

## **Understanding Barriers Faced by Rural Adolescent and Young Adult Cancer Survivors**

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### **Background and Hypothesis:**

The current 5-year survival rate for adolescent and young adult (AYA) cancer diagnoses is 85.8%. However, AYA cancer survivors face many challenges including loss of insurance, infertility, sexual health concerns, physical disability, education barriers, housing instability, food insecurity, and decreased financial well-being. Survivors in rural areas may face additional challenges, such as lack of access to cancer centers, tailored resources, and networks of fellow AYA cancer survivors that may be available in large cities. The study goal was to better understand specific barriers to survivorship care for this rural population, using a comprehensive interactive workbook distributed to cancer survivors in Southwest Indiana.

### **Methods:**

A prototype workbook was distributed to 42 AYA survivors in southwest Indiana. Follow-up interviews were conducted with 11 individuals. Interviews with the first wave of eligible participants (n=7) provided perspectives on the workbook, helped identify potential improvements, and offered further insight into their survivorship experiences. These eligible participants were also invited to participate in an online forum to facilitate group discussions on potential improvements to the workbook. Responses were evaluated through affinity mapping to identify common themes.

### **Results:**

AYA cancer was found to have a lasting impact on physical health, mental health, and relationships for many of the AYA survivors. Importantly, only 27% of participants who completed the workbook responded “yes” to having received a survivorship care plan, suggesting barriers in communication between survivors and healthcare providers. Regarding overall health, the three largest barriers identified by cancer survivors in rural southwest Indiana were insurance coverage, mental health services, and the availability of services needed.

### **Conclusion:**

To strengthen survivorship care to rural survivors, our study suggests a need for better distribution and explanation of survivorship care plans, as well as increased access to stable insurance, medical services, and mental health services.