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| TITLE:  Examining the Utility of Patient Portals in the Setting of Serious Illness and End of Life | | | | | |
| PRINCIPLE INVESTIGATOR(S): | | Jennifer Dickman Portz, PhD, MSW | |  | SITE(S) (if applicable): |
| Kaiser Permanente Colorado |
| COORDINATING SITE: | | CU Anschutz, PCRC Pilot Study | |  |
| STUDY PERIOD | | | |  |
| START: | | July | |  |
| LAST SUBJECT CONTACT: | | NA | |  |
| OBJECTIVES: | | | | | |
| Using Kaiser Permanente Colorado’s (KPCO) established patient portal, My Health Manager (MHM), we conducted a secondary data analysis of the effects of portal utilization on important palliative care and end of life (PCEOL) outcomes. The objectives of this project include:   * Describe MHM utilization patterns and user characteristics among deceased patients and their caregivers (via a proxy log-in option) in the last 12 months of life. * Conduct exploratory analysis to test the association between MHM utilization among deceased patients in the last 12 months of life and their proxy caregivers with important PCEOL outcomes including advance directive documentation, hospitalization near the end of life, and hospice referral/use. | | | | | |
| PARTICIPANTS | | | | | |
|  | ENROLLMENT | | ELIGIBILITY CRITERIA | | |
| Patients: | 6517 | | Patient portal users who died from a serious or chronic illness | | |
| Informal Caregivers: | 163 | | Portal proxy users of patients who died from a serious or chronic condition | | |
| Health Care Providers: | 0 | | N/A | | |
| METHODOLOGY: | | | | | |
| Design: Retrospective cohort study to investigate the utility of portals during PCEOL.  Sample: Deceased patient and caregiver MHM users over the age of 18 between 1/1/2016-6/30/2019. Patients and caregivers must have been registered for MHM during the 12 months prior to the patient’s death. Patients who did not die from a chronic or serious illness (i.e. accident) were excluded from analysis to accurately capture patient portal use at end of life.  Data Extraction: Data was extracted from KPCO’s integrated electronic medical record, KP HealthConnect—Epic Systems, Death Records—Research Data Warehouse, Health Trac and My Health Manager databases. Data extracted included patient characteristics (age, race, ethnicity, gender, diagnoses, rural/urban location, and socioeconomic status), Care Group flags (Advanced Illness, Serious Illness, Chronic Illness), date of flag, enrollment data, MHM utilization (number of log-ons, total time on site, and features used—Table 1), and PCEOL outcomes (advance directive documentation, hospitalization near end of life, and hospice referral/use)  Analysis: After cleaning the data and addressing data issues and concerns, univariate descriptive analysis was conducted. Frequencies, measures of central tendency, and percentages were used to create summary tables of utilization patterns for number of log-ons and used MHM features per month, over the 12-month period as the patient nears death. Utilization differences by patient characteristics were tested by t-test and anova as appropriate. We conducted exploratory analyses to examine associations between patient and caregiver proxy MHM utilization with PCEOL outcomes (advance directive documentation, hospitalization near end of life, and hospice referral/use). | | | | | |
| INTERVENTION (if applicable): | | | | | |
| Not applicable | | | | | |
| MEASURES: | | | | | |
| Characteristics: Age, gender, race, ethnicity, socioeconomic status, education, KPCO Care Group, Charston Comorbidity Index score, rural/urban location, and Alzheimer’s disease flag.  HM Utilization: Using raw utilization data we calculated number of log-ons and features used. *Number of log-ons* is the count of completed portal log-ons (i.e. signed-on using username and password) per month. Total *number of MHM features* visited was calculated per month. Utilization was then transformed to capture *use type* commonly used in the patient portal literature: no use (no patient portal log-ons), non-active use (e.g. log on and use health resources or clinic information), active use without provider (e.g. log on to view lab results, order prescriptions, schedule visits), and active use with provider (e.g. log on to email provider, use provider chat, or eVisit).  PCEOL Outcomes: Binary indicator for whether a patient had an advance directive on file at the time of death or not. Binary indicator for whether a patient died in hospice or not. Number of person-days for patient for follow-up for number of hospitalizations in last 30 days of life. Log of number of person-days for the patient for follow-up for number of hospitalizations in last 30 days of life. Count of number of hospitalizations for the patient in last 30 days of life (capped at 4 to mask small cell counts). | | | | | |

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| SUBJECT FLOW (CONSORT): |
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| STUDY CALENDAR:  ***A screenshot of a computer  Description automatically generated with low confidence*** |

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| BASELINE CHARACTERISTICS (TABLE 1) |

**PCRC STANDARDIZED DATA ELEMENTS**

***Please see the separate information sheet*** [***“DISC Standardized Data Elements”***](file:///Users/jenniferportz/Downloads/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.)** |  |  | EHR |
| 1. **Sex** |  |  | EHR |
| 1. **Ethnicity** |  |  | EHR |
| 1. **Race** |  |  | EHR |
| 1. **Age in years** |  |  | EHR |
| 1. **Current Marital Status** |  |  | EHR |
| 1. **Primary life-limiting diagnosis/illness** |  |  |  |
| 1. **Performance status (AKPS)** |  |  |  |
| 1. **Enrolled in Hospice** |  |  | EHR |
| * 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?** |  |  | EHR |
| 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**

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| **CONTENT**  *(e.g., PS)* | **ABBREV**  *(e.g., AKPS)* | **INSTRUMENT NAME**  *(e.g., Australian Modified Karnofsky Performance Status)* |
| None | None | None |
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