Community-Based Palliative Care Opportunity Analysis
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Background
While hospital-based palliative care services are prevalent in the US, community-based palliative care (CBPC) – defined as palliative care offered outside the acute care hospital and prior to enrollment in hospice -- is still relatively rare. Though there is an abundance of published evidence pointing to the benefits of home- and clinic-based palliative care, many provider organizations struggle to develop local data describing the need for CBPC and the expected impacts of such services. The Community-Based Palliative Care Opportunity Analysis (Opportunity Analysis) was designed to help fill this gap. The methods we propose should be well within the skill-set of individuals who use hospital financial and administrative data on a regular basis (i.e., analysts who work in the finance department, or similar job titles) and the data required to complete the analyses are readily available to most health systems.

Approach
The Opportunity Analysis retrospectively assesses utilization patterns in the final six months of life for patients with chronic, life-limiting disease who utilized your health system and died in a given calendar year. The analysis maps utilization across time and disease groups, in reference to National Quality Forum (NQF) measures addressing quality of care towards the end of life, and other measures of quality and efficiency, such as:

- Frequency of ED visits;
- Frequency, duration and intensity of hospitalizations;
- 30-day readmissions;
- In-hospital and 30-day deaths;
- Use and timing of specialty palliative care (SPC);
- Use and timing of hospice;
- Fiscal outcomes such as costs, contribution margin and net margin for inpatient care.

Sites with active CBPC services can contrast patterns and outcomes for patients who did and did not access SPC, or can look for differences in outcomes relative to timing of initial SPC contact (early vs late in the disease course.) See Appendix I for a list of standard Opportunity Analysis outputs.

Patient Population
The analysis focuses on patients with seven chronic, life-limiting diseases: cancer, congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), acquired immune deficiency syndrome/human immunodeficiency virus (AIDS/HIV), end stage renal disease (ESRD), neurological conditions (including dementia), and cirrhosis/liver failure. You can analyze outcomes for all or a subset of these groups, as appropriate for your site. A list of ICD-9 diagnosis codes that can be used to construct the seven disease groups is available in Appendix II.
Data Sources
The analysis utilizes three types of data:

1) **Data that identifies a population of decedents.** Such data are available from a few sources, including the Social Security Administration’s Death Master File (DMF), death records maintained by State or County public health offices, or, for cancer patients only, data from a hospital or health system Cancer Registry. These data are needed to identify decedents and date of death. Because the analysis uses an external source to identify the population of decedents you will not be limited to analyzing outcomes for patients who die in the hospital (the majority of patients die in other settings.)

2) **Claims and administrative data.** This includes data describing your patients (age, primary payer, diagnoses), and data describing contacts with your health system, which are needed to assess utilization and fiscal outcomes. The health system encounter data will at least include information describing hospital admissions and Emergency Department (ED) visits, but also might include data describing clinic visits, home health or hospice services, depending on the scope of services offered by your system.

3) **Data that describes use of Specialty Palliative Care (SPC),** if such data are not included in the health system administrative database (which is often the case). These data are needed to identify baseline penetration of existing SPC services, including interval between first contact with an SPC service and death.

See Appendix III for a list of minimum required data from all three sources.

Useful Tools
We have developed several tools that will assist you in collating and interpreting Opportunity Analysis outputs. All of the tools are available on the Coalition for Compassionate Care of California’s Palliative Care Access Project (PCAP) Web site:

http://coalitionccc.org/what-we-do/palliative-care-access-project/

A. **Opportunity Analysis Table 1: Baseline Utilization for EOL Population (OA Table 1)** is a handy tool for storing, assembling and presenting the summary values that the Opportunity Analysis generates. The MS Excel file has 5 sections, with tables that are ready for data input:

1) **Dataset construction:** for tracking the total number of patients in the 7 disease groups of interest, and all others, including how many cases were excluded from the final analysis population

2) **Demographics:** descriptive information about the analysis population, including proportion over age 65 and distribution across primary payers

3) **Utilization in the last 6 months of life:** summary of utilization of inpatient and emergency services for the entire last six months of life for each disease group, and all other decedents

4) **Utilization in the final 30 days of life:** summary of utilization of inpatient and emergency services in just the last six months of life for each disease group, and all other decedents

5) **Use of hospice and palliative care:** summary of current utilization of hospice and palliative care, across settings and over time
B. Opportunity Analysis Table 2: Month-to-Month Utilization (OA Table 2) is a handy tool for storing, assembling and presenting the month-to-month trend data that the Opportunity Analysis generates. The file has 10 tables that are ready for data input:

1) ED visits by disease group and month
2) # Admissions by disease group and month
3) Average length of stay for admissions by disease group and month
4) Total bed-days by disease group and month
5) ICU days by disease group and month
6) Re-admissions by disease group and month
7) Direct cost of care for admissions by disease group and month
8) Total cost of care for admissions by disease group by month
9) Contribution margin for admissions by disease group and month
10) Net margin for admissions by disease group and month

Populating the input tables will automatically populate the graphs that correspond to each table.

C. The Supportive Care Calculators (SCCs) will help you use the data generated by the Opportunity Analysis to answer questions like:

• How many patients could make use of a new CBPC service?
• How many visits per patient should be expected?
• How many FTE are needed to manage the expected volume?
• What will our staffing costs be?
• What revenues will be generated?
• What is the expected gap between costs and revenues?
• How will we demonstrate impact commensurate with investment and effort?

One version of the SCC addresses clinics; another is for home-based services. The MS Excel files have 8 sections, which are ready for data input:

1) Target Population (# patients who would likely benefit from SPC)
2) Proportion of Population Served by Clinics
3) Service Duration and Visit Volume
4) Clinic Days Required (for space & staffing considerations)
5) Staffing Costs
6) Billing and Expected Revenue
7) Summary Costs and Revenue
8) Hospital Utilization Impact Projections

To use the calculators, input data generated by the Opportunity Analysis, along with assumptions about referral patterns, length of engagement, staffing model, and billing revenues. The SCC’s will then generate a range of estimates regarding expected program volumes, costs and impacts, which should assist your team with program planning and developing business proposals.

Process for Conducting the Opportunity Analysis
We recommend the following process when completing the Opportunity Analysis.

1. Review the methods summary (below), list of needed data (Appendix I), summary of standard outputs (Appendix II) and the template tables (OA Table 1 and OA Table 2, which are available on the PCAP Web site.)
2. Specify the parameters of the *Opportunity Analysis* at your site, including the time period you want to look at (single year, or multiple years), the disease groups to include, elements to include in the summary of utilization / costs, and outcomes that will be assessed.

3. Decide on the source data you will use for identifying decedents – DMF, state registry, or local cancer registry.

4. Gather, clean and standardize formatting for all needed data

5. Combine datasets and conduct analyses

6. Investigate outlier / irrational / surprising findings - clean data as needed and rerun analyses

7. Populate summary tables and create charts, as desired.

**Methods Summary**

A. Identify the cohort of decedents who had some contact with your health system in the 6 months prior to death.

1. Create a table of unique Medical Record Numbers (MRNs) of patients >21 years of age who used your health system in your selected analysis period.

2. Use your hospital claims data to identify the subset of those patients who died in-hospital. By definition these patients used your health system in the last six months of life, and will be included in the analysis.

3. Link your table of MRNs (now excluding patients identified in Step A2, above) to your decedent identification source (DMF, state or county records, cancer registry records), identifying which patients died in the analysis period outside of the acute care hospital.

4. Remove from the analysis population patients that did not have contact with your health system in the 6 months preceding death.

5. Combine your files of inpatient and outpatient deaths – this is your decedent population.

B. Using *OA Table 1* as a guide, aggregate data to develop demographic information, summary data describing utilization in the final 6 months of life, summary data describing utilization in the final month of life, and use of hospice and palliative care, by disease group.

1. For all patients in your decedent population, gather inpatient and outpatient encounter data for your entire analysis period plus the preceding 7 months. For example, if you are analyzing outcomes for patients who died in calendar year 2013, you would need to pull encounter data for Jan-Dec 2013, plus June-December 2012.

2. Assign patients to disease groups, according to primary diagnosis. For patients that have multiple encounters that cross disease groups (some encounters for cancer, some for COPD, for example), assign the patient to the group that accounted for the largest proportion of costs in the analysis period.

3. Remove cases where patients had hospital admissions for trauma or transplant in the final 6 months of life, if you wish.
4. Assign patients to primary payer groups – Medicare, Medicaid, commercial insurance, self-pay/uninsured, and other.

5. Categorize ED visits, inpatient admissions, hospice referrals (and clinic visits and other services, if applicable) according to month prior to death (6 months prior to death, 5 months prior to death, and so on)

6. Calculate intervals between hospital admissions to identify 30-day readmissions and intervals between hospital discharge and death, to identify 30-day mortality cases.

7. Generate summary values for number of ED visits, admissions, hospital days, ICU days, direct costs, total costs, and revenues, by month prior to death.

8. Categorize patients according to contact with SPC: none, inpatient only, outpatient only, both inpatient and outpatient.

9. Calculate interval between initial SPC contact, if any, and date of death.

10. Summarize outcomes for the final 6 months of life, and the final month of life, to populate OA Table 1

C. Using OA Table 2 as a guide, summarize findings by disease group by month preceding death.

1. ED visits by disease group and month
2. # of admissions by disease group and month
3. Average length of stay for admissions by disease group and month
4. # of bed-days by disease group and month
5. ICU days by disease group and month
6. Re-admissions by disease group and month
7. Direct cost of care for admissions by disease group and month
8. Contribution margin for admissions by disease group and month
9. Net margin for admissions by disease group and month

D. Notes

1. Although most analyses will be limited to the six months prior to death, you still need to include in your dataset any encounter that closed in the last 7 months of life. In some instances, utilization in the 7th month prior to death needs to be examined (e.g., for identifying which 6th month admissions were 30-day re-admissions from discharges in the 7th month).

2. Although the standard Opportunity Analysis design assesses utilization in the 6 months preceding death, you may wish to extend the analysis period to the 12-18 months preceding death, if it is the practice (or goal) at your site to engage with patients much earlier in the disease course.
For some systems, hospice referrals may only be documented in the disposition-at-discharge field in the claims data for hospitalizations. In such cases be sure to be clear when presenting your data that you are NOT reporting total hospice utilization for all health system patients; rather, you can report that “among patients referred to hospice following an acute care hospitalization, “x” # had a hospice length of service of <3 days.”

If you have questions about the Opportunity Analysis or any of the supporting tools you may contact the developers:

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Appendix I. Standard Opportunity Analysis Outputs

All of the below can be modified or added to, to meet site-specific needs and preferences.

Descriptive data
- # of unique decedents per disease group
- # & proportion patients aged <65 years, and # and proportion ≥65 years
- Payor mix -- # and proportion of patients in each of 4 categories: Medicare, Medi-cal, commercial, self-pay

Metrics (reported for each disease group and for all patients in all seven disease groups, unless otherwise specified)
1) National Quality Forum (NQF) endorsed measures (# and proportion of patients)
   - Chemotherapy in last 14 days of life (cancer patients only)
   - Not referred to hospice
   - First referred to hospice < 3 days before death
   - ICU used in last 30 days of life
   - > 1 ED visit in the last 30 days of life

2) Other quality metrics (# and proportion of patients)
   - In-hospital deaths
   - Admitted to hospital in last 30 days of life
   - Median days from first hospice referral to death
   - Not referred to specialist palliative care (SPC)
   - First referred to SPC < 30 days before death
   - Median days from first SPC referral to death

3) Other patient-level analyses describing utilization and costs
   - Average # of ED visits per patient in last six months
   - Average # of admits and hospital days per patient in last six months
   - Average # of ICU days per patient in last six months

4) Analyses at encounter level
   - Average LOS per admit across last six months
   - # 30-day re-admits (all cause) across last six months
   - # 30-day mortality admits across last six months (may be more than 1 for some patients)
   - Average total and direct costs, net margin and contribution margin for hospital admissions, last six months

5) Analyses of month-to-month trends
   - ED visits, by month preceding death
   - # of admissions, by month preceding death
   - LOS per admission, by month
   - Total bed days and ICU days, by month
   - Readmissions by month
   - Direct costs, contribution margin and net margin per admission, by month
Appendix II. ICD-9 Diagnosis Codes for Defining Disease Groups

Cancer
- 140.x-172.x, 174.x-209.3x, 209.7x, 230.x-239.x, v58.0x (radiation), and v58.1x (chemo)
- (Thus generally 140-239 plus radiation & chemo, but excluding benigns 209.4x-209.6x, 210.x – 229.x, and ‘other skin’ 173.x)

Heart Failure
- 398.91, 402.01, 402.11, 402.91, 404.01, 404.03, 404.11, 404.13, 404.91, 404.93, 428.x

COPD / pulmonary diseases
- 416.8, 416.9, 490.x – 505.x, 506.4, 508.1, 508.8

HIV
- 042.x, 043.x, 044.x

Neuro (ALS, dementias, and other progressive neurological diseases)
- 290.x, 294.1x, 294.2x, 330x – 337x

Cirrhosis / liver disease
- 070.22, 070.23, 070.32, 070.33, 070.44, 070.54, 070.6, 070.9, 456.0-456.2, 570.x, 571.x, 572.2-572.8, 573.3, 573.4, 573.8, 573.9, V42.7

End-stage renal disease / chronic kidney disease
- 403.01, 403.11, 403.91, 404.02, 404.12, 404.92, 585.x, 586.x, 588.0, V42.0, V45.1x, V56.x
Appendix III. Minimum Data Requirements

Patient Data
- Date of birth
- Medical Record Number or similar patient identifier
- Social Security Number (SSN), if using DMF or state registry to identify population of decedents
- Date of death (from health system data, or values from DMF, cancer registry, or state registry)

Specialty Palliative Care Service Contact Data
- Medical Record Number or similar patient identifier
- Specialist palliative care program encounter dates (first encounter at minimum)
- Setting/type of encounter (inpatient, clinic, home, phone/distance)

Claims data
For hospital admissions and ED visits at minimum; data from other types of encounters, such as clinic visits or home-visits, can be added per user preferences

Encounter Level Data
- MRN
- Encounter number (unique identifier for each encounter)
- Account start date / admission date
- Account end date / discharge date
- Encounter type – ED visit, acute inpatient admission, outpatient visit, subacute inpatient admission, etc.
- Disposition at discharge
- Use of ED for patients admitted to the acute care hospital
- # bed days
- # ICU bed days
- Direct costs
- Total costs
- Net payment or reimbursement (may substitute expected payment if desired)
- Primary diagnosis (ICD-9 code)
- Secondary diagnoses (ICD-9 codes)
- Primary Procedure (ICD-9 code)
- Secondary procedure (ICD-9 codes)
- Primary payor (classified as Medicare, Medi-cal, commercial, or self-pay; subgroups within those 4 classifications can be used, per site preferences)

Detailed Billing Data (only needed for admissions that began >30 days prior to death and ended within 30 days of death and included some ICU days)
- MRN
- Encounter number
- Service date
- UB Code for bed type (to identify specific days in an ICU bed)
About the Authors

**J. Brian Cassel, PhD** is an Assistant Professor in the division of Hematology/Oncology and Palliative Care, and Director of Analytic Services at Massey Cancer Center, at Virginia Commonwealth University in Richmond, VA. His research interests include cancer informatics, and health services research on specialist palliative care services in the US and the UK, specifically the costs and financing of cancer care and palliative care. As a faculty member of VCU’s Palliative Care Leadership Center he has helped to train more than 140 palliative care teams from all over the US. He is a scientific member of the VCU Massey Cancer Center, where he helped to develop and currently oversees the Massey Data Analysis System. He serves as Co-Director of the Metrics Team for the Palliative Care Action Community, a one-year effort sponsored by the California HealthCare Foundation aimed at promoting the development, sustainability and growth of community-based PC services across California.

**Kathleen Kerr** is a health care consultant in private practice in Mill Valley, California. She has expertise in palliative care, quality improvement and program evaluation, with particular interest in assessing financial outcomes. Her professional experience includes more than a decade of work as a Senior Analyst in the Department of Medicine at the University of California, San Francisco, where she participated in educational, technical assistance and research efforts that promoted the growth and sustainability of quality palliative care programs. Currently, Ms. Kerr’s work is focused on developing sustainable models for community-based palliative care, with particular emphasis on evaluating the business case for such services. She is a member of the core advisory group for the Palliative Care Access Project, a state-wide palliative care learning community sponsored by the Coalition for Compassionate Care of California. Ms. Kerr is also co-director of the Metrics Team for the California HealthCare Foundation’s Palliative Care Action Community – an effort that has brought together 21 diverse organizations with an interest in enhancing their community-based palliative care programs. She is a longtime member of the Award Committee for the American Hospital Association’s Circle of Life Award, which recognizes excellence and innovation in the delivery of hospice and palliative care.