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| --- | --- | --- | --- | --- | --- |
| TITLE:  Understanding Bereavement Services Delivered in Hospice Settings for Family Members with Symptoms of Depression, Anxiety, and Complicated Grief | | | | | |
| PRINCIPLE INVESTIGATOR(S): | | Angela R Ghesquiere | |  | SITE(S) (if applicable): |
| MJHS Hospice |
| COORDINATING SITE: | | University of Colorado | |  |
| STUDY PERIOD | | | |  |
| START: | | 7/1/17-6/30/18 | |  |
| LAST SUBJECT CONTACT: | | N/A (all administrative data) | |  |
| OBJECTIVES: | | | | | |
| 1. To describe the frequency and type of support offered by hospice staff to family members with symptoms of depression, anxiety, or complicated grief. 2. To describe the interest in hospice bereavement support by family members with symptoms of depression, anxiety, or complicated grief. 3. To describe whether family members are satisfied with services received | | | | | |
| PARTICIPANTS | | | | | |
|  | ENROLLMENT | | ELIGIBILITY CRITERIA | | |
| Patients: | 0 | | Click here to enter text. | | |
| Informal Caregivers: | 3561 | | Primary caregivers of deceased patients at the partner hospice who were assessed by bereavement counselors from October 1, 2015, to June 30, 2016 | | |
| Health Care Providers: | 0 | | Click here to enter text. | | |
| METHODOLOGY: | | | | | |
| Review of hospice bereavement assessments completed with primary caregivers using electronic records. | | | | | |
| INTERVENTION (if applicable): | | | | | |
| N/A | | | | | |
| MEASURES: | | | | | |
| Bereavement services offered to and received by bereaved primary caregivers | | | | | |

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| SUBJECT FLOW (CONSORT): N/A- all primary caregivers seen by the hospice during the period examined were included in analyses. |
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| STUDY CALENDAR:   |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | **PILOT GRANT TIMELINE** | | | | | | | | | | | | | | | | | | Timing |  |  | 1 Year Project: 7/1/2017-6/30/2018 | | | | | | | | | | | | Post | | |  |  | Jun | Jul | Aug | Sep | Oct | Nov | Dec | Jan | Feb | Mar | Apr | May | Jun | Jul | Aug | | **Activities** |  | *Pre* | *M1* | *M2* | *M3* | *M4* | *M5* | *M6* | *M7* | *M8* | *M9* | *M10* | *M11* | *M12* |  |  | |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | Start Up: IRB |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | Start Up: Piloting chart review procedures |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | Chart review data transfer/management |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | Data quality checks |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | Data extraction |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | Data Cleaning & Analysis |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | Manuscript and report preparation |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | Publication |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | R01 preparation |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | Interim Reports |  |  |  |  |  |  |  | U24 |  |  |  | U24 |  |  |  |  | | Final Report |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | XX | |

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| BASELINE CHARACTERISTICS (TABLE 1) Sociodemographic data was only available as summary data on a subset of the sample (n=490).   |  | **n** | **%** | | --- | --- | --- | | Age |  |  | | 18-34 | 5 | 1.0 | | 35-54 | 116 | 23.6 | | 55-74 | 305 | 62.3 | | 75 or older | 64 | 13.1 | | Female gender | 366 | 74.4 | | Race/ethnicity |  |  | | White | 353 | 76.2 | | Black/African | 78 | 16.8 | | American |  |  | | Asian | 31 | 6.6 | | Indian/Alaska Native | 1 | 0.2 | | Hispanic | 64 | 13.1 | | Education level |  |  | | Less than high school | 14 | 2.8 | | High school graduate | 88 | 18.1 | | Some college | 98 | 20.2 | | Four-year college graduate | 127 | 26.1 | | More than 4-year college | 159 | 32.7 | | Language spoken at home |  |  | | English | 426 | 90.6 | | Spanish | 15 | 3.2 | | Chinese | 12 | 2.6 | | Other | 11 | 2.3 | |

**PCRC STANDARDIZED DATA ELEMENTS**

***Please see the separate information sheet*** [***“DISC Standardized Data Elements”***](file:///C:\Users\a_ghe\AppData\Local\Temp\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)** |  | ID | EHR |
| 1. **Who is the research participant? (e.g., patient, caregiver, etc.)** |  | n/a | All participants are caregivers |
| 1. **Sex** |  | n/a | Only available as a summary report from the hospice, not by participant |
| 1. **Ethnicity** |  | n/a |  |
| 1. **Race** |  | n/a |  |
| 1. **Age in years** |  | n/a |  |
| 1. **Current Marital Status** |  | n/a |  |
| 1. **Primary life-limiting diagnosis/illness** |  |  |  |
| 1. **Performance status (AKPS)** |  |  |  |
| 1. **Enrolled in Hospice** |  |  |  |
| * 1. **If yes to hospice, where is hospice care provided?** |  |  |  |
| 1. **Receiving Palliative Care (PC)?** |  |  |  |
| * 1. **If yes to receiving PC, where is PC provided?** |  |  |  |
| 1. **Source of Death information** |  |  |  |
| 1. **Location of Death** |  |  |  |
| 1. **Enrolled in Hospice at time of death?** |  |  |  |
| 1. **Receiving PC at time of death?** |  |  |  |

***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**

|  |  |  |
| --- | --- | --- |
| **CONTENT**  *(e.g., PS)* | **ABBREV**  *(e.g., AKPS)* | **INSTRUMENT NAME**  *(e.g., Australian Modified Karnofsky Performance Status)* |
|  |  | None were available in deidentified data shared by the hospice. |
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