

Childhood Cancer Survivor Study participants' perceptions and knowledge of health insurance coverage: implications for the 2010 Health Care Reform Law

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Background. Quality health insurance coverage is critical for childhood cancer survivors (CCS) who face long-term health consequences from their cancer and treatment. Compared to siblings, CCS are more likely to be uninsured and, if covered, are more likely to have public insurance. Improving health insurance, within the context of changes that are mandated by the 2010 health care reform law, requires understanding CCS: a) perceived quality of coverage, b) coverage needs and barriers, and c) knowledge of health-insurance related legislation.

Methods. From 09/09-02/10, we conducted in-depth interviews with 39 participants from the Childhood Cancer Survivor Study (a cohort of five-years survivors of cancers diagnosed < age 21). Interviews were recorded and transcribed; content analyses were conducted by 2 coders (Kappa=0.88) using NVivo 8. 25 participants were insured; 56% were < 30 years, and 74% were White, non-Hispanic.

Results. Most insured survivors reported being satisfied with the quality of their coverage but had low expectations for coverage. Over half reported annual out of pocket costs > \$2,000, an indicator of being underinsured, yet felt fortunate to simply have coverage. Most uninsured survivors were employed but had been uninsured for many years; cost and being unable to find a job that offered insurance were the most frequently cited coverage barriers. Understanding of insurance provisions was generally poor; most insured and uninsured survivors were unable to specify what types of services or coverage options they needed from a plan. Almost all participants lacked knowledge about existing insurance legislation (e.g. ADA).

Conclusions. Our findings about CCS' coverage perceptions and knowledge about insurance provisions and legislation are of concern. Insured CCS seemed primed for low coverage expectations, and uninsured CCS found insurance financial prohibitive. Both advocacy and education will likely be needed to assist CCS to access and utilize the new health care reform provisions (e.g., Medicaid expansion, eligibility for a high risk pool, or expansion of parents' insurance).