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| TITLE:  Experiences of family members of patients admitted to the ICU from the acute care floor | | | | | |
| PRINCIPLE INVESTIGATOR(S): | | Ann C. Long, MD, MS  J. Randall Curtis, MD, MPS | |  | SITE(S) (if applicable): |
| Harborview Medical Center (Seattle, WA)  Valley Medical Center (Renton, WA) |
| COORDINATING SITE: | | University of Washington (Seattle, WA) | |  |
| STUDY PERIOD | | | |  |
| START: | | 9/1/2014 | |  |
| LAST SUBJECT CONTACT: | | 6/30/2015 | |  |
| OBJECTIVES: | | | | | |
| Aim 1: To use rigorous qualitative methods to explore family member experiences during three specific periods of care: 1) at the time of their loved one’s hospital admission and during their stay on the acute care floor; 2) at the time a decision is made to pursue transfer to the ICU; and 3) during the period of time following ICU admission.  Aim 2: To perform an exploratory analysis of patient and family member factors associated with lower family member ratings of care for patients transferred from acute care to the ICU. | | | | | |
| PARTICIPANTS | | | | | |
|  | ENROLLMENT | | ELIGIBILITY CRITERIA | | |
| Patients: | 17 | | Individuals who were transferred from acute care to the ICU after spending >= 1 day on the acute care floor, who have been in the ICU for >= 48 hours and who do not have decision-making capacity. | | |
| Informal Caregivers: | 17 | | Family members of the patient that speak English, are able to participate in an in-person interview, and are involved in surrogate decision-making. | | |
| Health Care Providers: | n/a | |  | | |
| METHODOLOGY: | | | | | |
| Descriptive thematic analysis of semi-structured interviews with family members;  surveys, chart abstraction | | | | | |
| INTERVENTION (if applicable): | | | | | |
| n/a | | | | | |
| MEASURES: | | | | | |
| Age, sex, race/ethnicity, socioeconomic status, comorbid illness, family ratings of ICU care, length of stay | | | | | |

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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)** |  |  |  |
| 1. **Who is the research participant? (e.g., patient, caregiver, etc.)** |  | **Separate datasets for patient and family** |  |
| 1. **Sex** |  | **psex, fmsex** | Patient: abstracted from chart; Family: self-report |
| 1. **Ethnicity** |  | **ptethnic, fmethnic** | **Patient: abstracted from chart; Family: self-report** |
| 1. **Race** |  | **ptrace, fmrace** | **Patient: abstracted from chart; Family: self-report** |
| 1. **Age in years** |  | **ptage, fmage** | **Patient: abstracted from chart; Family: self-report** |
| 1. **Current Marital Status** |  | **maritalstatus** | **Patient: abstracted from chart; Family: self-report** |
| 1. **Primary life-limiting diagnosis/illness** |  | **Reason1** | Abstracted from chart |
| 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** |  | **diedlocation** | Abstracted from chart |
| 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.***

**PCRC OUTCOME INSTRUMENTS**

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| **CONTENT**  *(e.g., PS)* | **ABBREV**  *(e.g., AKPS)* | **INSTRUMENT NAME**  *(e.g., Australian Modified Karnofsky Performance Status)* |
| Satisfaction | FS-ICU | Family Satisfaction in the ICU |
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