Utilizing a Palliative Care Screening Tool in Patients With Glioblastoma

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Authors' disclosures of conflicts of interest are found at the end of this article.

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Abstract

Patients with glioblastoma have poor overall survival and experience significant burden from neurologic decline and adverse treatment effects. Despite the well-known benefits of early palliative care integration with oncology care, utilization of palliative care is low. The purpose of this quality improvement (QI) project is to investigate the feasibility, value, and effectiveness of using an adapted palliative care screening tool to improve outpatient palliative care screening and referral of glioblastoma patients. This QI project was conducted over a 10-week period. A glioma palliative care screening tool was developed and integrated into outpatient visits. Providers were required to use the screening tool during each patient visit. Patients 18 years or older who were diagnosed with a World Health Organization grade IV glioma and returning to the neuro-oncology clinic for a brain MRI evaluation were targeted. Screening, palliative care discussion, and referral rates were evaluated. Among 530 eligible patients who returned to the clinic over a 10-week period, the tool was available for 433 patients. Fifty-six percent (n = 294/530) of the patients were screened. Nine percent (n = 27) of screened patients were identified as candidates for a palliative care referral (score ≥ 5 on the screening tool). Of these 27 patients, the proportion of patients who had a palliative care discussion was 63% (n = 17). Overall, 71% (n = 12) of patients who had a palliative care discussion were referred to a palliative care provider. Integrating a glioma palliative care screening tool with outpatient visits can draw attention to palliative care needs and lead to a referral to palliative care.

High-grade gliomas, including glioblastoma (World Health Organization [WHO] grade IV), are the most common primary malignant central nervous tumors (Ostrom et al., 2017). Median overall survival of glioblastoma is 12 to 15 months (Alcedo-Guardia, Labat, Blas-Boria, & Vivas-Mejia, 2016). During the disease course, patients experience a significant symptomatic neurologic decline that leads to profound burden for the patient and their caregivers. The palliative care needs of glioblastoma patients are

complex due to significant symptom burden from functional, cognitive, and communication deficits. Symptoms that the patient with glioblastoma typically experience as the disease progresses include drowsiness, cognitive deficits, aphasia, motor weakness, seizures, and personality changes. Patients also experience adverse effects from chemotherapy or radiation therapy such as nausea, vomiting, fatigue, and cognitive decline (Walbert & Khan, 2014).

Walbert (2014) conducted a literature review of palliative care, hospice care, and end-of-life care in neuro-oncology practices. The review demonstrated that many high-grade glioma patients receive less palliative care than other cancer patients despite high symptom burden. One could attribute low utilization of palliative care to one or more of the following factors: (1) patients/family often assume palliative care is only appropriate at the end of life (Perrin & Kazanowski, 2015), (2) providers often perceive that palliative care is synonymous with hospice and decreases hope (Hui et al., 2015), or (3) most importantly, health-care providers may have a lack of knowledge or disagree about the criteria for palliative care referral.

Growing evidence in the literature supports the role of integrating early palliative care in the care of advanced cancer patients. Patients who received palliative care at an early stage of disease demonstrated improved quality of life, fewer mood disturbances (depression and anxiety), and decreased medical cost (Adelson et al., 2017; Davis, Temel, Balboni, & Glare, 2015; El-Jawahri et al., 2016; Grudzen et al., 2016; Nakajima & Abe, 2016; Salins, Ramanjulu, Patra, Deodhar, & Muckaden, 2016; Temel et al., 2016; Vanbutsele et al., 2018). Although there is increasing recognition that early palliative care can benefit patients with advanced cancers, a literature review showed a lack of knowledge by patients and health-care providers about how and when palliative care can be utilized. Lack of health-care provider referral is the main barrier to the use of palliative care (Kumar et al., 2012). To overcome the palliative care referral barrier, research suggests that using a screening tool to identify patients in need of palliative care support increases timely palliative care referrals. A prospective and retrospective study by Begum (2013) showed that the use of a screening

tool decreased the number of patients who were not referred to palliative care from 68% to 16% in a 4-month period.

The American Society of Clinical Oncology (ASCO) Clinical Practice Guideline recommends that outpatient oncology programs provide palliative care resources to patients with cancer who have high physical and psychosocial symptom burden (Ferrell et al., 2017). The National Comprehensive Cancer Network (NCCN) Guidelines recommend that providers repeatedly screen all advanced cancer patients for referral to palliative care (Swarm & Dans, 2018). However, Albizu-Rivera and colleagues (2016) reported that only 10% of NCCN member institutions use the NCCN Guidelines to screen oncology patients for palliative care referrals, and the majority of respondents were uncertain as to who should be referred for palliative care and when to make that referral. The adoption of a standardized needs assessment is required to promote the role of palliative care in oncology care. This quality improvement (QI) project used a palliative care screening tool to increase screening and referral to outpatient palliative care in glioblastoma (WHO grade IV) patients in an outpatient neuro-oncology clinic.

OBJECTIVES

The purpose of this project was to assess feasibility, value, and effectiveness of the implementation of a palliative care screening tool for patients with glioblastoma (WHO grade IV) who are returning to the Preston Robert Tisch Brain Tumor Center (PRTBTC) at Duke Cancer Institute (DCI) for a follow-up evaluation.

The first aim was to assess the feasibility of implementing a palliative care screening tool by determining the proportion of patients who are screened for palliative care needs using the glioma palliative care screening tool among eligible patients with WHO grade IV malignant glioma who return to the PRTBTC for a follow-up MRI.

The second aim was to assess the value of the screening tool by determining the proportion of patients who have a discussion regarding palliative care among those patients who score 5 or higher on the screening tool.

The third aim was to assess the effectiveness of the tool by determining the proportion of patients

who are referred to palliative care among the patients who had a palliative care referral discussion.

DESIGN

This QI project was designed to investigate the feasibility, value, and effectiveness of using a palliative care screening tool to improve outpatient palliative care screening and referrals in glioblastoma (WHO grade IV) patients. This QI project has been formally evaluated using a QI checklist and determined to be exempt from institutional review board review.

A literature search was performed to find a palliative care screening tool specific for neuro-oncology patients. However, a screening tool for neuro-oncology patients was not found. A simple palliative care screening tool (Glare, Semple, Stabler, & Saltz, 2011) developed for outpatient oncology patients based on NCCN palliative care screening criteria was identified in the literature review. The screening tool consists of five main screening items: (1) presence of metastatic or locally advanced cancer, (2) functional status score, according to Eastern Cooperative Oncology Group (ECOG) performance status, (3) presence of one or more serious complications of advanced cancer usually associated with a prognosis of fewer than 12 months, (4) presence of one or more serious comorbid diseases also associated with poor prognosis, and (5) presence of palliative care problems. A total score of 5 or greater is recommended to be the trigger for a referral. This screening tool was adapted for brain tumor patients after consulting the neuro-oncology team at the PRTBTC (Appendix A). Neuro-oncology providers do not use metastatic diseases in glioblastoma (WHO grade IV) as a descriptive because glioblastoma (WHO grade IV) is already an advanced disease and metastases outside of the central nervous system are exceedingly rare. Therefore, we identified progressive disease at a current visit to be equivalent to the presence of metastatic or locally advanced cancer (item 1 in Appendix A). For the functional status score (item 2), ECOG criteria were used in the screening tool (Glare et al., 2011) but Karnofsky Performance Status (KPS) is used at the PRTBTC. Simple conversion of the ECOG to KPS was included in the adapted screening tool. Any

serious complications of cancer associated with a prognosis of fewer than 12 months (item 3) was further defined with a clarifying example, "metastatic disease to the spine." The example was further clarified on day 10 of project implementation with the addition of "progression of disease more than twice," or "new multifocal disease." For the presence of comorbid disease associated with poor prognosis (item 4), moderate-to-severe congestive heart failure (CHF), stroke, dementia, renal disease, liver disease, pulmonary embolism, bowel perforation, cerebral edema, and obstructive hydrocephalus were initially added as clarifying examples. At day 10, the examples were further augmented to include a history of moderate-to-severe CHF, stroke, cognitive deficit, renal disease, liver disease, pulmonary embolism, bowel perforation, cerebral edema, obstructive hydrocephalus, cytopenia, or new active problem requiring intervention or hospital admission.

A questionnaire (Appendix B) was developed to collect the patient's age, sex, diagnosis, discussion and referral to palliative care, and to determine whether a referral was made to Duke palliative care or a recommendation to a local oncologist's office for local palliative care referral. The questionnaire also included a question about stating the reason for why a discussion regarding palliative care did not take place and/or a referral was not made if applicable.

Two weeks before the project implementation, a brief information session about the QI project was given to the clinical staff at the PRTBTC, including attending neuro-oncologists, nurse clinicians, and clinic nurses. A separate brief information session to each group of advanced practice providers (APPs) and certified medical assistants (CMAs) were given before the implementation of the project.

The CMAs gave the glioma palliative care screening tool (Appendix A) and the provider questionnaire (Appendix B) to APPs who were assigned to see eligible patients. Advanced practice providers screened palliative care needs during the patient exam and from the medical history. If the tool indicated a need for a palliative care referral (score ≥ 5), the APP discussed a referral to palliative care with the patient's attending physician and the patient. The referral was made only when

the patient's attending physician and the patient agreed to the referral. If the patient was local, the referral was made to Duke palliative medicine. A majority of patients at the PRTBTC are from out of the state. Thus, if the patient was not local, the APP made a recommendation for palliative care referral to the local oncologist's office. After the screening and decision regarding referral were made, the APPs filled out the questionnaire (Appendix B).

SETTING/SUBJECTS

This QI project was implemented at the PRTBTC at the DCI. The PRTBTC is a tertiary outpatient neuro-oncology clinic located in Durham, North Carolina. Adult primary brain tumor and spinal tumor patients are seen at the PRTBTC.

The target patient population for this QI project included patients who were 18 years or older, diagnosed with a WHO grade IV malignant glioma (glioblastoma or gliosarcoma), were able to speak English, and were returning to the PRTBTC for routine evaluation with a new brain MRI. Patients visiting the PRTBTC for pretreatment evaluations, new patient evaluations, and patients who had already had a discussion of palliative care referral and had been referred to palliative care were not eligible.

The key providers for the project included 10 board-certified APPs (7 nurse practitioners and 3 physician assistants). Six of the APPs had more than 5 years of experience. The PRTBTC APPs worked collaboratively with their supervising attending neuro-oncologists and communicated key care issues to the local medical oncology team. In addition to APPs, physicians, fellows, residents, and medical students completed the screening and questionnaire.

MEASUREMENTS

Analyses associated with this QI project are descriptive. The project's primary endpoint, the proportion of eligible patients who were screened for palliative care needs using the palliative care screening tool among eligible patients with WHO grade IV malignant glioma returning to the PRTBTC for a follow-up MRI, was evaluated during the 10-week implementation period. This endpoint was measured by counting the number of patients screened for palliative care using the adapted screening tool out of the total number of eligible patients.

The questionnaire (Appendix B) collected data about whether the discussion regarding palliative care referral took place or not. The project's second endpoint, the proportion of screened patients who discussed palliative care referral, was measured by counting the number of patients who discussed palliative care referral out of the number of patients who had a score of 5 or greater on the screening tool.

The third objective was assessed by determining the proportion of patients who agree to a palliative care referral among patients who had a palliative care discussion. The referral rate was measured by counting the number of questionnaires indicating that a referral was made to Duke palliative medicine or that a recommendation was made to local oncologist's office among screened patients with a score of 5 or greater.

RESULTS

During the 10-week implementation period from September to December 2018, a total of 530 patients were identified to be eligible for screening. Figure 1 shows the overall palliative care screening, discussion, and referral outcomes. Among the 530 eligible patients, the screening tool was given to providers for 433 patients. During the first 17-day period, the CMAs did not distribute the screening tool for 97 eligible patients. Thus, among the 433 patients, 294 patients (68%) were screened using the tool (Table 1).

Screened patients were generally male (60%) and had a KPS of 70% or higher (47%). Almost half of the patients (n = 131, 45%) had an NCCN Distress Thermometer score of zero. More than half of the patients (n = 177, 53%) were between 46 to 65 years old (Table 2).

In regards to assessing the feasibility of the palliative care screening tool and aim 1 of the study, among eligible patients, the proportion of the patients screened for palliative care needs using the glioma palliative care screening tool was 56% (294/530).

On measuring the value of a palliative care screening tool, 27 (9%) out of the 294 screened patients received a score of 5 or greater. The
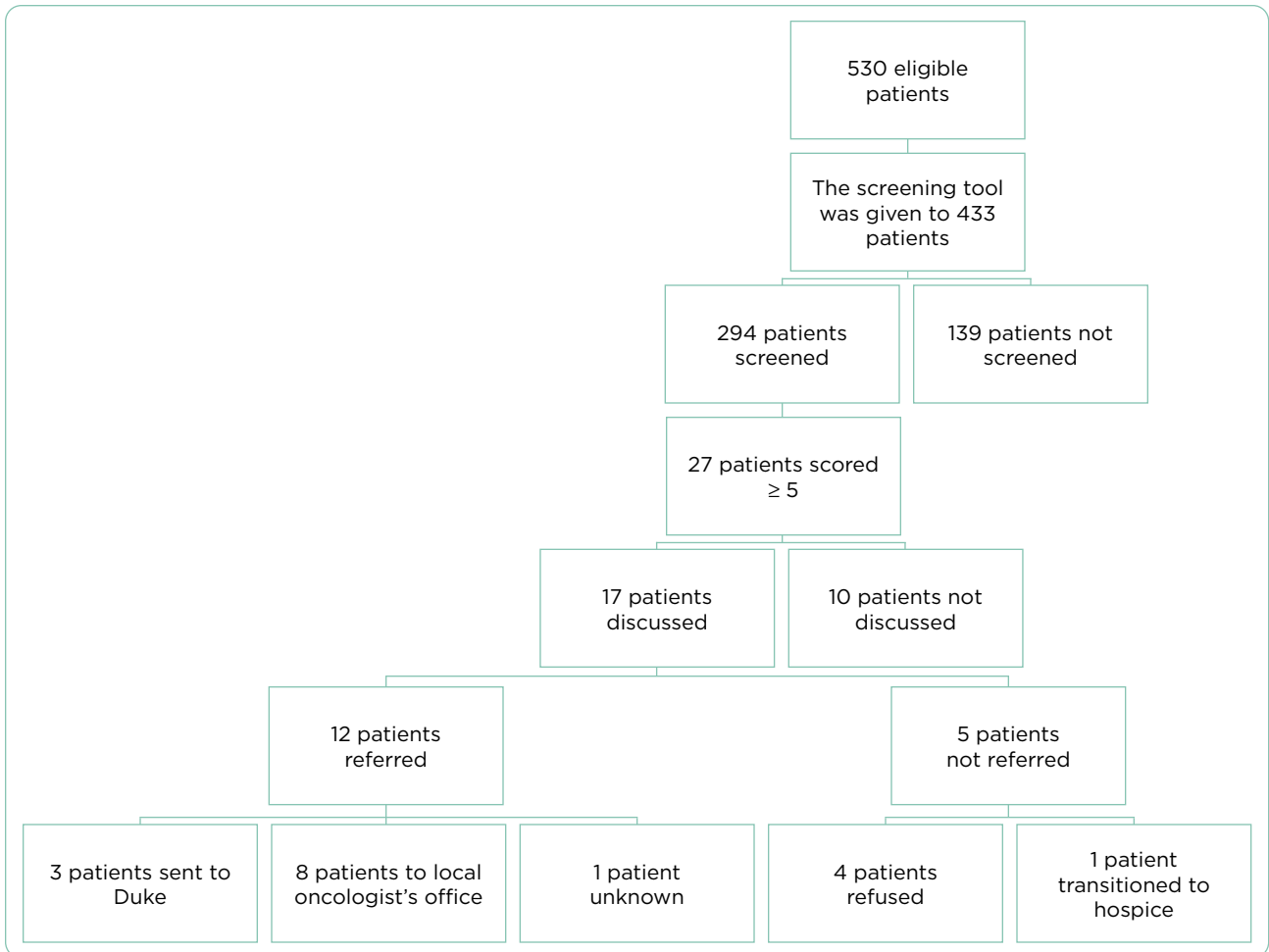
Figure 1. Palliative care referral outcomes.

proportion of patients who had a discussion regarding palliative care among those patients who scored 5 or greater on the screening tool was 63% (17/27). Among the 10 patients who did not discuss a palliative care referral, five patients did not have the discussion due to focusing on future treatment plans, three patients had an attending physician who did not agree with discussing a palliative care referral, and two patients lacked a reason.

Table 1. Project Outcomes

Outcome	Estimate	95% confidence interval
Proportion of eligible patients screened	294/530 (56%)	51%–60%
Proportion of eligible patients screened among those for whom the certified medical assistant provided the form to the APP	294/433 (68%)	64%–72%
Proportion of screened patients with score ≥ 5	27/294 (9%)	5.9%–12.5%
Proportion of patients with score ≥ 5 who had a palliative care discussion	17/27 (63%)	42%–81%
Proportion of patients with score ≥ 5 who were referred to a palliative care consult	12/27 (44%)	25%–65%
Proportion of patients with referral among those with a palliative care discussion	12/17 (71%)	44%–90%

The final aim of the study was to determine the effectiveness of the implementation of a palliative care screening tool. The proportion of patients referred to palliative care among patients who had a palliative care referral discussion was 71% (12/17). Among the 12 referred patients, three patients were referred to Duke palliative care, eight patients had a recommendation of palliative care referral made to local oncologist offices, and the last patient did not have a medical record note that detailed whether the patient was referred to Duke or a local oncologist office. Among the five patients who were not referred to palliative care, four patients refused the referral, and one patient was referred to hospice care.

The majority (89%) of patients (262/294) were screened by trained APPs. Providers who screened the patients using the screening tool also included a fellow, residents, and medical students. One patient was also screened using the tool by an attending physician.

DISCUSSION

Patients with high-grade gliomas, including glioblastoma (WHO grade IV) patients, experience significant neurologic symptoms and adverse effects from chemotherapy or radiation therapy. The benefit of early palliative care integrated with oncology care is widely known. With the unique, complicated symptomatic burden of high-grade glioma patients, screening patients for a timely referral to palliative care is crucial.

From the provider referral data for the fiscal year of 2018, an average of six brain tumor patients per 10-week period were referred to Duke palliative care. From a pilot study of early integration of palliative care with neuro-oncology care for glioblastoma patients, approximately two patients per 10-week period were referred to Duke palliative care. The results of this project showed that more than half (56%; 294/530) of eligible patients were screened using the tool, and a total of 12 patients were referred to palliative care during a 10-week period. This QI project demonstrated that integrating a palliative care screening tool to usual daily clinical care is feasible, can trigger attention to palliative care, and lead to a referral to palliative care.

Providers for 18% (97/530) of the 530 eligible patients did not receive the screening tool from

Table 2. Patient Demographics	
Gender	
Male	177 (60%)
Female	109 (37%)
Unknown	8 (3%)
Age	
< 25	18 (6%)
26–35	39 (13%)
36–45	49 (17%)
46–55	84 (29%)
56–65	71 (24%)
66–75	21 (7%)
> 75	10 (4%)
Unknown	2 (1%)
Karnofsky Performance Status	
90%–100%	133 (45%)
70%–80%	123 (42%)
50%–60%	35 (12%)
30%–40%	3 (1%)
10%–20%	0 (0%)
NCCN Distress Thermometer score	
0	131 (45%)
1	35 (12%)
2	26 (9%)
3	21 (7%)
4	17 (6%)
5	19 (6%)
6	8 (3%)
7	8 (3%)
8	4 (1%)
9	2 (1%)
10	3 (1%)
Unknown	20 (7%)

the CMAs for the first 17 days. Thus, APPs and a clinical staff member distributed the tool instead. Subsequently, the screening tools were appropriately administered for all eligible patients. If the screening tool had been distributed to all eligible patients, the proportion of patients screened could have been higher. One method to overcome this barrier is to make the screening tool more accessible by integrating the tool into the electronic medical record system. Increasing accessibility in addition to creating an automatic trigger based on a screening score of 5 or greater can encourage use of the screening tool and promote the long-term implementation of the tool.

This QI project involved a multidisciplinary team. As most of the patients are seen by APPs in conjunction with attending physicians, 89% of patients (262/294) were screened, and discussion of a referral to palliative care was initiated by APPs. This project indicated that APPs can play a pivotal role in integrating palliative care with standard

oncology care by initiating screening for a referral to palliative care.

An extensive literature search was performed to find a screening tool developed and validated for high-grade glioma or neuro-oncology patients; however, such a screening tool could not be found. To integrate the tool within a busy clinic setting, a simple screening tool (Glare et al., 2011) was carefully chosen and adapted to high-grade glioma patients after consulting the neuro-oncology team at the PRTBTC. One limitation of this project may be a lack of validation of the glioma palliative care screening tool. However, the original screening tool (Glare et al., 2011) was developed for outpatient cancer patients, and an inpatient version (Glare & Chow, 2015) was validated.

Although 27 patients out of the target population were eligible for palliative care, ten patients did not have a discussion regarding palliative care referral. Providers for five out of the ten patients indicated that they focused on discussing next treatment plans and clinical issues rather than palliative care. Busy clinical work and lack of time can minimize the attention paid to palliative care. If a palliative care visit could be combined with an oncology care visit as one visit, this could enhance the actual integration of palliative care with oncology care.

Although the screening tool indicated a referral and providers recommended referral to palliative care, four patients refused. This could be from patient misunderstanding of palliative care (symptom management rather than hospice care), lack of time, or financial burden from additional visits. An ideal model of integrating early palliative care in glioma care has not been established. In future studies, a query about patient acceptance regarding palliative care is required to identify the most effective and efficient model of early palliative care integrated with oncology care.

CONCLUSION

This project demonstrated that integrating a palliative care screening tool with daily clinical care is feasible. Application of a palliative care screening tool can trigger attention to palliative care and lead to a referral to palliative care. Easy access to the glioma palliative care screening tool such as integrating with an electronic medical record system to automatically notify when palliative care is appropriate may enhance the use of the tool. Moreover, providers' attention to palliative care and patients' acceptance of palliative care referral need to be improved to screen all palliative care needs and increase timely referral to palliative care. Utilizing a palliative care screening tool may facilitate early referral to palliative care and lead to improved patient outcomes in symptom management and quality of life. ●

Disclosure

The authors have no conflicts of interest to disclose.

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Appendix A. Glioma Palliative Care Screening Tool

Screening items	Points	Patient points
Progressive MRI at current visit	2	

Functional status of patient (ECOG score/KPS score)
  0: ECOG 0 = KPS 90%–100%
  1: ECOG 1 = KPS 70%–80%
  2: ECOG 2 = KPS 50%–60%
  3: ECOG 3 = KPS 30%–40%
  4: ECOG 4 = KPS 10%–20%
	0–4	

Any serious complication of cancer associated with a prognosis of < 12 months (e.g., progressive disease ≥ 2, new multifocal disease, leptomeningeal disease)	1	
Presence of one or more serious comorbid disease associated with poor prognosis (e.g., moderate-to-severe CHF, stroke, cognitive deficit, renal disease, liver disease, PE, bowel perforation, cerebral edema, obstructive hydrocephalus, cytopenia or NEW active problem requiring intervention or admission)	1	
Presence of palliative care problem • Uncontrolled symptoms (e.g., GI symptoms, headaches, fatigue, rash) • Moderate-to-severe distress (NCCN Distress Thermometer score of 4 or higher) • Patient/family concerns regarding course of disease and decision making • Patient/family requests palliative care consult • Team needs assistance with decision making	1 1 1 1 1	
Total	0–13	

Refer the patient to palliative care when the score ≥ 5

If the screening tool is not used, please write the reason below
_____

Note. ECOG = Eastern Cooperative Oncology Group; KPS = Karnofsky Performance Status; CHF = congestive heart failure; PE = pulmonary embolism; GI = gastrointestinal; NCCN = National Comprehensive Cancer Network. Adapted from Glare et al. (2011).

Appendix B. Provider Questionnaire

Day #   _____

Age   _____

Diagnosis   _____

Sex   M/F

NCCN Distress score   _____

Are you an APP?   ☐ Yes   ☐ No: Fellow/Resident/Med student

Screening score ≥ 5?
☐ Yes   ☐ No

Palliative care discussion with the patient done?
☐ Yes   ☐ No

Referral made?
☐ Yes   ☐ No

If yes, referral made to
☐ Duke palliative care
☐ Recommended to patient's local oncologist for palliative care referral

If screening score ≥ 5, and discussion did NOT take place and/or referral NOT made, why?
☐ Patient refused
☐ Provider did not agree: Attending/APP (please circle one)
☐ Other: _____