

Surviving survival

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With advances in the treatment of childhood brain tumors, more children, some say up to 90 percent, survive and the numbers of caregivers have increased as have the demands placed upon them. Usually their caregivers are their mothers and other family members, especially for those survivors who do not gain independence in terms of their ability to live on their own, find work, make friends, and form partner relationships.

In the largest study of its kind, researchers led by the University of Pennsylvania School of Nursing have investigated the caregivers of 186 mothers to childhood brain tumor survivors aged 14-40 whose care needs last long into adulthood. They based their research on a model containing factors central to nursing practice, namely the [caregiver](#), the survivor, and the [family](#). They discovered that a complex interaction among components of the model, the health of the caregivers, the demands experienced by the caregiver, the caregiver's perceptions about the health of the survivor, and the family's support interact to explain how the caregiver assesses herself in her role. The study was recently published in *Health Psychology*.

"Based on the results of this study, either family functioning or caregiver's perception about the survivor's health can be targeted to improve competence for caregivers of adolescent and young adult brain tumor survivors," said Janet A Deatrack, PhD, RN, FAAN, the Shearer Endowed Term Chair in Healthy Community Practices and Professor of Nursing. "Interventions targeted to survivor health could emphasize recovery expectations and reframe notions about the survivor's

functioning through family systems and cognitive-behavioral interventions." The tumors and their treatment (i.e. surgery, chemotherapy, and cranial and/or spinal irradiation) can result in a range of late effects, including one of the most severe risk profiles for [childhood cancer survivors](#) (chronic morbidities and reduced health-related quality of life) and for their caregivers (ongoing care demands).

Specifically, the researchers tested a hypothesized model which confirmed that both the functioning of the family and the health of the survivor contributed to the caregiver's sense of competence. "The direct relationship of family functioning with caregiving competence emphasizes the central role of family in the adaption of the caregiver to his or her role. Instead of being predicted by caregiver demand as hypothesized, this study revealed that caregivers' assessment of their role mastery is influenced most strongly by the functioning of their family," wrote Dr. Deatrck, the lead author.

The study's findings offered hope for families, noted Dr. Deatrck. "Researchers and medical personnel can target either [family functioning](#) or the [health](#) of the survivor as means of improving the competence of caregivers." Dr. Deatrck worked with colleagues and patients treated at The Children's Hospital of Philadelphia, including Wendy Hobbie, MSN, CRNP who also provides leadership in the School's nurse practitioner concentration that focuses on pediatric oncology.

Provided by University of Pennsylvania School of Nursing

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