

Improving Care Coordination for Adolescents and Young Adults with Cancer: Building a Bridge between Needs and Services

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Abstract

Many of the 70,000 adolescents and young adults (AYAs) diagnosed with cancer each year do not receive services to address the full scope of needs they experience during and after cancer treatment. Such unmet needs result in negative outcomes for this population, including higher distress, poorer health-related quality of life, and higher physical symptom burden. Although interventions have been used to improve care coordination for AYAs (e.g., patient-reported outcome measures), limitations to their usability and usefulness have frustrated their real-world implementation and impact on AYA outcomes.

To facilitate a more systematic and patient-centered approach to coordinating care for AYAs, we developed the AYA Needs Assessment & Service Bridge (AYA NA-SB), a care coordination intervention which includes (1) a holistic needs assessment, and (2) a suite of referral pathways connecting AYAs to services and resources based on the needs they report. To optimize the usability and usefulness of AYA NA-SB, I leveraged user-centered design (UCD), an iterative process for intervention development that relies heavily on the engagement of prospective users (e.g., cancer program providers and staff and AYAs).

At the study's onset, I convened a multidisciplinary design team comprised of researchers, cancer care providers, and AYAs from whom I solicited input throughout data collection and analysis. First, I used mixed methods to examine user interactions with an initial prototype, the Cancer Needs Questionnaire-Young People (i.e., usability testing). Second, I used ethnographic contextual inquiry, including 'guided tours' and semi-structured interviews with prospective AYA NA-SB users, to assess characteristics of users and context which should be considered in the design and implementation of AYA NA-SB. Finally, through two prototyping workshops, the design team collaboratively redesigned the Cancer Needs Questionnaire-Young People and designed referral pathways to optimize the tool's usability and usefulness. The product of the project, AYA NA-SB, has the potential to improve care coordination and subsequent outcomes for AYAs with cancer, an understudied and underserved population.

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