J Neurooncol (2017) 134:75–81
DOI 10.1007/s11060-017-2487-8

CLINICAL STUDY

End of life care for glioblastoma patients at a large academic cancer center

Kamini E. Kuchinad[1] · **Roy Strowd**[2] · **Anne Evans**[3] · **W. Anthony Riley**[3] · **Thomas J. Smith**[1,4]

Received: 29 December 2016 / Accepted: 14 May 2017 / Published online: 20 May 2017

Abstract Glioblastoma (GBM) is a universally fatal disease, complicated by significant cognitive and physical disabilities, inherent to the disease course. The purpose of this study was to retrospectively analyze end-of-life care for GBM patients at an academic center and compare utilization of these services to national quality of care guidelines, with the goal of identifying opportunities to improve end-of-life care. Single center retrospective cohort study of GBM patients at Johns Hopkins Hospital (JHH) between 2009 and 2014, using electronic medical records and hospice records. Comprehensive medical record review of 100 randomly selected patients with GBM, who were actively treated at JHH. Secondary analysis of all JHH GBM patients (n = 45) who received hospice care at Gilchrist Services, our largest provider, during this time period. Of 100 patients, 76 were referred to hospice. Despite the poor survival and changes in mental capacity associated with this disease, only 40% of individuals had documentation of code status and only 17% had any documentation of advance directives (ADs). None had documentation by a health care provider of a formal symptom, psychosocial, or spiritual assessment at greater than 50% of clinic visits. Only 17% used chemotherapy in their last month of life. 37% were hospitalized in the last month of life for an average of 9 days. Of the Gilchrist Services patients, the median length of stay in hospice was 21 days and 64% of these patients died in their residence with hospice services. Documentation of palliative care and end-of-life measures could improve quality of care for GBM patients, especially in the use of ADs, symptom, spiritual, and psychosocial assessments, with earlier use of hospice to prevent end-of-life hospitalizations.

Keywords Hospice · Palliative care · Glioblastoma

Introduction

Glioblastoma (GBM), the most common and aggressive primary brain tumor, accounts for 17% of all primary and metastatic brain tumors, and affects 2–3 individuals per 100,000 annually [1]. Despite maximal aggressive treatment, the 5-year survival rate is less than 10%, with a median survival of only 15 months [2]. GBM causes significant physical and cognitive disabilities including seizures, headaches, drowsiness, agitation, depression, focal neurological deficits, and limited communication [2–4]. Brain neoplasms such as GBM complicate the management of end-of-life care not only due to the extensive physical morbidities associated with the disease, but also because of the progressive cognitive and language deficits that inevitably occur. Given the poor survival outcomes and significant morbidity associated with GBM, palliative care interventions and end-of-life planning should be essential in creating high-quality care for these patients [5].

As defined by the World Health Organization, palliative care seeks to “improve quality of life of patients and

---

✉ Thomas J. Smith
tsmit136@jhmi.edu

[1] Johns Hopkins School of Medicine, Baltimore, MD, USA

[2] Brain Tumor Program, Johns Hopkins Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins Medical Institutions, Baltimore, MD, USA

[3] Gilchrist Services, Towson, MD, USA

[4] Harry J. Duffey Family Professor of Palliative Medicine, Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins Medical Institutions, 600 N. Wolfe Street, Blalock 369, Baltimore, MD 21287-0005, USA

families facing the problem associated with life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" [6]. Palliative care interventions can significantly improve the quality of life for patients with cancer by offering adequate symptom control, avoiding inappropriate prolongation of dying and providing psychosocial support for patients and caregivers [7]. Early end-of-life care interventions can significantly improve symptom management, overall quality of life and even survival outcomes among patients with small cell lung cancer [8]. Early palliative care consultation or practice is recommended by the American Society of Clinical Oncology (ASCO) clinical practice guidelines for all patients with serious cancer illness or symptoms and by the National Comprehensive Cancer Centers Network Palliative Care Clinical Practice guidelines [5, 9–11]. Most national guidelines call for advance care planning (ACP) to start when the person has about a year to live or has predicted cognitive deficits that require earlier documentation of durable power of medical attorney, written advance directives, and discussion of resuscitation status [12].

Limited data exists on current end-of-life care in GBM patients and no such studies have been done in the United States [13]. The existing literature suggests that while palliative care interventions can improve quality of care and cost-effectiveness of GBM management, these measures are used suboptimally. An audit at Royal Melbourne Hospital in Australia showed that of 181 GBM inpatients referred to the palliative care consultation service, 75% experienced three or more symptoms associated with their disease. Despite this high symptom burden, 28% of these patients had their first palliative care encounter in this inpatient setting [14, 15]. In an Italian study of 141 patients with GBM, those receiving the palliative care intervention had a rehospitalization rate of 8.3% as compared to 26.8% for those without the intervention as well as significantly reduced health care costs [16]. More recent data from the same group demonstrates the efficacy of palliative care measures utilized in the patient's home environment [17]. Furthermore, these findings suggest that proper preparation for end-of life issues can significantly reduce distress among family members [12]. A study of 33 German GBM patients showed that as patients became more impaired, the ability of usual scales to detect neuropsychiatric problems, and the ability of patients to complete them, declined, emphasizing the need for medical power of attorney designation and ACP early the disease course [18]. A comparative study of end of life care for glioma patients in three European countries found that chosen location of death, appropriate symptom management, and satisfaction with communication surrounding disease were all associated with high levels of patient-perceived quality of care despite differences in end of life care structure and implementation in each of these countries [19]. Symptom management was considered sufficient in only half of the patients in the three cohorts, suggesting the need for glioma specific interventions to appropriately address the distinct symptom burden and course associated with this disease [19]. The current literature suggests that more research is needed to further define appropriate symptom management and end-of-life care for this population [13, 19].

Therefore, the purpose of this study was to describe the documentation of end-of-life services and hospice use among GBM patients at Johns Hopkins Hospital (JHH). In addition, we sought to compare existing documentation of end-of-life services to established quality measures for supportive care as defined by existing standards set by the ASCO Quality Oncology Practice Initiative (QOPI) and the National Quality Foundation (NQF) [20].

Methods

A single-institution retrospective cohort study was conducted of patients treated at JHH between 2009 and 2014. Records of all patients with a diagnosis of glioblastoma seen at Johns Hopkins during this time period were requested from the Sidney Kimmel Cancer Center Tumor Registry. We selected 100 of these individuals to make a workable sample size by selecting every third patient. Patients with a diagnosis other than glioblastoma, <18 years old, or who did not receive therapy and follow up at JHH were excluded from the sample. Comprehensive medical record review was performed by one of us (KK). Decedents, documentation of hospice referral, code status and advance directives, use of chemotherapy in the last 4 weeks of life, hospitalization in last 4 weeks of life, and date of death were recorded. Pertinent psychosocial assessments per ASCO QOPI measures include formal multi-dimensional symptom assessments (pain, dyspnea, nausea, vomiting, and emotional well-being) at every clinic visit after diagnosis as well as spiritual assessments after diagnosis; these are to be done by the health care professional, or by referral [18]. Through review of clinic notes in the electronic medical record (EMR), we evaluated documentation of symptom assessment (dyspnea, pain, nausea, vomiting), performance status evaluation (KPS or ECOG) and any measure of emotional assessment or spiritual assessment at greater than 50% of clinic visits. We cross-checked the 20 of 100 paper charts as not all notes migrated to EPIC during this time. Johns Hopkins does not currently participate in the QOPI program.

To assess hospice-related outcomes, we conducted a secondary analysis of all individuals with GBM actively

Table 1 Demographics of sample, GBM patients treated at JHH

	N = 100	%
Age (median)	64.72 (11.0)	–
Male	62	62
Female	37	37
Race		
White	87	87
Black	10	10
Other	3	3

Table 2 Documentation of end of life services per ASCO QOPI measures

Measure	N = 100	%
Hospice referral	76	76
Code status	40	40
Advance directive	17	17
Use of chemotherapy in last 4 weeks of life	17	17
Hospitalization in the last 4 weeks of life	37	37
Average length of stay per hospitalization	8.75	–

Table 3 Documentation of symptom and psychosocial assessments at >50% of clinic visits

	N = 100	%
Performance status	54	54
Pain	12	12
Dyspnea	66	66
Emotional well-being	17	17
Spiritual assessment	0	0

treated at JHH who received hospice care at Gilchrist Services between 2009 and 2014. Gilchrist Services is the largest provider of hospice care for JHH. This sample included 32 individuals from our original sample, and 13 additional individuals who received hospice care at Gilchrist Services. We contacted Gilchrist Services to obtain corresponding hospice referrals and acceptances. Within this subset, we reviewed the date of referral to hospice, date of admission to hospice, length of stay in hospice and location of death.

Results

Three hundred and seventeen GBM decedents were seen at JHH between 2009 and 2014. One hundred individuals were selected to be included in our sample. As seen in Table 1, our sample was predominantly male (62%) and white (87%) with a median age of 62.

Table 4 Demographics of JHH patients who received care at Gilchrist Services

	N = 45	%
Age (SD)	62 (12.4)	
Male	29	64.4
Race		
Black	5	11.1
White	39	86.7
Other	1	2.2

Documentation of key end-of-life measures among the JHH cohort is shown in Table 2. Over this period of time, seventy-six individuals (76%) were referred to hospice. Forty participants (40%) had a documented code status and seventeen (17%) had a documented advance directive in the EMR. Only six individuals (6.1%) had documentation of advance directives within the first three visits after diagnosis, as recommended per QOPI measures for advanced and metastatic cancers. Of note, advance directive documentation was not mandatory at JHH during the period of study. Seventeen individuals (17%) had chemotherapy in the last 4 weeks of life and thirty-seven (37%) were hospitalized in the last 4 weeks of life (Table 2). For those hospitalized, the average length of hospital stay was 8.75 days.

Though they are considered important aspects of quality care in terminal disease management, symptom and psychosocial assessments were rarely done (Table 3). Sixty-six individuals had dyspnea assessed and seventy-three individuals had nausea and vomiting assessed in greater than 50% of clinic visits. In contrast, only twelve individuals had any pain assessment done on greater than 50% of clinic visits. Of note, these symptoms were rarely, if at all, documented using a standardized tool such as the Edmonton or Memorial Symptom Scale. Documentation of spiritual assessments was not seen for any of the individuals. In the audit of 20 paper charts to ensure that nothing was missed in the migration of notes to EPIC, we found no (0) outpatient multidimensional symptom assessments, or spiritual assessments. For patients who were hospitalized near the end of life, nearly all of the patients were seen by the social worker, and some by the chaplain, but again there were no formal assessments (psychosocial, symptom, or spiritual) done by health care providers. (Data not shown.)

The subset of individuals who received care at Gilchrist Services during this time period included forty-five total individuals: thirty-two from our original sample of one-hundred, plus an additional thirteen individuals referred during this time (Table 4). The demographics of this subset were similar to those of the original sample. Out of the 45 patients referred to Gilchrist Services, thirty-nine eventually enrolled in hospice care. Three individuals died prior to transfer to hospice and three individuals refused hospice care Individuals were referred to hospice with a median of twenty-two days before death and had a median hospice stay length of 21 days. Of those not enrolled in hospice, three participants refused hospice services and three participants died before hospice transfer. For those enrolled in Gilchrist Services, twenty-nine individuals died in home hospice while nine people died in inpatient hospice. Three individuals died in a licensed hospital with palliative care services (Table 5).

Discussion

This study is a first glimpse at end-of-life care for GBM patients in the United States. It provides a "snapshot" of how end-of-life care services are utilized at an academic institution, and how they compare to the recommended ASCO outpatient, health-care-provider-utilized QOPI measures for end-of-life and palliative care. Among the 100 sample patients, hospice utilization exceeded national averages: 76% were referred to hospice, higher than the national average of 54% for all cancer patients [21]. Among those enrolled in Gilchrist hospice, the median length of stay in hospice was 21 days, higher than the 17 days reported by NHPCO for all patients [22]. 64% of these patients died at home, as compared the 36% reported by the NHPCO for all patients [22].

Documentation of advance directives among our sample (17%) was less than the 18–30% of Americans who have completed advance directives and the 55% of patients with cancer who have completed advance directives by the time they die [23, 24]. Only six of these individuals had documented advance directives done within the first three visits after diagnosis, as per QOPI guidelines. All of these patients were contemporaneously charted in the available EMR. Some patients may have had advance directives that were never noted in the chart by a provider, or scanned into the record, but we did not find any in a subset paper analysis. This low rate represents a key area for improvement, as the National Consensus Project suggests that ACP should start when people have a terminal illness and be emphasized when patients have less than a year to live [12].

Table 5 Characteristics of hospice stay among Gilchrist hospice patients

	N	%
Enrolled in hospice	39	86.7
Length of stay in hospice (days)	21	
Days before death referred to hospice	22	
Location of death		
Home hospice	29	64.4
Inpatient hospice	9	20
Licensed hospital with PC	3	6.7
Extended care facility with hospice services	1	2.2
Unknown location of death	3	6.7

In the advent of the EMR, further standardization of location/documentation of advance directives is needed to honor patient preferences at the end-of-life [25, 26]. While this study was limited to assessing advance care planning measures at one institution, poor documentation of advanced care planning measures has been well documented across many institutions. Rates of advance care planning documentation vary depending on setting, but have been demonstrated to be suboptimal in both community and academic settings [27–31]. Lack of standardization and inability of physicians to find these documents can prevent the utilization of these key ACP tools. In a national survey of 736 physicians, 24% of physicians stated that there is no standardized place in the EMR to record an advance care plan; for those physicians who are able to report ACP in the EMR, only 54% reported that they were able to access the plans contents, representing a key area for improvement [32]. The documentation of advance directives can be increased by EMR prompts, standardization of ACP information within the EMR, and physician training [26, 33].Streamlining the uploading process of advance directives in the EMR can improve creation of and facilitate access to these documents. Allowing patients to upload these critical documents themselves could help improve this process. Development of easily accessible ACP tools and prompts in the EMR plays a key role in establishing effective end-of-life care.

Furthermore, cognitive decline inherent to GBM also may hinder effective advanced care planning. A study on decision-making in glioma patients in Amsterdam found that while up to 80% of individuals had capacity to make decisions in the last months before death, only half of patients in the cohort had decision-making capacity in the weeks before death, emphasizing the importance of early advance care planning and goals of care discussion in this population [34]. Similarly, a case–control study that assessed medical decision capacity between glioma patients and controls using a standardized psychometric instrument suggested that individuals with gliomas had significant losses in medical decision making capacity, often early in disease course [35]. Information on palliative care interventions in the context of cognitive decline are limited to those with dementia; even among this population, very few studies focus on palliative care interventions specific for individuals who suffer from cognitive impairment [36–38]. Cognitive decline inherent to GBM complicates the nature of end of life care for this population and emphasizes the need for evidence-based disease specific interventions to ensure patient-centered care, and quality of life for individuals with this terminal disease [39].

Chemotherapy use and hospitalization during the last 4 weeks of life suggest aggressive treatment at the end-of-life and indicates an area for improved palliative utilization. In our cohort, only 17% of GBM patients had chemotherapy in the last 4 weeks of life. However, thirty-seven percent (37%) were hospitalized in the last 4 weeks of life, with a median length of stay of 9 days. In other illnesses, unscheduled hospitalizations are strong predictors of a median survival of less than 6 months [40]. Earlier palliative care and hospice use can reduce such end-of-life hospitalizations and costs by providing a different level of care, and establishing the resources to allow patients to stay at home [41].

Documentation of formal pain and psychosocial assessments using standardized instruments also represent areas for improvement among GBM patients. During the time of this study, 2009–2014, conducting formal multi-dimensional symptom assessments such as the ESAS or MSAS, psychosocial assessments like the Distress Thermometer, or any spiritual assessments was not the norm; these tools were not part of the oncology outpatient or inpatient note template. Of the 100 JHH patients, only 12 had pain levels recorded in the chart for greater than 50% of clinic visits. Greater than 50% of GBM patients experience headaches at the time of presentation while 25% experience other sources of bodily pain [2, 42, 43]. Furthermore, effective management of headache and pain symptoms were considered to be a high priority for GBM patients, emphasizing the importance of effective management of these symptoms in this population [43]. Of 100 patients, none had any documented systematic assessment using standard instruments such as the Edmonton Symptom Assessment Scale (ESAS) or the Memorial Symptom Assessment Scale (MSAS) [44, 45]. Performance status was recorded in 54% of patients at greater than 50% of clinic visits. Documenting a patient-reported performance status at every clinic visit can help closely monitor patients' functional status and can help inform interventions to improve quality of life [46].

Psychosocial distress is particularly common among this population, with studies suggesting that 38% of patients and 78% of caregivers meet distress criteria at diagnosis, rising to 75% and 100% at recurrence [33]. While the clinical program likely does a good job of assessing psychosocial problems informally, very few had a formal psychosocial assessment. The use of standard assessments *by health care providers* represents an opportunity for improvement. These psychosocial and spiritual assessments can inform goals of care discussions, as cultural and spiritual beliefs can influence not only use of palliative care services but also can inform aggressive treatment use at end-of-life [47, 48]. While most patients had a social work and some had a chaplain consultation in their pre-terminal, pre-hospice hospitalization, there are opportunities to address significant issues like legacy and reconciliation that could be started while one has energy and time.

These findings suggest an opportunity for the use of standardized assessments in this patient population. Given the unique deficits and symptoms that GBM patients face, they also may suggest the need for a standardized symptom assessment tool specific for the needs of this population. Symptom assessments at end-of-life in patients with GBM are complicated by the cognitive impairment inherent to the disease. Though these scales can be very effective while patients are still cognitively intact, as patients decline, providers must depend on caregiver reports, as well as validated behavioral and nonverbal tools for pain and symptom assessment [49, 50]. More research is needed on the optimal methods for symptom assessment in the setting of both cognitive decline and terminal malignancy. In addition, longitudinal cognitive assessment may be useful in informing interventions to help delay further impairment, guide goals of care discussions and inform and empower caregivers [51]. Currently, scales for clinical trial outcome assessments are being developed for glioma patients [42, 52, 53]. Incorporation of these tools into drug development, quality of life outcome and palliative care intervention studies and clinical practice can help improve quality of care for this population.

Goals of care discussions can help direct treatment course and ensure early use of palliative care services. In this study, documentation of goals of care discussions were infrequent, perhaps limited by lack of documentation. The current literature suggests that earlier palliative care consultations and discussions are beneficial for patients. For instance, consultation (and discussion about place of death) more than 30 days before death led to a 2.2-fold increase in death at the place of preference compared to less than 30 days before death in one study and a 19% chance of dying in the hospital versus 51% chance of dying in the hospital in another [54, 55]. At JHH, if palliative radiation oncology patients had a documented goals of care discussion, they were more likely to utilize hospice [56]. Standardized documentation of goals of care discussions can enable consistent quality care for patients by informing future health care providers of the context of the patient's treatment course [57].

Documentation of end-of-life care measures in the EMR have been variable [33, 58]. In January 2016, the Centers for Medicaid and Medicare Services approved a billing code for voluntary provider end-of life discussions [32]. In a survey of 736 physicians throughout the country, while 99% of physicians supported this new Medicare benefit, only 14% reported that they have used this code to bill for ACP discussions in the 6 months since the billing code has been in effect [33]. However, 75% of those surveyed reported that the new billing code increases the likelihood that they will conduct these end-of-life discussions [22]. Expanding the CPT codes for end-of-life care beyond end-of life discussions, to include standardized symptom and psychosocial assessments, all of which inform practice decisions, could substantially improve quality of care for terminally ill patients at a systems level.

Strengths of this study include the ability to identify all the GBM patients with the tumor registry and the use of Gilchrist Services records to corroborate EMR findings. This study is limited by the inability to follow all the patients in the cohort, and recruitment from a single institution. In addition, due to the nature of this retrospective chart-review, this study can only assess the documentation of these quality measures, as opposed to the successful completion of these measures [59, 60].

Patients diagnosed with GBM face unique challenges as a result of their disease. Given its terminal nature, early and consistent palliative care interventions are important in ensuring quality of life. In this study, we retrospectively analyzed end-of-life care at an academic center and compared utilization of these services to national quality of care guidelines, with the goal of identifying opportunities to improve end-of-life care for GBM patients. Hospice referral and enrollment at Johns Hopkins exceeded national standards while documentation of advance directives, and psychosocial assessments demonstrated room for improvement. Next steps include prospectively evaluating palliative care and hospice use. Collaboration amongst providers including neuro-oncologists, medical oncologists, radiation oncologists, neurosurgeons, social workers, chaplains and other members of the care team can help optimize utilization of palliative care measures at the end-of-life and identify and establish necessary palliative care measures specific to the GBM population.

Funding TJS is supported by the Harry J. Duffey Family Fund and NCI grant P 30 006973.

Compliance with ethical standards

Conflict of interest All authors confirm that they have no conflicts of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study was approved by the Johns Hopkins eIRB.

References

1. The American Association of Neurological Surgeons. (2015, October 15). Retrieved July 02, 2016, from http://www.aans.org/patient information/conditions and treatments/glioblastoma multiforme.aspx
2. Lin E, Rosenthal MA, Le BH, et al (2012) Neuro-oncology and palliative care: a challenging interface. Neuro-Oncology 14:iv3–iv7
3. Pace A, Di Lorenzo C, Guariglia L, et al (2009) End-of-life issues in brain tumor patients. J Neurooncol 91:39–43
4. Ford E, Catt S, Chalmers A, et al (2012) Systematic review of supportive care needs in patients with primary malignant brain tumors. Neuro-Oncology 14(4):392–404
5. Smith TJ, Temin S, Alesi ER et al (2012) American Society of Clinical Oncology Provisional Clinical: The Integration of Palliative Care into Standard Oncology Care. J Clin Oncol 30(8):880–887
6. WHO | WHO Definition of Palliative Care. WHO. 2012. http://www.who.int/cancer/palliative/definition/en/. Accessed 1 Mar 2017
7. Parikh RB, Kirch RA, Smith TJ et al (2013) Early specialty palliative care—translating data in oncology into practice. N Engl J Med 369:2347–2351
8. Temel JS, Greer JA, Muzikansky A et al (2009) Early palliative care for patients with metastatic non-small cell lung cancer. N Engl J Med 363(8):733–742
9. Peppercorn JM, Smith TJ, Helft PR et al (2011) Toward individualized care for patients with advanced cancer. J Clin Oncol 29(6):755–760
10. Levy MH, Smith TJ, Alvarez-Perez A et al (2014) Palliative care, Version 1.2014. Featured updates to the NCCN guidelines. J Natl Compr Canc Netw 12(10):1379–1388
11. Levy MH, Adolph MD, Back A et al (2012) Palliative care. NCCN (National Comprehensive Cancer Network). J Natl Compr Canc Netw 10(10):1284–1309
12. Wilkinson A, Wenger N, Shugarman L (2007, June 01). Literature review on advance directives. Retrieved July 02, 2016, from https://aspe.hhs.gov/basic-report/literature-review-advance-directives#literature
13. Walbert T, Khan M (2014) End-of-life symptoms and care in patients with primary malignant brain tumors: a systematic literature review. J Neurooncol 117(2):217–224
14. Lin E, Rosenthal MA, Eastman P et al (2013) Inpatient palliative care consultation for patients with glioblastoma in a tertiary hospital. Intern Med J 43(8):942–945
15. Reville B, Miller MN, Toner RW et al (2010) End-of-life care for hospitalized patients with lung cancer: utilization of a palliative care service. J Palliat Med 13(10):1261–1266
16. Pace A, Di Lorenzo C, Capon A et al (2012) Quality of care and rehospitalization rate in the last stage of disease in brain tumor patients assisted at home: a cost effectiveness study. J Palliat Med 15:225–227
17. Pompili A, Telara S, Villani V et al (2014) Home palliative care and end of life issues in glioblastoma multiforme: results and comments from a homogeneous cohort of patients. Neurosurg Focus 37(6):E5. doi:10.3171/2014.9.FOCUS14493
18. Golla H, Ale Ahmad M, Galusho M et al (2014) Glioblastoma multiforme from diagnosis to death: a prospective, hospital-based cohort pilot feasibility study of patient reported symptoms and needs. Support Care Cancer 22(12):3341–3352
19. Koekkoek JAF, Dirven L, Reijneveld JC et al (2014) End of life care in high-grade glioma patients in three European countries: a comparative study. J Neurooncol 120(2):303–310. doi:10.1007/s11060-014-1548-5
20. ASCO Institute for Quality. (2014). Retrieved November 24, 2014, from http://www.instituteforquality.org/
21. Morden NE, Chang CH, Jacobson JO et al (2012) End-of-life care for Medicare beneficiaries with cancer is highly intensive overall and varies widely. Health Aff (Millwood) 31(4):786–796

22. Facts on Hospice and Palliative Care. (2015). Retrieved 5 July 2016, from http://www.nhpco.org/hospice-statistics-research-press-room/facts-hospice-and-palliative-care
23. Rocque GB, Barnett AE, Illig LC et al (2013) Inpatient hospitalization of oncology patients: are we missing an opportunity for end-of-life care? J Oncol Pract 9(1):51–54
24. Lorenz K, Lynn J, Morton SC, et al (2004) End-of-life care and outcomes. Agency for Healthcare Research and Quality (AHRQ), Rockville, MD, Dec 2004. Evidence Report/Technology Assessment #110, Publication #05-E004-1, Contract No. 290-02-0003
25. Wilson CJ, Newman J, Tapper S et al (2013) Multiple locations of advance care planning documentation in an electronic record: are they easy to find? J Palliat Med 16(9):1089–1094
26. Turley M, Wang S, Meng D, et al (2016) Impact of a care directives activity tab in the electronic health record on documentation of advanced care planning. Perm J 20(2):43–48
27. Ahluwalia SC, Chuang FL, Antonio ALM, Malin JL, Lorenz KA, Walling AM (2011) Documentation and discussion of preferences for care among patients with advanced cancer. J Oncol Pract 7(6):361–366. doi:10.1200/JOP.2011.000364
28. Wheatley E, Huntington MK (2012) Advanced directives and code status documentation in an academic practice. Fam Med 44(8):574–578
29. Resnick HE, Hickman S, Foster GL (2012) Documentation of advance directives among home health and hospice patients: united states, 2007. Am J Hosp Palliat Med 29(1):26–35. doi:10.1177/1049909111407627
30. Temel JS, Greer JA, Admane S et al (2010) Code status documentation in the outpatient electronic medical records of patients with metastatic cancer. J Gen Intern Med 25(2):150–153. doi:10.1007/s11606-009-1161-z
31. Grudzen CR, Buonocore P, Steinberg J et al (2016) Concordance of advance care plans with inpatient directives in the electronic medical record for older patients admitted from the emergency department. J Pain Symptom Manage 51(4):647–651. doi:10.1016/j.jpainsymman.2015.12.318
32. Poll-"Conversation Stopper: What's Preventing Physicians from Talking with Patients About End-of-Life and Advance Care Planning?" (2016, April 14). Retrieved July 05, 2016, from http://www.jhartfound.org/news-events/news/advance-care-planning-poll
33. Hayek S, Nieva R, Corrigan F et al (2014) End-of-life care planning: improving documentation of advance directives in the outpatient clinic using electronic medical records. J Palliat Med 17(12):1348–1352
34. Sizoo EM, Pasman HRW, Buttolo J et al (2012) Decision-making in the end-of-life phase of high-grade glioma patients. Eur J Cancer 48(2):226–232. doi:10.1016/j.ejca.2011.11.010
35. Triebel KL, Martin RC, Nabors LB, Marson DC (2009) Medical decision-making capacity in patients with malignant glioma. Neurology 73(24):2086–2092. doi:10.1212/WNL.0b013e3181c67bce
36. Murphy E, Froggatt K, Connolly S et al (2016) Palliative care interventions in advanced dementia. In: Murphy E (ed) Cochrane database of systematic reviews, vol 12. John Wiley & Sons, Ltd, Chichester. doi:10.1002/14651858.CD011513.pub2
37. Cheong K, Fisher P, Goh J, Ng L, Koh HM, Yap P (2015) Advance care planning in people with early cognitive impairment. BMJ Support Palliat Care 5(1):63–69. doi:10.1136/bmjspcare-2014-000648
38. Garand L, Dew MA, Lingler JH, DeKosky ST (2011) Incidence and predictors of advance care planning among persons with cognitive impairment. Am J Geriatr Psychiatry 19(8):712–720. doi:10.1097/JGP.0b013e3181faebef
39. Fritz L, Dirven L, Reijneveld JC et al (2016) Advance care planning in glioblastoma patients. Cancers (Basel) 8(11):102. doi:10.3390/cancers8110102
40. Trad W, Koh ES, Daher M et al (2015) Screening for psychological distress in adult primary brain tumor patients and caregivers: considerations of cancer care coordination. Front Oncol 5:203
41. Scibetta C, Kerr K, Mcguire J et al (2016) The costs of waiting: implications of the Timing of Palliative Care Consultations among a Cohort of Decedents at a Comprehensive Cancer Center. J Palliat Med 19(1):69–75
42. Sizoo EM, Braam L, Postma TJ, et al (2010) Symptoms and problems in the end-of-life phase of high-grade glioma patients. Neuro-Oncology 12(11):1162–1166
43. Armstrong TS, Bishof AM, Brown PD, et al (2016) Determining priority signs and symptoms for use as clinical outcomes assessments in trials including patients with malignant gliomas: Panel 1 report. Neuro-Oncology 18:ii1–ii12
44. Bruera E, Kuehn N, Miller MJ et al (1991) The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. J Palliat Care 7(2):6–9
45. Protenoy RK, Thaler HT, Kornblith AB et al (1994) The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence characteristics and distress. Eur J Cancer 30(9):1326–1336
46. LeBlanc TW, Back AL (2011) Linking palliative care and oncology practice: performance status as a common thread. J Oncol Pract 7(6):381–382
47. Johnson KS, Kuchibhatla M, Tulsky JA (2009) Racial differences in self-reported exposure to information about hospice care. J Palliat Med 12(10):921–927
48. Mazanec PM, Daly BJ, Townsend A (2010) Hospice utilization and end of life care decision making of African Americans. Am J Hosp Palliat Med 37(8):560
49. Warden V, Hurley AC, Volicer L (2003) Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. J Am Med Dir Assoc 4(1):9
50. Herr K, Bursch H, Ersek M et al (2010) Use of pain-behavioral assessment tools in the nursing home: expert consensus recommendations for practice. J Gerontol Nurs 36(3):18
51. Catt S, Chalmers A, Fallowfield L (2008) Psychosocial and supportive-care needs in high-grade glioma. Lancet Oncol 9:884–889
52. Blakely JO, Coons SJ, Corboy JR, et al (2016) Clinical outcome assessment in malignant glioma trials: measuring signs, symptoms and functional limitations. Neuro-Oncology 18:ii13–ii20
53. Avila EK, Chamberlain M, Schiff D et al (2017) Seizure control as a new metric in assessing efficacy of tumor treatment in low-grade glioma trials. Neuro Oncol 19(1):12–21
54. Poulose JV, Do YK, Neo PS (2013) Association between referral-to-death interval and location of death of patients referred to a hospital-based specialist palliative care service. J Pain Symptom Manage 46(2):173–181
55. Kumar P, Temel JS (2013) End-of-life care discussions in patients with advanced cancer. J Clin Oncol 31(27):3315–3319
56. Ellsworth SG, Alcorn SR, Hales RK et al (2014) Patterns of care among patients receiving radiation therapy for bone metastases at a large academic institution. Int J Radiat Oncol Biol Phys 89(5):1100–1105
57. Roze des Ordons AL, Sharma N, Heyland DK et al (2015) Strategies for effective goals of care discussions and decision-making: perspectives from a multi-centre survey of Canadian hospital-based healthcare providers. BMC Palliat Care 14:38
58. Kern LM, Barron Y, Dhopeshwarkar RV et al (2013) HITEC Investigators. Electronic health records and ambulatory quality of care. J Gen Intern Med 28(4):496–503
59. Soto CM, Kleinman KP, Simon SR (2012) Quality and correlates of medical record documentation in the ambulatory setting. BMC Health Serv Res 2:22
60. Hayrinen K, Saranto K, Nykanen P (2008) Definition, structure, content use and impacts of electronic health records: a review of the research. Int J Med Inform 77(5):291–304