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Peer i-Coaching for Activated Self-Management Optimization in Rural AYA Cancer Survivors and Parents: Intervention Protocol

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Purpose: An increasing growing burden of chronic illness has led to a shift in care models from curative, provider-centered care to adaptive, patient-centered self-management model. Applying this approach to the development of self-management skills for adolescents and young adult (AYA) cancer survivors is critical because AYA cancer survivors and their parents/caregivers experience unique challenges with their transition to survivorship and adult-based care. Thus, we developed a protocol for implementing peer i-coaching for activated self-management optimization (PiCASO) focused on developing AYA cancer survivors' independent self-management skills and patient activation as well as parents/caregiver transition from directive to non-directive support.

Methods: In a parallel group, two-arm, randomized controlled trial, 180 dyads of adolescents and young adults (16-26 years) and a parent/caregiver living in rural areas of NC, who are within three years of completion of active cancer treatment, are assigned to receive either the peer i-coaching for activated self-management (PiCASO) intervention or attention control. They will be enrolled in the study for six months. This mobile health technology intervention uses a secure platform to allow AYA cancer survivors to connect with a trained peer coach, who has successfully transitioned to survivorship and adulthood, to gain knowledge, experience, and support. The peer coach supports the AYA to identify their goals and feel a sense of success in progress towards goals within a supportive environment. The parent coaching intervention is delivered by parents of AYA cancer survivors. They will receive coaching in the transition from directive to non-directive support. The shared experience of being a cancer survivor, or a parent/caregiver of a cancer survivor, is unique and allows the provision of both instrumental and illness specific emotional support. Involving peers in supporting AYA cancer survivors to gain self-management and health care navigation skills will facilitate a shift in the typical over-reliance on the parents, to the development of independence. For parents/caregivers, support from an experienced parent-coach will assist in allowing the AYA cancer survivor to become a successful young adult and engaged cancer survivor while addressing complex emotions related to their child's survivorship. The primary outcome measures of self-management and patient activation will be measured at baseline, 1,3,6 months. Secondary outcome measures of impact of cancer, hopeful future expectations, and stress will also be measured at these time

points. In addition, qualitative interviews will be conducted for 50 purposively sampled dyads.

Results: AYA cancer survivors who receive peer coaching are expected to report higher self-management skills and patient activation as compared to the attention control group. Parents/caregivers will gain skills in the use of non-directive supportive tools associated with positive coping and with lower rates of depression/anxiety.

Conclusion: Increase in life expectancy for AYA cancer survivors has brought unique challenges with the associated disease burden, transition to survivorship and adult-based care, and need for independent self-management skills. Further adding to the challenges is the need for AYAs to progressively take over greater self-management responsibilities from their parents/caregiver. Therefore, an effective intervention is necessary to optimize self-management skills as well as to actively engage them into care.

Title:

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Keywords:

AYA cancer survivor, peer coaching and self-management

Abstract Summary:

This is an intervention protocol for a mixed-methods, randomized controlled trial of peer i-coaching for activated self-management optimization (PiCASO) in rural adolescent and young adult cancer (AYA) survivors and their parents/caregivers. The intervention aims to address challenges of transition to survivorship for rural AYA survivors and their parents/caregivers.

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