

7-11-2018

Measurements That Matter: Assessment & Management of the Symptoms of Chronic Illness Using the Integrated Palliative Outcome Scale (IPOS)

Deborah Jeffery
dmmcn3@mail.umsl.edu

Follow this and additional works at: <https://irl.umsl.edu/dissertation>



Part of the [Geriatric Nursing Commons](#)

Recommended Citation

Jeffery, Deborah, "Measurements That Matter: Assessment & Management of the Symptoms of Chronic Illness Using the Integrated Palliative Outcome Scale (IPOS)" (2018). *Dissertations*. 766.
<https://irl.umsl.edu/dissertation/766>

This Dissertation is brought to you for free and open access by the UMSL Graduate Works at IRL @ UMSL. It has been accepted for inclusion in Dissertations by an authorized administrator of IRL @ UMSL. For more information, please contact marvinh@umsl.edu.

Measurements That Matter: Assessment and Management of the Symptoms of Chronic
Illness

Using the Integrated Palliative Outcome Scale (IPOS)

Deborah M. Jeffery

M.S.N., University of Missouri-St. Louis, 2013

B.S.N., University of Missouri-Columbia, 2009

A Dissertation Submitted to The Graduate School at the University of Missouri-St. Louis

in partial fulfillment of the requirements for the degree

Doctor of Nursing Practice

August, 2018

Advisory Committee

Susan Dean-Baar, Ph.D., R.N., FAAN

Chairperson

Tonya Haynes, D.N.P., R.N.

Mary Fox, M.D.

ABSTRACT

Measurements that Matter: Assessment and Management of the Symptoms of Chronic Illness Using the Integrated Palliative Outcome Scale (IPOS)

Background: The mission of the Advanced Illness Management (AIM) program at the Visiting Nurse Association of Greater St. Louis (VNA) is to relieve the burden of serious illness by providing exceptional care to patients and families through symptom management. A validated symptom tool was needed for holistic assessment.

Purpose: This is a quality-improvement project aimed at enhancing symptom management in patients experiencing advanced illness in a community-based palliative care program. Provider use of the Integrated Palliative Outcome Scale (IPOS) as an assessment tool to deliver focused interventions was explored.

Methods: The IPOS tool was embedded in the Electronic Health Record (EHR) note template. The project used the PICO framework to identify the problem. The Population of interest were new patients admitted during a 90 day period. The Intervention of interest was the use of the IPOS by providers. The Comparison of interest was the absence of the IPOS prior to the project. The Outcome of interest was the use of the IPOS and documentation of interventions.

Results: There were 62 visits in the sample. Compliance rate with use of the tool was 93.5%. Poor mobility and weakness were the most common physical symptoms. The most common psychosocial symptom was the patient's perception of family anxiety. Poor mobility and weakness scored the highest number of aggregate symptoms: 39 and 37 times respectively. Providers intervened 74% and 76% of the time. While providers responded 100% of the time to overwhelming immobility, overwhelming weakness only received an intervention 66% of the time. The highest number of psychosocial/spiritual symptoms was the patients' perception of family anxiety. Thirty positive responses were recorded with an aggregate score of 76% interventions. The patients' own anxiety/worry was recorded 17 times with an aggregate intervention score of 88%.

Conclusions: Community-based palliative care programs need to be pro-active in the management of symptoms to provide holistic patient-centered care. This project used a validated tool that addresses not only the physical burden of chronic illness, but the emotional, mental, spiritual, and relationship aspects of illness.

MEASURES THAT MATTER

Introduction

Advanced Illness Management (AIM) is defined as “occurring when one or more conditions become serious enough that general health and functioning decline, and treatments begin to lose their impact. This is a process that continues to the end of life” (American Hospital Assoc., n.d.). Providers of AIM care must have experience in assessment, evaluation, diagnosis, and treatment of advanced illness and be knowledgeable of cultural and ethical situations involving patients and families. Individual providers approach to assessing symptom management created the need for consistent documentation which provides information to the interdisciplinary team. The Visiting Nurse Association of Greater St. Louis (VNA) has developed a community-based AIM program that addresses chronic disease in the elderly and disabled adult population in the St. Louis metropolitan region. Providers work within an interdisciplinary team model to provide quality care with measurable outcomes. The program is a team-based consultation co-management program based on a palliative care model. Palliative care was eliminated in the title of AIM as the general public has an immediate association with end-of-life care and terminal disease. In reality, palliative care is for any patient with chronic illness who is experiencing a decreased quality of life because of symptoms related to their illnesses or treatments (Mulvihill, 2014).

Palliative care (PC) is defined as, “Specialty medical care for people living with serious illness. It focuses on providing relief from the symptoms and stresses of serious illness whatever the diagnosis. The goal is to improve quality of life for both the patient and family” (California State University Institute for Palliative Care, n.d.) Patients have a high burden of symptoms that may be physical, emotional, spiritual, mental, or

MEASURES THAT MATTER

relationship/social in nature. In many cases of advanced illness, patients are not eligible for hospice or choose not to utilize hospice services if eligible. Patients may seek curative treatments concurrent with AIM care. Evidence-based treatments and processes aimed at quality improvement are necessary to ensure that care is provided appropriately regardless of the trajectory of illness. This paper describes a quality improvement project aimed at improving symptom management of patients experiencing advanced illness. A symptom tool was needed due to incomplete and inconsistent documentation by providers of interventions related to positive symptoms. Provider use of the Integrated Palliative Outcome Scale (IPOS) for a select patient population was explored.

The VNA community-based AIM Program is a grant-funded project of the Missouri Foundation for Health. The mission of the AIM Program is to help relieve the burden of serious illness by providing exceptional care to patients and families through symptom management. The program prepares patients and families to transition along life's continuum, and prepare for end-of-life when the time is appropriate. Stated goals related to grant-funding are that the project demonstrates its ability to provide quality and cost-effective care in the area of symptom management. Prior to this project, providers were trained to ask about pain, shortness of breath, and sleep habits during visits. These answers were "yes" and "no" responses or often not documented. This caused a gap in care and limited opportunities for team member follow up. There was no method for recording psychosocial symptoms that are important to holistic care. A validated assessment tool needed implementation by providers to screen patients for timely interventions from the interdisciplinary team.

MEASURES THAT MATTER

For this project, the IPOS has been embedded in the electronic health record (EHR) at a community-based palliative care specialty practice. The purpose of incorporating the IPOS into the EHR progress notes was to promote consistency in assessment and management of symptoms related to advanced illness by healthcare providers on the team. The IPOS tool has been developed over the past 15 years in palliative care settings worldwide. Patient related outcome measures (PROMs) are measures that reflect quality of life for patients and families dealing with the burdens of serious illnesses in the community. Use of IPOS allows providers to respond to PROMs by providing timely interventions related to patients' reported symptoms.

The problem statement is: a consistent and systematic holistic symptom assessment tool was needed to manage a gap in care. The IPOS is a validated symptom tool for management of patients in a community-based palliative care program. The PICOT question used to guide this evidence-based project was: "For chronically ill patients, will use of a validated symptom tool improve providers' responses to patient symptoms?" The population of interest (P) is all newly enrolled patients in the AIM program at the VNA December 1, 2017 – February 28, 2018. The intervention of interest (I) is the use of the IPOS tool by providers on all new patients admitted between December 1, 2017 – February 28, 2018. The comparison of interest (C) is the absence of use of the IPOS at the VNA prior to December 1, 2017. The outcome of interest (O) is the use of the IPOS and documentation of interventions (when indicated) by providers for the selected population and timeframe. The project was implemented December 1, 2017 – February 28, 2018. The first goal of care is stated in the Top Ten Measures that Matter (AAHPM, 2015): Palliative care patients receive a comprehensive assessment (physical,

MEASURES THAT MATTER

psychosocial, social, spiritual, and functional) soon after admission. These goals are ongoing in the plan of care for patients. The purpose of this quality improvement project was to enhance symptom management for patients in the AIM program. Provider use of the IPOS to deliver focused interventions was explored.

An audit tool was developed to review progress notes on provider visits occurring for 90 days on all visits including the initial visit. The selected new patient population was followed for 90 days after admission. Patients typically received 4 visits in the 90 day period after admission.

Review of the Literature

An extensive review of the literature regarding the use of outcome measures for control of symptoms in palliative care was done using the following databases: PubMed, Medline, CINAHL, Ovid, and Google Scholar. The keywords: palliative care, outcome measures, symptom management, symptom management tools, POS, and IPOS were used. Search years were 2000 to the present. The search resulted in approximately 90 documents inclusive of controlled trials, studies, white papers, policy statements, and consensus reports. Trials and papers that were conducted in hospital and office-based programs were excluded.

The literature was also reviewed for palliative care guidelines that provide processes for development of quality models. The American Academy of Hospice and Palliative Medicine report on Ten Measures to Drive Quality Palliative and Hospice Care, AAHPM (2015), provides strong evidence that the development of benchmark outcome measures must include validated tools for symptom management. The basis for quality palliative care is defined in the National Consensus Project for Quality Palliative

MEASURES THAT MATTER

Care (Ferrell et al., 2007) and describes the eight domains of care that define palliative care. The domains of care should be explored to care for patients and families in a holistic team setting. The domains of care identify symptom management as the key indicator for successful outcomes.

In addition to the National Consensus Project for Quality Palliative Care (2013), several papers and research studies offer strong evidence that community-based palliative care programs are valuable programs in management of patients with serious chronic illnesses who have difficulty leaving the home. Cohn et al. (2017) published a discussion paper that validates community-based palliative care in the management of chronically ill patients. Higginson, Hart, Koffman, Selman, & Harding (2007) conducted a systematic review in 2006 that develops the basic need for palliative care as a discipline in healthcare.

In a Cochrane systematic review completed by Gomes, Calazani, Curiale, McCrone, and Higginson (2012), the effectiveness and cost-effectiveness of home-based palliative care as an option for adults with advanced illness and their caregivers was discussed. The importance of symptom management as it related to quality of life is reviewed. Leff, Carlson, Saliba, and Richie's 2015 article on the state of home-based primary and palliative care in the United States (U.S.) led them to create the National Home-Based Primary and Palliative Care Network. The authors have developed a registry that will be used for quality care benchmarking, practice-based quality improvement, performance reporting, and comparative effectiveness research. The main focus of the quality of life domain is to optimize symptom management.

MEASURES THAT MATTER

Lorenz et al. (2006) conducted a systematic review on measures for symptoms and advanced care planning in cancer patients. Measures related to pain, dyspnea, depression, and advanced care planning are linked to quality of life measures in cancer patients. Muldoon, Barger, Flory, and Manuck (1998), discussed quality of life as it relates to the personal burden of illness and part of the psychosocial aspects of illness. This study is one of the early studies that directed a great deal of research toward quality of life issues in palliative care.

Bauseweine et al. (2011) interviewed providers to determine usage of outcome measures. The results indicate that measurement tools need to be easy to use and convenient to interpret to be used consistently. Providers indicated that the most common reason that tools are not used is that they do not have time to administer them.

The symptoms of serious illnesses dramatically affect the quality of life of patients and caregivers. The symptoms associated with serious illness can be physical, mental, emotional, spiritual, or psychosocial. This creates the necessity of the use of a tool that addresses symptoms in a holistic process. A tool that is validated for use in multiple illnesses and with diverse populations was needed to produce data useful to providers and results in appropriate interventions. Additionally, a tool that has been validated in multilingual settings is needed for diverse cultures and ethnicities. The Integrated Palliative Outcome Scale (IPOS) (Appendix) was originally developed at King's College in London, UK. POS: Palliative Outcome Scale (2012) is the IPOS precursor and has been tested extensively in Europe and Africa. It has been revised and refined over a 15 year validation period. Literature on the validity of the IPOS was reviewed to determine its appropriateness for use in a community-based program that

MEASURES THAT MATTER

manages multiple serious chronic illnesses in private homes as well as long-term care settings.

The current literature offers strong evidence that the IPOS is a valid tool for use in multi-cultural settings for multiple illnesses in palliative care settings. The following studies were reviewed as they relate to IPOS use in various palliative care settings.

Evans et al. (2013) assert that PROMs are the most useful outcome measures to determine patient quality of life in consensus workshop studies. The Palliative Outcome Scale (precursor) to IPOS is specifically cited as a valid tool to measure PROMs. Collins et al. (2015) conducted a systematic review of the use of the POS and the Support Team Assessment Schedule (STAS), which found support of these as valid tools in a variety of palliative care settings. Kane et al. (2017) evaluated the acceptability and feasibility of the IPOS in symptom management of heart failure patients in palliative care programs. They concluded that the IPOS is a valid tool for symptom management in heart failure. This is a notable study due to the high number of heart failure patients in palliative care programs.

Studies using the POS include the 1999 study by Hearn and Higginson who developed a scale to measure the physical, psychological, and/or spiritual domains of palliative care and tested it for validity on 450 patients with advanced cancer. This study was the basis for continued development of the POS as a validated tool to measure symptom burden. Lowther et al. (2012) used the POS in a randomized controlled trial (RCT) to measure symptom burden in HIV patients receiving antiretroviral therapy. Evans et al. (2013) identify the POS as a valid tool to measure PROMs by international experts attending a palliative care and end-of-life consensus workshop. Rugno and

MEASURES THAT MATTER

Marysia (2016) conducted an integrated literature review of 25 multi-cultural studies that validates the importance of the POS in research studies in palliative care. The review also included validity of the POS in clinical practice for symptom management.

Beck et al. (2017) validated the translation of the IPOS into Swedish. The IPOS was successfully adapted cross-culturally in general and specialized palliative care.

Schildmann et al. (2015) validated the translation of the IPOS into German. Results from these studies also validate that the tool is acceptable translated into specific cultural settings.

In 2016, Gao et al. used the IPOS with additional neurological emphasis successfully in a small study. This validated that the IPOS can be modified for use in specific patient populations. A specific IPOS for patients with progressive long-term neurological illnesses showed reasonable correlation with the original POS. The use of a specific IPOS tool for research purposes in monitoring outcomes over time in neurological diseases shows promise for detecting subtle progression of illness and slow decline.

Kane et al. (2017) used the IPOS in a large heart failure study that not only validated outcome measures, but a high compliance of provider use was recorded. The heart failure study had two parts. The first included education and training on patient-centered care, and the second part trained nurses on the use of the IPOS for heart failure patients. Murtagh et al. (2016) showed that the IPOS has good test-retest reliability and internal consistency. The IPOS was used in a Cochrane controlled trial for patients completing the questionnaire with their caregiver proxies. Clinical relevance was

MEASURES THAT MATTER

established by higher scores by both patients and proxies in unstable or deteriorating disease states.

The IPOS literature review includes strong evidence that the IPOS is a valid tool in palliative care specialties for measurement of the burden of symptoms. The IPOS was developed from the POS integrating the most clinically relevant aspects of quality of life. Symptoms may be physical, mental, emotional, spiritual, or psychosocial in nature. The tool has also been validated for use in multiple types of serious and/or chronic illnesses. The IPOS has been extensively used in studies conducted in Europe and Africa. There are gaps in studies on the use of the IPOS in the U.S. There is also a gap in studies that involve individuals affected by advanced dementia.

Framework of the Study

The framework of this study is the Plan, Do, Study, Act framework (Institute for Healthcare Improvement, n.d.) In the Plan phase, research was done on the validity of the IPOS as it not only addressed physical symptoms, but contained narratives necessary to understand the emotional, spiritual, psychosocial, mental, and relationship needs of patients and families facing serious and/or chronic illnesses in the community. Also, during the Plan phase, rights were obtained to use the tool in the practice setting and for research purposes. The information technology support team was engaged in the project to embed the tool into the EHR as a custom report that would allow quick and easy access by providers. The IPOS appears in the provider progress note and requires approximately five minutes to complete. Results can be exported to custom reports after de-identification for recording and research purposes.

MEASURES THAT MATTER

In the Do phase, training sessions for providers was accomplished in two sessions to provide adequate opportunity to discuss the use and importance of the tool in the practice to provide high quality of care to patients and families. The go-live date of December 1, 2017 was chosen to allow a 90 day period of collection for retrospective review on use and associated interventions in positive symptom burdens. Consistent use of the tool and interventions were audited following the initial period of use.

A 90-day Study phase began at the go-live date. Providers were instructed that the IPOS should be used during each visit on any newly admitted patient to the VNA AIM program from December 1, 2017 – February 28, 2018. Patients in the study were audited for all visits done in the 90 days following their admission.

After the 90-day Study, results of the audit were reviewed during the Act phase. The Act phase began with an EHR review of the target patient population. Provider notes were reviewed for appropriate use of the IPOS and documentation of corresponding interventions when indicated. Retraining and continued education of the providers will be done post-audit via team meetings to reiterate the significance of symptom management and to discuss implementation of goals of care six months following the audit period.

Method

Design

This is a quality improvement project. Retrospective chart audits were completed. The IPOS was used by clinical providers during visits on all new patients in the AIM program. Patients included in this project were admitted as new patients between December 1, 2017 and February 28, 2018. Documentation of results of the IPOS was recorded in the patient's EHR during the provider visit. The provider verbally read the

MEASURES THAT MATTER

questions to the patient during the visit and recorded the answers. The go-live date for implementation of the project was December 1, 2017. Beginning June 1, 2018, eligible patient EHRs were audited for provider compliance in the use of the IPOS and documentation of corresponding interventions for positive responses. Caregiver assistance if given, was documented on the IPOS.

Setting

The setting for the project was a community-based palliative care specialty practice. Patients were primarily over 65 years of age or disabled adults who were enrolled in VNA of Greater St. Louis AIM program. The patients or an approved designee signed consent forms to be treated by the providers and interdisciplinary team members of the AIM program. Provider visits occurred in the patient's primary residence, which may be a private home, long-term facility or senior housing.

Sample

The target population for this quality improvement project was all new patients admitted to the AIM program between December 1, 2017 and February 28, 2018. Patients qualifying for the program were 65 years and older or disabled adults with one or more chronic and/or serious illnesses. Patients were insured by Medicare, Medicaid or sponsored by the VNA. Patients were not excluded due to gender, race, ethnicity or sexual orientation. Patients who scored less than 7 on the 10-point cognitive screen with the Rapid Geriatric Assessment Tool (RGAT) (St. Louis University, 2016) were excluded from this project. The patient sample size was 17 patients. Each patient received approximately 4 visits in the 90 day intervention period. Patients who transitioned out of

MEASURES THAT MATTER

the program during the audit period, received less than 4 visits. All chart audits were completed by the project director with the audit tool created for this project.

Approval Processes

Providers of care and interdisciplinary team members have been notified of the study and the go-live date for use of the IPOS. Consent of the patient or approved legal designee to participate in the AIM program is obtained on admission. This is a non-invasive intervention. Information obtained from the tool will be used to improve the delivery and quality of care related to symptom management in advanced illness. The project was approved by the University of Missouri – St. Louis Institutional Review Board.

Data Collection/Analysis

Chart reviews for provider compliance with the use of the IPOS for assessment and management of symptoms related to the burden of serious illness were conducted by the project director on encrypted computers in a cloud-based EHR. A de-identified number was assigned by the auditor to each patient audited. Audits of patient records were performed using the EHR by the auditor authorized to use the system. The de-identified audit tools were paper records stored in locked cabinet at the VNA office. All chart audits occurred at that location. Compliance with the use of the IPOS tool and documentation of corresponding interventions for positive responses was recorded on the audit tool. The audit results will be used to improve care delivery and the quality of life for patients experiencing advanced illness.

MEASURES THAT MATTER

Procedures

This is a quality improvement project that included a retrospective chart review on all new patients enrolled in the AIM program at VNA of Greater St. Louis between December 1, 2017 and February 28, 2018. Patient provider visits occurring 90 days following the initial enrollment received chart reviews by the project director. The audit tool was developed by the project director to mirror the symptoms on the IPOS tool.

The following was evaluated per the audit tool: provider use of the IPOS, patient responses, and provider documentation of corresponding interventions when indicated. Patient responses to inquiries about pain, shortness of breath, weakness, nausea, vomiting, poor appetite, constipation, sore or dry mouth, drowsiness, and poor mobility that were recorded as “Moderately,” “Severely,” or “Overwhelmingly,” should have a corresponding intervention. Additionally, patient responses to “other” symptoms recorded as “Moderately” or greater should have a corresponding intervention. Patient responses to questions related to the last 3 days prior to use of the IPOS regarding patient anxiety, family anxiety, and patient depression should have a provider intervention to responses of “Most of the time” or “Always”. Patient responses to questions about feeling at peace, sharing feelings with family and friends, and having as much information as wanted should have a corresponding intervention recorded in the Plan section if the response is “Occasionally” or “Almost never”. Patient responses of “Problems hardly or never addressed” to the question regarding financial or personal problems addressed should have a corresponding intervention in the Plan section. The audit tool recorded the patient’s diagnosis, but no identifying demographics. Each provider in the AIM program

MEASURES THAT MATTER

who participated in this project was assigned an identifier to assess patterns of variability across providers and for individual education purposes. The end goal is the delivery of consistent, quality care.

Results

Table 1 Patient Population Totals

Total patients in project	17
Number of Initial Visits in project	17
Second Visits	15
Third Visits	15
Fourth Visits	12
Fifth Visits	3
Total Visits	62
Total Visits using IPOS resulting in 93.5% compliance during audit	58

During the 90-day enrollment period, 20 new patients were enrolled to the AIM program. Three patients were excluded due to cognitive scores below seven on St. Louis University's RGAT, (St. Louis University 2016). The sample for this project was 17. There were 62 visits in the sample and 58 of these had completed IPOS. This is a 93.5% compliance rate of providers' use of the tool.

MEASURES THAT MATTER

An unexpected result was that five patients transitioned to end-of-life care before the 90-day audit ended. These patients did not receive the expected four visits in the period.

Table 2 Patient Population by Diagnosis

Primary Diagnosis		
CHF	6	35%
Cancer (all sites)	4	24%
COPD/Asthma	2	12%
Interstitial Lung Disease	2	12%
Other	3	17%

Patient population results showed 35% were admitted with a primary diagnosis of Congestive Heart Failure (CHF). 24% were admitted with cancer, and 24% with lung diseases (Chronic Obstructive Pulmonary Disease, COPD was 12% and interstitial lung disease was 12%). The remaining 17% included caregiver stress, failure to thrive, and chronic pain. The majority of the patient population had multiple chronic illnesses that were co-managed by the primary care providers.

The rating scale in the IPOS for symptoms increase as the burden of the symptom increases. For physical symptoms, moderate equaled two points, severe equaled three points, and overwhelming equaled four points. Poor mobility and weakness were the most common physical symptoms, positive more often than pain or shortness of breath. These two symptoms were reported in all diagnoses as the most burdensome physical symptoms. The audit of interventions in response to physical symptoms was for symptoms scored moderately, severely or overwhelmingly. Patients' perceptions of family anxiety about their illnesses was the most common psychosocial symptom, rated

MEASURES THAT MATTER

more often than the patients' own anxiety. Interventions were expected in the audit when symptoms were rated most of the time or always. While patient anxiety is addressed 88% of the time by providers, family anxiety is addressed 76% of the time. When providers asked patients about "Peace," 17 patient visits recorded that they were only occasionally or almost never at peace. Generating meaningful discussions with patients and caregivers to concerns about the concept of peace, and referring to spiritual counselors as indicated allows patients to begin transitioning to end-of-life care.

Provider interventions for aggregate levels of physical symptom burdens ranged from 100% for vomiting to 14% for constipation and sore/dry mouth. When constipation was scored as moderate with 2 points assigned for each response and intervention, moderate constipation was 17% and severe constipation received 0% interventions. Moderate sore/dry mouth had 0% interventions and severe sore/dry mouth received interventions 43% of the time. Due to the adverse effects of these symptoms on patients' quality of life, education on guidelines and protocols will be reviewed with providers as part of future recommendations.

Poor mobility and weakness scored the highest number of aggregate symptoms: 39 and 37 times respectively. Providers intervened 74% and 76% of the time. While providers responded 100% of the time to overwhelming immobility, overwhelming weakness only received an intervention 66% of the time. Table 3 shows the intervention percentages for physical symptoms. Percentages in **bold** are below the standard of care percentages that will be established as a result of this baseline audit.

MEASURES THAT MATTER

Table 3 Percentage of Interventions in Response to Positive Physical Symptoms

	# Pos.	Aggregate %	Moderate %	Severe %	Overwhelming %
Symptom/Goal			85%	90%	95%
Pain	30	90%	95%	75%	100%
SOB	29	79%	80%	86%	-
Weakness	37	76%	68%	87%	66%
Nausea	6	67%	75%	50%	-
Vomiting	1	100%	100%	-	-
Poor Appetite	16	50%	33%	71%	-
Constipation	7	14%	17%	0%	-
Sore/Dry Mouth	14	14%	0%	43%	-
Drowsy	16	63%	58%	75%	-
Poor Mobility	39	74%	78%	60%	100%
Other	8	63%	43%	100%	-

Notes: Percentages in **bold** are below the proposed 6 month goals of:

Moderate= Intervention at least 85% of the time. Severe= Intervention at least 90% of the time.

Overwhelming= Intervention at least 95% of the time.

Items marked with (-) indicate that no data was generated in the audit

MEASURES THAT MATTER

The highest number of psychosocial/spiritual symptoms was the patients' perception of family anxiety. Thirty positive responses were recorded with an aggregate score of 76% interventions. The patients' own anxiety/worry was recorded 17 times with an aggregate intervention score of 88%

Table 4 Percentage of Interventions in Response to Positive Psychosocial Symptoms

	# Pos.	Aggregate %	Most of the Time %	Always %
SYMPTOM/GOAL			90%	95%
Anxiety/Worry	17	88%	89%	87%
Family Anxiety	30	76%	75%	78%
Depressed	13	77%	70%	100%

Notes: Percentages in **bold** are below the 6 month goal of Intervention at least 90% for Most of the time, and Intervention at least 95% for Always.

MEASURES THAT MATTER

Percentage of Interventions in Response to Positive Psychosocial Symptoms

	# Pos.	Aggregate %	Occasionally %	Not at All %
SYMPTOM/GOAL			90%	95%
Peace	17	88%	91%	83%
Family Sharing	7	86%	100%	80%
Info. Sharing	1	100%	100%	None

Notes: Percentages in **bold** are below the 6 month goal of Intervention at least 90% for Occasionally, and Intervention at least 95% for Not at All.

Percentage of Interventions in Response to Positive Psychosocial Symptoms

	Aggregate %	Hardly Addressed %	Never Addressed %
SYMPTOM/GOAL		90%	95%
Practical Problems	-	-	-

Notes: No patient symptoms were reported at these levels on this audit. Indicated with (-).

MEASURES THAT MATTER

Discussion

Community-based palliative care programs need to be pro-active in the management of symptoms to provide holistic patient-centered care. This project uses a validated tool (IPOS) that addresses not only the physical burden of chronic illness, but the emotional, mental, spiritual, and relationship aspects of illness. The project was heavily weighted toward the documentation of the full-time AIM providers as they perform the majority of the patient visits in the first 90 days. It is by program design that the two most experienced providers provide consistent stabilization of patients immediately after admission when they are at the highest risk of hospital readmission. An unexpected result of patients transitioning to hospice during the audit period decreased the expected number of visits during the 90-day audit period.

Subsequent audits will need a comprehensive review of all providers as the program grows and new providers and census increase. Future training on the use of the IPOS needs to incorporate the experience of staff who have consistently administered it successfully over the 90-day audit period. Providers consistently used the tool in 93.5% of their visits. Incorporating the tool in a conversational review of symptoms often generated narrative from patients that aided providers in determining decreased coping by patients and/or increased caregiver stress and anxiety. Providers indicated that the tool was not too time consuming, and it triggered reminders of documentation of positive symptoms.

This audit will be used to formulate a quality improvement initiative within the AIM program to be reviewed 6 months post-baseline audit on individual providers'

MEASURES THAT MATTER

intervention response to symptoms. A second 90 day audit will be performed on random visits for individual providers after education on the expected percentages of intervention. This project provides the AIM program with a valid baseline on provider responsiveness to symptom burden in chronically ill patients across all admitting diagnoses. Providers administered the IPOS during 93.5% of their visits during the 90-day audit period. The goal in six months is to maintain a 95% administration rate for all providers. Goals for physical symptoms at 6 months is 95% of patients receive interventions for symptoms rated as overwhelming, 90% for symptoms rated severe, and 85% for symptoms rated moderate. The six month goal for the psychosocial symptoms of patient anxiety, family anxiety and depression rated most of the time is 90% of patients receive interventions and if rated always is 95%. Psychosocial symptoms of peace, family sharing of feelings and information rated as occasionally receives an intervention 90% of the time, and if rated not at all 95%. Problems hardly addressed receive an intervention 90% of the time. Problems not addressed receive an intervention 95% of the time. Implementation of these goals will guarantee consistent quality of life through timely symptom management.

Dementia patients scoring less than 7 on the Rapid Geriatric Screen (St. Louis University, 2016) were excluded from this project. This exclusion of three patients in the 90-day audit generates an opportunity to conduct another project using IPOS administered to caregiver proxies during visits in comparison to a tool specifically designed for dementia patients.

An integral part of the success of the program is the telephone “touch” calls completed by the medical secretary. The IPOS page 1 was integrated into the telephone encounter form when doing status checks. This allows consistent management with each

MEASURES THAT MATTER

encounter. Consistent themes during a series of encounters allows providers to direct interventions toward recurring problems.

The most common physical symptoms that patients reported were poor mobility and weakness. These two symptoms were reported in all diagnoses as the most burdensome physical symptoms. The audit of interventions in response to physical symptoms was for symptoms scored moderately, severely or overwhelmingly. Patients' perceptions of family anxiety about their illnesses was the most common psychosocial symptom, rated more often than the patients' own anxiety. Interventions were expected in the audit when symptoms were rated most of the time or always. While patient anxiety is addressed 88% of the time by providers, family anxiety is addressed 76% of the time. When providers asked patients about "Peace," 17 patients stated that they were only occasionally or almost never at peace. Generating meaningful discussions with patients and caregivers to concerns about the concept of peace, and referring to spiritual counselors as indicated allows patients to begin transitioning to end-of-life care.

Education for providers on the availability of resources that can easily be accessed is indicated from the low intervention scores on some symptoms. This resource list would include all AIM and community partners to be used as resources when positive physical and psychosocial symptoms are noted. These team and partner resources may include behavioral health, physical and occupational therapy, home infusion, laboratory and radiology home services, and many others. Part of the commitment to effective home management is a network of services to address symptoms in all domains of care.

The next step in improving the quality of care is re-educating providers on the importance of interventions relating to positive symptoms expressed by patients.

MEASURES THAT MATTER

Interdisciplinary team members need education on interpretation of positive symptoms revealed in their domains of specialty. Integration of the IPOS for tracking outcomes over time increases the importance of corresponding interventions to provide quality care over time. The symptoms addressed in IPOS page 1 have already been embedded in the telephone encounter form. This extends the opportunity of addressing the possibility of positive symptoms at every encounter with the AIM team. Future projects include researching guidelines and best practices for managing individual symptoms that emerged in common themes from this project in order to provide consistent interventions among providers.

Guidelines can be inserted in the patient's care plan. They include pharmaceutical and non-pharmaceutical teaching interventions. Implementation of these guidelines and best-practices help establish patient-centered goals of care and empower patients' and families' autonomy.

Conclusion

Community-based programs managing chronic illnesses as specialty palliative care is a new and growing concept in U.S. healthcare. The AIM program in St. Louis is funded by the Missouri Foundation for Health to test quality, patient satisfaction, and cost-effectiveness. AIM will not only be judged using the Institute for Healthcare Improvement's Triple Aim of improving the health of populations, patient-centered care, and cost-effectiveness, (Institute for Healthcare Improvement, n.d.), but for sustainability. Outcomes can be improved by effective symptom management that satisfies the Institute of Medicine's goals for the patient's experience of care: safe, effective, efficient, timely, equitable, and patient-centered (Institute of Medicine, 2016). Data collected from IPOS

MEASURES THAT MATTER

audits will drive guidelines and best-practice information to assist providers in providing consistent, quality patient care. Information will be obtained from Joint Commission, Institute of Medicine, and the Center for the Advancement of Palliative Care to assist in certification of the AIM program as the specialty grows in U.S. healthcare programs.

References

- American Academy of Hospice and Palliative Medicine: (Feb. 16, 2015). *Ten measures to drive quality palliative and hospice care*. Retrieved at: www.aahpm.org/uploads/homepage/MWM_Release.pdf
- American Hospital Association (n.d.) Advanced Illness Management Strategies-Part 1. Retrieved at: <http://www.aha.org/about/org/aim-strategies.shtml>
- Bauseweine, C., Simon, S., Behalia, H., Downing, J., Mwangi-Powell, F., Daveson, B., Harding, R., & Higginson, I. (2011). Implementing patient reported outcome measures (PROMs) in palliative care – users’ cry for help. *Health Quality of Life Outcomes*; 9:27. Published online April 20, 2011. DOI: 10.1186/1477-7525-9-27
Retrieved at: <http://europepmc.org/articles/PMC3112059?jsessionid=64E04CBC81F6981AF1303D6533A8BEBC>
- Beck, I., Moller, U.O., Malmstrom, M., Klarare, A., Samuelsson, H., Hagelin, C.L., Rasmussen, B., & Furst, C.J. (2017). Translation and cultural adaptation of the integrated palliative care outcome scale including cognitive interviewing with patients and staff. *BMC Palliative Care*; 16:49. Published online Sept. 11, 2017. DOI: 10.1186/s12904-017-0232-x Retrieved at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5594532/>
- California State University Institute for Palliative Care (n.d.). Palliative Care Education- Anytime, Anywhere, Mapping Your Success in Palliative Care. Retrieved at: <https://www.csupalliativecare.org/palliativecommunity/what-is-palliative-care/>

MEASURES THAT MATTER

Cohn, J., Corrigan, J., Lynn, J., Meier, D., Miller, J., Shega, J. & Wang, S. (2017).

Community-based models of care delivery for people with serious illness.

Perspectives: National Academy of Medicine. Retrieved at:

<https://nam.edu/community-based-models-of-care-delivery-for-people-with-serious-illness/>

Collins, E., Witt, J., Bauseweine, C., Daveson, B., Higginson, I. & Murtagh, F. (2015). A

systematic review of the use of the palliative care outcome scale and the support team assessment schedule of palliative care. *Journal of Pain and Symptom Management*;

50:6 pp. 842-853. Retrieved at:

<https://www.ncbi.nlm.nih.gov/pubmed/26335764>

Evans, C., Benalia, H., Preston, N., Grande, G., Gysels, M., Short, V., Daveson, B.,

Bauseweine, C., Todd, C. & Higginson, I. (2013). The selection and use of

outcome measures in palliative and end-of-life care research. The MORECare international consensus workshop. *Journal of Pain and Symptom Management*;

46:6 pp. 925-937. Retrieved at: <https://www.ncbi.nlm.nih.gov/pubmed/23628515>

Ferrell, B., Connor, S.R., Cordes, A., Dahlin, C., Fine, P.G., Hutton, N. et al. (2007).

National Consensus Project for Quality Palliative Care Task Force, Members. The national agenda for quality palliative care: *The National Consensus Project and the National Quality Forum*. [Review] *Journal of Pain and Symptom Management*;

2007; 33:6 pp. 737-744. Retrieved at:

[http://www.jpmsjournal.com/article/S0885-3924\(07\)00174-1/pdf](http://www.jpmsjournal.com/article/S0885-3924(07)00174-1/pdf)

MEASURES THAT MATTER

Gao, W., Crosby, V., Wilcock, A., Burman, R., Silber, E., Hepgul, N., Chadhuri, K. R. &

Higginson, I. (2016). Psychometric properties of a generic, patient-centered palliative care outcome measure of symptom burden of people with progressive long-term neurological conditions. *PLOS One Open Access Journal*; 11:10
Published online Oct. 25, 2011. pp, 1-15. DOI: 10.1371/journal.pone.0165379.

Retrieved at:

<http://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0165379&type=printable>

Gomes, B., Calazani, N., Curiale, V., McCrone, P. & Higginson, I. (2012). Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database of Systematic Reviews 2013*, Issue 6. Art No: CD007760 pp.1-22. DOI: 10.1002/14651858.CD007760.pub2.

Retrieved at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4473359/>

Hearn, J. & Higginson, I., on behalf of the Palliative Care Core Audit Project Advisory Group (1999). Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. *Quality in Health Care*; 8:4 pp. 219-227. Retrieved at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2483665/>

Higginson, I., Hart, S., Koffman, J., Selman, L & Harding, R. (2007). Needs assessment in palliative care: an appraisal of definitions and approaches used. *Journal of Pain and Symptom Management*; 33:5 pp. 500-505. DOI: 10.1016/j.jpainsymman.2007.02.007 Retrieved at:

[http://www.jpainjournal.com/article/S0885-3924\(07\)00109-1/fulltext](http://www.jpainjournal.com/article/S0885-3924(07)00109-1/fulltext)

MEASURES THAT MATTER

Institute of Healthcare Improvement (n.d.) Plan-do-study-act (psda) worksheet. Retrieved at: <http://www.ihl.org/resources/Pages/Tools/PlanDoStudyActWorksheet.aspx>

Institute of Healthcare Improvement (n.d.) Triple aim for populations. Retrieved at: http://www.ihl.org/Topics/TripleAim/Pages/default.aspx?gclid=EAIaIQobChMI_NPb7_Wo2wIVwbrACh0ipgZFEAAAYASAAEgJeHvD_BwE

Institute of Medicine (2016). The six domains of healthcare quality; Agency for Healthcare Research and Quality. Rockville, MD. Retrieved at: <http://www.ahrq.gov/professionals/quality-patient-safety/talkingquality/create/sixdomains.html>

Kane, P., Daveson, B., Ryan, K., Ellis-Smith, C., Mahon, N., McAdam, B., McQuillan, R., et al. (2017). Feasibility and acceptability of a patient-reported outcome intervention in chronic heart failure. *BMJ Support Palliative Care*: Retrieved at: <http://spcare.bmj.com/content/early/2017/09/01/bmjspcare-2017-001355.long>

Leff, B., Carlson, C., Saliba, D. & Ritchie, C. (2015). The invisible homebound: setting quality-of-care standards for home-based primary and palliative care. *Health Affairs*; 34:1 pp. 21-29. DOI: 10.1377/hlthaff.2014.1008. Retrieved at: <http://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2014.1008>

Lorenz, K., Lynn, J., Dy, S., Wilkinson, A., Mularski, R., Shugarman, L., et al. (2006). Quality measures for symptoms and advanced care planning in cancer: a systematic review, *Journal of Clinical Oncology*; 24: 4933-4938. Retrieved at: <https://www.ncbi.nlm.nih.gov/pubmed/17050878>

MEASURES THAT MATTER

Lowther, K., Simms, V., Selman, L., Sherr, L., Gwyther, L., Kariuki, H., et al. (2012).

Treatment outcomes in palliative care: the TOPCare study. A mixed methods phase III randomised controlled trial to assess the effectiveness of a nurse-led palliative care intervention for HIV positive patients on antiretroviral therapy (2012). *BMC Infectious Diseases*; 12:288. Published online Nov. 6, 2012.

Retrieved at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3538672/>

Muldoon, M., Barger, S., Flory, J. & Manuck, S, (1998). What are quality of life

measurements measuring? *British Medical Journal*; 316: 542-545. Retrieved at:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2665651/pdf/9501721.pdf>

Mulvihill, K., (Oct. 21, 2014). Palliative care? but I am not dying! Wolters Kluwer-Emmi

Solutions Blog Post. Retrieved at: <https://www.emmisolutions.com/resource/blog-palliative-care-but-i-am-not-dying/>

Murtagh, F., Ramsenthater, C., Firth, A., Groeneveld, E., Lovell, N., Simon, S., Denzel,

J., Bernhardt, F., Schildmann, E., Bauseweine, C. & Higginson, I. (2016). A brief patient- and proxy-reported outcome measure for the adult palliative population:

validity and reliability of the integrated palliative outcome scale (IPOS). The

Cochrane Central Register of Controlled Trials (Central) 2017 Issue 2: pp. NP11.

Retrieved at:

<https://www.onlinelibrary.wiley.com/doi/10.1111/ccc.12111>

National Consensus Project for Quality Palliative Care Guidelines 3rd edition (2013).

Retrieved at: <https://www.nationalcoalitionhpc.org/ncp-guidelines-2013/>

MEASURES THAT MATTER

POS: Palliative Care Outcome Scale (2012). Cecily Saunders Institute Kings College, London, England. Retrieved at: <https://www.pos-pal.org>

Rugno, F. & Marysia, M (2016). The palliative outcome scale (POS) applied to clinical practice and research: an integrative review. *Revista Latino-Americana de Enfermagem*. On line version ISSN 1518-8345. Retrieved at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4996092/>

Schildmann, E., Groeneveld, E.I., Denzel, J., Brown, A., Bernhardt, F., Bailey, K., et al. (2015). Discovering the hidden benefits of cognitive interviewing in two languages: the first phase of a validation study of the Integrated Palliative Care Outcome Scale. *Palliative Medicine*; 30:6 pp. 599-610. DOI: 10.1177/0269216315608348. Retrieved at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4873725/>

St. Louis University, Rapid Geriatric Screening Tool (2016). Retrieved at: http://aging.slu.edu/uploads/RGA_Algorithms_and_Pt_Info_Sheets_Updated_7_9_2016.pdf

Appendix

IPOS Patient Version

Patient name :

Date (dd/mm/yyyy) :

Patient number : (For staff use)

Q1. What have been your main problems or concerns over the past 3 days?

1.
.....
2.
.....
3.
.....

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick one box that best describes how it has affected you over the past 3 days.

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Shortness of breath	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Weakness or lack of energy	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Nausea (feeling like you are going to be sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Vomiting (being sick)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Poor appetite	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Constipation	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Sore or dry mouth	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

MEASURES THAT MATTER

Drowsiness	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Poor mobility	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
<p>Please list any <u>other</u> symptoms not mentioned above, and tick one box to show how they have <u>affected</u> you <u>over the past 3 days</u>.</p>					
1.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
2.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
3.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

Over the past 3 days:

	<i>Not at all</i>	<i>Occasionally</i>	<i>Sometimes</i>	<i>Most of the time</i>	<i>Always</i>
Q3. Have you been feeling anxious or worried about your illness or treatment?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q4. Have any of your family or friends been anxious or worried about you?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q5. Have you been feeling depressed?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

MEASURES THAT MATTER

	<i>Always</i>	<i>Most of the time</i>	<i>Sometimes</i>	<i>Occasionally</i>	<i>Not at all</i>
Q6. Have you felt at peace?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q8. Have you had as much information as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
	<i>Problems addressed / No problems</i>	<i>Problems mostly addressed</i>	<i>Problems partly addressed</i>	<i>Problems hardly addressed</i>	<i>Problems not addressed</i>
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
	<i>On my own</i>	<i>With help from a friend or relative</i>			<i>With help from a member of staff</i>
Q10. How did you complete this questionnaire?	<input type="checkbox"/>	<input type="checkbox"/>			<input type="checkbox"/>

If you are worried about any of the issues raised on this questionnaire then please speak to your doctor or nurse

