Caregiving lifelines: Understanding the patient and caregiver perspective

Teresa Martin

Undergraduate Student, School of Nursing
Mentor: Dr. Rose Sakamoto

Background: The majority of worldwide "caregiving" for the sick takes place in the home, by a family member who is unpaid. Family caregiving dyads are at the center of healthcare however little qualitative research has been conducted to explore the aspects of this relationship that promote both the patient and the caregiver's sense of effective healing during this time.

Objective: The intent of this investigation was to uncover themes on what works in the caregiving relationship between family members and to share those findings with the broader public.

Methods: A qualitative, thematic analysis was conducted using Jean Watson's Theory of Human Caring framework. Fourteen key informants who self identified as both the "patient" and "caregiver" on separate occasions over the last three years were interviewed. Four open-ended questions were given to participants prior to the interview. Interview coders were trained and demonstrated acceptable inter-rater reliability.

Results: Having a community support system was more important to interviewees than the physical environment or professional support. The role of caregiver and patient were described as a learned role that evolved over time. And finally, bidirectional empathic and reflective communication was essential for healing.

Conclusions: The family dyad between patient and caregiver that promotes healing and a sense of wellbeing relied on three key ingredients: 1) consistent use of informal communities for support, 2) transforming or "becoming" the patient or the caregiver was learned over time, and 3) empathic listening was central and bidirectional in both roles and the relationship. Future research will be needed to understand how informal communities may best support the evolving patient-caregiver healing relationship.