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Adherence to Measuring What Matters (MWM) Items When Caring for Patients with Hematologic Malignancies

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Abstract

Context—“Measuring What Matters” (MWM) prioritizes quality measures in palliative care practice. Hematologic malignancy patients are less likely to access palliative care, yet little is known about their unique needs. Differences in MWM adherence may highlight opportunities to improve palliative care in hematology.

Objectives—To assess adherence to MWM measures by palliative care clinicians caring for patients with hematologic malignancies, compared to those with solid tumors.

Methods—We used the Quality Data Collection Tool (QDACT) to assess completion of MWM measures across nine sites.

Results—We included data from 678 patients’ first visits and various care settings; 64 (9.4%) had a hematologic malignancy, while 614 (90.6%) had a solid tumor. Hematology patients were more likely to be seen in a hospital (52 or 81.3% vs. 420 or 68%), while solid tumor patients were

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more frequently seen at home or in clinics (160 (26%) vs. 7 (10.9%)). Of the 9 MWM measures we assessed, high adherence (>90%) was seen regardless of tumor type in measures #3 (Pain Treatment), #7 (Spiritual Concerns), #8 (Treatment Preferences) and #9 (Care Consistent with Preferences). Clinicians seeing hematology patients were significantly less likely to meet measures #2 (Screening for Physical Symptoms; 57.8% vs 84.2%, $p<0.001$), and #5 (Discussion of Emotional Needs; 56.3 vs 70.0%, $p=0.03$).

Conclusion—MWM adherence regarding symptom assessment and meeting emotional needs was lower for patients with hematologic malignancies compared to those with solid tumors. This finding suggests two key areas for quality improvement initiatives in palliative care for patients with hematologic malignancies.

Keywords

quality; quality measures; measuring what matters; collaboratives; QDACT

Introduction

Hematologic malignancies are fundamentally different than most solid organ tumors. Many hematologic malignancies are indolent, and behave more like chronic diseases. On the other hand, some are very aggressive, but curable with chemotherapy alone. Still others have a poor prognosis statistically, yet maintain a small possibility of cure even amid relapse, contrary to the generally incurable nature of most metastatic solid tumors. As such, hematologists tend to have difficulty prognosticating, and may not know that a patient's situation is terminal until late in their illness.[1] Furthermore, hematologic malignancy specialists are more likely to view palliative care as end-of-life care, or as a euphemism for hospice care,[2] and may have different views than solid tumor specialists about the appropriateness of aggressive therapies near the end of life.[3] Owing to these features, patients with hematologic malignancies are less likely to utilize any type of palliative care services than patients with solid tumors.[4–8]

Evidence suggests that patients with hematologic malignancies have unmet palliative care needs. For example, compared to patients with advanced solid tumors, hematology patients are more likely to die in the hospital, utilize intensive care at the end of life, or receive chemotherapy in the last two weeks of life.[9, 10] They are also less likely to utilize hospice care, and when they do, they are more likely to die within 24 hours or within seven days than patients with solid tumors.[11] Hematology patients probably have a symptom burden akin to that of patients with advanced solid tumors.[12] Given this disconnect between palliative care needs and actual use of services, there is growing interest in better describing the barriers to palliative care use among patients with hematologic malignancies and their physicians. To date, however, comparatively little is known about these potentially unique needs and issues compared to those of patients with advanced solid tumors. Research in this area has the potential to significantly impact practice, and policy.[13]

Measuring What Matters (MWM), an initiative of the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association,[14] provides a framework through which to assess how clinicians care for palliative care patients. Quality

measures assess what processes occur during a clinical visit, providing insight into how clinicians approach specific populations. MWM measures are now being collected among a number of member sites of the Palliative Care Research Cooperative group (PCRC), and additional community-based sites. Using these data, which are collected in the course of routine clinical care, we sought to assess completion of MWM measures by clinicians caring for hematologic malignancy patients compared to patients with solid tumors. We hypothesized that differences in adherence to MWM measures might signal differences in the palliative care needs in these two different cancer populations. In other words, if palliative care clinicians tend to focus on significantly different issues in hematology patients than they do when caring for those with solid tumors, this would suggest something different about their assessments of patients' needs. Alternatively, clinicians' different focus may also signal a tendency to overlook certain core palliative care issues in hematology patients, highlighting opportunities for practice improvement. Insights from our study will be useful in informing targets for future research, intervention development, and education of palliative clinicians about specific issues in patients with hematologic malignancies.

Methods

In this cross-sectional study, we describe clinicians' reporting of MWM quality measures at the time of initial palliative care consultation among patients with cancer. To better understand differences among patients with hematologic malignancies, we stratified this analysis by tumor type (hematologic vs. solid organ). Data were collected prospectively as part of routine clinical care at six PCRC sites and three other sites, using the Quality Data Collection Tool (QDACT).[15] The analysis dataset includes clinician-entered data from January 2nd, 2014 through September 18th, 2015. This work is approved by the Institutional Review Board (IRB) at Duke University (Pro00035703, Pro00055212), and participating sites' IRBs (as applicable).

Settings

The PCRC is a multi-site palliative care research cooperative group funded by the National Institutes of Nursing Research (NINR).[16, 17] For this analysis, we analyzed data from six PCRC sites that differ in geographic and population makeup: Capital Caring, Duke University, Four Seasons, the University of Colorado, the University of California San Francisco, and the University of North Carolina at Chapel Hill, and also three additional QDACT sites: Innovative Care solutions, Southeastern Regional Medical Center, and Catawba Hospice. These organizations have each developed a method for incorporating the QDACT tool into routine care practices across a variety of clinical care settings including inpatient, outpatient, critical care, home care, long-term care, and the emergency department.

Data Collection

Clinicians used the QDACT electronic data collection tool to capture clinical quality data at point of care. QDACT allows clinicians to report quality data in near real-time, and facilitates the structured assessment of issues in domains that are important to patients and families receiving palliative care (e.g. symptoms, spiritual well-being, physical function,

etc.).[18] QDACT's data elements map to published guidelines, such as the domains of quality palliative care proposed by the National Consensus Project,[19] and to nine of the ten MWM measures (as listed in Table 2).

QDACT includes several well-validated scales commonly-used in palliative care, such as the Edmonton Symptom Assessment System (ESAS).[20] Clinicians, research assistants, and support staff use QDACT to enter data at point of care using a Web-based interface, either during or after a clinical encounter. By assessing completion of a particular item in QDACT, we are able to assess adherence to a particular MWM item. For example, for MWM item #2, Screening for Physical Symptoms, we can consider this measure satisfied when QDACT reflects that the ESAS is completed.

Measures and Definitions of MWM Measure Adherence

We assessed clinician adherence to nine of the ten MWM items. The tenth item could not be included as it is an outcome measure that focuses on patient and family assessments of care quality (QDACT is a clinician-facing instrument). This item is addressed elsewhere in the MWM article series.[21] For this analysis, we utilized the same methodology to define MWM measure adherence as described by Kamal, et al.[22] Briefly:

For Measure #1 (Comprehensive Assessment) we utilized a consensus definition derived by QDACT users. This measure was counted as met if there was at least one documented assessment in each of the following domains: functional, physical, psychological, spiritual and social, and also an assessment of spiritual distress, family burden, performance status, overall well-being, and at least four symptoms screened.

Measure #2 (Screening for Physical Symptoms) was satisfied when there were responses for the following four symptoms: pain, dyspnea, nausea, and constipation.

Measure #3 (Pain Treatment) was satisfied when patients with moderate or severe pain (score of 4–10 of 10) had a documented treatment in place.

Measure #4 (Dyspnea Screening and Management) was satisfied when patients with moderate or severe dyspnea had a treatment in place.

Measure #5 (Discussion of Emotional or Psychological Needs) was satisfied when any anxiety or depression screen was documented.

Measure #6 (Discussion of Spiritual/Religious Concerns) was satisfied when clinicians completed the one-question screening item, "Are you at peace?"[23]

Measure #7 (Documentation of Surrogate) was satisfied when there was documentation of a healthcare proxy (or its absence).

Measure #8 (Treatment Preferences) was satisfied when there was documentation of resuscitation preferences or an advance directive.

Measure #9 (Care Consistent with Documented Care Preferences) was satisfied whenever resuscitation preferences were documented in vulnerable elders (age >65)

Statistical analysis

We compared MWM measure adherence between patients with hematologic malignancies and those with solid tumors at patients' first visit with a palliative care clinician. We applied descriptive statistics to the groups, and used two-tailed Fisher exact tests to compare proportions. Missing responses for each measure were counted as not meeting that measure. Each site had at least one patient with hematologic malignancy, and the mean proportion of patients with hematologic malignancy at each site was 8.2% (SD 3.3).

Results

We enrolled 678 patients with cancer into the QDACT quality registry during the study period. Of these, 64 (9.4%) had a hematologic malignancy, and 614 (90.6%) had a solid organ tumor. The cohort, as described in Table 1, was mostly white, with a slight female predominance. Most patients had moderate to poor performance status, with over half having a Palliative Performance Status (PPS) score of 60 or less. Patients with hematologic malignancies were more frequently seen in acute care settings compared to patients with solid tumors, with 52 (81.2%) having been seen either in the hospital or intensive care unit setting, compared to 420 (68.4%) solid tumor patients. Hematologic malignancy patients were less often seen in clinic or at home (n=7; 10.9%), compared to solid tumor patients (n=160; 26%).

Measures #3, #7, #8 and #9 had adherence rates of over 90% for both tumor types (Table 2); however, we also noted significant differences in adherence to some MWM measures across tumor types. For example, clinicians seeing hematologic malignancy patients were less likely to meet MWM Measure #2 (Screening for Physical Symptoms; 57.8% vs 87.2%, $p=0.0001$). Similarly, adherence was lower with Measure #5 (Discussion of Emotional or Psychological Needs; 56.3% vs. 70%, $p=0.03$). Adherence to Measure #1 (Comprehensive Assessment) was also lower for hematology patients (10.9 vs 21.2%, $p=0.07$), as was adherence to Measure #6 (Spiritual Assessment; 26.6 vs. 36.2, $p=0.13$). These differences approached but did not reach statistical significance. Similarly, adherence to Measure #4 (Dyspnea Screening and Management) was 66.7% vs. 72.5% ($p=0.71$). There were very few observations for Measure #4 in the hematology group, limiting our ability to detect a meaningful difference. While not all differences were statistically significant, these differences were consistently in the same direction, pointing towards a lower likelihood of meeting MWM measures when seeing hematologic malignancy patients compared to solid tumor patients.

We also stratified this analysis across settings of care (acute vs. non-acute), because hematologic malignancy patients are known to have a higher likelihood of dying in the hospital, and a lower likelihood of utilizing hospice care compared to patients with solid tumors. Here we noted lower measure adherence in acute care settings for most measures. Again, adherence was particularly high in both tumor types for Measures #3(Pain Treatment), #7 (Documentation of Surrogate), #8 (Treatment Preferences) and #9 (Care Consistent with Documented Care Preferences) regardless of care setting. Neither group did particularly well with regard to Measure #1 (Comprehensive Assessment).

Discussion

In this analysis, several important findings emerged. First, we found high adherence to measures of pain treatment, documentation of a surrogate, treatment preferences, and receiving care consistent with documented preferences. This was true regardless of tumor type or care setting. On the other hand, we noted significantly lower adherence to measures dealing with other non-pain physical symptoms, and with emotional or psychological needs, among patients with hematologic malignancies compared to those with solid tumors. In short, we observed that palliative care clinicians approach the care of patients differently based on cancer type. To our knowledge, this is the first description of such variation across cancer types.

This finding is concerning. With regards to physical symptoms, data suggest that patients with hematologic malignancies have a similar if not worse symptom burden than patients with solid tumors.[12, 24–26] Thus, one might argue that perhaps *more* attention is needed to the assessment and management of symptoms in this population, yet we saw less in our cohort. This finding may be a reflection of other differences among patients with hematologic malignancies, such as setting of care. In our study, patients with hematologic malignancies were more often seen in intensive care unit or inpatient settings compared to solid tumor patients, and it may be that there are differences in what palliative care clinicians tend to focus on in those different care settings. Our finding may therefore reflect later referral to palliative care, and/or consultation amid more serious illness, which may change clinical priorities as to which items to address. Further, these findings could reflect what palliative care clinicians are asked to focus on by referring teams, such as family meetings or establishing goals of care. Regardless, we contend that careful attention to the assessment and management of symptoms should be core to the care of any patient with cancer. More attention to symptom assessment is needed among patients with hematologic malignancies.

The difference in assessing emotional or psychological needs is equally concerning. Data suggest that patients with hematologic malignancies face significant challenges regarding emotional well-being, which in some cases may be more significant than that faced by patients with many solid tumor types.[27–29] Here too, differences in setting of care may explain this finding, yet if anything it remains the case that hematology patients probably need more attention to emotional well-being issues than they are currently receiving. Challenges related to the assessment and management of symptoms and emotional needs should be the focus of ongoing research and intervention development in hematologic malignancies.

Taken together, these differences in MWM measure adherence by tumor type raise questions about the feasibility of applying cross-cutting quality measures in different settings of care, and across diseases that may have fundamentally different expected patient experiences and care needs. Should certain measures be more frequently applied in critical care settings? Should others be applied more or less often across different disease types? Do the needs of patients with hematologic malignancies warrant a specific set of quality measures to precisely measure and address unmet needs? Further study is needed in these areas.

There are a few limitations to this work. First, these data are collected through stand-alone software separate from the electronic health record. Adherence analysis reflects data recorded, which may underestimate actual care delivered. Second, much of these data comes from academic practice settings, which may impart some bias; however, since many types of hematologic malignancies are treated preferentially at academic centers, these data probably approximate typical practice settings. Third, our data cannot tell us *why* a particular measure was not met. There are probably many good reasons for not meeting certain measures in particular clinical contexts. It is unlikely that 100% adherence to all measures is an achievable or desirable target. Further study is needed to better understand appropriate targets for quality measures and to better capture clinicians' reasons for focusing on certain areas over others.

Conclusions

When caring for patients with cancer of any type, palliative care clinicians' adherence to MWM measures was high for items about pain treatment, documentation of a surrogate, treatment preferences, and receiving care consistent with documented preferences. However, MWM adherence regarding symptom assessment and meeting emotional needs was lower when caring for patients with hematologic malignancies compared to those with solid tumors. This finding suggests two key areas for quality improvement initiatives in palliative care in hematology.

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Table 1

Characteristics of Patients and Consultation Visits

	Hematologic Malignancy	Solid Tumor
Total Number of First Visits	64 (of 678; 9.4%)	614 (of 678; 90.6%)
Gender	N (%)	
Female	32 (50%)	355 (57.8%)
Male	32 (50%)	255 (41.5%)
Missing	0 (0%)	4 (0.7%)
Race		
White	38 (59.3%)	377 (61.4%)
Black of African American	12 (18.8%)	95 (15.5%)
Asian	1 (1.6%)	10 (1.6%)
American Indian, Alaska Native, Native Hawaiian or other Pacific Islander	0 (0%)	14 (2.3%)
Other	1 (1.6%)	13 (2.1%)
Not reported	1 (1.6%)	10 (1.6%)
Unknown	1 (1.6%)	12 (2.0%)
Missing	10 (15.6%)	83 (13.5%)
Cancer Type	Lymphoma- 27 (42.2%) Leukemia (including MDS)- 26 (40.6%) Multiple myeloma (including amyloidosis)- 11 (17.2%)	Lung (non-small cell)- 98 (16.0%) Breast- 82 (13.4%) Colon, rectal, anal- 61 (9.9%) Other upper GI (liver, gastric, esophageal, carcinoid, etc)- 52 (8.5%) Ovarian/peritoneal- 52 (8.5%) Pancreas- 49 (8.0%) Uterine, cervical, vaginal- 49 (8.0%) Head and neck- 47 (7.7%) Prostate- 32 (5.2%) Lung (small cell)- 20 (3.3%) Melanoma- 19 (3.1%) Renal- 19 (3.1%) Brain- 18 (2.9%) Bladder (including urethral)- 13 (2.1%) Thyroid- 3 (0.5%)
Palliative Performance Scale		
0–30	11 (17.2%)	99 (16.1%)
40–60	36 (56.3%)	326 (53.1%)
70 or higher	4 (6.3%)	126 (20.5%)
Unknown	3 (4.7%)	19 (3.1%)

	Hematologic Malignancy	Solid Tumor
Missing	10 (15.6%)	44 (7.2%)
Location of Consultation		
Hospital – General Floor	45 (70.3%)	393 (64.0%)
Long Term Care	5 (7.8%)	33 (5.4%)
Hospital ICU	7 (10.9%)	27 (4.4%)
Home	2 (3.1%)	61 (9.9%)
Outpatient	5 (7.8%)	99 (16.1%)
Emergency Department	0 (0%)	1 (0.2%)

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Table 2

Measure Feasibility by Tumor Type and Location

	Tumor Type	TOTAL	P value for heme vs. solid overall	Acute Care	Non-Acute Care	P value for acute vs. Non-acute
MWM#1: Palliative care and hospice patients receive a comprehensive assessment (physical, psychological, social, spiritual and functional) soon after admission	Heme N (%)	7/64 (10.9%)	0.07	3/52 (5.8%)	4/12 (33.3%)	0.02
	Solid N (%)	130/614 (21.2%)		43/421 (10.2%)	87/193 (45.1%)	0.0001
MWM#2: Seriously ill palliative care and hospice patients are screened for pain, shortness of breath, nausea and constipation during the admission visit	Heme	37/64 (57.8%)	0.0001	27/52 (52.0%)	10/12 (83.3%)	0.06
	Solid	517/614 (84.2%)		363/421 (86.2%)	154/193 (79.8%)	0.06
MWM#3: Seriously ill palliative care and hospice patients who screen positive for at least moderate pain receive treatment (medication or other) within 24 hours	Heme	31/31 (100%)	1.0	23/23 (100%)	8/8 (100%)	1.0
	Solid	258/265 (97.4%)		170/173 (98.3%)	88/92 (95.7%)	0.24
MWM#4: Patients with advanced or life-threatening illness are screened for shortness of breath and, if positive to at least a moderate degree, have a plan to manage it	Heme	6/9 (66.7%)	0.71	5/7 (71.4%)	1/2 (50%)	1.0
	Solid	66/91 (72.5%)		39/51 (76.5%)	27/40 (67.5%)	0.36
MWM#5: Seriously ill palliative care and hospice patients have a documented discussion regarding emotional needs	Heme	36/64 (56.3%)	0.033	26/52 (50%)	10/12 (83.3%)	0.05
	Solid	430/614 (70.0%)		262/421 (62.2%)	168/193 (87.0%)	0.0001
MWM#6: Hospice patients have a documented discussion of spiritual concerns or preference not to discuss them	Heme	17/64 (26.6%)	0.13	7/52 (13.5%)	10/12 (83.3%)	0.0001
	Solid	222/614 (36.2%)		93/421 (22.1%)	129/193 (66.8%)	0.0001
MWM#7: Seriously ill palliative care and hospice patients have documentation of the surrogate decision-maker's name (such as the person who has healthcare power of attorney) and contact information, or absence of a surrogate	Heme	58/64 (90.6%)	1.0	48/52 (92.3%)	10/12 (83.3%)	0.32
	Solid	553/614 (90.1%)		386/421 (91.7%)	167/193 (86.5%)	0.06
MWM#8: Seriously ill palliative care and hospice patients have documentation of their preferences for life-sustaining treatments	Heme	61/64 (100%)	1.0	50/52 (96.2%)	11/12 (91.7%)	0.47
	Solid	582/614 (94.8%)		406/421 (96.4%)	176/193 (91.2%)	0.01
MWM#9: Vulnerable elders with documented preferences to withhold or withdraw life-sustaining treatments have their preferences followed	Heme	29/29 (100%)	0.25	23/23 (100%)	6/6 (100%)	1.0
	Solid	279/303 (92.1%)		182/191 (95.3%)	97/112 (86.6%)	0.02

Bold denotes statistical significance at a threshold of p<0.05