American women, adolescents, women over 35, single mothers, smokers, women with hypertension, preeclampsia, and women with low maternal weight gain.<sup>22</sup> It is believed that social support for pregnant women has an effect on birth outcomes; however, the effect of social support during pregnancy on LBW is not well understood.<sup>22</sup>

Poverty, racism, lack of access to health care, and recent immigrant status are associated with worsening perinatal outcomes.<sup>17</sup> However, in the United States, Mexican immigrant women have birth outcomes (as measured by low birth weight and infant mortality) that are equal to or slightly better than Caucasian women. This phenomenon has been termed the “Latina paradox.”

A preterm birth has been described as an endpoint of a long term, sometimes lifelong, cycle of environmental, psychological, and emotional stressors.

– Sylvia Berman

**The Latina Paradox:** Protective practices such as strong taboos on smoking and drug use, healthy traditional eating habits, marianismo (selfless devotion to the maternal role), combined with strong family and community social support may overcome the adverse health effects of poverty and racism. However, these protective factors erode with acculturation, and subsequent generations born in the United States have increased incidence of low birth weight infants.<sup>23</sup>

## CHILDBIRTH

There are approximately 4 million births per year in the United States. Ninety-nine percent of these take place in hospitals.<sup>24</sup> The task of providing culturally competent care during childbirth is to elicit from each woman her desires and expectations and to accommodate them to the greatest possible extent and provide culturally sensitive choices to laboring women and their families. Midwives bring a wealth of experience and communication skills to the labor and delivery process. They help families articulate their wishes and concerns surrounding childbirth and explain circumstances where deviations from the birth plan are necessary. Kaiser Permanente continues to increase the availability of midwifery care in labor and delivery and prenatal care. Welcoming doulas and other birth helpers arranged by families into labor and delivery gives patients more power to create the birth experience that they desire.

**Cultural Beliefs and Practices About Childbirth:** Throughout the world, childbirth is imbued with culturally significant customs and expectations. Important considerations in many cultures that are sometimes overlooked in the labor and delivery unit include modesty, the role of the extended family, and the desire to be attended exclusively by female providers. An example of a traditional Islamic Arabic woman in labor is discussed below to illustrate the intricacies of culturally competent care.

Islam values safety and health; in fact, the practice of Islam allows for any religious requirement to be suspended if it jeopardizes health. However, Islam, like many religions, also values adherence to family roles, religious observance, and modesty. Modesty is also extremely important in Jewish, Asian and Latino cultures. Modesty dictates that a woman not expose parts of her body unnecessarily and that she be examined only by female providers. In the traditional Arabic Islamic family it is the duty of the husband to speak for his wife, which may not align with the concept of patient autonomy in Western medicine. At the time of birth, the baby's father is the first to speak to the newborn, whispering the call to prayer (Adhaan) into the baby's right ear and the prayer commencement call (Iqaamah) into the left ear.<sup>25</sup>

The following are some ways to help respect a woman's wish for modesty in a busy labor and delivery unit:

- Offer the patient long-sleeved gowns and a cap for her hair.
- Knock and wait before entering a room.
- Drape the patient carefully when examining her.
- Minimize the number of different examiners.
- Discuss the availability of female providers. If the patient will be cared for by a male provider, introduce him to the family as early as possible with the patient covered and comfortable.
- Inquire about birth rituals and labor support on admission to labor and delivery.

**Birth Rate by Race and Ethnicity in the United States:** The general fertility rate (GFR) measures births per 1,000 women of childbearing age (15–44). In 2004, the GFR for non-Hispanic white women was 58.5/1,000, 97.7/1,000 for Hispanic women, 58.9/1,000 for Asian/Pacific Islander women, 66.7/1,000 for non-Hispanic black women, and 58.9/1000 for Native American women. Hispanics are the fastest growing population in the United States, followed by non-Hispanic African-Americans and Asian and Pacific Islanders.<sup>26</sup>

## RISK FACTORS AND OUTCOME DISPARITIES

**Maternal Mortality:** Maternal mortality decreased by 99% during the twentieth century, from 850 maternal deaths/100,000 in 1900 to 7.5 maternal deaths/100,000 in 1982. Since 1982, no further decrease has occurred in the United States. However, it is difficult to determine exact maternal mortality rates, since maternal mortality is not consistently classified either within the United States or internationally.<sup>27</sup>



The American College of Obstetrics and Gynecologists (ACOG) and the CDC define pregnancy-related death as the death of a woman while pregnant or within one year of pregnancy, regardless of duration and site of pregnancy (e.g., ectopic pregnancy), from any cause related to or aggravated by her pregnancy or its management. From 1991 through 1999, 4,200 deaths were classified as pregnancy-related in the United States. The most common causes of death were embolism, hemorrhage, pregnancy induced hypertension, and infection. African-American women are four times more likely to die from pregnancy-related causes than Caucasian women. The risk of pregnancy-related death for Asian/Pacific Islander women and Native American women is lower than African-American women and higher than Caucasian women.<sup>28</sup>

**Preeclampsia:** Preeclampsia accounts for approximately 18% of pregnancy-related deaths in the United States each year. The risk factors for preeclampsia are:

- Maternal disease such as maternal hypertension, renal disease, obesity, and diabetes.
- Immunogenic factors such as first pregnancy, differing paternity, presence of HLA-DR4 (a recessive immunoresponse gene), and paternal family history of preeclampsia.<sup>29</sup>

A 2005 analysis by Caughey et al.<sup>29</sup> examined preeclampsia in low risk women who delivered in the Kaiser Permanente Northern California region. Of these women, 3.9% were diagnosed with preeclampsia. African-American women had the highest rate of preeclampsia (5.2%) and Asian women had the lowest rate (3.5%).

African-American women are not only more likely to develop preeclampsia or eclampsia, they are also more likely to die from it. African-American women have preeclampsia pregnancy-related mortality rates that are three times higher than Caucasian women. Women who receive no prenatal care are seven times more likely to die from complications of preeclampsia or eclampsia than those women who received prenatal care.<sup>29</sup>

**Postpartum Hemorrhage:** In the United States, postpartum hemorrhage complicates 2–4% of vaginal deliveries.<sup>30</sup> Asian-American women have the highest risk of postpartum hemorrhage while African-American and Latina women have the lowest risk. When compared to Caucasian, African-American, and Latina women, Asian women have the greatest risk for gestational diabetes and the second greatest incidence of chorioamnionitis. These conditions are risk factors for postpartum hemorrhage and may explain the increased incidence in Asian-American women.

**Third- and Fourth-Degree Lacerations:** A 5-year retrospective study of all births in California found the overall incidence of third- and fourth-degree lacerations to be 5.85%. The highest rates occur in East Indian women, Filipina women, and other Asian women. African-American and Native American women have the lowest rates of third- and fourth-degree lacerations.<sup>31</sup> Episiotomy increases the risk of fourth-degree lacerations and instrumented deliveries increases the risk of third- and fourth-degree lacerations.<sup>31</sup>

**Cesarean Section Rate:** In 2004 the cesarean section rate in the United States reached a high of 29%. The Healthy People 2010 target rate for cesarean delivery is a 15% primary cesarean rate and a 63% repeat cesarean rate. African-American women have the highest primary cesarean rate (31.0%), followed by non-Hispanic Caucasian women (29.0%), Asian and Pacific Islander women (28.4%), and Latina women (27.9%). Native American women have the lowest cesarean rate (25.1%).<sup>32</sup> African-American women have a higher chance of having a potentially unnecessary primary cesarean section compared with Caucasian or Latina women. Caucasian women have a higher likelihood of having a potentially unnecessary repeat cesarean section.<sup>33</sup>

A significant cause in the rise in the cesarean section rate is due to the decrease in the number of women attempting vaginal birth after cesarean section (VBAC). In 2004, ACOG issued revised practice guidelines for attempting VBAC. These guidelines included the recommendation that VBAC be attempted only in settings where a physician and anesthesia provider and operating room personnel were immediately available throughout active labor. The rate of trial of labor after cesarean had already been falling since 1997. After these guidelines were released, the availability of a trial of labor declined further in spite of the proven safety of trial of labor under controlled circumstances. The rate of VBAC was greater than 25% in 1996. Today it is less than 10%.<sup>34</sup>

Another cause in the rise of the cesarean section rate is the maternal request for primary elective cesarean section. Elective primary cesarean section is the cesarean delivery of a singleton pregnancy by maternal

request without any medical or obstetrical indication. There is no strong evidence that cesarean delivery in women with no contraindication to vaginal birth demonstrates better short term or long term health outcomes.<sup>35</sup> Planned cesarean delivery may decrease the rate of hemorrhage compared to that of planned vaginal birth resulting in an unplanned cesarean delivery. However, planned cesarean delivery increases rates of neonatal respiratory distress and neonatal intensive care unit admissions. It also increases the risk of abnormal implantation of the placenta, placenta accrete, hysterectomy, and intensive care unit admissions in subsequent pregnancies.<sup>36</sup> There is no good evidence that shows elective cesarean to be protective against long term maternal urinary incontinence or pelvic organ prolapse.<sup>36</sup> Elective primary cesarean section raises two implications in terms of culturally competent care:

- Cesarean delivery may be perceived by some women as preferable because it is more expensive and therefore seen as a more modern and elite mode of childbirth.
- Cesarean delivery is more expensive.<sup>37</sup> If the medical system absorbs the cost of primary elective cesarean delivery, fewer resources are available to address medical outcome disparities between racial and ethnic groups.

## BREASTFEEDING

The American Academy of Pediatrics recommends that infants in the United States be exclusively breastfed for six months after birth followed by the introduction of appropriate complementary foods and continued breastfeeding until at least twelve months of age.<sup>38</sup> The Healthy People 2010 goals for breastfeeding are to increase the proportion of women that 1) breastfeed immediately postpartum to 75%, 2) breastfeed at 6 months of age to 50%, and 3) breastfeed at 1 year of age to 25%. As of 2004, the rate of initiation of breastfeeding was approaching 75%. However, breastfeeding is not well sustained through the first year of life. The rates of breastfeeding in the United States vary by race and ethnicity and are shown below:<sup>39</sup>

	Ever breastfed	Breastfed at 6 months
Caucasian	71.0%	36.2%
African-American	50.4%	21.1%
Latino	79.2%	34.8%
Asian/Pacific Islander	74.9%	39.9%
American Indian/Alaskan Native	65.5%	29.2%

**Cultural Beliefs about Breastfeeding:** One of the greatest obstacles to breastfeeding is overcoming myths that formula feeding is more modern, more scientific, and better for infants than breastfeeding. In the United States, great progress has been made in dispelling these myths in the last several decades.

Among immigrant Latinas, less acculturation is associated with higher breastfeeding rates. Traditionally in some Latin America countries breastfeeding in public and on demand is normal practice. A mother's breasts are viewed primarily as an organ of nourishment for her infant, rather than associated with sexuality. This perception counters the conflicts and inhibitions many women in the United States may feel about breastfeeding in public. In some cultures, colostrum is considered bad for the baby and/or insufficient for the baby's needs. In Southeast Asia, for example, colostrum is considered "stale" milk and is discarded.<sup>40</sup> The infant may be formula fed or nursed by another lactating woman for the first few days.

**Interventions that Support Breastfeeding:** Increasing breastfeeding initiation and duration is a national health priority, which is reflected in the substantial amount of research that evaluates the effectiveness of breastfeeding promotion strategies.

**Education:** Antenatal breastfeeding education classes have been shown to be the single most effective intervention for improving breastfeeding initiation rates.<sup>26</sup> Classes are more effective than counseling alone by the primary provider. Family support, specifically the support of the spouse or partner, improves breastfeeding duration. Therefore it is important to include both parents in the educational process.



**Professional and Peer Support:** Professional support, such as the availability of lactation consultants, is effective in increasing duration of breastfeeding up to six months.<sup>41</sup> Peer postpartum support such as *La Leche League International* and bilingual/bicultural peer lactation consultants improve initiation and duration of breastfeeding. Workplace support and media campaigns also improve breastfeeding outcomes.

**Intrapartum and Immediate Postpartum Support:** Supportive practices during labor and delivery and the maternity stay in the hospital have been shown to improve both initiation and duration of breastfeeding. Hospital practices most effective in promoting breastfeeding have been incorporated into the Baby Friendly Hospital Initiative's *Ten Steps to Successful Breastfeeding*.<sup>42</sup> The "Baby Friendly" designation by the World Health Organization and the United Nations Children's Fund is awarded to hospitals that implement these ten steps. The Kaiser Permanente facility in Hayward/Fremont, California, was awarded this designation in 2001.

## THE TEN STEPS TO SUCCESSFUL BREASTFEEDING:

- Have a written breastfeeding policy that is routinely communicated to all health care staff.
- Train all health care staff in skills necessary to implement this policy.
- Inform all pregnant women about the benefits and management of breastfeeding.
- Help mothers initiate breastfeeding within a half-hour of birth.
- Show mothers how to breastfeed and how to maintain lactation if they should be separated from their infants.
- Give newborn infants no food or drink other than breastmilk, unless medically indicated.
- Practice rooming-in – allow mothers and infants to remain together 24 hours a day.
- Encourage breastfeeding on demand.
- Give no artificial teats or pacifiers (also called dummies or soothers) to breastfeeding infants.
- Foster the establishment of breastfeeding support groups and refer mothers to them on discharge from the hospital or clinic.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

### Pregnancy and Prenatal Care

- Include a cultural assessment as part of the first prenatal visit.
- Screen patients for stress and offer interventions such as counseling and stress reduction tools such as exercise, meditation/reflection, and yoga.
- Consider the role of the extended family and honor the patient as an individual and in relation to her family.
- Early access to prenatal care is essential for the timely diagnosis and treatment of ectopic pregnancy. Screen appropriately for Chlamydia and gonorrhea and provide education about STDs and treatment.
- Screen for nicotine, drug and alcohol use, and level of social support. Explain the maternal and fetal benefits of interventions such as Early Start, support groups, and smoking cessation programs.
- Timely glucola testing and dietary and exercise recommendations are an important part of prenatal care. Interventions such as prenatal exercise classes and support groups for gestational diabetics help motivate and support patients.
- Include women of diverse communities in the development of culturally specific childbirth classes. Consider interventions such as hosting a web-based pregnancy discussion board or conducting group prenatal visits to strengthen support networks for pregnant women.

### Childbirth

- Review the family's hopes for their birth experience on admission to labor and delivery. Welcome family's customs into the labor room whenever possible after consideration of any legal and facility regulations. Discuss possible interventions, such as an episiotomy, early in the course of labor.

- Clearly explain who is available to care for the patient. Explain the roles of various providers.
- Encourage the use of doulas or staff members of the same cultural background as the patient.
- Access to prenatal care, early detection, and prompt treatment are crucial to minimize serious complications of preeclampsia. Pay special attention to the African-American population.
- Asian women are most likely to have third- and fourth-degree lacerations. Judicious use of episiotomy and instrumented deliveries is especially important in the care of Asian women.
- Give thorough and informed consent regarding trial of labor after cesarean. Trial of labor is a safe and appropriate option in many settings. Elective primary cesarean section has serious risks. If this option is available, women need to have thorough informed consent about maternal and neonatal risks and risks for subsequent pregnancies before consenting to this procedure.

### Breastfeeding

- Encourage patients and partners to attend breastfeeding classes during pregnancy.
- Work with labor and delivery, nursery, and postpartum staff to implement the “Ten Steps to Successful Breastfeeding” in the facility.
- Encourage patients to utilize peer and professional support systems such as the *La Leche League* to support breastfeeding efforts.

## RESOURCES

Healthy People 2010 - [www.healthypeople.gov](http://www.healthypeople.gov)

Center for Disease Control – Pregnancy and Reproductive Health. See [www.cdc.gov/women/az/reprhlth.htm](http://www.cdc.gov/women/az/reprhlth.htm)

CulturedMed™ – [www.culturedmed.sunyit.edu/bib/childbearing/index.html](http://www.culturedmed.sunyit.edu/bib/childbearing/index.html)

The Compendium on Preterm Birth – [www.marchofdimes.com/pretermbirth](http://www.marchofdimes.com/pretermbirth)

American College of Nurse Midwives – [www.mymidwife.org/caesareans.cfm](http://www.mymidwife.org/caesareans.cfm)

Welcome to Baby-Friendly USA – [www.babyfriendlyusa.org](http://www.babyfriendlyusa.org)

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- <sup>42</sup> Welcome to baby-friendly USA. [www.babyfriendlyusa.org](http://www.babyfriendlyusa.org)

# PRESERVATION OF REPRODUCTIVE HEALTH

Debbie Postlethwaite

## AUTHOR FOREWORD

Women today have, on average, 13 menstrual cycles per year for 37 years, or a possible 481 chances of becoming pregnant. This means that the majority of women (who have sex with men) spend at least 1/3 of their lives trying to become pregnant, being pregnant, or trying to prevent an unintended pregnancy. Preservation of reproductive health is as important to lesbian women as it is for heterosexual women. Health care providers and staff can play a key role in enhancing the reproductive health of women. A greater understanding of women as a “culture” as it pertains to her reproductive health, is an integral part of this process. I hope this chapter provides you with a deep understanding of women’s reproductive health across cultures so you are better able to meet your women patient’s needs in the context of their biological, social, and cultural identity.

## WHAT IS REPRODUCTIVE HEALTH?

The International Conference on Population and Development (ICPD) in Cairo, 1994, stated “Reproductive health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this last condition is the right of men and women to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable women to go safely through pregnancy and childbirth...”<sup>1</sup>

Reproductive health is a culmination of many of the health experiences that occur during childhood and young adulthood and extend far beyond the reproductive years. This chapter discusses the history and importance of fertility and fertility control including the many controversies this entails. This chapter also discusses specific elements in reproductive health including preconception health, unintended pregnancies, maternal and infant mortality, and sexually transmitted diseases from a diversity perspective and offers specific recommendations for the care of women of reproductive age.

## BACKGROUND AND HISTORY OF FERTILITY CONTROL

Access to contraception has for the most part been governed by political and societal trends. As far back as 1550 BC, in an ancient medical manuscript called the Ebers Papyrus, women were advised to grind dates, bark from the acacia tree, and honey into a paste and dip seed wool into it as a vaginal contraceptive.



Debbie Postlethwaite, an Ob/Gyn nurse practitioner since 1978, grew up in New Mexico, “the Land of Enchantment.” Ms. Postlethwaite was the director of projects for the Women’s Health Leadership for Northern California for 7 years and a lead consultant for the Women’s Health Research Institute. She currently conducts research for the Kaiser Permanente Division of Research and assists with residency research. Her hobbies include running, travel, sewing, and collecting Latin American folk art and old record albums. This mountain girl still travels back to New Mexico every year to get her yearly supply of green chile.



Acacia eventually ferments into lactic acid, a known spermicide and vaginal lining protector.<sup>2</sup> In the late 1900s, Anthony Comstock, an anti-birth control crusader believed that providing contraception to women promoted lust and lewdness, which resulted in prostitution and pornography. His work resulted in the U.S. Congress passing the Comstock Act in 1873, which defined contraception as obscene and illicit, making it a federal offense to provide birth control through the mail or across state lines.<sup>3</sup> These laws remained unchallenged until Margaret Sanger, a nurse in the early 20th century, observed women dying from illegal abortions that resulted from unintended pregnancies. She published “What Every Mother Should Know,” which was controversial for its time as it gave women advice on how to avoid becoming pregnant. At that time, it was illegal for physicians to impart that information to patients. In 1916, Margaret Sanger was arrested for opening the first birth control clinic in the United States and spent most of her adult life in jail.<sup>4</sup>

In 1936, it became legal for physicians to distribute contraception across state lines, paving the way for legitimizing contraception in the United States. In 1970, the U.S. government enacted Title X, the only federal grant program dedicated to providing comprehensive family planning and related preventive health services. By law, priority was given to persons from low-income families. Publicly funded agencies through Title X have prevented 20 million pregnancies and 9 million abortions over the past 20 years.<sup>5</sup> Overall, 61.9% of Title X family planning patients have been non-Hispanic whites.<sup>6</sup>

Emergency Contraception (EC) is an example of the controversial nature of fertility control and its vulnerability to political and societal trends over time. Between 2004-2006 the manufacturers of an emergency contraception, Plan B<sup>®</sup> applied for Over-the-Counter (OTC) status with the Food and Drug Administration (FDA). Even though two FDA advisory boards overwhelmingly recommended that the progestin-only EC was safe and effective for all women, the FDA chose not to permit OTC status. Finally in 2006, due to political pressures from “pro-EC” members of Congress, EC became available to adult women in the United States “behind the counter.”

In 1996, Kaiser Permanente in San Diego had the first pre-packaged Emergency Contraception kit with instructions in English and Spanish. This pilot demonstration project paved the way for the first FDA approved EC products.<sup>7</sup>

## PRECONCEPTION HEALTH

Healthy pregnancy outcomes have always been dependent on the health status of women before conception and during pregnancy. Important lifestyle, medical, and environmental factors that play an important role in preconception health are listed below for the provider to consider in encounters with all women.

- Contraception use and promotion
- Tobacco, alcohol, and drug use
- Chronic medical condition management
- Prescription medications and exposure to teratogens
- Diet and weight management
- Exposure to domestic violence
- Prevention of infections

Healthy People 2000 goals set a target of 60% of health care providers to give age appropriate preconception care (PCC). Unfortunately, this goal was removed from the Healthy People 2010 objectives because of the difficulty measuring attainment of this goal.<sup>8</sup> In a recent study of obstetrician and gynecologist opinions and perception of PCC care, the majority of physicians responded that they provided PCC to women (including diabetic and obese women) planning a pregnancy. Only 13% of physicians defined PCC as routine care and were more likely (than the almost 87% of physicians who defined PCC as specialized pre-pregnancy care) to offer it to women who were simply sexually active or using birth control.<sup>9</sup>

To improve preconception health for all women of childbearing age, health care providers must consider the following with women patients:

- Promote planned pregnancies and reproductive life planning.
- Promote the use of multivitamins (calorie free) with 0.4 mg folic acid regardless of pregnancy planning

from the age of puberty. Adequate preconception intake of folic acid and food folate has been shown to decrease the risk of Neural tube defects by 50 to 70%.

- Encourage lifestyle changes that encourage weight management, exercise, smoking cessation, and moderation of alcohol.
- Assess contraception use as a “vital sign” in all reproductive age women, especially when caring for women with chronic medical conditions and before prescribing medication.
- Provide and encourage a prophylactic supply of emergency contraception in case unprotected sex occurs.
- Screen for chronic health conditions in reproductive age women.
- Screen for immune status and provide immunizations (Rubella, Hep B, etc).
- If a pregnancy termination is needed, provide it as early in the pregnancy as possible to decrease maternal and future pregnancy risks.

## PREGNANCY INTENTION: INTENDED VS. UNINTENDED

**Definition** – The definition of an intended pregnancy is based on the desire to become pregnant starting at the time of conception. If a pregnancy is desired at the time of conception, it is considered intended or planned. If the pregnancy is not desired at the time of conception it is considered unintended or unplanned. Unintended pregnancies include both mistimed (desired at a later date) or unwanted (did not want to become pregnant at all).<sup>10</sup>

**Impact of unintended pregnancies** – Pregnancy planning status, when known by the health care provider at the onset of prenatal care, can help identify and support women in prenatal behaviors such as diet and nutrition management, referral to support systems to reduce substance abuse, intimate partner violence screening, depression screening, and postpartum contraceptive planning that are associated with healthy outcomes and appropriate infant care.<sup>11</sup> Unintended pregnancies are attributed to a greater risk of poor pregnancy outcomes such as birth defects, preterm delivery, low birth weight, maternal and fetal morbidity and mortality.<sup>11,12,13</sup> Indirectly, families with unintended pregnancies are also at greater risk for domestic violence and child abuse or neglect. Whether mistimed or unwanted, overall, about half of all unintended pregnancies result in an abortion and half result in a birth.<sup>11,12,13</sup> Births that result from unintended pregnancies are at greater risk for unintended exposure to alcohol, tobacco, and teratogenic or fetotoxic drugs, whether prescribed or obtained for recreational use.

**U.S. Demographics for Unintended Pregnancies** – The United States has the highest unintended pregnancy rate in the industrialized world. Statistics from the 2002 National Survey of Family Growth (NSFG) show that 49% of over 3.0 million pregnancies each year in the United States are unintended.<sup>8</sup>

A study by the Women’s Health Research Institute and the Division of Research at Kaiser Permanente, Northern California (KPNC) showed that 37% of pregnancies by women receiving prenatal care within KPNC were self-reported as unintended. Self-report of unintended pregnancies varied across KPNC from 52% to 31%, depending on geographic medical service area (Postlethwaite D, Armstrong MA, Hung YY, Shaber R. Pregnancy Outcomes by Pregnancy Intention. *Matern Child Health J.*, 2009 Jan 19; Volume 13 Number 2 (Epub ahead of print).

In multiple data sources, the women at highest risk for unintended pregnancies were women between 18-24, who were unmarried, with low incomes, and who were black or Hispanic.<sup>8,14</sup> Unintended pregnancies have also been found to occur in larger proportion to women with chronic medical conditions that may have a negative impact on pregnancy (e.g., obesity, diabetes, hypertension, HIV/AIDS).<sup>15,16,17</sup> Conversely, certain chronic medical conditions such as breast cancer may also be adversely affected by the pregnancy. Women of color are at greater risk for the development of many chronic medical conditions which puts them at greater risk for poor pregnancy outcomes associated with their chronic medical conditions.<sup>18</sup>

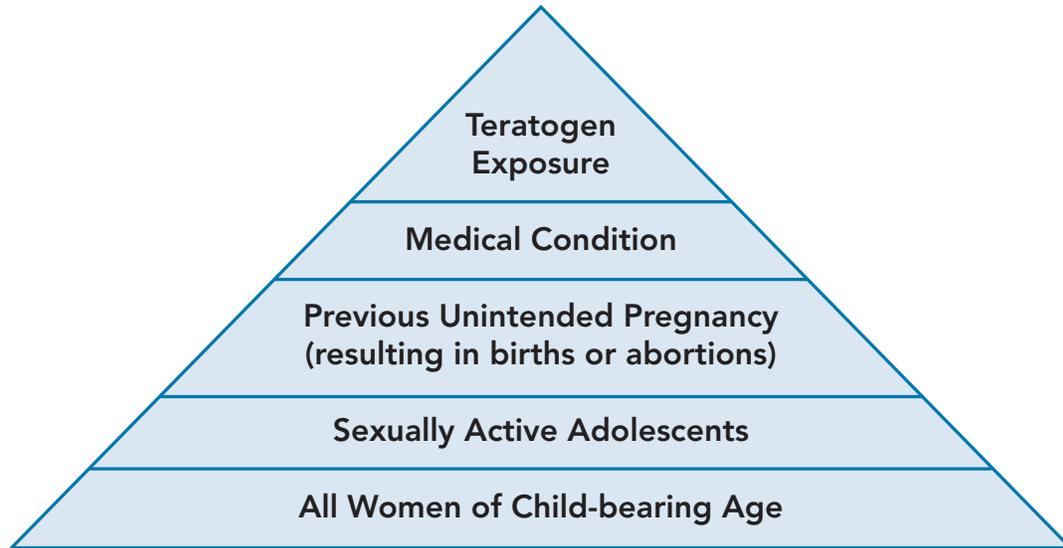
Providers must consider assessing pregnancy intention of all women patients at the onset of their prenatal care to identify potential risk factors for poor birth outcomes and support the women in behaviors toward a positive birth outcome.



A sample question used by Kaiser Permanente, California to assess a woman's pregnancy intention is: At the time that you conceived, did you want to become pregnant? If not, did the pregnancy come sooner than you wanted, or did you not want to become pregnant at all?

### Population Based Model for Women in the United States at Risk for an Unintended Pregnancy

Below is a population based model for looking at women at risk for an unintended pregnancy. Almost all reproductive age women are at risk for an unintended pregnancy. Important factors and subgroups to consider are:



[Postlethwaite DA, created 1999, Unintended Pregnancy Prevention Model]

**Teratogen Exposure:** Women exposed to teratogens are at among the highest risk for birth defects and other poor pregnancy outcomes. A teratogen is a substance, organism, or physical agent capable of causing abnormal development, abnormalities of structure or function, growth retardation, or death of the organism.<sup>19</sup> The severity of abnormality depends on the timing and amount of exposure to the teratogen and susceptibility of the mother. Teratogen exposure can result from prescribed medications such as statins, certain antihypertensives, antidepressants and anticonvulsants, as well as other substances that are well known for contributing to birth defects such as alcohol.

Recent study findings of the Early Start Program at Kaiser Permanente, Northern California found that pregnant women who received screening and treatment for substance abuse early in their pregnancy had the same level of risks for stillborn, preterm delivery, or placental abruption as the group of women (in the control group) who did not use any cigarettes, alcohol, or drugs during their pregnancy.<sup>20</sup> It is important to assess substance use for women of reproductive age regardless of whether they are planning a pregnancy or not.

**Chronic Conditions:** Women with chronic diseases such as diabetes are another subgroup of women at risk for unintended pregnancy and poor birth outcomes. More young women are entering their reproductive years with diabetes. A recent Southern California Kaiser Permanente (KP) study of a large racially and ethnically diverse population of teenage and adult women confirmed significant increases in pre-pregnancy diabetes among every age, racial, and ethnic group.<sup>21</sup> The incidence of pregnant women with poorly controlled diabetes leading to major congenital malformations in offspring is 6-9% as compared to the general population risk of 2-3%, and spontaneous abortion is twice the rate as in women without diabetes.<sup>16,19</sup> Gestational diabetes complicates 4-14% of pregnancies in the U.S. annually.<sup>22</sup> Malformations linked to insulin dependent diabetes (IDDM) account for 30% to 50% of perinatal deaths.<sup>16,19</sup> Pregestational diabetes (type 1 and 2) has been associated with adverse pregnancy outcomes such as fetal macrosomia or low birth weight, premature birth, cesarean delivery, and fetal congenital malformations. Women with insulin-dependant diabetes run a greater risk (4 times more likely) for neural tube defects (NTD) such as

anencephaly and spina bifida. Women with diabetes have reported that they planned their pregnancies only 34-41% of the time despite the increase in risk for poor birth outcomes and birth defects.<sup>15,16,17</sup>

About 3-4% of all births in the U.S. have at least one serious birth defect.<sup>23</sup> Obesity (BMI 29 or > before pregnancy) has been shown to double the risk for NTDs. Consuming folic acid in recommended amounts may not mitigate the excess risk for obese women. Weight loss, however, does decrease the excess risk for NTDs among obese women.<sup>24</sup> Providers must promote planned pregnancies and effective contraception for all women, especially for those with chronic medical conditions. An assumption should not be made that women with a chronic medical condition are not sexually active or not at risk for an unintended pregnancy. For women with pre-existing diabetes, along with pregnancy planning, glycemic control must be achieved especially during the reproductive years.

**Previous Unintended Pregnancies:** Women with previous unintended pregnancies are a large subgroup at risk for a future unintended pregnancy. Repeat unintended pregnancies result from contraception method failure as well as non-use of contraception. In the 1995 NSFG, the nonuse of contraception accounted for 47% of all unintended pregnancies and 53% of unintended pregnancies were from contraceptive failure or improper/inconsistent use of contraceptives. The percent of women reporting use of no method of contraception in the 2002 NSFG was 10.7%.<sup>8</sup> Contraception non-use is greatest amongst women who are of low income, black, and with lower educational attainment.<sup>8</sup> Providers must assess pregnancy intention at the onset of prenatal care, as pregnancy planning status, when known by the health care provider, can help identify and support women in prenatal behaviors that are associated with healthy outcomes and contraceptive planning postpartum. For women who have just experienced an unintended pregnancy, providers must promote long-acting methods of contraception.

**Sexually active teens:** Sexually active teens are another important subgroup of women at risk for an unintended pregnancy. The United States has the highest teen pregnancy rate in the industrialized world where the majority of pregnancies (more than 80%) are unintended.<sup>25</sup> Nationwide, 46.7% of high school students report they have had sexual intercourse in their lifetime. Among adolescents, black females (60.9%) report higher prevalence of sexual intercourse than white females (43.0%) and Hispanic females (46.4%). One third of adolescent mothers in the United States will have a second child within one year and one fourth of adolescent mothers will have a second within 2 years of the first.<sup>26</sup> Providers must consider providing long-acting reversible contraception as an option for sexually active teenagers and teenage mothers to allow them the opportunity and time to complete their education. Long-acting methods may require less effort to use and may allow teenagers to focus their efforts on preventing the spread of STDs with condom use.

Based on national trends, Healthy People 2010 established the goal of reducing unintended pregnancies from 49% to 30%.<sup>8</sup> Improved fertility control allows women and couples to have children when they are best prepared physically, socially, and financially to assume parenting responsibly. Comprehensive strategies to reduce unintended pregnancies should be tailored and relevant to each of these subgroups.

## FAMILY SIZE AND SPACING

Around the world, family size or lifetime births per woman (total fertility rate, TFR) have decreased over time. The average worldwide fertility rate is estimated at 2.8 per woman, with 2.0 per woman in the United States. The highest fertility rates worldwide occur in Africa (Western, Eastern, and Middle), with rates as high as 8.0 per woman. The lowest fertility rates are in Hong Kong, China where the rate is 0.9.<sup>27</sup> Fertility rates are highly correlated to child spacing practices.<sup>27</sup> The countries with the highest fertility rates result primarily from early and late childbearing and less child spacing practices. In the United States, the average family size is 3 people.<sup>27</sup>

## CONTRACEPTION

Contraception is an important component of preconception health as it gives a woman the ability to plan a pregnancy. Contraception use and nonuse by women in the United States has been based on a number of personal factors and beliefs about convenience, safety, and effectiveness of methods and perceived risk



of pregnancy. The 2002 NSFG data found that 90% of all reported contraceptive method use in the United States (in order of use) consisted of:

- Pill (used by 19% or 11.6 million women).
- Female sterilization (17% or 10.3 million women).
- Male condom (5.4 million using as sole method, 3.6 million used with another method).
- Male sterilization.
- 3 month injectable.
- Long-acting, reversible Intrauterine Contraception or Subdermal Implant, used by less than 1%.<sup>8</sup>

## ABORTION

Data on abortions in the United States is believed to be under-reported with wide variation from state to state on the information about abortions reported. The US abortion rate as of 2005 was 19.4/1000.<sup>28</sup> In a recent survey of women receiving abortions, 54% reported using a method of contraception during the month they conceived and 46% reported no use of contraception. Incorrect or inconsistent use of oral contraceptives (76%) and condoms (49%) were the most common reasons cited by women who became pregnant and obtained an abortion. The most common reason cited by 33% of women reporting no use of contraception was the perception that they were at a low risk of pregnancy, or that sex was unexpected.<sup>28,29</sup> Three quarters of women in the United States cited responsibility for other children or other dependants, an inability to afford another pregnancy, and interference with work or school plans as the primary reasons for obtaining an abortion. Over 40% of women obtaining abortions reported they were unmarried and nearly 40% said they had completed their desired childbearing.<sup>28</sup>

**Abortion rates by region and population demographics** – According to the Alan Guttmacher Institute (AGI) data, abortion rates vary by region across the country with the highest rates occurring in the Western states (33.9/1000) and the lowest rates occurring in the Midwest (18.8/1000) for year 2000.

It is estimated that by the age of 45, more than 1/3 of all women in the United States can expect to have an abortion resulting from an unintended pregnancy.<sup>12</sup> According to the CDC, the highest percentage of abortions in 2004 occurred to unmarried women (80%) who were white (53%) and less than 25 years old (50%).<sup>30</sup>

Of all abortions where gestational age is reported, close to 61% have been performed by eight weeks gestation or less and 88% of all U.S. abortions were performed by 13 weeks or less.<sup>30</sup> Abortions performed after 20 weeks gestation are most often the result of prenatal diagnosis of congenital anomalies (birth defects).

**Abortion-related mortality** – Since the legalization of abortion in the United States in 1973 (Roe v. Wade, 410 U.S. 113, 1973), there has been an 85% decline in abortion-related mortality rates in the United States from 4.1/100,000 in 1972 to 0.6/100,000 in 1997.<sup>31</sup> The risk of death increases by 38% with each additional week of gestation. It is estimated that 87% of all deaths in women that occurred after 8 weeks gestation could have been avoided if women had accessed abortion services before 8 weeks gestation. Abortion related deaths can be attributed to hemorrhage, infections, emboli, complications of anesthesia and other cardiac and cerebral events. Race plays a significant role in risk of abortion related mortality. Women of color were 2.4 times more likely as white women to die of complications at all gestational ages. Women of color have tended to have abortions at later gestational ages, but even when the rates are adjusted for, death rates are still significantly higher in women of color. No statistically significant differences in abortion-related mortality rates have been observed in women by age or parity.<sup>31</sup>

Providers must recognize that when abortion is a necessary choice, early access to services decreases future maternal and infant morbidity and mortality. Long-acting contraceptive options (IUDs, implants, injectables) should be promoted after a pregnancy termination. Providers must also recommend or prescribe emergency contraception as a back-up to regular contraception.

## MATERNAL MORTALITY

Since the early 1900s, maternal mortality and infant mortality has declined sharply in the United States. The maternal mortality rate (MMR) in 2004 was 13.1/100,000 live births for all races. Maternal mortality in the U.S. is primarily caused by hemorrhage, hypertension, blood clots, infection, amniotic fluid in the blood stream and heart muscle disease. There is a racial and ethnic disparity in maternal mortality with the 2004 MMR for blacks at 36.1/100,000 compared to the rate for whites at 9.8/100,000. The estimated MMR for women of Hispanic origin is 8.5/100,000; however this should be interpreted with caution due to inconsistent reporting on death certificates. These disparities can in part be attributed to socioeconomic differences, but even when these factors are controlled for, the disparities still exist.<sup>32</sup>

## INFANT MORTALITY

The United States ranks 29th in infant mortality in the world in 2004.<sup>33,34</sup> Like maternal mortality, disparities are also found between races in infant mortality rates (IMR= infant deaths/1000 live births) in the United States. The IMR for African Americans in 2002 was 14.4 compared to the overall rate of 7.0, and 5.8 for whites. IMR and all death rates for Hispanics are underestimated due to under-reporting of Hispanic origin on death certificates. Sixty-eight percent of all infant deaths have been attributed to 10 leading causes. In order of ranking they are: congenital malformations, disorders related to short gestation or low birth weight, sudden infant death syndrome, maternal complications, cord and placental complications, unintentional birth accidents, respiratory distress, sepsis, infant circulatory diseases, and intrauterine hypoxia.<sup>34</sup>

## SEXUALLY TRANSMITTED DISEASES

Women are biologically more vulnerable than men to all sexually transmitted diseases (STDs) including HIV. The CDC's "2006 STD Surveillance Report" showed racial and ethnic disparities in STD prevalence in the United States and are associated with health status determinants such as poverty, access to quality health care, health care seeking behavior and illicit drug use.<sup>35,36</sup>

Chlamydia remains the most commonly reported infectious disease in the United States, with an estimated 2.8 million new cases each year with most cases believed to remain undiagnosed. The 2006 Chlamydia case rate for females in the United States was 3 times higher than for males largely due to increased screening of women. The highest Chlamydia rates are for women between the ages of 15-19. The second highest rates are for women ages 20-24. The reported 2006 prevalence of Chlamydia in black women was more than 7 times higher than for white women, and more than twice that of Hispanic women. The rate among American Indian/Alaskan Native women was second highest and Asian/Pacific Islanders had the lowest rate.<sup>35,36</sup>

Gonorrhea has been reported as the second most commonly reported infectious disease in the United States. Like Chlamydia, gonorrhea can cause Pelvic Inflammatory Disease (PID), ectopic pregnancies, infertility, and death, if untreated. The gonorrhea infection rate in 2006 was 120.9/100,000, an increase of 5.5% since 2005.<sup>35,36</sup> Like Chlamydia, gonorrhea has been under-diagnosed and under-reported. Significant racial and ethnic disparities are prevalent in reported gonorrhea rates with prevalence of gonorrhea highest in black women at 618.1 per 100,000 women followed by Native Americans and Alaska natives at 175.6 per 100,000 women.<sup>35,36</sup>

Among women, primary and secondary syphilis is 16 times higher for black women, and 1.9 times higher for Hispanic women, and 1.7 times higher in American Indian/Alaskan Native women than among white women. Asian and Pacific Islanders are less likely than white women to acquire syphilis.<sup>35,36</sup>

The CDC data collected in 2004 indicated that high risk heterosexual contact was the source of 80% of newly diagnosed HIV infections in U.S. women.<sup>37</sup> AIDS in black women is 23 times higher and 4 times higher in Hispanic women compared to white women. Even though black and Hispanic women represented 24% of the U.S. female population in 2005, they represented 82% of all AIDS cases.<sup>37</sup>

Human Papilloma Virus (HPV) infections are highly prevalent in young sexually active women and are usually self limiting and resolve without treatment within 1 year. Certain strains of this virus that are more virulent and likely to progress to cervical cancer, are called "high risk" HPV. One national study (NHANES) of 1921 women 14-59, showed that "high-risk" HPV was present in 15.6% of participants corresponding



to a population prevalence of 12,028,293 U.S. women.<sup>38</sup> It also showed that women living below the poverty line were more likely to have “high risk” HPV, compared to women living 3 or more times above the poverty line. Among the women above the poverty line, being black, unmarried, and of younger age were associated with “high-risk” HPV infections.<sup>38</sup> Providers must offer the HPV vaccine to all girls age 9 and older before they become sexually active and to all virginal teens and sexually active teens up to the age of 18 if they have had less than 5 lifetime partners, even if they have had an abnormal pap or positive HPV culture. The HPV vaccine should be prescribed to all women up to the age of 26 if they have had less than 5 lifetime partners. This vaccine is not recommended for women over the age of 26; providers should continue with regular cervical cancer screening recommendations.

## CONCLUSION

An understanding of a woman’s cultural background, education, lifestyle choices, family structure, and economic realities helps health care providers engage in shared decision making with the woman regarding her reproductive health. Since half of all U.S. pregnancies are unplanned, efforts should be aimed at all reproductive age women regardless of when they plan to start a family.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- Promote planned pregnancies and reproductive life planning for all women, including high risk women with chronic medical conditions or teratogen exposure.
- Promote the use of multivitamins (calorie free) with 0.4 mg folic acid regardless of pregnancy planning from the age of puberty.
- Encourage lifestyle changes that encourage weight management, exercise, smoking cessation, and moderation of alcohol.
- Assess contraception use as a “vital sign” in all reproductive age women, especially when caring for women with chronic medical conditions and before prescribing medication.
- Provide a prophylactic supply of emergency contraception in case unprotected sex occurs.
- Screen for chronic health conditions in reproductive age women.
- Screen for immune status and provide immunizations (Rubella, Hep B, etc.).
- Screen for STDs in all sexually active women age 25 and younger, and as needed in higher risk situations.
- If a pregnancy termination is needed, provide it as early in the pregnancy as possible to decrease maternal and future pregnancy risks.
- Assess pregnancy intention at the onset of pregnancy to help support women in prenatal behaviors associated with healthy outcomes and with contraceptive planning postpartum.
- Promote long-acting reversible contraceptive methods, especially with high risk women.
- Offer the HPV vaccine to all girls and teens before the onset of sexual activity or before they have had 5 lifetime partners.

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# SETTING ASIDE FEAR, LIVING IN UNCERTAINTY, WELCOMING WISDOM: ACCOMPANYING OUR DYING PATIENTS PHYSICALLY, MENTALLY, AND SPIRITUALLY

Kelly Childress

## AUTHOR FOREWORD

Fifteen years ago, I got off an airplane in Portland and drove to an out-of-town hospital to see my brother, Michael. It remains the worst day of my life. It is also a day that set me on a path to grow spiritually, to offer support and comfort to those in need, to make my own peace with death, and to help others make theirs. My eyes had seen his emaciated body wasted by AIDS but I could not register that he was going to die. Before he died I sometimes accompanied my brother on medical visits and witnessed the times a physician or staff member treated him like a disease, spoke at him, hurried their work with him, touching him only when necessary with a nonchalant clinical air. I also witnessed those times when providers approached him without rushing, calling him by name, listening to his stories, holding his fear and pain in their gaze without flinching. The former made him feel dehumanized and exacerbated his fear and sense of isolation. The latter reminded him of his value and his humanity and assured him that he was not alone, that others cared about him.

When women come in with physical complaints, most often the focus stays on the physical. Yet given the chance many, perhaps most, women would say that they see themselves as more than sick bodies. Of course they need to know that their physician is a skilled and knowledgeable medical practitioner. However they want to know that their physician sees them as a whole person — body, mind, and spirit — and is both able and willing to consider and understand the non-physical aspects of who they are. This becomes even more significant when women face what can be the most frightening and challenging part of a human life — mortality. The aim of this chapter is to address the role of spirituality and how it effects the end of life health care experience for women, and to offer hope that facing mortality, rather than being something that is necessarily depressing, can bring new life to the living and the dying. I hope that in reading this chapter you gain more knowledge, skills, and comfort in thinking about and dealing with death and dying— your patient’s and perhaps even your own.

## BACKGROUND: SPIRITUALITY AND RELIGION

Religion can be conceptualized as an organized set of beliefs about the cause and nature of the universe, the attempt to understand Divinity and the purpose of being human. Every religion has its own character and ritual, its own canons and ethics, and its own traditions. Spirituality tends to be understood more as the individual human search for existential truth and meaning, and the drive to connect to a deeper self, to others and to an ultimate Source. Some may consider themselves “spiritual but not religious,” some see spirituality and religion as two sides of the same coin.

The way women approach or avoid end-of-life issues may be informed and nuanced by both their religious training and practice, and their spiritual awareness and practice. To avoid generalizations, providers must ask questions that empower women to speak about their particular cultural, historical, social, racial, ethnic,



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spiritual, and religious background and beliefs. In this way, providers invite the patient to bring her whole self to the clinical encounter. Through careful listening, compassion is nurtured and trust is deepened. It is not within the scope of this chapter to offer definitive information about the religious or spiritual traditions that providers will encounter in their patients.<sup>1</sup> Rather than try to explain religion and how it is expressed in various cultures, the focus of this chapter is to understand how religion, ritual, and spirituality might impact Kaiser Permanente members, especially women, facing a medical crisis, including a terminal diagnosis.

## IMPORTANCE OF SPIRITUALITY IN THE HEALTH CARE EXPERIENCE

Many studies have found that religious and spiritual practices are integral to the creation of meaning and perspective, a sense of hope and purpose, and an ability to cope with challenges. In one study of 108 women with gynecological cancers, 93% reported that their spiritual beliefs helped them cope with their illness and 75% stated that their religion was important to them.<sup>2</sup> In another study of hospitalized patients, 94% stated that their spiritual health was as important to them as their physical health, and 77% of these patients believed that their doctors should include their spiritual needs in the plan of care.<sup>3</sup> A spiritual connection may infuse women with a sense of purpose and hopefulness, peace and fulfillment. Fourteenth century Christian mystic Julian of Norwich assures that because of The Holy One's consistent presence: "All shall be well; and all shall be well; and all manner of things shall be well."<sup>4</sup> In times of transition: dying, death of a loved one, divorce, etc., experiencing a deeper connection to something beyond the ego may become particularly important. In the words of Tibetan monk Sogyal Rinpoche:

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*The fundamental message of the Buddhist teachings is that if we are prepared, there is tremendous hope, both in life and in death. For someone who has prepared and practiced, death comes not as a defeat but as a triumph, the crowning and most glorious moment of life.<sup>5</sup>*

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## SPIRITUAL AND RELIGIOUS PERSPECTIVES ON THE END OF LIFE

There are common themes and great divergence in how individuals express their religious beliefs and faith at the end of life. Even given no hope for physical recovery, some Christians might demand all available treatments, fighting to live as long as possible, fervently believing that God will provide a miracle. Jewish, Islamic and Christian teachings emphasize that for those who have lived an ethical life, death is not to be feared because there is resurrection – rebirth in an afterlife where one is eternally united with the Divine. In contrast, some Hindus may view life, past and future, as part of an unbroken and unending life-stream. Death is the door one passes through, toward the next birth, and the next, until one merges with the Ultimate Spirit, the Brahma. Pagan traditions likewise believe that one has many lives, and that becoming embodied again and again is a way for the soul to learn new lessons. In Buddhism, the moment of death may be considered the greatest opportunity for liberation. Some Native-American traditions emphasize balance and walking in harmony with nature as an integral component of one's personal identity. Humanists or atheists may seek meaning in the natural world, within the mind, reason, or in scientific discovery and law, and may view death as the end of life.

When faced with the reality of a terminal diagnosis, the beliefs of a lifetime may be challenged for many women. Questioning why they suffer or why God would allow the diagnosis of a terminal illness when they have lived a moral life is a common response to the awakening that death is coming.

## SUFFERING AND GRIEF

Medical practitioners generally view pain and suffering through a somatic lens. If physical pain reaches a level that reduces or destroys any chance for peace it must be vigorously treated. The same is true of spiritual and emotional suffering. When a woman is confronted with her own mortality, she may feel anguish about broken relationships, plans or dreams not fully realized, or fears about what will happen to family members when she is gone. As women play multiple roles within the family and may take on primary caretaking responsibilities, this anxiety may be all the more acute. Existential distress can include wondering what will happen when she dies, or feeling separated from God in her time of greatest need.



**Suffering:** Many spiritual traditions do not view suffering as negative per se. Some women in the Christian tradition may believe that Jesus is with them as they suffer and that their ability to endure suffering as Jesus did (though not necessarily without the help of medication) can prepare them to meet God. In Islam, enduring suffering opens an opportunity for one's sins to be forgiven, thus, suffering can be seen as a gift from Allah. Similarly in Judaism, reciting the prayer of repentance can transform suffering, the prayer allowing one to atone for past mistakes. Among Hindu women, suffering can be seen as a result of Karma and an opportunity to examine the fruits of one's actions in order to grow spiritually. In Buddhism, contemplating the nature and ubiquity of suffering is seen as helping the individual to develop and deepen compassion for themselves and for all other beings.<sup>6</sup>

However a provider conceives of the nature and meaning of suffering, one cannot fully meet the suffering of another unless one is in touch with, and is compassionate toward the suffering in one's own life. Theologian Dorothee Soelle states that those who deal with personal suffering "through illusion, minimization, suppression, apathy" will approach another's suffering in the same way.<sup>7</sup> Soelle states further, "we can only help sufferers by stepping into their time-frame. Otherwise we would only offer condescending charity that reaches down from on high."<sup>7</sup> This requires the provider's willingness to sit with discomfort, fear, and helplessness with the patient, which calls for self-awareness, vulnerability, and self-compassion.

Adequately meeting suffering also necessitates a deeper understanding of the patient's experience. Physician and ethicist Eric Cassell acknowledges that "pain is only one among many sources of human suffering."<sup>8</sup> Addressing suffering requires sensitivity to, intuition and observation of, and inquiry about the non-physical aspects that may be exacerbating a woman's pain. In his study of suffering, Cassell discerns three facts. First, suffering is not confined to physical symptoms. Suffering can be caused by spiritual or emotional factors unrelated to the physical condition. Second, patients suffer from the treatment of disease, not the disease alone (consider chemotherapy, or weekly dialysis). Third, as a woman's perception of pain determines her experience of suffering, clinicians cannot anticipate what a woman will state is a source of suffering – they must ask<sup>8</sup> (would a woman in labor refer to her pain as *suffering*?).

Attempting to understand and help lessen a woman's suffering means spending time with her, and this might feel difficult to do. The culture of modern medicine is results-oriented and fast-paced. While the busyness of a clinical schedule must be dealt with, it is nonetheless important to be a healing presence in every aspect for the patient. In the words of Theologian Henri Nouwen, one must avoid leaving patients feeling, "healed of their physical illness but hurt in their feelings by the impersonal treatment they received...."<sup>9</sup> Interactions with patients can be seen for what they truly are – important opportunities to serve another with compassion and love.

**Grief:** Related to suffering is grief. Every person experiences grief, mild to intense, resolved and unresolved, throughout life. Grief, and in particular, unresolved grief, increases emotional and physical pain in the end of life.

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*To understand the immensity of emotional pain experienced by a dying person, reflect on a period of your life when you lost something that you greatly cherished: perhaps a beloved home, the possibility of a future career, or your partner or spouse ... Seeing how painful and difficult it is to come to terms with just one loss in our life, we may understand more clearly the extreme circumstances of those facing death. They're not just losing one thing or one relationship they cherish – they're losing everything and everyone, all at the same time!<sup>10</sup>*

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If grief were external, like an amputated limb, then the patient herself, friends, family, and the rest of society would clearly see that she suffers from a profound wound that will require time and care in order to heal properly. The fact that grief is hidden can make enduring it more painful. Women experiencing grief from a terminal diagnosis, either for herself or a loved one, may find a lack of understanding from others about what they need, and may feel pressure to hurry up and get past the pain. This can lead them to feel isolated, and to wonder what is wrong with them when they don't just "bounce back."

Yet grieving is hard, complicated work and can involve a wide variety of issues, such as whether or not there is unfinished business at the end of life, whether the death is expected or not, or guilt over what was or not said or done. Most women will benefit from words of assurance that affirm and normalize their grief and help them understand the physical, emotional, and spiritual issues that may arise in grief, so they can accept grieving as a natural and necessary process. Assuring them that there is no one right way to grieve, no particular time frame within which they should be done with grief, and that they are not alone, will comfort. Offering support and education about the grief process, and perhaps referring women to grief support groups, can be extremely helpful.<sup>11</sup>

## SENSE OF IDENTITY

Among other challenges in illness and the end-of-life process is one's sense of identity. Women are socialized into taking on particular roles throughout life, such as mother, breadwinner, artist, healer, etc. Illness can strip away layers of identity and roles built up over the years that leave women without the security of "who" they thought they were. Core existential questions may arise: *Who am I? What is my purpose? Have I fulfilled it? Why am I suffering? What is my value if I cannot contribute in particular ways? Do I have unfinished business? What will happen when I die?* Such questions cannot be answered with surgery or medication — they must be wrestled with at the deepest levels of one's being. In this struggle is great potential: "When you confront your own mortality, the person other people expect you to be falls away, and a new self is born – or rather, your original self surfaces."<sup>12</sup> This is the self that has always been present, underneath personality, and habits of behaving. It is the self that can notice what it tends to like and dislike, judge and fear, but that chooses to respond in new, perhaps surprising ways to whatever arises.

With skillful assistance women can uncover and nurture a renewed sense of purpose and hope that is not necessarily dependent on their physical healing. One of the main ways a provider can help is through offering a grounded, unhurried, compassionate presence. Of course, there are demanding time constraints in the clinical setting. Yet the time constraint exists whether one meets patients in a state of stress, or in a state of grounded peace and with an open heart.

## THE CULTURE OF MEDICINE AND LIFE AND DEATH

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*We hide death as if it were shameful and dirty. We see in it only horror, meaninglessness, useless struggle and suffering, an intolerable scandal, whereas it is our life's culmination, its crowning moment, and what gives it both sense and worth. It is nevertheless an immense mystery, a great question mark that we carry in our very marrow.*<sup>13</sup>

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Medical schools and residency programs train and acculturate physicians to diagnose disease, heal sickness, and to defy and defeat death. Biomedical culture tends not to see death as that which gives our lives ultimate meaning but more as a fearsome enemy to be vanquished. If a woman dies, her physician may feel a sense of having failed the patient. The hospice movement has increased awareness of end of life issues, yet the culture of medicine is set up to fight death off as long as possible.

The tools of medicine and the methodical finesse with which medical experts wield them, from the art and science of disease diagnosis and treatments that prolong life and cure, to the drama of literally bringing someone back from death are truly incredible. Within a context of death denial common in both biomedical culture and often the larger society, it is imperative for providers to discern when to utilize life-prolonging technologies, and when to move toward comfort measures. Providers must talk about advance directives with the patient before the patient finds herself in an emergency room or critical care unit.<sup>14</sup>

## ELEMENTS IN END OF LIFE CARE

**Communication:** Difficult discussions can be made easier when there is understanding about how the woman and her family would like to communicate with the provider. For example, contrary to Western cultural beliefs, many women may not wish to receive medical news directly, particularly when the information could be painful or frightening. Some women, may prefer the provider to give medical news



to the family rather than directly to the patient. In some cultures, words carry great power that, once spoken, could become real and possibly harmful. Therefore the words used to convey information must be chosen mindfully and carefully.<sup>15</sup> It is critical for the physician to ascertain how the woman and family want information conveyed to them.

- Does the woman want to participate in discussions, or does she prefer to hear about what is happening to her through her family?
- Does the woman want to make the decisions about her care, or would she prefer her family be the decision-makers?
- Is she or are her family comfortable speaking with a physician who is not from their particular ethnic background?<sup>15</sup>

In asking these kinds of questions the physician communicates care and respect, and allows the family and patient to release the extra burden of trying to accommodate a culture that may be unfamiliar to them (i.e., medicine in a time of heightened vulnerability).

**Decision-Making:** It is important to be aware that decision-making and communication can be affected by experiences of racism and segregation. For example, some African-American women may believe that physicians undervalue African-American patients and may stop treatment too soon in order to save money, or, as in the case of Tuskegee, deny treatment under the guise of medical research.<sup>15</sup> Such worries are not unfounded. Numerous studies have indicated a positive correlation between being a low-income person of color and a lower likelihood of receiving adequate medical treatment when needed. While these studies vary, the evidence shows that “nonwhites, even after controlling for income, insurance status, and age, are less likely to receive a range of common medical interventions such as cardiac catheterization, immunizations, and analgesics for acute pain.”<sup>15</sup> The wariness that this can engender is potentially embedded into every interaction between the provider and patient, especially those of different ethnic backgrounds. The power imbalance between doctors and patients may further heighten these fears.

Decision-making is even more complex due to advances in technology that allow physicians to keep bodies alive even as whatever made a person who they uniquely were has gone. Families often want “everything” done, and depending upon the patient’s hopes, needs, and understanding of her situation, doing “everything” can either bring peace of mind, or cause tremendous pain and suffering in the end of life for the patient and all involved. It may be helpful to understand that the need to do everything is often rooted in religious and cultural mores.

For example, some in the Christian tradition may fervently believe that there could be a miracle, and they would not accept stopping aggressive treatment prematurely because they know that God is with them and it is up to God to decide when the patient will die. In Jewish law, life is understood to be a gift from God and thus it is sacred. One must therefore do everything possible, no matter how small the chance, to sustain life. In some Asian cultures, offspring may not wish to stop aggressive treatment of a parent because filial respect requires of them to do everything possible to help the patient live.

Whatever the rationale, Dr. Rachel Naomi Remen, Co-Founder and Medical Director of the Commonweal Cancer Help Program in Bolinas, California and a pioneer in the mind/body holistic health movement has suggested that, “...we have made death into a technological and management issue and robbed it of its holy significance and dignity... which diminishes us all...”<sup>16</sup>

There are no easy answers in how to address these kinds of end-of-life issues; they are issues that will require continued exploration and communication by individuals, families and society. What is clear is that health care providers can create a care experience that is welcoming and compassionate even in the most hectic of circumstances, even when communication with the patient and her family may be challenging or there is disagreement about the course of treatment.

**Pain Management:** In addition to the overwhelming effect of confronting one’s own mortality, women need to cope with the daily challenges of disease and treatment. In this regard, pain and symptom

management is a critical component of providing quality care, particularly at the end of life. A dying process encumbered by uncontrolled pain and suffering vitiates the possibility of a “good death.” In a 2006 study by the California Health Care Foundation, about 68% of Californians interviewed were concerned about pain and discomfort when asked about death and dying; this percentage in African Americans and Asians increased to 79%.<sup>17</sup>

While pain can be a subjective symptom, studies suggest that even after controlling for age, income level and health insurance status, minority patients are less likely to receive analgesics for acute pain.<sup>15</sup> A 2005 study of women with cancer who underwent mastectomy followed by chemotherapy indicated that a low socio-economic status and being a Latina were important predictors of poor pain management.<sup>18</sup> Dealing with such injustice requires of every health care provider to understand one’s own unconscious bias, social forces that could work against them, and the commitment to personally ensure that every woman in need of pain management receives the best available care.

The perception of pain and pain control can vary considerably from what providers may expect. For example, some women may attach spiritual meanings to the phenomenon of pain, thus are more willing and able to tolerate pain because of the meaning they ascribe to it. Physicians are in the best position to help their patients through the various difficulties that can arise in end of life care when they have taken the time to understand their patient’s perspectives. When the important spiritual and cultural questions have been explored, physicians will have a much more useful road map to help them guide their patients in their most difficult moments.

## SPIRITUAL HISTORY

Taking a spiritual history can offer a deep insight into one’s patients—what gives them hope and from where they draw strength. Working with professional chaplains is helpful, but is not always possible in the clinic setting. Therefore, providers can use a screening tool to better understand their patient and discern how they can best offer support in the transition from seeking a cure to dying. Dr. Christina Puchalski, founder and director of The George Washington Institute for Spirituality and Health, has created a template, FICA, to assist physicians in asking patients about their spiritual history and to learn what helps them cope. Dr. Puchalski recommends the following when a provider is taking a spiritual history<sup>19</sup>:

- Consider spirituality as a potentially important component of every patient’s physical well being.
- Address spirituality at each complete physical examination and continue addressing it at follow-up visits if appropriate.
- Respect a patient’s privacy regarding spiritual beliefs.
- Make referrals to chaplains, spiritual directors, or community resources as appropriate.
- A physician’s own spiritual beliefs may overflow in encounters with patients to make the doctor-patient encounter a more humanistic one.

Including a spiritual history with a physical history can help providers gain information to help meet the diverse needs of their patients as they begin to prepare for important life transitions. In this endeavor, hope is as essential to emotional and spiritual palliation as morphine might be to physical palliation.

## ROLE OF HOPE IN END OF LIFE

Even when a physician determines there can be no reasonable expectation for cure or remission of disease, hope can live on. Breaking difficult news to a patient (if that is the agreement between doctor and patient) does not mean that hope must be broken in the process. Rather, hope should be encouraged — not false hope, but authentic openness to mystery (sometimes surprising things do happen), or to ways in which a dying patient can continue to participate in life. While the doctor’s prognosis is taken seriously, many women believe that ultimately the time of death cannot be predicted by humans. In one study a patient stated “up there, everybody has got a number that says when you will die. Believe in it. When it’s time for the Lord to call you, it’s time for you to go.”<sup>20</sup> Holding out hope for healing even to the last breath does not mean one died in denial. Awareness of the probability of impending death can co-exist with hope because



**F—Faith and Belief:** Do you consider yourself spiritual or religious? Do you have spiritual beliefs that help you cope with stress? [If not, the physician might ask] What gives your life meaning?

**I—Importance:** What importance does your faith or belief have in your life? Have your beliefs influenced how you take care of yourself in this illness? What role do your beliefs play in regaining your health?

**C—Community:** Are you part of a spiritual or religious community? Is this of support to you and how? Is there a group of people you love or who are important to you? [Communities such as churches, temples, and mosques, or a group of like-minded friends can serve as strong support systems for some patients.]

**A—Address in Care:** How would you like me, your healthcare provider, to address these issues in your healthcare?

*Used with permission from Dr. Christina Puchalski, M.D., FACP*

healing can be physical, spiritual, and emotional. Hope for healing may change or include hope that one will not be alone or in pain, hope that one will be met “on the other side” by loved ones who have preceded them in death, hope that good things will happen to loved ones in their lives, and much more.

## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS

- **Provider Self Awareness:** Providers cannot avoid unhelpful projections and judgments about a patient’s end of life until they have faced their own mortality. Coming to some level of peace with death can take away death’s power to consume one with dread — a sense that is felt by not only the provider, but by the patient as well. French Renaissance writer Michel de Montaigne writes:

*To begin depriving death of its greatest advantage over us, let us adopt a way clean contrary to that common one; let us deprive death of its strangeness, let us frequent it, let us get used to it... We do not know where death awaits us: so let us wait for it everywhere. To practice death is to practice freedom. A [person] who has learned to die has unlearned how to be a slave.<sup>21</sup>*

- **Inquiry:** Providers must approach their patients especially those at the end of life with a sense of openness, curiosity, the willingness to ask questions, and listen without judgment. This way providers can get to know their patients, learning how best to meet the needs of the individual before them. Fr. Henri Nouwen wrote that such knowing is embedded in the profound meaning of diagnosis: gnosis = knowledge, dia = through and through.
- **Compassion:** To help a patient face mortality requires great compassion. One cannot authentically meet people with compassion without first extending true compassion toward oneself. Providers can help patients at the end of life move through fear, regret, and remorse toward a place of acceptance and peace if they stretch beyond being the powerful one — diagnostician, technician, healer — to accept also being the human one, knowing that there is a point when the curative tools of modern medicine are best set aside and the tools of comfort enhanced.
- **Listening:** Providers must practice sitting with the patient’s pain, fear, and confusion without flinching and deeply listening to a patient’s anxious worries without trying to fix them. It could be that the price for doing everything in one’s power to hold death at bay may be that one’s patient’s last days are robbed of the potential for non-physical healing: the chance to heal relationships, to say “I love you” and “goodbye,” to consciously transition from this life to whatever may come next. Providers can learn to be at greater ease with the inevitability of death, to trust in one’s power to heal if that is possible, and let go when it is time.

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### Dramatic Film:

- The Diving Bell and the Butterfly
- The Doctor

### Documentary Film:

- So Much, So Fast. A film by Steven Ascher and Jeanne Jordan. <http://www.westcityfilms.com/smsf.html>
- The Vanishing Line. A film by Dr. Maren Monsen. <http://www.frif.com/new98/vanline.html>
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# THE COMPLEXITIES OF SEXUALITY: CULTURAL FACTORS

Priya Batra

## AUTHOR FOREWORD

Threaded through our human strengths and tribulations are our complex pasts and lived experiences. Where we have been and where we are cannot be extricated from where we are going. My culture and the context within which I grew up shaped my interest in sexuality. My parents immigrated to the United States from India and three years later I was born in New York City. Over the years, more relatives arrived from India and while the love flowed freely, not every topic was open to discussion. Matters related to sex were most often met with discomfort and avoidance. My intent in writing this chapter is to make clear the impact of culture, race, and ethnicity, and its interaction in sex, sexual health, and sexuality.

Let's fast forward a few decades. I recently returned from a trip to India during which I saw the following advertisement on a fairly non-descript shopping bag from a local non-profit organization: "Sexuality Matters: A central aspect of all people whether explored, denied, or celebrated." With voices like mine, organizations like theirs, and a spirit of openness, change can be brought about wherein sexuality can become an arena of life that is better understood, truly enjoyed, and seen as an essential domain of health, both for you and your patients.

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*Analyse any human emotion, no matter how far it may be removed from the sphere of sex, and you are sure to discover somewhere the primal impulse, to which life owes its perpetuation.*

— Sigmund Freud

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## INTRODUCTION

Though universal and ubiquitous, the topic of sex is all too often avoided, misunderstood, and feared. While sex is one of the most basic human drives, open discussions about sex and sexuality can be difficult to engage in. Within the medical setting, it is important that health care providers be adept at handling the sexual health questions and concerns of patients – this is true across disciplines and specialty areas. This skill, however, is often complicated by cultural factors that shape beliefs, ideologies, and opinions about sex. This is true not just for the patient, but for the health care provider as well. In the United States, threaded through conversations about sexuality are often debates about morality and expectations about what is considered to be normal and/or acceptable. This dynamic is further complicated by the individual and cultural history each person brings to this broader social context. Education, intervention, and treatment about sexual health matters are shaped by these cultural and personal histories, as are the decisions of patients to heed directions from health care providers.



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What lessons about sex and sexuality were you taught by family, faith-based institutions, school, the media, friends, and members of your cultural group?

Given such complexities, respectful inquiry can serve as the compass from which to navigate. Any conversation between the patient and provider is an intercultural exchange; the worldview of the patient can best be delved into via inquiry, dialogue, and listening to what the patient thinks is the cause of her distress and the best possible strategy for treatment.

This chapter explores female sexual health from a broad perspective that includes how culture and other key factors impact sexual identity and functioning. Different populations groups are highlighted, and the sexual response cycle in relation to key sexual disorders is reviewed.

## BACKGROUND

**A Mind/Body Perspective on Sexuality:** Just as mind/body approaches to medicine suggest that psychosocial factors impact health (e.g., the relationship between stress and heart disease, the management of chronic pain, etc.), sexual health is also a composite of both the psyche and the physique. There are three intersecting components that comprise sexual functioning and sexual identity and the unifying element of these three realms is overall health.

**Emotional Health:** A sense of well-being; the absence of mood disorders (e.g., depression and/or anxiety); positive body image.

**Relational Health:** Safety, trust, and security with one's partner(s); the absence of abuse; functional communication patterns; a desire to mutually inquire about and meet the needs of the partner (in all domains of the relationship).

**Physical/Medical Health:** General sense of wellness; absence of ailments or good control over chronic conditions; a sense of vitality.

Many women arrive at their doctors' offices hoping for a solution that is quick and easy – often a pill analogous to Viagra. While some sexual problems may have physiological etiologies where medical interventions are sufficient for providing a 'cure' (such as medication adjustment or change, hormone replacement therapy [HRT], or laparoscopy for endometriosis), more times than not, the root of the problem is multi-factorial in nature and lies in the interplay between emotional status, relationship status, and physiology. "In contrast to male sexual response, female sexuality tends to be less genitally focused and more sensitive to and affected by the contextual, romantic, intimate, and sensual aspects of sex."<sup>1</sup>

## BROAD FACTORS THAT SHAPE SEXUAL IDENTITY

All people are raised with overt, subtle, or inadvertent messages about sex. Within families there is tremendous variation in the degree of openness about sex and sexuality and differences in the depth of communication that is permitted, confronted, or enjoyed. Familial factors to consider include:

**Religion:** Religious beliefs may influence views about contraception and sexual frequency. It may affect the degree to which an individual may believe that the purpose of sex is for procreation and not pleasure, and whether they engage in physical intimacy only as a marital duty or as a platform for mutual sensuality and pleasure. For example, in the Judeo-Christian faiths, Madonna versus whore dichotomies may influence followers. In such a context, women are often rendered into polemic dichotomies such as "pure" versus "tainted" and "good" versus "bad."

**Gender Expectations:** Assumptions about masculine and feminine stereotypes and appropriate behaviors influence sexual behavior in many ways including who initiates intimacy, the range of appropriate expression of pleasure, open communication about sexual likes and dislikes, and expectations about dominance and submissiveness. For example, during adolescence, some families may find it appropriate for their sons to "sow their wild oats" while this same expectation may not be held for daughters. In other words, sexual exploration and self-discovery may be acceptable and tolerated with adolescent males, but not adolescent females.

**Cultural Messages:** Media outlets and popular discourse help to establish a cultural narrative about the “types” of women who enjoy sex and certain sexual behaviors. In many South Asian cultures for example, men and women are provided with very little sexual education during their formative years. At the time of marriage, they are expected to learn about sexual matters from their friends and via first-hand experience with the new spouse.<sup>2</sup> In the United States, pleasure for both partners of the heterosexual couple is encouraged and discourse about female sexual pleasure can be readily found. This is exemplified through titles of popular sexual health books – *For Each Other* (Barbach), *She Comes First* (Kerner), *Secrets of the Sexually Satisfied Woman* (Berman & Berman), and *The Multi-Orgasmic Couple* (Chia, et al.). Unfortunately, in my experience, discussion about mutual sexual pleasure among same-sex couples is not particularly advanced and this is why the term ‘heterosexual couple’ was used above. (See the Lesbian Health chapter for information on safer sex behaviors among same-sex couples).

Given familial and societal pressures around sexuality, many individuals may feel compelled to be either sexually experienced or sexually innocent. In recent years, there has been more discussion and debate about the issue of “technical virginity.” This term applies to individuals who have engaged in sexual behaviors such as oral sex or mutual masturbation, but not insertive sex. This phenomenon may be the result of a strong emphasis on virginity held by members of certain cultures.

A combination of any of these factors may influence whether a woman primarily becomes the recipient of her partner’s sexual appetite or is a willing participant in pleasure-seeking and sexual expression.

## PERSONAL FACTORS THAT SHAPE SEXUAL IDENTITY

As noted above, the lingering effects of exposure to early cultural and religious messages about sex and sexuality should not be underestimated. At the same time, several other factors have the power to shape sexual functioning.

**Sexual Orientation:** Assumptions should not be made about sexual identity. In a recent study published by the Centers for Disease Control and Prevention (CDC), 11% of women surveyed (between the ages of 18 and 44) acknowledged that they had engaged in sexual relations with another woman; however, when asked to specify their sexual preference, 90% said that they were straight.<sup>3</sup> It may prove helpful to pose the question “In the past and now, have your sexual partners been men, women, or both?” instead of asking, “Are you gay, straight, or bisexual?”

**Physical and Sexual Abuse:** History of abuse plays a major role in developing sexual identity. It is estimated that 27% of women are victims of some form of childhood sexual abuse (i.e., incest, molestation, rape).<sup>4</sup> Sexual abuse survivors may experience lingering memories of what their abuser told them (“You really want this,” “No one else is ever going to want you,” etc.), or the tendency for certain cues to evoke negative emotional reactions (e.g., a cologne similar to that of the abuser’s, certain types of touch that their abuser exhibited, requests for particular sexual behaviors, etc.).

**Intimate Partner Violence:** Intimate Partner Violence (IPV) is all too common; it is represented in 1 in 3 female trauma victims and 1 in 6 pregnant women.<sup>5</sup> A review of the literature has demonstrated that a history of IPV and sexual dysfunction are linked.<sup>6</sup> Abuse may have a negative impact on sexual functioning. Women in a physically and/or emotionally abusive relationship may not initially disclose the abuse, but they may present with diffuse complaints regarding their sexual functioning such as decreased libido or a reduced ability to achieve orgasm as they once did. When probed about abuse, some may acknowledge that this is a problem yet still assert that it should not manifest itself in the sexual dynamic. Providers can highlight the importance of trust and physical and emotional safety as integral aspects of a fulfilling sexual relationship with patients experiencing abuse. Abuse can decimate self-esteem, confidence, and self-expression, and these are very often essential components of a fulfilling sexual relationship. (See the Intimate Partner Violence chapter for more information).

**Secrets:** While secrets may or may not manifest in overt behavior, they certainly can drift to the surface and create problems in one’s sexual life. Non-disclosure of abuse is often paired with self-blame, shame, confusion, and depression. Likewise, other personal secrets, such as infidelity (the partner’s, one’s self,

or both) or the use of pornography without the knowledge of one's partner, or excess use even with the partner's awareness may also affect patients' sex lives. Resolution may be needed before healthier sexual and relationship patterns can be established.

**Body Image:** No discussion of sexual identity and expression would be complete without mention of body image. Many women have some level of insecurity about their bodies and level of attractiveness. While some women compare themselves to what they once were (e.g., "I used to be a size 4 and now I wear a 12."), others compare themselves to what they deem to be the cultural ideal (e.g., "I will never look like a supermodel so why would he or she want me?"). It is helpful to have patients consider not just the physical aspects of intimacy, but the emotional ones as well. Helping patients to learn to value the enhanced closeness and other positive relational factors that come from intimacy can be powerful.

Findings of sexual satisfaction amongst obese women vary in the research literature. In one study, a higher body mass index was related to impairment in sexual quality of life (i.e., not enjoying sexual activity, hypoactive desire, problems with sexual performance, and avoidance of physical intimacy). This study also found that these issues affect obese women more so than obese men.<sup>7</sup> However, in Areton's qualitative study of 112 obese women with an average weight of 298 pounds, she found that 67% of the women reported sexual satisfaction. Predictors of such satisfaction were open communication about sex, positive body image, and perceived partner enjoyment of the sexual relationship.<sup>8</sup> Providers should avoid assumptions about sexual functioning and sexual satisfaction with obese patients. As with all patient populations, they too should be asked about sexual health matters.

Personal schemas about acceptable and attractive body types can be affected by social and cultural factors. Studies have found that the degree of acculturation affects how individuals ascribe judgment about their bodies, as does the influence of peers, media exposure, and familial messages about thin idealization and fat acceptance.<sup>9</sup> Namely, as individuals become "more American," some experience improved levels of confidence and esteem about their bodies, while for other groups, it worsens.<sup>10</sup> While taking a sexual health history, include questions about acculturation and how this affects personal views on sexuality and sexual expression. For example, asking patients where they received their most influential information about sexuality (e.g., parents, a religious institution, the media, friends, other family members, etc.) may help shed light on the development of such viewpoints and behavior.

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*Love is a matter of Chemistry, but sex is a matter of Physics*

—Unknown

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## ADDITIONAL FACTORS THAT MAY IMPACT SEXUAL IDENTITY AND FUNCTIONING

**Role Changes:** The birth of a first child leads to role changes on an individual level and within the context of the marriage and partnership. Within the first three months of childbirth, 83% of women report sexual problems and up to 33% still struggle one year after delivery.<sup>11</sup> Lactation is accompanied by lower androgen levels which can affect sex drive. Equally important, the demands of a newborn can quickly result in parental exhaustion. Couples may also find it difficult to feel sexy after having attended to childcare. Creating and prioritizing times for couples to check in with one another should be a preliminary recommendation by the provider. The issue of role change is also pertinent for single mothers. Mothers who raise children alone whether by choice or by circumstance also experience changing roles at work, with friends, and in the pursuit of companionship.

**Hysterectomy:** Undergoing a hysterectomy also evokes concern in many women that their sexual functioning will be negatively impacted. In a study of 170 patients status-post hysterectomy, 60% reported no change in their sexual functioning, 21% improved, and 18% worsened.<sup>12</sup> Many women report feeling "less like a woman" with their uterus and/or ovaries removed. Providers can assure these women that their feelings are normal and that they may experience grief about the loss of their reproductive capacity.

**Menopause and Aging:** Major hormonal events, such as the postpartum period, perimenopause, and menopause, are often accompanied by changes in sexual identity and functioning. As women's bodies experience major drops in hormonal production during the perimenopausal and menopausal phases of



their lives, psychological factors affect their mind and body as well. Coming to peace with aging and mortality is an important phase. If such phases are paired with a sense of lost vitality, refocusing patients on that which is still ahead, that which they are still capable of, and the best means by which to stay healthy could prove to invoke a healthy change in perspective. “Life stressors, contextual factors, past sexuality, and mental health problems are more significant predictors of midlife women’s sexual interest than menopause status itself.”<sup>13</sup> (See the Menopause chapter for more information).

**Medical Conditions:** Medical conditions can and do affect female sexual functioning. Conditions that alter blood consistency and flow (e.g., diabetes and heart disease) may affect a woman’s sexual response cycles. In a study of diabetic women, the researchers found that disease acceptance was a crucial variable in sexual functioning. They also found that the women who had the most complications (e.g., neuropathy) also had more sexual distress.<sup>14</sup> With heart disease, atherosclerosis of the vessels supplying the vagina and clitoris can lead to arousal disorders. Other conditions that most frequently impact female sexual health include vascular disorders (e.g., hypertension, leukemia, and sickle-cell anemia), neurological disorders (e.g., head injury, multiple sclerosis, epilepsy, spinal cord injury, and stroke), hormonal/endocrine conditions (e.g., diabetes, hepatitis, and kidney disease), voiding disorders, and debilitating diseases such as cancer, degenerative diseases, and lung disease. Patients undergoing fertility treatment should also be asked about their sexual relationships with their partners. As procreation becomes medicalized, the joys of physical intimacy can diminish. In this case, health care providers can remind couples to focus on their relationship, including the aspects of intimacy that once were positive.

**Medications:** Medications listed throughout the literature as having the most impact on female sexual functioning include: antihypertensives, beta blockers, steroids, antihistamines, anticonvulsants, and a number of psychiatric drugs (e.g., selective serotonin reuptake inhibitors [SSRIs], benzodiazepines, tricyclic antidepressants [TCAs], and antipsychotics). SSRIs tend to affect a large percentage of women who are prescribed these drugs. Though minimally studied, over-the-counter ginkgo biloba can reverse the sexual side effects of SSRIs in some women. Women with bleeding/clotting conditions or those about to undergo surgery cannot take ginkgo. Adding Wellbutrin (while keeping the patient on the SSRI she is already taking) can also help reduce some of the sexual side effects from the SSRI. Overall, patients often don’t report the sexual side effects they experience – rates of report are four times higher when they are asked directly.<sup>15</sup> Such a discussion, and subsequent problem-solving, can help avoid possible discontinuation of a necessary drug.

**Substance Use:** To thoroughly assess and treat female sexual concerns, providers must have a discussion with the patient about drug and alcohol use as this can lead to sexual problems in that women may provide consent to people and/or activities that they would not normally. If women indicate that this is the only way in which they can relax (e.g., “I have to have a glass of wine in order to get in the mood”), other coping strategies should be discussed with the patient.

## ISSUES OF SEXUALITY WITH DIVERSE PATIENT POPULATIONS

**Single women:** Women without partners should have the topic of sexuality discussed with them. Unpartnered women will sometimes present to a medical clinic inquiring about changes that they have noticed in their sexual response cycle when they engage in masturbation. Just as with a partnered patient, the un-partnered patient may have considerable concerns and a number of questions about her condition and her treatment options. Masturbation is a topic that can often trigger discomfort or avoidance on the part of the health care provider.

**Older adults:** In a culture where youth and beauty are greatly valued, older adults and seniors are often assumed to be asexual. In a study of 2,109 women aged 40–69 years conducted by the Reproductive Risk Factors for Incontinence Study at Kaiser Permanente, 71% of the women were sexually active in the last year.<sup>16</sup> Of these women, nearly two thirds were somewhat or very satisfied with their sexual activity.

**Women with disabilities:** Women with disabilities are often an invisible group when it comes to matters of sexuality and the ability to sexually perform. Providers must not assume that women with disabilities lack concerns about their sexual functioning. In addition, women with disabilities are at high risk for partner and sexual abuse. The essential point is that all patients get asked about their sexual functioning – this includes personal expectations, current performance, desired performance, and the need for more

information. Consider the following examples: Women with pain conditions may require information on positions that may be less painful. Women with multiple sclerosis may have questions about determining whether to proceed with intimacy and how vigorously to proceed based upon pain and fatigue symptoms, lubrication and sensitivity issues, and recurring bladder infections. Female patients with paralysis disorders may want to know how best to enhance sexual sensation or whether this is possible at all.

**Female genital cutting:** Worldwide estimates of women who have undergone female genital cutting number around 130 million.<sup>17</sup> The rationale for such practices includes control of female desire and behavior and increasing male pleasure. Women who have been subjects of genital cutting (also known as female genital mutilation or female circumcision) may present with a number of different sexual health concerns. Such women may require basic education about their bodies, and in particular, their sex organs. Feedback on how best to minimize pain with sexual activity could prove helpful, as would normalization of any avoidance or disinterest in sexual activity. While the patient may report that it is one's duty to be intimate with her husband, it may be reassuring to the patient to understand why she has issues around low desire, limited arousal, absent orgasms, and/or pain. As with any clinical presentation, sensitivity to the patient's cultural and religious background is of the utmost importance. This may be especially true in cases of female genital mutilation where the provider's response may be marked by horror, discomfort, or shock.

**Tattooing and body piercing:** The issue of tattooing and body piercing and assertions that this is a form of self-expression and art as opposed to a form of self-mutilation requires that the provider ask the patient about self expression and sexuality, should a patient present with numerous tattoos and/or multiple body piercings.

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*Nothing in life is to be feared. It is only to be understood.*  
— Marie Curie

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## THE SEXUAL RESPONSE CYCLE

In helping patients understand what may be negatively affecting their sexual functioning, reference to the sexual response cycle with the work started by Masters and Johnson in the 1960s may prove helpful in conceptualization of the presenting issue.

**Desire:** Desire is the most cerebral stage of the cycle. It is the cognitive component of the sex drive wherein one thinks about being intimate, has fantasies, and often experiences physical sensations. This is also known as libido. Many women come to know this sensation as their cue to move forward with an intimate encounter. However, such feelings can diminish over time without one's awareness, knowledge, or acceptance. Many women report that though their fantasies and thoughts about sex have diminished over time (this phenomenon is particularly pronounced after menopause), they are still able to get aroused when they move forward with an intimate encounter. Although desire may no longer be as consistently present or as intense, it does not mean that patients cannot move forward with a perfectly enjoyable intimate encounter. Desire can also be side-tracked by stress. With the number of obligations, roles, and responsibilities that many women have to fulfill, other priorities can supersede a desire for sex. For other woman, after concerns about pregnancy are removed (e.g., placement of an intrauterine device (IUD), being status-post hysterectomy, having a partner who has undergone vasectomy), the desire for sex may actually increase.

**Arousal:** Arousal is the body's physical responsiveness to sexual stimulation (through thoughts, touch, or both). In women, arousal includes increased blood flow to the pelvic region and the breasts. There is vaginal, clitoral, and labial engorgement and vaginal lubrication. At times of hormonal fluctuation (e.g., pregnancy, lactation, postpartum, menopause) the usual experience of arousal may be altered. The vast majority of postpartum women will return to baseline functioning within a year. Post-menopausal women may want to discuss hormone replacement therapy (HRT) with their providers as a means of improving decreased arousal. (See the Menopause chapter for more information about HRT).

**Orgasm:** Orgasm includes contractions of the pelvic floor, uterus, and vagina (the motor contractions of the pelvic floor are followed by uterine and vaginal smooth muscle contractions). The pleasurable sensation is deemed the climax of the sexual experience by many and often, the "goal" of a sexual encounter. Some

women are capable of achieving multiple orgasms within a given encounter and some women produce an ejaculate during this phase.

**Resolution:** Resolution is the body's return to physiologic baseline (e.g., normal heart rate, perspiration, blood pressure, muscle tone, physical sensitivity).

## FACTORS THAT IMPACT THE SEXUAL RESPONSE CYCLE

Many factors influence the sexual response cycle, and the transition from one phase to the next.

**Stress and Fatigue:** Stress plays a very large role in one's overall functioning and certainly can impact sexual expression. Increased stressors can lead to decreased fantasizing and a diminished desire for physical intimacy. Likewise, as stress increases, so can fatigue. Many women may report a desire to prioritize sleep over sex in order to better tackle the next day's demands.

**Role and Task Obligations:** Women occupy many roles in their lives and these often include wife, partner, mother, daughter, and employee. Such roles come with many demands and if sex becomes another obligation, it often gets prioritized with all the other tasks.

**Aging:** Aging must also be given consideration as changes in the response cycle start to present over time. As desire and arousal become less robust in some women as they age, they often attribute the change to some sort of personal deficiency rather than as a normal part of the aging process. However, concerns of older patients should not just be dismissed as a normal part of aging; older Americans engage in sex and expect interventions when they raise concerns about their sexual health.

## FEMALE SEXUAL DISORDERS

When diagnosing a patient's sexual problem, conceptualization of the issues should begin at the lowest level of the response cycle that is impacted (i.e., address issues of desire before addressing those around arousal). The following are some common conditions that patients will present with:

**Hypoactive Sexual Desire Disorder:** Hypoactive Sexual Desire Disorder is a consistent and bothersome lack of sexual thoughts, fantasies, and impulses which causes the patient distress. This is the most commonly reported sexual dysfunction in women. While the number of women with low desire increases with age, vocalized distress about the condition actually decreases with age. With such presentation, it is important for providers to inquire about overall stress levels and relationship dynamics with the partner.

**Sexual Arousal Disorder:** Sexual Arousal Disorder involves a lack of sexual excitement marked by inadequate lubrication and engorgement. Again, diagnosis requires that a patient reports distress about the issue. The lack of genital response may include decreased sensitivity, decreased clitoral and labial engorgement, and failure of vaginal smooth muscle relaxation. It is very common for post-menopausal women to complain of vaginal dryness or for other women with this condition to note that they no longer feel "tingly" once intimacy is initiated. Lubricants can be recommended, as can advice around varying a couple's normal routine around intimacy.<sup>18</sup>

**Orgasm disorders:** Orgasm disorders include an absence of orgasm where it once was typical (i.e., anorgasmia) or increased difficulty in achieving orgasm as frequently or as intensely. Women who say they have never had an orgasm have a primary condition, where it would be considered secondary in women who report an alteration in their previous functioning. Primary anorgasmia has been linked with history of trauma (physical, emotional, or sexual), lack of sex education, anxiety about sexuality, and high religiosity. Secondary orgasm problems can be linked to hormonal imbalances, surgery, pelvic trauma, and weak pubococcygeus muscles. Treatment for orgasm disorders include sex education, couple's sex therapy, sensate focus activities, Kegels, and directed masturbation exercises.

**Dyspareunia/Sexual Pain Disorders:** Dyspareunia/Sexual Pain Disorders are the presence of pain at any point during intimacy. Possible etiologies include insufficient lubrication, atrophy, infections, endometriosis, vestibulitis, cystitis, sexual trauma/history of abuse, surgical scarring, pelvic masses, and untreated sexually transmitted diseases (STDs). This condition should be considered a pain condition with sexual sequelae rather than a pure sexual dysfunction.

**Vaginismus:** Vaginismus can be considered a pain or an anxiety condition. Involuntary contractions of the vaginal muscles occur upon insertion of a finger, tampon, speculum, and/or penis. Treatment may include progressive in vivo exposure (with relaxation techniques and through use of dilators). The presentation of this condition is correlated with a history of sexual abuse/trauma, limited sexual education, relationship factors, and holding negative beliefs about being a sexual person. Vaginismus is also common in women with strong conservative religious backgrounds. In my practice, I have treated this condition among many women originally from the Middle East and South Asia. They will talk of wanting to avoid sexual contact out of fear of it unleashing intense physical pain. While they may talk of their husband's desire for sex as motivation for treatment, they may simultaneously assert that their emotional and physical reactions to sexual overtures are normal. They typically hold few positive schemas around their own sexuality (e.g., "I am a sexual being with sexual curiosities and desires.").

**Sexual Aversion Disorder:** Sexual Aversion Disorder is also an anxiety condition. There is aversion to and avoidance of contact with one's sexual partner accompanied by personal distress about the reaction. Typically, there is a history of trauma (physical, emotional, or sexual) with such patients that needs to be addressed through psychotherapy. For other women, sexual aversion disorder may be rooted in a sense of body aversion including appearance (e.g., obesity, lack of physical tone, being too thin), bodily odors, or aversion to the tactile sensations that accompany intimacy (e.g., bodily fluids, hair). Cognitive behavioral intervention may be helpful with patients affected by sexual aversion disorders. Such techniques will foster change in the recurring internal dialogue of the patient, invite new ways of thinking, and alternate behaviors to engage in when desires to avoid or flee become compelling. In Simons and Carey's review of the literature, they note that there is a 5-46% prevalence of desire disorders in women, 7-10% for arousal disorders, 7-10% for orgasmic disorders, and 10-15% for sexual pain conditions.<sup>19</sup> Another study found that the general prevalence rates of these disorders among women are 7-22%.<sup>20</sup>

Women may be very affected by their partners' sexual dysfunctions and may take responsibility for the problem without reporting their partners' dysfunction. It should be routine procedure to ask women if their partners have any sexual functioning concerns (e.g., erectile dysfunction, low libido etc.). The language providers use when talking to women about such issues is important. Some women may be comfortable with slang, and others with medical jargon. Providers should ask the woman what she herself calls certain sexual behaviors and body parts.

In a study of middle-aged and older woman (mean age of 55.9), 33% of the women studied reported a problem in one of four domains (i.e., desire, arousal, inability to relax, and orgasm). This study included women of color (18.2% were African American, 16.6% Hispanic, and 16.4% Asian American) and some findings were significant – sexual frequency was lowest among Asian women, and African American women reported lower levels of sexual dysfunction and high levels of sexual satisfaction.<sup>21</sup>

## CONCLUSION

When a diverse group of patients was surveyed about physician comfort with topics surrounding sex in general, they stated that the provider's demeanor was essential and that they hoped for a calm delivery marked by frankness, directness, and a lack of assumptions.<sup>22</sup> Similarly, in a study from the United Kingdom, older patients (50-92) reported that barriers to speaking with their doctor about sexual matters were attributable to age and gender of the physician (in other words, not a match with the patient themselves), provider attribution of the problems as a normal part of aging, and a lack of time and privacy in the consultation.<sup>23</sup>

It can take great courage for female patients to broach the topic of their sexual functioning with their providers. This is especially true for women who were raised to believe that women were not to have sexual desires or that the needs of their partners were paramount. Given this, it is important that providers listen to the patient, normalize her concerns, and are armed with and offer a repertoire of concrete recommendations.

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*For each of us as women there is a dark place within where hidden and growing...Our true spirit rises.*

— Audre Lorde

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## IMPLICATIONS FOR KAISER PERMANENTE PROVIDERS:

- From a non-judgmental and nuanced perspective of patients' belief systems providers can provide appropriate interventions for sexual health matters. Health care providers also need personal insight about their own biases and normative assumptions about sexuality.
- Consider the overall health of the patient who presents with sexual health and functioning concerns including their psychological status, physical wellness, and relationship health.
- The health care provider can respectfully inquire about the cultural factors that are contributing to the patient's presenting sexual issue including religious background, gender role expectations, and messages about sex and sexuality from both the familial context and the broader American culture.
- An inquiry about childhood sexual abuse or any such form of sexual or sexualized abuse (e.g., sexual harassment) during adulthood is an essential element of the sexual history. If the patient reports such a history, consider assessing the impact of the prior abuse in her current life and consider a referral to psychological treatment.
- Many states have mandatory reporting guidelines about patient disclosure of abuse. Know the local reporting laws should a patient disclose current abuse or abuse of a child. Steps should be taken to be compliant with the reporting laws of the practicing provider's state.<sup>24</sup>
- Encourage patients to explore sexual secrets with a counselor to better understand how these incidents may affect their current sexual functioning.
- Sexual functioning in many women may be inhibited by a negative body image. Helping patients to view intimacy in an emotional and relational context (and not just physical) may be of benefit to such women.
- As couples become parents, remind them to continue to nourish their relationship with one another and, schedule time alone for fun, communication, and romance.
- Throughout a woman's life cycle, providers should always emphasize overall health and healthy behaviors: a nutritional diet, adequate sleep, healthy relationships, a balanced approach to managing stress, and activities that improve self-esteem.
- Changes in one's sexual functioning during perimenopause and after menopause are common.
- Women undergoing hysterectomy should be assured that a worsening of sexual functioning is rare. Psychological processes among such women regarding feelings and concerns about femininity and her identity as a woman may require intervention.
- Asexuality should not be assumed about patients who are single, widowed, or older.
- It is important to convey to patients that fluctuating levels of arousal throughout their lives and inconsistency of orgasm are normal.
- Desire can diminish a great deal over time in women. Interventions for low desire include addressing stress and time management issues, strengthening communication and problem-solving within the relationship, and altering expectations around desire having to precipitate the rest of the response cycle.
- After times of hormonal change in a woman's life, discussion should be initiated about arousal changes and whether or not treatment is necessary (i.e., postpartum women may be instructed to give their bodies some time to return to baseline, while hormonal strategies may be discussed with post-menopausal women). Arousal problems can be responsive to pharmacological intervention or a behavioral intervention such as sensate focus. An instructive overview of sensate focus can be found at: <http://health.discovery.com/centers/sex/sexpedia/sensate.html>.
- Providers can educate patients about clitoral stimulation, the use of sex toys, and sexual positions that stimulate the G-spot.
- When changes in sexual functioning occur, attention should be paid to recent life changes, a rearrangement of priorities, and means of enhancing self-care.

- Women should be encouraged to not establish an orgasm as the goal of the sexual encounter. Other positive aspects of a good sexual encounter include enhanced intimacy with the partner and other pleasurable sensations that are both emotional and physical.
- For some patients, masturbation may be the primary venue for sexual expression and concerns raised should be taken as seriously as the sexual issues of partnered individuals.
- When women present with sexual dysfunctions, sort through the contributing factors that are physical in nature and those that are more relational and psychological. Recommendations and referrals in both domains should be offered.
- Patients should be cautioned about the lotions, potions, tablets, pills, and herbal products that are marketed for female sexual conditions. Data is limited and oversight is minimal. Patients should be encouraged to tell their providers about any supplements that they are taking as some herbs and supplements may be contraindicated with some medications.

## RESOURCES

Each clinic should compile a list of books that they believe provide a comprehensive educational overview on female sexuality and a sufficient number of practical recommendations. Excellent first-line resources include: *For Women Only* (Berman and Berman), *The New Male Sexuality* (Zilbergeld), *For Yourself: The Fulfillment of Female Sexuality* (Barbach, Lonnie), *The Ultimate Guide to Sex and Disability* (Kaufman, Miriam, Silverberg, Cory, and Odette, Fran), *The Whole Lesbian Sex Book: A Passionate Guide for All of Us* (Newman, Felice), *The Mother's Guide to Sex: Enjoying Your Sexuality through All Stages of Motherhood* (Semans, Anne and Winks, Cathy) and *For Each Other* (Barbach).

Recommendations pertaining to masturbation can include a handout from the following web page: <http://sexuality.about.com/od/anatomyresponse/ht/masturbatewomen.htm> and a discussion of sexual toys. Reputable adult shops that sell these items as well as helpful websites can be referred to (e.g., [www.goodvibes.com](http://www.goodvibes.com); [www.xandria.com](http://www.xandria.com); [www.kissntellstore.com](http://www.kissntellstore.com); [www.mypleasure.com](http://www.mypleasure.com)).

In many cases, problems with sex are the symptomatic manifestation of a greater relational problem. Patients can be given information on couple's therapy, individual psychotherapy, and couple's sex therapy. A list of board certified sexologists in California can be found at: <http://www.sexologist.org/listings/californ.htm>.

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\_\_\_\_ Training/Workshop      \_\_\_\_ Individual Request      \_\_\_\_ Other: specify (\_\_\_\_)

2. Please rate the effectiveness of the Women's Health Handbook as a learning tool:

Not at All		Somewhat		Extremely
1	2	3	4	5

3. Please rate the effectiveness of the Women's Health Handbook in improving cross-cultural clinical skills:

Not at All		Somewhat		Extremely
1	2	3	4	5

4. Describe what you like about the Women's Health Handbook:

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5. Describe how we could improve the Women's Health Handbook:

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6. Other comments?

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DAVID NEWHOUSE, MD, MPH



Sunset at Anchor Bay

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*Mendocino Coast*

*December 21, 2007*

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