Symptom Management Series

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# Symptom Management of Chronic Illness in the Adult Outpatient Setting

conditions.

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Veterans, as a distinct population, experience high rates of recidivism, with 75% of those older than 65 years having symptomatic chronic illness. Five diagnoses, congestive heart failure, chronic obstructive pulmonary disease, chronic kidney disease, dementia, and cancer, account for 25% of health care visits associated with high rates of recidivism. A convenience sample of 37 veterans with advanced chronic illness from 1 rural home-based primary care clinic was evaluated. All subjects had at least 1 of the 5 listed diagnoses. One-way repeated-measures analysis of variance was used to evaluate retrospective and prospective data at 30, 60, and 90 days before/after implementation of palliative care modalities. Congestive heart failure and chronic obstructive pulmonary disease accounted for 53% of diagnoses. Sixty-five percent had 2 or more diagnoses. By day 90 after palliative management, there were 122 fewer emergency department/hospital days (P < .01) with an estimated cost avoidance of \$220 000. Initiating palliative care early in the trajectory of symptomatic illness reduces recidivism and overall costs of care through management of symptoms and focusing on patient/caregiver-directed goals for improving life. Additional studies are needed to evaluate symptomatic, chronic illness for diseases outside of cancer. Education of stakeholders on the philosophy of palliative care and interdisciplinary management is vital for improved health outcomes.

### **KEY WORDS**

chronic illness, palliative care, recidivism, symptom management, veterans

hronic illness is defined as any condition lasting longer than 6 months requiring ongoing care, cannot be cured, and may limit activity. Characteristics found throughout the literature describe symptoms associated with chronic illness as those affecting quality of life leading to high rates of morbidity and mortality.<sup>1-4</sup> These

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symptoms include deviations in psychological state, functional status, and spirituality and are often associated with comorbid conditions. The most prevalent symptoms reported by veterans and patients in the community include pain, fatigue, dyspnea, anxiety, and hypersomnolence.<sup>5-10</sup> Research has shown that care provided to individuals with symptomatic, chronic illness or those approaching end of life is less than optimal, leading to skyrocketing costs. Even though the Veterans Health Administration (VHA) has made substantial improvement in services, opportunities abound for improved care delivered to veterans with chronic medical

Forty-five percent of the adult US population, inclusive of veterans, has 1 or more chronic disease processes, and those numbers increase with age. Within the VHA, the fastest growing segment of care is associated with veterans with 4 or more chronic health conditions. As of September 30, 2013, there are nearly 22 million veterans in the United States, with 9.6 million older than 65 years. Currently, 8.76 million veterans 65 years or older are enrolled in the VHA health care system, with 75% of those having 1 or more chronic disease process.<sup>11-16</sup> Veterans 85 years or older increased by 190% between 2000 and 2010, whereas the general US population of the same age rose by only 44%.<sup>17</sup>

Many of the symptoms associated with chronic disease processes leave individuals physically and cognitively debilitated, making routine care more difficult to obtain. As symptomatic disability progresses, individuals often become homebound and experience higher rates of fear and unrelieved suffering, lending to a rapid decline in health status. This leads to higher rates of emergency department visits and hospital stays. Once an individual becomes homebound, most will experience death within 2 years.<sup>18-22</sup> Currently, there are more than 2 million individuals older than 65 years categorized as homebound because of impairment associated with chronic illness, with 20% of those being veterans. The chronically ill homebound are expected to increase by more than 65% over the next 10 years.<sup>23,24</sup>

Veterans have higher rates of chronic illness than do those of similar age in the community.<sup>11,25-27</sup> Within the veteran population of 1 Midwest VHA in fiscal year 2012, 5 of the top 10 diagnoses associated with highest rates of recidivism, morbidity, and mortality were cancer, congestive heart failure (CHF), chronic kidney disease (CKD), chronic obstructive pulmonary disease (COPD), and both

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unspecified and Alzheimer-type dementias. These 5 diagnoses entailed 25% of the health care visits made that year, accounting for 121 073 health care visits by 11 347 veterans, averaging 10.67 visits.<sup>28,29</sup> This compares to average visits of 9.49 for the same 5 diagnoses for those 65 years or older in the community.<sup>28</sup>

Chronic disease touches the lives of every American citizen in some way. Individuals with chronic illness often receive inadequate education on management of symptoms associated with their particular disease process or may not understand the illness and options for management and care. Untreated symptoms affect quality of life for the individual and add burden and stress to the family/caregiver. Poorly managed symptoms account for 67 million emergency department visits and 836 000 unplanned 30-day hospital readmissions annually. Annual costs associated with recidivism due to exacerbation of chronic health conditions account for more than \$25 billion in inappropriate hospital readmissions and \$38 billion in inappropriate emergency department visits.<sup>21,30,31</sup>

With respect to age, older individuals have higher annual health care costs. Data from the Department of Veterans Affairs and US Census Bureau show that the 2010 veteran population comprises nearly 53% of the total population, with veterans making up 71% of the total population for the subgroup of 85 years or older. Veterans 65 years or older have an average annual health care expenditure of \$15 000, whereas annual costs for individuals older than 85 years average \$23 700.<sup>12</sup> During fiscal year 2012, for 1 Midwest VHA, payments of \$5.97 million were made to hospitals other than the VHA for care to veterans with the diagnoses of CHF, COPD, cancer, CKD, and dementia.<sup>32</sup> This number does not include the cost of care associated with veterans with the same diagnoses who went to hospitals other than the VHA using Medicare, Medicaid, or third-party insurance. Veterans dually insured by Medicare and the VHA account for 41% of the total population.<sup>33</sup>

In addition to the staggering costs of care for the individual with chronic illness, there is also the cost associated with caregiving. In the United States, 29% of the adult population, more than 65 million individuals, serve as caregivers to someone who has a chronic illness.<sup>34</sup> Seventeen percent of these caregivers are attending to veterans.<sup>35</sup> By 2025, it is estimated nearly half the US population will have 1 or more chronic disease process, adding to symptom burden for the individual and increased burden to caregivers.<sup>36,37</sup>

# THEORETICAL FRAMEWORK

The theory proposed for the project was based on the Revised Symptom Management Conceptual Model by Dodd and associates.<sup>38</sup> The Revised Symptom Management Model is a midrange theory chosen based on its

practicality for use in both research and clinical practice. The expanded model takes into account the multiplicity of symptoms. Assumptions made by the theorist regarding symptoms are as follows:

- 1. Symptoms are based on whatever is reported as symptoms;
- 2. Symptoms are based on the disease process as an individual may be at risk for the symptom;
- 3. All distressing symptoms, reported or suspected based on patient's actions, must be managed appropriately based on disease processes; and
- 4. Symptom management is dynamic and must be modified as often as needed based on individual responses.

The experience is associated with the individual's perception of any change from the norm, anything the individual reports affecting quality of life. Management of those symptoms can be self- care but is usually in coordination with a provider who has made recommendations for care and treatment with prescribed modalities. Outcomes focus on specific factors of functional status, self-care, cost, quality of life, emotional status, mortality, and morbidity. During evaluation of the outcome phase, the individual could have complete freedom from the distressing symptom, at which time the model is discontinued. If the symptom continues or other comorbid conditions apply, the goals of care change and the model continues.<sup>2,38</sup>

The ultimate goal of care is relief of symptoms. For the model to be effective, the health care provider and patient must work closely together and adhere to goals and treatment plan as agreed upon, regardless of what that plan is. Following the Institute of Medicine (IOM) and Affordable Care Act mandates of health care reform, all goals are patient centered and focused on the patient's, and family's, if appropriate, desired outcomes.<sup>6,7,10,39-42</sup>

#### Group

The target group consisted of a convenience sample of veterans admitted to the Home-Based Primary Care (HBPC) clinic. The targeted sample had (1) symptoms associated with chronic disease processes lasting more than 6 months, (2) advanced illness, (3) repeated visits to health care providers for management of symptoms, (4) disease progression, and (5) loss of independence. Veterans chosen for palliative care were those whose disease process was serious, expected to worsen, and whom the health care provider would not be surprised if death occurred within 1 year. Specific symptomatic chronic conditions related to CHF, COPD, CKD, cancer, and dementia were evaluated. Forty-five veterans were enrolled in palliative care within the HBPC clinic, with 40 meeting diagnostic criteria to participate. No potential risks to participants were identified. All participants were veterans and current clients within the VHA.



Retrospective and prospective analysis of data was done at 30, 60, and 90 days before/after implementation of palliative care modalities to evaluate effects on recidivism. The project leader collected data from an existing database of information obtained in the provision of care using aggregate data only. The project evaluated veterans enrolled in the HBPC palliative care clinic from March 2012 through July 2013, with data collection taking place September 2013.

# HUMAN SUBJECTS PROTECTION

No medical testing was required. All data collected were secondary related to the veteran's health care needs and readily available within the medical record. The project leader was the primary care provider for these individuals. All identifying information was removed, including elements that could be used to identify individual data in the project. Institutional review board approval was received from the University of Southern Indiana's Institutional Review Board and project approval was granted by the Tennessee Valley Geriatric Research Education and Clinical Center.

# RESULTS

Analysis of veterans enrolled in palliative care within 1 Midwest VA HBPC clinic from March 2012 through July 2013 was completed. Of 45 veterans enrolled, 40 met diagnostic inclusion criteria. Three additional participants who died during the 90-day observation period were also excluded from the analysis. Of the remaining 37 veterans, 24 (65%) had 2 or more of the 5 diagnoses being evaluated, shown in Table 1.

All veterans were men, ranging in age from 54 to 94 years, with a mean age of 82.33 years and a median age of 86 years. One was African American (2.7%), with the remainder white (97.3). Ten veterans from the study died with an average length of stay in palliative care of 290.2 days. The breakdown of diagnoses for each veteran is shown in Table 2. The total equals more than 37 as 24 of the sample group had more than 1 of the 5 diagnoses.

Within the analysis, commonalities were found. The most common dyad was dementia/CHF. The most common triad

TABLE 1Percentage of Veterans Having 1or More of Reviewed Diagnosis		
No. of Reviewed Diagnosis	%	
1	36	
2	39	
3	19	
4	6	
5	0	

TABLE 2 Breakdown of Diagnoses		
Diagnoses	%	
Cancer	8	
Dementia	19	
Chronic kidney disease	20	
Chronic obstructive pulmonary disease	26	
Congestive heart failure	27	

was COPD/CHF/CKD. Tables 3 and 4 illustrate the frequency of comorbidities for 2 and 3 of the 5 diagnoses reviewed.

A 1-way repeated-measures analysis of variance was conducted to determine if there was a significant difference between the number of days a veteran experienced an emergency department visit or hospital stay in 30-day increments over a period of 90 days before and after receiving palliative care. The results show that there was a significant difference in the number of days admitted to a care facility between the 30-day increments. Post hoc analyses found that the number of days admitted to a care facility was significantly less in the period of 61 to 90 days after palliative care (mean [SD], 0.18 [0.59]) than the period of 31 to 60 days before receiving palliative care (mean [SD], 1.63 [2.54]). The difference in the days of recidivism between the period of 61 to 90 days after palliative care and 1 to 30 days before receiving palliative care was observed to be approaching significance (P = .06). Days of care in the emergency department or hospital before and after initiation of palliative care are shown in Figure 1.

After completion of data, costs of care associated with recidivism were calculated. Using the Midwest VHA costs of care from the financial database, average daily costs of care for each day of emergency department visit or hospital stay based on the top 5 diagnoses were obtained. Taking

TABLE 3 Dyad Themes		
COPD/CHF	20%	
Dementia/CHF	27%	
CHF/CKD	13%	
Dementia/CKD	20%	
Cancer/COPD	6%	
Dementia/COPD	7%	
Cancer/CHF	7%	
Abbreviations: CHF, congestive heart failure; CKD, chronic kidney disease;		

Abbreviations: CHF, congestive heart failure; CKD, chronic kidney disease; COPD, chronic obstructive pulmonary disease.

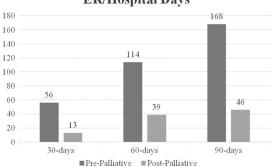
TABLE 4 Triad Themes		
COPD/CHF/CKD	50%	
Dementia/COPD/CKD	12%	
Dementia/CHF/CKD	12%	
Cancer/CHF/CKD	13%	
Dementia/Cancer/CHF	13%	
Abbreviations: CHF, congestive heart failure; CKD, chronic kidney disease; COPD, chronic obstructive pulmonary disease.		

the mean cost of daily care, an average of \$1806 (median, \$1940; SD, \$541) cost avoidance through utilization of palliative modalities was calculated. Table 5 highlights savings in both days and costs of care through reduced recidivism after initiation of palliative care modalities.

Limitations to the study include the small sample size (n = 37) and collection of data over only 90 days before/after focusing on homebound veterans in a rural setting. A longitudinal evaluation of a larger sample size including a more diverse population would provide better representation. Although data were found to be reliable based on the diagnoses reviewed, future studies on the impact of a larger demographic of chronic illness and comorbidities would be of value. No additional costs were associated with providing palliative care to veterans in this particular setting as they were already receiving care through the VHA home-based clinic. For future studies, it would be beneficial to obtain financial costs of providing home-based palliative care to provide a better picture of costs of care as compared with costs avoided.

#### RECOMMENDATIONS

The experience of symptoms is an individual's perception of the frequency, intensity, distress, and meaning as it occurs. Symptoms can be 1 area that affects quality of life but are often multiplicative in nature produced as a



**ER/Hospital Days** 

**FIGURE 1.** Rates of recidivism pre/post palliative modalities. *Abbreviation:* ER, emergency room.

TABLE 5 Total Savings in Days/Dollars		
30 d (43 fewer ED/hospital days)	\$77 658.00	
60 d (75 fewer ED/hospital days)	\$135 450.00	
90 d (122 fewer ED/hospital days)	\$220 332.00	
Abbreviation: ED, emergency department.		

byproduct from the failure of 1 or more body systems.<sup>43</sup> Instituting a strong patient-centered program with emphasis on symptom management, patient satisfaction, reduced patient and caregiver stress, and reduced health care costs is an attainable measure. Health care providers will have an additional avenue of consultation available when routine clinic visits fail to produce desired results in terms of improved health status. Management of symptoms through palliative care is congruent with the IOM mandates and the VHA Strategic Plan focusing on patient-centered care, improved health status, and reduced health care costs.<sup>7,10,39,40,44</sup>

An incidental finding from this project has shown a high incidence of multimorbidity evaluating just 5 chronic disease processes. Sixty-four percent of the veterans enrolled in this study had 2 or more of just 5 chronic disease processes, correlating with the finding from Schneider and associates<sup>42</sup> that 67% of adults have 2 or more of any chronic health condition. New research evaluating multimorbidity and comorbidity as independent and interdependent disease processes that may occur in clusters is essential to evaluate how treatment of 1 symptom may affect another disease process or symptom.

Changing care from an acute model to one focused on the specific needs of each individual patient promotes cost effective, quality care throughout the VHA and into the community. Governmental and private insurance sources can also benefit from outpatient management of chronic disease processes with reduced costs of care from recidivism and improved self-care modalities. Further implications include adding to the knowledge base for chronic illness, outpatient care, palliative care, the patient-centered medical home model of care, interdisciplinary collaboration, home health, and hospice care. Nursing's role in health care reform focusing on patient-centered care from the perspective of bedside caregiver, primary care provider, educator, and organizational leadership is an additional implication for study.

### **CONCLUSION**

The purpose of the project was to evaluate strategies improving health care for the chronically ill veteran as well as providing a mechanism for attaining and sustaining improved care processes. Although nursing has been on the forefront of many advances in symptom management

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and end-of-life care, the work is often challenging because of environments focused on life-sustaining measures rather than goals of care that are patient centered addressing disease processes and the potential outcomes through prognostication. Management of symptoms using palliative care has evolved to include a wide range of patient demographics. Individuals experiencing chronic, symptomatic illness often fail to attain alleviation of suffering through standard protocols of clinic visits, emergency department visits, and hospitalizations. Studies have shown that implementing strategies such as the Patient-Centered Medical Home model of care and home-based primary care improves not only access to care but also delivery of care through utilization of clinicians providing expertise in symptom management.

An evaluation of the research has shown a need for evaluating symptomatic, chronic illness for diagnoses outside of cancer. Palliative care is a step in the right direction for meeting the IOM, Affordable Care Act, and patient-centered recommendations. This project has shown that management of symptoms in the chronically ill within their own home that involves the goals of veterans and their caregivers reduces recidivism and overall health care costs. Providing palliative care through HBPC is not based on income produced, but rather cost avoidance through reduced recidivism. Although not qualitatively evaluated, the improvements seen in management of symptoms through reduced recidivism, improved function, and chief complaint changing from "I'm terrible" to "I feel better than I have in years" made the project worthwhile. Setting up personalized goals of care for living the remainder of their lives and, if needed, assisting veterans and their families complete those final moments of living were an honor and privilege. No price can be placed on improved quality of life for patients and caregivers through alleviation of suffering.

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