Symptom Assessment and Hospital Utilization in a Home-Based Palliative Care Program

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Palliative care delivery is shifting to the home, yet data are limited on symptom assessment tools and protocols for that setting. A quality improvement project was done in a home-based palliative care program to imbed the Edmonton Symptom Assessment System into the electronic health record. The purpose of the quality improvement project was to track symptom severity and collect utilization data. Baseline data were collected on 35 patients for symptom presence and severity as well as hospital utilization and readmission. The most common symptoms were tiredness, pain, and a lack of feeling of overall well-being. The most severe symptoms, those with a rating of 6 of 10 or higher, were pain, drowsiness, and anxiety. Seventy-seven percent of the symptoms within the Edmonton Symptom Assessment System showed an improvement over the 3-month QI project per the electronic health record data. Hospitalization rates also went from 4.2% to 2.6% and 30-day readmissions were reduced from 15% to 0%. The results suggest that the palliative care program was able to improve symptoms through the use of Edmonton Symptom Assessment System and that that may have affected hospital utilization.

KEY WORDS

home-based care, hospital utilization, palliative care, quality improvement, symptom assessment

As individuals with multiple chronic conditions age, they have an increased need for medical services but a limited ability to get to outpatient clinics. Home-based primary care and palliative care are therefore a solution because they can target high-need and high-medical-cost populations in their preferred setting—home.[1,2] Evidence to date about home-based primary and palliative care programs is limited, but studies have shown decreased symptom burden and decreased hospitalizations with such

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programs.[3-9] There is also evidence that patients are highly satisfied with them.[2,6] Finally, for patients wishing to die at home, there is evidence that home-based palliative care can increase that likelihood.[10-12]

As this is a new type of care, there are also gaps in the literature regarding quality measures for home-based palliative care programs.[1,13,14] The Center to Advance Palliative Care has developed a toolkit for home-based palliative care that recommends a range of quality areas to be monitored, including utilization, operational, and outcome measures.[15] Tracking symptom improvement and collecting hospital admissions/readmissions data are 2 quality metrics recommended.[15] The 2013 palliative care guidelines from the National Consensus Project recommend patient-centered coordinated care delivered by an interdisciplinary team (IDT),[16] and these guidelines will be updated in 2018 to extend emphasis on the community setting.[17] The literature also supports program measures, including tracking effective communication through the use of an electronic health record (EHR), clear communication of patient goals, regular IDT meetings, utilization of standardized patient assessment tools, and around-the-clock telephone access to providers.[1,8-14]

Based on a literature review of home-based primary and palliative care, a home-based program delivering both primary and palliative care conducted a needs assessment and found that many of the recommendations from the literature were already being implemented; however, there was limited use of standardized patient assessment tools within the practice. A quality improvement (QI) project was designed. The purpose of the QI project was to implement a tool into the EHR that the IDT could use to track patient symptoms. Also being tracked was the effectiveness of the palliative care services in reducing hospitalizations and readmissions, as evidence has shown that palliative care can reduce these.[3-5,8,9]

This organization was already participating as 1 of the sites for Medicare's Independence at Home (IAH) Demonstration. That demonstration ran from 2012 to 2017 and consisted of 14 medical practice sites testing the effectiveness of comprehensive primary care services delivered in the home for the frail elderly with the goals of improved quality and reduced cost.[18] Independence at Home medical practices provided in-home primary care visits and coordinated care for patients with functional limitations and

multiple chronic conditions.[18] The IAH practices also offered 24/7 telephone access to on-call providers. Interdisciplinary teams also made posthospital follow-up visits within 48 hours of any hospitalization to ensure that patient needs were adequately met.[18] Results to date show that the demonstration saved an average of $746 per beneficiary.[18] The medical practice where the QI project was implemented had the lowest IAH year 2 expenditures in the demonstration and was 1 of 7 practices that received incentive payment based on delivery of quality, cost effective care.[18]

QI METHODS

Setting

This QI project took place at a home-based primary care practice in Portland, Oregon, that had recently started a home-based palliative care program. The practice was the only Medicare IAH demonstration site west of Texas.[18] The QI project took place in participants' dwelling places, where roughly 17% resided in private homes, 28% in adult foster homes, and 55% in assisted living facilities. The clinicians in the practice function as the sole primary care provider for enrolled patients, which is common in IAH and many home-based practices.[19] The practice employs 20 primary care providers made up of 3 physicians, 15 nurse practitioners, and 2 physician assistants. The additional palliative care team consists of 2 nurses, 1 social worker, and 1 chaplain. The practice has an average census of 1450 patients, of which 40 to 70 patients are also enrolled in the home-based palliative care program. General palliative care services are integrated into primary care for all of the 1450 patients, providing access when needed to spiritual care, social work, symptom management, and advanced care planning. There are several triggers used to identify patients in need of the additional support from the home-based palliative care program. One is the surprise question, a commonly used way to screen for palliative care referrals[20] that involves asking the primary care providers whether they would be surprised if their patient were to die in the next year. Other criteria used to identify patients for the additional palliative care program include having frequent hospitalizations and/or emergency room visits, conflicted goals of care between patient and family, a high volume of calls from patients or caregivers due to symptoms, and frequent requests from the primary care provider for additional nursing support.

QI Project Plan

The QI project consisted of 4 phases: (*a*) implementation of the symptom assessment tool into the EHR, (*b*) a 2-hour training session at the beginning of the project for primary care providers on the new symptom assessment protocol as well as a pre-post survey to assess their understanding of it, (*c*) patient symptom assessment using the new tool, and (*d*) data collection on patient demographics, symptoms, and hospital utilization.

The primary care providers and palliative care team worked together to manage symptoms. The palliative care team provided thorough symptom assessment and nonpharmacologic interventions, whereas the primary care provider managed pharmacologic interventions. The team also worked together to manage follow-ups. Typically, primary care providers saw patients monthly, whereas the palliative nurses followed up 1 to 2 times per week and had the responsibility for follow-up coordination. If symptoms were severe, the teams would coordinate schedules to ensure that either the primary care provider or palliative nurse was available for an in-person follow-up visit.

Tools

The Edmonton Symptom Assessment System (ESAS) was selected as the tool based on the body of literature supporting its reliability.[21,22] It is also recommended for use in home-based care by the Center to Advance Palliative Care.[15] The ESAS is a 1-page screening tool covering 9 symptom categories, each with a visual analog scale.[23] It uses a 0-to-10 scale to measure symptoms including pain, drowsiness, tiredness, nausea, appetite, shortness of breath, depression, anxiety, and feeling of overall well-being.[24] Its reliability has been maintained whether the health care provider, patient, or caregiver provides the responses.[21] The ESAS has been widely used in the inpatient palliative care setting and has also been used effectively in a home-based palliative care program.[9] This QI project also tracked IAH demonstration quality measures including hospital admission rates and 30-day readmission rate.[18]

Procedure

A primary care provider education survey was given before and after the educational session on the ESAS tool. The educational session included a brief overview of the ESAS tool as well as a detailed synopsis of how the team would use it, including how to access it within the EHR. The survey had 3 questions and asked what the primary care providers' understanding was of how the palliative nurses assessed symptoms, the providers' awareness of the protocol to assess symptoms using a formalized tool, and their knowledge of accessing the tool within the EHR. The pre/post survey was developed for this QI project and not validated before its use.

All patients enrolled in the palliative care program between October 2015 and February 2016 were included in the QI project if they did not opt out of participation. Before implementation, University of South Alabama Institutional Review Board approval was obtained.

Intervention

The project was implemented over a 3-month period. In the first month, the ESAS was imbedded into the EHR and the palliative care nurses were trained on how to document patient and caregiver responses to it. The primary care providers received training on the new symptom assessment protocol and the ESAS tool.

The new protocol consisted of palliative care nurses interviewing the patient and/or caregiver during a home visit using the ESAS and documenting their reported findings in the EHR. This was done initially upon admission to the palliative care program. The palliative nurse then reported any existing symptoms to the primary care provider. The palliative care patients received coordinated care from the primary care provider, palliative nurses, palliative social worker, and palliative chaplain to address any symptoms or other issues. Regularly scheduled follow-up visits were completed by the palliative nurses, usually weekly or biweekly based on patient condition. More frequent follow-up visits were triggered by any reported change in the patient's condition made by telephone call by the patient, family member, or facility staff. During months 2 and 3, the ESAS was again administered by the palliative care nurses during 1 of their visits as time and patient interest allowed.

Outcome Measures and Data Analysis

Outcome measures for the QI project included symptom presence and improvement, hospitalization, and 30-day hospital readmission rates. Symptom type and severity data were collected through EHR chart audits. Hospital admissions were calculated as a percentage per 100 patient-months and were calculated on participating patients before and after QI project implementation. Microsoft Excel was used for data analysis. A t score was calculated for each symptom category for patients who had at least 2 ESAS documented in the EHR. The mean symptom improvements were calculated for each category. A negative score meant improvement in symptoms, and a positive score showed worsening of symptoms. Descriptive statistics were used for the provider education survey results, patient demographics, and hospitalization rates. These data were collected and analyzed directly at the end of the 3-month QI project.

RESULTS

Patients

Thirty-five home-based palliative care program patients were enrolled in the QI project during the 3-month period (Table 1). No patients opted out of participation. Over three quarters of participants were women. Nearly half of all enrolled patients were 90 to 99 years of age. The

| TABLE 1 Patient Demographics	
	Percentage of Patients
Age	
40-49	2.9%
50-59	5.9%
60-69	2.9%
70-79	20.6%
80-89	17.6%
90-99	47.1%
100-105	2.9%
Sex	
Female	27 (77%)
Male	7 (13%)

most common primary diagnosis for enrolled patients was Alzheimer's dementia, followed by unspecified dementia; more than half of all enrolled patients had a primary diagnosis of some type of dementia. The next most common diagnosis was congestive heart failure (Table 2). During the 3-month QI project, no patients died, 4 patients were transferred to hospice, 10 were discharged from the additional palliative care services because of improvement in their condition or their palliative needs were able to be managed by their primary care provider alone, and an additional 6 declined the follow-up ESAS assessment. This resulted in 15 patients (42%) with follow-up ESAS results documented at the time of data collection.

Symptoms

The most commonly reported symptoms throughout the QI project were tiredness, pain, and lack of feeling of overall well-being. Severe symptoms were those with a rating of 6 of 10 or greater. The most common of the severe symptoms were drowsiness, anxiety, and pain. Eighty percent of the drowsiness, 70% of the shortness of breath, and 50% of the anxiety categories were rated as severe.

For the categories of pain, tiredness, nausea, depression, anxiety, drowsiness, and appetite, more patients had improvement than had worsening of symptoms (Figure). In the category of overall feeling of well-being, 5 patients had improvement and 5 patients had worsening of symptoms. Shortness of breath was the only category that had more patients with worsening of symptoms than improvement. Findings in tiredness, depression, and anxiety were all improved and were found to be statistically significant, with a P value of less than .05 (Table 3).

ESAS Symptom Category
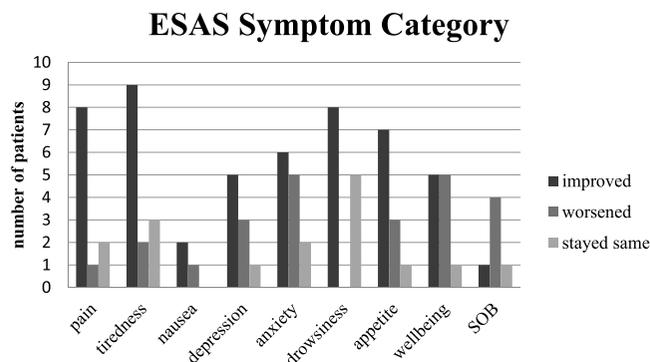
FIGURE. ESAS follow-up.

Hospitalization Rates

Hospital admission rates were collected for the 35 enrolled patients for the 3 months before palliative care program enrollment. After enrollment in palliative care, hospital admissions were also calculated during the 3-month QI project. Hospitalizations were reduced from 4.2% to 2.6%. Thirty-day readmission rates before palliative care and during the QI projected were collected for the 35 enrolled patients. None were readmitted within 30 days of discharge from the hospital during the QI project, as opposed to 15% before it (Table 4).

TABLE 2 Primary Medical Diagnoses	
Primary Diagnosis	**Patients, n (%)**
Alzheimer's dementia	10 (26%)
Dementia NOS	8 (20%)
CHF	6 (15%)
COPD	2 (5%)
Lewy body dementia	2 (5%)
History of traumatic brain injury	1 (3%)
Parkinson's dementia	1 (3%)
Postpolio syndrome	1 (3%)
Spinal stenosis	1 (3%)
Cirrhosis	1 (3%)
ESRD	1 (3%)
CAD	1 (3%)
Obesity hypoventilation	1 (3%)
Progressive nuclear palsy	1 (3%)
Abbreviations: CAD, coronary artery disease; CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; ESRD, end stage renal disease; NOS, not otherwise specified.	

DISCUSSION

The most commonly reported symptoms in this QI project were tiredness, pain, and a lack of feeling of overall well-being. The most common severe symptoms were drowsiness, anxiety, and pain. This somewhat contradicts previous evidence that found that pain, tiredness, and loss of appetite were the most common symptoms noted in 1 group of homebound patients enrolled in home-based primary and palliative care.[9]

This QI project conducted the follow-up in the home but had a follow-up rate of only 42%. Ornstein et al[9] found symptom relief after implementation of the ESAS in their home-based primary and palliative program but had only 52% participation at follow-up. Their follow-up design was over the telephone, and they recommended that future studies conduct follow-up in the home.[9] The reasons for this QI project's lack of follow-up assessments were multifactorial. As noted, in addition to some being transferred to hospice or discharged from palliative care services because of improvement in their condition, an additional 6 patients declined the follow-up assessment. The palliative care nurses reported that patients declining the follow-up ESAS were overwhelmed with the number of symptom categories they were asked about. They also reported discomfort in completing the ESAS on behalf of the patients because they were not with the patients for long periods of time, in comparison with inpatient nurses who spend many hours in a day providing direct care. Given the chronically ill population in the QI project, it is difficult to know if more reassessments could be achieved in the future. The large number of patients who were discharged from the palliative care program because of improvement in their condition suggested that some may have not needed to be in the additional palliative care program. This has prompted the practice to investigate better methods for identifying patients in need of additional palliative care support on top of what their primary care provider is already delivering.

TABLE 3	Edmonton Symptom Assessment System Follow-Up Statistics								
Statistics	Pain	Tiredness	Nausea	Depression	Anxiety	Drowsiness	Appetite	Well-being	SOB
Mean	−1.82	−1.5	−2.67	−0.78	−0.85	−2.38	−0.55	−0.5	0.83
SD	2.6	3.08	6.81	2.86	3.26	2.81	4.57	2.81	2.71
Significance	$P = .08$	Yes, $P = .046$	$P = .47$	Yes, $P = .024$	Yes, $P = .017$	$P = .22$	$P = .053$	Yes, $P = .005$	Yes, $P = .009$

Abbreviation: SOB, shortness of breath. Yes indicates statistically significant with a $P < 0.05$.

During the project implementation, none of the 35 enrolled patients were readmitted into the hospital within 30 days of discharge, although this was a small base of patients over a short period of time. A similar program compared their patients with a control group that was not receiving home-based palliative care and found statistically significant reductions in 30-day readmissions for chronic obstructive pulmonary disease, heart failure, and dementia, with mean 30-day readmission rates being 0.41 for the control group and 0.14 for the group receiving home-based palliative care.[5] This QI project's palliative care nurses worked diligently to coordinate timely posthospital discharge home visits with patients that included symptom assessment and advance care planning discussions, as this has been shown to reduce hospital utilization.[4-8] Because the home-based practice already used an EHR for care coordination, had protocols for clear documentation of patient goals, conducted regular IDT meetings, and provided 24/7 telephone access to providers, it is difficult to know the impact of the new symptom assessment project on the reduction in hospital readmissions.

This QI project showed that the assessment by the palliative care nurses using the ESAS was feasible to track and monitor symptom severity. However, the palliative nurses reported difficulty in assessing some symptom categories, especially for patients diagnosed with dementia. This is consistent with the literature, as symptoms are difficult to assess in patients with dementia regardless of the setting of care.[9,25] To overcome this challenge, there are nonverbal tools that providers and caregivers can use to assess pain in advanced dementia, such as the Pain Assessment in Advanced Dementia, which is widely used across settings, including in home-based care.[25] The Integrated Palliative Care Outcome Scale for Dementia has been developed to assess other symptoms besides pain in dementia patients, and future research could be targeted towards the validation of this tool in homebound patients.[26]

Practical issues were also identified with implementing the ESAS into this QI project. The palliative nurses discussed the time challenges they faced in administering the tool as it added more time to the nursing visit. This has been noted in other home-based programs and represents an administrative challenge in this setting.[27] In addition, symptoms such as shortness of breath can change quickly and fluctuate, which is difficult to track in the home-based primary/palliative care setting given the less frequent contact. There is also the issue of addressing symptoms in real time. This challenge has been experienced by other home-based programs as well.[27] Another practical point is that it is also difficult to track symptoms more frequently in patients at home because of the current limited financial resources and reimbursement for home-based palliative care. One innovative practice used the ESAS as a way to triage home-based palliative care patients, using the severity of symptoms as a guide for how soon follow-up visits would be scheduled, which could be a model for this and other home-based programs.[28]

LIMITATIONS

There were several limitations with this QI project. First, as is typical with QI projects, the sample size of 35 patients is small and the subsamples for the individual symptoms are too small to do statistical and clinical analysis. Another limitation was the low symptom follow-up. Then, it is unclear whether all the nurses administering the ESAS were using it the same, as interrater reliability could not be feasibly tested in this QI project with limited resources. Finally, it is not possible to determine anything but associations between the palliative care intervention and utilization given the QI nature of the project.

CONCLUSION

Home-based palliative care is growing, yet robust quality measures and processes are currently lacking. Symptom

TABLE 4	Hospital Utilization	
	Pre–Palliative Care	During Palliative Care
Hospitalizations	4.2%	2.6%
30-Day readmission	15%	0%

management has been established as an important component of quality palliative care, and there now needs to be work to determine how ideally to do this for home-based populations. As new home-based care programs emerge, they will hopefully contribute to the evidence on quality measures and assessment. Future studies should use designs that can test any correlations or causation between symptom management and other outcomes, such as hospital utilization.

Acknowledgments

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