

Scarring, Disfigurement and Quality of Life in Long-Term Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study

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Abstract:

PURPOSE: Childhood cancer survivors are at increased risk for adverse outcomes and chronic medical conditions.

Treatment-related scarring, disfigurement and persistent hair loss, and their long-term impact on psychological distress or health-related quality of life (HRQOL) has received little attention.

METHODS: Self-reported scarring/disfigurement and persistent hair loss were examined in 14,358 survivors and 4,023 siblings from the Childhood Cancer Survivor Study. Multivariable models were used to examine associations with demographic and cancer treatment. The impact of disfigurement and hair loss on HRQOL (i.e. Medical Outcomes Short Form–36) and emotional distress (i.e. Brief Symptom Inventory–18) was examined.

RESULTS: Survivors reported a significantly higher rate of scarring/disfigurement compared to siblings for head/neck (25.1% vs. 8.4%), arms/legs (18.2% vs. 10.2%), chest/abdomen (38.1% vs. 9.1%) and hair loss (14.0% vs. 6.3%). In age-, sex-, and race-adjusted models, cranial radiation exposure ≥ 36 Gy increased risk for head/neck disfigurement (RR=2.42; 95% CI=2.22-2.65) and hair loss (RR=4.24; 95% CI=3.63-4.95). Adjusting for cranial radiation, age, sex, race, education, and marital status survivor hair loss increased risk of anxiety (RR=1.60; 95% CI=1.23-2.07), while head/neck disfigurement increased risk of depression (RR=1.19; 95% CI=1.01-1.41). Limitations due to emotional symptoms were associated with head/neck disfigurement (RR=1.24; 95% CI=1.10-1.41), arm/leg disfigurement (RR=1.19; 95% CI=1.05-1.35) and hair loss (RR=1.26; 95% CI=1.09-1.47).

CONCLUSION: Survivors of childhood cancer are at increased risk for disfigurement and persistent hair loss, which is associated with future emotional distress and reduced quality of life. Future studies are needed to better identify and manage functional outcomes in these patients.