

# Social Determinants of Health Impacting the Experience of Young Adults With Cancer at a Single Community Urban Hospital: A Retrospective Cohort Study

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## Abstract

Adolescent and young adult (AYA) cancer patients receive palliative medicine consultation at a late stage and face diagnostic delays. Failure to address social determinants of health (SDOH) and AYA-specific needs can adversely impact patient experience. This retrospective observational cohort study used data from chart review to assess the frequency of SDOH impacting AYA patients and setting of initial diagnosis at a US urban safety-net hospital. The association of SDOH variables with delays in treatment, loss of follow-up, and no-shows was tested using Chi-square and t-tests. One hundred seventy five patient charts were reviewed. Sixty-two percent were diagnosed in acute care settings. Substance use disorders, financial, employment, and insurance issues were associated with delayed treatment, with weak to moderate effect sizes. Mental health diagnoses, substance use disorder, homelessness, and financial burdens were associated with patient no-shows, with moderate to large effect sizes. Twenty-five percent of patients received palliative medicine consultation; 70% of these occurred at end of life. This study demonstrates the impact of SDOH on AYA cancer care and the need for policy allowing for intervention on SDOH.

## Keywords

AYA cancer patients, palliative medicine, social determinants of health

## Key Findings

1. Substance use disorders, financial, employment, and insurance issues were associated with delayed treatment.
2. Mental health diagnoses, substance use disorders, homelessness, and financial burdens were associated with patient no-shows.
3. Seventy percent of Palliative medicine consultations were near the end of life.
4. Failure to appropriately document and address social determinants of health may adversely impact the outcomes and experience of AYA patients in community-based settings.

employment, raising children, and anticipatory grief over the significant life change.<sup>1,2</sup> Prior research shows that palliative medicine was consulted in AYA patients an average of 4 to 16 days before death.<sup>3</sup> Often, this occurs only when the medical team has acknowledged further intervention may not improve the clinical outcome. In another study of AYA cancer survivors, 18% of males and 38% of females were

## Introduction

Adolescent and young adult (AYA) patients with cancer are defined as those 15 to 39 years old. Unique needs of this population include issues of fertility, finance, loss of

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unable to make fertility preservation arrangements because they were unaware of these treatment options.<sup>4</sup> This was more likely to occur in patients of lower socioeconomic status or without insurance. AYA patients are also likely to report unmet psychosocial needs in survivorship in addition to practical needs and healthcare needs such as transportation, physical therapy, and mental health care.<sup>5</sup> Failure to address social determinants of health (SDOH) and AYA-specific needs can adversely impact the patient experience, add to the disruptions in life faced by AYA patients, and adversely affect health outcomes.<sup>6-8</sup> AYA patients often experience a delay in diagnosis due to their young age and the lack of screening recommendations, financial issues or lack of insurance, and delays in seeking medical attention.<sup>1,9</sup>

Despite these known issues, there is still little research into where AYA patients obtain their diagnosis. Additionally, outside of the adverse impact of lower socioeconomic status and insurance status,<sup>10,11</sup> there remains a gap in understanding the impact of other comorbidities and SDOH on AYA cancer care, which can be identified and addressed upon initial diagnosis. These limitations make it difficult to employ effective protocols for their care. Potential protocols could include the creation of interdisciplinary teams, including palliative care, social work, child life, addiction medicine, and psychiatry, that could positively impact patient experience upon diagnosis rather than later in their disease course when they are acutely declining. The aim of this study was to determine what location AYA patients received their cancer diagnosis, determine the frequency of specific SDOH impacting their care, and test the association of individual SDOH on treatment delays and patient follow-up in a safety-net setting.

## Methods

This study was a retrospective cohort study using data from chart review of adult AYA patients aged 19 to 39 at Denver Health and Hospital Authority (DHHA), US safety-net healthcare system, who had a new cancer diagnosis from 2016 to 2021. Specific SDOH and AYA-specific needs included child life or family planning needs, behavioral health, substance use, homelessness or housing insecurity, financial burden, employment issues, and being uninsured or underinsured. Data available from chart review was used to examine the association between the patient burden of SDOH and AYA-specific needs with delays in treatment, loss of patient follow-up, and missed outpatient appointments. Patients were identified using the Epic electronic medical record “SlicerDicer” functionality. Patients were excluded if they received most of their care outside the DHHA system, were incarcerated, were hospital employees, or were diagnosed with cancer outside the specified age range. Incarcerated patients and hospital employees were excluded for ethical considerations as these variables may impact access to the health

system and follow-up and confound analysis of the other SDOH variables. Meetings between the investigators were conducted to determine operational definitions of the independent variables and study outcomes, train data abstractors (JMC, KF, and KI), and resolve conflicts prior to finalizing the data abstraction form. The methods of patient sampling, operational definitions for SDOH and AYA-specific needs, and dependent variables are included in the Appendix. Early stage surgically treatable disease, stage III/IV solid tumors, and acute leukemia or high-grade lymphoma have differing expected diagnostic lagtimes and expected timelines for initiating treatment. Therefore, delayed treatment included the diagnostic lagtime plus treatment delay and was defined as a delay in the initial presentation, diagnosis, oncology referral, or between treatments that could adversely impact outcomes based on the tumor type (Appendix). Loss of follow-up was defined as a patient no longer within the health system despite planned follow-up (Appendix). The EMR recorded patient no-shows.

## Data Analysis

After achieving agreement on operational definitions and pilot assessments of abstractor agreement, a final chart review of 20 charts per abstractor was used to calculate the interrater reliability as percent agreement for each variable using  $>0.75$  as our goal for reporting results (see Appendix for IRRs).<sup>12</sup> Independent variables or SDOH for which chart abstractors had an IRR  $<0.75$  were excluded from the final analysis. Data abstractors also documented additional notes related to specific patient care needs pertaining to the study variables.

The percentage of patients experiencing an independent variable category (eg, financial burden) was reported as a proportion of the number of charts included in the study. A Chi-square test of independence was used to evaluate the association between specific patient needs and dichotomous dependent variables delayed treatment and loss of patient follow-up. Student's *t*-test was used to test the association of the AYA-specific SDOH categories on the continuous variable of patient no-shows. Cramer's V and Cohen's *d* values were calculated to measure effect size for dichotomous and continuous variables, respectively. Statistical analyses were performed in SAS 9.3 (SAS Institute, Cary, NC).

**Ethics.** The Colorado Multiple Institutional Review Board approved this study as exempt.

## Results

The analysis included 363 charts, 163 of which were excluded, leaving 175 in the final analysis. Demographics and insurance status are presented in Table 1. One hundred eight of the 175 (62%) were diagnosed in an acute care

**Table 1.** Patient demographics and insurance status.

Sex	Male (%), Female (%)
	74 (42) 101 (58)
White	35 (20)
Hispanic/Latino/a, Mexicano/a	Total—110 (63)
	• White = 70
	• Other = 39
	• Black = 1
Black	19 (11)
Asian/Pacific Islander	6 (3)
Native American/Alaskan Native	3 (2)
Middle east	2 (1)
Insurance status <sup>a</sup>	Number (%)
• Medicaid	92 (53)
• Medicare	11 (6)
• Private	26 (15)
• Community or hospital discount program	43 (25)
• Uninsured	30 (17)
Vital status	Alive (%)
	Deceased (%)
	137 (78) 38 (22)

<sup>a</sup>The numbers do not add up to 175 patients on account of changes in insurance status. The percentiles indicate the percentage of the 175 patients included who had the associated type of insurance at any time during the study period.

setting (ED, urgent care, inpatient). Seventeen percent were uninsured at diagnosis; 25% of these patients required community or hospital discount programs. The frequency of occurrence of identified SDOH variables is presented in Figure 1. Referrals to palliative medicine (44/175; 25%) and child life specialists (15/175; 9%) were underutilized. Notably, 31 of the 38 deceased patients received a palliative medicine consultation. For 26 of 175 (15%) charts, chart abstractors could not determine one or more of the SDOH or AYA-specific needs.

### Delayed Treatment

Bivariate analysis showed that substance use disorders ( $P = .047$ , Cramer's  $V = 0.150$ ), financial constraints ( $P < .001$ , Cramer's  $V = 0.331$ ), loss of employment ( $P = .002$ , Cramer's  $V = 0.286$ ), homelessness ( $P = .001$ , Cramer's  $V = 0.196$ ), and issues relating to insurance ( $P < .001$ , Cramer's  $V = 0.314$ ) were significantly associated with delayed treatment (Figure 1). The effect size was moderate for financial constraints and underinsured status, and weak for substance use disorders, homelessness, and employment issues.

### Loss to Follow-up

No independent variable SDOH categories were associated with a patient being lost to follow-up.

### No-Shows

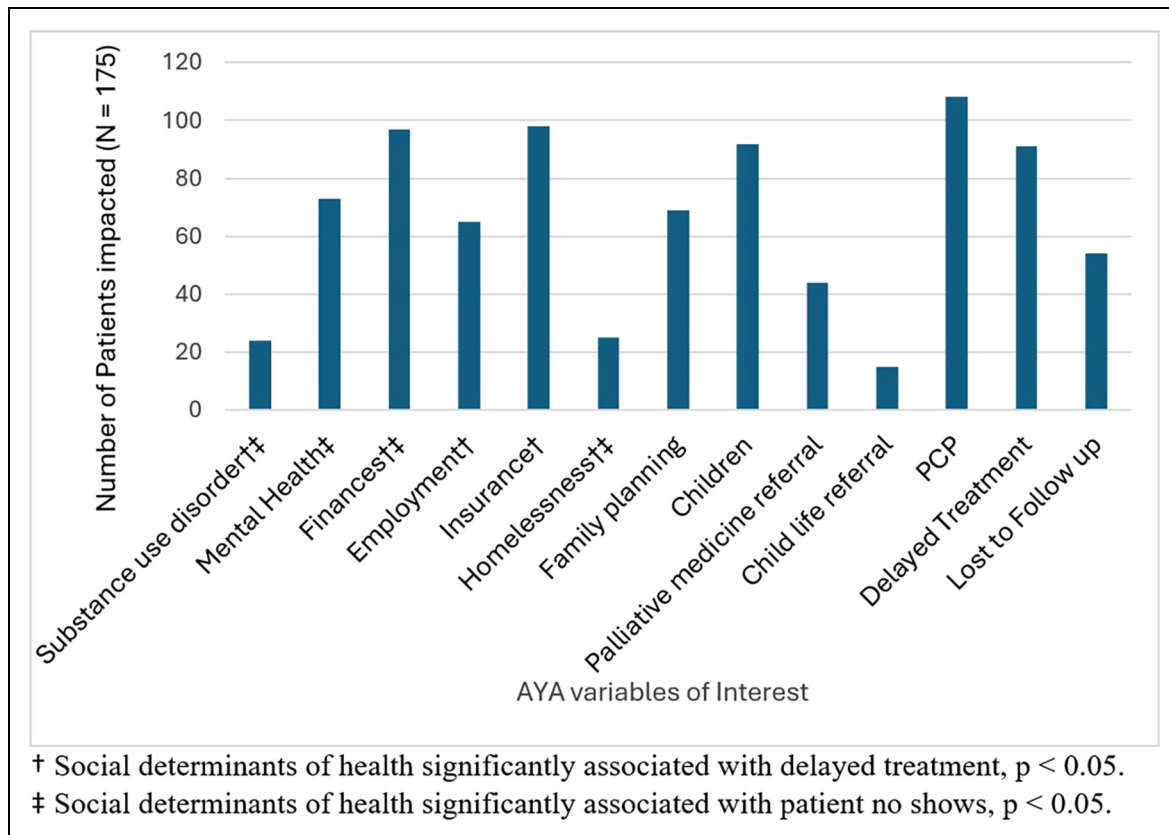
When treated as a continuous variable, the total count of patient no-shows was significantly associated with substance use disorder ( $P < .0001$ , Cohen's  $d = 0.89$ ), behavioral/mental health disorder ( $P = .0003$ , Cohen's  $d = 0.60$ ), financial concerns ( $P < .0001$ , Cohen's  $d = 0.76$ ), and homelessness ( $P = .0008$ , Cohen's  $d = 1.1$ ). No associations were found between patient no-shows and employment or insurance issues (Figure 1). The effect size was large for substance use disorder and homelessness, and moderate for behavioral/mental health and financial concerns.

### Discussion

Our urban safety-net health system cares for many uninsured patients and has a proactive process to screen patients and enroll them in hospital discount programs if necessary. Many of the social work staff are knowledgeable regarding grants for chemotherapy treatments or charity hospice services if needed. However, 52% of included patients experienced treatment delays. The SDOH most likely to be associated with treatment delays included underinsured status, financial strain, loss of employment, and homelessness. Consistent with previous literature, chart reviewer notes indicated that many of the treatment delays in underinsured AYA patients were due to transfers between systems due to lack of insurance and inability to schedule outpatient follow-up rather than delays receiving treatment once established in our system.<sup>11,13</sup> While none of the SDOH categories were independently associated with loss of patient follow-up, a significant number were lost to follow-up (31%) and may have experienced a lack of supportive care and wellness during survivorship, a common experience of AYA patients.<sup>14,15</sup>

In this cohort study, 62% of AYA patients received their initial cancer diagnosis in the acute care setting. Although this is a single-center study, this data could be generalized to other community hospitals or urban safety net hospitals caring for patients experiencing SDOH associated with reduced access to specialty centers.<sup>16</sup> This suggests a critical location to evaluate hospital policy promoting protocols involving multidisciplinary teams and palliative medicine to identify AYA needs upon diagnosis. Many AYA patients presenting to our safety-net hospital lacked previous access to primary care and palliative medicine, experienced significant socioeconomic strain, such as being underinsured or uninsured, experiencing mental health and/or substance use disorders, and reported financial or employment difficulties. This reinforces the critical importance of policy that moves beyond identifying SDOH to provide pathways aiding physician and health system intervention on SDOH to prevent adverse outcomes associated with delayed access to care.<sup>11,16</sup>

Data abstractors notes revealed several cases in which a child life specialist or palliative medicine consultation was offered but declined. Two hypotheses are that given patients'



**Figure 1.** Frequency of outcomes and association between each social determinant of health with delayed treatment, loss of follow-up, and no-shows.

time constraints, financial burdens, and transportation concerns, scheduling more visits or consults may not improve the perception or feasibility of care<sup>17</sup>; alternatively, the perception of palliative care as “end-of-life” care and “culture of hope” caring for AYA may limit referrals at earlier stages of disease.<sup>3,18</sup> As only 20% of patients identified as White, future studies should include diverse AYA patient perspectives about culturally competent care delivery, earlier palliative medicine involvement, and culturally sensitive best practices for child life issues and survivorship.<sup>19</sup> Studies using implementation science methods will aim to improve hospital policy implementation of structured assessments of social needs and earlier palliative care consultation to evaluate if such interventions mitigate the burden of psychosocial stressors associated with delayed treatment in AYA patients.<sup>20</sup>

## Limitations

The use of a single-center study design may affect the generalizability of this study’s findings. The use of chart review may have improved our ability to detect patient-reported experience of SDOH compared to using administrative EMR data. However, this study may have been underpowered to detect a significant impact of other SDOH on AYA

outcomes. This study was underpowered to determine whether financial assistance and discount insurance programs reduce the burden of treatment delays, loss to follow-up, or missed outpatient appointments. Deficiencies in chart documentation likely resulted in underreporting of the number of patients experiencing hardship during their cancer treatment. This may have biased our results towards the null hypothesis for categories such as mental health concerns or issues related to employment.

## Conclusion

Most AYA patients presenting to an urban safety net health system received their cancer diagnosis in the acute care setting. The SDOH most associated with treatment delays included substance use disorders, financial, employment, and insurance issues. Homelessness and financial concerns were most associated with patient no-shows. Palliative Medicine consultation was underutilized, and frequently Palliative Medicine was consulted towards the end of life. This study will guide future dissemination and implementation studies to improve implementation of clinical protocols or policies to address and intervene on the SDOH experienced by AYA patients initially managed in community safety-net hospitals.

## Author Contributions

John Cunningham, Kelly Ferraro, and Kimberly Indovina designed the study. John Cunningham, Kelly Ferraro, and Kimberly Indovina drafted the manuscript, and provided critical revisions. Josh Durfee analyzed the data and provided statistical support in interpreting the data. All authors provided and have revised the article critically for clarity and intellectual content provided revisions and have approved this version for submission.

## Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Ethical Approval


This study was approved by the Colorado Institutional Review Board as exempt (COMIRB # 20-1658) on August 05, 2020. This is an IRB-approved retrospective study, all patient information was deidentified and patient consent was not required.


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## Supplemental Material

Supplemental material for this article is available online.

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