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Tales of roller coaster rides and resilience: Lung transplant caregivers in their own words

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Purpose: The lung transplantation process is stressful for both patient and caregiver. Infection and rejection are post-transplant concerns that may impact long-term survival. Several qualitative studies have assessed caregiver feelings, but none of these have analyzed the effects of complications and re-hospitalization on caregiver stress and anxiety. The purpose of this study was to assess stress and anxiety levels of post-lung transplant caregivers, and how these may be affected by re-hospitalization and/or development of complications. The authors also wanted to gain an increased understanding of the post-transplant experience from the perspective of the caregiver.

Methods: A convenience sample of 94 caregivers was recruited from a large tertiary medical center. Caregivers were approached during the hospitalization of their significant other. Each caregiver completed the Perceived Stress Scale (PSS), and the State Trait Anxiety (STAI) inventory on three occasions; baseline, 4 weeks, and 8 weeks. Interviews took place at those times asking about the patient's location and health, and a description of the caregiving experience. Each interview lasted 30-60 minutes. The baseline interview was conducted face-to-face in the hospital; the 4 and 8 week follow-ups were by telephone. Interviews were written and transcribed as soon as possible.

Results/Conclusion: Nineteen caregivers dropped out or were lost to follow-up; 2 patients died during the study. Thirteen other records were deemed incomplete and were not included in the analysis. 60 interviews are currently being reviewed and coded. Most caregivers were married, white, female, and high school graduates. Both the PSS and STAI scores at all three data collection points were higher than normed group scores. Time since transplant and PSS scores were statistically significant ($r=0.29$ $p=0.005$) indicating the longer the caregiving experience, the higher the stress. Six themes have emerged from the interviews thus far. They include; 1) Concern for recipient health, 2) Concern for caregiver's health and well-being, 3) Not being prepared for the transplant experience, 4) Significant life changes made for recipient 5) the Honeymoon phase, and 6) Resilience. These are preliminary results; data analysis is on-going.

Biography

Alice Jane Haines has obtained her BSN from West Virginia Wesleyan College and her Master of Science in Nursing Education and Doctor of Nursing Practice from the University of Pittsburgh. She is currently an Assistant Professor in the Department of Acute and Tertiary Care at the University of Pittsburgh. She has worked for 33 years in Nursing and has 25 years of Nursing Education experience. She has also worked as a Staff Nurse for more than 5 years on a Lung Transplant Step-down Unit. Caring for Lung Transplant recipients and their caregivers is truly her passion.

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