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Storying and Re-stor(y)ing End Stage Renal Disease

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A diagnosis of end stage renal disease (ESRD) creates substantial disruption in one's perceptions of self and life story. Increasing numbers of people with ESRD live in-between the promise of treatment and the threat of death and yet this experience is not well understood. This presentation will focus on findings from a narrative inquiry exploring how people living with ESRD story and re-stor(y) their lives. Participants in the study included 14 people with ESRD, ranging in age from 43-83; 10 were male, 4 female; 9 were on dialysis, 3 had been transplanted, and 2 had stage 4 CKD. One participant also was HIV positive and 3 also had cancer. The primary mode of data collection for this study was in-depth interviews. Four interviews, ranging from 1 to 3.5 hours, were held with each participant over three years.

Findings from the study revealed that trajectories of illness were continually changing; some participants lived in a state of relative wellbeing, others lived with increasing burdens of illness, some experienced life-threatening events, and a few progressed to end of life care. Participants used narratives to communicate information, manage the responses of others (including health care providers), and foreground what was important to them. From this disrupting experience, participants encountered pivotal questions related to spirituality, meaning and purpose of life, and their own identity within illness. Findings also demonstrate the significance of meta-narratives (e.g. stigma of illness and death) that shaped peoples' experiences. These findings challenge assumptions that health narratives are complete, unified, consistent, and enduring. Rather they are often incomplete, chaotic, inconsistent, and fluctuating. Care for people with ESRD needs to consider the uniqueness of each person's story and the shifts in storying over time.

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