Unaddressed cancer-related distress is associated with more unmet needs, lower quality of life.

Rural survivors do not know how to access supportive care resources post-treatment completion. "Appointment stacking" occurs during treatment, prioritizing medical care; supportive care has less emphasis.

Rural survivors travel long distances when they need to return to the site where they received primary treatment. Survivors are less willing to travel for supportive care than treatment.

Rural Cancer Survivorship Impacts of Rurality on Quality of Life

Many cancer practices deliver survivorship care plans (SCPs) at the end of treatment visit. Timing of Survivorship Education

At the conclusion of treatment, rural survivors are focused on having survived, not what is coming next.

Assessment and education after the end of treatment visit and uncoupled from the medical aspects of treatment may be warranted to aid understanding of and adherence to SCP recommendations for health promotion and cancer surveillance. However, the optimal timing of survivorship education is not clear and may not be the same for all survivors.

There were approximately 53,000 men and women diagnosed with head and neck cancer (HNC) in the United States in 2019.


BACKGROUND

Rural Cancer Survivorship

- Survivors travel long distances when they need to return to the site where they received primary treatment.
- PCPs receive little education or training in cancer survivorship. Rural PCPs manage survivors of an array of cancers, from different treatment sites, making their care of rural survivors highly complex.
- Rural survivors have lower survival rates than their urban counterparts, and lower quality of life.

Limited Recognition of Cancer-Related Distress

- “Appointment stacking” occurs during treatment, prioritizing medical care; supportive care has less emphasis.
- Rural survivors do not know how to access supportive care resources post-treatment completion.
- Survivors are less willing to travel for supportive care than treatment.

Impacts of Rurality on Quality of Life

- Unaddressed cancer-related distress is associated with more unmet needs, lower quality of life.
- Rural HNC Survivors’ “Unmet Needs”
  - Unmet needs are those that are needs that go unaddressed during cancer treatment and survivorship. Unmet needs impact quality of life.
  - Approximately 2/3 of HNC survivors have unmet needs during their survivorship trajectory; 5.8 unmet needs per person.
  - In one study, 25% of HNC survivors meet screening criteria for depression, 22% meet criteria for anxiety, and 27% are at risk for PTSD.
  - Linger ing physical symptoms drive unmet needs.
  - One year post operatively survivors physical symptoms, pain (45.1%) and difficulty swallowing (45.7%), dry mouth (95.4%), taste change (82.8%), and fatigue (76.1%).
  - Four to five years post-treatment completion still 3.7 per person.

Travel distance is independently associated with more unmet needs and poorer quality of life during head and neck cancer survivorship.

INTERVENTION

Comprehensive Assistance: Rural Interventions, Nursing and Guidance (CARING) involves a three step protocol with a specialized oncology registered nurse: Assessment, Education, and Referral.

The CARING intervention involves remote assessment with the NCCN Distress Thermometer and Problem List. The DT-PL was amended for a HNC survivorship population. Our version includes jaw swelling, hearing difficulties, and difficulty swallowing. The nurse reads the list to the survivor, and the survivors rates each area on a scale of 0 - 10. The nurse discusses the highest levels of distress with the survivor. Targeted education is provided. High distress (≥4 or identified through discussion) guides the referral component of the intervention.

Tel ehealth allows rural HNC survivors to connect to a visit with a UVA specialty practice oncology nurse via the UVA Center for Telehealth. Survivors with broadband access at home can connect from home. Others connect from another broadband-enabled location of their choosing or one of the UVA Center for Telehealth 100+ sites statewide.

Pictured: Allen Cupp, RN simulates a telemedicine assessment using the NCCN Distress Thermometer and Problem List with study team member Dr. Ivora Hinton.

RESULTS and NEXT STEPS

Eleven of 20 participants were offered a referral to supportive care. Only 7/11 accepted.

We are evaluating the how rural resilience may impact referral uptake.

Next steps involve evaluating impact of the intervention on quality of life and unmet needs outcomes.

SELECTED REFERENCES


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