

Anoushka Sinha, MD, MS

Faculty Mentors: Sumeet Banker, MD, MPH; Justine Kahn, MD, MS

CHONYCorps: A Pilot Study of a Storytelling Intervention on Adolescents and Young Adults with Cancer and Their Caregivers

Study Purpose and Rationale:

Adolescents and young adults (AYAs) with cancer experience considerable stress and anxiety as they adjust to a multitude of changes and yet strive to assert their developing voices and identities.¹ Meanwhile, it is well known that family caregivers of patients with cancer also carry high levels of stress and anxiety.^{2,3} Resilience-promoting interventions that involve meaning-making activities have been introduced for AYA patients⁴⁻⁹ and caregivers¹⁰ separately, but few interventions have sought to leverage and nurture the family bond by formalizing conversations that could help both AYAs and their parents cope together.

StoryCorps is a nonprofit founded in 2003 that promotes “conversations about what’s really important in life” with the premise of recording an interview between two people who know each other.¹¹ Participants choose and/or generate a list of questions to ask as well as identify those questions which they would not feel comfortable addressing before they complete an approximately 40-minute interview. This format offers an opportunity for AYA patients and their caregivers to engage in a meaning-making conversation and for patients, as interviewees, to feel centered in expressing themselves on their own terms, which may in turn promote resilience and decrease psychological distress.

Study Design:

This pilot study will employ a mixed-methods approach. Goal enrollment is 10 patient-caregiver dyads. Eligible patients and caregivers who are admitted to the hospital will be ascertained from the electronic medical record and invited by a treating provider to speak to a study investigator. If the patient and caregiver agree, an investigator will approach and invite them to participate in a StoryCorps-inspired interview (“CHONYCorps”). If both patient and caregiver consent to participate, they will be asked to complete a baseline survey that asks for name, age, gender, race/ethnicity, insurance status, and time point in illness and includes validated resilience and psychological distress scales. They will then be given a list of potential questions drawn from the StoryCorps archive and arrange a day and approximate time during the current admission to complete the interview. The investigator will facilitate the interview by providing the patient and caregiver with microphones and recording an approximately 40-minute conversation.

After completing the interview, the patient and caregiver will complete a survey that reassesses their resilience and psychological distress and includes questions about the impact of the experience (“What did you learn about your parent/child?”; “What did you learn about yourself?”; “Would you recommend this experience to another patient/caregiver? Why/why not?”; “Would you change anything about this experience? If yes, please describe.”). The patient and caregiver will also have the options of having their photo taken; sharing an approximately

10-minute cut of their interview with their providers; sharing that 10-minute cut with the public as a podcast episode and/or on Radio Lollipop; receiving a personal copy of the 10-minute cut; and attending a Zoom listening party with other patients and caregivers at the end of the study period.

If they choose to share the clip with their providers, it will be sent to their care team and primary oncologist along with a survey about the impact of listening (“Has your understanding of the patient changed? If so, how?”; “Do you think that information will make your patient easier to treat? Please elaborate.”; “Would you refer another patient to participate in CHONYCorps?”).

At an outpatient visit about 3 months after participating in the interview, the patient and caregiver will be asked to complete a third and final survey that reassesses their resilience and psychological distress and asks for their feedback about the project (including, if they had chosen to share the clip with their providers, whether they think doing so impacted their quality of care).

Statistical Procedures:

The Connor-Davidson Resilience Scale and Kessler-6 Psychological Distress Scale are validated scales that have been successfully applied both to AYAs with cancer and adults. The 10-Item Connor-Davidson Resilience Scale has a total score ranging from 0 to 40, while the Kessler-6 Psychological Distress Scale has a total score ranging from 6 to 30. The primary outcome of this study is to use these scales to detect differences in resilience and psychological distress for participants from baseline to post-intervention. Given an expected improvement of ~15 points from baseline, power analysis using paired t-test to detect a difference between scores, a sample size of <6 patients and caregivers should be sufficient with 80% power using an alpha value of 0.05. I will aim to enroll 10 patient-caregiver dyads.

Hypotheses:

- CHONYCorps will have a beneficial and sustained impact on resilience and psychological distress in both the AYA patient and caregiver.
- If the interview clip is shared with the patient’s care team, the patient and caregiver will endorse improved quality of care.
- If the patient’s providers listen to the interview clip, they will endorse improved understanding and ease of treating the patient.

Potential Risks:

Participating in the study could elicit uncomfortable emotions and provoke potential conflict between the patient and caregiver. There are no anticipated medical risks associated with participation in the proposed research.

Potential Benefits:

Participating in the study could provide an opportunity for participants to express themselves, engage in a creative endeavor, and develop a stronger connection to themselves and their family.

Alternatives:

Patients may choose not to participate in the study and continue to receive usual care.

References:

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