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Uptake of germline cancer genetic services in a randomized trial of remote telehealth services as compared to usual care: a report from the Childhood Cancer Survivor Study (CCSS)

Background: Limited access to genetic services in community practices, leaves many childhood cancer survivors who are genetic carriers unidentified and at risk for subsequent malignant neoplasms (SMNs) due to therapy or an inherited cancer predisposition. The **ENG**aging and **A**ctivating cancer survivors in **Ge**netic services (ENGAGE) study evaluated the effectiveness of an in-home, collaborative PCP (primary care provider) model of remote centralized telehealth services to increase uptake of cancer genetic services in survivors compared to usual care.

Methods: 414 survivors were randomized to remote services by phone or videoconference (n=281) or usual care (n=133). The primary outcome was uptake of genetic counseling or testing at 6 months. In secondary analyses we evaluated baseline characteristics and patient reported outcomes associated with uptake of services. We used Fisher's Exact tests, Chi-squared tests, and T-tests for analyses.

Results: Participants were identified through the NCI-funded CCSS and included 189 (45.7%) male, 88 (21.1%) nonwhite participants with mean age 52 years (SD 0.65), recruited from over 40 states with a history of CNS tumors (n=190, 46%), sarcoma (n=116, 28%), or SMN or a family history of cancer (n=108, 26%). At 6 months, 40% (n=113) of survivors in the remote telehealth services arms utilized genetic services as compared to 16% (n=21) in the usual care arm (p<0.001). Factors associated with uptake of services included lower baseline genetic knowledge score (31.0, SD 5.8 without uptake versus 29.7, SD 5.1 with uptake, p=0.025), having more relatives with cancer (1.6, SD 1.5, without uptake versus 2.0, SD 1.8 with uptake, p=0.019), having a higher perceived risk of cancer on a Likert scale (3.6, SD 1.0 without uptake versus 3.9, SD 0.8 with uptake, p=0.011), having a history of internet use (35% uptake with use versus 0% without use, p=0.040), and not having a high deductible plan (30% uptake with high plan versus 42% without, p=0.025). Having a higher positive attitude toward genetic testing score (e.g. higher perceived value, lower perception of high cost and lower anticipated distress) was associated with uptake of services (29.5, SD 4.3 without uptake versus 31.2, SD 4.4 with uptake, p<0.001).

Conclusions: These data suggest that offering remote centralized telehealth genetic services increases the uptake of genetic services in survivors of childhood cancer across the US using a collaborative PCP model. Although uptake was higher than usual care, barriers to uptake of genetic services remain, including concerns about cost and negative perceptions about genetic testing. Strategies to address multi-level barriers to genetic services are needed to realize the potential of genetic testing in childhood cancer survivors and patients in community practices.