“Nothing Is as Great a Learning Experience as Getting a $15,000 Bill”: A Mixed-Methods Study of Young Adult Cancer Survivors' Experience With Insurance Coverage

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Purpose: To explore long-term young adult (YA) cancer survivors' experience with health insurance in a post-Affordable Care Act (ACA) era.

Methods: This was a mixed-methods analysis of insurance-related data collected from a cohort of English-speaking YA (currently age 18-39 years) blood cancer survivors, ?3 years from diagnosis, recruited from six US hospitals as part of a financial navigation interventional study (ClinicalTrials.gov identifier: NCT05620979). Participants completed baseline questionnaires, with a subset participating in semistructured interviews after the 6-month study period. Summary statistics were reported for survey responses. Qualitative interviews were coded using directed content analysis.

Results: A total of 130 long-term (median, 10 [IQR, 6-16] years from diagnosis) YA survivors were enrolled, and 45 participated in interviews. Among the total cohort, most (63%) had employer-based private insurance; 22% had public insurance through Medicaid. Eighteen percent reported seeking a new health insurance plan in the past year to afford survivorship care. Over a fifth (23%) reported not knowing how to seek help navigating insurance, while 30% reported delaying or forgoing survivorship care because of not understanding their insurance plan. Four themes emerged from the interviews: (1) Many YA survivors experience insurance churn (ie, moving between plans or between insured and uninsured status); (2) learning to navigate the insurance system is confusing and not straightforward; (3) interactions related to insurance coverage are time-consuming and stressful; and (4) insurance churn and/or out-of-pocket costs affect YAs' ability to receive optimal medical care.

Conclusion: Ongoing insurance-related challenges persist for YA cancer survivors in a contemporary post-ACA era. Although the ACA has provided essential coverage for many patients, ongoing issues include excessive insurance churn, lack of navigation resources, and the continued financial burden of out-of-pocket costs.

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