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## TALES OF A GYPSY DOC: PERSPECTIVES ON SOCIAL AND MEDICAL ASPECTS OF CARE OF THE AMERICAN GYPSY POPULATION

*Note: Many of the observations in this presentation are derived from Dr. Thomas' experiences caring for approximately 80 Gypsies as a resident at Massachusetts General Hospital in the early 1980s.*

With a population of close to 500 000 in the United States, the American Gypsy community is a poorly understood group whose unique culture is often misunderstood by medical providers.

Gypsies represent a distinct cultural and racial group; they trace their origins to the Punjab region of India, as ascertained by blood group and HLA haplotype analysis, as well as by their language, *Romani*, which is very similar to Hindi. They migrated from India about 1000 years ago, arriving in eastern Europe around 1500 (leading to the misnomer "Romanian" Gypsies). The largest waves of Gypsies arrived in America at the end of the 19th and the beginning of the 20th centuries; their descendants now are scattered throughout the United States, with especially large communities in New York, Boston, Chicago, and Los Angeles.

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### CONTEMPORARY GYPSY CULTURE

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The extended family (*familia*) forms the focus of Gypsy life, and three or four generations typically live under the same roof; in addition, patriarchal links to distant relatives throughout the United States (*vitsa*) are maintained. Children are only sporadically educated through grade school, and most drop out of school completely by puberty, with widespread illiteracy still observed. Marriages are arranged for children in their teens, usually with the groom's family paying approximately \$10 000 in "bride price." In adult life, Gypsies sustain them-

selves with a mixture of fortune-telling, auto body work, and petty thievery, with many on public assistance.

A strong moral code runs throughout Gypsy culture, dividing items and deeds into those that are pure (*wuzho*) or polluted (*marime*). For example, the upper body is considered *wuzho*, while the lower is *marime*, leading to the curious practice of having separate wash basins for upper and lower body clothes. Non-Gypsies (*gaje*) are considered *marime*, and men are considered relatively more *wuzho* than women. There exists a sophisticated legal system to enforce the Gypsy moral code. After passing through several appellate tribunals, a case may ultimately reach the *kris romani*, a sort of Gypsy supreme court consisting of *vitsa* elders from several states.

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### GYPSIES AND HEALTH CARE

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In their encounters with the medical profession, Gypsies bring a number of unspoken beliefs that may have a critical impact on the doctor-patient relationship. First of all, they are an immensely proud people who will insist on seeing the most famous doctors at the most prestigious medical centers. Their care can be facilitated considerably if even a brief visit can be arranged with a well-known physician, who can then pass off the care to "his assistant." Hospitalization is a particularly turbulent time in the life of the Gypsy, as it may be the only time he has ever been away from the Gypsy community. Hundreds of distant relatives (*vitsa* members) may converge on the medical center to provide support in his time of sickness. The situation can often be controlled to some degree by allowing a single family member to stay in the room with the patient at all times and have ready communication with the remainder of the family who then remains in the hospital waiting area. It is also important to channel all communication from a single physician to a single family member to avoid misunderstandings about minor fluctuations in laboratory

values. As noted above, Gypsies consider the body below the waist impure and always cover the legs completely in their dress. They thus find usual hospital attire extremely degrading, a fact those caring for them should bear in mind.

The majority of the American Gypsy population have very poor health habits, with a high percentage of smoking, heavy salt and fat intake, obesity, and consanguineous marriages. Not surprisingly, this has led to an extremely high prevalence of hypertension, diabetes, and occlusive vascular disease, with strokes and myocardial infarctions observed in patients as young as their 20s. Many of these habits, such as smoking and obesity, are culturally ingrained and are very difficult for them to break.

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#### GYPSY FUNERAL RITUALS

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Should a Gypsy die in the hospital, it is imperative that hospital personnel allow the family to perform a brief grieving ritual. This involves lighting a candle under the bed with the patient positioned next to an open window. He is then rubbed down with holy oil as the entire extended family engages in a brief but intense grieving period, with hair torn out, faces scratched, and relatives throwing themselves to the floor. A 3-day wake then follows, and after burial, four large feasts are held to mark the 3-day, 9-day, 6-week, and 1-year anniversaries of the patient's death. These feasts are full of symbolic rituals, in which food, clothing, and incense are offered to the departed relative.

Understanding a patient's culture and outlook is critical to any doctor-patient interaction, but especially so when dealing with the Gypsy population. Understanding the reasons behind some Gypsy requests and behavior should facilitate effective medical care and allow for a more satisfying interaction with their care-givers.

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#### SUGGESTED READING

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## ENDOCRINE CAUSES OF IMPOTENCE

**I**mpotence affects 10 to 20 million men in the United States. Yet, despite this prevalence, little is known about the disorder from a biologic perspective, especially in terms of endocrinology.

Overall, probably 5% to 10% of impotence cases have an endocrine component. Clinicians should consider endocrine disorders as a possible cause of impotence, because these disorders can be diagnosed readily with laboratory tests and, in the majority of patients, can be cured with appropriate therapy.

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#### ANDROGEN DEFICIENCY

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Hypoandrogenism may cause impotence. Low circulating androgen levels may be due to primary gonadal dysfunction or may result from hypothalamo-pituitary disease. In the majority of patients, testing for low androgen levels is straightforward, namely, the measurement of total serum testosterone. Gonadotropin measurements may be helpful in delineating the etiologic site of hypoandrogenism. Particularly in obese individuals, total testosterone levels may be misleadingly low as a result of low levels of sex hormone-binding globulin, but free (unbound, biologically active) testosterone levels may be normal. In such patients, gonadotropin levels are usually normal and treatment with androgen is generally of no value.

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#### HYPERPROLACTINEMIA

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Hyperprolactinemia is another endocrine disorder for which patients with impotence should be screened. About 80% of men who have prolactin levels above 50 ng/mL (normal = 2 to 12 ng/mL) complain of diminished libido and impotence. Prolactin excess results in impaired secretion of gonadotropin-releasing hormone, so that there is usually concomitant hypogonadotropic hypogonadism. Additionally, there is a direct inhibitory effect of prolactin excess on sex drive and function. Thus, treatment with androgen alone is not generally effective in such patients. Primary therapy should be directed