Rural Cancer Survivorship Disparities

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Disparities

- Differences in the incidence, prevalence, mortality, and burden of diseases...that exist among specific population groups in the United States (National Cancer Institute).
  - Race or ethnicity
  - Gender
  - Sexual identity
  - Age
  - Disability
  - Socioeconomic status
  - Geographic location
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Common Sources of Cancer Disparities

• Lack of health care coverage
  – Medically underserved populations are more likely to be diagnosed with late-stage diseases
  – These might have been treated more effectively or cured if diagnosed earlier

• Low socioeconomic status
  – Low SES affects cancer disparities more than race or ethnicity
  – Predicts the likelihood of an individual's or a group's access to education, certain occupations, health insurance, and living conditions
Virginia Rural Cancer Survivors

- Over 1 million of Virginia’s 8.2 million residents (12.9%) live in rural areas.
- In 2012, there were over 300,000 survivors in Virginia
  - Nearly 40,000 cancer survivors living in rural Virginia
Rural Virginians are far Poorer than Urban Virginians

• In Virginia
  – Per-capita income in rural areas is $33,532 compared to $48,377 in urban areas
  – Rural poverty rate is 18.3% compared to 10.8% in urban areas.
Rural Cancer Disadvantage is Based on Lack of Geographic Access and Lack of Financial Access

- Logistical and financial challenges make it more difficult to ensure appropriate provision of services
  - Rural cancer survivors **travel long distances** to screening and treatment sites
  - Lack of financial resources exacerbated by **lack of resources in their regions**
Rural Cancer Patients Lack Resources to Maximize Care

- **Informational needs**
  - Rural patients lack information about screening and education, clinical and psychosocial needs, transportation, and financial assistance
  - Rural patients have *more difficulty understanding the education* they are given

- **Psychosocial needs**
  - Survivors experience a *lack of ongoing support*, particularly for depression

- **Financial needs**
  - **U.S. rural survivors are poorer** and more likely to be on Medicaid than their non-rural counterparts
  - Have higher unemployment and lower household income
Rural Virginia Academic Cancer Center

STAKEHOLDER ASSESSMENT
A stakeholder assessment was conducted at an academic cancer center in rural Central Virginia. The purpose was to evaluate how well patients’ needs were being met, from multiple perspectives.
**Methods**

- **Quantitative**: Patient surveys with Likert-scale response design were placed in waiting rooms across all Cancer Center sites.
- **Qualitative**: Nearly 50 interviews and four focus groups were conducted and transcribed.
Identification of barriers to care at each stage of the cancer care continuum
Patient Knowledge of Extended Survivorship Resources is Minimal

- Patient **awareness of resources in their home community for post-support treatment** is low (2.9/5.0)
  - Awareness of survival resources is **lower for those who live more than 10 miles from their treatment site** than those who live close by ($\bar{x} = 2.5$ and $3.7$, $p < .01$)
“We really try to follow, like the NCCN guidelines...we usually dictate into our notes that this is the follow-up protocol we would recommend. I don’t know how well some of the patients follow it, but you know, at least we do provide recommendations.”

- Medical Care Provider
Are We Looking in the Wrong Place?

Barriers to Rural Survivorship Care May Begin During Treatment
Our Care Providers Try to Minimize Rural, Low-Income Patients’ Financial Outlays During Treatment

“It’s usually a month’s income to make a trip to Charlottesville for some of these people.”

-Medical care provider

“A lot of patients are coming from 6 hours away and they’re indigent or very low income, so to ask them to come back 2 or 3 times is very hard.”

-Medical care provider

 “[Cancer patients] want the one stop shop they can get when they come here ...especially if they’re traveling from 4, or 5 or 6 hours away.”

-Support Care Provider
Appointment “Stacking” May Unintentionally Cause Rural Patients to Miss Support Care Providers During Treatment...

“We have patients with head and neck cancer who can’t swallow, we have patients in radiation ... whose chest wall is being irradiated and they can’t swallow anything because they have esophagitis... Who’s called in nutrition? Nobody.”

- Support Care Provider

“They leave the clinic and I have to call them to [coordinate their care] over the phone and it’s not ideal.”

– Support Care Provider
...which may be linked to lack of tie-in to support care services during survivorship

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“Sometimes I see [patients in the survivor phase] by accident. Sometimes they still come to support groups or they’re across the street [in another part of the medical center], or they’re here with a family member or they’re just here for a follow-up in the system for another service. A lot of the ones I see ...are there to see the doctor and I just happen to be in clinic that day and see them.”

–Support Care Provider
Next Steps: Current Study

• Survivorship needs of Rural, Low-Income Breast Cancer Survivors
• “Appointment stacking” phenomenon
• Survivorship Care Plans
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Survivorship Care Plan

• The Commission on Cancer Standards for Accreditation requires Survivorship Care Plans (SCPs) for Patients with Cancer

• SCP
  – A comprehensive care summary
  – Follow-up plan
  – At the completion of treatment

• Original goals were pared back due to widespread difficulty with implementation of SCPs
  – 25% of patients should have an SCP by January 1, 2016
References


