

# Correlates of Long-Term Follow-Up Care in Adolescents and Young Adults

Jasmin Medina-Martinez  
mjasminm@nursing.upenn.edu



## Introduction

- Adolescent and young adult (AYA) engagement in long-term follow-up care (LTFU) is vital to the management of physical and psychosocial late effects and surveillance of relapses or new cancer diagnoses in AYA survivors.
- AYA childhood cancer survivors experience cancer-related worries related to future risks and late effects.
- Managing AYA cancer-related worries may be important for successful engagement in LTFU.

### Aims

- Describe engagement in follow-up care among AYA cancer survivors.
- Investigate demographic (age, gender, race/ethnicity), medical (age at dx and time off tx), and psychosocial (cancer-related worries) correlates of annual follow-up engagement.

## Methods

### Design

- Subsample (57 AYA) from a longitudinal 3-year study tracking engagement and self-management.

### Participants

- Ages 16 to 25 AYA who have survived childhood cancer.
- At least 5 years since diagnosis and at least 2 years from end of treatment.
- Have seen a CHOP provider in the last 18 months.

### Procedures

- At baseline, AYA reported on demographics and completed the cancer-related worries scale (6 items, 0-3 scale). A total cancer worry score was computed (/18).
- Electronic health record review ascertained dx/tx history and whether participants had attended and/or had an appointment scheduled 1-year post enrollment.
- Independent sample t-test examined age and psychosocial correlates and chi-square test examined correlates in BIPOC.

Table 1: Participant Characteristics (n=57)

Age M (SD)	19.4 (2.0)
Age at diagnosis M (SD)	6.8 (4.6)
Years of treatment M (SD)	11.1 (4.5)
Non-Hispanic White n (%)	47 (82.5%)
BIPOC n (%)	10 (17.5)
Gender n (%)	
Male	22 (38.6)
Female	35 (61.4)
Highest level of education completed n (%)	
College degree or higher	4 (7.0)
Some college	14 (24.6)
High school diploma	20 (35.1)
< High school	19 (33.3)
LTFU Engagement n (%)	
Yes, attended an appointment	16 (28.1)
No, but one is scheduled	13 (22.8)
No, and none scheduled	28 (49.1)
<b>Cancer-Related Worries Total Score M (SD)</b>	<b>8.1 (4.2)</b>

## Results

Figure 1. Race/Ethnicity Across Engagement

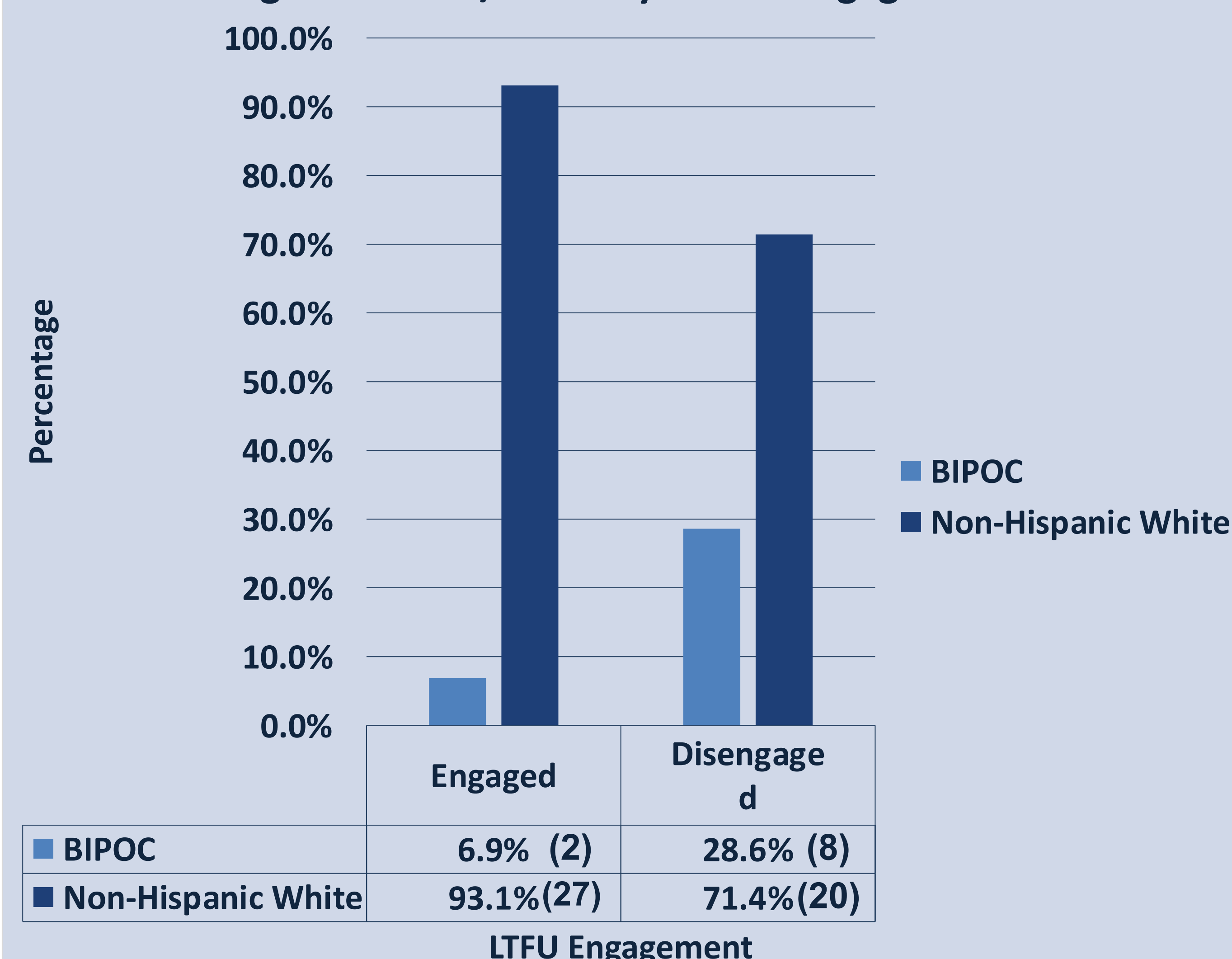


Figure 2. Mean Age Across Engagement

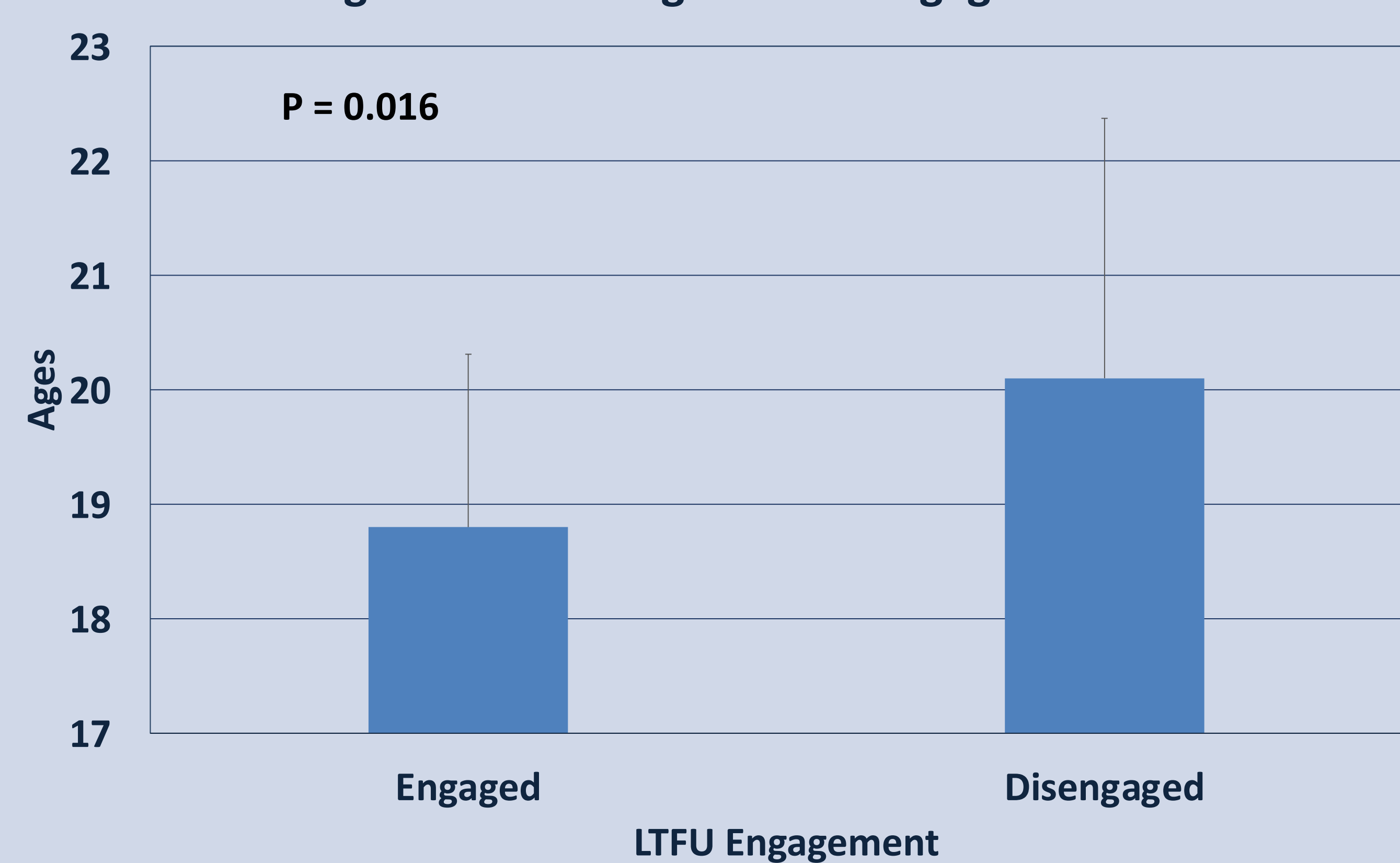
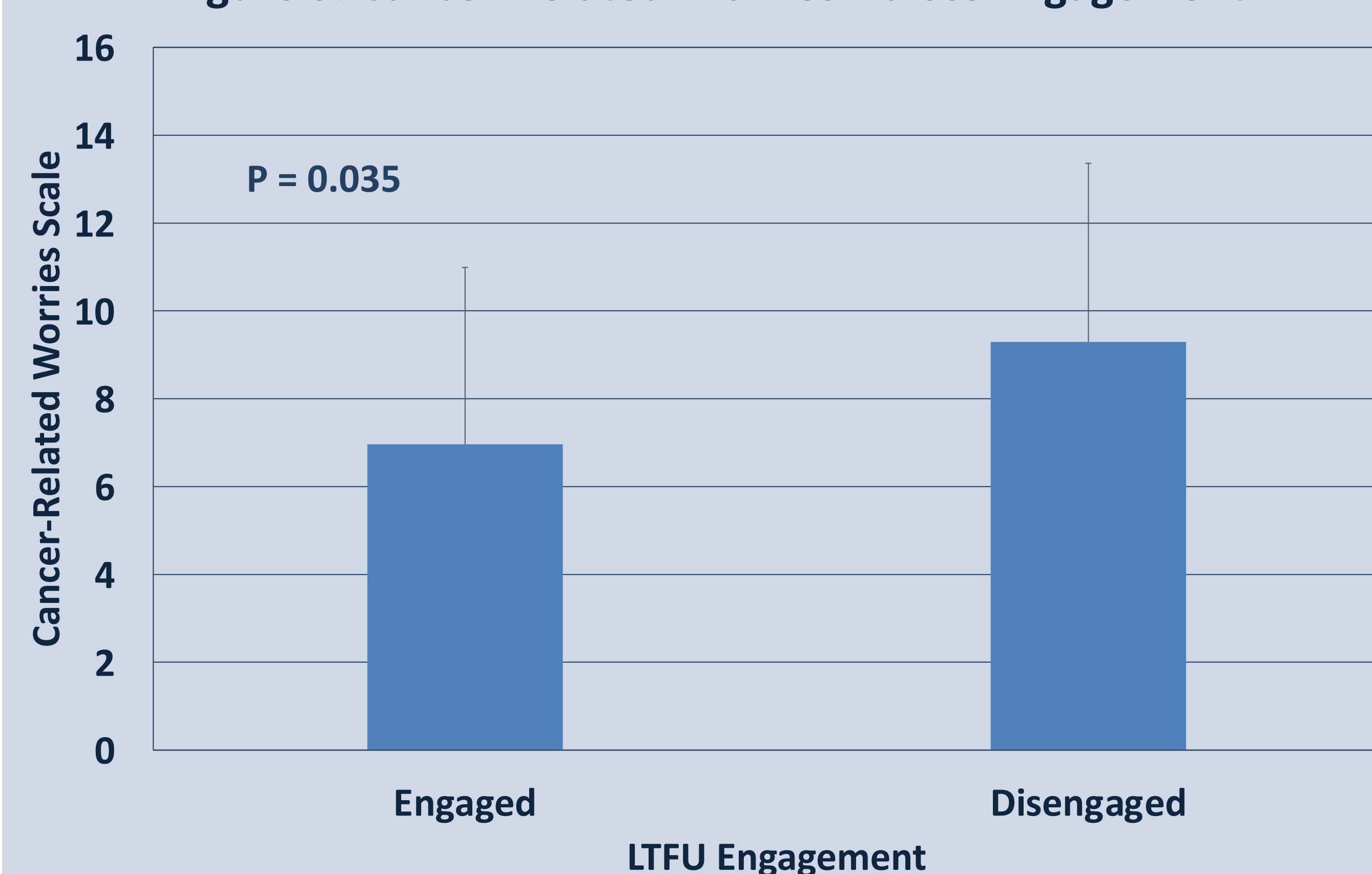


Figure 3. Cancer-Related Worries Across Engagement



- 80% of BIPOC were in the disengaged group, making up 28.6% of the total disengaged group, in contrast to the 20% BIPOC in the engaged group, making up 6.9% of the total engaged group ( $\chi^2 = 4.626$ ,  $p = 0.031$ ).
- Participants in the engaged group were younger [(M (SD) = 18.8 (1.51)] compared to those in the disengaged group [(M (SD) = 20.1 (2.27)] ( $t = 2.50$ ,  $p = 0.016$ ).
- Participants in the engaged group had lower cancer-related worries [(M (SD) = 6.96 (4.03)] compared to the disengaged group [(M (SD) = 9.29 (4.07)] ( $t = 2.16$ ,  $p = 0.035$ ).

## Results, cont.

- Participants in the disengaged group reported greater worry on the "I worry about late effects that might happen to me" item ( $t = 2.29$ ,  $p = 0.026$ ).
- Participants in the engaged group reported greater worry on the "Cancer is always at the back of my mind" item ( $t = 2.47$ ,  $p = 0.017$ ).
- There were no differences in gender, age at dx, or time of tx between both engaged and disengaged groups.

## Conclusion

- Despite a small sample size, a significantly smaller proportion of BIPOC engaged in their annual follow-up care.
- Older AYA being more likely to be disengaged supports findings of decline in LTFU engagement during young adulthood.
- Unexpectedly, disengaged AYA reported greater cancer-related worries compared to those who were engaged, indicating that worry/anxiety may function as a barrier to LTFU care engagement. Consistent with a traumatic stress framework, those who have elevated worries may be avoidant of reminders of cancer.

## Future Directions

- That a greater percent of AYA of BIPOC disengaged from their follow-up care may be influenced by a variety of factors.
- There is a need to conduct further research to better understand relationships between race/ethnicity and cancer-related worries and their impact on LTFU engagement.
- Examining individual cancer-related worries items along with perceptions of healthcare systems will reveal the barriers to LTFU engagement in AYA of BIPOC populations.

## References

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