

Evaluating patient engagement with a digital intervention for adolescent and young adult (AYA) stem cell transplant survivors

Kellie E. Krohn^{1, 2}, Maria Camero¹, Andrea K. Galvan¹, Martha A. Askins¹, Jeffery McLaughlin³, Demetrios Petropoulos¹, Partow Kebriaei¹, Susan K. Peterson¹
¹The University of Texas MD Anderson Cancer Center; ²Saint Mary's College; ³Radiant Digital

Introduction

- Recovery from a hematopoietic allogeneic stem cell transplant (HSCT) is prolonged and requires rigorous self-care immediately after hospital discharge.
- For adolescents and young adults (AYAs), developmental and life stages present unique challenges and barriers to HSCT recovery.
- Stempowerment* is an online, interactive intervention to reduce barriers and increase motivation for self-care behaviors in AYA HSCT survivors, with the goals of optimizing medication adherence, hydration, activity and psychological well-being post-discharge (Figure 1).
- Process evaluations are an important component in interpreting and understanding facilitators and barriers to recruitment and retention, particularly for trials that include patients with a serious illness.

Study Aim

As part of a mixed-methods process evaluation, we evaluated study enrollment plus engagement with and completion of the intervention in order to identify potential problems, barriers, and strategies for improvement.

Materials and Methods

- Eligibility: age 18-39; English-speaking; allogeneic HSCT for leukemia or lymphoma diagnosis.
- Process evaluation assessed study recruitment and refusal rates, participants' website access and social interactions, completion of intervention components (i.e., "Quests") and surveys, and end-of-study interview.
- Demographic and clinical data were obtained from medical and study records.
- Literature review evaluated published interventions for AYAs HSCT survivors and relative burden.

Results

Figure 1. Study protocol

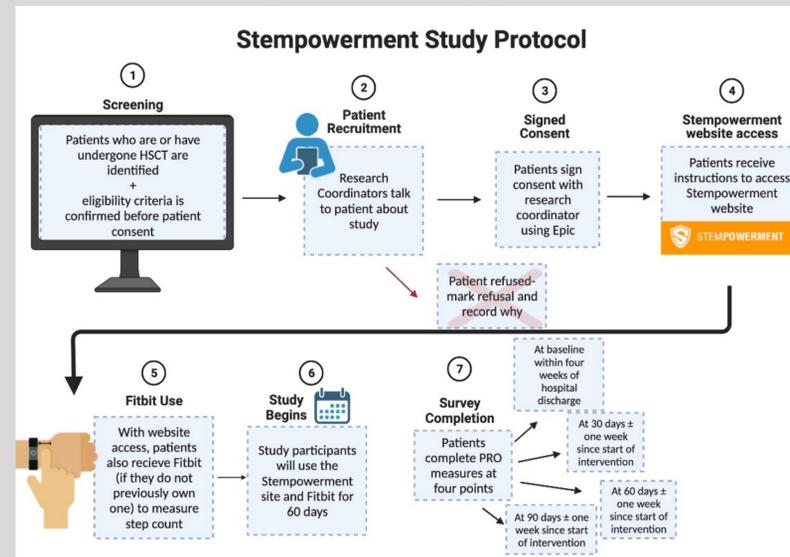
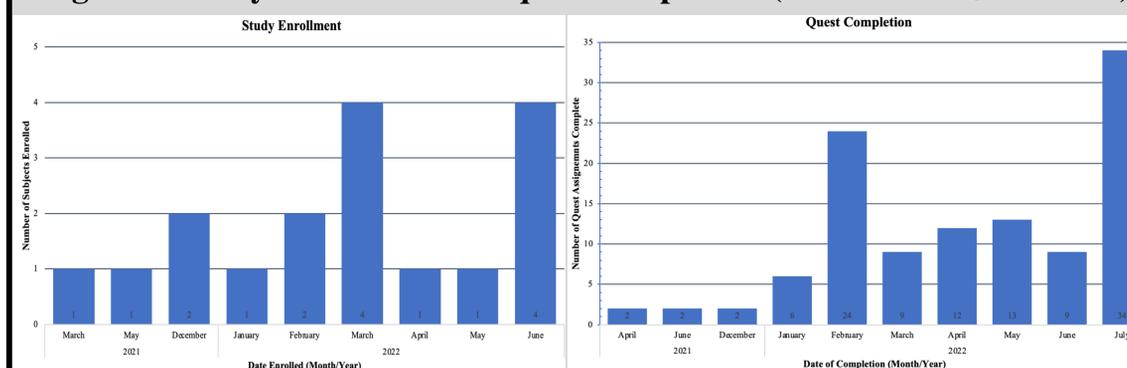


Table 1. Clinical and demographic data

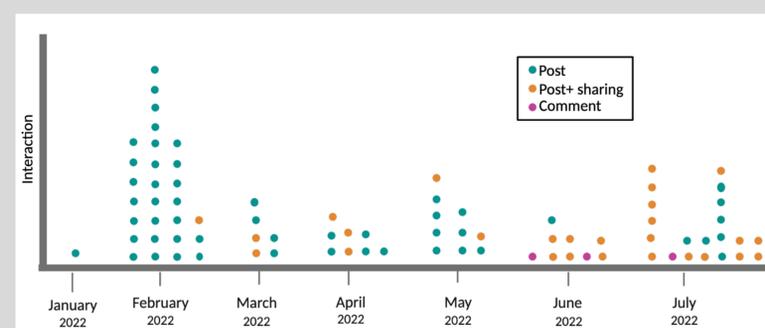
Participants (n=23)		Withdrawn (n=5)		Refused (n=16)	
Age (yrs.), range, mean	(20-39); 28.82	Age (yrs.), range, mean	(20-37); 30.2	Age (yrs.), range, mean	(19-36); 29.0625
Sex, male %	60.87%	Sex, male %	60%	Sex, male %	31.25%
Race/Ethnicity, White	59.10%	Race/Ethnicity, White	80%	Race/Ethnicity, White	62.5%
Black	9.10%	Black	20%	Black	12.5%
Hispanic	27.30%	Hispanic	20%	Hispanic	6.25%
Asian	4.50%	Asian	0	Asian	12.5%
Other	18.20%	Other	0	Other	12.5%
Married/S.O.	34.80	Married	40%	Married	43.75%
Diagnosis, Lymphoma	17.4%	Diagnosis, Lymphoma	0%	Diagnosis, Lymphoma	0%
Leukemia	82.6%	Leukemia	100%	Leukemia	100%

Figure 2. Study enrollment and quest completion (March 2021-June 2022)



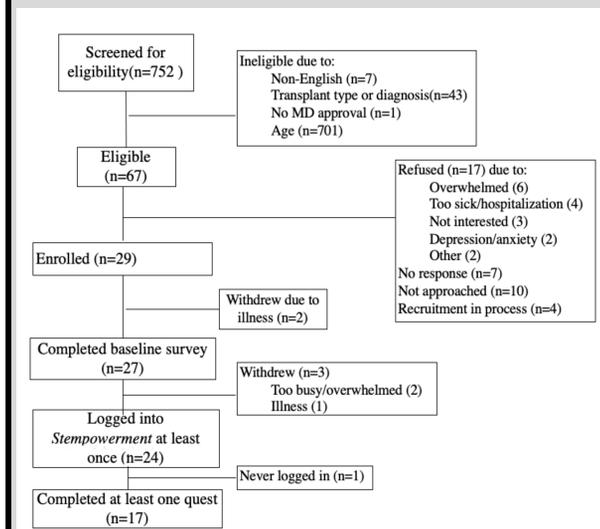
17.4% (n=4) completed all quests

Figure 3. Online social interactions (Jan-June 2022)



Results

Figure 4. Study enrollment & completion



Conclusions

- Consistent with other studies, common reasons for refusal or withdrawal include illness severity and feeling overwhelmed with HSCT.^{1, 2, 3}
- Univariate analyses comparing those who enrolled, refused or withdrew showed no differences in demographic or clinical variables.
- Most participants completed the baseline survey and completed at least one quest, however, only 4 (17.4%) completed all quests. Most online social interactions were limited to sharing quest completions.
- To address these findings, our participant communication plan was revised to increase text messaging reminders and include varied messages reinforcing participation.
- Preliminary qualitative evidence suggests that although the quantity of social interactions have not increased, more recent posts appear to be more frequent and may reflect greater engagement with the intervention and other users.
- Strategies to improve participation and engagement with digital interventions are needed, particularly for patients coping with serious illness and difficult treatments.

References

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