

Moffitt researchers find adolescents with cancer concerned about their future reproductive health

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Researchers at Moffitt Cancer Center and colleagues have found that adolescents newly diagnosed with cancer have strong concerns about their ability to have children as cancer survivors. They also found that standard health-related quality-of-life survey tools used to elicit answers from teens with cancer did not accurately reflect these concerns. Parents, who often answer survey questions as proxies, often inaccurately relayed their child's reproductive concerns.

The study, carried out by Moffitt researchers and colleagues from the University of South Florida, the University of Florida, All Children's Hospital and Children's Hospital of Orange County Children's Cancer Institute (Orange, Calif.) was published in a recent issue of *Pediatrics* (129:4). The study was funded by National Institutes of Health grants UL1 DE19587 and UL1 DE019587. It was funded through subcontract from the Oncofertility Consortium at Northwestern University and done in collaboration with Caprice Knapp, Ph.D., a UF researcher and Moffitt member.

According to study lead author Gwendolyn P. Quinn, Ph.D., associate member at Moffitt and director of the Survey Methods Core Facility, in [pediatric cancer](#) settings there are occasions when parents act as proxies and answer surveys for their children.

"Our study found inaccuracies in parent-predicted responses of their

daughters' reproductive concerns," Quinn said. "Parents often underestimated their daughters' concerns about having children in the future. These parental [misperceptions](#) suggest that the health-related quality-of-life survey instruments designed to answer these questions are inappropriate for adolescents with cancer."

To carry out this study, the research team interviewed 14 adolescents ages 12 to 18 who were newly diagnosed with cancer at hospitals in St. Petersburg, Fla., and Orange, Calif. They also interviewed a parent of each patient, in most cases the mothers, who were asked to predict how their child would answer specific questions concerning fertility and their reproductive concerns for the future.

Audio-taped interviews with patients and parents were carried out separately to ensure that parents did not prompt adolescent answers or prevent their children from expressing their feelings. Fourteen adolescent-parent pairs were interviewed. One of the research objectives was to determine whether health-related quality of instruments intended to capture reproductive concerns was sensitive and appropriate for adolescent patients with cancer.

The interview questions ranged from determining understandings about fertility, to asking if one day the participant would like to have a baby, to "do you feel like you can talk with your parents about fertility" and how would the patient feel if she could not have a baby in the future.

"Sixty-four percent of the parents provided answers that were incongruent with how they predicted their child would answer the questions," explained Quinn. "For example, half of the parents who said their daughter did not want to know about risks to fertility posed by [cancer](#) and treatment were also incongruent on five or more statements."

The researchers also found that 75 percent of parents who said that their

daughters did not worry about having a baby in the future were also incongruent on more than five other questions.

"Overall, parents underestimated their daughters' reproductive concerns," Quinn said. "The majority of adolescents reported a strong desire for future parenthood, whereas [parents](#) expected their daughters to be satisfied with survivorship."

The researchers also concluded that health-related quality-of-life surveys used to establish the reproductive concerns of adolescents by parental proxy reporting are "not suitable for capturing specific emotions and feelings that are impacted by ... a life-threatening illness and long-term goals."

They further noted that researchers should use child self-report whenever possible and that it should be documented when a parent-proxy response has been made.

"Our findings suggest that discussion about future parenting should be encouraged with adolescent patients before they begin treatment," concluded Quinn.

Provided by H. Lee Moffitt Cancer Center & Research Institute

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