

## **Eliciting Medical History: Genetic Counseling a Prisoner**

Thanks to Allison Ossege, WISE (Women in Science and Engineering) Summer Student, University of Cincinnati, for her work as a contributing author for this case.

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### **Learning Objectives**

By the end of this case, genetic counselors will be able to:

1. Describe health disparities related to prisoners and the prison environment.
2. Recognize the sociological, social psychological and psychopathological variables linked to criminal behavior.
3. Explain the laws and policies regarding medical treatment in jails and prisons and acknowledge that regulations may differ between jurisdictions.
4. Describe strategies for building patient trust and eliciting a medical history for individuals belonging to vulnerable cultural populations, such as inmates.

*Bianca Lynn has been an inmate at the Greenville correctional facility for women for the past two months due to a parole violation. She has had several convictions for forging bad checks. Bianca has not been feeling well in the last few weeks. After vomiting twice last week, she was finally seen in the prison clinic. The prison doctor determined that she was approximately four months pregnant and that her uterus seemed small for dates. He sent Bianca for an ultrasound at a perinatal center located close to the prison. During the ultrasound, the perinatologist detected fetal heart abnormalities. He referred Bianca to you, the genetic counselor working at this perinatal center. You have a copy of the ultrasound results and Bianca's prison medical record. The ultrasound showed the pregnancy is 21.5 weeks gestation but that fetal growth is delayed by approximately two weeks. There is also a large ventricular septal defect in the fetus. The prison record indicates that Bianca was intoxicated at the time of arrest and that she has a history of drug abuse.*

### **Personal Reflections**

What is your first instinct in this situation?

Have you ever been in a situation like this?

What is your past experience working with patients who are prisoners?

What do you know about the health care services in prison?

Has anyone close to you been incarcerated?

How do you feel about counseling this patient?

### **Perspectives**

What does Bianca know about genetic counseling?

What has been Bianca's experience with counselors of any type?

What benefits might Bianca derive from genetic counseling?

How is Bianca's case different or similar to other cases of abnormal ultrasounds you have seen?

How do you think Bianca will react to the news of the abnormal fetal heart development?

What thoughts does this case evoke related to power? Authority? Directiveness/non-directiveness? Providing patient-centered care?

As a prisoner, does Bianca have the same rights and options as other women carrying a fetus with a heart anomaly? Is terminating a pregnancy an option for a woman in prison?

What emotions does Bianca demonstrate? How will you explore how she is feeling and coping?

How will you assess if Bianca has any support?

*Bianca arrives at the genetic counseling appointment 30 minutes late, in leg shackles, dressed in an orange prison jumpsuit, and escorted by a female guard. Due to your heavy afternoon clinic schedule and Bianca's late arrival, you will only have about 20 minutes to meet with Bianca if you are to stay on time for the rest of your appointments. You ask the female guard to wait just outside of the counseling room while you are with Bianca as you will be collecting private health information. In the counseling room, Bianca seems agitated and wary of her surroundings. When you ask Bianca about the pregnancy, she states that she didn't actually know she was pregnant until last week because her periods are often irregular. You ask how much she thinks she drank in the early part of the pregnancy. Bianca mentioned that while she doesn't usually drink heavily, sometimes it happens. She seemed hazy on the details, but replied, "Sometimes I drink so I don't think about not being able to keep a roof over my kids' heads. When my boyfriend, Rinaldo, walked out on me, I couldn't manage. Now my kids are in foster care." You would typically engage the client in conversation about her psychosocial history at this time, but you are trying to stay on time for your next patient, and you decide to skip it.*

### **Medical History:**

What thoughts do you have about counseling a woman in shackles? How do you think you would feel (i.e. nervous, anxious, more/less empathetic, etc)?

What is your differential diagnosis? What questions are essential for eliciting the medical history?

Does Bianca have any physical, mental or emotional health illnesses? Is she under any treatment, or has she been?

Why might Bianca not want to share all the information she knows about her medical, family or pregnancy history?

What are the resources for maintaining a pregnancy, giving birth and caring for a baby when the mother is a prisoner?

What rights and resources does Bianca have in prison?

Are there support groups or education programs for pregnant women in prison? What resources for pregnant women are available specifically at Greenville?

*You press on with the history taking. You explain to Bianca that you'll also be asking her medical history questions about Rinaldo's health. To allow Bianca to think about the questions before she answers (and maybe save time), you list the questions you will pose: "Was Rinaldo born with any birth defects, particularly any kind of heart disease? Does he have any ongoing medical concerns? How much alcohol does he typically drink and when? Is he a drug user?" Bianca seemed increasingly tense and alarmed. In a loud voice she tells the guard, "You don't know*

*what you're asking about! Get me OUT of here!" The guard comes into the room and escorts Bianca out of the facility.*

### **Reflections:**

What thoughts and emotions might have prompted Bianca's reaction?

Why do you think Bianca shut down when the genetic counselor asked a litany of questions about Rinaldo?

Why might Bianca be reluctant to answer the usual medical intake questions?

How might your contracting and intake procedures be modified when working with clients who are prisoners?

What strategies do you use to build trust within a genetic counseling session? Which strategies would you use in this genetic counseling session?

How does the genetic counselor's comfort level with this patient affect the counseling agenda, the patient's reactions and the session outcome?

### **Health Disparities**

Prisoners, ex-offenders, the communities they leave behind, and the communities they return to may be viewed as a distinct vulnerable population (Perez & Treadwell, 2008). The population is considered vulnerable due to physical and mental health disparities. Physical health problems often seen in prisoners are due to infectious diseases. Unusually high rates of individuals convicted of crimes will enter prison with HIV/AIDS, hepatitis, and tuberculosis (Williams, 2007). The physical health of inmates is jeopardized due to overcrowded facilities and lack of resources to adequately care for medical conditions (Williams). When an inmate arrives with physical health concerns that go untreated, there may be an impact on the health of other inmates and staff in the facility.

In addition, the lack of treatment during incarceration has the potential to affect the families and the communities to which inmates return. When individuals are released from jail, they often have limited employment opportunities and no access to health insurance. These outcomes may affect the functioning and financial status of inmate's families and add significant stress to their lives (Williams, 2007; Kruger & Hill De Loney, 2008). Research has shown that stress levels are highest during the period right before an inmate is scheduled for release, perhaps due to the fear of returning to society lacking direction and resources (Castellano & Soderstrom, 1997).

To review current trends of health care in correctional facilities, visit the *Journal of Correctional Health Care* at: <http://jcx.sagepub.com>. This Journal is exclusively devoted to prison healthcare and includes original research, articles on ethics, information on health disparities, ideas about improving healthcare, etc. We suggest reviewing the following articles:

Williams (2007), *Prison Health and the Health of the Public: Ties that Bind* discusses the social, economic, and health consequences of incarceration. The author lists causes of health disparities and provides solutions to mitigate poor prison healthcare.

Winter (2008), *Improving Quality of Health Care Delivery in a Corrections Setting* suggests the steps that should be taken to alleviate poor health care for incarcerated individuals.

### **The Prison Environment**

The four main types of offenses that can lead someone to jail or prison are crimes of violence, property, drug, and public order. *Jails* are county run institutions; individuals in jails have committed minor crimes, are on trial, or are serving short sentences. *Prisons* are federal or state run institutions; offenders committed to prisons have been convicted of state or federal crimes and sentenced to serve anywhere from a few years to a lifetime.

Criminal behavior is closely linked to sociological, social psychological and psychopathological factors. Sociological factors such as social stratification, culture, and social interactions have been found to be correlated with criminal behavior. A 2002 study by the U.S. Census Bureau showed that criminal behavior may be influenced by recent homelessness and a history of foster home care (James & Glaze, 2006). Sex and race are sociological factors correlated with criminal behavior that are well documented in U.S. prisons. Black and Hispanic men have incarceration rates 6.6 and 2.5 times higher, respectively, than White men (Kruger & Hill De Loney, 2008). African American females have incarceration rates 10.5 times higher than Hispanic females, and 20.5 times higher than white females (Hatton, Kleffel, & Fisher, 2006). Men, regardless of race, have dramatically higher incarceration rates than women. In 1983, women composed only 7% of the nation's jail population. By 2003, women composed 12% or 1/8 of the total prison population (Elias, 2007).

Social psychological issues (individuals' thoughts, feelings, and behaviors as they affect, and are affected by others) are also relevant. There are common variables among the family member of inmates. In 2002, self-reports by inmates indicated that 56% grew up in a single-parent household, 31% had grown up with a parent or guardian who abused drugs and 46% had an incarcerated family member (U.S. Department of Justice).

Psychopathological issues (mental illness, mental distress or the manifestation of abnormal behaviors due to mental illness) also contribute to criminal behavior. Studies of state prisoners have found that approximately 15% have serious mental illness, which is three to four times more prevalent than in the general population (Jemelka, Rahman, & Trupin, 1993; Ditton, 1999). Estimates suggest that at least 50% of prisoners with a mental illness also have co-occurring psychiatric and substance abuse disorders (PBS, 2006). Typically, inmates with mental illness have lengthier criminal histories than non-mentally ill inmates (Lurgio & Snowden, 2008).

A 2002 study by the U.S. Census Bureau showed that the current percentage of inmates with substance abuse problems ranges from 58.4% to 70.6% (Kerridge, 2009). It is difficult to determine if crime leads to drug use or vice versa but it is important to be able to treat both problems to prevent recidivism (re-incarceration). When inmates have co-occurring disorders of crime and addiction they need to be assessed for dependence issues and learned behavioral patterns of crime. Positive results have been obtained from cognitive-behavioral treatment programs such as academic, vocational, and social skills training classes. In one study of individuals released from prison, the group of academically trained individuals had recidivate rates of 18%, while individuals from the non-academically trained group had reincarceration rates of 70% (Deitch, Koutsennok, & Ruzi, 2000).

Life in prison is based on deprivation of liberty, which is markedly different than the freedom of action and choice enjoyed by members of the outside community (Castellano, 1997). This complete change of lifestyle impacts prisoners physically, mentally, and emotionally. The mental health of prisoners is affected by the stress of incarceration, formal restrictions, and/or unspoken rules of conduct. A common unspoken rule is for inmates to explicitly disregard the problems of other inmates. For example, inmates will choose not to inform the prison staff if a fellow inmate demonstrates deteriorating mental health (Lurgio, 2008).

Prisoners may be deeply affected by many emotions including distress, concern for their children, concern about the consequences of drinking, concern for their personal future, humiliation, vulnerability, powerlessness, and fear of guards along with other feelings (Lurgio, 2008; Taylor, Williams & Eliason, 2002; Castellano, 1997). These issues suggest the importance of including

psychologists on the prison staff. However, it is appropriate to consider what level of treatment is acceptable when inmates require mental health services (Lurgio). The dual role as the mental health evaluator and therapist (Palermo, 2009) may undermine psychologists' therapeutic effectiveness (Decaire, 2009). It can be difficult to gain prisoners' trust due to fears that their confidentiality may be breached.

### **Women in Prison**

Female crime offenders tend to be young, poor, minority group member, single, and imprisoned for nonviolent drug-related crime(s) (Taylor, 2002). Prior to incarceration, women are often susceptible to health problems due to a history of sexually transmitted diseases, suicide attempts, exchanging sex for money or drugs, and lack of healthcare (Conklin, Lincoln, & Tuthill, 2000). While in prison, women often need health services for pregnancy, STDs, mental health issues, cancer, HIV and TB. Treatment for HIV is especially needed because it is ten times more prevalent in female prisoners than in individuals in the general population (Taylor, 2002).

Incarcerated women face healthcare barriers due to long waiting times for treatment as well as their concerns regarding privacy, dignity, co-payments, and attempts to conceal health problems in order to obtain work opportunities (Hatton, 2006). Health care services specific to imprisoned women suffer when funding is short and gynecological services are often the first to be cut (Thayer, 2004). A 1994 study by the National Institute of Corrections found that only half of state prison systems offered female-specific services such as mammograms and Pap smears (U.S.A. Amnesty International, 2009).

It is estimated that 67% of female inmates have a history of sexual abuse, 79% have a history of physical abuse, and 43% have a history of trading sex for drugs (Fickenscher, 2001). Many of these women cannot escape such situations in prison. They may face physical and sexual assaults by other inmates and prison employees. Male employees have been known to routinely abuse their authority by exchanging "privileges"—such as food, basic hygiene products, or time with visiting family—for sex (Thayer, 2004). According to the U.S.A. Amnesty International, female inmates develop feelings of powerlessness, humiliation, and fear of retaliation because of the imbalance of power between inmates and guards (U.S.A. Amnesty International, 2009). These feelings often exacerbate previous medical and mental health problems. More information on improving correctional institutions to meet the needs of female inmates is available at: <http://nicic.org/Downloads/PDF/Library/022247.pdf>

### **Laws and Policies Specific to Prisoners**

As the result of deleterious research conducted on inmates in the United States, prisoners are classified as a unique vulnerable population. The Department of Health Education and Welfare condemned the use of prisoners in human subject research in 1978, which was codified in Title 45 of the Code of Federal Regulations (Reiter, 2009). Prisoners were excluded from human research studies, although this decision is not without controversy. The arguments against the code are that the current regulations are outdated; prisoners could benefit from new treatments; and that they deserve the right to choose to participate (Perez, 2008). However, some researchers manage to evade the system and succeed in using inmates as experimental subjects. For example, between 2006 and 2008, the drug company Hythian contracted with at least 5 jurisdictions and "diverted" drug offenders into an experimental treatment program for addiction treatment, in which one participant died (Reiter, 2009).

In 2001 the Eighth Amendment gave prisoners the right to "equal high quality" health care (The Constitution of the United States). However, a 2006 report by the Commission on Safety and Abuse in America's Prisons stated that healthcare continues to be inadequate because of required co-payments for inmates, inability of inmates to receive Medicare or Medicaid, lack of prison healthcare staff, poor funding, and inconsistent health screenings (Gibbons, 2006). The poor quality of health care is accentuated by limited mental health care resources.

Despite the mandate for jails and prisons to provide mental health care for inmates, (Cohen & Dvoskin, 1992), it is apparent that uniform standards are not in place. Initial mental health screenings conducted in correctional facilities are not reliable (Ford et al., 2007) and may be highly variable. The mental health training and experience of corrections staff is likely to be relatively low (Ford). Most prisons provide initial mental health screenings but mentally ill patients often go undetected and untreated. According to the U.S. Department of Justice, 83% of correctional facilities provide initial mental health screening, but inmates with mental illness were reportedly overlooked 64% of the time (Ford). In 2002, a female inmate was denied mental healthcare services and wrote to an unknown recipient before she died:

“I’ve been in the S.H.U [secure housing unit] for over 6 ½ years where I’ve been locked in a cell for 23 to 24 hours a day, 7 days a week. In March of 2002, I had a mental breakdown... and attempted to commit suicide by swallowing 150 pills. I was saved and sent to Central New York Psychiatric Center (CNYPC) for treatment for 7 weeks...When I was discharged I was sent to Wende Correctional Facility [a maximum security prison]...where I was kept for 25 days in a stripped cell. I was mistreated and denied everything. There was no heat in the place. I was put in a dirty and bloody cell. I was jumped and assaulted by the officers and was left unattended by mental health staff. In the time I was there, I continually requested to be sent back to (CNYPC) for further treatment because I went into relapse and could not bear being locked in a cell 24/7 again” (Lurgio, 2008).

Despite national health information privacy standards (HIPAA), exceptions exist related to prisoners’ healthcare. The following are loop-holes in the standard regulations:

- I. *Permitted Disclosure.* Healthcare providers may disclose to a correctional institution or a law enforcement official having lawful custody of an inmate if the correctional institution or such law enforcement officials request such protected health information for:
  - a. The provision of health care to such individuals
  - b. The health and safety of the inmate and other individuals
  - c. The health and safety of officers or employees or other at the correctional institution
- II. *Access to protected health information.* An inmate’s request to obtain a copy of protected health information may be denied without an opportunity for review.
  - a. Jeopardize the health, safety, security, custody, or rehabilitation of the individual, other inmates, or employees, and others.
- III. *Notice of Privacy Practices:* An inmate does not have the right to notice of the uses and disclosures of protected health information.

To learn more about the HIPAA regulations, you may want to visit:

<http://www.hhs.gov/ocr/privacy/index.html>.

### **Pregnant Inmates**

Roughly 6 to 10% of inmates are pregnant. These pregnancies should be considered high risk because of additional health threats related to miscarriage, mental instability, and a lack of health resources. The miscarriage rate for women in prison is approximately 30%, due to drug abuse and poor maternal health (Taylor, 2002). The mental health of a pregnant inmate should also be considered. Studies have shown that 64% of women who are pregnant during incarceration have a history of mental illness (Taylor).

Recommended national standards have been established for pregnancy-related health care in correctional settings by the National Commission of Correctional Health Care (NCCHC) and the

American Public Health Association (APHA). To learn more, visit the websites provided in the resources section. These organizations have published standards for prenatal medical examinations, prenatal laboratory tests (including HIV), advising inmates on safe levels of physical activity, education on proper nutrition, documenting postnatal care, written agreement with community health facilities for delivery, access to family planning, training for healthcare providers in prisons on pregnancy, identification and referral of high-risk pregnancy, prohibition of shackling during pregnancy, and standing arrangements for deliveries that allow mother and infant time together (American Civil Liberties Union, 2008).

Despite these recommendations, many jurisdictions follow their own specialized procedures or they do not have any pregnancy-related standards. According to the American Civil Liberties Union (American Civil Liberties Union, 2008), pregnancy-specific laws could only be identified for 35 out of 51 jurisdictions in the U.S. and the District of Columbia. The ACLU also found that out of those 35 jurisdictions, only eight mention that medical examinations should be included as a component of prenatal care, four mention HIV testing, nineteen mention prenatal nutritional counseling, seven require an agreement with a facility for the delivery, and only three restrict the use of restraints during labor and delivery. To access a state-by-state department of corrections directory of information, resources and policies, visit:

<http://www.aclu.org/reproductiverights/gen/pregnancycareinprison.html>

### **The Genetic Counseling Session**

Like other patients attending a genetic counseling appointment to discuss an abnormal ultrasound, Bianca may be emotional and sensitive. Initiating the appointment by asking questions about drugs and alcohol abuse may cause Bianca to feel guilty and defensive. It is important to use neutral terms when counseling imprisoned women. Explain to Bianca that you are using standard forms and protocols for documenting prenatal exposures to drugs and alcohol and that you ask all patients these questions. When counseling a pregnant woman who is an inmate, the genetic counselor should focus on building trust, eliciting medical history while providing psychosocial support, completing a mental health assessment, and locating resources that are available at the specific correctional facility.

Bianca may feel uncomfortable having her medical information disclosed to the prison staff. The genetic counselor may wish to explore with the guard whether there would be any personal safety concerns if you met with Bianca privately. The guard could wait outside the genetic counseling room, with the door kept open. If that seemed sensible, the genetic counselor could offer Bianca a choice to ask the guard to wait outside. Giving Bianca this personal choice is an act of respect that builds trust for your conversation to follow. To gain the inmate's trust, confidentiality should be discussed at the outset of the genetic counseling session. The genetic counselor may wish to explain to Bianca that according to the HIPAA regulations for inmates, there is no need to disclose the details of the genetic counseling discussion to others unless she or someone else is in danger, or if the institution needs to know for the sake of her own healthcare.

By informing Bianca of her rights and options, the genetic counselor is more likely to engage her trust. In general, when the counselor is genuine and truthful clients will understand a situation more clearly, leading to increased autonomy (Veatch, Leroy, Bartels, 2003). Building an alliance with your client is ideal. Relationships in health care and medical research are based on trust, because patients are especially vulnerable (Wynia, 2003). Unlike individuals from majority groups who are likely to trust their counselor until they feel the trust has been abused, individuals from minority groups may be inclined to distrust their counselors until the trust is earned (Cormier & Cormier, 1991). Building trust with Bianca is especially important to promote her participation in the genetic counseling sessions.

However, trust is more difficult to achieve in short-term counselor-client relationships (Kessler, 2000). Whatever the venue, the genetic counselor should strive to create an open and honest environment. If Bianca's verbal and non-verbal communications express disengagement,

suspicion and/or distrust, it is important for the counselor to remain non-defensive. Bianca's actions may be attributed to previous experiences of discrimination or exploitation (Weil, 2001). After initiating the session, the genetic counselor should continue to build rapport and begin eliciting the medical history.

When Bianca disclosed personal information during the session, the genetic counselor had an opportunity to provide short term counseling and support. By failing to engage the client in further discussion about her life, the genetic counselor marginalized Bianca's expressed concerns. When patients disclose personal information, they may be "testing the waters" to see how safe it is to discuss sensitive issues with you (Cormier, 1991). When the counselor avoids further discussion of this information, the patient may feel that she is being judged, and she may put up an emotional shield.

The genetic counselor can contribute to the client's well-being by helping assess her mental and physical environment. For example, it is important to consider that an inmate may or may not eventually have custody of her child in prison and how these concerns may affect Bianca's mental and emotional health. The genetic counselor can help Bianca take stock of medical, emotional, and mental health issues and direct her to resources that she can access while incarcerated, and after release.

### **Eliciting Medical History**

Current genetic counseling job tasks were determined by the American Board of Genetic Counseling as the outcome of a Genetic Counseling Practice Analysis (Hampel et al., 2009). The following is a list of the **Eliciting Medical History** tasks:

1. Elicit/Review General History
  - a. Specific Health Problems and Age of Onset
  - b. Hospitalizations and Surgeries
  - c. Congenital Anomalies/Birth Defects
  - d. Current Medications (i.e., indication, dosage, duration)
2. Elicit/Review Pregnancy History
  - a. Maternal Age at delivery
  - b. Serum screening
  - c. Ultrasound findings
  - d. Number of outcome of pregnancies
  - e. Maternal illnesses/conditions
3. Elicit/Review Gynecological History: Infertility
4. Elicit/Review Cancer History
  - a. Date of/age of diagnosis
  - b. Anatomic location
5. Elicit/Review Exposure History
  - a. Type (e.g., carcinogens, teratogens, occupational, environmental)
  - b. Dose, duration, and timing

Several components of Bianca's medical history were documented in her prison chart prior to the genetic counseling appointment. But, much can be learned from eliciting medical history directly from Bianca, without making inferences or assumptions. The following is an overview of what you know about Bianca, the assumptions you may have made, and what is not known:

#### **What you know about Bianca:**

1. Bianca has several convictions for forging bad checks, and has been arrested for parole violation.
2. Bianca's ultrasound detected fetal heart abnormalities.

3. The ultrasound showed 21.5 weeks of gestation with delayed fetal growth and large ventricular heart defect.
4. Bianca has a history of drug abuse.
5. Rinaldo is her boyfriend.

**Assumptions you made:**

1. Bianca has additional convictions.
2. Fetal alcohol exposure is responsible for the fetal anomalies.
3. Rinaldo is the father of the baby.

**What you do not know:**

1. Rinaldo is not the father of the baby.
2. The actual father of the baby was born with a congenital heart defect of the ventricular septum.
3. The actual father of the baby is involved with illegal activities; Bianca fears the negative consequences associated with discussing him.
4. Bianca is serving time as a result of attempting to keep the father of her baby out of trouble.

**Your emotional biases:** You have seen a few other pregnant women referred for genetic counseling from this correctional facility. You feel extremely uncomfortable every time you have to see such patients. You don't feel scared, but whenever you counsel inmates you tend to focus on your discomfort and not on the client's agenda. These cases haven't ever gone well for you. You notice that you use haste as an excuse to get out of uncomfortable situations. You tend to do this whenever drug or alcohol abuse is relevant. You have heartfelt sadness for Bianca and other women who face so many personal and medical challenges, including the additional new challenge of the abnormal fetal ultrasound. You were unsure about discussing psychosocial matters, since Bianca is supposed to be an inmate at Greenville for another year. Maybe Greenville has good mental health counseling resources to help Bianca sort out her challenges. You were glad when Bianca left.

**Summary: Eliciting Medical History**

In light of the general information that is available about the population of women who are in jail, Bianca's history is likely to be complex. Eliciting medical history will require a complete assessment of the client's medical, pregnancy, gynecologic, cancer and exposure history to determine an appropriate differential diagnosis, rule out potential inherited disorders, identify teratogenic exposures, etc. Every aspect of the history is important. Assumptions pose a significant threat to eliciting medical history and to truly understanding the patient. Assumptions are often grounded in cultural stereotypes and biases. Further, your emotions may negatively impact your ability to fully focus on the client. If you are concerned that your emotions may get in the way of eliciting medical history, use standardized intake forms that can help you stay on track.

During the session, if you are concerned that Bianca has not been properly screened for mental health issues, the genetic counselor can integrate several questions from routine screening tools into the medical intake procedure. The National Institute of Justice created two brief gender-specific mental health screening tools, the Correctional Mental Health Screening (CMHS) and the Brief Jail Mental Health Screening (BJMHS). Visit <http://www.ncjrs.gov/pdffiles1/nij/216152.pdf> to

access these screening tools and consider how you might use or adapt them for the genetic counseling intake protocol. If you believe that Bianca has mental health concerns, after asking Bianca her permission to do so, touch base by phone with the prison doctor to communicate your insights. Unfortunately, in Bianca's session, the genetic counseling encounter ended prematurely, leaving you with more questions than insights into her mental health status.

Providing suggestions for resources and support information may be futile if the resources the client needs are not available in the prison environment. Genetic counselors often suggest online resources and support groups for clients. But, what do we know about the resources available to Bianca? Does she have access to computers in the Greenville facility? Rather than assuming that she does, it will be important to ask. The genetic counselor or the social worker in your center should print out relevant information for Bianca to take with her. Relevant information may include facts about causes and treatment of the fetal heart defects, recommended prenatal care and tests, and information about delivery and surgical options for a fetus with this heart defect. It is unlikely that a support group will be available to Bianca in prison. However, this is a point that the counselor may wish to explore with the specific facility, especially if the facility makes regular referrals to the genetics center. A general support group to help inmates deal with issues of loss and grief may be available.

Intake questions including those intended to elicit medical history can inadvertently divert a genetic counseling session in ways that ultimately break down, rather than facilitate, counselor-client communications. By focusing on Bianca's history of alcohol and drug abuse, the genetic counselor failed to consider other potential causes of the abnormal ultrasound. When Bianca shared with the counselor the reasons she had abused alcohol, she made herself emotionally vulnerable for a fleeting moment. Admitting to previous experiences and her struggles coping with unfortunate life decisions could have facilitated intimacy and behavior change within the genetic counseling session. Instead, the counselor's biases affected the dynamics of the session, and vital steps in genetic counseling process were overlooked. By failing to engage Bianca in a discussion about her psychosocial history, the counselor missed an opportunity to understand Bianca for who she was, who she currently is, and who she wants to be, in light of the ultrasound results.

### **Cultural Competence**

- Focus on the client's needs. If your emotions or biases prevent you from properly attending to the patient and providing appropriate information and choices, refer the patient to a colleague. Reflect. Set goals for managing your emotions and biases.
- Ensure confidentiality and privacy, within the parameters allowed by the law. If you are not sure, ask. In general, HIPPA privacy standards apply to prisoners. However, exceptions exist and you may be asked to disclose information to a correctional institution or lawful custodian of the inmate. An inmate's request for a copy of protected information may be denied if it poses a risk to others.
- Build trust by creating an open and honest environment.
- Provide information and support, and locate resources that the patient may continue to access while in prison.
- Pregnant prisoners should be treated as high risk, in medical, psychosocial, and mental health domains.
- Use standardized assessment forms to help you keep on track.
- Let a complete assessment, and not your biases, determine the course of the session.

## Resources

<http://www.aclu.org/reproductiverights/gen/pregnancycareinprison.html>

A report from The American Civil Liberties Union lists the state-by-state pregnancy related policies. The report also includes suggested standards recommended by the American Public Health Association and National Commission of Correctional Health Care.

<http://nicic.org/Downloads/PDF/Library/022247.pdf>

An article by Gail Elias on the behalf of the National Institute of Corrections. The author discusses the gender-specific needs for female inmates. She provides solutions to improve future planning in female correctional facilities.

<http://jcx.sagepub.com>

The Journal of Correctional Health Care is the only national, peer-reviewed scientific journal to address correctional health care topics. The articles are released quarterly and include original research. Various authors also review other studies and discuss ethical trends, health disparities, and potential solutions to insufficient prison healthcare policies and services.

<http://www.ojp.usdoj.gov/bjs/dcrp/prisonindex.htm>

Lists the deaths in state prisons from 2001 to 2006 - U.S. Department of Justice, Office of Justice Programs Bureau of Justice Statistics. Deaths are categorized by cause, personal characteristics and state.

<http://www.thewomens.org.au/Alcohol>

FASD Advisory Workgroup of Canada presents the current personal and economic impact of FAS. The group provides recommendations for helping forestall birth complication due to FASD. The group has suggestions for screening strategies and provides examples of effective language to use while eliciting pregnancy and environmental histories.

<http://www.hhs.gov/ocr/privacy/index.html>

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule website has the current privacy regulations for healthcare. The website also has FAQs, special topics, related news, training materials, page to file a complaint, and much more.

<http://www.ncjrs.gov/pdffiles1/nij/216152.pdf>

An article sponsored by the U.S Justice Department National Institute of Justice discusses the importance of correctional facilities providing initial mental health screening. The article points out that screening activities are unreliable and inconsistent, leading to undetected mental illness. The article suggests screening tools for U.S. correctional facilities.

<http://www.ncchc.org>

Visit the National Commission of Correctional Health Care website to search any related topic. The group's focus is to improve correctional health care, and have their suggested regulations legally incorporated in jails and prisons. The site includes resources, publications, and up to date information on their progress.

<http://www.apha.org>

The American Public Health Association website presents health issues and has current events in the advancement of public health. The website includes a list of events, publications, and health policies.

## References

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## Assessment and Evaluation Questions

### Eliciting Medical History: Genetic Counseling a Prisoner

1. True/False

Criminal behavior is closely linked to social psychological, psychopathological, and sociological factors.

2. True/False

It is illegal to conduct human subjects' research on inmates.

3. True/False

Inmates have the right to the same HIPAA privacy regulations as citizens in the general population.

4. True/False

Female inmates are more likely to be incarcerated for crimes of violence than for crimes involving property or drugs.

5. True/False

There are pregnancy specific laws for all prisons and jails in all U.S. states.

6. True/False

Inmates may not receive adequate health care because they are unable to pay for health service co-payments.

7. True/False

Eliciting and reviewing the exposure history of imprisoned patients is the single most important part of the genetic counseling process.

8. True/False

For the safety of the genetic counselor, the prison guard is required to sit in on the prisoner's genetic counseling session.

9. True/False

The genetic counselor should not expect clients who are prisoners to have ready access to computers and support groups within the correctional facility.

10. True/False

Studies of state prisoners have found that approximately 45% have serious mental illness.

### The following questions are for CEU learners only:

1. I feel I have achieved the following objective as a result of this learning activity:

Describe health disparities related to prisoners and the prison environment.

**4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all**

2. I feel I have achieved the following objective as a result of this learning activity:

Recognize the sociological, social psychological and psychopathological variables linked to criminal behavior.

**4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all**

3. I feel I have achieved the following objective as a result of this learning activity:

Describe strategies for building patient trust and eliciting a medical history for individuals belonging to vulnerable cultural populations, such as inmates.

**4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all**

4. I feel I have achieved the following objective as a result of this learning activity:

Explain the laws and policies regarding medical treatment in jails and prisons and acknowledge that regulations may differ between jurisdictions.

**4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all**

5. Please rate the overall effectiveness of this case in promoting learning.

**4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all**

6. Please rate the overall quality of this case.

**4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all**

7. The content of this case was presented without bias of any commercial drug or product.

**4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all**

8. The technology used was appropriate and effective.

**4= Great extent 3= Moderate extent 2= Slight extent 1= Not at all**

### **Disclaimer**

The purpose of the Genetic Counseling Cultural Competence Toolkit (GCCCT) is to improve the delivery of culturally responsive, client-centered genetic counseling to diverse populations and to reduce health disparities. The GCCCT is an educational resource; any suggestions do not define the standards of clinical or educational practice. All cases and scenarios are hypothetical. The JEMF, NSGC and Nancy Steinberg Warren, MS, CGC will not be liable for any medical or psychosocial applications connected with the use of or reliance upon any information obtained from this website or associated links and resources.

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This work has been supported by the Jane Engelberg Memorial Fellowship, the 2009 grant from the Engelberg Foundation to the National Society of Genetic Counselors, Inc.  
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