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Coping with glioblastoma: prognostic communication and prognostic understanding among patients with recurrent glioblastoma, caregivers, and oncologists

Leah E. Walsh¹ · Laura C. Polacek¹ · Katherine Panageas² · Anne Reiner² · Tobias Walbert³ · Alissa A. Thomas⁴ · Justin Buthorn⁵ · Allison Sigler⁵ · Holly G. Prigerson⁶ · Allison J. Applebaum¹ · Eli L. Diamond⁵

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Abstract

Purpose Glioblastoma (GBM) is a devastating neuro-oncologic disease with invariably poor prognosis. Despite this, research shows patients have unrealistic perceptions of their prognosis, which may relate in part to communication patterns between patients, caregivers and oncologists. The purpose of this study was to examine communication processes and goals among patients, caregivers, and oncologists to elucidate drivers of prognostic understanding (PU) in the context of recurrent GBM.

Methods This was a prospective, multi-center study enrolling adult patients with GBM, caregivers, and oncologists, who independently reported the content of a specific discussion involving the disclosure of GBM recurrence. Communication processes and goals were characterized for each participant, and concordance between all dyads and patient-caregiver-oncologist triads were calculated.

Results Seventeen patient, caregiver, and oncologist triads were analyzed. At the individual level, three (17.6%) patients and 8 (47.1%) caregivers reported having discussed prognosis during the clinical encounter, as compared to ten oncologists (58.8%). Seven patients (41.2%) and 5 caregivers (29.4%), versus thirteen oncologists (76.5%) reported *ever* discussing prognosis or life expectancy at previous appointments. Generally, patient-caregiver concordance (i.e., both answered the same) regarding communication goals and processes was low. Triads showed limited concordant responses in discussing curability ($n=5$), prognosis ($n=4$), end-of-life treatment goals ($n=4$), and ever discussing prognosis ($n=3$).

Conclusion Patients, caregivers and oncologists had discordant views regarding communication processes and prognostic goals, even when recalling a single discussion. This study highlights the importance of clear and frequent communication about prognosis, and the need for further research on communication and PU in the neuro-oncology setting.

Keywords Glioblastoma · Prognosis · Communication · Supportive care · Cancer caregiver

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Introduction

Glioblastoma (GBM) is an aggressive and incurable form of brain cancer [1]. Patients with GBM face a limited life-expectancy with a median overall survival of approximately 15–18 months [2–4]. When GBM patients and caregivers are informed by oncologists about tumor growth, such discussions contain communication *processes* (i.e., discussion of prognosis, life expectancy), and *goals*, the beliefs and preferences that arise from communication processes, such as prognostic understanding (PU)—one's understanding of cancer stage, treatment options, curability, and life expectancy [5]. Across all cancers, discussions about prognosis are difficult for patients, caregivers, and oncologists, but are particularly challenging in the setting of GBM due to cognitive and functional decline.

Despite the challenges of having candid discussions, PU is associated with favorable psychosocial outcomes [6]. Among patients with various advanced cancers, accurate PU is associated with reduced anxiety, increased trust in physicians and coping capacity, and better satisfaction with care [7], and has been shown to help facilitate discussions around end-of-life (EOL) care and related goals/wishes [8, 9]. Importantly, intentional discussions regarding prognosis have been shown to increase patients' understanding of the nature of their disease [10–13] and do not harm the physician–patient relationship; instead, they may improve patient-physician alliance [14]. Furthermore, patients and caregivers having a *shared* understanding of prognosis positively impacts engagement in advance care planning [15, 16]. As such, PU is impacted by interpersonal processes, such as how information is discussed and what aspects of information are exchanged.

Despite the importance of PU, the extent to which it is shared between GBM patients and caregivers has not been comprehensively studied. In a prospective study of patients with malignant glioma (MG) and their caregivers, only 40% of patients had full PU, whereas 69% of caregivers were fully aware of the patient's prognosis [17]. Another study found that MG patients were significantly more likely than their caregivers to believe that the goal of treatment was to cure the cancer and that their oncologist shared similar beliefs [18]. Discrepant or inaccurate perceptions of treatment goals between GBM patients and caregivers may impact healthcare decisions near the EOL. While existing studies of patient and caregiver PU have examined *what* participants believe or understand from all sources of information, there has been little study of *how* patients and caregivers recognize and understand prognostic information from the same discussion with a healthcare provider. The purpose of the present study was to compare communication processes and goals between

patients, caregivers, and oncologists, as they occurred within a single outpatient encounter when GBM progression was disclosed.

Method

Study participants

This was an IRB-approved, prospective, multi-center study of adult patients with GBM, a paired family caregiver, and their treating neuro-oncologist, conducted at Memorial Sloan Kettering Cancer Center (MSK), Henry Ford Hospital, and University of Vermont Medical Center. Participants were recruited from outpatient neuro-oncology practices between March 2015 and November 2019. Screening was performed by clinical or research staff through review of upcoming outpatient clinic rosters. Eligibility criteria for patients included: ≥ 18 years of age, histopathologically-determined diagnosis of GBM, and fluency in English. At the time of consent, patients were evaluated for orientation to self, place, month, and year as published previously [17]. Patients were excluded if the neuro-oncologist felt that, based on clinical evaluation, they did not have the capacity to consent. An eligible caregiver was someone ≥ 18 years old, proficient in English, and identified by the patient as a relative, friend, or partner who provided *unpaid* care (i.e., physical or emotional assistance), and who was likely to attend medical visits. Caregiver participation was required for every patient at the time of study registration. All patients and caregivers provided informed consent upon enrollment. All treating neuro-oncologists provided informed consent to the overall Principal Investigator (E.L.D.) to cover their participation in the study. Participating neuro-oncologists provided data for one or many of their patients.

Study procedures and assessments

Upcoming medical visits and MRI scans for tumor surveillance were screened by the research team for enrolled patients. Participant neuro-oncologists were informed in advance if their patient had an upcoming visit to discuss scan results. Following the visit, the study team conferred with the neuro-oncologist as to whether the MRI had demonstrated tumor growth, in which case study questionnaires were administered to the patient and their caregiver within one month of the encounter. The neuro-oncologist completed study assessments on the same day as the encounter. Patients and caregivers completed survey assessments online (via WebCore of MSK) or by phone. Patients, caregivers and oncologists completed surveys about health communication, treatment preferences, and perceived life expectancy to examine their independent perceptions of communication

content during the disclosure of GBM recurrence. These surveys were previously implemented in the multi-center Coping with Cancer II study [19].

Clinical data and questionnaire items

Clinical and demographic variables including age, sex, tumor location and disease status were captured from the medical record. Demographic information was collected from caregivers including age, sex, race/ethnicity, education, marital status, household income, place of birth, relationship to the patient, and the patient's insurance status.

Variables related to whether prognostic communication took place during the clinical encounter were collected from the patient, caregiver, and oncologist, who answered yes/no/I don't know to the following questions: *Was curability discussed at the last visit?*; *Was the patient's prognosis discussed at the last visit?*; *Were goals of EOL care discussed at last visit?*; *Have you EVER discussed prognosis or life expectancy with the oncologist/patient?*

The following categorical variables related to PU were collected from patients and caregivers: *What is the purpose of treatment?*; *If you could, what plan of care would you choose for yourself/the patient?*; *Has the patient completed a Do-Not-Resuscitate order (DNR)?*; *What stage do you think the patient's cancer is?*. The following items were asked of caregiver and oncologist: *When you think about the patient's time to live, do you think in months or years?*; *If you had to choose for the patient, do you think they would prefer... (curative versus palliative treatment).*

Data analysis

Data elements that were available for a nearly complete triad of patient, caregiver, and oncologist were analyzed (i.e., the patient, caregiver, and oncologist completed the majority of each survey). For items related to prognostic communication, concordance between dyads and triads were calculated and defined as participants' providing congruent responses for a given question, including the answer "I don't know." Discordant responses included any dyad or triad whose answers to the same question differed. Frequency of concordance and discordance across dyads and triads were calculated for each item as a percent agreement and summarized for all items together. Concordance for perceived life expectancy was operationalized as follows: neuro-oncologists provided their estimated life expectancy for the patient as a range of time (weeks, months, years), and if the caregivers perceived that patient life expectancy fell within the oncologist's estimation of life expectancy, then responses were coded as concordant. We summarized results for the entire study population and stratified results by recurrence status (first versus second or more).

Results

Seventeen patient, caregiver, and oncologist triads were analyzed (Table 1). Patients were diagnosed with heterogeneous tumor locations: 5 (29.4%) in the temporal lobe, 3 (17.6%) each in the parietal and frontal lobe, 2 (11.8%) each in the occipital and temporal-parietal lobe, and 1 (5.9%) in the parieto-occipital and corpus callosum. At the time of study participation, GBM status was first recurrence ($n = 7$, 41.2%), second recurrence ($n = 8$, 47.1%), and 2 patients had multiple recurrences (11.8%). We combined second or more recurrences in subsequent results. Patients were mostly male ($n = 12$, 70.6%), White ($n = 14$, 82.4%), and non-Hispanic/Latino ($n = 14$, 82.4%). Caregivers were mostly female ($n = 12$, 70.6%) almost all White ($n = 16$, 94.1%) and non-Hispanic/Latino ($n = 14$, 82.4%), and between the ages of 46 and 64 (88.2%).

Communication processes—frequency

A minority of patients ($n = 3$, 17.6%) and caregivers ($n = 8$, 47.1%) reported having discussed prognosis during the clinical encounter in which tumor progression was disclosed, whereas most oncologists reported having discussed prognosis ($n = 10$, 58.8%; See Table 2). Fewer than one-quarter of patients ($n = 4$, 23.5%) reported having discussed curability; however, over half of caregivers ($n = 9$, 52.9%) and almost three-quarters of oncologists ($n = 12$, 70.6%) reported having discussed the patient's disease curability. Three patients (17.6%) and 6 caregivers and oncologists (35.3%) reported having discussed the patient's EOL goals, but 3 patients (17.6%) could not recall this discussion. Finally, 7 patients (41.2%) and 5 caregivers (29.4%) reported having *ever* discussed prognosis or life expectancy with their oncologist, whereas 13 oncologists (76.5%) reported discussing this matter. Generally, more participants reported discussing different aspects of prognosis when the patient had a second or later recurrence of disease.

Communication processes—concordance

Patient-caregiver dyads were only partially concordant in their reports of what had and had not been discussed at the last visit with the oncologist (Table 3): 8 dyads (47.1%) agreed on whether prognosis had been discussed, 10 dyads (58.8%) agreed on whether curability was discussed, and 7 dyads (41.2%) agreed on whether goals of EOL care had been discussed. However, only 3 dyads (17.6%) had concordant reports of whether a discussion of prognosis or life expectancy with the oncologist had ever occurred. Regarding caregiver-oncologist dyads, 11 (64.7%) agreed on

Table 1 Patient and caregiver demographics

	N(%)
Status of GBM at recurrence discussion	
First recurrence	7 (41.2)
Second recurrence	8 (47.1)
Third or later recurrence	2 (11.8)
Patient's tumor location	
Temporal lobe	5 (29.4)
Parietal lobe	3 (17.6)
Occipital lobe	2 (11.8)
Frontal lobe	3 (17.6)
Frontal-parietal	0
Parieto-occipital	1 (5.9)
Temporal-parietal	2 (11.8)
Occipito-temporal	0
Cerebellum	0
Basal Ganglia	0
Corpus Callosum	1 (5.9)
Patient sex	
Male	12 (70.6)
Female	5 (29.4)
Patient age	
≤ 45	2 (11.8)
46–54	4 (23.5)
55–64	10 (58.8)
≥ 65	1 (5.9)
Patient race	
White	14 (82.4)
Not provided	3 (17.6)
Patient ethnicity	
Hispanic/Latinx	0
Not Hispanic/Latinx	14 (82.4)
Not provided	3 (17.6)
Caregiver sex	
Male	5 (29.4)
Female	12 (70.6)
Caregiver age	
≤ 45	2 (11.8)
46–54	4 (23.5)
55–64	10 (58.8)
≥ 65	1 (5.9)
Caregiver race	
White	16 (94.1)
Not provided	1 (5.9)
Caregiver ethnicity	
Hispanic/Latinx	1 (5.9)
Not Hispanic/Latinx	14 (82.4)
Not provided	2 (11.8)
Caregiver religion	
Catholic	6 (35.3)
Jewish	2 (11.8)
Protestant	3 (17.6)

Table 1 (continued)

	N(%)
Muslim	0
Not religious	3 (17.6)
Other	3 (17.6)
Caregiver highest education	
High School	4 (23.5)
Some College	2 (11.8)
College degree	4 (23.5)
Graduate degree	7 (41.2)
Caregiver marital status	
Married	15 (88.2)
Not married	2 (11.8)
Caregiver born in the United States?	
Yes	14 (82.4)
No	3 (17.6)
Does the patient have health insurance?	
Yes	17 (100.0)
Caregiver relationship to patient	
Spouse	14 (82.4)
Child	2 (11.8)
Sibling	1 (5.9)
Friend	0
Caregiver annual household income	
\$21,000–30,999	0
\$31,000–50,999	1 (5.9)
\$51,000–99,999	4 (23.5)
\$100,000 or more	9 (52.9)
I prefer not to answer	2 (11.8)
I don't know	1 (5.9)

whether prognosis had been discussed, 10 (58.5%) agreed on whether curability had been discussed, and 11 (64.7%) agreed on whether EOL goals had been discussed. However, less than half of caregiver-oncologist dyads agreed regarding whether a discussion of prognosis or life expectancy had ever occurred ($n = 6$, 35.3%). Patient and oncologist pairs agreed less often regarding discussing prognosis ($n = 6$, 35.3%), curability ($n = 7$, 41.2%), goals for care at EOL ($n = 6$, 35.3%), and *ever* discussing prognosis or life expectancy ($n = 6$, 35.3%). Variability in concordance by recurrence status was evident, although there was often greater concordance in dyads where the patient had a second or multiple recurrence.

Concordance between patient, caregiver, and oncologist was ascertained for the discussion of curability, prognosis, and EOL treatment goals at the last visit (Table 4). Out of the 17 triads, between 3 (17.6%) and 5 (29.4%) triads showed fully concordant responses concerning whether curability, prognosis, and EOL goals had been discussed at the last visit and whether prognosis had *ever* been discussed. One

Table 2 Patient, caregiver, and oncologist report of prognostic discussion processes

	Patient			N(%) Caregiver			Oncologist		
	First recurrence	Second or more	Total	First recurrence	Second or more	Total	First recurrence	Second or more	Total
Was prognosis discussed?									
Yes	1 (5.9)	2 (11.8)	3 (17.6)	5 (29.4)	3 (17.6)	8 (47.1)	4 (23.5)	6 (35.3)	10 (58.8)
No	6 (35.3)	8 (47.1)	14 (82.4)	2 (11.8)	7 (41.2)	9 (52.9)	3 (17.6)	4 (23.5)	7 (41.2)
Was curability discussed?									
Yes	2 (11.8)	2 (11.8)	4 (23.5)	5 (29.4)	4 (23.5)	9 (52.9)	5 (29.4)	7 (41.2)	12 (70.6)
No	5 (29.4)	8 (47.1)	13 (76.5)	2 (11.8)	6 (35.3)	8 (47.1)	2 (11.8)	3 (17.6)	5 (29.4)
Were EOL goals discussed?									
Yes	2 (11.8)	1 (5.9)	3 (17.6)	3 (17.6)	3 (17.6)	6 (35.3)	2 (11.8)	4 (23.5)	6 (35.3)
No	3 (17.6)	8 (47.1)	11 (64.7)	4 (23.5)	7 (41.2)	11 (64.7)	5 (29.4)	6 (35.3)	11 (64.7)
I don't know	2 (11.8)	1 (5.9)	3 (17.6)	0	0	0	0	0	0
Have you ever discussed prognosis or life expectancy with oncologist?									
Yes	3 (17.6)	4 (23.5)	7 (41.2)	4 (23.5)	1 (5.9)	5 (29.4)	5 (29.4)	8 (47.1)	13 (76.5)
No	4 (23.5)	6 (35.3)	10 (58.8)	3 (17.6)	7 (41.2)	10 (58.8)	0	1 (5.9)	1 (5.9)
I don't know	0	0	0	0	2 (11.8)	2 (11.8)	2 (11.8)	1 (5.9)	3 (17.6)

EOL end-of-life

triad was fully concordant across reporting the discussion of curability, prognosis, and EOL treatment goals (all reported not discussing these aspects of care). Concordance between patient, caregiver, and oncologist occurred more frequently when everyone reported not having discussed that aspect of care, versus agreeing that an aspect of care was discussed.

Communication goals—frequency

Patients endorsed their cancer stage mostly as middle stage ($n=5$, 29.4%), late stage ($n=5$, 29.4%), or unsure ($n=5$, 29.4%), whereas caregivers identified the patient's cancer stage as middle ($n=4$, 23.5%), late stage ($n=8$, 47.1%), or end stage ($n=4$, 23.5%; See Table 5). Most patients ($n=7$, 41.2%) and caregivers ($n=10$, 58.8%) endorsed wanting a plan of care which relieved pain or discomfort as much as possible. Three patients (17.6%) and 1 caregiver (5.9%) were unsure of their preferences regarding a plan of care. Caregivers' estimates of the patient's life expectancy ranged from 3 months to 3 years, whereas oncologist's estimated life expectancy ranged between 3 months to 2 years. Most patients ($n=10$, 58.8%) and caregivers ($n=11$, 64.7%) identified the purpose of treatment as controlling or slowing down the cancer—no patients

or caregivers identified the purpose of treatment as cure. Nine patients (52.9%) and 11 caregivers (64.7%) reported the patient having completed a DNR order.

Communication goals—concordance

Communication goals were variably concordant between patients, caregivers, and oncologists (Table 3). Just over half of caregiver and oncologist dyads had similar perceptions of patients' treatment preferences ($n=8$, 47.1%). Only 9 dyads offered their perceived life expectancy, and 5 (55.6%) were concordant with the oncologist's report. Of the 11 dyads who responded, patient and caregiver dyads generally agreed on the purpose of the patient's treatment ($n=8$, 72.7%), particularly for patients with a second or multiple recurrence. Most patient-caregiver dyads ($n=12$, 70.6%) agreed on the patient's status of completing a DNR.

Table 3 Concordance on reports of prognostic discussions

Reports of prognostic discussion	Patient and Caregiver			Caregiver and Oncologist			Patient and Oncologist		
	First recurrence	Second or more	Total	First recurrence	Second or more	Total	First recurrence	Second or more	Total
	N (%)			N (%)			N (%)		
Was prognosis discussed? (<i>Yes, No, I don't know</i>)									
Concordance	3 (17.6)	5 (29.4)	8 (47.1)	6 (35.3)	5 (29.4)	11 (64.7)	4 (23.5)	2 (11.8)	6 (35.3)
Discordance	4 (23.5)	5 (29.4)	9 (52.9)	1 (5.9)	5 (29.4)	6 (35.3)	3 (17.6)	8 (47.1)	11 (64.7)
Was curability discussed? (<i>Yes, No, I don't know</i>)									
Concordance	4 (23.5)	6 (35.3)	10 (58.8)	5 (29.4)	5 (29.4)	10 (58.8)	2 (11.8)	5 (29.4)	7 (41.2)
Discordance	3 (17.6)	4 (23.5)	7 (41.2)	2 (11.8)	5 (29.4)	7 (41.2)	5 (29.4)	5 (29.4)	10 (58.8)
Were EOL goals discussed? (<i>Yes, No, I don't know</i>)									
Concordance	2 (11.8)	5 (29.4)	7 (41.2)	4 (23.5)	7 (41.2)	11 (64.7)	2 (11.8)	4 (23.5)	6 (35.3)
Discordance	5 (29.4)	5 (29.4)	10 (58.8)	3 (17.6)	3 (17.6)	6 (35.3)	5 (29.4)	6 (35.3)	11 (64.7)
Have you EVER discussed prognosis or life expectancy with oncologist? (<i>Yes, No, I don't know</i>)									
Concordance	3 (17.6)	0	3 (17.6)	4 (23.5)	2 (11.8)	6 (35.3)	3 (17.6)	3 (17.6)	6 (35.3)
Discordance	4 (23.5)	10 (58.8)	14 (82.4)	3 (17.6)	8 (47.1)	11 (64.7)	4 (23.5)	7 (41.2)	11 (64.7)
Reports of prognostic discussion goals									
N (%)									
What stage is the patient's cancer? (<i>No evidence, early stage, middle stage, late stage, end stage</i>)									
Concordance	2 (11.8)	1 (5.9)	3 (17.6)	-	-	-	-	-	-
Discordance	5 (29.4)	7 (41.2)	12 (70.6)	-	-	-	-	-	-
Patient refused to answer	0	2 (11.8)	2 (11.8)	-	-	-	-	-	-
Has the patient completed a DNR? (<i>Yes, No, I don't know</i>)									
Concordance	4 (23.5)	8 (47.1)	12 (70.6)	-	-	-	-	-	-
Discordance	3 (27.3)	2 (11.8)	5 (29.4)	-	-	-	-	-	-
What is the purpose of treatment? (<i>Relieve symptoms, cure cancer</i>) (<i>n = 11</i>)*									
Concordance	1 (5.9)	7 (41.2)	8 (72.7)	-	-	-	-	-	-
Discordance	1 (5.9)	2 (11.8)	3 (27.3)	-	-	-	-	-	-
Perceived life expectancy of patient (<i>n = 9</i>)*									
Concordance	-	-	-	3 (27.3)	2 (11.8)	5 (55.6)	-	-	-
Discordance	-	-	-	3 (27.3)	1 (5.9)	4 (44.4)	-	-	-
If you could, what plan of care would you choose for the patient?									
Concordance	5 (29.4)	3 (27.3)	8 (47.1)	-	-	-	-	-	-

Table 3 (continued)

Reports of prognostic discussion N (%)	Patient and Caregiver			Caregiver and Oncologist			Patient and Oncologist		
	First recurrence	Second or more	Total	First recurrence	Second or more	Total	First recurrence	Second or more	Total
	Discordance	1 (5.9)	5 (29.4)	6 (35.3)	-	-	-	-	-
Patient refused to answer	1 (5.9)	2 (11.8)	3 (17.7)	-	-	-	-	-	-
Do the caregiver and oncologist perceive the patient's treatment preferences the same?									
Concordance	-	-	-	5 (29.4)	3 (27.3)	8 (47.1)	-	-	-
Discordance	-	-	-	2 (11.8)	7 (41.2)	9 (52.9)	-	-	-

*For these prompts, several dyads had missing data. Accurate dyad numbers and valid percents are reported
EOL end-of-life

Discussion

This study characterized the frequency and concordance of communication processes and goals as reported by GBM patients, their caregivers, and oncologists during a single event of disclosure of recurrence. Caregivers had more concordant reports of the occurrence of prognostic discussion with oncologists than did patients. Patients and caregivers showed more discordant responses with respect to cancer stage, but other communication goals, such as completion of DNR orders and treatment purpose, showed less discordance in the patient-caregiver dyad. Discordance arose in almost all patient-caregiver-oncologist triads regarding the occurrence of communicating processes, such as prognosis, curability, and EOL goals of care. Patients and caregivers generally did not understand the prognostic discussion in the way oncologists recalled, although caregivers were slightly more prognostically aware than patients.

Discordant PU between patients, caregivers, and healthcare providers is common in the oncology setting. In terminally ill Taiwanese cancer patients, patient-caregiver concordance regarding patient preferences for life-sustaining treatments was generally poor, with only slight improvement in concordance as the patient neared death [20]. Discordance was also higher when patients were more distressed or when caregivers were opposed to more aggressive life-sustaining treatment options, suggesting the importance for open discussion of values and treatment preferences. In a study of caregivers and oncologists of adult cancer patients, only 28% of dyads relayed concordant life expectancy estimates, and multivariable analyses showed that caregivers reporting greater depressive symptoms were more likely to have life expectancy responses that were concordant to those of their oncologist [21] suggesting “depressive realism”; on the other hand, anxiety has been shown to undermine accurate PU [22]. This discrepancy may also reflect either a lack of accurate understanding of prognosis, or a variable willingness to report such understanding [23]. Our research showed a similar pattern where oncologists recalled communicating more realistic understanding of the cancer trajectory than patients and caregivers.

A small yet growing body of literature has focused on PU in patients with brain tumors. In one study of caregivers of patients with MG, over two-thirds were aware of the incurability of the disease and had accurate estimates of life expectancy, yet half desired more thorough information regarding the patient's prognosis [24]. Other studies have shown variability in patients' and caregivers' PU over time. In a longitudinal study of newly diagnosed MG patients and their caregivers, PU fluctuated over time,

Table 4 Concordance of prognostic understanding between patient, caregiver, and oncologist

Triad	Recurrence status	Was curability discussed at the visit?			Was prognosis discussed at the visit?			Were end-of-life treatment goals discussed at the visit?			Did you discuss prognosis at a prior visit?		
		Patient	Caregiver	Oncologist	Patient	Caregiver	Oncologist	Patient	Caregiver	Oncologist	Patient	Caregiver	Oncologist
1	Second or more	-	+	+	-	+	+	-	+	-	?	+	
2	First	-	-	-	-	-	-	-	-	-	-	?	
3	Second or more	-	-	-	+	-	-	-	-	+	-	+	
4	First	-	-	+	-	+	-	+	+	+	+	+	
5	Second or more	+	-	+	-	-	-	-	-	+	-	+	
6	Second or more	-	-	+	-	-	+	-	+	+	-	+	
7	First	+	+	-	-	-	-	?	-	-	-	+	
8	First	+	+	+	+	+	+	?	-	+	+	+	
9	Second or more	-	+	+	-	+	+	-	+	-	+	+	
10	First	-	+	+	-	+	+	-	+	+	+	+	
11	Second or more	-	-	+	-	-	+	-	+	-	-	+	
12	Second or more	-	-	+	-	-	+	-	+	-	?	+	
13	First	-	+	+	-	+	+	+	+	-	-	?	
14	Second or more	-	-	-	-	+	-	-	-	+	-	-	
15	Second or more	-	+	-	+	+	-	?	-	-	-	?	
16	Second or more	+	+	+	-	-	+	+	-	-	-	+	
17	First	-	+	+	-	+	+	-	+	-	+	+	

Minus signs depict answering "no", plus signs depict answering "yes", question marks depict "I don't know"

Table 5 Patient and caregiver report of prognostic discussion goals

What stage is the patient's cancer?	Patient			Caregiver		
	First recurrence	Second or more	Total	First recurrence	Second or more	Total
No evidence of cancer	0	0	0	1 (5.9)	0	1 (5.9)
Early stage	0	0	0	0	0	0
Middle stage	2 (11.8)	3 (17.6)	5 (29.4)	3 (17.6)	1 (5.9)	4 (23.5)
Late stage	2 (11.8)	3 (17.6)	5 (29.4)	3 (17.6)	5 (29.4)	8 (47.1)
End stage	0	0	0	0	4 (23.5)	4 (23.5)
I don't know	3 (17.6)	2 (11.8)	5 (29.4)	0	0	0
Prefer not to answer	0	2 (11.8)	2 (11.8)	0	0	0
Has the patient completed a DNR?						
Yes	4 (23.5)	5 (29.4)	9 (52.9)	6 (35.3)	5 (29.4)	11 (64.7)
No	1 (5.9)	4 (23.5)	5 (29.4)	0	4 (23.5)	4 (23.5)
I don't know	2 (11.8)	1 (5.9)	3 (17.6)	1 (5.9)	1 (5.9)	2 (11.8)
What is the purpose of treatment?						
To cure the cancer	0	0	0	0	0	0
To control or slow down the cancer	1 (5.9)	9 (52.9)	10 (58.8)	5 (29.4)	6 (35.3)	11 (64.7)
To treat their symptoms	0	1 (5.9)	1 (5.9)	0	2 (11.8)	2 (11.8)
To help them live longer	1 (5.9)	0	1 (5.9)	0	1 (5.9)	1 (5.9)
Missing	5 (29.4)	0	5 (29.4)	2 (11.8)	1 (5.9)	3 (17.6)
If you could, what plan of care would you choose for the patient?						
Extend life as much as possible	2 (11.8)	2 (11.8)	4 (23.5)	2 (11.8)	4 (23.5)	6 (35.3)
Relieving pain/discomfort as much as possible	3 (17.6)	4 (23.5)	7 (41.2)	4 (23.5)	6 (35.3)	10 (58.8)
I don't know	1 (5.9)	2 (11.8)	3 (17.6)	1 (5.9)	0	1 (5.9)
Prefer not to answer	1 (5.9)	2 (11.8)	3 (17.6)	0	0	0

*DNR do not resuscitate order

such that patients and caregivers were at times highly optimistic and at other times more realistic. However, discordance between patients and caregivers existed in over two-thirds of dyads at each timepoint [25]. Interestingly, authors noted that patients were more likely to predict a shorter life expectancy at specific timepoints when they discussed discontinuing treatment or hospice during the medical encounter. One interpretation of this finding is that patients may be more attuned to understand their prognosis when discussions are grounded in the choice of specific treatments and goals of care. Our findings mirror those previously observed of substantial discordant understanding existed between patients and caregivers and adds the unique perspective of PU among healthcare providers, which has yet to be specifically examined in neuro-oncology. It may be particularly difficult for patients, caregivers and oncologists to discuss aspects of prognosis in brain tumor patients with such a precipitous drop in functional capacity. These conversations require attention among researchers to identify where difficulties in these conversations may arise. The caregiver role may be leveraged by oncologists in these conversations as they may

be more functionally able to understand information and make decisions.

Our results suggest that perceptions of a prognostic discussion may differ between oncologists and patients/caregivers. Several factors may shape *how* and *what* is digested by patients and caregivers during prognostic discussion. First, it is possible that what an oncologist perceives as a prognostic discussion may not be understood as such by patients and caregivers. Cognitive impairment or the presence of anxiety and distress among patients and caregivers at the time of tumor progression may impact capacity to receive and fully process information. Prior studies have found that among patients with cancer, higher levels of anxiety have been associated with less accurate understanding of scan results [22]. Despite the many benefits of prognostic disclosures mentioned above, discussing advanced care planning and prognosis is difficult for all parties involved, and in some cases, oncologists may be hesitant to share prognostic information or lack the proper training to initiate these conversations. Tailoring the goals and processes of prognostic discussions to patients' values and preferences may likely increase patients' understanding and facilitate oncologists' ability to

achieve openness in such conversations. Interventions which help oncologists communicate the “gist” of prognostic information in a simple, yet accurate manner have been developed to augment accurate PU [26].

This study has several limitations. The sample was limited to patient-caregiver-oncologist triads who had nearly complete data, resulting in a small sample size. We acknowledge the overall small sample size and the impact of this upon generalizability. Our sample also lacked diversity, with most patients and caregivers identifying as White and non-Hispanic. Oncologists completed one assessment which was not inclusive of all questions asked of patients and caregivers, further limiting our ability to fully examine patient-oncologist or oncologist-caregiver concordance. Additionally, this study focused on a single discussion between patient, caregiver, and oncologist, and required participants to reflect on aspects of prognosis discussed solely in that conversation. Subsequent discussions of prognosis may have attended to more thorough aspects of patient’s PU and their capacity to hear, process, and act on information shared by their oncologist. As some patients and caregivers completed the study surveys at home, we cannot be sure that the surveys weren’t discussed or completed together; however, in the process of informed consent, participants verbalized understanding that assessments were intended to be completed separately.

Despite these limitations, our findings highlight gaps between patient, caregiver, and oncologist understanding of communication processes and goals related to disease progression. Moving forward, oncologists need to communicate more directly around aspects of prognosis to help patients and caregivers understand that this is the topic of conversation. Further research is needed to identify where discordant understanding regarding goals and communication processes are fostered to help facilitate accurate PU.

Author contributions ED, HP, KP, AA, and AR designed the study. ED, AT, and TW collected data. JB, AS, LW, KP, AA, and AR analyzed the data. ED, LW, HP, KP, AR, and AA interpreted the data. LW, LP, AA, HP, KP, AR, and ED wrote the manuscript. All authors revised and approved of the final manuscript.

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Data availability The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

Code availability Not applicable.

Declarations

Competing interest Dr. Diamond discloses unpaid editorial support from Pfizer, Inc, and paid advisory board membership for Day One

Biopharmaceuticals and Springworks Therapeutics, both outside the submitted work. Dr. Applebaum receives support from Bluenote Therapeutics. Dr. Walbert discloses paid advisory board membership for AstraZeneca and work for NovoCure.

Ethical approval This study was approved by the ethics at each institution (IRB Number 15-034 at Memorial Sloan Kettering Cancer Center; IRB number 17-0540 at University of Vermont, IRB number 11458 at Henry Ford Health System).

Informed consent Informed consent was obtained from all individual participants (patients, caregivers, and physicians) included in the study. Consent for publication was obtained via informed consent and all data presented have been de-identified.

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