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

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INTRODUCTION

- The growing burden of chronic illness has led to shifts in care models from curative, provider-centered care to patient-centered self-management model.
- The development of self-management skills for adolescents and young adult (AYA) cancer survivors is critical they and their parents/caregivers experience unique challenges in transition to survivorship and adult-based care.
- We developed the intervention protocol "***Peer i-coaching for activated self-management optimization" (PiCASO***) to focus on the development of independent self-management skills and patient activation in AYA cancer survivors as well as parents/caregiver's transition from directive to nondirective support.

PURPOSE

Aim: To address challenges of transition to survivorship for rural AYA cancer survivors and their parents/caregivers

METHODS

Design: A mixed-methods, randomized controlled trial design

Goal: A total of 180 dyads of adolescent and young adult (AYA) cancer survivors 16 to 26 years of age and a parent/primary caregiver

Recruitment: Participants will be recruited through the Duke Cancer Institute's (DCI) Teen and Young Adult Oncology Program

Eligibility Criteria

AYA inclusion

- AYA cancer survivor 16 to 26 years
- Completed active treatment
- Read and speak English
- Access to internet via computer or Smart Phone
- Access to telephone (if no Smart Phone; text feature can be accessed via internet)
- Parent or primary caregiver able to participate in study

AYA exclusion

- Diagnosed cognitive dysfunction

Parent inclusion

- Parent of AYA cancer survivor (16-26 years) who has consented/assented to study
- Read and speak English
- Access to internet via computer or Smart Phone
- Access to telephone (if no Smart Phone; text feature can be accessed via internet)

Parent exclusion

- Known cognitive impairment

METHODS continued

Intervention:

- PiCASO, a mobile health technology intervention, uses a secure interface to connect AYA cancer survivors with a trained peer coach.
- AYA coaching intervention is delivered by young adults (18-30 years) who transitioned from active treatment to post-treatment survivorship at least 3 years prior to the study and trained using a tested curriculum (i.e. motivational interviewing techniques, nondirective health coaching process)
- The peer coach supports the AYA to identify goals and achieve success in progress towards goals within a supportive environment
- The parent coaching intervention is delivered by parents of AYA cancer survivors.
- The benefits of peer relationships over a shared experienced such as cancer survivorship allow the provision of both instrumental (i.e. health maintenance skills, resource identification) and illness specific emotional support

Table 1. Outcome Measures

Type	Name	Time frame	Brief description
Primary	Partners in Health Scale (PIH)	Baseline, 1-, 3-, 6-months post randomization	Assesses chronic condition self-management, partnership in treatment
Primary	Patient Activation (PAM)	Baseline, 1-, 3-, 6-months post randomization	Measures patient activation through self-reports of knowledge, skills, confidence related to self-management
Secondary	Impact of Cancer for AYAs (IOC-AYA)	Baseline, 1-, 3-, 6-months post randomization	Validated scale; 4 subscales (social life, uncertainties/worries, identity, life goals/purpose)
Secondary	Parent Experience of Child Illness Scale	Baseline, 1-, 3-, 6-months post randomization	Assessment of parental adjustment related to caring for a chronically ill child
Secondary	Child Self-Report Response to Stress Questionnaire-Pediatric Cancer Survivor	Baseline, 1-, 3-, 6-months post randomization	Cancer related stressor self-report for AYA cancer survivor
Secondary	Parent Report-Response to Stress Questionnaire-Pediatric Cancer Survivor	Baseline, 1-, 3-, 6-months post randomization	Cancer related stressor self-report for parent of AYA cancer survivor
Secondary	Parent-Patient Activation Measure	Baseline, 1-, 3-, 6-months post randomization	Measures patient activation related to self-management of child's activation
Secondary	Hopeful Future Expectations	Baseline, 1-, 3-, 6-months post randomization	4 items from the original 13-item HFE measure

Statistical Method:

- A target sample size of 180 AYAs (PiCASO N=120; control: N=60) will provide at least 80% statistical power with medium effect (Cohen's d equivalent of 0.50)
- Descriptive statistics to detail the (a) sample characteristics and (b) AYA and parents measures collected at four assessment points
- Non-directional statistical tests will be performed with the significance level set at 0.05 for each test
- Effect sizes and 95% confidence interval to address clinical significance for the efficacy analyses

HYPOTHESES

- AYA cancer survivors in the intervention group are expected to report higher self-management skills and patient activation as compared to the attention control group.
- Parents/caregivers will gain better ability to use nondirective supportive tools that has been associated with positive coping and with lower rates of depression/anxiety in response to an emotional stressor.

CONCLUSIONS

- 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.

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