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| TITLE:  Barriers to Hospice and Palliative Care Utilization Among Adolescent and Young Adult Cancer Patients  Living in Poverty | | | | | |
| PRINCIPLE INVESTIGATOR(S): | | Jennifer Mack, MD MPH | |  | SITE(S) (if applicable): |
| University of Iowa  University of Alabama, Birmingham  University of California, San Diego |
| COORDINATING SITE: | | University of Colorado, Duke University, University of California San Francisco | |  |
| STUDY PERIOD | | | |  |
| START: | | August 2016 | |  |
| LAST SUBJECT CONTACT: | | July 2018 | |  |
| OBJECTIVES: | | | | | |
| Aim 1: To examine the extent and determinants of socioeconomic disparities in use of hospice and  palliative care among AYA patients at the EOL. We will (a) develop a cohort of 250 AYA decedents from  2013-2016 at 3 Palliative Care Research Cooperative Group (PCRC) sites; (b) evaluate use of hospice and  palliative care and location of death using medical records; and (c) examine relationships between  socioeconomic status, race/ethnicity, urban/rural neighborhood, hospice accessibility, and EOL care. The goal  of this aim is to evaluate whether AYA patients in poverty have unique needs that can be targeted with strategic  interventions, and which AYAs are most at risk.  Aim 2: To explore caregiver experiences and decision-making about location of EOL care and  involvement of hospice and palliative care. We will (a) identify surviving family caregivers of our cohort’s  AYA decedents and (b) conduct 30 semi-structured interviews to evaluate decision-making about use of  palliative care and hospice and about location of death, including barriers to hospice/palliative care use and  home death. The goal of this aim is to understand mechanisms for disparities amenable to intervention.  Aim 3: To evaluate quality of care near death among AYA patients as a function of socioeconomic status  and hospice and palliative care use. We will use a questionnaire-based interview among 100 family caregivers  to evaluate quality of care near death as a function of hospice and palliative care use. The goal of this aim is to  evaluate care models that offer high quality EOL care for poor AYAs, for development in a future intervention. | | | | | |
| PARTICIPANTS | | | | | |
|  | ENROLLMENT | | ELIGIBILITY CRITERIA | | |
| Patients: | 252 | | Patients will be included if they  (1) died between January 1, 2013-December 31, 2016;  (2) were aged 15-39 at death, consistent with the NCI definition of AYA;  (3) were diagnosed at least 30 days prior to death, such that there was opportunity for referral to hospice or  palliative care; and  (4) were receiving care through their site [1. University of Iowa, 2. University of California San Diego, and 3.  To Be Determined, respectively] during the month of death, such that information about care can be found in  available records. | | |
| Informal Caregivers: | 35 | | Bereaved family caregivers will be eligible for interviews if they meet the following eligibility criteria:  • Primary caregiver of an AYA decedent identified in Aim 1  • Able to speak English or Spanish  • 18 years or older at the time of the interview  • At least 4 months post-death of the AYA decedent | | |
| Health Care Providers: | N/A | | N/A, not enrolled in this study | | |
| METHODOLOGY: | | | | | |
| * Aim 1 (medical record review) design/study type is a medical record review. Aim 1 will use a case report form (CRF) designed for this study.   • Aim 2/3 (100 interviews) design/study type is social behavioral qualitative & quantitative research. | | | | | |
| INTERVENTION (if applicable): | | | | | |
| This study is observational, not interventional.  • Aim 1 (medical record review) will not use any interventions nor any interactions with patients.  • Aim 2/3 (100 interviews) will not use any interventions, but will consist of interactions with participants (administration of interview). | | | | | |
| MEASURES: | | | | | |
| Aim 1 (medical record review) will not use any instruments.  Aim 2/3 (100 interviews):  o Interview Version 1 (to be administered to 70 out of the 100 caregiver participants) will use a questionnaire instrument. The questionnaire will be read aloud to the participant over the phone and take approximately 30-45 minutes to complete. The questionnaire will consist of items from the following domains: quality of care; family-centered care; satisfaction with care; caregiver burden; socioeconomic status; and family structure.  o Interview Version 2 (to be administered to 30 out of the 100 caregiver participants) will use the same questionnaire instrument as version 1 plus a semi-structured interview. Semi-structured interviews will be conducted using an interview guide developed for this study, with probing questions to facilitate discussion and expansion on themes. Interviews will focus on potential barriers to hospice and palliative care, including understanding of prognosis, provider communication of care options, personal/family wishes for care, and other experiences of barriers. Version 2 of the interview will take approximately 45-60 minutes to complete. | | | | | |

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| SUBJECT FLOW (CONSORT): |
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| STUDY CALENDAR: N/A for this project |

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| BASELINE CHARACTERISTICS (TABLE 1) |

**PCRC STANDARDIZED DATA ELEMENTS**

***Please see the separate information sheet*** [***“DISC Standardized Data Elements”***](Info%20Sheet%20-%20DISC%20Standardized%20Data%20Elements_v2018.08.docx) ***for the exact wording and format of the data elements.***

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| **DATA ELEMENT** | **Collected?** | **Var Name(s)** | **Data source (e.g. self-report, EHR) or reason not applicable** |
| 1. **Site ID (if multi-site)** |  | sitename | N/A |
| 1. **Who is the research participant? (e.g., patient, caregiver, etc.)** |  | Aya\_initials | EHR |
| 1. **Sex** |  | sex | EHR |
| 1. **Ethnicity** |  | ethnicity | EHR |
| 1. **Race** |  | race | EHR |
| 1. **Age in years** |  | Age\_at\_death | EHR |
| 1. **Current Marital Status** |  | marital | EHR |
| 1. **Primary life-limiting diagnosis/illness** |  | Cancer\_site | EHR |
| 1. **Performance status (AKPS)** |  |  |  |
| 1. **Enrolled in Hospice** |  | hospice | EHR |
| * 1. **If yes to hospice, where is hospice care provided?** |  | Hospice\_loc | EHR |
| 1. **Receiving Palliative Care (PC)?** |  | Pc\_doc\_consult | EHR |
| * 1. **If yes to receiving PC, where is PC provided?** |  | Pc\_loc | EHR |
| 1. **Source of Death information** |  |  |  |
| 1. **Location of Death** |  | Loc\_death | EHR |
| 1. **Enrolled in Hospice at time of death?** |  | Hosp\_tod | EHR |
| 1. **Receiving PC at time of death?** |  | Pc\_tod | EHR |

***Cells in blue only need to be collected for patient research participants. Cells in orange should be collected regardless of participant type.***

**PATIENT REPORTED OUTCOME INSTRUMENTS**

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| **CONTENT**  *(e.g., PS)* | **ABBREV**  *(e.g., AKPS)* | **INSTRUMENT NAME**  *(e.g., Australian Modified Karnofsky Performance Status)* |
| QOC | Toolkit | Toolkit After-Death Bereaved Family Member Interview |
| SES | MEPS | Medical Expenditure Panel Survey |
| SC | FAMCARE | FAMCARE-2 |
| CB | BCOS | Bakas Caregiving Outcomes Scale |
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