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Prognostic Awareness and Communication of Prognostic Information in Malignant Glioma: A Systematic Review

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Abstract

Malignant glioma (MG) is a devastating neurological disease with a uniformly poor prognosis and a clinical course characterized by progressive functional and cognitive impairment. A small body of literature addresses patients' and caregivers' prognostic awareness (PA), or understanding of prognosis in patients with cancer. Studies that examine PA and desire for prognostic information among patients with MG are limited. We sought to review the existing literature on PA and communication of prognostic information to patients with MG. Fourteen studies examining PA or experience and preferences regarding communication of prognostic information were included. The definition and measurement of PA across studies varied, and the prevalence of accurate PA ranged from 25% to 100% of participants. There is likely a subset of patients who do not desire accurate prognostic information, although the patient and disease characteristics that predict this preference are currently unknown. This review suggests that patients with MG desire prognostic information communicated in a manner that preserves hope. Systematic investigation to define communication needs for prognostic information in the unique clinical setting of MG is needed.

Keywords

Prognostic awareness; malignant brain tumor; glioblastoma; prognosis; communication; information needs; supportive care

Introduction

Among patients with advanced cancer, prognostic awareness (PA) is the awareness of terminal prognosis or shortened life expectancy. PA has become a topic of increasing interest in the fields of healthcare communication and psycho-oncology as accurate PA is associated with reduced psychological distress [1-4], improved end-of-life planning and establishment

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of advanced directives, and improved quality of life [5-8]. Evidence suggests that patients with advanced cancer often do not understand the seriousness of their illness and believe that palliative treatments have curative intent [9, 10]. Physicians' practices in discussing prognosis have evolved over recent decades, but attitudes regarding the psychological impact of disclosing prognosis remain an impediment to successful communication [11-13]. Accurate PA varies significantly across studies of patients with advanced cancer, but in some as few as one-third of patients demonstrate full PA [14, 15]. Variation in estimates of PA is multiply determined, but may in large part be due to inconsistency in the definition and measurement of PA and cultural differences in the practice of disclosure of prognostic information to patients with cancer and their caregivers [9].

Malignant glioma (MG) is an aggressive brain tumor that compromises cognitive function and has a uniformly poor prognosis. It is often challenging to discern PA and preferences for information about prognosis in this population. There is no consensus about the optimal method of assessing PA, preferences for the communication of prognostic information, or strategies for communicating prognosis in MG. Three review articles have addressed communication in MG generally, although none focused specifically on communication of prognostic information or PA in light of preferences for communication [16-18]. The purpose of this study was to review the existing evidence about PA and communication of prognosis in MG and the extent to which this area is currently addressed in clinical practice.

Method

Five databases with no specified date range or age group were searched: MEDLINE (via PubMed), Embase, The Cochrane Library, Web of Science, and PsycINFO (via OVID). We also searched grey literature sources, including: American Academy of Neurology, Society for Neuro-Oncology, American Society of Clinical Oncology, European Organisation for Research and Treatment of Cancer, Online Computer Library Center, WorldCat, and New York Academy of Medicine Grey Literature Report. The search strategy had four components, and all concepts were linked with the AND operator: (1) neoplasm or glioma; (2) awareness or communication; (3) prognosis; and (4) brain (Figure 1). A study was deemed relevant to PA if it presented a quantitative or qualitative description of participants': (1) awareness of incurability of MG; or (2) awareness of survival estimates for MG. A study was deemed relevant to communication of prognostic information if it presented a qualitative or quantitative description of patients': (1) preferences for content or timing; or (2) overall experience of communication regarding the prognosis of MG. It was not required that the participant population was comprised predominantly of patients with MG, only that the proportion of participants with MG was defined. Of the 8,539 records retrieved, 10 met inclusion criteria for this systematic review. Four additional articles were added from bibliographic searches, for a total of 14 studies, three of which were relevant review articles (Table 1).

Results

Prognostic Awareness

Of the 14 studies retrieved, six evaluated PA (Table 2). Approaches to the measurement of PA have previously been categorized as structured methods (i.e., participants respond to identical questions about PA), semi-structured methods (i.e., an interview guide containing a list of questions and topics to be covered allows participants' responses to shape the interview), or unstructured methods (i.e., using open-ended interviewing techniques) [9]. Three of the studies reviewed used semi-structured methods, and three used unstructured methods. Criteria for defining PA varied among the studies; five framed PA with respect to awareness of incurability, although incurability was often referenced by proxy or euphemism (e.g., "grave danger" or "inescapable implications of the diagnosis"), and only one made specific reference to life expectancy. Only two studies measured the association between accurate PA and psychological distress [19, 20]. Cognitive deficits were measured in one study [20] and were specifically mentioned as excluding participation in the assessment in two [19, 21].

The first study of PA [19] consisted of sequential qualitative interviews with 75 patients at diagnosis of MG, 58 patients after radiotherapy, and 27 at recurrence. Patients with poor cognitive function were excluded, although no specific criteria were provided. Open-ended interviews explored the experience of radiotherapy and awareness of likely prognosis. PA, defined as the extent to which patients believed that radiotherapy might cure them and whether they were aware that they might die from their disease, was rated as full, partial, or none. Psychological distress demonstrated during the interview was rated as "marked, moderate, some, or nil." Fewer than 25% of patients had full PA at diagnosis, 32% had partial PA, and 43% had no awareness, believing they had a reasonable chance of cure. At disease recurrence, 52% of the patients had full PA and 26% had no awareness. Inter-rater reliability ranged from moderate to good for a subset (N=13) of patients assessed. Concordance of PA between patients and relatives was low; nearly three times as many relatives had full PA (67%) as patients. Qualitative analyses suggested that relatives felt it was their role to protect the patient from accurate prognostic information. Patients with full PA were more likely to demonstrate psychological distress in the interview.

These findings vary greatly from those of Salander et al. [21], who performed two qualitative interviews with 30 patients with MG. Eleven were interviewed but excluded from the analyses because of cognitive impairment. The interview contained structured and unstructured components exploring experiences of medical care, knowledge about the disease, familial relationships, and thoughts about the future. The authors found that a majority of patients (58%) had full PA defined as the "awareness that the disease may be fatal." The focus of qualitative analyses was patients' cognitive strategies for creating hope as a manner of coping with the disease and its prognosis.

Lyons et al. described PA in 20 patients with MG in a mixed-methods study in which a semi-structured interview was combined with the PRESTON quality of life scale [22]. PA emerged *post hoc* in the context of an interview about coping with the "inescapable future" and was defined as "the degree of insight that the patient had into her/his conditions."

Qualitative analysis demonstrated three groups of MG patients with respect to PA, although the proportions of each were not described: (1) those who did not have accurate PA because of cognitive impairment or because the family concealed prognostic information; (2) those who did not want to know or demonstrated denial; and (3) those with full awareness. Those with full PA indicated that discussion about their prognosis with friends, family, or medical professionals was experienced as taboo and that the research interview itself was “liberating.”

Eight patients with glioblastoma undergoing stereotactic radiosurgery were examined for PA with open-ended interviews about their experiences with this treatment [23]. Transcripts were analyzed using qualitative methods. Although measurement of PA was not an aim of the study, one of the identified themes was “awareness of diagnosis,” and “all” participants were aware of their poor prognosis and disease-related survival statistics. Nonetheless, participants maintained hope that radiosurgery would extend their survival beyond what was expected.

In 40 patients with brain tumors, 16 with MG, the relationship between mood disorders, physical and psychological functioning, and PA was studied [20]. However, PA was evaluated in caregivers—not patients—via a semi-structured interview evaluating caregivers’ perception of patients’ knowledge of diagnosis and prognosis. Patients were categorized into one of four categories of awareness, ranging from complete denial of their illness to acceptance of the diagnosis and its implications: 49% were fully aware, 7% were completely unaware, and the remaining 43% had intermediate levels of knowledge. Fewer patients with MG had full PA compared to those with low-grade tumors. There was a trend suggesting that patients’ fuller awareness of prognosis was associated with less psychological distress.

Sequential interviews prior to diagnosis, following diagnosis, after the initiation of treatment, and six months into treatment were performed in 26 patients with a suspected brain tumor, 17 with confirmed MG [24]. Interviews evaluated the experience of receiving the diagnosis of a brain tumor, existential concerns, and thoughts about death. PA was loosely defined as awareness that “progression of their disease was likely.” The authors found that “most” were “aware” although the proportion of patients with accurate PA was not quantified. Anxiety and preoccupation about life expectancy were found to be prominent, although the proportion of patients expressing this feeling was not calculated. The authors concluded that prognosis should be a topic of discussion from the time of diagnosis of MG.

Communication of Prognostic Information

Five studies evaluated patient preferences or experiences related to communication of prognostic information (Table 3). Three addressed the question of how much prognostic information patients with MG desire [25-27]. In all studies, potential participants were excluded because of cognitive impairment, although the measurement and parameters of impairment were not defined. In one study, 19 with MG had semi-structured interviews within one year of diagnosis [26]. The interviews focused on patients’ needs for information and support, specifically the content, timing, and comprehension of prognostic information they had received. Themes that emerged included uncertainty regarding prognosis, the need

for prompt and accurate prognostic information, and frustration with vague or unclear information. However, some patients did not want full information, preferring only minimal or positive information. Proportions of patients with varied preferences were not discussed.

Patient-physician communication was examined in 26 patients with MG, including preferences for information about prognosis, comprehension of information, and satisfaction with information [25]. Relationships between these constructs and anxiety and depression were analyzed. Sixteen of the 42 patients were excluded because of cognitive impairment or their stated or perceived wish not to discuss prognosis. Data were collected with a brief questionnaire with Likert-type responses. Fifty percent of participants preferred “all information,” while the remainder wanted only “important” or “critical” information. Sixty-nine percent of patients reported “full” or “satisfactory” comprehension of the information provided. Patients who preferred “all” information and had good reported comprehension of and satisfaction with information had significantly lower levels of anxiety than those who did not want or understand this information. The authors concluded that adequate communication of information promotes adaptation to the diagnosis of MG and improved psychological well-being.

The experiences of 19 patients with MG and their 21 caregivers of receiving diagnostic and prognostic information were evaluated using semi-structured interviews assessing the amount and quality of prognostic information they had received. [28]. Several themes emerged from qualitative analyses, including: (1) difficulty assimilating prognostic information; (2) the experience of receiving detailed prognostic information (i.e., specific estimates of life expectancy) as injurious to hope; (3) the need for individually-tailored prognostic information; and (4) ineptitude in physicians’ communication skills. The study highlighted the difficulty of delivering prognostic information to patients with MG early in the disease trajectory and the need to adapt information for individual patients and caregivers.

A study of focus groups of patients with brain tumors and their caregivers suggested, however, that prognosis is not discussed early enough in MG [29]. The broad topic of the focus groups was supportive care in many dimensions, with communication not a central concern *a priori*, although a specific communication-oriented theme emerged *post hoc*. Qualitative analyses of the transcripts indicated that anxiety related to reduced life expectancy was typically addressed in the hospice setting, but both patients and caregivers wanted support and information about shortened survival before this stage. These findings suggest that discussion to optimize support and coping with poor prognosis is a necessary intervention in the routine continuum of care of patients with MG.

Ten patients with malignant brain tumors and four of their caregivers participated in semi-structured interviews consisting of 31 items pertaining to maintaining and promoting hope [27]. Six questions focused on communication of information about the disease, and specifically, the delivery of bad news and preferences for “positive” or “negative” information. Results indicated that patients wanted “both good and bad news” about their prognosis, and that “most” even prefer to be told explicit statistics such as median survival time. However, participants also preferred that such information be intermixed with

presentation of hopeful examples and reminders of the possibility of survival beyond standard estimates. The authors concluded that prognosis should be discussed in a manner that is factual but emphasizes the individual trajectory of every patient.

Discussion

The six studies reviewed here reported disparate findings regarding PA in MG. Although the precise definition of PA differed across studies, the essence of PA in nearly all was awareness of the incurability of MG. Full PA was found in as few as 25% of participants in one study [19] and as many as 100% of participants in another [23]. The reasons for inaccurate PA were not consistent across studies, and while observational studies are limited in their ability to determine causality, three potential contributing factors were discussed: (1) patients' preference to not know their prognosis; (2) caregiver efforts to conceal prognosis; and (3) poor delivery of information by physicians. Demographic or clinical features of patients with inaccurate PA are not known. Interviewing methodology (e.g., structured, semi-structured, or unstructured) did not appear to affect the reported prevalence of PA, as has been found in studies of PA in advanced systemic cancers [9]. Only three of the six studies quantified a proportion of patients with full PA [19-21] and these were the three studies for which PA was the intended research question. Furthermore, these were the only studies that demonstrated a proportion of participants with inaccurate PA. These prospective and quantitative approaches are more reliable with respect to PA measurement, and therefore we conclude that there is likely a sizable portion of patients with MG who are unaware of the incurability of their disease. Characterizing this subset of patients and the reasons for inaccurate PA requires further study. In our experience, the assessment of PA in the clinical setting is extremely challenging as optimistic statements can be mistaken for inaccurate PA if taken in isolation or out of context. The most reliable assessment of PA, we find, takes place over time and over many conversations throughout the disease trajectory.

Data about participants' preferences for and experience of communication of prognostic information in MG is limited. Our review suggests that prognosis is a central concern for patients with MG, but that: (1) wishes for information are conflicting, and (2) communication of prognostic information is perceived as unsatisfactory when it is detrimental to hope. In studies measuring the desire for prognostic information, some patients with MG desire "all" prognostic information while others prefer only "positive" information. One study quantified patients' wishes for prognostic information [25] and found that 50% of patients wanted "all" information. Findings regarding satisfaction with communication of prognostic information were also disparate, with prognostic information characterized as vague and insufficient in one study and overwhelming in another. The recurring theme of hope raises the possibility that the level of detail of prognostic information may be less intrinsically important for satisfaction with communication than the delivery of accompanying and counterbalancing information promoting and maintaining optimism. The beneficial effects of optimism on quality of life among patients with advanced cancer has been described, although it has been shown that patients vary in their preferences and ability to incorporate both candid prognostic information and hopeful information simultaneously [30, 31]. It is uniquely challenging in the setting of MG to provide truthful information and to sustain hope in an authentic manner; strategies include

the provision of examples of optimistic outcomes, emphasis upon the favorable aspects of a patient's present situation such as their otherwise good physical health, or the demarcation of short-term survival milestones that are achievable in the immediate future [21, 27, 32]. We have found that the very act of verbalizing this paradox—which is to say that we explicitly communicate our wish to be simultaneously both factual and optimistic—is helpful for patients and families in navigating this tension and in fostering an environment of honest yet compassionate communication. The studies reviewed suggest that communication of prognostic information is particularly challenging in early phases of the disease—perhaps because of the possibility of a deleterious effect upon hope—and that communication is likely least effective and satisfactory in this period. Future studies are needed to examine communication strategies that foster hope while allowing patients and their caregivers to have an accurate understanding of their illness trajectory and maintain trust in their physician's honesty.

Although the literature on the measurement of PA in patients with advanced cancers is generally limited [9], studies have yielded findings similar to those reported here. There is no consensus on how PA should be defined, and definitions of PA have ranged from an awareness of metastatic or advanced disease to specific survival estimates. There remains great variation in the methods of assessing PA among patients with advanced cancer generally. While two measures have received great attention and have been widely used [1, 33], the validation of these measures across patients with a variety of cancer types—including MG—is needed. Future studies are needed to evaluate the relative utility of these measures and their validity and appropriateness in the context of MG.

For both PA and preferences for communication of prognostic information in patients with MG, there are several dimensions that are critical to understand and are largely unexplored. First, patient-related factors such as age, race, ethnicity, and religion may be associated with patterns of PA and communication preferences, and these have yet to be identified. Second, disease-related factors such as neurocognitive impairment and its relationship to PA are unexplored. In the studies reviewed, cognitively impaired patients were excluded, and minor impairments were neither measured nor analyzed. Examinations of PA that account for the nature and severity of cognitive impairments are necessary to obtain a more thorough understanding of PA and its determinants in MG. Additionally, the relevance of cognitive impairment to communication preferences has not been evaluated. Impaired cognition could potentially alter numerous dimensions of an individual's experience of prognostic information, including comprehension and retention of information, preferences for information, and affective response to information. The effect of cognitive impairment on patient-physician communication in cancer generally is poorly understood, although there is limited evidence suggesting even minor impairments may affect end-of-life decision making [34]. As cognitive impairment is essentially ubiquitous in MG, its impact must be studied to achieve a comprehensive understanding of communication preference of patients with this disease.

Whether accurate PA is associated with psychological distress is a critical and unanswered question in MG. Two studies reviewed here addressed this relationship. One [19] examined the association between PA and psychological distress, although “distress” in this study was

measured subjectively by distressed affect demonstrated in interviews with patients rather than via a measure of an ongoing psychological state. Importantly, sadness or anxiety expressed during discussion of prognosis may not reflect an overall relationship between PA and psychological state. Another study [20] evaluated participants' prognosis-related anxiety through caregiver perception, also an insufficient source from which to draw conclusions about the relationship between PA and the psychological wellbeing of patients. The question of this important correlate of PA remains largely unexplored and should be the focus of future study.

Limitations

Several limitations of this review must be acknowledged. First, articles reviewed were limited to those written in English. The number of articles meeting inclusion criteria was quite small, and the reviewed studies were generally modest in terms of sample size. Therefore, while we have synthesized the collective findings, they may not generalize to the larger population with MG. It is possible that articles in the supportive care literature addressing this topic peripherally were not captured in our search, but we believe that we have captured all studies of PA and communication in the MG population.

Conclusion

This review suggests that prognosis is a central concern for patients with MG and that the delivery and assimilation of prognostic information is a challenging process for patients and physicians. A significant proportion of patients with MG likely do not possess full PA, and the underlying reasons for this are multifaceted and poorly understood. Outcomes related to PA such as psychological well-being and quality of life have yet to be adequately examined. Patients' preferences for communication of prognostic information require further clarification, although our review suggests ambivalence regarding the desire for factual information and the need to maintain hope. Additionally, caregiver PA and communication needs are essentially unexplored. Further research is necessary to understand PA in patients with MG and their caregivers, as PA has significant implications for patient and caregiver wellbeing, treatment planning, and bereavement outcomes.

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Figure 1. Search strategy

The databases included were MEDLINE (via PubMed), Embase, The Cochrane Library, Web of Science, and PsycINFO (via OVID). For PubMed, Embase, The Cochrane Library, PsycINFO, both controlled vocabulary and text words were used in the development of the search strategies. The Web of Science database does not employ a controlled vocabulary, so it was searched using only text words. Filters were used to limit results to English, Spanish, and French, languages in which at least one of the authors is proficient. All search results were combined in a bibliographic management tool (EndNote) and duplicates were eliminated both electronically and manually. Articles were screened by title, abstract, and then full text. Four articles were identified outside of the systematic search.

Table 1

Design and Methods of all Studies

Author	Year	Country	Design	Methods/Measures
Anderson [20]	1999	UK	Cross-sectional	Quantitative analysis of understanding of disease and psychological distress
Catt [18]	2008	United Kingdom	Systematic review	Review of psychosocial and supportive care needs in MG
Cavers [24]	2012	United Kingdom	Longitudinal	Qualitative analysis of interviews about the experience of receiving the diagnosis of a brain tumor, existential concerns, and thoughts about death
Davies [19]	1996	United Kingdom	Longitudinal	Qualitative analysis of interviews about the experience of radiotherapy, awareness of likely prognosis, and psychological distress
Davies [17]	2003	United Kingdom	Systematic review	Review of needs for communication and information in MG
Diaz [25]	2009	Spain	Cross-sectional	Quantitative analysis of preferences for information, comprehension of information provided, and satisfaction
Ford [16]	2012	United Kingdom	Systematic review	Review of supportive care needs in MG
Halkett [26]	2010	Australia	Cross-sectional	Qualitative analysis of an interview about information needs
Janda [29]	2006	Australia	Cross-sectional	Qualitative analysis of focus group discussions about supportive care needs
Lobb [28]	2011	Australia	Cross-sectional	Qualitative analysis of an interview about the experience assimilating diagnosis and prognosis
Lyons [22]	1996	United Kingdom	Cross-sectional	Qualitative analysis of an interview about hope, living with disease, and accepting prognosis
Rosenblum [27]	2009	United States	Cross-sectional	Qualitative analysis of an interview about maintaining hope in MG
Salander [21]	1996	Sweden	Longitudinal	Qualitative analysis of open-ended interviews about coping with the diagnosis of MG.
Ward-Smith [23]	1997	United States	Cross-sectional	Qualitative analysis of an interview about experience with radiosurgery

Table 2

Prognostic Awareness in Malignant Glioma

Author	Patients	Timing	PA definition	Results
Anderson (1999) [20]	40 with brain tumors, 16 with MG	16 months of initial treatment	“Understanding the diagnosis and its implications”	<ul style="list-style-type: none"> 49% had full PA 43% had limited PA 7% no PA
Cavers (2012) [24]	26 with suspected brain tumors, 17 with MG	6 months of initial treatment	“Awareness that progression of disease was likely”	<ul style="list-style-type: none"> “Most” possessed PA
Davies (1996) [19]	75 with MG	At diagnosis, after radiotherapy, and at recurrence	“Belief in the possibility of cure and thoughts about the possibility of death”	<ul style="list-style-type: none"> 25% had full PA at diagnosis 52% had full PA at recurrence
Lyons (1996) [22]	20 with MG	Any time in disease course	“Understanding and acknowledging the seriousness of their illness”	<ul style="list-style-type: none"> “Some” did not understand prognosis “Others” did not want to know “Others” understood fully
Salander (1996) [21]	19 with MG	At diagnosis	“Awareness that the brain tumor exposed them to grave danger”	<ul style="list-style-type: none"> 58% had full PA
Ward-Smith (1997) [23]	8 with MG	1 year from diagnosis	Awareness that prognosis is poor and awareness of survival statistics	<ul style="list-style-type: none"> 100% had full PA

Table 3

Communication of Prognostic information in Malignant Glioma

Author	Patients	Timing	Outcome Evaluated	Results
Diaz (2009) [25]	26 with MG, 18 caregivers	At diagnosis	Preferences for information about diagnosis and prognosis. Satisfaction with information.	<ul style="list-style-type: none"> • 50% wanted all information about disease. • 68% fully or sufficiently comprehended information received. • Desire for information and comprehension of information was associated with reduced anxiety.
Halkett (2010) [26]	19 with MG	1 year of diagnosis	Preferences for information about diagnosis and prognosis.	<ul style="list-style-type: none"> • Prognostic information is inaccurate and not delivered early enough. • Some patients prefer only minimal/optimistic prognostic information.
Janda (2006) [29]	18 with brain tumors, 6 with MG	Any time in disease course	Supportive care needs, including communication and information.	<ul style="list-style-type: none"> • Anxiety about prognosis and life expectancy exists throughout the disease course but is often addressed only in the hospice setting.
Lobb (2011) [28]	19 with MG, 21 caregivers	1 year of diagnosis	Communication of prognosis during first visit.	<ul style="list-style-type: none"> • Delivery of prognostic information can minimize hope. • Delivery of prognostic information should be individually tailored.
Rosenblum (2009) [27]	10 with MG, 4 caregivers	Any time in disease course	Information needs to promote hope.	<ul style="list-style-type: none"> • Patients want “good and bad” information about prognosis. • “Most” want estimates of life expectancy. • Optimism and examples of positive outcomes can allow for the preservation of hope in the delivery of prognostic information.