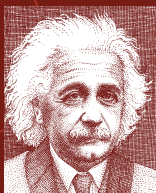


TEACHING CASES EXPLORING CROSS-CULTURAL CARE

A Project of the AECOM Faculty Task Force on Disparities and Cross-Cultural Training
~ Bronx Center to Reduce and Eliminate Racial and Ethnic Health Disparities (BxCREED) ~



ALBERT
EINSTEIN
COLLEGE OF MEDICINE
OF YESHIVA UNIVERSITY



2007

Teaching Cases Exploring Cross-Cultural Care

A Project of the
AECOM Faculty Task Force on Disparities and Cross-Cultural Training
~ Bronx Center to Reduce and Eliminate Racial and Ethnic Health Disparities ~

~ ~ ~

Editorial Team

Shoshana Silberman, NP
Nereida Correa, MD, MPH
A. Hal Strelnick, MD
Janet Townsend, MD
Hope M. Spano

Bronx Center to Reduce and Eliminate Racial and Ethnic Health Disparities (BxCREED)
Albert Einstein College of Medicine
Bronx, New York
2007

TABLE OF CONTENTS

Introduction	3
Case Criteria	4
Cases	
1 Pregnant HIV Positive Patient Who Wants the OB Team to Lie About her Condition <i>Lisa Rucker, MD</i>	5
2 Sociocultural Aspects of Working with a Family Affected With a Rare Autosomal Recessive Condition <i>Siobhan Dolan, MD; Robert Marion, MD and members of the Genetics faculty</i>	10
3 Three Pediatric Scenarios <i>Alex Okun, MD and Blanche Benenson, MD</i>	18
4 Cross-Cultural Communication: Pre-School Child and Primary Care <i>Karen Warman, MD</i>	25
5 Exploring Issues of Culture and Trust: Human Trafficking, Gynecology and Contraception <i>Amy S. Boldosser, MIA, Consultant</i>	30
6 Rejecting Dialysis: A Patient's Choice <i>James Fausto, MD</i>	34
7 Cambodian Rites and Rituals and Cross Cultural Care <i>Lyla J. Correoso, MD</i>	39
AECOM Speakers' Bureau and Faculty Task Force	43
AECOM Faculty Task Force Members	44
Evaluation	46

Introduction

This case compilation was created in response to discussions in the Albert Einstein College of Medicine (AECOM) Faculty Task Force for Disparities and Cross-Cultural Training. The Task Force is an outgrowth of the Health Disparities Education Core of the Bronx Center to Reduce and Eliminate Racial and Ethnic Health Disparities (BronxCREED).

In discussion, it was agreed that case-based teaching is one of the most effective ways to address issues of health disparities and culture. An expert in the field, Dr. Debbie Salas-Lopez, then Chief of the Division of Academic Medicine, Geriatrics and Community Programs at New Jersey Medical School, was invited to lead workshops on developing cases for cross-cultural teaching, which were held on December 12, 2006. The workshops were enthusiastically received. On September 18, 2007, Dr. Salas-Lopez will return to lead an advanced train-the-trainer workshop on the pedagogy of using cases to teach cultural issues.

After the first workshops it was decided that many departments and programs could easily expand their teaching of cross-cultural issues if a variety of teaching cases were made available. A call went out for faculty and others to develop and submit cases according to specific criteria designed to maximize cross-cultural teaching (see page 4). The cases reflect diverse areas of clinical expertise and are based on evidence from the literature that supports behavioral objectives. Many of the cases were originally developed by participants in the December 2006 workshop. The cases are based on real patients and situations; all identities have been altered to maintain confidentiality.

We hope that these cases assist in the complex and nuanced process of teaching the knowledge, skills, and attitudes necessary to provide care for diverse populations, and that the process is productive and enjoyable. Please let us know your thoughts and comments so that we can learn from your experience and continue to incorporate this important content into the medical and residency curricula of our institutions. There is a brief evaluation form on the last page of this booklet. Please complete it and return it as indicated. This evaluation page can be copied or additional evaluations may be requested from bxcreed@acom.yu.edu.

This case compilation was made possible by the efforts of the following members of the Department of Family and Social Medicine: Hal Strelnick, MD, PI, Bronx CREED; Hope Spano, Administrator, Hispanic Center of Excellence; and Janet Townsend, MD, Director of Faculty Development. Also, we thank Debbie Salas-Lopez, MD, MPH, Chief, Division of General Internal Medicine, Lehigh Valley Hospital and Health Network; and Carmen McLaughlin, MPH, Manager, Division of Academic Medicine, Geriatrics and Community Programs of New Jersey Medical School for their expertise and guidance.

This work is supported by grant number P60MD000514-04 from the National Institutes of Health's National Center for Minority Health and Health Disparities.

The following criteria provided the structure for case submissions.

CASE CRITERIA

➤ **Learning Objectives**

(please phrase as questions)

➤ **Narrative/Case Summary**

(500 word minimum) that addresses 3 to 5 of the following teaching points:

1. Patient's perspective on chronic illness
2. Social stressors and support networks
3. Fears about potential consequences of medications and/or illness
4. Complimentary/alternative therapies
5. Family decision-making and withholding information
6. Effects of migration and acculturation on family dynamics and beliefs
7. Language barriers and communication
8. Religious beliefs and spirituality
9. The culture of medicine
10. Disease and illness
11. Discrimination and racial/ethnic disparities
 - a. Stereotyping and clinical decision making
 - b. Mistrust and communication style
 - c. Effect on patient's outcome

➤ **Teacher's Guide**

Explanation of case background (500 word minimum)

➤ **References**

➤ **Visual Aids** (Optional)

Pregnant HIV Positive Patient Who Wants the Obstetrics Team to Lie About her Condition

Lisa Rucker, MD
Department of Medicine, Albert Einstein College of Medicine
Jacobi Medical Center

This case uses the method of progressive disclosure, posing questions to the learner(s) before all of the case information is available.

Learning Objectives

At the completion of this case, learners will be able:

1. To identify the cultural barriers that affect a patient's requests.
2. To define and discuss ethical precepts of veracity, autonomy, and beneficence and how they interplay in this case.
3. To identify and analyze the social stressors and the described effects of acculturation on family dynamics and beliefs.
4. To discuss the ethical and legal implications of providing false information or withholding information in a clinical situation.

Case Summary

J.C. is a 21-year-old Hispanic female who lives with her mother. She is unmarried and pregnant. She has previously been healthy and takes no prescribed medications. She has a family history of diabetes in her grandmother and "heart disease" (details unknown) in her father's relatives. Neither she nor her mother has seen her father in many years. She has no siblings. She lives alone with her mother in an apartment. J.C. attended public school and graduated from high school three years ago. She works as a cashier and part-time stocker in a small neighborhood grocery store while she decides whether or not to attend college. She denies smoking, alcohol, and drug use. She is heterosexual, has been sexually active with five different boyfriends over the years and relates that she did not have intercourse with any of them until she dated at least three months. She is not currently in a romantic relationship. The father of the baby is no longer involved with J.C. and has not participated in any of the pregnancy decision-making.

J.C.'s first prenatal appointment was at five months. She learned that she was HIV positive when she underwent voluntary testing as part of the initial prenatal blood work. Her viral load was very high, indicating active HIV disease.

***Interrupt here and focus the learner by addressing the following:
Contrast and compare the experience of a first pregnancy as described
in this case with the typical expectations of a first pregnancy.***

Case Continued

J.C. did not tell her mother about her HIV diagnosis. Her mother has made it clear that she has a low opinion of people who have AIDS because she has known the parents of too many drug users and promiscuous offspring who have contracted AIDS. Her mother has commented that "those bad parents are responsible for their children's risky behaviors" and stated that she is quite proud of her only daughter, who has remained sensible and disease-free. Mrs. C. feels that the environment in the Bronx is not ideal for young women in particular, and would happily move back to Puerto Rico, where "girls live a more proper Catholic life than they do here."

Her mother is aware that J.C. was sexually active, but was only grudgingly accepting of the fact. J.C. admitted that after several months her mother has accepted the diagnosis of pregnancy and is looking forward to becoming a grandmother, but laughed as she said that her mother would throw her onto the street if she finds out that J.C. has AIDS.

Interrupt here and discuss the concerns and fears J.C. may have regarding her diagnosis. Identify what her supports may be.

After considering the advantages and risks of therapy, J.C. began taking anti-retroviral medications. Her pregnancy progressed without other complications. However, J.C.'s HIV disease did not respond well to treatment. Although she was compliant with her treatment regimen and had no undue adverse effects from the medication, her viral load remained very high. She continued to feel well and to show no outward signs of AIDS. As she approached her ninth and final month of pregnancy, J.C. and her obstetrician discussed issues related to childbirth. The obstetrician informed J.C. that the baby's risk of HIV infection would be decreased if a Cesarean section were performed. J.C. responded, "I want to do whatever is best for the baby, but I don't want my mom to know that I have AIDS. You have to tell my mom there is some reason other than AIDS to do the C-section." The obstetrics team discussed J.C.'s request.

Teaching points - Additional Questions

Knowledge:

- How do you think the mother's religious and cultural beliefs affect J.C.'s decision?
- Is it acceptable for J.C. to exercise autonomy by withholding information from her mother?
- Should the obstetrics team tell a lie? What about the ethical precept of veracity and the legal implications of lying to the patient's mother?

Skills:

- What response might you make to J.C.'s request if you were the obstetrician? Primary care physician?
- How might you assist J.C. in considering whether and how to disclose her diagnosis to her mother?

Attitudes:

- Is the obstetrician's recommendation for C-section in the best interest of J.C.?
- Who is (or should be) the patient in this case?
- How might the cultural backgrounds (individual and medical) and health beliefs of members of the health care team influence their reactions to this situation and their discussions with J.C.?

Teacher's Guide

This vignette is based on an actual case. Most of the learning objectives and teaching points are designed to facilitate discussion, but have neither a right nor a wrong answer. The legal questions are answered below, along with some suggestions for the discussion. We do not have all the possible answers to questions students may ask. For instance, J.C.'s joking assertion that her mother would throw her onto the street was interpreted as a real probability, but could have been a joke, albeit not so humorous. J.C. was guarded about her social network and totally unwilling to discuss the baby's father, so there is very little factual information to add to the class discussion. J.C. was herself not overly bothered by the stigma of single motherhood and having AIDS. She did not seem too concerned about her future and the disease. Her intelligence seemed normal. Her approach appeared to be that of somebody who is focused on the present, rather than the future.

The discussion among the obstetrics team was extensive. Who is the patient? The team felt that both J.C. and her baby should be considered as their patients. The team debated whether it was legal to lie to the grandmother (it is legal, as she is not the patient and the patient's wishes were going to be documented), and whether it was ethical to lie.

The ethical discussion is a much more murky issue than the legal. The ethical points here are as follows:

1. Physicians should tell the truth (Veracity).
2. Physicians should act in the best interest of the patient (Beneficence).
3. Physicians should do the right thing for the patient (Justice).
4. Patients have the right to make their own decisions (Autonomy).
5. Doctor-Patient discussions are privileged and confidential (Confidentiality).

Under New York state law, J.C. has the right to make decisions for the baby. In New York, this is a right of pregnancy. In other words, had J.C. been 15, she still would have the legal right to be the primary decision-maker for her child.

The teaching points of this case can be used by the teacher to give insight into clinical care. Learning about J.C.'s pregnancy and how it differs from the stereotypical pregnancy gives a view of the potentially stronger need for the involvement of J.C.'s mother. The family in this case can be defined as grandmother/mother- J.C.- baby. Deception on J.C.'s part may prove to be detrimental to the relationships within this family unit. We know little about their finances and social supports, but J.C. does have Medicaid. J.C.'s mother appears to have a more traditional value system than her daughter and because of cultural/religious reasons has not readily accepted her daughter's intimate relationships and the resulting pregnancy.

We need to recognize our own personal biases regarding the issues in this case, notably caring for an HIV positive patient, prevention of HIV transmission to the baby, and caring for an unwed mother. Do our feelings influence the care we give?

Providing a safe haven for open discussion between J.C. and her mother might circumvent the "need" to lie. J.C.'s mother has accepted other imperfections about her daughter and may well be able to deal with her diagnosis of HIV infection. Encourage the learners to be creative as they verbalize what they would do if they were on the obstetrics team. Responses could include finding out exactly what J.C.'s concerns are, educating J.C. and her mother, helping J.C. break the news to her mother and agreeing only to tell her mother that J.C.'s condition is confidential and she will have to get details from J.C. herself. Role playing or suggesting exact wording of questions to ask J.C. could be helpful.

Confidentiality is an important theme here. J.C.'s mother had no legal right to know the content of any private discussions between J.C. and her doctor. J.C. relied on the fact that her discussions with the doctor were confidential. That confidentiality was extended to the members of the health care team.

What ultimately happened in this case was that after much debate, the team decided to follow the patient's request, telling J.C.'s mother that a C-section was necessary because the baby was in a "bad position." The team made certain that everybody who could conceivably speak with J.C.'s mother, including the housekeeping employees on duty, knew the plan. (It's about confidentiality).

It is reasonable to discuss possible issues that will be important when J.C. returns home. What is the likelihood that J.C.'s mother will not discover that the baby is taking medications for HIV? What is J.C.'s mother's risk of contracting HIV if she does not protect herself from the baby's bodily fluids?

Here are a couple imaginary scenarios for the post-hospitalization course:

1. J.C.'s mother finds J.C.'s medications and after some detective work, realizes that they are anti-retrovirals. She angrily confronts J.C., who admits that she has HIV, and that she is not responding to therapy. J.C.'s mother kicks J.C. and the baby out of her house. J.C. is homeless, becomes sick, and social services eventually removes the baby.
2. J.C.'s mother has a fresh, uncovered cut on her hand. The baby now has gastroenteritis, and if J.C.'s mother helps with changing diapers and cleaning vomit, J.C. realizes that she is at risk for contracting HIV. Out of love for her mother, J.C. tells her the truth.
3. After learning the truth, her mother and J.C. discuss plans for the baby's care if J.C. gets sick with AIDS. J.C.'s mother is aging, and although she is well and looking forward to being a grandmother, she certainly does not want to have sole responsibility for this baby.

References

- DaSilva CH, Cunta RL, Tonaco RB, et al. Not telling the truth in the patient-physician relationship. *Bioethics*. 2003; 17: 417-24.
- Davidhizan R. Honesty: the best policy in nursing practice. *Today's OR Nurse*. 1992; 14:30-4.
- Gadow S. Truth: treatment of choice, scarce resource, or patients' right? *Journal of Family Practice*. 1981; 13:857-60.
- Hochhauser M. Therapeutic misconception and "recruiting doublespeak" in the informed consent process. *IRB*. 2002; 24: 11-12.
- Hutchings D. Communicating with metaphor: a dance with many veils. *American Journal of Palliative Care*. 1998; 15: 282-4.
- Levine RJ. Consent to incomplete disclosure as an alternative to deception: case study. *IRB*. 1982; 4:9-11.
- Smith WR, Bussey-Jones J, Horowitz CR, Whitehurst-Cook M, Chen AH. Case studies in multicultural medicine and health disparities. In: Satcher, David, Pamies, Ruben, eds. *Multicultural medicine and health disparities*. 2006; 361-368.
- Simpson DE, Yindra KJ, Towne JB, Rosenfeld PS. Medical students' perceptions of cheating. *Academic Medicine*. 1989; 64: 221-2.
- Tucker AG. Truth-telling in clinical practice and the arguments for and against: a review of the literature. *Nursing Ethics*. 2004; 11: 500-13.

Sociocultural Aspects of Working with a Family Affected with a Rare Autosomal Recessive Condition

Siobhan Dolan, MD; MPH, Robert Marion, MD, and members of the Genetics Faculty
Albert Einstein College of Medicine / Montefiore Medical Center

Learning Objectives

At the completion of this case, learners will be able to:

- 1) Explain the basic standards for translators in medical care
- 2) Appreciate that inaccuracies introduced early in a family's experience can be hard to modify and can irreparably influence family relationships
- 3) Identify with clinicians who want to help but feel powerless to provide a family with their desired outcome
- 4) Explain autosomal recessive inheritance and recurrence risk, with a focus on how to deal with uncertainty, in ways that are appropriate for an individual with limited English language skills and limited numeric skills
- 5) Consider ways to help a family cope with "blame" and repeated adverse pregnancy outcomes, especially in the setting of an autosomal recessive genetic condition where both partners must be carriers and the risk for each pregnancy is only 25%, but each pregnancy is 100% affected

Case Summary

The family, who were subjects of the report, *First-trimester diagnosis of Bartsocas-Papas syndrome (BPS) by transvaginal ultrasound: case report and review of the literature* by Dolan et al. (Prenatal Diagnosis 2003; 23:138-142), lived in the Bronx and received their care at a local hospital.

The medical facts of this case – a couple who are both carriers (consanguineous) of a rare severe autosomal recessive condition and have an affected child and several subsequent affected fetuses – is underscored by the sociocultural factors and language considerations that affected their care. These are presented in this case.

When we first met B.J., the mother in this case, she was 19 years old and had recently emigrated from Gambia to marry a 37-year-old Gambian man who had already been in the US for many years. After the couple's first child, a male, was born with multiple congenital anomalies consistent with Bartsocas-Papas syndrome, a rare, autosomal recessively inherited multiple malformation syndrome, B.J. had great difficulty understanding the situation in which she found herself. First, she spoke only her native language, making it difficult to communicate with individuals outside her community. Early in the course of her care, her husband, who spoke some English, served as the translator for her, but it became clear that he was telling his wife that her behavior and diet had been the cause of their son's condition (although the truth was that both parents carried a mutation that led them to have an affected fetus). When the physicians and social workers became aware of this, they required that a Gambian-

speaking translator be present at all counseling sessions. However, even with the translator accurately translating the physicians' explanations, the fact remained that, in the context of the couples' relationship, the "blame" was placed squarely on the mother.

B.J. became pregnant again the next year and with her second pregnancy, she and her husband were quoted a 25% recurrence risk and a 75% chance of having an unaffected child. Thus, when she was told that the second pregnancy was affected, B.J. was appropriately devastated. Given the options, she chose not to terminate the pregnancy; however at 33 weeks, she experienced a spontaneous intrauterine fetal demise.

B.J., who desperately wanted a child, became pregnant a third time, but this time sought care at Hospital B. Here, she stated that the genetics team at Hospital A had repeatedly given her bad news, so she had changed hospitals in hopes of a "fresh start." Because of the rarity of the condition, as soon as the genetics team at Hospital B took her history, they immediately contacted the geneticists at Hospital A (ultimately, the same Genetics Consult Service) in order to get more information. Unfortunately, once again, the fetus was affected and B.J. chose to terminate the pregnancy.

When last seen, this couple had had three affected fetuses resulting in one affected liveborn, one intrauterine fetal demise, and one termination. Sadly, when the first child was born affected with BPS, B.J. could not bond with the child and subsequently put him up for adoption. He spent many years in rehabilitation at a specialized children's hospital, where he underwent repair of his orofacial cleft and bilateral below-knee amputations with placement of prostheses, and learned to eat. At the age of six, he is now living with an adoptive family, is thriving, has normal intellect, and is able to walk and run on his prostheses. He continues to attend school at the children's hospital and is a well-adjusted, friendly, outgoing child. Meanwhile, his biological mother, B.J., went on to have only affected fetuses and has yet to have a healthy child, thus she feels lonely and disappointed that she does not have a family.

Teacher's Guide

Please read the attached case report and article, *First-trimester diagnosis of Bartsocas-Papas syndrome (BPS) by transvaginal ultrasound: case report and review of the literature* by Dolan et al. (Prenatal Diagnosis 2003; 23:138-142) which describes the clinical picture and inheritance patterns of the Bartsocas-Papas Syndrome. The case presented here outlines the sociocultural aspects that surround the medical facts of dealing with a recurring autosomal recessive condition and provides a framework for consideration and discussion.

Questions for discussion

- 1) How can parents understand the complexity of autosomal recessive inheritance and manage the complex feelings of guilt and responsibility that accompany being healthy themselves but passing on an autosomal recessive trait to their child who is then severely affected?
- 2) How did this family begin to see the care providers as part of the problem, and what were they seeking as they switched points of care? How does trust play a role and how could the first team of providers have addressed that issue?
- 3) What are considerations when deciding the constraints in using family members as translators?
- 4) What are key requirements for using translators in clinical care?
- 5) What questions could be asked to understand health and cultural beliefs that led to B.G. being blamed for the bad prenatal outcome? How could you address this? (Consider involving someone from the Gambian community to provide support and “cultural interpretation”)
- 6) How can families be counseled when they are quoted relatively low risks but keep having adverse outcomes?
- 7) Do you think there is a way that B.J. could have been aided to bond with her child and could have experienced life with the family she desires?

References

- Carillo JE, Green AR, Betancourt JR. Crosscultural primary care: A patient-based approach. *Annals of Internal Medicine*. 1999; 130:829-834.
- Dolan SM, Shanske AL, Marion RW, Gross SJ. First-trimester diagnosis of Bartsocas-Papas syndrome (BPS) by transvaginal ultrasound: case report and review of the literature. *Prenatal Diagnosis*; 2003; 23:138-142
- National Standards of Practice for Interpreters in Health Care. September 2005. Pages 11-16 and Glossary are particularly useful.
- National Council on Interpreting in Health Care. www.ncihc.org.

First-trimester diagnosis of Bartsocas–Papas syndrome (BPS) by transvaginal ultrasound: case report and review of the literature

Siobhan M. Dolan^{4*}, Alan L. Shanske¹, Robert W. Marion² and Susan J. Gross³

¹Center for Congenital Disorders, Children's Hospital at Montefiore, Albert Einstein College of Medicine, Bronx, NY, USA

²Center for Congenital Disorders, Children's Hospital at Montefiore, Albert Einstein College of Medicine, Bronx, NY, USA

³Director, Division of Reproductive Genetics Department of Obstetrics & Gynecology and Women's Health, Albert Einstein College of Medicine and Montefiore Medical Center, Bronx, NY, USA

⁴Division of Reproductive Genetics, Department of Obstetrics & Gynecology and Women's Health, Albert Einstein College of Medicine and Montefiore Medical Center, Bronx, NY, USA

Initially described in 1972, Bartsocas–Papas syndrome (BPS) is an autosomal recessively inherited disorder combining multiple pterygia, ankyloblepharon, cleft lip and palate, filiform bands between the jaws, syndactyly, and other anomalies. Although described as lethal, review of the literature reveals three individuals who survived into childhood with this condition. We describe a fourth surviving patient and what we believe to be the first prenatal diagnosis of BPS in the first trimester. Copyright © 2003 John Wiley & Sons, Ltd.

KEY WORDS: popliteal pterygium syndrome; first trimester diagnosis; transvaginal ultrasound

INTRODUCTION

Initially described in 1972, Bartsocas–Papas syndrome (BPS) is an autosomal recessive disorder that has been called a 'lethal' form of the popliteal pterygium syndrome (Bartsocas and Papas, 1972). Clinically, the disorder combines multiple pterygia, ankyloblepharon, cleft lip and palate, filiform bands between the jaws, syndactyly, and other anomalies. Although there are numerous reports of the antenatal diagnosis of lethal multiple-ptyerigium syndromes (LMPS) in the second and third trimesters (Lockwood *et al.*, 1988; Zeitune *et al.*, 1988; Meizner *et al.*, 1993; Anthony *et al.*, 1993; Sciarone *et al.*, 1998; Entezami *et al.*, 1998; Hertzberg *et al.*, 2000), we report what we believe to be the first prenatal diagnosis in the first trimester in a woman with a previously affected living child.

Case 1: affected living child

A 19-year-old African woman, a recent immigrant from Gambia, was first seen for routine prenatal ultrasound at 29 weeks. Her singleton fetus had cleft lip, syndactyly of the 3rd and 4th fingers bilaterally, and widened 'sandal gap' between the first and second toes bilaterally. She and her 37-year-old husband were consanguineous, related through her father and his mother who were half-siblings. Amniocentesis revealed a normal 46,XY karyotype.

*Correspondence to: Siobhan M. Dolan, Division of Reproductive Genetics, Department of Obstetrics & Gynecology and Women's Health, Albert Einstein College of Medicine and Montefiore Medical Center, 1635 Poplar Street, 2nd Floor, Bronx, NY 10461. E-mail: siobhanmdolan@yahoo.com

At 36 weeks, due to intrauterine growth restriction (IUGR), oligohydramnios, and breech presentation, cesarean delivery of a male infant weighing 2165 g (<5th percentile) was performed. Apgars were 7 and 9.

The newborn had bilateral popliteal pterygia (Figure 1), bilateral talipes equinovarus with hypoplastic toes, and syndactyly of the 3rd and 4th fingers bilaterally (Figure 2). Also noted were ankyloblepharon, low-set ears, cleft lip and palate (Figure 3), trismus due to anomalies of the temporo-mandibular joint, and intraoral fibrous bands connecting the maxillary and mandibular alveolar ridges. Obstructive apnea was noted and an emergency tracheostomy was performed. Owing to persistent anomalies of the temporo-mandibular joint, the baby had difficulty swallowing and a percutaneous gastrostomy tube was placed. Following stabilization, the infant was transferred to a pediatric rehabilitation hospital. Because of vascular compromise due to pterygia, below-knee amputations were performed at 11 months. The child had his cleft lip and palate surgically repaired. Presently, he is a healthy two-year-old. He walks with prostheses, is fed through his gastrostomy tube, taking small amounts of nutrition orally, and appears to have normal cognitive development.

Case 2: first-trimester diagnosis via transvaginal ultrasound

One year later, the mother again became pregnant and a transvaginal sonogram was performed at 11 5/7 weeks gestation. This fetus showed marked soft-tissue thickness behind the knees consistent with popliteal pterygia (Figure 4A). The lower limbs had a markedly decreased range of motion and were consistently maintained in



Figure 1—Leg pterygia



Figure 2—Syndactyly

a tightly flexed position. A clubfoot was noted. Subsequent ultrasounds confirmed the diagnosis, revealing pterygia of all extremities (Figure 4B and 4C), bowing of the long bones, bilateral clubfoot deformity (Figure 5A and 5B), syndactyly, and intrauterine growth restriction.

At 33 weeks, the patient complained of decreased fetal movement and ultrasound confirmed an intrauterine fetal demise. Induction was undertaken and a 1050 g (<5th percentile) macerated female stillborn



Figure 3—Cleft lip

fetus was delivered vaginally. Autopsy was performed and revealed findings consistent with Bartsocas-Papas syndrome. These included large pterygia in the popliteal fossae bilaterally (6.0×3.0 cm.) (Figure 4D), contractures of the lower extremities with distortion of joints, nail hypoplasia of the fingers and toes, and syndactyly of the 2nd and 3rd fingers of the right hand and the 2nd through 4th toes bilaterally. Low-set ears, a flattened nose, bands connecting the lower lip with the maxilla (Figure 6), and fused eyelids with filiform bands (Figure 7) were also noted.

DISCUSSION

In 1984, Hall reviewed the reported cases of lethal multiple-ptyerygium syndrome (LMPS) and established a widely accepted four-group classification system (Hall, 1984). Bartsocas-Papas syndrome (BPS), the first of the four groups described, is notable for marked popliteal pterygia, syndactyly of the hands and feet, facial and oral clefts, filiform bands between the jaws, ankyloblepharon, synostosis of the hand and foot bones, and digital hypoplasia and syndactyly (Bartsocas and Papas, 1972; Di Stefano and Romeo, 1974; Hall *et al.*, 1982; Papadia *et al.*, 1984; Francesco and Nicola, 1988). Subsequent cases have been reported and classified according to this system (Reich *et al.*, 1984; Martinez-Frias *et al.*, 1991; Giannotti *et al.*, 1992; Massoud

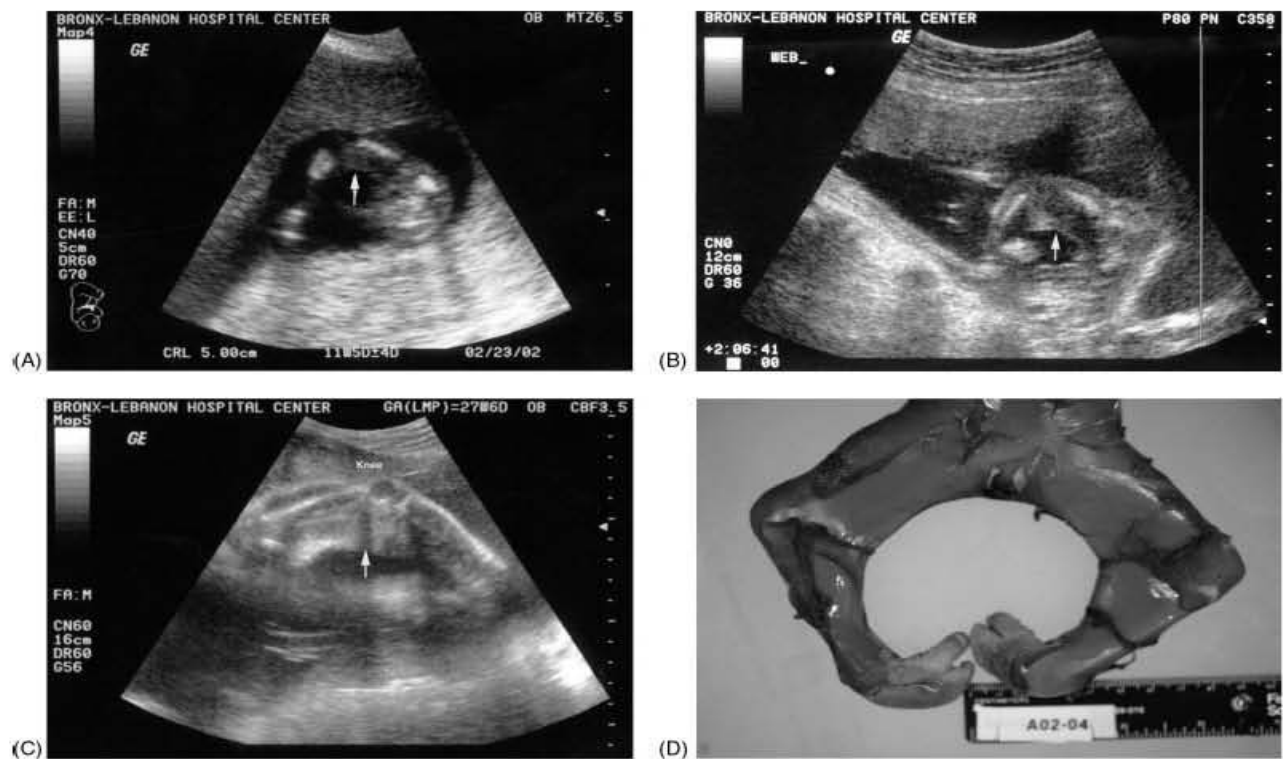


Figure 4—(A) Popliteal webbing at 11 5/7 weeks gestational age; (B) popliteal webbing at 17 6/7 weeks gestational age; (C) popliteal webbing at 27 6/7 weeks gestational age; and (D) popliteal webbing at autopsy

et al., 1998). The inheritance pattern of BPS is autosomal recessive.

The other three groups that Hall delineated are variants of LMPS and are classified according to the nature of the bone abnormalities. Although all four categories of LMPS share some similarities, most importantly the presence of pterygia, one unique aspect of BPS is the absence of edema. This may provide some etiologic clues. Hall proposed that pterygia of the joints form in the absence of limb and joint movement (Hall *et al.*, 1982). The role of edema in the very-early development of pterygia is uncertain. Since early edema may lead to restricted joint mobility and a subsequent fetal akinesia sequence in the lethal pterygium syndromes (Witters *et al.*, 2001), the absence of edema in BPS may point toward a unique etiology or pathogenesis. Indeed, Martinez-Frias *et al.* propose a generalized vascular insult as the causative agent in BPS (Martinez-Frias *et al.*, 1991).

Although BPS is considered as a lethal condition, there are three previous reports of affected infants who survived at least into childhood (Papadia *et al.*, 1984; Giannotti *et al.*, 1992; Reich *et al.*, 1984). The patient reported by Reich, who was eight years old at the time of the report, is now a healthy adult (Reich, 2002). The living child in this family has been previously described (Staffenberg *et al.*, 2000) and represents a fourth case. This child established the high-risk status that allowed for early diagnosis in the

subsequent pregnancy. Also, his survival with good cognitive function, added to the three cases previously reported, underscores the fact that this disorder is not lethal. Aggressive care, including tracheostomy and feeding tube, may be recommended in newborns with BPS following discussion with the family.

Second- and third-trimester antenatal ultrasonographic diagnosis of LMPS has been reported on multiple occasions (Lockwood *et al.*, 1988; Zeitune *et al.*, 1988; Meizner *et al.*, 1993; Anthony *et al.*, 1993; Sciarone *et al.*, 1998; Entezami *et al.*, 1998; Hertzberg *et al.*, 2000). Many of the reports focus on the antenatal diagnosis of cystic hygroma and generalized edema, which is present in LMPS but not in BPS, and most report the presence of limb pterygia. This case represents the first antenatal diagnosis of BPS on ultrasound and the first ultrasonographic diagnosis of any of the LMPS-spectrum disorders in the first trimester. The greater availability of first-trimester transvaginal sonography and the ability to detect popliteal pterygia, decreased movement, and clubfoot at 11 5/7 weeks suggests that prenatal diagnosis of BPS by first-trimester ultrasonography is practical and reliable.

This family is the first report of the Bartsocas–Papas syndrome in an African family. Previous reports have been in Mediterranean families, predominantly Greek, Spanish, and Italian, although one East-Indian family (Hall *et al.*, 1982) and one Arab family (Massoud *et al.*,



(A)



(B)

Figure 5—(A) Clubfoot deformity with sandal-gap toe (at autopsy); and (B) clubfoot deformity with sandal-gap toe (on ultrasound)

1998) have been reported. These families offer evidence that the condition is panethnic.

REFERENCES

- Anthony J, Mascarenhas L, O'Brien J, Battachargee AK, Gould S. 1993. Lethal multiple pterygium syndrome. The importance of fetal posture in mid-trimester diagnosis by ultrasound: discussion and case report. *Ultrasound Obstet Gynecol* **3**: 212–216.
- Bartsocas CS, Papas CV. 1972. Popliteal pterygium syndrome: evidence for a severe autosomal recessive form. *J Med Genet* **9**: 222–226.
- Di Stefano G, Romeo MG. 1974. La Sindrome Dello Pterigio Popliteo (Contributo Casistico). *Riv Pediatr Sic* **29**: 54–75.



Figure 6—Filiform bands connecting the lower lip with the maxilla (at autopsy)



Figure 7—Fused eyelids with filiform bands (at autopsy)

- Entezarni M, Runkel S, Kunze J, Weitzel HK, Becker R. 1998. Prenatal diagnosis of a lethal multiple pterygium syndrome type II: case report. *Fetal Diagn Ther* **13**: 35–38.
- Francesco P, Nicola L. 1988. Nosological difference between the Bartsocas-Papas syndrome and lethal multiple pterygium syndrome. *Am J Med Genet* **29**: 699, 700.
- Giannotti A, Digilio MC, Standoli L, Zama M, Dallapiccola B. 1992. New case of Bartsocas-Papas syndrome surviving at 20 months. *Am J Med Genet* **42**: 733–735.
- Hall JG, Reed SR, Rosenbaum KN, Gershanik J, Chen H, Wilson KM. 1982. Limb pterygium syndromes: a review and report of eleven patients. *Am J Med Genet* **12**: 377–409.
- Hall JG. 1984. Editorial comment: the lethal multiple pterygium syndromes. *Am J Med Genet* **17**: 803–807.
- Hertzberg BS, Kliever MA, Paulyson-Nunez K. 2000. Lethal multiple pterygium syndrome: antenatal ultrasonographic diagnosis. *J Ultrasound Med* **19**: 657–660.
- Lockwood C, Irons M, Troiani J, Kawada C, Chaudhury A, Cetrulo C. 1988. The prenatal sonographic diagnosis of lethal multiple pterygium syndrome: a heritable cause of recurrent abortion. *Am J Obstet Gynecol* **159**: 474–476.
- Martinez-Frias ML, Frias JL, Vazquez I, Fernandez J. 1991. Bartsocas-Papas syndrome: three familial cases from Spain. *Am J Med Genet* **39**: 34–37.
- Massoud AA, Ammaani AN, Khan ASS, Katraman BV, Teebi AS. 1998. Bartsocas-Papas syndrome in an Arab family with four affected sibs: further characterization. *Am J Med Genet* **79**: 16–21.
- Meizner I, Hershkovita R, Carmi R, Katz M. 1993. Prenatal ultrasound diagnosis of a rare occurrence of lethal multiple

- pterygium syndrome in two siblings. *Ultrasound Obstet Gynecol* **3**: 432–436.
- Papadia F, Zimbalatti F, La Rosa CF. 1984. The Bartsocas-Papas syndrome: autosomal recessive form of popliteal pterygium syndrome in a male infant. *Am J Med Genet* **17**: 841–847.
- Reich E, Wishnick M, McCarthy J, Tzimas N. 1984. Long term follow up in an 8-year old with the 'lethal' popliteal pterygium syndrome (Bartsocas-Papas Syndrome). *Am J Med Genet* **36**(Suppl.): 70s.
- Reich. 2002. *Personal Communication*.
- Sciarrone A, Verdiglione P, Botta G, Franceschini P, Todros T. 1998. Prenatal diagnosis of lethal multiple pterygium syndrome in mid-pregnancy. *Ultrasound Obstet Gynecol* **12**(3): 218, 219.
- Staffenberg D, Shanske A, Russell B, Rosen O. 2000. Bartsocas-Papas syndrome (MIM 263650) in a West African family: prenatal diagnosis and further delineation. *Am J Hum Genet* **67**(4): (Suppl. 2): 131.
- Witters I, Moerman PH, Van Assche FA, Fryns JP. 2001. Cystic hygroma colli as the first echographic sign of the fetal akinesia sequence. *Genet Couns* **12**(1): 91–94.
- Zeitune M, Fejgin MD, Abramowicz J, Aderet NB, Goodman RM. 1988. Prenatal diagnosis of the pterygium syndrome. *Prenat Diagn* **8**: 145–149.

Three Scenarios from the Pediatrician's Office

Alex Okun, MD and Blanche Benenson, MD
Division of General Pediatrics, Department of Pediatrics
Albert Einstein College of Medicine/Children's Hospital at Montefiore

~ ~ ~

Note: This case format is unique, presenting three brief scenarios for interactive role play to provoke analysis and discussion. Learning Objectives and a Teaching Guide follow the scenarios. The facilitator should read all sections of this guide before beginning the exercise.

Introduction

The following cases were developed for interactive role play in a two-hour workshop intended to help learners build skills in culturally effective health care. Held for second-year pediatrics residents in our department during a required rotation in Developmental-Behavioral Pediatrics, these workshops are small, with three to five learners and one or two faculty facilitators per session. The resident participants know one another and the faculty members very well and have been on rotation together for between one and three weeks by the time it is held.

In each simulated encounter, one resident volunteers to play the role of doctor and another plays the role of the mother. Each "actor" is presented with a description of his or her role. The workshop facilitators and other participants have a chance to see both role descriptions.

CASE I: Weaning

Mother:

You have brought your 6 month-old daughter for shots to your regular pediatrician and would like advice on how to wean her from breast to formula, as you return to work. You came to San Diego one year ago from Puebla, Mexico. You enjoy seeing your daughter's pediatrician, who moved here from New York City about the time your daughter was born.

You are concerned about the possibility that your daughter will be harmed if you withdraw the breast too quickly: that she will become depressed, weak and skinny ("caida de la mollera", or "fallen fontanelle"). You are also worried that she may develop an intestinal blockage or infection if the breast milk and formula become mixed in her stomach ("empacho"). It does not occur to you that your pediatrician would not know about these common concerns. You want to know whether purified water or Pedialyte would be the better choice to flush the baby's system before weaning.

Doctor:

You are seeing one of your favorite mother-baby dyads for a primary care visit at the community-based health center in a poor suburb of San Diego where you started working six months ago just out of your residency training in New York City. This mom has breastfed well since delivery but now would like to wean the baby to formula in order to work. The baby is happy and chubby, but the mother seems concerned that the baby will become sad, fail to thrive, vomit or even die if she somehow weans the baby the "wrong way."



You are surprised by these concerns and wonder why she is so worried. In your resident continuity clinic, they taught you to encourage breastfeeding for the whole first year. This mom is young, and it is her first baby, but that's common here. You are new to this area and to the job and realize you have lots to learn, too. You would like to give her advice that will be comforting to her and best for the baby.

Case II: Mal de ojo (evil eye)

Mother:

You have brought your 2 month-old son to the doctor for a check-up. You are the oldest daughter from a family of six that emigrated from the Dominican Republic three years ago to Webster Avenue and 192nd St. in the Bronx. Your doctor speaks Spanish well but has never been to the Dominican Republic. She seems rather young and always has an old man come in to say hello after the baby's check-up. At each of your prior visits, your doctor has asked you questions about the necklace and bracelet your son wears against the evil eye. You are beginning to worry that she disapproves of them. But removing them would be very risky, according to the old lady who gave them to you to put on your son. You wonder if the old man is going to make your doctor report you to child protective services because you have heard of that happening in this clinic. Your doctor is always talking about choking, not breathing, sleeping this way and that, and it is very confusing. Perhaps you should start going to a Dominican doctor.



Doctor:



You are seeing a 2 month-old boy for health care maintenance at your continuity practice near the medical center in the northwest Bronx. This is his mother's first baby, and you are concerned about the potential for choking created by the bracelet and the necklace he wears. You have brought this up with the mother before, but the baby still wears the jewelry. She has always seemed upbeat to you, and she seems to like you a lot, perhaps in part because you speak Spanish well. Today, however, she gets quiet and grows guarded when you bring up this issue again. This mother is young, but so are you. You would like to give her advice that she is comfortable with, that is respectful of her beliefs, and that is safest and best for the baby.

Case III: Teeth-grinding

Mother:

You have brought your three year-old daughter to a doctor new to these parts of the Kentucky mountains. This doctor is here on a government job and has been in the community for a year. You have heard good things about him, but he's from Chicago, and some people say he is Jewish. He was at the hospital and helped bring back your neighbor, Buddy, when he had his heart attack last spring, so he must be good. You figure that you will try him out, since the old doctor in town does not take insurance and gave your nephew a bad infection with one of his antibiotic shots.

Your daughter has been grinding her teeth a lot at night, which means she needs worm medicine. Folks say that it is at night when the worms come up, and that when they do, the kids chew them to pieces. It does not occur to you that your doctor would not have the common sense to know what to do for teeth-grinding. Maybe you should have just wormed your daughter along with your older kids when they started school last September.

Doctor:

You moved to a small town in Appalachia a year ago into a National Health Service Corps position as a pediatrician, and you are having a great time. At first business was slow. Ever since you helped resuscitate Mr. Collier after his M.I. when they wheeled him into the ER (where you just happened to be walking through), lots of people have been bringing their kids to see you. Your administrator is happier with your productivity.



The mother of a three year-old patient who is new to you is asking about her daughter's bruxism. This has turned out to be a common concern down here, one you never learned about in continuity clinic, along with a lot of other issues, from ascaris to co-sleeping. The mom keeps changing the subject from bruxism to "medicines for worms", making this a confusing encounter. You would like to give her medically sound advice and education, while remaining respectful of her beliefs and maintaining your growing popularity in town.

Learning Objectives/Teaching Points

Physicians in training will refine their skills in cross-cultural communication about health beliefs and practices. In so doing, they will learn more about the beliefs and practices that are common in the communities in which they work and develop deeper respect for them. They will accomplish these objectives in the course of simulated medical encounters by attending to the questions listed below.

Frameworks for achieving these learning objectives can be modified to conform to the educator's preferred paradigms of education in cross-cultural health care. We have used two different published frameworks in our seminars (see, References):

1. Miller and Schmidt (1999)

- a. *What are the patient/caregiver's perspectives on the problem, the views of his or her loved ones and family, and your own ideas about what's wrong or what should be done?*
- b. *In what areas do these perspectives converge or differ, and how might potential conflicts hinder forming a connection with the patient/caregiver?*
- c. *How can you, acting altruistically, negotiate resolution of these conflicts so as to maximize the well-being of the child, respect the caregivers and family, and support their views on the problem?*

2. Pachter (2000)

- a. *What culturally-based health beliefs relevant to this clinical situation are commonly held in the communities in which you practice, and what related practices are followed?*
- b. *To what degree does the patient/caregiver hold these beliefs, follow these practices and wish (or need) to adhere to them in the current situation?*
- c. *How can you best integrate the biomedically-based diagnostic and treatment suggestions you would like to make and the beliefs and needs of the patient/caregiver?*

Teacher's Guide

In our workshop series with second year pediatrics residents, we have used these two published frameworks for learning cross-cultural healthcare. Miller and Schmidt (1999) called on physicians to adopt a "habit of humanism" in all their encounters with patients and families. They outlined "three essential tasks: 1) identifying the multiple perspectives in any clinical encounter, 2) reflecting on how these perspectives might converge or conflict; and 3) choosing to act altruistically" (p. 800). Pachter (2000) proposed that physicians follow a three-step approach to improved collaboration in cross-cultural encounters with patients through 1) increased awareness of "commonly held health beliefs and practices in the communities where [they] work" (p. 37); 2) assessing the degree to which the "specific patient or family relates to these beliefs and practices, and under what circumstances" (p. 38); and 3) negotiating in ways that integrate beliefs and practices of the patient and family with "biomedical treatment, health education and health maintenance" (p. 41). Many other paradigms, guides and frameworks exist, none empirically tested, that have been proposed as ways to facilitate the development or refinement of "cultural competence" in physician trainees (See Additional Reading, References).

Each of the three role plays is designed to last twenty to thirty minutes. Before starting the improvisational exercise, the actors are taken aside privately for encouragement from the facilitator and

an opportunity to ask questions about the assignment. Actors are told that once the “action” begins (once they start), they can feel free to “call a time out” (stop) for questions or to make “asides” (remarks) to the “audience” (the remaining one or two residents and faculty members in the workshop). The facilitator plays the role of “director”, calling breaks in the action (“Cut!”) to solicit comments and advice from the audience members. Spontaneous interjections are encouraged. These breaks serve to 1) keep the mood light; 2) promote a healthy sense of humor about both the challenges of the task and the ways in which the role plays evoke awkward moments in clinical care; 3) offer perspectives that may be easier to see from outside the action; and 4) support the actors’ courage and dramatic skills. Following the improvisational exercise, the group discusses the simulated encounter to address specific learning objectives and explore other issues raised, to review process and to express appreciation to the actors. Actors should be encouraged to debrief at the conclusion of the role play.

The cases were written from real-life experiences that posed challenges to one author’s understanding of cultural health beliefs and practices and to his skills in cross-cultural care. The cases touch on 1) complementary and alternative therapies, 2) the effects of migration and acculturation on family beliefs, 3) trust of the medical establishment and 4) caregivers’ fears about potential consequences of illness or culturally determined behaviors. They incorporate strong incentives for the physician to try as hard as possible to deliver culturally effective care.

The workshop runs best beginning with case material that is more familiar to the trainees and with volunteers who are more comfortable performing in front of their peers. In our practices in the Bronx, many residents have wondered how to negotiate some of their concerns captured in the case involving amulets worn to protect against “mal de ojo”. A workshop held for trainees in the Southwest United States might start with the case addressing that mother’s fears of “caida de la mollera” and “empacho”.

As described in the Introduction, the context for these role plays is warm, familiar, and light-hearted. The workshop is held in a private conference room during a relatively stress-free rotation. The material is relevant to the learners’ everyday practice in primary care. The facilitators introduce role play exercises as a way to practice valuable skills. We remind the learners that communication skills are not like lists of factual knowledge that can be assimilated through reading, attending lectures or studying, but more like technical skills that have to be rehearsed, practiced with supervision, and then refined (Blatner 2002). We promise an opportunity for them to leave the workshop with an “improved set of skills” in cross-cultural communication if they will only “buy into” this often-maligned method of accommodative learning. Maintaining a healthy sense of humor about educational initiatives in this domain is helpful to overcoming skepticism among some learners who have been turned off in past experiences.

The actors in these simulated cases retain their roles throughout each exercise. This creates an asymmetry of demand on the actor playing the role of pediatrician. The simulated “mother” can have a lot of fun with her role, making it as easy or as hard for her child’s “pediatrician” as she likes. But the actor playing the pediatrician, watched closely by the audience members, may feel more pressure to make the “right inquiries” or “propose the best compromise” in the course of the improvisation.

The Geology Department at Carleton College, Northfield, MN, has developed a website that is very useful for faculty embarking on role play in resident education (see References). As described in the text on that site, interactive role-playing exercises, when run well, are “student-centered, open-ended and feel more like real life than lectures and tests.”

References

- Blatner A. Role playing in education. 2002. Available at <http://www.blatner.com/adam/pdntbk/rlplayedu.htm>. Accessed March 4, 2007.
- Miller SZ, Schmidt HJ. The habit of humanism: A framework for making humanistic care a reflexive clinical skill. *Academic Medicine*. 1999; 74:800-803.
- Pachter LM. Working with patients' health beliefs and behaviors: The awareness-assessment-negotiation model in clinical care. In Pachter LM (ed): *Child Health in the Multicultural Environment, Report of the Thirty-First Roundtable on Critical Approaches to Common Pediatric Problems*. Columbus, Ohio: Ross Products Division, Abbot Laboratories. 2000;pp. 36-43.
- Why use interactive role-playing exercises? Webpage of Guertin L, MacDonald H, Mackay B, et al. *Starting point: Teaching entry level geoscience*. Available at <http://serc.carleton.edu/introgeo/roleplaying/interwhy.html>. Accessed March 4, 2007.

Additional Reading

- Berlin EA, Fowkes WC. Teaching framework for cross-cultural health care. *Western Journal of Medicine*. 1983; 139:934.
- Carillo JE, Green AR, Betancourt JR. Cross cultural primary care: A patient-based approach. *Annals of Internal Medicine*. 1999; 130:829-834.
- Kleinman A, Eisenberg L, Good B. Culture, illness and care: Clinical lessons from anthropological and cross-cultural research. *Annals of Internal Medicine*. 1978; 88:251-258.

Cross-Cultural Communication: Pre-School Child and Primary Care

Karen Warman, MD
Dept. of Pediatrics, The Children's Hospital at Montefiore
Albert Einstein College of Medicine

Learning Objectives

At the completion of this case, learners will be able:

1. To understand the importance of identifying families' fears and concerns in order to develop implementable treatment plans.
2. To explore how families' educational planning for their child is influenced by their social and cultural beliefs.
3. To develop a treatment plan that jointly respects the parent's social and cultural beliefs while addressing the child's medical and educational needs.
4. To understand how family dynamics may influence decision-making and withholding of information.
5. To examine how the current culture of medicine may interfere with identifying the psycho-social concerns of patients and their families.
6. To learn how the use of open-ended questions and active listening may improve communication.

Case Summary

In December 2006, a 4-year old boy of Puerto Rican descent was brought to the pediatric out-patient clinic by his mother for follow-up of a cough. According to his mother, the cough, which began in late September, had now completely resolved. The mother stated that he was no longer troubled by the cough and had had a recent cold with no subsequent cough. The mother clearly stated that she was no longer concerned about the cough and that it had completely resolved.

Sensing a hidden agenda for the visit, the pediatrician asked an open-ended question, "How is everything else going?" To this the mother replied that her son had recently been suspended from pre-school. According to his mother, he had been attending a Catholic pre-school since September. Each week he had been sent to the principal's office for behavioral concerns in the class, and he had received many "time-outs." Now, after hitting another child with a truck, he was suspended from school. The mother recounted that the other children were afraid of him because of his aggressive behavior. She believed that part of his difficulties in socializing may have been from being an only child without playmates or cousins who were his peers. The mother appeared tense and sad when describing his classroom difficulties.

His past medical history was remarkable for a diagnosis of speech delay at the age of two. He had been referred for a speech evaluation and hearing screen, but the mother did not follow through with the appointments. Since that initial diagnosis, he had been seen by multiple different physicians. He had been re-referred for speech evaluation by another physician at age two and a half, but again his mother did not follow through. He had a peanut allergy, but was otherwise well.



Family history was remarkable for maternal history of depression and paternal history of allergies.

Social History

The patient was the only child of a married Puerto Rican couple. At the time of his birth his mother was 36 years old and his father was 39. His mother had had an elective abortion at age 20 years and had lost a pregnancy at 26 weeks gestation. The father worked as a New York City policeman, and the mother was currently at home with the child.

The mother explained that the school had suspended him and that she was working at home with him in a structured way with the hopes of preparing him to return to school in a few months. The curriculum at this Catholic pre-school was rigorous and included an emphasis on academic skills. This private school did not offer any resources for speech therapy or behavioral counseling. The parents were informed that free resources were available through the public school system, but the father felt strongly that he wanted his son to receive a Catholic school education.

Doctor's assessment:

Although the mother was dedicated to helping this child by creating a structured teaching environment at home, it seemed unlikely that without specialized help, including speech therapy, this child would catch up to his peers. His speech delay and behavioral issues would interfere with his ability to excel at school and to develop the necessary social skills to foster positive social interactions.

Discussion Questions

1. What can we learn from this mother and child's experience with the school system and medical establishment?
2. What could have been done to have this child's speech delay evaluated and addressed earlier?
3. What contributed to the parent's reluctance to have the child evaluated or to receive special services?
4. Who makes decisions in the family? How can we convince the decision maker to pursue our suggestions?
5. How could we align the parents' and physician's goals to best serve the needs of the child?
6. Would having had an ongoing relationship with a trusted physician led to earlier resolution of these issues?

Teacher's Guide

1. What can we learn from this mother and child's experience with the school system and medical establishment?

This case illustrates the point that access to medical care and even to private school education is not sufficient to promote the healthy growth and development of a child. Individualized, tailored plans that respect families' social and cultural beliefs are needed to best serve the needs of children and their families. In this case the school system had a strict academic curriculum and was unwilling or unable to provide the special services that this child needed. While the mother had frequent visits to the primary care center, she did not have continuity of care with a trusted physician who was able to elicit her concerns and fears regarding her child's speech and later school difficulties. There were many missed opportunities to better serve this child and to meet the needs of this family.

2. What could have been done to have this child's speech delay evaluated and addressed earlier?

In the end, the mother agreed to speech therapy with the idea that this would enable him to return to the Catholic pre-school setting. The mother was very clear that the father felt very strongly that he wanted his son to attend a Catholic preschool. Perhaps understanding the importance of this as a long-term goal of the family would have aided in creating a therapeutic alliance to obtain services for this child. Sadly, the child was seen by six different pediatric providers over a two year period, and the issue of speech was not pursued. Longitudinal care may foster open communication and overcome some ethnic and socio-cultural differences that may be affecting the ability to follow-up on the treatment plan. Furthermore, asking open-ended questions such as "how is everything going?" may give permission to the family member to discuss important, unaddressed psycho-social information. A review by Willems and colleagues of 12 papers examining the relationship of patient socio-economic status with doctors' communication style suggests that doctors are more directive, less positive and less encouraging of participation with patients from low socio-economic backgrounds.

3. What contributed to the parent's reluctance to have the child evaluated or to receive special services?

As already stated, the parents felt strongly that the child should attend a Catholic pre-school, even though appropriate developmental and behavioral services were not available there. Other factors that may have contributed to delays in services were the parents' denial that developmental concerns existed and not wanting to give up on the notion of the "perfect child." It can be difficult for families to accept that their child has limitations or special needs, and families may perceive this as a personal failure. Furthermore, parents may be reluctant to have their child labeled as "special education." In part, there may be concern regarding stigmatization. There is a fear that labeling a child as "special ed" will reduce the school's expectations for his educational development. Furthermore, for minority populations there is a concern based on historical precedent that minorities are inappropriately placed in special education classes for reasons related to racial bias rather than ability.

4. Who makes decisions in the family? How can we convince the decision maker to pursue our suggestions?

At first the mother would not agree to accept referrals for evaluation and services for the patient. Rather than make any commitments, she stated that she would have to discuss things with her husband. When we were able to come up with a solution that prioritized his returning to Catholic pre-school, the mother stated that she would take our advice for services and convince her husband.

5. How could we align the parent's and physician's goals to best serve the needs of the child?

In this case, respecting the parents' desire for him to return to Catholic pre-school and helping to come up with a plan that would enable the family to achieve its goals, allowed us to align our goals to meet the needs of this child. If we were to use the physician's logic rather than respecting the parent's beliefs and attitudes, it would be easy to conclude that a free public school program that provided services would be best. However, in this case, respecting the parents' value system and religious preferences was necessary to achieve a therapeutic plan to meet this child's educational needs and his family's cultural needs and expectations. This case offers an opportunity for patient-centered care (or family-centered), which shares many core features with cultural competence including understanding the patient (or parent) as a unique person, exploring the patient's or parent's experience of illness, finding common ground regarding treatment through shared decision-making, and an emphasis on building the doctor-patient relationship Error! Bookmark not defined.

6. Would having had an ongoing relationship with a trusted physician led to earlier resolution of these issues?

This parent had multiple encounters in the same clinical setting but saw many different physicians. In a visit in mid-September, soon after pre-school started, a physician's note included mention of the mother's reported difficulty with separation from the child at school and concerns regarding hyperactivity. It was subsequently revealed that the mother was fearful of him being labeled as hyperactive. At this visit the mother also stated that she would like to have a more consistent physician for her child and stated that she would ask for a particular doctor she had seen previously. Interestingly, this was the same doctor she had seen two years prior who had first diagnosed speech delay and recommended an evaluation.

Conclusion

The mother came to see the physician with the chief complaint of "follow-up of a cough." The physician remembered the mother and child. The unaddressed speech difficulty resurfaced. The mother revealed her fears of her child not being able to attend a Catholic pre-school or of being labeled as hyperactive. The mother was receptive to a referral for speech therapy with the idea that this would facilitate his successful return to the classroom. Psychological services were also offered, but because of out of pocket expenses, his parents declined these services. He was diagnosed with a moderate to severe articulation defect in early January 2007. He continues with speech therapy. The parents are now strongly considering psychological services for him with the hope that this will facilitate his transition to a regular classroom with the ultimate goal of returning to a Catholic private school.

References

- ¹ Goode TD, Dunne MC, and Bronheim SM. The Evidence Base for Cultural and Linguistic Competency in Health Care. The Commonwealth Fund. October 2006. Available at: http://www.cmwf.org/publications/publications_show.htm?doc_id=413821. Accessed March 12, 2007
- ² Beach MC, Saha S, and Cooper LA. The Role and Relationship of Cultural Competence and Patient-Centeredness in Health Care Quality. The Commonwealth Fund, October 2006. Available at: http://www.cmwf.org/publications/publications_show.htm?doc_id=413721 Accessed March 12, 2007
- ³ Wissow LS, Roter D, Larson S. Longitudinal care improves disclosure of psychosocial information. *Archives of Pediatrics and Adolescent Medicine*. 2003; 157; 419-55.
- ⁴ Willems S, De Maesschalck S, Devengel M, Derese A, De Maeseneer J. Socio-economic status of the patient and doctor-patient communication: does it make a difference? *Patient Education and Counseling*. 2004; 56:139-46.
- ⁵ Finn, J. D. Patterns in special education placement as revealed by the OCR survey. In K. A. Heller, Holtzman, W. H., & Messick, S. (Ed.). *Placing children in special education: A strategy for equity*. Washington, DC: National Academy Press. 1982; pp. 322-381.

Exploring Issues of Culture and Trust: Human Trafficking, Gynecology and Contraception

Amy S. Boldosser, MIA, Consultant

Learning Objectives

At the completion of this case, learners will be able:

1. To explore the socio-economic circumstances that may influence a person's decision to take the risks presented in this case.
2. To explore religious and cultural issues related to access to care, perceptions of the examination and self-prescription of contraception.
3. To describe issues related to trust, family support and immigration status that may influence information a patient is willing to share and her ability to adhere to the proposed treatment plan.
4. To identify possible strategies for discussing sensitive topics with patients from different cultural backgrounds

Case Summary

A.M., a 20 year old Spanish speaking woman from Mexico, presented to a social services case manager in New York City (NYC). She has been relocated to NYC by federal authorities following escape from a home in California where she was held as a victim of human trafficking for almost two years. A.M. was trafficked to the United States when she was 18 years old and was forced to work as a domestic servant in the home of her trafficker. During her captivity, she was raped at least four times by her trafficker and suffered additional physical violence. She reports shame at having been raped indicating that she was a virgin when she was trafficked to the United States. She now says she feels that perhaps the rapes were a test from God of her faith.

She has not provided information on whether she was sexually assaulted or otherwise abused during travel to the United States, as often happens to trafficking victims. She reports being nulliparous, and has not shared any information about possible abortions, voluntary or forced, after the rapes. She responded to her case manager's questions about abortion by indicating that she is an observant Catholic and does not believe in abortion.

A.M. appears generally healthy now but has not had a medical evaluation, knows little of her medical history and has never had a gynecological exam. It is uncommon for young women in her town in Mexico to receive gynecological care, and there is a perception that such exams "take a girl's virginity."

A.M. is currently awaiting adjudication of her case against her trafficker and the federal prosecutor responsible for her case has requested a forensic gynecological exam. Although she was raped over the course of two years, the last incidence of rape was more than a year ago. Because she was unable to leave the home where she was being enslaved to seek help, no forensic exams were conducted following the actual rapes. The prosecutor is hoping that there may be some residual evidence that a forensic exam could detect. If the rapes cannot be proven, the trafficker will receive a much lighter sentence with no prison time. A.M. knows that, despite her apprehension, if she does not

have the exam, she risks her trafficker not being brought to justice. She expresses to her case manager that she feels very ashamed when the prosecutor asks her questions about her sexual health.

Now that A.M. has re-settled in NYC where she has friends and family, she has also become sexually active with an older man she refers to as her boyfriend. A.M. mentions that she has obtained a supply of contraceptive patches from a friend in her Washington Heights neighborhood and is using them for pregnancy prevention because she has heard that condoms are not approved for use by the Catholic Church. Although she had previously indicated a religious aversion to pre-marital sex, A.M. claims that she is not being forced to have sex with her boyfriend.

A.M. has been brought to your hospital today for a forensic gynecological exam combined with a comprehensive pelvic exam, pap and STI testing including an HIV test. Her Spanish speaking case manager accompanies her but will not be in the room for the examination. A.M. is expressing fear and apprehension at the possibility of being examined by a male doctor. She does not speak English, so will require use of an interpreter. She also expresses concern that the hospital staff is aware that she is an undocumented immigrant. Although she may receive a special visa as a victim of human trafficking, she is not yet holding that visa and is distrustful of what she perceives as state run institutions like the hospital clinic.

Questions for Discussion

1. Consider what assumptions you may have as a healthcare provider when you learn the details of A.M.'s case and enslavement. If the forensic exam at this late date is unable to detect any evidence of rape, do you feel the patient had a role in not escaping and seeking treatment after the rapes? What do you know about human trafficking as modern day slavery? How might these assumptions affect the course of your treatment of AM?
2. What cultural issues might need to be addressed to make A.M.'s initial contact with the healthcare system and a gynecological provider in the United States more comfortable?
3. How can A.M.'s religious concerns about the gynecological exam or birth control methods be addressed in a sensitive way? What assumptions or prejudices might arise for you when she raises opposition to treatment or care based on religious values?
4. How can we establish trust in our medical practices with a patient who has been accustomed to traditional practices of relying on community members for medical advice and provision of medications such as contraceptives or antibiotics? What misperceptions might the patient have about this clinic/hospital setting that you could help to correct with education? How will you address her immigration concerns?
5. Beyond physical treatment, what mental health issues may need to be addressed with this patient? Consider the cultural acceptance of therapy and counseling in the United States versus in other cultures.
6. A.M. has received little education on sexual and reproductive health as evidenced by her confusion about birth control modalities (condoms versus the patch). She may also be unaware of the risks of HIV and other STIs. How can you sensitively communicate this basic information to her and prepare her for the potential results of the testing she will undergo? How could her understanding of the treatment plan you propose affect her adherence?

Teacher's Guide

Cultural competence in health care delivery typically refers to the requirement that providers have “an understanding of the beliefs, values, traditions and practices of a cultural group, including culturally-based beliefs about the etiology of illness and disease and concepts of health and healing practices.” (Policy Brief 1, 1999) Focusing on provision of culturally competent patient care has been shown to improve health outcomes for patients and their communities while increasing levels of patient satisfaction and improving cost efficiency. (Hispanic Federation, 2005)

The Health Resources and Services Administration (HRSA) indicates that culturally competent care improves provider practice in the following ways:

- Providers are able to obtain more specific and complete information to make a diagnosis
- Treatment plans developed by the provider and patient are more likely to be adhered to by the patient and supported by the family
- Overall communication and interaction between patient and provider is enhanced. (DHHSS, 2001)

Some of the particular health care barriers faced by Latinas in the United States that may be relevant to this case include:

- Poverty and socioeconomic stress
- Lack of health insurance
- Discrimination in health care delivery and public health policies
- Lack of linguistically appropriate and culturally competent health care services (Hispanic Federation, 2005)

It is important to note that the provision of culturally competent services must also include the delivery of linguistically appropriate services. A 2002 study by the Commonwealth Fund found that 43% of Spanish dominant Latinos reported communication difficulties with their health providers. Another 16% of Latinos reported not following their health care provider's advice simply because they did not understand it. (Betancourt, 2002)

In A.M.'s case, the provider will also be faced with issues related to her mental and emotional state following her two years in slavery. Although many Americans are aware of smuggling of persons into the United States illegally, there is less familiarity among health care providers about human trafficking. Human trafficking is a modern-day form of slavery. Victims of human trafficking are subjected to force, fraud, or coercion for the purpose of sexual exploitation or forced labor. The US Department of State estimates that approximately 800,000 to 900,000 victims are trafficked across international borders annually with between 14,500 and 17,500 of those victims being trafficked into the United States. (USDHHS). Victims can be young children, teenagers, men or women. Victims of human trafficking, like A.M., may be working in forced labor situations as domestic servants (nannies or maids), sweatshop workers, janitors, restaurant workers, migrant farm workers, fishery workers, hotel or tourist industry workers, or as beggars (USDHHS). Additional information about human trafficking specifically for health care providers is available from the US Department of Health and Human Services at <http://www.acf.hhs.gov/trafficking/index.html>

References

- Arte Sana. Suggestions for Upgrading the Cultural Competency Skills of Sexual Assault Response Teams. 2001. http://www.arte-sana.com/articles/suggestions_upgrading.htm
- Betancourt, Joseph R et al. Quality of Care for Underserved Populations, Cultural Competence in Health Care: Emerging Frameworks and Practical Approaches. Field Report. 2002. No. 576. The Commonwealth Fund.
- Hispanic Federation. Las Olvidadas/The Forgotten Ones. 2005
<http://www.hispanicfederation.org/res/Pub%20download/HF%20AIDS%20Report%202005.pdf>
- National Center for Cultural Competence, Georgetown University Center for Child and Human Development University Center for Excellence in Developmental Disabilities. "Policy Brief 1: Rationale for Cultural Competence in Primary Health Care." Winter 1999. 10 Mar. 2004
<http://gucchd.georgetown.edu/nccc/nccc6.html>
- Omar, H.,Richard, J. Cultural sensitivity in providing reproductive care to adolescents. *Adolescent and pediatric gynecology. Current Opinion in Obstetrics & Gynecology.* 16(5):367-370, October 2004
- U.S. Department of Health and Human Services. Cultural Competence Works. HIV/AIDS Bureau, HRSA. 2001. No. 98-0372(P).
- The Campaign to Rescue and Restore Victims of Human Trafficking Fact Sheet: Human Trafficking. US Department of Health and Human Services, Administration for Children and Families. http://www.acf.hhs.gov/trafficking/about/fact_human.html

Rejecting Dialysis: A Patient's Choice

James Fausto, MD
Department of Family and Social Medicine
Montefiore Medical Center, Albert Einstein College of Medicine

Learning Objectives

At the completion of this case, learners will be able:

1. To identify issues that affect this patient's choices, his care and his healthcare outcomes
2. To discuss the role of fear, life experience, and belief systems, and their relation to a patient's treatment
3. To analyze the social strengths and stressors in the case and their relevance to the patient's acute care, chronic care, and potentially end of life care

Case Summary

ID: The patient is a 44 year old male who recently immigrated from Ghana, and who has end stage AIDS (CD4 = 4). He is not taking Highly Active Anti-Retroviral Therapy (HAART) and has developed end-stage renal failure, but is refusing dialysis despite a creatinine of 14.4 .

Chief Complaints:

- 1) Difficulty breathing with activity/weakness x 2 weeks
- 2) "Bad kidneys"
- 3) Rash x 3 months

History of Present Illness:

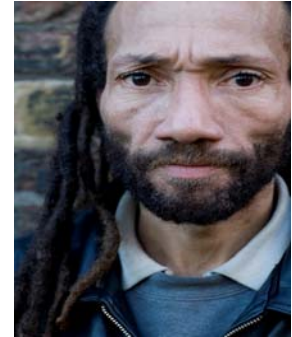
44 y/o male with a history of end stage AIDS (CD4 = 4) and end stage renal failure (Creatinine = 14.4) presenting with shortness of breath with activity and severe fatigue for two weeks. The patient reports a history of AIDS, while not being on HAART treatment because of his dislike of medication side effects. The patient has dyspnea on exertion, dizziness, fatigue, shortness of breath, blood tinged sputum, and decreased appetite. He reports having a rash for the past three months, which he had never experienced before. The rash started as a small fluid filled bump that breaks open to form a scab. He reports that no creams or medicines have helped with the rash. The patient also reports knowing he has "bad kidneys", but adamantly states that he does not want dialysis. He says, "I will take any medicine that will help my kidneys but I do not want dialysis." When questioned, he reports, "people who start dialysis die from dialysis." Further attempts to discuss dialysis and his concerns about it are met with refusal to discuss the topic and ultimately, refusal to talk with the medical team.

Past Medical History

- HIV/AIDS diagnosed >3 years (heterosexual infection), never on HAART
- End stage renal disease (diagnosed during previous admission for abdominal pain)
- Thrush (Opportunistic Infection x2 years)
- Malaria (many years ago)

Social History:

A recent immigrant from Ghana, the patient moved to the U.S. 3 years ago, initially planning on coming to the US for a short trip to visit his mother living in Brooklyn. During his visit, the patient became ill and was hospitalized and diagnosed with AIDs. He moved in with his mother for a while but left due to frequent conflicts, possibly related to substance abuse (cocaine and marijuana). After parting ways with his mother he moved from Brooklyn to a small apartment in the Bronx. He no longer is in contact with her. He currently denies using cocaine, but continues to smoke marijuana and tobacco. The patient is currently not working and receives welfare. He identifies as a Rastafarian and repeats often that, although he is sick, God will take care of him. Immigration status and level of education are unknown.



The patient experienced the following problems during this admission:

- 1) Pneumocystis carinii pneumonia, treated
- 2) Chronic renal failure (Bun/Creat = 120/14.4) secondary to HIV Associated Nephropathy: medical management was not adequate to reverse renal disease. The patient refused to discuss dialysis as a treatment modality
- 3) AIDS (CD4 = 4): Patient could not start HAART treatment due to poor kidney function. Patient aware that he was at risk for opportunistic infections if his CD4 remained this low. Patient was made aware that his CD4 count may improve with HAART, but to start HAART his kidney function had to be improved. Thus, he needed dialysis to start HAART.
- 4) Rash: The rash was biopsied showing suppurative dermatitis

Teacher’s Guide

DISCUSSION:

1. Compile a list of “WHAT IS AT STAKE” for the patient and the providers in this case.

WHAT IS AT STAKE:

<u>For the Patient</u>	<u>For the Providers</u>
1)	1)
2)	2)
3)	3)
4)	4)
5)	5)

WHAT IS AT STAKE: (TEACHERS GUIDE: SOME EXAMPLES)

<u>For the Patient</u>	<u>For the Providers</u>
1) His life	1) Fear of not communicating correctly
2) Self image	2) Fear that the patient may die
3) Fear of dialysis	3) Effective treatments refused
4) Quality of Life	4) Treated his acute illness but not his chronic and terminal disease
5) Trust in the medical system	

2. As a group compile a list of learning issues from the case that would be interesting to discuss.
 - A helpful technique involves brainstorming a list: Write on board or large sheet of paper. Once a list is established, begin discussing these topics in further detail
 - If you have a quiet group, get the group to identify teaching points within the case related to topics below.

Possible points to consider:

1. Patient's perspective on chronic illness
 2. Social stressors and support networks
 3. Fears about potential consequences of medications and/or illness
 4. Complementary/alternative therapies
 5. Family decision-making and withholding information
 6. Effects of migration and acculturation on family dynamics and beliefs
 7. Language barriers and communication
 8. Religious beliefs and spirituality
 9. The culture of medicine
 10. Disease and illness
 11. Discrimination and racial/ethnic disparities
 12. Stereotyping and clinical decision making
 13. Mistrust and communication style
 14. Effect of patient's mistrust and communication style on his outcome
3. Once the group has a list of topics, discuss the topics. Encourage members of the group to teach each other about their cultures, belief systems, personal experiences and insights patients have taught them.

If the group has a difficult time developing discussion points, consider the following questions and discuss them in relation to the case.

Issues/Questions:

1. How did the patient's perspective about his AIDS/renal disease/possible death affect his health and well being?

The patient felt like he had a cold but he did not feel the effects of his renal failure. Bun/Creat = 120/14.4 meant nothing to him. He was still able to go about his day and function almost normally. The doctors, on the other hand, see this as an ominous sign that his kidneys were failing, and that soon his electrolyte values would not sustain life.

The patient had some experience with dialysis or some conception of dialysis that he would not share with the team. This element of his perspective is crucial to understanding how he felt about life and death. Also his issues regarding quality of life versus just sustaining life could not be explored in conversing with the patient, due to his refusal to discuss the matter at all. If this issue could have been discussed, it would have been easier to plan goals of care. In some ways his perspective on renal dialysis (not being willing to talk about it – regardless if he decided to start dialysis) prevented the patient and staff from discussing all of his health care options.

2. How did his fear of dialysis affect his ability to treat his Chronic Renal Failure, AIDS and his overall health? Why did he fear that dialysis equaled death? Was this fear reasonable from a medical perspective and/or from a lay person's perspective?

Clearly, his fear of dialysis prevented treatment of his renal failure. The patient could not start HAART therapy because it would cause his renal failure to become worse. Therefore, by not receiving dialysis, he could not receive HAART, and he left himself susceptible to opportunistic infections and ultimately, an earlier death.

It often does happen that people who start dialysis die a short time later. However, is the dialysis the cause as this patient felt, or does dialysis just extend the inevitable? It is easy to see how people may connect death to dialysis instead of prolonged life with dialysis. Why this patient concluded that dialysis equals death is difficult to know because of his unwillingness to discuss the topic.

3. In what ways did his relatively recent history of migration affect his life and health? (ability to work, family relations, support systems, social stressors, etc.)

Common stressors affecting the migrant community can be discussed here. This patient was not unique with regard to migrant social stressors. Immigration status may have influenced the degree of trust he had for the medical system.

4. What role did his use of multiple medical care systems affect his encounter with the medical institutions?

The same effect that any patient suffers when using multiple health care systems and no relationship with a primary care provider: loss of follow-up, repeat testing and examination, no continuity of care, over-medicalization and ultimately, loss of faith in the health care institutions.

5. In what ways could his religious and spiritual beliefs be a strength for his health and well being? How could they hinder his care?

In difficult times, patients often turn to their faith as a source of strength and hope. Also, patients can often find a supportive community and tangible resources via a network of people within this community. This patient definitely turned to his faith to sustain his will to live.

Alternatively, rejection of life sustaining treatments due to a belief that God will save them in the end, can lead to premature death.

6. Was his marijuana use part of his religious belief system, a method of self medication and/or an addictive behavior? How may it have affected his health outcomes?

No correct answer here.

7. Could language have been a barrier?

Language could have easily been a barrier. Although many recent immigrants are able to understand English, their competency may not extend to fully understanding the English language in a medical setting. Some patients are also proud of being able to speak multiple languages, but it is essential to ascertain how well a patient understands the medical team's explanations. If there is even the slightest concern about comprehension secondary to language barriers, the team should provide an interpreter in person or by phone.

8. How do you think all of these factors in combination may have affected his medical plan and treatment for this admission?

Again, there is no correct answer to this question.

Hopefully, the group will have had a fruitful conversation. Often, the group will teach each other much more about cultural competency than the case. Use the case as a starting point to begin a conversation. Ultimately, the greatest lesson one can take from this case or any case, involves remembering to treat each patient as an individual and trying to understand that person's belief system.

Summary of hospitalization

Multiple specialists were consulted during the admission. The Renal physician attempted to speak with the patient about his kidney disease. They shared with him the process of dialysis and offered to show him the dialysis unit. The patient refused to engage in the conversation. They ultimately shared with him the risks of not undergoing dialysis, which included death due to renal failure. The patient was also seen by an HIV specialist who explained the benefits of HAART treatment, which interested the patient, but when it was explained that the patient could not start HAART without improved kidney function, the patient opted not to start HAART. Psychiatry was consulted to assess competency and the patient was found competent to make decisions for himself. The patient requested that his mother not be contacted unless he became too ill to make decisions for himself. In the end, the patient was treated for his pneumocystis carinii pneumonia, which improved. He continued to show signs of worsening kidney function but there was nothing more that inpatient treatment could offer him.

The patient was discharged home. Several months later the patient's mother contacted the hospital floor and notified the floor doctors that the patient had lapsed into a coma and was now being dialyzed at another hospital in the Bronx. The patient's mother wanted to know why we had not given him dialysis in the past.

Resources: Cultural Competency Education

- CENTER FOR EFFECTIVE COLLABORATION AND PRACTICE
<http://cecp.air.org/> Specific to Cultural Competency - <http://cecp.air.org/cultural/>
- American Medical Student Association (AMSA): impressive list of references for further reading
<http://www.amsa.org/programs/qpit/cultural.cfm>
- US Department of Health and Human Services– Health Resources and Services Administration (HRSA): Cultural Competence Resources for Health Care Providers
<http://www.hrsa.gov/culturalcompetence/>

Cambodian Rites and Rituals and Cross Cultural Care

Lyla J. Correoso MD
Visiting Nurse Service of New York

Learning Objectives

At the completion of this case, learners will be able:

1. To discuss and describe the effects of migration and acculturation on family dynamics and beliefs
2. To explore differences in family decision-making and effects of disease and illness on these
3. To identify the use of alternative therapies and the potential problems with misunderstanding these practices
4. To describe the effects of mistrust and communication styles/patterns on the patient's outcome

Case Summary

This is an 82 year old Cambodian male who has been referred to hospice after a decline in his condition secondary to a stroke 4 weeks ago. The patient has a history of diabetes controlled with Glipizide and history of first stroke with a right hemiparesis 6 months ago. After his first stroke, the patient had stabilized. He was approached by the inpatient team to discuss completing a healthcare proxy form. The patient speaks English and has 2 sons and 6 daughters. His wife is frail and only speaks Cambodian. At the time of the discussion of the healthcare proxy (HCP), the patient's wife, Kalliyon, 76 years old; 33 y/o daughter, Veata; 24 y/o youngest son, Sopheara; and 27 y/o middle daughter Pheap, were present. The patient understood the conversation about the HCP but did not want to sign the form at that time. He finally stated that he would wait until his other daughter, 28 year old Chantrea, came. An hour later his private physician (PMD) came and stated that the patient had completed the directive making his son, Sopheara, the HCP and Veata, the back-up. The PMD noted that the youngest son, Sopheara, had been reluctant to allow his father to choose him as the HCP, although he understood his father's wishes. The patient indicated that he would not want to be placed on life support of any kind. He said that he had fought the communists and was strong and would not want any type of support.

The patient is now at home after his second stroke which has been much more debilitating. He has a tracheotomy and a peg tube. Upon visiting the patient it is noted that he is bedbound, poorly responsive and has excessive secretions from the tracheotomy. The patient is developing more contractures of his extremities. It is noted that his skin and overall care is excellent. Upon signing on to hospice, Veata has indicated that she does not want her father hospitalized or ever placed on a ventilator again. The other present family members are his wife and all of the children except for the oldest son, 31 year-old Sovaan. All present agree with Veata.

Over the next 8 weeks the patient does well, except for recurrent pulmonary infections that are treated with atropine drops and antibiotics via the peg tube. He has also had recurrent problems with constipation. Appropriate laxative regimen has been ordered, but the lactulose bottle remains unused. When asked about the difficulties with using the laxative, Veata, who has been the primary caregiver along with Pheap, promises to use the medication as directed. Because of the concern for aspiration

pneumonia, since the patient has a residual when the feeding tube is checked, the amount of the feeds has been decreased to see if the patient can tolerate this better.

Suddenly the patient develops a fever of 102.4. The patient is placed on Tylenol and a broadspectrum antibiotic is ordered. Labs for comprehensive metabolic profile and CBC are ordered. The patient is congested but not any different than previously. The hospice nurse visits the patient and feels that he can remain at home. In the middle of the night the patient is admitted to the local hospital and placed on a ventilator. When the hospice team inquires about the admission and ventilator placement, the family states that Sovaan had made the decision and that the family is in agreement with the decision. The patient is once again stabilized and taken off the ventilator. Again, the PMD speaks with the 1st and 2nd HCP's, and they are in agreement not to re-hospitalize the patient, but to allow him to remain at home with symptom control. Within three weeks, the same scenario recurs. Once again the patient is weaned from the ventilator, and the health care proxies agree that they will speak with their brother, Sovaan.

The frequency of the nursing visits at home is increased to see if there can be a better way to work with the family. The patient has again become constipated, and has increased upper airway secretions. He is also running a low grade fever. Upon examination, it is noted that he has several linear red marks bilaterally across his upper back. The marks appear to be suggestive of physical abuse. When the family is questioned, they state it is called "coining".



It is also noted that there is a thick, foul-smelling liquid that is at the bedside and that also appears to be coating the inside of the PEG tube. The nurse and social worker are very concerned and feel that Adult Protective Service should be called. At this time the hospice physician is called to assess the patient.

Questions for discussion

1. What is the decision making style of this Cambodian family?
2. How has decision-making in this family become disrupted?
3. What other interventions should have been considered prior to selecting the HCP?
4. Has acculturation had any effect on the family dynamics and beliefs? Explain.
5. Are these re-hospitalizations demonstrative of mistrust of the medical system?
6. Did the health care team demonstrate stereotyping in caring for this patient and family?

7. In what way could the health care team improve the communication with and within this family?
8. How might lack of understanding about alternative therapies result in discrimination and impair clinical decision-making?

Discussion and Teacher's Guide

One might think that the family has experienced significant acculturation to this country such that the naming of the second son and the eldest daughter would be reflective of how decisions will be made. However, if we look closely at the clues that were originally left by the patient, and the ultimate way in which major decisions are being made, one can see that the problem first developed when the HCP form and agents were assigned. Apparently, the patient reverted to his usual custom of showing respect to the doctor by agreeing with him and signing the HCP naming his second son and eldest daughter. However, traditional decision-making is through the first born son, who would be Sovann. This is probably why the patient did not initially want to sign the form- because he wanted his eldest son to be involved in the decision. The cultural error made by the healthcare team was in not knowing the power of the decision-making process in this culture, nor the depth of respect the family showed the eldest son by allowing him to make these decisions even though he was not selected by the father.

Upon further elucidation of the history of this family, it becomes apparent that the family is unable to let go of the patient by allowing him to die because he is so revered in the family. The patient had given information about his power and significance when he mentioned that he had fought the communists. Upon further probing the family explains that the father had been able to help eleven of his family members escape the Pol Pot regime in Cambodia. He was able to guide the family out when many of the neighboring families were murdered, kidnapped, and never seen again. The patient guided them through this dangerous time to America where they were given asylum. Because of their gratitude to and reverence for this man, it is very difficult for them to allow him to die, despite their desire to obey his wishes. When a member of the team speaks with Sovann, he indicates that he feels that all must be done for his father because he is a hero in the family. Otherwise, distant family members and others would feel that the immediate family showed indifference and were not brought up appropriately. The issues of demonstrating respect and of saving face are of great importance in this situation.

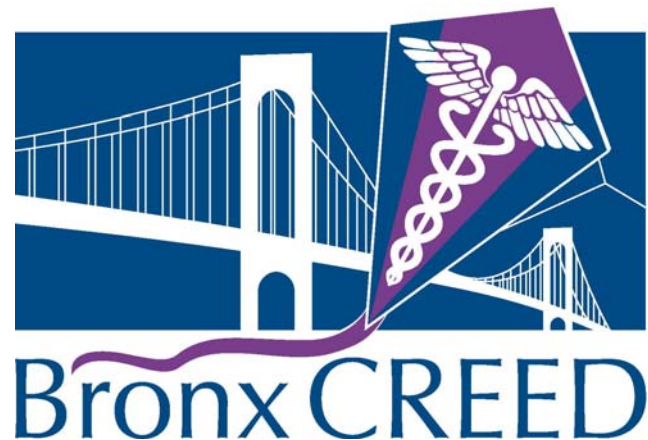
Regarding the use of medication, it is often thought that once a medication is effective, it is no longer indicated. For this reason, it is common to find that prescribed medications are not utilized or are under-utilized. The use of the foul smelling liquid was a home remedy that was suggested by the herbalist with whom they consulted. When looking at the use of complementary and alternative medicine in East and Southeast Asian patients, they may believe that there is an imbalance in the yin/yang or hot/cold. They may try to utilize foods that are identified as "cold" to counter a condition that is "hot" such as a fever. They may also practice a treatment called cupping or coining, a traditional Asian form of healing. Coining involves heating a coin or putting oil on it and vigorously rubbing the affected area. The result is raised welts or red areas on the skin where rubbing has occurred. It is believed that the skin will turn red if illness is present and that the red area represents the sickness coming to the surface and leaving the body.

Had the healthcare team reacted to what they were seeing without asking the family questions, they could have further complicated the case by calling Adult Protective Service. Other signs that this patient was not being abused were that, during the time that he was cared for at home, the patient was always washed, clean and well cared for. It was obvious that the family truly cared for this patient.

One of the difficulties in caring for someone of a different culture is being able to provide culturally congruent care. The best way to begin this is by asking the patient/family about different encounters they have had since they came to this country. Often, because of the difficulty that families have in assimilating, hearing these experiences can help the care team to avoid making the same mistakes that others before them have made. Reading articles about health practices of the culture of your patient will not only educate you but will indicate to the family that you and your team truly care. Not all families are purists in the way that they may maintain practices from their country of origin. The longer that a person has been in a country, the more likely they are to have become somewhat assimilated culturally. Second or third generation members of immigrant families are more likely to be acculturated.

References

- Ahn, Q. Ngo-Metzger, A. T. R. Legedza et al. Complementary and Alternative Medical Therapy Use Among Chinese and Vietnamese Americans. *American Journal of Public Health*. April 2006; 96(4):647–53
- Cultural Competence in Cancer Care: A Health Care Professional's Passport. *Intercultural Cancer Council*. Baylor College of Medicine: Houston, TX. 2004; p. 84
- Galanti, G.A., Caring for Patients from Different Cultures. University of Pennsylvania Press; 2004



The **AECOM Faculty Task Force on Disparities and Cross-Cultural Training** welcomes faculty and residents of all disciplines. If you would like to be notified of future events or projects, or attend a Faculty Task Force meeting, please use the contact information below.

The Faculty Task Force has created an **AECOM Speakers' Bureau**. Listed are 143 faculty and community health leaders, all of whom have expertise in an area related to disparities or cross-cultural health. To view the list, contact a speaker, or add your name as a resource, please contact us at:

Bronx Center to Reduce and Eliminate Racial and Ethnic Health Disparities (BxCREED)

bxcreed@aecom.yu.edu

(718)430-2792

AECOM Faculty Task Force on Disparities and Cross-Cultural Training

Acosta, Robert, MD Pediatric Emergency	Fornari, Alice, EdD Family & Social Medicine	Langman, Yaron, MD Medicine
Alfalla, Celia, MD, Bronx Community Health Network	Galowitz, Paula, JD NYU Law School	Lee-Rey, Elizabeth, MD, PI Hispanic Center of Excellence
Bhalla, Rohit, MD Medicine	Gilaad, Talya, MD PGY-4 Psychiatry	Lieman, Harry, MD Ob/Gyn
Birmingham, Mary, MD Pediatric Emergency	Gonzalez, Ruben E., MD Psychiatry	Litman, Nathan, MD Pediatrics
Calderon, Yvette, MD Emergency Medicine (Jacobi)	Gucalp, Rasim, MD Oncology	Marzan, Maria, MPH Office of Education
Chen, Lugen, MD Hematopathology	Guess, Marsha, MD Ob/Gyn	McHenry, Janet, RN, CNS Palliative Care/Family Medicine
Colemon, Yolanda, MD Psychiatry	Guilbe, Rose, MD Family Medicine/Palliative Care	Milstein, David, MD Nuclear Medicine
Correa, Nereida, MD Bronx CREED	Haynes, Hilda, NP Radiation Oncology	Monrad, E. Scott, MD, CM Medicine
Correoso, Lyla, MD Visiting Nurse Service of NY	Hobson, Elizabeth, MD Pediatrics	Mossavar-Rahmani, Yasmin, Ph.D. Epidemiology & Pop. Health
Cortijo, Amaryllis, MD Mt. Hope Family Practice	Holden, Lynne, MD Emergency Medicine	Muenzenmaier, Kristina, MD Psychiatry
Davitt, Michelle, MD Emergency Medicine	Hutcheson, Allen, MD Palliative Care/Family Medicine	Mutyala, Subhakar, MD Radiation Oncology
Deen, Darwin, MD Family & Social Medicine	Jackson, Bettie Dept. of Education	Myers, Dan, MSW Office of Education
Di Martino, Joan, MD Pediatrics	Jirasevijinda, T., MD Pediatrics (Bronx Lebanon)	Myrie-Weir, Jacqueline, Manager Quality Management
Donevan, Paul Division of Education	Jones, Hollie, MD Medicine/Endocrinology	Newsome, Nadine, DDS Dental
Duvivier, Roger, MD Ob/Gyn	Katz, Nadine T., MD, Assoc. Dean for Students; Ob/Gyn	Noble, Lawrence, MD Pediatrics
Fausto, James, MD Family & Social Medicine	Katznelson, Nelly, MD Psychiatry	Nychka, Arriadna., MD Cytopathology
Fleurant, Marshall, MD MSIV	Kennedy, Gary, MD Psychiatry/Geriatrics	Ocava, Lenore, MD Neurology (Jacobi)
Floris-Moore, Michelle, MD Epidemiology & Pop. Health/Medicine	Korin, Eliana, MA Family & Social Medicine	Pierre, Phedy Quality Management

AECOM Faculty Task Force on Disparities and Cross-Cultural Training

Rainone, Francine, D.O.
Family Medicine

Ratech, Howard, MD
Hematopathology

Reichgott, Michael, MD
Assoc. Dean Clinical Affairs

Roberts, Kirsten, MD
Pediatrics (Jacobi)

Rosenberg, Maris, MD
Pediatrics/Child Development

Ross, Allan, MD
Pediatrics (Jacobi)

Ruben, Robert J., MD
ENT

Sclair, Sheira, MD
Medicine

Schuster, Victor, MD
Medicine

Shaknovich, R., MD
Pathology

Sharif, Iman, MD
Social Pediatrics

Silbiger, Sharon, MD
Internal Medicine

Silberman, Shoshana, NP
Bronx CREED

Snow, Daniel, MSW
Palliative Care

Strelnick, Hal, MD
Bronx CREED/Family & Social
Med.

Suhrland, Mark, MD
Pathology

Tamir, Jonathan,
Administrator Medicine

Tardieu, Marie-Ange, MD
Plastic Surgery (private
practice)

Towns Miranda, Luz, PhD
Family & Social Medicine

Townsend, Janet, MD
Family & Social Medicine

Vig, Susan, PhD
Pediatrics, Child Development

Vuolo, Magalis, MD
Pathology

Warman, Karen, MD
Pediatrics

Wylie-Rosett, Judy, MD
Epidemiology & Pop. Health

Weiss, Andrea, MD
Psychiatry

Weiss, Jeff, MD
Medicine

Wilcox, Wendy, MD
Ob/Gyn

Zelevsky, Melvin, MD
Radiology (Jacobi)

Zonszein, Joel, MD
Medicine



Teaching Cases Evaluation

**Please answer the questions below and return to Bronx CREED
at Fax (718) 430- 3729 or to AECOM, Mazer 104**

Please Circle the appropriate responses

1. Which case(s) did you use for teaching?

1 2 3 4 5 6 7

2. Who were your learners?

Pre-Clinical Medical Students Medical Student Clerks Other Students: _____
Residents Fellows Faculty Mixed Group
Other Health Professionals: _____

3. In what setting did the case teaching occur?

Departmental Rounds Grand Rounds Conference Precepting
Lecture Journal Club Other _____

4. In general, how useful did you find this case as a cross-cultural teaching tool?

Very Somewhat Undecided Not Useful

5. What component was most useful?

Narrative Learning Objectives Teaching Guide References N/A

6. What component needs improvement?

Narrative Learning Objectives Teaching Guide References N/A

7. Would you use this teaching tool again?

Yes No Unsure

8. Other comments about this experience or suggestions for cross-cultural teaching:

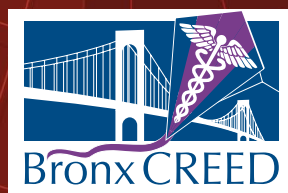
If you would like to be kept informed of other cross-cultural training activities please provide the following information or contact us at bxcreed@aecom.yu.edu

Name/Title: _____

Department: _____

E-mail address: _____

Telephone Number: _____



Bronx Center to Reduce and Eliminate Racial and Ethnic Health Disparities (BxCREED)

ALBERT EINSTEIN COLLEGE OF MEDICINE OF YESHIVA UNIVERSITY
Jack and Pearl Resnick Campus • 1300 Morris Park Avenue • Mazer 100
Bronx, New York 10461
Bxcreed@acom.yu.edu • 718.430.2792