

## Suffering at the End of Life in the Setting of Low Physical Symptom Distress

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### ABSTRACT

**Background:** Alleviation of suffering is a fundamental goal of medicine, especially at the end of life. Although physical distress is a component of suffering, other determinants likely play a role. This study attempted to elucidate these other components in an effort to understand the nature of suffering better.

**Methods:** Prospective cohort study conducted in the Population-based Palliative Care Research Network (PoPCRN) among English-speaking adults. Data were collected at hospice admission and at frequent intervals until death or discharge. This paper presents patient-reported data collected at the first available assessment after admission, using the Condensed Memorial Symptom Assessment Scale (MSAS; 0 = not distressing, 4 = very distressing), the McGill Quality of Life Questionnaire (MQOL; 0 = worst QOL, 10 = best QOL) and 2 suffering scales, overall suffering and suffering caused by physical symptoms (0 = not suffering, 10 = extreme suffering). The study population ( $n = 48$ ) is limited to those with physical symptoms less than "somewhat" distressing on the MSAS-PHYS. Respondents were divided into two groups: no-mild overall suffering (0-3) and moderate-severe overall suffering (4-10) and compared based on demographics, MQOL scores, MSAS-PSYCH scores and suffering caused by physical symptoms.

**Results:** Mean age 70 years (range, 33-91), mean Karnofsky score 46, 46% married, 54% male, 71% cancer, 93% non-Hispanic white. Compared to patients reporting no-mild overall suffering, patients reporting moderate-severe overall suffering were more likely to have a diagnosis other than cancer (83% vs. 57%,  $p = 0.05$ ), be younger (65 vs. 75 years,  $p = 0.02$ ) and have lower scores on the MQOL-psychological subscale (6.4 vs. 8.0,  $p = 0.02$ ) and overall QOL scale (6.2 vs. 7.2,  $p = 0.04$ ). No significant differences were noted with respect to gender, marital status, MSAS-PSYCH, or MQOL existential and support subscales. Study patients reporting worse overall suffering also reported worse suffering caused by physical symptoms (6.3 vs. 2.1,  $p < 0.0001$ ). There was little association between the MSAS-PHYS score and either overall suffering (correlation coefficient = 0.18,  $p = 0.21$ ) or suffering resulting from physical symptoms (correlation coefficient = 0.22,  $p = 0.13$ ).

**Conclusion:** Patients reporting lack of distress resulting from physical symptoms did not necessarily indicate lack of suffering because of physical symptoms or lack of overall suf-

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fering. Factors other than physical symptom distress, such as diagnosis, age, and QOL appear to affect the perception of suffering. In order to better address suffering at the end of life, care must be taken to understand differences between physical symptom distress, suffering caused by physical symptoms and overall suffering.

## INTRODUCTION

**A**LLEVIATION OF SUFFERING is the fundamental aim of end-of-life care. Despite tremendous technological innovations, which have enabled treatment of once incurable diseases, care providers' understanding of the basic components of suffering remains primitive. For years, health care providers specializing in palliative care have recognized pain and physical distress as part of the puzzle.<sup>1</sup> Nevertheless, this does not appear to be the only cause of suffering near life's end.<sup>2</sup> In 2003, 34% of respondents in a multinational survey reported that their greatest suffering was from nonphysical sources (E. Lesho, personal communication, 2004). A conceptual framework for suffering should include burdens of illness that have little direct impact on one's physical comfort. In addition to physical distress, life-altering changes such as loss of career, loss of hope, loss of independence, isolation, depression, and guilt may contribute to suffering.

Dr. Eric Cassel defined suffering as "challenges that threaten the intactness of the person as a complex social and psychological entity."<sup>3</sup> Cassel delineates a "topology of a person" that extends beyond pain to include a person's emotional, spiritual and cultural dimensions. He believes when these dimensions are threatened, suffering ensues.<sup>3</sup> Years after Cassel's paper, health care provider attention remains centered on treatment of pain in terminally ill patients. While this is a noble goal, more thorough treatment of suffering should also incorporate the nonphysical dimensions of suffering.

In order to address gaps in understanding of suffering at the end of life, we sought to identify and describe characteristics of a terminally ill patient population that is suffering without acknowledging significant distress from physical symptoms. We hypothesized that we would identify a terminally ill patient population that does not report significant physical symptom distress but does report moderate-severe suffering. We believed that when we compared this group of patients to a group that also lacks significant physical symptom distress but reports no or mild

suffering we would find quantifiable differences with respect to realms other than physical distress.

## METHODS

### *Study setting and population*

A prospective cohort study was conducted in the Population-based Palliative Care Research Network (PoPCRN), a hospice-based research network modeled on primary care practice-based research networks.<sup>4</sup> English-speaking adults who were receiving care from the study hospices participated in the study. Because the focus of this analysis is patient suffering, which is inherently subjective, the study population is limited to those patients who were able to provide responses. Study subjects provided informed consent according to the requirements of the Colorado Multiple Institutional Review Board (COMIRB), which approved the study. Of the 100 enrolled patients, 63 had patient response data on their first, second, or third visits. The initial sample for this study was the data from these patients. However, 11 of these patients had missing data for either or both of the primary measures (answers to the questions, "Overall how much are you currently suffering?" and calculable MSAS-PHYS score) leaving 52 patients with usable data. Of these 52 patients, 48 had MSAS-PHYS scores indicating, on average, physical symptoms were less than "somewhat distressing" over the preceding 7 days. These 48 patients form the study population.

### *Data collection*

A designated hospice staff member from each participating site selected study patients, obtained informed consent, conducted the interviews and collected data. Each hospice was provided with a study notebook containing detailed instructions and participant-specific study notebooks containing all of the study instruments. Site coordinators completed and returned the study instruments in preaddressed stamped envelopes.

PoPCRN researchers assisted participating hospices in the Denver and Colorado Springs areas with enrolling and interviewing patients whenever possible. Data were collected from patients at hospice enrollment, at 1 week, and 2 weeks after enrollment. For those who survived beyond 2 weeks, data were collected monthly until death or hospice discharge. The data reported here represents the first available data collected because of the significant decline in available patient reports over time.

### *Study instruments*

The study instruments were pilot tested to evaluate ease of use, respondent burden, and content validity. Minimal revisions were required prior to implementation.

*Suffering questions.* Two suffering questions were asked:

1. Overall, how much are you currently suffering due to physical symptoms?
2. Overall, how much are you currently suffering?

These questions were modified from a previous suffering study by Baines and Norlander.<sup>2</sup> Response options were 0–10 (not suffering–extreme suffering).

*Memorial Symptom Assessment Scale.* The Memorial Symptom Assessment Scale (MSAS) is a patient-rated, multidimensional instrument that evaluates the intensity, frequency, and distress associated with symptoms. High correlations with clinical status and quality of life measures support the validity of the MSAS.<sup>5</sup> In this study, we used the Condensed MSAS, which is an adaptation of the MSAS Short Form focusing on distress related to the most prevalent symptoms among patients at the end of life. This scale includes 17 predefined symptoms and allows patients to fill in two additional symptoms if different from those listed. The MSAS yields several validated subscale scores, including a Global Distress Index (GDI), a Physical Symptom subscale score (MSAS-PHYS), and a Psychological Symptom subscale score (MSAS-PSYCH).<sup>5–8</sup>

*McGill Quality of Life Questionnaire.* The McGill Quality of Life Questionnaire (MQOL), which

was developed to measure quality of life among patients with advanced cancer receiving palliative care, consists of 17 items that are scored on a 0–10 scale. When appropriate, items are recoded so that a score of 0 always indicates the least desirable and 10 the most desirable situation. In addition to a single-item scale (SIS) measuring overall quality of life (QOL), the MQOL consists of a total score and scores on 4 subscales: physical, psychological, existential well-being, and support.<sup>9</sup> The MQOL has been used both as a single assessment and multiple assessments over time.<sup>10</sup>

*Demographics and functional status.* The study instrument also included basic demographic questions about the patient (gender, age, race/ethnicity, marital status, referral source, date of admission, diagnoses, and treatment setting) and a measure of functional status (Karnofsky Performance Scale).<sup>11</sup>

### *Analyses*

Descriptive statistics were generated for each variable. Frequency tables were constructed for each ordinal and nominal variable. MSAS-PHYS score was calculated as an average of the scores for the following symptoms: lack of energy, lack of appetite, pain, dry mouth, weight loss, feeling drowsy, shortness of breath, nausea, constipation, cough swelling of arms or legs, difficulty swallowing, and any symptoms that patients added to those that were listed. The study population was limited to study patients who indicated their physical symptoms were less than “somewhat distressing” on the MSAS-PHYS scale ( $n = 48$ ).

We divided patients into two groups based on their response to the question, “Overall how much are you currently suffering?” For analytic purposes we assumed that patients who responded with a score of four or greater on the single item question regarding overall suffering were experiencing at least moderate suffering while those with scores of three or less were experiencing no more than mild suffering.

Comparisons between the moderate–severe and no–mild suffering groups were made using  $\chi^2$  tests for categorical variables and  $t$  tests for continuous variables. All tests were two-sided and tests with  $p$  values of less than 0.05 were considered significant. Correlations were reported using Pearson’s correlation coefficients.

TABLE 1. STUDY POPULATION CHARACTERISTICS

<i>Patient characteristics (n = 48)</i>	
Male gender, <i>n</i> (%)	26 (54)
Cancer diagnosis, <i>n</i> (%)	32 (67)
Non-Hispanic white, <i>n</i> (%)	43 (90)
Married, <i>n</i> (%)	22 (46)
Age, mean (range)	70 (33–91)
Karnofsky score, mean (range)	46 (10–100)

Percentages based on number of patients who provided data of 48 total.

## RESULTS

Patient characteristics are listed in Table 1. Study patients are reflective of hospice patients in the United States, except their functional status was higher, reflecting inclusion of only patients that could consent to participate and complete the study instruments.

In response to the question, “Overall how much are you currently suffering?,” 25 of the 48 patients (52%) rated their level of suffering on the 11-point scale, (0 = not suffering, 10 = extreme suffering) as 3 or less, indicating no or mild suffering. Twenty-three rated their level of suffering as 4 or greater, indicating moderate–severe suffering. The patients reporting no–mild overall suffering were, on average, older than those reporting more overall suffering (75 years versus 65 years,  $p = 0.02$ ). Patients experiencing less overall suffering were more likely to have cancer than those reporting moderate-severe suffering (83% versus 57%,  $p = 0.05$ ). There was no statistically significant gender, marital status, or functional difference between the two groups (Table 2).

The group reporting no–mild suffering differed from the group reporting moderate–severe suffering in response to the question, “Overall how much are you currently suffering because of

physical symptoms?” In the group reporting no–mild overall suffering, the mean response was 2.1 (95% confidence interval [CI] (1.2–3.0) on a 0–10 scale. The mean score for patients with moderate to severe overall suffering was 6.3 (95% CI (5.2–7.3,  $p < 0.0001$ ) suggesting that, in our study, patients who experienced more overall suffering also suffered more because of physical symptoms (Fig. 1).

Response to the question, “Overall how much are you currently suffering?” strongly correlated with response to the question, “Overall how much are you currently suffering due to physical symptoms?” ( $r = 0.76$ ,  $p < 0.0001$ ). There was a weak but significant inverse correlation between the question about overall general suffering and MQOL-Psych subscale ( $r = -0.35$ ,  $p = 0.01$ ). However, there was little correlation between response to the question about overall suffering and the MSAS-PHYS score, which measures the intensity of physical symptom distress over the preceding week ( $r = 0.18$ ,  $p = 0.21$ ). Response to the question, “Overall how much are you suffering because of physical symptoms?” did not significantly correlate with the MSAS-PHYS score ( $r = 0.22$ ,  $p = 0.13$ ) but did have a weak inverse correlation to the MQOL-Psych subscale ( $r = -0.36$ ,  $p = 0.01$ ).

The study groups differed significantly in response to questions on the MQOL psychological subscale but not on the existential or support subscales (Fig. 2). The patients in the group experiencing no–mild overall suffering reported better psychological well-being (8.0, 95% CI 7.1–8.9) than those in the group experiencing moderate-severe overall suffering. (6.4, 95% CI 5.4–7.4;  $p = 0.02$ ). The overall quality of life score was also higher among patients in the group with no–mild suffering (7.2 [95% CI = 6.5–7.9] versus 6.2 [95% CI = 5.6–6.8];  $p = 0.04$ ).

TABLE 2. DEMOGRAPHIC DIFFERENCES BETWEEN SUFFERING GROUPS

	<i>No-mild suffering (n = 25)</i>	<i>Moderate-severe suffering (n = 23)</i>
Age, mean (range) <sup>a</sup>	75 (43–91)	65 (33–90)
Cancer dx, N (%) <sup>a</sup>	20 (83)	12 (57)
Male, N (%)	14 (56)	12 (52)
Karnofsky, mean (range)	44 (30–100)	49 (10–80)
Non-Hispanic white, <i>n</i> (%)	22 (96)	21 (91)
Married, <i>n</i> (%)	10 (40)	12 (52)

<sup>a</sup> $p < 0.05$ .

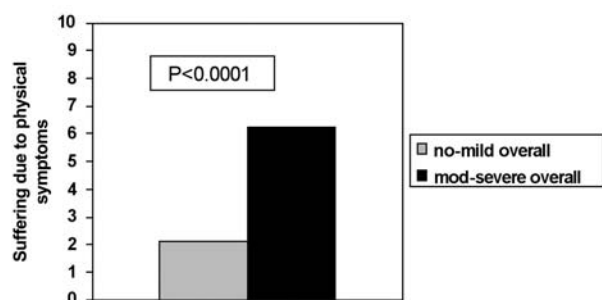


FIG. 1. Patients experiencing more overall suffering report more current suffering because of physical symptoms.

## DISCUSSION

In a hospice setting, suffering persisted even in patients who rated their physical symptoms as less than somewhat distressing. Patients experiencing more suffering reported worse psychological well-being and worse quality of life than those who were suffering less. Younger patients and those with noncancer diagnoses reported more severe suffering. Interestingly, patients with low scores on the Support and Existential MQOL subscales were no more likely to report suffering than those with higher scores. In an apparent paradox, while the entire study population had MSAS-PHYS responses indicating that average physical symptoms were less than “somewhat distressing” over the preceding 7 days, the group with no-mild suffering reported less “current suffering due to physical symptoms.”

Previous studies have qualitatively assessed the relationship between symptom relief and quality of life in hospice settings from both patient and caregiver perspectives. These studies support our finding that relief of pain is just one of many dimensions which affect quality of life near life’s end. Additional factors that have been found to enhance quality of life include relieving burden on family members, strengthening relationships among loved ones, achieving a sense of control, and satisfaction with hospice care.<sup>12,13</sup>

Baines and Norlander<sup>2</sup> have explored the relationship between pain and various types of suffering in a hospice population. They concluded that pain and suffering are distinct entities, but they did not study other features which may contribute to suffering. Our research adds to their findings by specifically studying the relationship between suffering and domains other than pain. Additionally, rather than dividing suffering into

distinct categories (e.g., physical suffering, spiritual suffering, and family suffering) we chose to focus on global suffering. We believe that in doing so we allow for a more complete understanding of a complex, individual process.

Our most striking finding is the apparent paradox that despite the fact that all study patients, by design, had MSAS-PHYS scores indicating that physical symptoms were less than “somewhat distressing” over the preceding 7 days, patients reporting a greater degree of suffering reported greater “current suffering because of physical symptoms” when responding to a single question, 0–10 scale. This apparent discrepancy deserves comment. Interpreting these results requires asking several questions. Are the MSAS-PHYS and the 0–10-point physical suffering scale measuring different concepts? Are these questions interpreted differently by patients? Finally, are we interpreting the raw data and categorizing the responses correctly?

With respect to the first question, it is important to look at the methodology underlying the MSAS-PHYS. The MSAS is a validated patient-rated instrument that was initially used to characterize physical and psychological symptom severity, frequency and distress in a population with cancer.<sup>14</sup> In the MSAS-PHYS, patients are asked first whether or not they are having a symptom (e.g., pain, cough, shortness of breath), and then they are asked the amount of distress caused by this symptom (e.g., not at all, a little bit, very much). The mean score for physical distress weights all symptoms equally. If a symptom is not present, the distress score for that symptom is 0, but the number of symptoms used in the denominator to calculate the average score remains the same. In theory this could skew the results for people with a few, extremely distressing symptoms. For example, a patient with severe

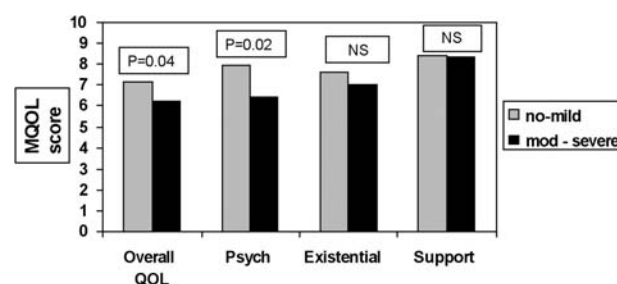


FIG. 2. Quality of life (QOL) differences between suffering groups.

dyspnea may be suffering tremendously from this physical symptom alone. However, if no other physical symptoms were causing distress or if the dyspnea was severe enough to mask other problems, the calculated MSAS-PHYS would indicate very low distress. On the other hand, the 0–10-point suffering scale simply asks patients to rate how much they were currently suffering because of physical symptoms. If dyspnea was one's only symptom, but was causing extreme suffering, this would be reflected in the patient's response.

In an attempt to adjust for this phenomenon, we also calculated a modified MSAS-PHYS score by removing symptoms that patients were not experiencing from the denominator. Average scores using the modified MSAS-PHYS did significantly correlate with responses to the question, "Overall how much are you currently suffering?" ( $r = 0.30, p = 0.037$ ), but still did not significantly correlate with the question, "Overall, how much are you currently suffering because of physical symptoms?" ( $r = 0.24, p = 0.10$ ) This appears to refute the notion that methodological differences alone account for the apparent paradox.

Another potential difference is the time scale difference between the two instruments. The MSAS-PHYS asks respondents to rate distress over the past 7 days. With the 0–10-point suffering question, patients are asked how much they are currently suffering. It is conceivable that some patients had an increase in their symptoms around the time of the survey and thus rated distress over the preceding 7 days lower than they rated current suffering.

Patient interpretation of the words distress and suffering may also help explain the divergence. We did not conduct *post hoc* interviews with patients to determine how they interpreted survey questions, so we are forced to speculate how interpretations may have varied. Distress has been defined as the combination of pain and anxiety. Suffering has been defined as the specific state of distress that occurs when the intactness of a person is threatened.<sup>15</sup> We propose that "distress" may be a different concept in patients' minds than "suffering." It is possible that patients might have difficulty figuring out whether a particular symptom (e.g., cough) was causing distress versus whether or not that symptom is causing suffering. Patient uncertainty or different interpretations may lead to varied responses and skew the results.

Another reasonable explanation for the results is the possibility that we are misinterpreting patient responses to the 0–10-point suffering scale. Patients were informed only that 0 represented no suffering and 10, extreme suffering. There were no guidelines regarding scores between the two extremes. All patients with answers 4 and above were lumped into the moderate to severe suffering category. Although this is a reasonably accepted approach to interpreting an 11-point scale,<sup>2</sup> perhaps patients answering the question with a 4 do not feel they are experiencing moderate suffering.

Regardless of the reasons underlying the discrepancy we observed, the implications for palliative care research and clinical care are important. Our study shows that use of the MSAS-PHYS is not a substitute for asking patients directly how much of their suffering is because of physical symptoms. Researchers and clinicians involved in end-of-life care should take heed. While we have proposed some mechanisms that may account for this phenomenon, further studies are required to explain it adequately. Additional efforts are also required to determine the most valid method of measuring the impact of pain and physical distress near life's end and whether the MSAS-PHYS and a single-item suffering question can be used adjunctively.

Our findings indicate that while psychological well-being and quality of life were negatively associated with suffering, somewhat counter intuitively higher Support-related QOL and Existential QOL were not associated with lesser degrees of suffering. Previous published studies suggest that fear of becoming a burden to loved ones is one of the greatest stressors in terminally ill patients.<sup>12,16</sup> Perhaps those with strong support networks experience greater anxiety about caregiver burden, offsetting the positive aspects of having loved ones around them. Alternatively, those with greater support networks and those with greater existential well-being may, in some sense, have a stronger desire to live, creating what might be considered a suffering gap because they have more to lose than those who are less fortunate during times of good health.

There are limitations to this research. The data are derived from responses to questionnaires from terminally ill patients at a specific point in time. Although methods were standardized as much as possible, we could not account for numerous factors which may have affected the re-

sults such as the respondent's mood, energy level, and degree of interest when answering. By nature, patient responses were subjective and based on their personal experiences.

Our paper excludes patients reporting average MSAS-PHYS scores indicating their physical symptoms were more than "somewhat" distressing. We acknowledge that choosing a different MSAS-PHYS cutoff may have varied our results considerably. Additional studies should focus on the differences between patient populations with high and low MSAS-PHYS scores with respect to suffering near life's end. One hypothesis could be that patients with high physical symptom distress suffer more because of physical causes while psychological and existential quality of life issues contribute more to suffering amongst those with low physical symptom distress.

Our results cannot be generalized to all terminally ill patients for several reasons. First, the patient population was homogeneous ethnically. The vast majority of patients in our study were Caucasian. Our results may not translate well to other ethnic groups that constitute a significant percentage of the general population. Additionally, our population was not the sickest of the sick. In order to qualify for the study, patients needed to have enough energy and cognitive capacity to answer a fairly in-depth questionnaire. It is not at all clear that our findings would apply to patients with more advanced disease processes.

Finally, a quantitative study of suffering that relies on numbers and categories is inherently somewhat simplistic. Qualitative research dominates this area because suffering is an individually unique and subjective experience. Our data provide interesting information and correlations but do not capture many of the subtle nuances that take place near life's end.

Some have argued that categorizing suffering dehumanizes the process and increases this feeling among those who are ailing.<sup>17</sup> While we agree that suffering is personal and individualistic, we do not share the view that researching this question increases distress. Instead, describing commonalities and differences between those who suffer and those who do not can enhance care for the terminally ill. Our results are an important contribution to this process.

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