


PAPER

Prognostic awareness and communication preferences among caregivers of patients with malignant glioma

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Funding information

Translation and Integrative Medicine Award, awarded to Drs. Diamond and Applebaum; NIH/NCI Cancer Center Support, Grant/Award Number: P30 CA008748, PI: Craig Thompson; Conquer Cancer Foundation of the American Society of Clinical Oncology, awarded to Dr. Diamond; National Cancer Institute Training Grant, Grant/Award Number: T32 CA009461, PI: Jamie Ostroff

Abstract

Objective: Malignant glioma (MG) is a devastating neuro-oncologic disease with almost invariably poor prognosis, yet many families facing malignant glioma have poor prognostic awareness (PA), or the awareness of the patient's incurable disease and shortened life expectancy. Accurate PA is associated with favorable medical outcomes at end-of-life for patients and psychosocial outcomes for informal caregivers (ICs) through bereavement. To date, however, no study has specifically examined PA among MG ICs and the information they receive that shapes their awareness.

Methods: Thirty-two ICs of patients with malignant glioma completed a semi-structured assessment of their awareness of the incurability and life expectancy of their loved one's illness, and to understand their sources of prognostic information and preferences for communication of prognostic information.

Results: Twenty-two (69%) ICs had full PA—awareness of the incurability of malignant glioma and accurate estimates of their loved ones' life expectancy. Twenty-three (72%) felt that prognostic information was *extremely* or *very* important to possess, and 16 (50%) desired more prognostic information. The majority of ICs received prognostic information from physicians and the Internet. Qualitative analyses revealed that many ICs had difficulty navigating medical encounters in which they concurrently wanted to elicit prognostic information from physicians and protect patients from such information.

Conclusions: Accurate and timely PA is necessary for ICs to serve as critical members of health care teams. Interventions are needed to foster ICs' skills in navigating prognostic communication with patients and health care providers and thereby improve their ability to advocate for their loved one's wishes.

KEYWORDS

advanced care planning, cancer caregivers, communication, malignant glioma, prognostic awareness

1 | BACKGROUND

Informal caregivers (ICs) provide uncompensated care for medically ill relatives that involves significant time and energy and requires the performance of tasks that may be physically, emotionally, socially, existentially or financially demanding. In 2015, approximately 39.8 million people in the United States served as ICs, including 3 million for cancer patients.¹ The important role of ICs to patients' health care and treatment decision making is increasingly appreciated.² ICs frequently broker

information flow between patients and health care professionals³⁻⁵ and commonly report withholding negative prognostic information from patients.^{6,7} Unfortunately, such protective buffering creates a vicious cycle in which patients and ICs share less and less candor with one another about the patient's illness and what the future may hold.⁶ By contrast, open disclosures between ICs and patients are related to better quality of life, greater relationship satisfaction and intimacy, and less distress for patients and ICs.⁸

Prognostic awareness (PA) is the awareness of a patient's incurable disease and shortened life expectancy. PA is necessary for ICs to

effectively advocate for their loved one's interests in treatment decision making, a central responsibility of ICs' role as designated health care proxies and critical to achieving patient-centered care. Yet, a growing body of literature highlights ICs' lack of sufficient—and desire for more—prognostic information,⁹ as well as a discrepancy in PA between patients and ICs.^{8,10} It is well documented that disagreements are common between patients and ICs about end-of-life (EOL) treatment preferences,^{2,5,10,11} with ICs more likely to prefer aggressive EOL care.^{5,10,12} Moreover, ICs are generally unsuccessful in estimating their loved one's EOL treatment preferences,^{10,13,14} and dysfunctional family communication about prognosis magnifies that discrepancy.¹⁰ Therefore, understanding *what* ICs know about their loved one's prognosis and *how* they go about developing that understanding is critical to equipping them with the skills needed to advocate for their loved ones' wishes and ensure patients' interests are represented, particularly at EOL.

1.1 | Malignant glioma and those it affects

Malignant glioma is a devastating neurologic illness leading to progressive functional decline, cognitive impairment, and almost invariably death. Despite the universally poor prognosis in malignant glioma, outcomes associated with poor quality of life at the EOL (eg, acute hospitalization within 30 days of death and initiation of hospice within 7 days of death) are common,^{15,16} as is the report that patients with malignant glioma and their ICs have low PA, notwithstanding the severity of disease at time of diagnosis. Little is known from systematic research about the landscape of PA and prognostic communication in malignant glioma. Our systematic review¹⁷ found 6 studies to have investigated PA in this population, though only 3 prospectively.^{18–20} In these, findings varied with 25% to 58% of patients demonstrating “accurate” PA, although the definition of PA varied widely and none investigated participants' estimates of life expectancy or examined discrepancies in patient's and IC's reports of PA. Moreover, literature on patients' with malignant glioma and ICs' wishes for prognostic information is limited. While some studies suggest patients wish that prognosis was discussed in greater depth earlier in the disease course, others describe patients who do not want to discuss prognosis, especially when such discussion is experienced as deleterious to maintaining hope.^{21,22}

To date, no study has examined both PA and communication preferences in a sample of patients with malignant glioma and their ICs. Here, we present data from the first study of PA and preferences for prognostic communication in patients with malignant glioma and their ICs. The purpose of this study was to understand what ICs of patients with malignant glioma understand about their loved one's prognosis, how they derived this information, what additional information they would like, and the existence of discrepancies in prognostic understanding between ICs and patients with malignant glioma.

2 | METHODS

2.1 | Participants

This was an IRB-approved, prospective, mixed-methods study of adult patients with malignant glioma admitted to the inpatient Neurology

service at Memorial Sloan Kettering Cancer Center, and their ICs. Eligibility criteria of patients included age of at least 18 years, diagnosis of malignant glioma, and intact sensorium defined by full wakefulness and orientation to self, place, current month and year, and age. This level of orientation was required to eliminate the potential confound of disorientation to the measurement of PA. An eligible IC was 18 years of age or older and was designated by a patient participant as someone close or important to him/her who provided unpaid help and support. ICs completed a separate written informed consent form. IC participation was encouraged but not required. Of the 50 patients enrolled, 32 had matched ICs who completed participation. IC and patient demographic information was captured via self-report, and patient medical information was captured from medical records.

2.2 | Procedures

Individual interviews were conducted by 1 of 3 members of the study team. Patients and ICs were assessed separately. The assessment of PA and communication preferences had 2 components. A widely used semi-structured assessment tool²³ was used to evaluate participants' understanding of the patient's prognosis. The measure included 4 questions as follows: (1) *What do you understand about your/your loved one's illness?* (2) *How serious do you believe things are?* (3) *What have you been told?* and (4) *Do you have a sense of how much time might be left for you/your loved one?* These prompts were posed with the precise wording above. Unstructured follow-up questions were added to probe responses and to elicit the participant's (a) belief whether the disease was curable or incurable and (b) her/his estimation of life expectancy. These follow-up questions also encouraged participants to express *hopes* and *beliefs* about curability and life expectancy. The interview attended to participants' hopes because of research suggesting that prognostic discussions are most effective and compassionate when experienced in accord with optimism,^{19,24} and so that expressions of hope were not conflated with objective prognostic beliefs in interview analyses. Upon completion of the PA assessment, the interviewer completed a form indicating whether any PA prompts were not asked verbatim, and if so, the reason for this. If participation triggered notable sadness or worry, participants were offered consultation with the Memorial Sloan Kettering Cancer Center (MSK) Psychiatry Service. Verbatim interview transcripts were analyzed by a clinical psychologist and clinical neuro-oncologist, neither of whom had a treating relationship with the participants. The estimate of prognosis was based upon standard clinical features such as tumor histology and number of recurrences, although individual features of each case were considered (eg, the emotional and affective tone of the communication).

After the PA interview, a short multiple-choice questionnaire about participants' perspectives on prognostic information and communication was completed. This included 3 questions selected from the Prognosis and Treatment Perceptions Questionnaire, an assessment of prognostic perceptions of adolescent cancer patients adapted for adults.^{25–28} Here, participants rated: (1) how important it is to them to know about their/their loved one's prognosis (phrased as “the likely outcome of your/your loved one's brain tumor over time” with the following response options: *extremely important*, *very important*, *somewhat important*, *a little bit important*, and *not at all important*); (2) the quantity

of information about prognosis they possessed (wishing they had more information, wishing they had less, or that the information they possessed was as desired); and (3) the quality of prognostic information they have received thus far (excellent, very good, satisfactory, fair, or poor). Additionally, participants indicated in a binary fashion whether the physician, nurse and/or Internet were sources of information. Interviews were conducted by 1 of 3 trained members of the study team and audio-recorded and transcribed verbatim by 2 study team members. The narratives were reviewed by using inductive thematic textual analysis, an iterative process of review, interpretation, and consensus discussions.²⁹ The analysis team read the narratives and identified important content,³⁰ and shared their independent coding results and collectively generated overarching themes that emerged.

Study procedures were reviewed by the MSK Institutional Review Board (approval number 13-253), and all participants provided informed consent before enrollment.

2.3 | Data analysis

Demographic information including sex, race, and educational attainment was captured and summarized. For patients, tumor grade (grade 3 versus grade 4), location, laterality, recurrence status, and prior trial participation were summarized, as well as a battery of neuropsychological tests completed (described in Diamond et al³¹). For the Prognosis and Treatment Perceptions Questionnaire, importance of prognostic

information was dichotomized to extremely/very important versus other responses, quantity of information was dichotomized to desiring more information versus other responses, and quality of information was dichotomized to excellent/very good/satisfactory versus other responses.

2.3.1 | Prognostic awareness rating

Full PA was defined as both (1) awareness of the incurability of malignant glioma and (2) a reasonably accurate estimate of life expectancy. Although subjective, this definition aimed to favor a score of full PA in a situation of ambiguity through the following principles: any reference made to standard survival statistics, or a similar estimate, constituted full PA; and any survival estimate of 3 years (from diagnosis) or less for malignant glioma was considered full PA, although longer estimates were designated as full PA if prognostic factors (such as methylation of the O6-methylguanine-DNA methyltransferase [MGMT] gene, which is a molecular feature with relevance for response to chemotherapy in glioma, and resection status) were cited. Additionally, participants citing longer life expectancies in the context of patients' unique disease trajectories (ie, a glioblastoma patient alive for 5 years from diagnosis) were considered to have full PA. Limited PA was defined as (1) awareness of the incurability of malignant glioma but (2) a fundamentally inaccurate estimate of life expectancy, such as several years beyond standard survival statistics or estimates inconsistent with

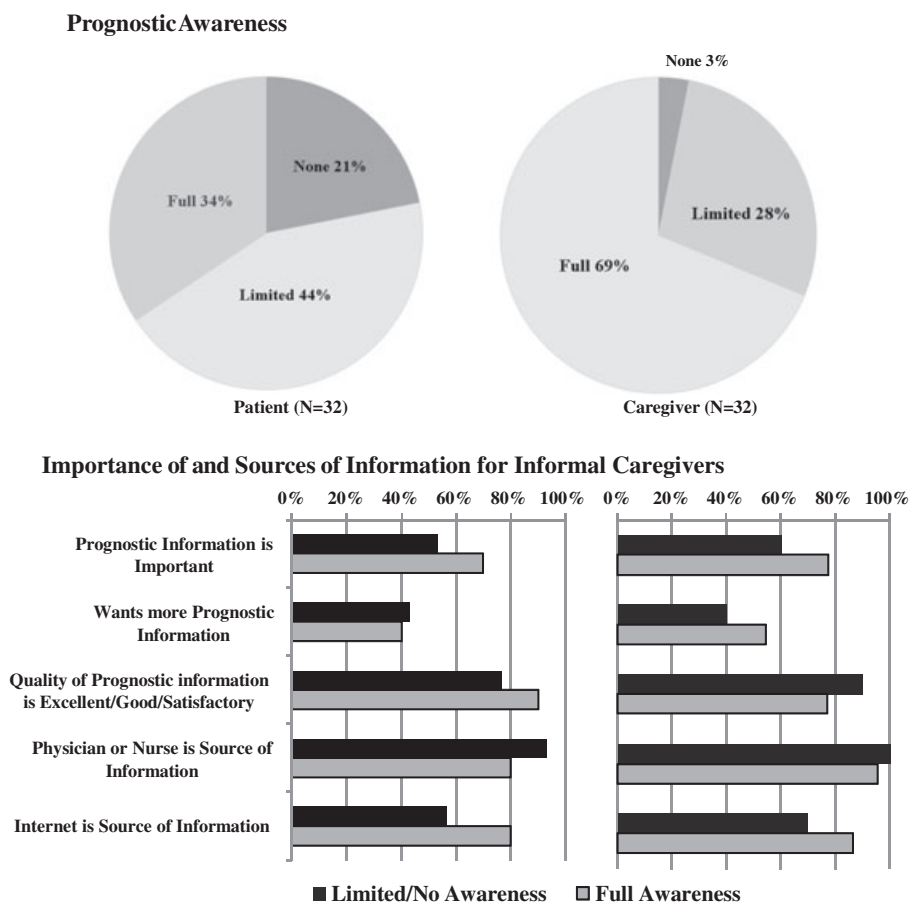


FIGURE 1 Prognostic awareness and sources of prognostic information

disease status (eg, citing 5 year survival in the context of multiply-recurrent glioblastoma). No PA was defined as the belief that malignant glioma is a curable disease. Citing examples of cure or long-term survivorship was viewed as an expression of hope and optimism that was compatible with full PA when expressed with awareness that this is rare.

3 | RESULTS

Thirty-two ICs completed assessments of PA and information preferences. ICs were, on average, 50 years old, primarily female (64%), Caucasian (62%), and highly educated (70% had at least a college degree).

TABLE 1 Informal caregivers' sources of prognostic information (N = 32)

Physician	96.9% (31)
Nurse	59.4% (19)
Other health care professionals	62.4% (20)
Counseling or patient support groups	50.1% (16)
General audience print materials	43.7% (14)
Materials from physicians	59.3% (21)
Medical journals or books	31.3% (13)
Television or radio	25.0% (8)
Internet	81.3% (26)
Friends or family	62.5% (20)

Source % (n)

Patient-related data have been previously reported.³¹ Similar to ICs, the 32 patients were on average, 50 years old, Caucasian (75%), and highly educated (63% had a postgraduate degree). Patients were predominantly male (72%).

The majority of ICs (69%) had full PA, 28% had limited PA, and 3% had no PA (Figure 1). Comparing ICs with full PA to those with limited or no PA, there were no differences with respect to age, sex, race, or education. Twenty-three (72%) ICs felt that information about prognosis was extremely or very important to have, 16 (50%) indicated that they wanted more prognostic information and 26 (81%) rated the information they had received as excellent, very good or satisfactory. Thirty-one (97%) ICs indicated that a physician was a primary source of prognostic information, while 26 (81%) listed the Internet was a source of this information (see Table 1). There was no significant difference between full PA and limited or no PA with respect to sources of prognostic information or information preferences.

Figure 1 presents data on PA and information preferences for both ICs (N = 32) and patients (N = 32) enrolled in the study. Ratings of PA were concordant among a little over half of our sample of ICs (N = 18, 56.3%) and the patients for whom they provided care. In terms of the 14 ICs whose PA ratings were not in accord with those of patients, only one had lower awareness than the patient, whereas 93% of those ICs had higher states of awareness than patients. Due to the small sample size, in order to evaluate differences in PA ratings between ICs and patients, we dichotomized PA into "full" versus "limited or none" and found a trend suggesting that a greater proportion of ICs had full awareness of prognosis than patients, $\chi^2(1, N = 32) = 3.83$, $P = .056$.

TABLE 2 Qualitative themes from interviews with informal caregivers

Theme	Representative Responses
Avoidance	<p>"I do not want to know. And I told them that right off the bat. No one ever told us much, but when we met with the doctor, it seemed she wanted to reveal to us where we stood, and I interrupted her, and said that I really do not want to, I cannot hear that so please do not share that with me."</p> <p>"Initially when we first came to MSK, she said she could give us the numbers. And (patient) and I both said we didn't want to know."</p> <p>"We have not asked a lot of questions about prognosis with the doctors because of (patient's) desire to not really talk about that part."</p> <p>"I wish I did not know so much sometimes."</p> <p>"We try to avoid looking at the future; we try to live one day at a time, one step at a time. We know how serious it is but we try not to get too caught up in it."</p> <p>"We treat our life as if despite all of these setbacks that she's going to live a normal lifespan. We haven't made any plans."</p> <p>"We were given statistics and we were asked if we wanted to know more, and we both looked at each other and said no."</p>
Curiosity	<p>"I have not specifically asked. It's not that we do not want to hear what the worst case scenario is; I think sometimes I do not even know what to ask."</p> <p>I am interested in understanding his prognosis, I believe that information exists, it's just a matter of me sitting down to read and understand."</p> <p>"I'd like to be more aggressive in getting information."</p> <p>"When he was first diagnosed I read everything that I could find on his condition."</p>
Discordant preferences	<p>"I have read constantly about the future, but I do not discuss it with (patient). As far as what I have read online and that sort of thing, I know it's very bad. But we do not discuss that directly with her doctors, I'd like to, but I know he doesn't want to know."</p>
Prognostic information	<p>"Two years ago we had an appointment with the doctor and we discussed on the way down that she wanted to know how long she had to live. And I disagreed with that, I thought it would have been better not to know. But it's her life, I said whatever you want to do is fine with me."</p>
Hope	<p>"I don't want to know. And I told them that right off the bat. No one ever told us much, but the doctor when we met with her, she seemed to be at a point where she wanted to reveal to us where we stood, and I interrupted her, and I said I really don't want to, I can't hear that so please don't share that with me. We're hopeful people and we need to believe that there's hope, and we're optimistic people and we need to progress with what we've got."</p> <p>"We've preferred to keep optimism as the front and center, with a lot of prayers backing it up."</p> <p>"I don't know how much time (the patient) has left. We always approach things, every therapy, with the notion of hope, that it will either control or hopefully cure his condition."</p> <p>"We know it's bad and we're really focusing on treating it rather than worrying about it...He's got a great attitude. And we're basically taking it day by day."</p>

3.1.1. | Qualitative results

Four unique themes emerged from in-depth analysis of participants' narratives (see Table 2): *avoidance, curiosity, discordant preferences for prognostic information, and hope*. As illustrated in Table 2, some ICs reported wishing that they had less prognostic information or were resistant to communication with physicians about prognostic information. Specifically, many of the narratives revealed that ICs felt that they had received too much prognostic information without their or the patient's consent during the medical encounter. In these instances, the information was experienced as shocking and often perceived as conveyed insensitively and in a rushed manner.

More frequently, however, ICs reported desiring more information than they had been given by physicians. This desire may have led ICs to rely more on alternative information sources such as the Internet. Importantly, the narratives highlighted that many ICs felt that they did not have the skills needed to elicit prognostic information from physicians and that they required guidance in navigating the medical encounter. This, too, may have contributed to their seeking information elsewhere.

Potentially related to this stated desire for more information but limited ability to direct communication in the medical encounter is the third theme of discordant information preferences between ICs and patients. Not surprisingly in the context of our quantitative data above, many of the ICs interviewed here reported having and wanting more prognostic information than the patients for whom they were providing care. It is clear from narratives that ICs wanted prognostic information but, out of respect for patients' desire to avoid conversations about prognosis with physicians, many ICs were left withholding questions during the medical encounter.

It is also clear from the fourth theme that many ICs wanted to maintain their—or the patient's—hope for the future. Specifically, for several ICs, having open conversations about prognosis was perceived as discordant with maintaining hope. Others reported allowing PA and hope to co-exist (eg, “I don't know how much time he has left...we always approach things with hope” and “We know it's bad and we're really focusing on treating it rather than worrying about it. He's got a great attitude and we're basically taking it day by day”).

4 | CONCLUSIONS

To our knowledge, this is the first study investigating PA and preferences for prognostic information among ICs of patients with malignant glioma. The majority of participants felt that information about prognosis was important and actively sought it out, which likely contributed to over two-thirds of the sample being rated as having full PA (and only 1 IC rated as having no PA). Importantly, despite high levels of PA, the majority of participants felt that the amount of information they received from oncologists about prognosis was, in one way or another, problematic in its content or timing. Indeed, 83% of ICs reporting dissatisfaction with the quality of information provided by the oncologists were rated as having full PA. Moreover, our qualitative findings highlight a complex decision-making process among ICs who concurrently desire prognostic information and strive to maintain hope for their loved ones. These competing goals can lead ICs to both seek out

prognostic information in some instances but withhold questions during the medical encounters. The possibility of concurrently engaging in open conversations with patients and physicians about prognosis while maintaining hope should be a focus of future study.

Our data suggest that while ICs are aware of their loved ones' prognoses, they are seeking and receiving much of their prognostic information outside of the medical encounter, such as through the Internet or print materials. While these sources may prove beneficial in gathering prognostic information, each case of malignant glioma is unique, and as such, information derived outside of the context of the medical encounter may be a potential source of misunderstanding. Conflicting knowledge states and information preferences around prognosis among patients and ICs has the potential to contribute to poorly guided advanced care planning,^{32,33} a phenomenon highlighted through in-depth analysis of the interview transcripts. Therefore, in order to be meaningful and helpful to families facing malignant glioma who are tasked with making critical EOL care decisions, prognostic information needs to be tailored to the unique presentation and history of the patient.

Perhaps not surprisingly, there was discrepancy in rating of PA among a large proportion of study participants and the patients for whom they were providing care. Among IC/patient dyads with discrepant PA ratings, almost all (93%) ICs had higher PA, and among the entire sample, a trend suggested that ICs had higher PA than patients overall. This is in accord with previous studies that have found higher PA among ICs than patients³⁴ and is likely attributable to the previously mentioned desire of ICs to receive more information than provided in the medical encounter and seek this additional information elsewhere. It is also possible that this discrepant PA may reflect discrepant understanding of shared communication with the medical team. This is particularly important in the context of the neurocognitive changes associated with malignant glioma³⁵ which over time undoubtedly shape patients' abilities to engage fully in the medical encounter and eventual EOL care decision making.³⁵ Interestingly, desire for prognostic information and belief in the importance of prognostic information was associated with cognitive impairment among patients, especially in the area of working memory capacity (see Diamond et al³¹). Despite this, impaired patients were almost consistently less aware of their prognosis than ICs. In addition to discrepant understanding of information shared in the medical interaction, this finding may also represent an absence of prognostic communication altogether for a disease that is almost invariably incurable and associated with very limited life expectancy. Indeed, our recent findings of frequent late hospital admission and late referral to hospice in malignant glioma—outcomes associated in other cancers with inaccurate prognostic understanding^{15,16}—support this explanation as well as the information seeking behaviors among participating ICs outside of the context of the medical encounter.

4.1 | Limitations

Several limitations of this study must be acknowledged. First, our sample size of 32 matched IC/patient dyads limited our ability to conduct complex analyses of between group differences. However, in light of the often rapid decline of patients with malignant glioma and the

difficulty of recruiting and maintaining ICs of patients with malignant glioma in clinic trials, and considering the unique context of this disease group and topic of study, the sample size is noteworthy. Additionally, this study was conducted at a single institution in a population that was of limited racial diversity among highly educated ICs who actively sought disease related information, and therefore the generalizability of our findings is restricted. Finally, and importantly, the assessment of PA is itself intrinsically subjective. Our combining a structured instrument consisting of unambiguous prompts with open-ended questions to elicit awareness of curability and life expectancy, while conscientiously allowing for expressions of optimism, was a rich and meaningful method to address this complex construct. Moreover, verbatim transcripts were analyzed by both a neuro-oncologist and clinical psychologist with particular expertise in the measurement of PA. While the methods in this study were effort intensive, we believe that we obtained detailed and believable PA assessments and that future studies may consider a similar approach.

4.1.1 | Clinical implications

This study highlights ICs' of patients with malignant gliomas awareness of their loved ones' prognoses, their desire for information about prognosis, and challenges they face in soliciting and discussing prognostic information. The majority of our participants had full awareness of their loved ones' prognoses but desired and actively sought out additional information. Moreover, while a large body of literature indicates that prognostic information is not associated with poor psychosocial outcomes (eg, depression, anxiety^{25,36}), the receipt of information by ICs about prognosis in malignant glioma is undoubtedly a difficult emotional experience, and the desire for information is a personal decision impacted by family and cultural values. As such, communication between physicians and families should be sensitive to patients and ICs' preferences for information. This requires a physician who is attuned and flexible in relation to the unique context of each family facing malignant glioma.

Our results emphasize the need for IC-specific communication-oriented interventions to improve the flow of prognostic information between physicians and families to facilitate advanced care planning and shared understanding between patients and ICs of prognosis. Open physician-patient-IC communication is necessary for ICs to effectively advocate for their loved one's interests in treatment decision making, a central responsibility of ICs' role as designated health care proxies and critical to achieving patient-centered care. While patient and physician communication training interventions have increased effective patient-centered communication with health care professionals,³⁷ in the context of cognitive decline associated with malignant gliomas, such training is not sufficient to ensure patient preferences are represented over the long term. A clear gap remains, therefore, in the direct training of ICs to effectively serve as members of the health care team and to advocate for their loved one's wishes. Future studies should address this gap through the development and evaluation of communication skills training programs for ICs. Such programs are needed to increase ICs' skills to engage in discussions about advanced care planning both while patients are capable of discussing

their EOL wishes and when advocating for these preferences as the patients' conditions deteriorate.

ACKNOWLEDGEMENTS

Funding for this work was provided in part by:

1. Translation and Integrative Medicine Award from the Department of Medicine at Memorial Sloan Kettering Cancer Center and the Brain Tumor Center at Memorial Sloan Kettering Cancer Center, awarded to Dr. Diamond and Dr. Applebaum.
2. NIH/NCI Cancer Center Support Grant P30 CA008748, PI: Craig Thompson.
3. Conquer Cancer Foundation of the American Society of Clinical Oncology awarded to Dr. Diamond.
4. Drs. Shaffer and D'Agostino are supported by the National Cancer Institute Training Grant T32 CA009461, PI: Jamie Ostroff.

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How to cite this article: Applebaum AJ, Buda K, Kryza-Lacombe M, et al. Prognostic awareness and communication preferences among caregivers of patients with malignant glioma. *Psycho-Oncology*. 2018;27:817-823. <https://doi.org/10.1002/pon.4581>