

AFTERWORD

The poetry written by teenagers at the Youth Transplant Kamp (YTK), sponsored by the National Kidney Foundation of Utah and Idaho, has had a far-reaching impact, crossing geographical and cultural boundaries. I experienced this firsthand when I was asked to speak at the First Congress of Multidisciplinary Management of Children with Kidney Disease in Guatemala City, Guatemala, in March 2006. The meeting was sponsored by the Guatemalan Society of Nephrology and the University of San Carlos. The University of Utah (U of U) Pediatric Renal Disease Program had initiated a relationship with the Guatemalan Foundation for Children with Kidney Disease in 2003. They are a part of an international program, “Sister Renal Centers” launched in 1997, in which Supportive Centers of Excellence are paired with Emerging Centers in developing countries. I was asked, along with my interdisciplinary team members at the U of U, to speak about psychosocial care in the kidney disease setting.

While I was honored by this request, I initially wondered, *What do I have to offer?* The economic, social, and cultural realities of health care in an emerging country were no doubt vastly different from Utah. With our wealth of resources, how could I comprehend the challenges facing children and families in the developing world? I understood that in Guatemala, 57% of the 12 million inhabitants lived below the poverty line, represented by an income of \$1 per day. One in 5 Guatemalans lived in extreme poverty with 50% of children suffering from chronic malnutrition. It was estimated that only 35% of patients with renal failure would ever be diagnosed and treated.

Social work concerns itself with the social support structures of our society: hospitals, schools, financial institutions, health-care resources. We advocate within and mobilize resources to support our patients and their families throughout the illness. We have access to a myriad of community resources, including specialty camps like YTK. Where could I find commonality, a bridge between the two worlds of pediatric psychosocial care? As I thought about it, the answer became quite obvious: through the voices of the patients themselves.

I approached the task with confidence that the poetry the YTK teenagers wrote would resonate with the medical caregivers in Guatemala. After all, Susan Sample and I had presented the poetry many times to transplant care professionals at local and national conferences. Our audiences reported feeling enlightened and inspired. I hoped and believed that our Guatemalan colleagues would as well.

In preparation for the presentation, the poetry needed to be translated into Spanish. With a large Spanish-speaking patient population in our transplant program, we relied on translators from U of U Hospital's interpreter pool. One young woman had worked with us in a variety of settings, including our transplant clinics. She interpreted for patients and families during critical illness junctures: initial diagnosis, discussions of treatment options, and rejection episodes. I witnessed a unique sensitivity and empathy in her interactions with families. I believed that she would capture the essence and authenticity of the teens' words.

I selected a group of poems that highlighted the themes Susan has so richly illustrated throughout this book: identity, body image, peer belonging, survival, hope, and mortality. During our poetry workshops, Brad Nelson, U of U hospital photographer, had volunteered to take informal candid portrait photos of the individual campers. Each presentation slide included the translated poem accompanied by the teen's portrait.

We arrived in Guatemala several days before the conference. Our hosts shared with us the richness of their country, the geography and the culture. They introduced us to their medical care system. We toured the hospital, clinics, and the future space that would become the first pediatric dialysis unit in Guatemala. Their passion about bringing pediatric care to the children of this area was contagious. We all felt a great honor as we shared our experiences and expertise.

During my presentation, I read the poems in English while they appeared on screen in Spanish: an interplay of written Spanish and spoken English – two languages, one voice. My audience was attentive, nodding in recognition throughout. On occasion, eyes brimmed. I imagined that they were seeing and hearing the voices of their patients in our patients'. I felt the poetry had made a universal connection.

After the presentation, individuals expressed their appreciation, and we strategized the logistics of setting up similar programs. What remains imprinted in my memory was a senior physician exclaiming, *Que regalo nos han dado!* Even with my limited Spanish, I knew what he was saying: "What a gift you have given to us!"

Our medical team, too, has been the recipient of this gift. The teens, some eagerly and others with hesitation, have shared their individual poems and chapbooks with their doctors and nurses. Patients and their medical staff

primarily communicate in the language of illness – vital signs, labs, medications. The poetry has provided the staff with a window into the teens’ inner world through a new language. The medical staff has come to see their patients in expanded ways. One teen reported that his doctor loved his poem and wanted a copy to hang in his office. When the teens shared their poetry, I suspect that they felt newly seen.

For me, participating in the YTK poetry workshops has truly been a gift, one of the highlights of a 30-year career. As a clinical social worker, I spent many hours with our young patients in hospital waiting rooms, at the bedside, on dialysis, in clinics, in school, and at camp. Through these shared experiences, I developed a clinical grasp of their unique struggles and needs. The intimacy that the art of poetry reveals has further deepened my understanding and informed my work.

Perhaps the greatest gift of the poetry workshops is what the teens have gifted to themselves: courage, introspection, shared intimacy, and peer connection through the honest expression of their common struggle.

I have always been acutely aware of the enormous benefits the expense-free camp – the National Kidney Foundation of Utah and Idaho pays for every youth to attend – and the poetry workshops provided for our patients. As I prepared for our visit to Guatemala, I found myself framing the camp and the poetry as “luxuries.” Yet, what is a luxury and what is essential? I struggled with this question. I thought about the essential needs so basic in developing countries such as food and health-care security. Now that I have witnessed the healing impact the poetry has had on our teenage transplant survivors as well as on medical staff here and in Guatemala, I would argue that it, too, is essential.

Pamela Grant, MSW, LCSW,
Retired Pediatric Renal Transplant Social Worker,
University of Utah Health Transplant Services,
Salt Lake City, Utah