



AMERICAN NEPHROLOGY NURSES' ASSOCIATION

**ANNA'S 42<sup>ND</sup> NATIONAL SYMPOSIUM**  
**MARCH 27-30, 2011**  
**HYNES CONVENTION CENTER, BOSTON, MA**

**Stories of End Stage Renal Disease (ESRD): Listening for the Un-say(able)**

*Kara Schick Makaroff, RN, BScN, MN PhD(c), Doctoral Candidate, Victoria, BC, Canada*

According to the United States Renal Data System (2010), the unadjusted mortality rate in the Chronic Kidney Disease population is 47-51% for those between 66-74 years old. Yet a societal denial of death prevails and consideration of ESRD as a life-limiting disease is not often discussed with ESRD patients or their families. Living with a chronic and life-threatening illness such as ESRD impacts quality of life, raises difficult questions about life, and is challenging to articulate. However, little is known about the aspects of living with ESRD that are difficult to discuss, ineffable, and beyond words.

The purpose of this narrative research project was to explore individuals' stories of living with ESRD particularly those experiences that are un-say(able). Un-say(able) refers to that which is both within yet beyond language, sayable and unsayable. Examples of the un-say(able) may include: not speaking of the risk of death; or ineffable aspects of confronting one's mortality that are hard to articulate and perhaps beyond words. Fourteen individuals with ESRD participated in 3 in-depth interviews. The participants had a mean age of 66, 10 were male and 4 female, time from diagnosis ranged from 1 to 50 years; 3 also had cancer and 1 had HIV.

A secondary analysis of the research project entitled "Re-stor(y)ing Life Within Life-threatening Illness" was completed. This project explored people's stories of facing life-threatening illnesses and how these experiences affected their understandings of health. Findings identified that the un-say(able) included that which: participants choose not to say; was alluded to but not said directly; was sayable but often unasked or unsaid; and was ineffable. Further, findings reveal that consideration of the un-say(able) may illuminate the diverse array of experiences that accompany ESRD and offer insights for nurses working to enhance the quality of life for these individuals. Attending to the un-say(able), as it is interwoven within language, may illuminate and provide insight into how to best support people and to promote quality of life for those living with ESRD.

*Abstract selected for presentation at ANNA's 42nd National Symposium, Boston, MA, 2011*