Abstract:

When a child is diagnosed with cancer, families face a complex transition. After the cancer diagnosis, parents are presented with the daunting task of learning new ways to care for their child and family. The ‘pre-cancer’ family norms and practices change to a rearranged family life with new norms and experiences. Families often do not feel prepared to care for the intense emotional, mental, spiritual, physical, and constantly changing needs of their child and family. Transition is “a passage from one life stage or state to another and refers to both going through the process of a change and the outcomes of the change”. Inability of families to meet the complex care needs of patients are associated with many negative outcomes. Conversely, families who can adequately address the needs of the patient and family have reported positive outcomes and transition experiences. Currently, healthcare providers do not have enough information, time, and skills to systematically measure and assist families with the complex caregiving needs that are experienced during transitions at the diagnosis and treatment phase.

There are 67 specific skills, actions, and attitudes parents use to address holistic care needs of children with cancer in order to meet daily goals focused on caring for the family, partnering with healthcare providers, and living with cancer. Parents need assistance in developing and managing these extensive caregiving skills. Nurses, as the constant provider throughout the illness course, are the logical individuals to assist families with the assessment and development of these skills. Focusing on the initial stages of the cancer trajectory can promote early and long lasting positive parental and child health outcomes. Research focused on identifying, evaluating, and intervening in the transition experience and caregiving skills of families of children and young adults newly diagnosed with cancer is my priority and the Oncology Nursing Society Foundation Doctoral Scholarship is an integral part of my support network. My ultimate research goal is to identify and enhance the nurse’s role and patient/family experience as they transition through the cancer trajectory. Interventions that are identified to improve patient and family resilience, psychosocial outcomes, and quality of life for those diagnosed with cancer and their families would be further developed into an evidence-based guideline for healthcare systems and public policy.