Title: Effects of Digital Stories Intervention on Psychosocial Well-being for Cancer Patients and Caregivers undergoing Hematopoietic Stem Cell Transplantation (HCT) PI: Kim

ASU: Larkey, Langer, Todd
Mayo: Khera; Consultant: Weihs

Award number: R15CA213035 to Arizona State University by National Cancer Institute of the National Institutes of Health
NCT number: NCT03654599
Date: 9/21/2023

Scientific Background

Patients undergoing hematopoietic stem cell transplantation (HCT) are at particular risk for reduced psychosocial well-being. The process is extremely rigorous, requiring relocation to a transplant center, and is associated with multiple acute medical and psychosocial sequelae. HCT patients often report anxiety, depression, and social isolation due to the intense and aggressive transplant experience, such as prolonged recovery and multiple post-HCT complications that result in frequent hospitalizations. Caregivers of HCT recipients also experience high levels of psychosocial distress due to stressors such as caregiving responsibilities and beyond, plus deep concern for their loved ones. Interventions that help cancer patients authentically express and disclose their emotions through supportive open dyadic communication with caregivers have been found to be effective for reducing emotional distress, but time and resources to access professional services are often severely limited. Thus far, however, interventions to alleviate psychosocial distress for both patients and caregivers after HCT have been rare and have yielded inconclusive results.

A narrative-based (storytelling) approach may be an effective intervention tool for HCT patients and caregivers coping with psychosocial distress. Although narratives have been applied and tested to influence health behavior in cancer education and care, there have been **only a few** rigorous tests of narrative effects for therapeutic purposes, and **none of this research has been conducted with HCT patients and caregivers**. Our preliminary data show that stories shared by individuals in which a range of emotional expressions or resolutions are described may have beneficial effects on emotional well-being. In a pilot study with breast cancer patients, participants who viewed digital stories about others coping adaptively with emotions showed reduced emotional distress. In a recent pilot study of a 3-day digital storytelling workshop, we produced a series of digital videos with narratives from a panel of HCT survivors. **We propose to use these digital stories (DS), to be viewed and discussed by HCT patient/caregiver dyads, as a therapeutic intervention and to examine the influences on their psychosocial status.** This low-cost, non-invasive, and easy-to-deliver psychosocial support vehicle has never been formally tested as an intervention for HCT patients or patient-caregiver dyads.

Design and Methods

To build upon our preliminary studies and to pilot test the efficacy of this series of DS, 110 adult patients undergoing HCT at the Mayo Clinic Arizona and their respective adult caregivers (N=220 total participants) were randomized to either (a) an intervention using DS (dyadic exposure to four 5-minute modules) or (b) an information control (IC) video group (dyadic exposure to four videos containing *only information* about post-HCT care) followed by encouragement to discuss as a dyad. Exposure occured once per week over 4 weeks via a secure web-based data collection platform (REDcap) with a weekly email notification and reminder phone call. Participants completed questionnaires at baseline (T1), after the 4-week intervention (T2), and 3 months (100 days) later (T3). Using our model of ***Narrative Effects on Socio-Emotional Well-Being,*** we also examined expected mediating factors to determine how stories may "work" to reduce psychosocial distress by fostering emotional processing, acceptance, vicarious emotional expression and dyadic disclosure of emotions.

Objectives and Aims

Specific Aim 1: To test whether DS are more efficacious for improving psychosocial well-being in patient-caregiver dyads after HCT than an information-only control (IC) condition. Emotional outcomes were measured using the Profile of Mood States (POMS), and social outcomes were measured using the Functional Assessment of Cancer Therapy-General (FACT-G) social well-being scale.

Primary Hypothesis 1: HCT patients and caregivers exposed to DS (intervention arm) will experience less psychosocial distress than those exposed to the information videos (IC arm) at post-intervention (4 weeks, Time 2) and at 3-month post-intervention follow-up (Time 3).

Exploratory Question (EQ) 1: How do DS influence patients and caregivers (differently and/or similarly) in their experience of psychosocial distress, expressed through qualitative in-depth interviews (n=20)?

Specific Aim 2: To examine potential mediators and moderators of the influences of DS on psychosocial well-being in HCT patients and caregivers.

EQ2: What factors (e.g., age, gender, types of other support, treatment) moderate responses to the DS?

EQ3: Do hypothesized mediating variables explain the effects of DS on psychosocial distress, including transportation (i.e., getting carried away by the stories for vicarious emotional expression), emotional processing, identification with DS, and the disclosure of emotions between patients and caregivers?

Specific Aim 3: To employ an existing mentorship program with the Barrett Honors College at Arizona State University that will expose undergraduate nursing students to behavioral and psychosocial oncology research.

IMPACT: We expect DS to be useful to HCT patients and caregivers and to foster improved psychosocial well-being by providing relevant, enriching stories that help the dyads face emotional challenges. Testing the efficacy of narrative-based stories to reduce distress, improve quality of life, and reduce mortality and morbidity rates in HCT patients serves as a critical first step in our larger program of research. If this investigation is successful, we will develop a DS intervention for people with other cancers and in other languages to **reproduce and extend** the study for even broader dissemination of this potentially distress-relieving tool.