



Published in final edited form as:

Clin J Oncol Nurs. 2020 October 01; 24(5): 538–546. doi:10.1188/20.CJON.538-546.

Characterizing pain experiences: African American patients with multiple myeloma taking around-the-clock opioids

Sarah M. Belcher, PhD, RN, OCN^{1,*}, Deborah Watkins Bruner, PhD, RN, FAAN^{1,3}, Craig C. Hofmeister, MD, MPH^{2,3}, Jaime Kweon, MSN, FNP^{1,**}, Salimah H. Meghani, PhD, MBE, RN, FAAN⁴, Katherine A. Yeager, PhD, RN, FAAN^{1,3}

¹Nell Hodgson Woodruff School of Nursing, Emory University, Atlanta, Georgia;

²School of Medicine, Emory University, Atlanta, Georgia;

³Winship Cancer Institute, Emory University, Atlanta, Georgia;

⁴School of Nursing, University of Pennsylvania, Philadelphia, Pennsylvania.

Abstract

Background: Patients with multiple myeloma experience severe pain that can necessitate treatment with opioids. Despite known disparities in multiple myeloma prevalence and outcomes, cancer pain assessment, and pain treatment by race, studies to date have paid limited attention to pain characterization among African American patients with multiple myeloma, particularly among patients taking around-the-clock opioids.

Objective: To characterize the pain experience, beliefs about pain and pain control, and additional symptoms among African American patients with multiple myeloma taking around-the-clock opioids.

Methods: Secondary analysis of baseline data from a completed longitudinal study of opioid adherence in African American patients with cancer. Descriptive statistics were used to characterize the sample, pain experience (Brief Pain Inventory), beliefs regarding pain and pain control (Barriers Questionnaire), and related symptoms (Edmonton Symptom Assessment Scale and Patient Health Questionnaire).

Findings: Participants (n=34) experienced every day pain and additional symptoms, 50% of whom experienced depression. Pain management barriers included dislike of pills, fear of addiction, and bothersome side effects from pain and medication. Future larger studies should incorporate multi-level factors that may contribute to high burden of pervasive pain and depression among this population.

Correspondence concerning this article should be addressed to Dr. Sarah Belcher, School of Nursing, University of Pittsburgh, 415 Victoria Building, 3500 Victoria Street, Pittsburgh, PA 15261. Contact: sarah.belcher@pitt.edu.

Author Contributions

DWB, SM, and KAY contributed to the conceptualization of the parent study, and JK and KAY collected the data. SMB, JK, and KAY contributed to the conceptualization and design of this secondary analysis and analyzed the data. DWB, CCH, and SM provided expertise on interpretation of findings. SMB, JK, and KAY wrote the manuscript with input from all authors. All authors read and approved the final document.

*Dr. Belcher is now at the University of Pittsburgh School of Nursing, Pittsburgh, PA.

**Ms. Kweon is now at Community Health Services, Inc., Hartford, Connecticut.

Keywords

multiple myeloma; cancer; pain; opioids; African American; supportive care

In 2020, over 32,000 people will be diagnosed with multiple myeloma (Siegel, Miller, & Jemal, 2020). While considered relatively rare, multiple myeloma, a cancer resulting from abnormal proliferation of blood plasma cells, is the most common hematologic malignancy among African Americans (National Cancer Institute, 2019c). Further, African Americans versus Whites are two to three times more likely to be diagnosed with and to die from multiple myeloma and are at risk of experiencing disparate care (Ailawadhi et al., 2019; Baughn et al., 2018; Ganguly, Mailankody, & Ailawadhi, 2019; National Cancer Institute, 2019a, 2019c). Patients with multiple myeloma experience notable physical symptoms related to their disease and treatment. Patients may suffer pathologic long bone and vertebral compression fractures leading to severe bone pain that can necessitate treatment with opioids; treatment-related peripheral neuropathy; pancytopenia (e.g., infection, anemia); hypercalcemia; and renal failure (Colson, 2015; Kiely, Cran, Finnerty, & O'Brien, 2017; Martin, 2013).

Due, in part, to recent advances in supportive care and novel combination therapies, post-diagnosis survival for patients with multiple myeloma has doubled from 3–4 years to 7–8 years since the 1990's (Kumar et al., 2008; National Cancer Institute, 2019c). However, patients with multiple myeloma undergo repeated cycles of treatment followed by an inevitable relapse until the patient's myeloma is resistant to available treatment. Similar to other cancers for which survival has improved, patients with multiple myeloma are now living longer (Kiely et al., 2017) but often live life with chronic pain, potentially necessitating the use of around-the-clock opioids.

Acute and/or chronic pain is a hallmark symptom for patients with multiple myeloma that can impede mobility and affect quality of life (Ramsenthaler et al., 2016). Pain among patients with multiple myeloma is primarily due to 1) osteolytic bone lesions due to plasma cell infiltration of bone and 2) treatment-related neuropathic pain. Eighty to ninety percent of patients with multiple myeloma experience pain related to bone involvement, and 60% of patients develop pathologic fractures (Sandra Rome et al., 2017). While few patients present at diagnosis with disease-related peripheral neuropathy, up to a quarter of patients treated with proteasome inhibitors or the immunomodulatory drug (IMiD) thalidomide will suffer grade 3 or 4 peripheral stocking-glove neuropathy (Moreau et al., 2011; Nielsen et al., 2019). Treatment-related peripheral neuropathy can be debilitating and dose limiting. Evidence to support the use of opioids to treat neuropathic pain is controversial and is generally not considered first line treatment (McNicol, Midbari, & Eisenberg, 2013). Bisphosphonates, radiotherapy, and kyphoplasty may be used to reduce pain, while psychotropic medications such as duloxetine, gabapentin, and pregabalin are often used as opioid-sparing medications to reduce burning neuropathic pain; duloxetine is the only one to show benefit in a randomized trial (Smith et al., 2013). In addition to radiation therapy and the aforementioned supportive care medications, patients may be prescribed around-the-clock opioids, such as extended-release morphine, to help manage

their pain (DynaMed Plus, 2018; National Comprehensive Cancer Network, 2019; Sloat et al., 2015). For continuous pain, the National Comprehensive Cancer Network (NCCN) endorses maintenance opioid therapy as standard of care, including regularly scheduled and supplemental pain medication doses for breakthrough pain (National Comprehensive Cancer Network, 2019).

The burden of cancer pain is not borne equally across racial groups. When compared to other racial groups, African American patients with cancer experience higher levels of pain severity and pain interference (Green, Hart-Johnson, & Loeffler, 2011; Meghani, Thompson, Chittams, Bruner, & Riegel, 2015) and disparities in the assessment of and treatment of pain (Meghani et al., 2015; National Academies of Sciences Engineering and Medicine, 2019). Patient-provider interactions can negatively impact the pain experience for cancer patients who are African American (Check et al., 2018). In a nationwide study of 4,704 cancer survivors experiencing pain, African American patients were more likely than white patients to experience individual, provider, and system level barriers to pain management (Stein, Alcaraz, Kamson, Fallon, & Smith, 2016). To date, the experience of cancer pain is poorly understood from the perspective of patients who are African American, especially as it relates to treatment with opioids, and has seldom been described in studies of patients with multiple myeloma. This knowledge gap prevents us from understanding the potentially unique pain experience that may exist for African American patients with multiple myeloma. Given the increased risk of multiple myeloma among African Americans, the pervasiveness of pain among patients with multiple myeloma, and the known pain disparities that exist by race, a focus on understanding the pain experience of patients who are African American is important especially in multiple myeloma, where the burden of disease and resulting pain is profound. Therefore, the purpose of this exploratory study, drawing from a holistic pain framework (Ahles, Blanchard, & Ruckdeschel, 1983; Ferrell, Grant, Padilla, Vemuri, & Rhiner, 1991), was to characterize the pain experience, beliefs about pain and pain control, and associated symptoms among African American patients with multiple myeloma taking around-the-clock opioids.

Methods

Design and Parent Study Description

This exploratory secondary analysis analyzed baseline data from a prospective, observational study of factors related to around-the-clock opioid adherence for pain treatment in 105 African American patients with cancer (Yeager et al., 2019). Participants were recruited from medical oncology, radiation oncology, and palliative care clinics within an urban safety-net hospital and a tertiary care cancer center in the Southeast United States. Parent study eligibility criteria included having a cancer diagnosis; having an around-the-clock opioid prescription; self-identifying as Black or African American; age 21 years; mental competency; and residing in the U.S. for 10 years, in their current home residence, for 6 months. Individuals who had surgery in the prior month or used a pill box due to parent study aims evaluating medication adherence were excluded. For this secondary analysis, additional inclusion criteria included having a diagnosis of

multiple myeloma. Additional details regarding recruitment and study procedures have been previously published (Yeager et al., 2019).

Sample

Thirty-four patients met study inclusion criteria of having a multiple myeloma diagnosis and were included in the analyses.

Variables and Measures

Data were collected on the following variables of interest: cancer pain, beliefs regarding pain and pain control, severity of additional symptoms, and depression.

The 13-item Brief Pain Inventory (BPI) short form was used to assess cancer pain (Atkinson et al., 2011; Cleeland & Ryan, 1994). This instrument has been widely used among African American patients with cancer and includes items assessing pain frequency, location, pain treatment, amount of pain relieved by analgesic treatment, and pain interference within the past 24 hours. Pain interference represents the mean of seven interference items, including general activity, mood, walking ability, normal work (including housework), relations with other people, sleep, and enjoyment of life. Reliability (Cronbach's alpha = 0.77 – 0.91) is based on the two-factor structure of four pain severity and seven pain interference items.

The Barriers Questionnaire (BQ-13) (Boyd-Seale et al., 2010; Wilkie et al., 2017) measures beliefs regarding pain and pain medication (Cronbach's alpha = 0.73–0.86). Participants rate their level of agreement with 13 statements. The total mean score ranges from 0 (do not agree) to 5 (agree very much), with higher scores indicating that the respondent has more beliefs that act as barriers to pain relief.

The Edmonton Symptom Assessment Scale (ESAS) (Bruera, Kuehn, Miller, Selmsler, & Macmillan, 1991) is a 9-item symptom scale developed to assess common symptoms experienced by patients with cancer (Cronbach's alpha = 0.79). Patients rate the severity of their symptoms, including pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath, using a 0–10 numerical scale, where 0 = symptom absent and 10 = worst possible severity. An additional item, constipation, was added to the parent study, because it is a frequent side effect of opioid drugs (Oosten, Oldenmenger, Mathijssen, & van der Rijt, 2015). For individual symptom items, 4 is generally indicative of moderate symptom severity.

Patient Health Questionnaire-8 (PHQ-8), which does not include the item assessing self-harm, includes items based on the DSM-IV diagnostic criteria for depression (Kroenke et al., 2009). The PHQ-8 asks the number of days in the past 2 weeks the patient has experienced a depressive symptom with items ranging from 0 (not at all) to 5 (nearly every day), yielding a 0–24 total sum score. PHQ-8 scores ≥ 10 are considered major depression, while scores ≥ 20 are considered severe major depression. Internal consistency has been well-established in patients with chronic conditions (Cronbach's alpha = 0.86) (Ory et al., 2013).

Sociodemographic and clinical data were collecting using a self-report sociodemographic questionnaire (i.e., age, sex, ancestry, marital status, educational level, employment, religious affiliation, insurance status, and number of chronic illnesses besides cancer) and medical record review (i.e., years since cancer diagnosis and other chronic illnesses).

Ethical Considerations

The parent study received institutional review board approval prior to participant recruitment, with initial approval received on October 21, 2013.

Analyses

Data were collected on paper then entered and managed using REDCap electronic data capture tools hosted at Emory University (Harris et al., 2019; Harris et al., 2009). IBM® SPSS® software, version 25 (IBM Corp., Armonk, NY), was used to perform descriptive analyses to characterize the sample. Descriptive statistics (means, standard deviations, and ranges or medians and interquartile ranges for continuous variables; frequency counts and percentages for categorical variables) were computed for study variables.

Findings

Sociodemographic and clinical characteristics are summarized in Table 1. The mean age of the study participants was 57.7 (SD = 9.1) years. Most were female (n = 24, 70.6%) and self-identified as having African American ancestry (n = 31, 91.2%). About half (n = 18, 52.9%) were married, while 9 (26.5%) were divorced or separated. Most participants had completed high school or bachelor's level education (n = 22, 64.7%) and did not work outside the home (n = 29, 85.3%). Most participants reported Christian-based religious affiliations (n = 30, 88.2%) and had public insurance (n = 20, 58.8%). While a range of years had passed since participants' multiple myeloma diagnoses (0–15), the average time since diagnosis was 5.3 (SD = 3.8) years. Twenty-four participants (70.6%) reported additional chronic illnesses besides cancer, of which 20 (58.8%) had high blood pressure.

Table 2 includes participants' pain characteristics. All participants (n = 34) reported everyday pain. The most commonly endorsed locations of every day pain were the lower back (left and right sides), feet, and hands; the back was the site of the most severe pain. The mean pain severity score was 4.6 (SD = 2.3), while the worst pain score was 6.3 (SD = 3.0). The mean pain interference score was 5.1 (SD = 3.2). Top rated activities of daily living with which pain interfered included sleep (M = 5.7, SD = 4.1), work (M = 5.6, SD = 3.5), walking (M = 5.4, SD = 3.8), and general activity (M = 5.2, SD = 3.4). On average, participants said that 69.1% (SD = 28.3%; range = 0%–100%) of their pain was relieved with analgesic treatment. Consistent with parent study inclusion criteria, all participants were on an around-the-clock opioid; most (n = 21, 61.8%) were on extended-release morphine, while the rest (n = 13, 38.2%) were on extended-release oxycodone.

Table 3 includes participants' beliefs about pain and pain management. Highest single-item mean barrier scores support that patients disliked taking pills (M = 4.0, SD = 1.6), were worried about addiction (M = 3.5, SD = 1.7), were upset by constipation (M = 3.2, SD

= 2.1), and were bothered by drowsiness ($M = 3.0$, $SD = 2.0$). Further, over 60% of the sample were concerned about decreased effectiveness of pain medication over time and were distressed by medication-related nausea.

Additional symptom severity scores are reported in Table 4, with tiredness, pain, decreased appetite, lack of wellbeing, and drowsiness reported as the most severe. Of these symptoms, tiredness, pain, and decreased appetite all exceeded the threshold of 4 for moderate symptom severity. The mean PHQ-8 depression score was 9.6 ($SD = 5.5$), just below the clinical cutoff of 10 for depression. However, PHQ scores ranged from 1–22 with half ($n = 17$) of participants meeting or exceeding the clinical cutoff score for depression and one meeting criteria for severe major depression.

Discussion

This exploratory study is one of the first to characterize the pain experience among African American patients with multiple myeloma taking around-the-clock opioids, drawing attention to a vulnerable population often underrepresented in research studies who is at risk for disparate health outcomes, including disparate pain management (National Academies of Sciences Engineering and Medicine, 2019). Validated measures of pain, pain barriers, and symptoms further strengthen our findings. We identified the pervasive nature of moderate-level every day pain, despite around-the-clock opioid regimens, and interference with patients' lives. Further, using the Barriers Questionnaire, we explored attitudes and beliefs about pain and pain treatment, which are known to influence individuals' pain experience and medication taking behaviors (Gunnarsdottir, Donovan, Serlin, Voge, & Ward, 2002; Gunnarsdottir et al., 2017; Yeager et al., 2019).

Moderate level, every day pain was a universal experience among study participants, particularly in participants' back, feet, and hands. This likely represents the bone breakdown and peripheral neuropathy that has been well documented in this patient population and resulting impact on daily activities, such as sleep, work, walking, and general activity (Rome, Noonan, Bertolotti, Tariman, & Miceli, 2017). This is in line with the decreased quality of life described among patients with multiple myeloma in other studies (Nielsen, Jarden, Andersen, Frederiksen, & Abildgaard, 2017). Most participants reported pain-related barriers to effective pain management, including participants' dislike of taking pills, fear of addiction, bothersome side effects, and worry about decreased effectiveness over time. These mean barrier item scores were higher than those reported in other studies, including samples of patients with solid tumors consisting of 34% and <5% of participants who were African American (Boyd-Seale et al., 2010; Wilkie et al., 2017), potentially indicating higher influence of barriers to effective pain management in our sample of African American patients with multiple myeloma.

This sample of African American patients with pain experienced additional clinically relevant symptoms. Consistent with published multiple myeloma literature (Ramsenthaler et al., 2016), the most severe additional symptoms that were identified in this sample using Edmonton scores were fatigue/tiredness, decreased appetite, and lack of well-being. However, the prevalence of participants whose PHQ-8 scores met the cutoff for major

depression, 50%, exceeded findings from a systematic review of 35 studies of patients with multiple myeloma (23.6%). Uncontrolled symptoms, including pain duration and pain severity, are risk factors for depression (National Cancer Institute, 2019b), which may contribute to the depression scores observed in this study and broader population. A recent systematic review of studies of patients with multiple myeloma found that pain and fatigue were associated with global distress and depression; authors suggested that psychological distress interventions may be considered as adjuvant strategies to mitigate pain and fatigue in this patient population (Rogers & Rennoldson, 2020). Further, another study of patients with lung cancer (n = 1043) found that race and sex interacted to predict depressive symptom risk and that African American patients were less likely to receive desired help for mood from their doctors than white patients (Traeger et al., 2014).

An historically important point is that data for this study were collected between 2013 and 2015, which was before the height of the U.S. opioid epidemic. It is important to place these data in historical context to the U.S. opioid epidemic. During 2016, drug overdoses accounted for 52,404 U.S. deaths, with 63% involving an opioid (Rudd, Seth, David, & Scholl, 2016). Recent increases in death rates are driven by fentanyl and heroin, and, regrettably, the nonmedical use of prescription opioids is a significant risk factor for heroin use (Compton & Chang, 2017). While the use of opioids is under intense and well-deserved scrutiny, pain remains a significant problem for individuals with cancer (van den Beuken-van Everdingen, Hochstenbach, Joosten, Tjan-Heijnen, & Janssen, 2016). To address this epidemic, guidelines on the use of opioids have been published (Bruera & Paice, 2015; Dowell, Haegerich, & Chou, 2016; Paice et al., 2016). The concerns of clinicians and the American public about the opioid epidemic, especially concerns about addiction, may influence multiple myeloma patients' attitudes and pain medication taking behavior, requiring a thorough assessment and detailed care plan for these patients living with ongoing pain.

Limitations to this exploratory study include small sample size and inquiry that is within the scope of data collected for the parent study. Generalizability of findings is limited to patients who are prescribed long acting opioids. Further, findings may not generalize to patients outside of the southern region from which these patients were recruited. However, this study achieved our goal of characterizing the pain experience of a historically underrepresented and underserved group of African American patients with multiple myeloma. Future studies should further delve into factors such as biases, institutional racism, and stigma related to depression and pain that have been implicated as root causes for negative patient outcomes (National Comprehensive Cancer Network, 2020; Paradies et al., 2015).

Implications for Practice

The ongoing, every day pain experience of African American patients with multiple myeloma is important for both clinical practice and research. The American Society of Clinical Oncology provides guidance on the management of chronic pain in cancer survivors and recognizes that opioid therapy may be needed for patients who do not respond to conservative management (e.g., nonopioid and adjuvant analgesics) (Paice et al., 2016). If pain is severe and persistent, cancer patients are prescribed a long-acting opioid formulation

with an around-the-clock dosing schedule. This strategy can reduce pill burden, simplify the administration schedule, and provide consistent pain relief (Bruera & Paice, 2015). The key to effectiveness of around-the-clock dosing is adherence to the fixed schedule. Additionally, nurses and other care providers need to assess and address patient concerns about addiction and symptoms that may interfere with adherence to the pain management plans. When long-acting opioids are a component of cancer pain management, communication, education, and counseling is essential to ensure that patients are willing and able to follow the treatment plan. Training aimed at nurses initiating culturally sensitive, patient-centered pain barrier discussions with patients would be a worthwhile endeavor for both research studies and quality improvement projects.

Symptom management guidelines for patients with multiple myeloma also include enlisting palliative care specialists as important interdisciplinary care team members early in the disease trajectory (Merlin et al., 2019). Palliative care team members' expertise can complement and enhance nurses efforts to achieve optimal symptom management for patients with multiple myeloma. Further, the high level of depressive symptoms identified in this sample of African American patients with multiple myeloma experiencing pain reinforces the critical need to screen for and adequately treat depression. Our findings support the importance of application of the NCCN's Distress Management Guidelines, which includes screening for distress at every medical visit as part of ideal, patient-centered care across the disease trajectory (National Comprehensive Cancer Network, 2020). In addition to the NCCN Distress Thermometer and Problem List, the PHQ-2 is another brief depression screening tool that nurses can use in the clinical setting (National Comprehensive Cancer Network, 2020; Wagner et al., 2017).

Conclusion

This exploratory study expands upon previous findings by highlighting a historically underrepresented group of patients at risk of poor health outcomes and poor pain management. Pain and additional symptoms were pervasive across the disease trajectory, with clinically significant depression prevalence that was higher than what has been documented in previous literature. Nurses, multi-disciplinary clinicians, and researchers can build upon identified barriers to effective pain management when seeking to improve supportive care and symptom management among African American patients with multiple myeloma. Future research should investigate these findings in larger samples and intervene upon symptom management, mental health, and potential multi-level barriers to care access in this population.

Implications for Practice:

1. Recognize that African American patients with multiple myeloma are at risk of experiencing health disparities that may affect pain and related symptoms.
2. Utilize screening tools such as the NCCN Distress Thermometer and the PHQ-2 to routinely screen for pain and depression across the disease trajectory as part of optimal symptom management among African American patients with multiple myeloma.

3. Implement culturally sensitive, patient-centered symptom management guidelines that include identification and mitigation of potential barriers to distress management, and consider palliative care consultation early in the disease trajectory.

Acknowledgements

The authors wish to acknowledge the individuals who participated in this study. The source data research was funded, in part, by a grant from the National Institute of Nursing Research (K01NR014673, Yeager). Over the last 24 months, Dr. Hofmeister has received research grants from Takeda & Oncolytics Biotech; research and personal grants from Janssen, BMS, Sanofi, Nektar, and Karyopharm; and personal grants from Imbrium Pharmaceuticals and Oncopeptides, all outside the submitted work; other authors have no conflicts of interest to disclose.

References

- Ahles TA, Blanchard EB, & Ruckdeschel JC (1983). The multidimensional nature of cancer-related pain. *Pain*, 17(3), 277–288. doi:10.1016/0304-3959(83)90100-8 [PubMed: 6657288]
- Ailawadhi S, Parikh K, Abouzaid S, Zhou Z, Tang W, Clancy Z, ... Xie J (2019). Racial disparities in treatment patterns and outcomes among patients with multiple myeloma: A SEER-Medicare analysis. *Blood Advances*, 3(20), 2986–2994. doi:10.1182/bloodadvances.2019000308 [PubMed: 31648322]
- Atkinson TM, Rosenfeld BD, Sit L, Mendoza TR, Fruscione M, Lavene D, ... Basch E (2011). Using confirmatory factor analysis to evaluate construct validity of the Brief Pain Inventory (BPI). *J Pain Symptom Manage*, 41(3), 558–565. doi:10.1016/j.jpainsymman.2010.05.008 [PubMed: 21131166]
- Baughn LB, Pearce K, Larson D, Polley M-Y, Elhaik E, Baird M, ... Rajkumar SV (2018). Differences in genomic abnormalities among African individuals with monoclonal gammopathies using calculated ancestry. *Blood Cancer Journal*, 8(10), 96. doi:10.1038/s41408-018-0132-1 [PubMed: 30305608]
- Boyd-Seale D, Wilkie DJ, Kim YO, Suarez ML, Lee H, Molokie R, ... Zong S (2010). Pain barriers: Psychometrics of a 13-item questionnaire. *Nurs Res*, 59(2), 93–101. doi:10.1097/NNR.0b013e3181d1a6de [PubMed: 20216011]
- Bruera E, Kuehn N, Miller MJ, Selmsler P, & Macmillan K (1991). The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. *J Palliat Care*, 7(2), 6–9. [PubMed: 1714502]
- Bruera E, & Paice JA (2015). Cancer pain management: Safe and effective use of opioids. *Am Soc Clin Oncol Educ Book*, e593–599. doi:10.14694/EdBook_AM.2015.35.e593 [PubMed: 25993228]
- Check DK, Chawla N, Kwan ML, Pinheiro L, Roh JM, Ergas IJ, ... Kushi LH (2018). Understanding racial/ethnic differences in breast cancer-related physical well-being: The role of patient-provider interactions. *Breast Cancer Res Treat*, 170(3), 593–603. doi:10.1007/s10549-018-4776-0 [PubMed: 29623576]
- Cleland CS, & Ryan KM (1994). Pain assessment: Global use of the Brief Pain Inventory. *Ann Acad Med Singapore*, 23(2), 129–138. [PubMed: 8080219]
- Colson K (2015). Treatment-related symptom management in patients with multiple myeloma: A review. *Support Care Cancer*, 23(5), 1431–1445. doi:10.1007/s00520-014-2552-1 [PubMed: 25646616]
- Compton P, & Chang YP (2017). Substance abuse and addiction: Implications for pain management in patients with cancer. *Clin J Oncol Nurs*, 21(2), 203–209. doi:10.1188/17.Cjon.203-209 [PubMed: 28315549]
- Dowell D, Haegerich TM, & Chou R (2016). CDC Guideline for Prescribing Opioids for Chronic Pain - United States, 2016. *MMWR Recomm Rep*, 65(1), 1–49. doi:10.15585/mmwr.rr6501e1
- Plus Dynamed. (2018, December 4). Multiple myeloma. Retrieved from <https://www-dynamed-com.proxy.library.emory.edu/topics/dmp~AN~T116888>

- Ferrell B, Grant M, Padilla G, Vemuri S, & Rhiner M (1991). The experience of pain and perceptions of quality of life: Validation of a conceptual model. *Hosp J*, 7(3), 9–24. doi:10.1080/0742-969x.1991.11882702 [PubMed: 1820306]
- Ganguly S, Mailankody S, & Ailawadhi S (2019). Many shades of disparities in myeloma care. *American Society of Clinical Oncology Educational Book*(39), 519–529. doi:10.1200/edbk_238551 [PubMed: 31099639]
- Green CR, Hart-Johnson T, & Loeffler DR (2011). Cancer-related chronic pain: Examining quality of life in diverse cancer survivors. *Cancer*, 117(9), 1994–2003. doi:10.1002/cncr.25761 [PubMed: 21509777]
- Gunnarsdottir S, Donovan HS, Serlin RC, Voge C, & Ward S (2002). Patient-related barriers to pain management: The Barriers Questionnaire II (BQ-II). *Pain*, 99(3), 385–396. doi:10.1016/s0304-3959(02)00243-9 [PubMed: 12406513]
- Gunnarsdottir S, Sigurdardottir V, Kloke M, Radbruch L, Sabatowski R, Kaasa S, & Klepstad P (2017). A multicenter study of attitudinal barriers to cancer pain management. *Support Care Cancer*, 25(11), 3595–3602. doi:10.1007/s00520-017-3791-8 [PubMed: 28653107]
- Harris PA, Taylor R, Minor BL, Elliott V, Fernandez M, O’Neal L, ... Duda SN. (2019). The REDCap consortium: Building an international community of software platform partners. *Journal of Biomedical Informatics*. doi:10.1016/j.jbi.2019.103208
- Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, & Conde JG (2009). Research electronic data capture (REDCap) - A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, 42(2), 377–381. doi:10.1016/j.jbi.2008.08.010 [PubMed: 18929686]
- Kiely F, Cran A, Finnerty D, & O’Brien T (2017). Self-reported quality of life and symptom burden in ambulatory patients with multiple myeloma on disease-modifying treatment. *Am J Hosp Palliat Care*, 34(7), 671–676. doi:10.1177/1049909116646337 [PubMed: 27141015]
- Kroenke K, Strine TW, Spitzer RL, Williams JB, Berry JT, & Mokdad AH (2009). The PHQ-8 as a measure of current depression in the general population. *J Affect Disord*, 114(1–3), 163–173. doi:10.1016/j.jad.2008.06.026 [PubMed: 18752852]
- Kumar SK, Rajkumar SV, Dispenzieri A, Lacy MQ, Hayman SR, Buadi FK, ... Gertz MA (2008). Improved survival in multiple myeloma and the impact of novel therapies. *Blood*, 111(5), 2516–2520. doi:10.1182/blood-2007-10-116129 [PubMed: 17975015]
- Martin TG (2013). Peripheral neuropathy experience in patients with relapsed and/or refractory multiple myeloma treated with carfilzomib. *Oncology (Williston Park)*, 27 Suppl 3, 4–10.
- McNicol ED, Midbari A, & Eisenberg E (2013). Opioids for neuropathic pain. *Cochrane Database Syst Rev*(8), Cd006146. doi:10.1002/14651858.CD006146.pub2
- Meghani SH, Thompson AM, Chittams J, Bruner DW, & Riegel B (2015). Adherence to analgesics for cancer pain: A comparative study of African Americans and Whites using an electronic monitoring device. *J Pain*, 16(9), 825–835. doi:10.1016/j.jpain.2015.05.009 [PubMed: 26080042]
- Merlin JS, Patel K, Thompson N, Kapo J, Keefe F, Liebschutz J, ... Ritchie CS. (2019). Managing chronic pain in cancer survivors prescribed long-term opioid therapy: A national survey of ambulatory palliative care providers. *J Pain Symptom Manage*, 57(1), 20–27. doi:10.1016/j.jpainsymman.2018.10.493 [PubMed: 30342243]
- Moreau P, Pylypenko H, Grosicki S, Karamanesht I, Leleu X, Grishunina M, ... Harousseau JL. (2011). Subcutaneous versus intravenous administration of bortezomib in patients with relapsed multiple myeloma: A randomised, phase 3, non-inferiority study. *Lancet Oncol*, 12(5), 431–440. doi:10.1016/s1470-2045(11)70081-x [PubMed: 21507715]
- National Academies of Sciences Engineering and Medicine. (2019). Pain management for people with serious illness in the context of the opioid use disorder epidemic: Proceedings of a Workshop. Washington, D.C.: The National Academies Press.
- National Cancer Institute. (2019a, March 11, 2019). Cancer disparities. Retrieved from <https://www.cancer.gov/about-cancer/understanding/disparities>
- National Cancer Institute. (2019b, April 18, 2019). Depression (PDQ) - Health Professional Version. Retrieved from <https://www.cancer.gov/about-cancer/coping/feelings/depression-hp-pdq>

- National Cancer Institute. (2019c). SEER cancer stat facts: Myeloma. Retrieved from <https://seer.cancer.gov/statfacts/html/mulmy.html>
- National Comprehensive Cancer Network. (2019). NCCN Practice Guidelines in Oncology (NCCN Guidelines): Adult cancer pain, Version 3.2019 - June 24, 2019. In.
- National Comprehensive Cancer Network. (2020). NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Distress Management. In (Version 1.2020).
- Nielsen LK, Jarden M, Andersen CL, Frederiksen H, & Abildgaard N (2017). A systematic review of health-related quality of life in longitudinal studies of myeloma patients. *European Journal of Haematology*, 99(1), 3–17. doi:10.1111/ejh.12882
- Nielsen LK, Stege C, Lissenberg-Witte B, van der Holt B, Mellqvist UH, Salomo M, ... Zweegman S (2019). Health-related quality of life in transplant ineligible newly diagnosed multiple myeloma patients treated with either thalidomide or lenalidomide-based regimen until progression: A prospective, open-label, multicenter, randomized, phase 3 study. *Haematologica*. doi:10.3324/haematol.2019.222299
- Oosten AW, Oldenmenger WH, Mathijssen RH, & van der Rijt CC (2015). A systematic review of prospective studies reporting adverse events of commonly used opioids for cancer-related pain: A call for the use of standardized outcome measures. *J Pain*, 16(10), 935–946. doi:10.1016/j.jpain.2015.05.006 [PubMed: 26051219]
- Ory MG, Ahn S, Jiang L, Lorig K, Ritter P, Laurent DD, ... Smith ML (2013). National study of chronic disease self-management: Six-month findings. *Journal of Aging and Health*, 25(7), 1258–1274. doi:10.1177/0898264313502531 [PubMed: 24029414]
- Praice JA, Portenoy R, Lacchetti C, Campbell T, Chevillat A, Citron M, ... Bruera E (2016). Management of chronic pain in survivors of adult cancers: American Society of Clinical Oncology Clinical Practice Guideline. *J Clin Oncol*, 34(27), 3325–3345. doi:10.1200/jco.2016.68.5206 [PubMed: 27458286]
- Paradies Y, Ben J, Denson N, Elias A, Priest N, Pieterse A, ... Gee G (2015). Racism as a determinant of health: A systematic review and meta-analysis. *PLoS One*, 10(9), e0138511. doi:10.1371/journal.pone.0138511 [PubMed: 26398658]
- Ramsenthaler C, Kane P, Gao W, Siegert RJ, Edmonds PM, Schey SA, & Higginson IJ (2016). Prevalence of symptoms in patients with multiple myeloma: A systematic review and meta-analysis. *European Journal of Haematology*, 97(5), 416–429. doi:10.1111/ejh.12790 [PubMed: 27528496]
- Rogers LPW, & Rennoldson M (2020). Are pain and fatigue in multiple myeloma related to psychosocial factors?: A systematic review. *Cancer Nursing*, Publish Ahead of Print. doi:10.1097/ncc.0000000000000786
- Rome S, Noonan K, Bertolotti P, Tariman JD, & Miceli T (2017). Bone health, pain, and mobility: Evidence-based recommendations for patients with multiple myeloma. *Clin J Oncol Nurs*, 21(5 Suppl), 47–59. doi:10.1188/17.Cjon.S5.47-59 [PubMed: 28945729]
- Rome S, Noonan K, Bertolotti P, Tariman JD, Miceli T, & International Myeloma Foundation Leadership Board. (2017). Bone health, pain, and mobility: Evidence-based recommendations for patients with multiple myeloma. *Clin J Oncol Nurs*, 21, 47–59. doi:10.1188/17.CJON.S5.47-59 [PubMed: 28945729]
- Rudd RA, Seth P, David F, & Scholl L (2016). Increases in drug and opioid-involved overdose deaths - United States, 2010–2015. *MMWR Morb Mortal Wkly Rep*, 65(50–51), 1445–1452. doi:10.15585/mmwr.mm655051e1 [PubMed: 28033313]
- Siegel RL, Miller KD, & Jemal A (2020). Cancer statistics, 2020. *CA Cancer J Clin*, 70(1), 7–30. doi:10.3322/caac.21590 [PubMed: 31912902]
- Slout S, Boland J, Snowden JA, Ezaydi Y, Foster A, Gethin A, ... Ahmedzai SH (2015). Side effects of analgesia may significantly reduce quality of life in symptomatic multiple myeloma: a cross-sectional prevalence study. *Support Care Cancer*, 23(3), 671–678. [PubMed: 25160491]
- Smith EM, Pang H, Cirrincione C, Fleishman S, Paskett ED, Ahles T, ... Shapiro CL (2013). Effect of duloxetine on pain, function, and quality of life among patients with chemotherapy-induced painful peripheral neuropathy: a randomized clinical trial. *Jama*, 309(13), 1359–1367. doi:10.1001/jama.2013.2813 [PubMed: 23549581]

- Stein KD, Alcaraz KI, Kamson C, Fallon EA, & Smith TG (2016). Sociodemographic inequalities in barriers to cancer pain management: A report from the American Cancer Society's Study of Cancer Survivors-II (SCS-II). *Psychooncology*, 25(10), 1212–1221. doi:10.1002/pon.4218 [PubMed: 27421683]
- Traeger L, Cannon S, Keating NL, Pirl WF, Lathan C, Martin MY, ... Park ER (2014). Race by sex differences in depression symptoms and psychosocial service use among non-Hispanic black and white patients with lung cancer. *Journal of Clinical Oncology*, 32(2), 107–113. doi:10.1200/JCO.2012.46.6466 [PubMed: 24323033]
- van den Beuken-van Everdingen MH, Hochstenbach LM, Joosten EA, Tjan-Heijnen VC, & Janssen DJ (2016). Update on prevalence of pain in patients with cancer: Systematic review and meta-analysis. *J Pain Symptom Manage*, 51(6), 1070–1090.e1079. doi:10.1016/j.jpainsymman.2015.12.340 [PubMed: 27112310]
- Wagner LI, Pugh SL, Small W Jr., Kirshner J, Sidhu K, Bury MJ, ... Bruner DW (2017). Screening for depression in cancer patients receiving radiotherapy: Feasibility and identification of effective tools in the NRG Oncology RTOG 0841 trial. *Cancer*, 123(3), 485–493. doi:10.1002/cncr.29969 [PubMed: 27861753]
- Wilkie DJ, Ezenwa MO, Yao Y, Gill A, Hipp T, Shea R, ... Wang ZW (2017). Pain intensity and misconceptions among hospice patients with cancer and their caregivers: Status after 2 decades. *Am J Hosp Palliat Care*, 34(4), 318–324. doi:10.1177/1049909116639612 [PubMed: 27006391]
- Yeager KA, Williams B, Bai J, Cooper HLF, Quest T, Meghani SH, & Bruner DW (2019). Factors related to adherence to opioids in black patients with cancer pain. *J Pain Symptom Manage*, 57(1), 28–36. doi:10.1016/j.jpainsymman.2018.10.491 [PubMed: 30316809]

Table 1.

Sample Sociodemographic and Clinical Characteristics (n=34)

Characteristics	N	%
Age <i>Mean (SD) and Range</i>	57.7 (9.1)	41–74
Sex, Female	24	70.6
Ancestry (self-identified), African American ^a	31	91.2
Marital Status		
Married	18	52.9
Divorced/Separated	9	26.5
Other	7	20.6
Education Level, Highest Completed		
High School	8	23.5
High School – Bachelor’s Degree	22	64.7
> Bachelor’s Degree	4	11.8
Worked Outside Home, No	29	85.3
Religious Affiliation		
Christian	30	88.2
Muslim	2	5.9
Other	2	5.9
Insurance Status		
Public	20	58.8
Private	10	29.4
Public and Private	4	11.8
Time Since Multiple Myeloma Diagnosis, years <i>Mean (SD) and Range</i>	5.3 (3.8)	0–15
Chronic Illnesses Besides Cancer, Yes	24	70.6
Type of Chronic Illnesses Endorsed ^b		
High Blood Pressure	20	58.8
Diabetes	5	14.7
Heart Disease	3	8.8
Respiratory Disease	3	8.8
Kidney Disease	3	8.8
Arthritis	2	5.9
Stroke	2	5.9

^aOther ancestry included Hebrew Israelite, Trinidadian, and West Indian.

^bParticipants could endorse any number of chronic illnesses besides cancer.

Table 2.**Cancer Pain**

Variables	N	%
Everyday Pain, Yes	34	100
Everyday Pain Locations ^a		
Lower Back, left	18	52.9
Lower Back, right	18	52.9
Feet	13	38.2
Hands	10	29.4
Site of Most Pain ^b		
Back	16	47.1
Legs and Feet	5	14.7
Chest and Abdomen	2	5.9
Head, Shoulders, Neck	1	2.9
Pelvis and Hips	1	2.9
Pain Severity (0–10), <i>Mean (SD) and Range</i>	4.6 (2.3)	0–9
Least Pain <i>Mean (SD) and Range</i>	3.2 (2.3)	0–8
Worst Pain <i>Mean (SD) and Range</i>	6.3 (3.0)	0–10
Current Pain <i>Mean (SD) and Range</i>	2.9 (3.1)	0–9
Average Pain <i>Mean (SD) and Range</i>	4.8 (2.3)	0–10
Pain Interference (0–10), <i>Mean (SD) and Range</i>	5.1 (3.2)	0–10
Pain interferes with sleep.	5.7 (4.1)	0–10
Pain interferes with work.	5.6 (3.5)	0–10
Pain interferes with walking.	5.4 (3.8)	0–10
Pain interferes with general activity.	5.2 (3.4)	0–10
Pain interferes with enjoyment of life.	4.9 (3.6)	0–10
Pain interferes with mood.	4.6 (4.1)	0–10
Pain interferes with relationships.	4.2 (3.8)	0–10
Prescribed Around-the-Clock Opioid		
Extended-Release Morphine	21	61.8
Extended-Release Oxycodone	13	38.2
Percentage of Pain Relieved with Treatment		
<i>Mean (SD) and Range</i>	69.1 (28.3)	0–100

^aParticipants could endorse more than one pain location.

^bSites determined based on participants' marks on a paper body diagram.

Table 3.

Perceived Pain-Related Barriers to Pain Management (n=34)

Barrier Questionnaire Items	Item Mean (SD) ^a	N (%) Agreeing with Statement ^b
I do not like taking pills.	4.0 (1.6)	31 (91.2)
People get addicted to pain medication easily.	3.5 (1.7)	30 (88.2)
Constipation from pain medicine is really upsetting.	3.2 (2.1)	24 (70.6)
Drowsiness from pain medication is really a bother.	3.0 (2.0)	27 (79.4)
If you take pain medicine when you have some pain, then it might not work as well if the pain becomes worse.	2.9 (1.8)	28 (82.4)
Nausea from pain medicine is really distressing.	2.2 (2.1)	21 (61.8)
It is more important for the doctor to focus on curing illness than to put time into controlling pain.	2.1 (2.9)	16 (47.1)
Confusion from pain medication is really a bother.	1.8 (2.1)	18 (52.9)
It is easier to put up with pain than with the side effects that come from pain medicine.	1.8 (2.1)	17 (50.0)
Having pain means the disease is getting worse.	1.7 (2.1)	17 (50.0)
Pain medication cannot really control pain.	1.7 (2.0)	17 (50.0)
It is important to be strong by not talking about pain.	1.6 (2.0)	17 (50.0)
Pain medicine often makes you say or do embarrassing things.	1.0 (1.7)	10 (29.4)

Note. Statements reflect single items on the Barriers Questionnaire.

^aFor each item, mean findings spanned a range of scores reflective of the 0–5 scale range.

^bBarrier Questionnaire single item agreement represents responses of either 4 or 5.

Table 4.

Additional Symptom Severity

Symptoms	Mean (SD)	Range
Severity of Individual Symptoms ^a		
Tiredness	4.5 (3.3)	0–10
Pain	4.2 (3.0)	0–10
Decreased Appetite	4.1 (3.3)	0–10
Lack of Wellbeing	3.8 (2.8)	0–10
Drowsiness	3.3 (3.2)	0–9
Depressive Symptoms		
Major depression ^b prevalence, <i>N and percentage</i>	17	50%
Severe major depression ^b prevalence, <i>N and percentage</i>	1	2.9%

^aDisplaying top 5 symptoms, based on Edmonton item symptom scores, for how participant is feeling right now. Scores ≥ 4 are considered moderate intensity.

^bPHQ-8 scores ≥ 10 and ≥ 20 are considered major depression and severe major depression, respectively.