SOCIOCULTURAL CHALLENGES IN TWO INDIGENOUS PEDIATRIC PATIENTS WITH CHRONIC KIDNEY DISEASE

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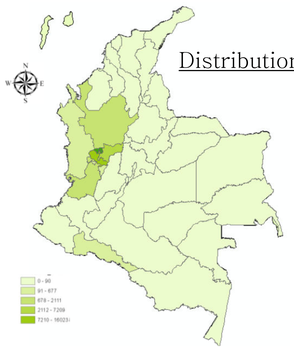
Introduction and Aims

Chronic Kidney Disease (CKD) presents particular challenges and has important repercussion in patients' personal and family lifes. Pediatric nephrologists and renal interdisciplinary teams must develop special skills in dealing with these patients and their families.

When not only a family, nut an entire community from a singular cultural heritage is involved, as the Emberá Chamí indigenous group in western Colombia, new consideration must be taken into account.

Two cases of children from the Emberá Chamí community with CKD are exposed in order to explore the implications of a different worldview in patient management.



Cartografía de la diversidad – Dirección de poblaciones. (2010). [*Map of Colombia showing the distribution of the Emberá – Chamí people*] Retrieved from http://www.mincultura.gov.co/?idcategoria=41768#

Methods

Clinical records were reviewed and health care workers were consulted. Literature about the Emberá Chamí community was also consulted.

Results

J is the third child of an indigenous couple under the age of 30. When he was two months old, he was diagnosed with vesicouretral reflux, dysplasic kidneys and ESKD. J's mother had no prenatal controls; the nearest conventional health facility was four walking hours away. ***J*** was hospitalized and put on peritoneal dialysis, he was accompanied by his mother during the first month of his hospital stay. Both his parents visited him every other month and stayed for two weeks during each visit.

Results (cont.)

The father said he would act as a kidney donor in spite of his wife's objections, but then changed his mind after consulting his mother in law. Although the Emberá Chamí are organized in nuclear family subgroups, the extended family remains in important control.

J would have long ago been treated as an outpatient, if not for the physical restraints in accessing medical help, and the fear as to whether the community would or would not be able to provide him with peritoneal dialysis. In a community where 25.6% of the population is illiterate and 8.2% has little regard for basic sanitation, a toddler on dialysis or post transplant is quite the challenge. Hence, the search for an adequate foster family has begun, with its own challenges.

The second patient, ***A***, is a boy with dysplasic kidneys. He went into ESRD when he was one year old. As his parents did not take care of him he was put up for adoption. He was put into peritoneal dialysis and received a living donor transplant at age four, with a very good outcome. He presently has two guardians: his biological mom and his adoptive family. He lives outside the indigenous community.

Risks associated with the patient remaining among the Emberá - Chamí	Risks associated with prolonged hospitalization
Difficult access to conventional health facilities	Emotional deprivation
Infections due to sanitary practices	Hospital acquired infections
Physical restraints in providing peritoneal dialysis	Difficulties in ensuring adequate stimulation and experiences for a normal development
Communication barriers in assuring the community understand and are willing to manage the boys' disease	Loss of cultural heritage and identity
Possible abuse, alienation due to different views of health and disease	Separation of a family

Guez, B. (2009) [photo of the Emberá Chamí]. Used with permission.

Conclusions

When dealing with a patient from a different cultural background, special care must be taken in making sure the family understands the exact nature of their child's disease and the possible treatments. Having them grow outside their own cultural heritage will pose, with time, and emotional burden on the child and his family, as well as a loss for an entire community and country.

J is currently under the care of a medical institution trying to assume a role for which it is not prepared: guardianship. Patient ***A*** has two caregivers, and he is growing up in a healthy environment and is still having contact with his family and their culture. Different worldviews should be considered when discussing treatment options in indigenous children.

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