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Symptoms Experienced by Heart Failure Patients in Hospice Care

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Introduction

Heart failure patients are a rapidly emerging hospice population. While cancer patients still comprise the largest disease group in hospices, they account for less than 50% of patients while a rapidly growing population is the group with heart disease.¹ Cardiac disease is the second most prevalent medical diagnosis, accounting for 14% of hospice admissions nationwide,² with heart failure being the most common designation. Patients with heart failure endure numerous physical and emotional symptoms. Research indicates patients experience sustained symptoms of shortness of breath, edema, dry mouth, fatigue, pain, anxiety, sadness³ and depression that adversely impact quality of life.⁴ Importantly, depression is a common co-morbidity among heart failure patients that is frequently overlooked.⁵

Symptom management in the outpatient¹ and inpatient⁵ settings continue until end stage disease may bring patients to a hospice. Hospice services can mitigate the infirmities of heart failure by focusing on symptom management.⁶ In the hospice setting the average length of stay (LOS) for heart failure patients (M=54 days, SD=93) is longer than for cancer patients (M=27 days, SD=37).² This puts HF patients at an advantage in that they are better able to benefit from the management of patients' symptom prevalence, severity, and distress and support of quality of life offered by hospice team members.

In this research, symptoms from the Memorial Symptom Assessment Scale for Heart Failure (MSAS-HF) such as fatigue, dyspnea, edema, loss of appetite and pain were examined. Evaluation of depressive symptoms using the Profile of Mood States-Depression Scale (POMS-D) experienced by heart failure patients in hospice care was included to provide a more holistic picture of the end stage heart failure patient upon admission to hospice. The purpose of this study was to report the most frequent, intense, and distressing symptoms experienced by heart failure patients upon admission to hospice home care as well as to examine the relationships among depressive symptom, and symptom frequency, severity and distress.

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Methods

This study was a secondary analysis using data from an NIH-funded study (R21NR011224) of hospice patients with heart failure. Only baseline data collected upon admission to hospice was used in this analysis.

Setting and Sample

The study took place at a large not-for-profit hospice in southwest Florida. This hospice has an average daily census of about 2,000 patients, of whom, 13% have a diagnosis of heart failure. At the time the study was conducted this hospice had an average length of stay that was 120 days with a median of 30 days.

In order to be a participant in this research, the patient had to be receiving hospice homecare with support of a family caregiver, and the primary diagnosis of heart failure (HF) was the expected cause of death of the patient. The patient had to have at least a sixth grade education, be able to read and understand English, and be able to pass a cognitive screening tool with a minimum score of 8 on the Short Portable Mental Status Questionnaire.⁷⁻⁸ Additionally participants were excluded if at least two of the following five symptoms of dyspnea, chest pain, other pain, constipation, and depression were not present at baseline data collection.

Measures

Memorial Symptom Assessment Scale-Heart Failure—The Memorial Symptom Assessment Scale-Heart Failure (MSAS-HF)⁹ was used to evaluate symptom prevalence, severity, and distress. Zambroski et al.⁹ modified the original MSAS¹⁰ to evaluate symptoms specific to heart failure patients. Zambroski et al.³ reported strong internal consistency ($\alpha=.83-.92$) scores on the MSAS-HF. Internal consistency of the MSAS-HF was evaluated as a part of this study, and reliability coefficients are reported in the results section.

For each of the 32 items, the patient indicated whether he or she had experienced the symptom by selecting a “yes” or “no”. If “yes” was selected, the severity of a symptom over the last 7 days was assessed using the response metric of (0) Not at all (1) A little bit (2) Somewhat Severe (3) Severe and (4) Very Severe. For symptoms endorsed by patients, they were then asked to assess the distress caused by a symptom with the response metric (0) Not at all (1) A little bit (2) Somewhat (3) Quite a bit or (4) Very Much. Higher scores on the MSAS-HF indicate greater symptom prevalence, symptom severity, and symptom distress.

Profile of Mood States—The Profile of Mood States (POMS), a 24-item instrument, composed of two subscales, assesses an individual’s anxiety and depression. The depression subscale (POMS-D) includes 10 items that may be used as a stand-alone measure without the 9 items from the anxiety subscale. The POMS-D, with 15 items, was administered. The response metric: (0) Not at All (1) A Little (2) Moderately (3) Quite a Bit (4) Extremely, quantifies the frequency of experiencing a feeling over the duration of a day and over the past 7 days. Higher scores on the POMS indicate higher levels of depressive symptoms. Reliability of the POMS scores as indicated by alpha coefficient of .95 for depression is favorable.¹¹⁻¹² Internal consistency of the POMS-D was evaluated, and the reliability coefficient is reported in the results section.

Demographic Data—Standard demographic data were collected to describe the sample. Age, sex, ethnicity, marital status, length of time since the patients provided diagnosis, religion, home location, and years of education.

Procedures

Prior to the accrual of patient-caregiver dyads, the hospice bioethics committee and the University Institutional Review Board approved the research protocol. Prior to enrollment in the study, informed consent was obtained from both the patients and their family caregivers. Following consent, baseline data were collected. The following case study may provide insight into the population of interest for this research.

A 74 year old white male was admitted to home hospice care. Six months ago his cardiologist told him that he was in the end stage of heart failure. He continues to receive optimal medical therapy, has an ICD (Internal Cardiac Defibrillator), and is not eligible for a heart transplant. Over the last six months his systolic blood pressure remains low, and there is evidence of progressive renal insufficiency. In the past three months he was admitted to the hospital three times for acute decompensated heart failure. He and his family, with the assistance of the palliative care team, made the decision during this past hospitalization to begin hospice services in his home. His wife is caring for him in their home.

Data Analysis

Patient baseline scores from the MSAS-HF and POMS-D for patients (n=40) were analyzed using SPSS 19.0. Descriptive statistics (means, standard deviations, and percentages) were calculated to characterize the baseline MSAS-HF and POMS-D responses. Pearson correlations were used to look for relationships between the number of MSAS-HF symptoms endorsed, symptom severity and distress, and depression scores.

Results

Symptom Prevalence and Frequency

Symptom prevalence was the total number of symptoms a patient endorsed with a possible maximum of 32 using the MSAS-HF. The frequency of a symptom was the percentage of participants from the sample who experienced that specific symptom. Using the MSAS-HF, patients can report from 0 to 32 symptoms, and the mean number of symptoms experienced per patient was 12.1 (SD = 5.8). Lack of energy, dry mouth, shortness of breath, numbness or tingling of arms or legs, pain other than chest pain, and feeling drowsy were reported by more than half of the patients (Table 1). The least reported symptoms were problems with urination, diarrhea, problems with sexual interest or activity, vomiting and weight gain. A significant correlation was found between age and the total number of MSAS-HF symptoms endorsed ($r = -.32$, $p = .028$). Time since diagnosis of heart failure and patient age were moderately correlated ($r = 0.32$, $p = 0.43$).

Symptom Severity

For each of the MSAS-HF symptoms, a mean symptom severity score was calculated using the severity scores assigned to that symptom by patients that indicated they experienced it. An overall mean severity score for the sample was calculated from the mean severity scores for all symptoms experienced across all participants. The symptoms with the greatest mean severity scores were difficulty breathing while lying flat, lack of energy, pain other than chest pain, difficulty sleeping, constipation, and chest pain. The symptoms experienced with the least severity were weight gain, vomiting, nausea, problems with urination, and diarrhea (see Table 1). The severity of symptoms ranged from 0 “none” to 4 “greatest severity”, with a mean severity of 1.05 (SD = .09) in this sample. There were strong correlations between symptom severity and the number of symptoms reported ($r = .98$, $p < .001$) and symptom distress ($r = .85$, $p < .001$) were strongly correlated. There was weak correlation between age and the total number of MSAS-HF items endorsed ($r = -.329$, $p = 0.041$) and reported symptoms severity ($r = -.320$, $p = .047$).

Symptom Distress

Symptoms reported as the most distressing were weight gain, difficulty sleeping, palpitations, other pain, and numbness/tingling in hands and feet, as seen in Table 1. The least distressing symptoms were feeling irritable, vomiting, problems with sex interest or activity, sweats, nausea, problem with urination, and cough caused the least distress. The distress caused by symptoms ranged from 0 “none” to 4 “greatest distress”. The mean distress score for a symptom was 1.29 (SD = 1.9) in this sample. The mean level of distress caused by the symptoms a patient experienced ranged from 6 to 63 and was 26.1 (SD = 15.4). The internal consistency of MSAS-HF scores in this study was good ($\alpha = 0.82$), further supporting the reliability of the MSAS-HF scores with hospice patients with heart failure. Pearson correlations between the total numbers of endorsed MSAS-HF symptoms, symptom severity, symptom distress was very strong as seen in Table 3. According to this finding patients experiencing symptomatology of heart failure do so with high severity and distress in hospice.

Symptoms of Depression

Scores on the POMS-D can range from 0 to 60 and for this sample ranged from 0 to 27. Patients most frequently endorsed the symptoms hopeless, unhappy, sorry, and unworthy. The Highest mean scores were found on discouraged, hopeless, and gloomy (Table 2). The average number of endorsed items was about 8 out of a possible 15 ($M = 7.86$, $SD = 4.85$). The internal consistency for the POMS-D scores in this study was very strong ($\alpha = 0.99$), supporting reliability of the POMS-D scores in heart failure patients in hospice.

The distress from MSAS-HF symptoms was moderately correlated ($r = .48$, $p < .009$) with the number of depressive symptoms endorsed using the POMS-D. No significant relationships were found between number of MSAS-HF symptoms endorsed, symptom severity scores, age, or time since diagnosis (see Table 3.).

Patient Characteristics

The majority of patients were white males with a very small number of African American patients represented (Table 4). The mean age of the participants was 79 years ($SD = 11$). Most patients had had the diagnosis of heart failure for one to ten years, with four patients having had the diagnosis for over 25 years. The majority of patients indicated they had 7 to 12 years of education and were non-Catholic Christians living in suburban areas.

Discussion

These results indicate that although the average patient in the study was experiencing an average of 12 co-occurring symptoms, there is an overall low severity of the symptoms experienced among heart failure patients in our sample. There was also an overall low level of distress per symptom in these patients. Similarly, the mean number of depressive symptoms reported was also lower ($M = 7.86$; $SD = 4.85$).

MSAS-HF Symptoms

Heart failure patients experience numerous symptoms in hospice and outpatient settings. Our findings provide a picture of a heart failure patient leaving the acute care setting and entering the hospice setting. The mean number of symptoms reported using the MSAS-HF in our sample was 12.1 ($SD = 5.8$), which was consistent with the mean number of symptoms ($M = 11.9$, $SD = 5.96$) reported from earlier hospice research.¹³ However, compared to the mean number of symptoms (15.1, $SD = 8.0$) reported in heart failure outpatient clinics using the MSAS-HF,³ patients in hospice reported fewer symptoms. It is unclear why this might have been the case. It is possible that through years of experience,

patients and their families had learned to manage symptoms so that they were less severe and bothersome. Or it might be that HF patients in hospice care are more sedentary and so are less influenced by symptoms that might be experienced if they were leading more active lives. Further study is warranted.

The mean distress scores and mean severity scores for this sample were lower. Plausible explanations being that patients in the sample experience multitude of symptoms, but a select few of them were experienced with tremendous severity and/or distress. Another explanation may be the age of the heart failure population as they may be experiencing a diminution of sensation so that physical symptoms actually do not cause as much discomfort.¹⁴ This result may also be happening because of the years of experience older patients have had in managing their HF symptoms. Or it may be that older patients expect to have symptoms as they age, so they discount them to some degree. They may be less active for other reasons, which might cause them to have fewer exacerbations of symptoms. Further study is warranted to address disparities of reported symptom severity in heart failure patients in hospice.

A higher level of symptom severity was not necessarily indicative of a high level of symptom distress in our sample. This was exemplified by a lack of energy and problems with sex being reported as symptoms experienced with the greatest severity but among the least distressful. McMillan and colleagues¹³ reported the severity of dry mouth experienced by heart failure patients in hospice was not as distressing or bothersome when compared to their lack of energy, shortness of breath, tingling of their extremities, feeling drowsy or their pain other than chest pain.

Shortness of Breath

Shortness of breath is as a hallmark symptom of heart failure, one that is common and distressing to patients.¹⁵ Our findings of shortness of breath in over 50% of patients in our sample is consistent with other studies in the outpatient^{3,4,15} and hospice settings.¹³ However, difficulty breathing while laying flat (25%) was far less prevalent in our hospice sample compared to the findings from McMillan et al.⁸ in which 50% of hospice patients reported experiencing shortness of breath upon exertion and at rest.

Lack of Energy

Lack of energy is the most frequently reported symptom in outpatient heart failure clinic settings^{3,4,15} and the second most frequently reported in this study. The high incidence of fatigue (lack of energy) in the hospice setting supports the earlier findings of McMillan and colleagues.¹³ In addition, fatigue was among the most severe and distressing of the symptoms. Feeling drowsy, a problem that might be expected to accompany fatigue, was reported by slightly more than half of patients, and was not reported to be among the most severe or distressing symptoms. About a third of the patients indicated they had problems sleeping, which may be somewhat related to the greater age of this sample, as sleep problems increase as patients age. Although not seen in a majority of patients, difficulty sleeping was reported as among the most severe and distressing symptoms in our sample; these findings were similar to those from the outpatient setting.³ Interestingly, other symptoms with relatively low frequency but greater severity and distress were shortness of breath when lying flat, as well as weight gain, itching and palpitations. This confirms the need to conduct more systematic assessments of symptoms so that hospice team members fully understand the patients' symptom experiences.

Lack of Appetite

Lack of appetite has been a frequently reported symptom among HF patients in hospice.¹³ However, in our sample lack of appetite, nausea, and vomiting were low in reported frequency, severity and distress. In heart failure patients nausea can result from the pressure from an enlarged, congested liver, or gastric stasis.⁵ Two plausible explanations for these diverse findings are that patients from our sample were receiving management of the symptoms of nausea and vomiting, or they simply had become accustomed to feeling the symptoms over the course of the disease. Further study on the manifestation of anorexia, nausea and vomiting in hospice is needed to help guide researchers, clinicians and educators.

Weight Gain

Weight gain was the symptom endorsed by the fewest patients, as well as the least severe; however, when it occurred, the patients reported it to be their most distressing symptom. Because the patients had had heart failure over a longer period of time, it is likely that they knew the significance of weight gain, and were distressed that their heart failure might be advancing. Given the etiology of swelling of the extremities in heart failure along with the prevalence of swelling of the extremities, a greater prevalence of weight gain was expected. Swelling of the upper extremities was among the most endorsed symptoms in our sample, affecting almost half of patients. Reported swelling of extremities in the hospice setting is consistent with end stage heart failure. In earlier studies, hospice patients report more swelling and edema¹³ than heart failure patients in outpatient settings.⁴

Other Pain

Pain that is poorly managed can affect 40–75% of end stage heart failure patients.¹⁶ Although the patients in the sample all had heart disease only 45% reported chest pain. However, over half of the patients (52.2%) reported experiencing pain other than chest pain. Co-morbidities as sources of the other pain are expected in patients with a median age of 75 years.¹⁷ Co-morbidities identified as sources of pain include degenerative joint disease, chronic back pain, anxiety and depression.^{5,16} In our sample, 16 patients indicated their other pain was from joint and/or musculo-skeletal sources and 5 indicated non-musculo-skeletal sources. Of these 21 patients, eight reported two sources of pain, 9 patients reported three sources, and six reported one source. Importantly, this pain was among the highest in symptom severity and distress. Our findings are consistent with the outpatient setting³ in which other pain was not only more prevalent but more burdensome/bothersome than chest pain. Because this pain is not related to the patient's reason for hospice admission, there is a risk that it might be overlooked; however, our results suggest that there is a real need for the hospice team to address this "other" pain.

Problems with Urination and Sex

In our sample, men over the age of 88 reported greater severity and distress from problems with urination. Problems with sexual interest or activity were reported by less than one third of the men in our sample, with only one woman reporting such problems. Men over the age of 70 reported a greater severity in problems with sexual interest or activity. However, problems with sex was reported as one of the least distressing symptoms. This latter finding is not supported by earlier research in which a problem with sex was reported as among the most distressing symptoms in the outpatient setting.¹⁶ This difference in distress by setting might be at least partially explained by the age differences in the two groups and different expectations.

These findings may provide clinicians and nurses with an important direction for assessment and intervention in older male heart failure patients in hospice and the outpatient setting. A

more thorough assessment of sexual concerns to decrease prevalence and burden of sexual dysfunction in heart failure patients is needed.³ Findings regarding sexual concerns of heart failure patients in the hospice and outpatient settings warrant additional research.

Worrying, Sadness and Feeling Nervous

The MSAS-HF includes items assessing feelings of worry, sadness and nervousness. Half of the patients experienced worry. Importantly, worry was one of the most distressing symptoms experienced by heart failure patients. Although we did not ask the source of the worrying, it might be expected that these patients are worrying about their health and prognosis. It continues to be essential for hospice team members to offer support to patients who are likely to be worrying. In the outpatient setting, previous research has found significant sadness,³ and depression in heart failure patients.⁴ The role of these emotional issues should not be under-estimated; hospice team members need to focus on these issues as they work to improve overall quality of life of heart failure patients.

Depressive Symptoms

In our sample the overall number of reported depression symptoms was low; indicating heart failure patients in hospice still find pleasure in life. A plausible explanation is that patients were at home and supported by a family caregiver, something that may increase their life satisfaction. We tried to avoid response bias by assessing the patient privately, and away from family members to insure that patients would be frank and honest in their reports of symptoms. This strategy was to encourage patients not to minimize their symptoms for the benefit of family.

Given the goals of emotional support for patients receiving hospice care, addressing all reported symptoms of depression is important. Among the depression items, feeling hopeless led the list, followed by unhappy, sorry, and unworthy as the most frequently reported symptoms as seen in Table 2. A third or more of patients indicated they experienced hopelessness, unhappiness, sadness, and nervousness. However, the overall severity of these depressive symptoms was low.

The symptom on the depression measure with the highest severity was discouraged, with half of patients rating themselves as quite a bit or extremely discouraged. The cause of the intense feelings of discouragement was not determined by this study, but this is an issue that is extremely relevant to the care of hospice patients with heart failure as they approach the end of their lives.

When death is eminent, the role of hope takes on an important meaning, and may appear to be strong within the dying person and family.⁵ Indeed, despite being at the end of their lives, more than half of our sample indicated they still felt hope. What these individuals are hopeful for was not ascertained by our measures. However, unrealistic hope, such as hope for a cure, may become problematic.⁵ Further exploration of hopefulness and hopelessness in heart failure patients through research is needed to provide patient information and guidance to members of the hospice care team.

The finding that a relationship exists between symptom distress and depressive symptoms in heart failure patients in hospice was not unexpected. This confirmation of a relationship may provide clinicians with imperative information and should remind them to be alert for depression in patients with multiple severe and distressing symptoms and to accurately assess and manage symptoms of depression. Importantly, there was no significant correlation between depression and the total number of MSAS-HF symptoms or the severity from those endorsed symptoms.

There total number of MSAS-HF items endorsed and the total number of POMS-D items endorsed were not significantly correlated. The overall number of MSAS-HF items endorsed was consistent with the heart failure literature.⁸ It would logical to expect that patients having more symptoms would perceive themselves as more ill and therefore closer to death; thus, more symptoms of depression might be expected in this group. However our findings of low POMS-D scores in our sample indicate this may not be the case and may have resulted in the lack of correlation between number of MSAS-HF items endorsed and number of POMS-D items endorsed.

Patient Characteristics

Patient characteristics were similar to those found by Baim, Strassels and Whellan⁶ when comparing heart failure patients and cancer patients receiving hospice services. The majority of heart failure patients were predominately white (81.7%) with a mean age of 85 (SD = 9.0). Cancer patients using hospice services, who were also predominantly white (75.9%) with a mean age 71.1 (SD = 13.4), were notably younger than the heart failure patients. Heart failure literature indicates the age of heart failure patients in the outpatient setting (not receiving hospice service) varies. Recently, Bekelman et al.⁴ conducted an outpatient palliative care record review in which 70% of the patients were in Class III or Class IV heart failure. Of these patients the median age was 51 years old and only 28% were women. However, other outpatient heart failure studies reported the mean ages of 55³, to 74 years old,¹⁸ but consistently report that patients are predominately white males.^{3,18-19} Our results suggest that hospice patients with HF are older than HF patients in other outpatient settings; this may be related to the fact that most if not all are in the final stages of heart failure, and 40% had had heart failure for more than a decade. Future research, whether in outpatient or hospice settings, should include more diverse samples.

Current research found 50% of people diagnosed with HF will die within 5 years.²⁰ In the outpatient setting, the majority of patients reported at least four years as the length of time since diagnosis.³⁻⁴ In our sample, over a third of the patients reported a diagnosis for least 5 years, and notably, several patients indicated having the diagnosis of heart failure for one or two decades. A plausible source of this discrepancy between the outpatient and hospice setting is that the patients who have had heart failure for a longer period of time will be more likely be at the end stage of HF as opposed to the patients in the outpatient setting.

Implications

Our findings convey important information for education, research and clinical practice. Without the specialized training to care for hospice patients, nurses will find themselves unable to provide the necessary symptom control and amelioration of suffering.⁵ It is important that both formal educational programs at all levels in schools of nursing and continuing education programs be developed to provide this specialized training to prepare nurses and other practitioners to optimally care for hospice patients with heart failure patient.

Only very limited research has been conducted in hospice patients with HF, and this study needs to be replicated in a larger and more diverse sample. Further investigation of the source of patients' feelings also is needed. According to the American Heart Association,²¹ when advanced heart failure patients discuss their goals, patients typically are not only concerned about how long they will live but also how well they will live. Our findings show that the most prevalent symptoms may not be the most severe or distressing. A symptom may not affect all patients, but might have great impact on the quality of life of those who are affected. In addition, the level of symptom severity does not necessarily correspond to

the symptom distress. This difference means that clinicians should systematically assess both severity and distress of the symptoms that patients are experiencing.

Limitations

The small sample size and cross sectional design were limitations of this research. Thus it was limited to only the baseline assessment and could not provide a longitudinal perspective on symptoms of heart failure patients in hospice. The inclusion of patients from only one hospice in one part of the country may limit the generalizability of the findings. Only patients who were able to self-report and who were receiving home care were included making all other patients unable to participate. Finally, because of the focus of the parent study on five specific symptoms, patients who did not report two of these symptoms were excluded; this might have biased the sample to some unknown degree.

Conclusions

A picture of patients from the acute care setting coming into hospice was captured from the research. Study results indicate that heart failure patients entering hospice care have multiple symptoms requiring management, many of which cause considerable distress. Noteworthy is the finding that symptoms with the greatest reported severity were not necessarily those with the greatest distress as well as the correlation between symptom distress and depressive symptoms. Clinicians in hospice may consider specifically focusing part of their assessment and management of symptoms by first addressing symptom severity and distress.

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Table 1

Frequency (F) and Percent (%) of Symptom Prevalence, Mean and Standard Deviation (SD) for Symptom Severity and Symptom Distress Scores

Symptom	F	%	Severity	Distress
Dry mouth	29	72.5	2.0(1.1)	2.1(1.1)
Lack of Energy	28	70	2.4(1.0)	2.6(1.1)
Shortness of Breath	26	65	2.3(1.0)	2.2(1.1)
Numbness/Tingling in hands or feet	22	55	2.3(1.1)	2.7(1.1)
Other Pain	21	52.5	2.4(1.1)	2.7(0.91)
Feeling Drowsy	21	52.5	1.8(.75)	2.0(.95)
Weight Loss	21	52.5	1.9(1.0)	2.0(1.4)
Worrying	20	50	1.9(.99)	2.5(1.2)
Change in Taste	20	50	2.0(.91)	2.1(1.0)
Swelling of arms	19	47.5	2.2(.97)	2.6(1.1)
Dizziness	18	45	1.9(.80)	2.2(.86)
Chest Pain	18	45	2.3(1.19)	2.6(1.2)
Cough	18	45	1.5(.87)	1.8(.93)
Difficulty Concentrating	16	40	1.6(.50)	1.8(.8)
Itching	16	40	1.9(1.18)	2.6(1.1)
Lack of Appetite	15	37.5	1.8(.86)	2.5(1.1)
Feeling Sad	15	37.5	1.8(1.01)	2.7(1.1)
Difficulty Sleeping	14	35	2.4(1.12)	2.8(78)
Waking up breathless at night	14	35	1.8(.77)	2.0(1.0)
Feeling Irritable	21	32.5	1.3(.65)	1.3(.67)
Feeling Nervous	12	30	1.9(.94)	2.0(1.0)
Constipation	12	30	2.4(.90)	2.5(1.0)
Sweats	11	27.5	1.7(1.10)	1.5(1.0)
Feeling bloated	10	25	1.8(.78)	2.0(.92)
Difficulty Breathing when lying flat	10	25	2.6(1.0)	2.5(.92)
Palpitations	8	20	1.8(.69)	2.8(.44)
Nausea	8	20	1.5(.53)	1.8(.75)
Problems with Urination	7	17.5	1.5(.78)	1.8(1.3)
Diarrhea	7	17.5	1.8(1.0)	2.1(1.3)
Problems with sexual interest or activity	5	12.5	2.8(1.0)	2.1(1.3)
Vomiting	4	10	2.2(1.2)	1.5(.57)
Weight Gain	3	7.5	1.3(.57)	3.0(1.0)

Note: n=40, M=mean SD= Standard Deviation

Table 2

Correlation Table of the MSAS-HF, POMS-D, and Patient Characteristics in End Stage Heart Failure Patients in the Hospice Setting.

Variable	Age	Time	Total	Severity	Distress	POMS-D
Age	1.0					
Time Since Dx						
r	.322	1.0				
p	.043					
n	40					
Total MSAS-HF						
r	-.329	-.159	1.0			
p	.041	.334				
n	39	39				
Symptom Severity						
r	-.320	-.187	.985	1.0		
p	.047	.225	.000			
n	39	39	39			
Symptom Distress						
r	-.308	-.063	.855	.877	1.0	
p	.056	.701	.000	.000		
n	38	39	38	38		
Total POMS-D						
r	.085	.243	.324	.329	.487	
p	.669	.218	.093	.088	.009	1.0
n	28	28	28	28	28	

Note: Dx=Diagnosis; MSAS-HF=Memorial Symptom Assessment Scale-Heart Failure; POMS-D= Profile of Mood States-Depression Scale; r= Pearson Correlation Coefficient; p=p value; n=Sample Size.

Table 3Frequency and Percent of Patients *Responding Quite a Bit* or *Extremely* on POMS-D Items

Item	f	Prevalence (%)	Quite a bit or Extremely
Hopeless	14	36	10
Unhappy	14	36	9
Sorry	11	28	9
Unworthy	11	28	4
Discouraged	9	23	20
Terrified	7	25	0
Gloomy	4	10	10
Lonely	3	7	0
Guilty	1	2	0
Miserable	1	2	6

Note: n=38.

Table 4

Demographics of Heart Failure Patients in Hospice (N=40)

Variable	Frequency	Percent (%)
Gender		
Male	26	65
Female	14	35
Ethnicity		
White	34	85
African American	3	7.5
Asian/Pacific Islander	1	2.5
Other	1	2.5
Time since dx (years)		
Less than 1 year	7	17.5
1 to 5 years	8	20
6 to 10 years	9	21.5
11 to 15 years	6	15
16–20 years	6	15
25–30 years	3	7.5
32 + years	1	2.5
Religious Affiliation		
Catholic	5	12.5
Non-Catholic	21	52.2
Jewish	1	2.5
Other	2	2
None	3	3
Home Setting		
Urban	5	12.5
Suburban	12	30
Rural	2	5
Missing data	21	52.5
Education (years)		
7 to 11	16	40
12	13	32.5
13 to 17	11	27.5

Table 5**Clinical Management of End Stage Heart-Failure Patients in Hospice**

The least frequent symptoms may be the symptoms may cause the most distress.
Management of experienced symptom distress may favorably manage depressive symptoms.
Pain management should include a systematic assessment of other sources of pain from co-morbidities.
Management of a symptom experienced with greater severity may not alleviate the distress caused by symptoms.
Assessment and management of sleeplessness may be a central tenant to symptom management in end stage heart failure patients in hospice.