

## Odyssey of hope: a physician's guide to communicating with brain tumor patients across the continuum of care

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Received: 3 December 2008 / Accepted: 23 February 2009  
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**Abstract** The optimal treatment of a patient with a malignant brain tumor requires attention to the physical and emotional well-being of the affected individual and the family. We review the concept of hope as a critical support modality throughout the continuum of care for brain tumor patients and families. We offer suggestions based on our own observations over 17 years as well as the lessons taught to us by our patients and their families over that time and through a structured interview process.

**Keywords** Brain tumors · Hope ·  
Physician communication

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*Just as despair can come to one another only from other human beings,  
hope, too, can be given to one only by other human beings*  
—Elie Wiesel

A newly diagnosed brain tumor patient with a newborn and toddler called our group to ask if we could help; her neurologist had just told her that she had less than a year to live. We told the young mother not to believe the prognosis. That first phone meeting in 1993 led her to multiple surgeries, chemotherapies, radiation therapies, investigative studies, and a bone marrow transplant. We still see her today. Fifteen years ago, prognoses for malignant astrocytoma weren't characterized by molecular markers, but we had a good sense of factors in her favor: age, general health, tumor location. We had new therapies available as a member of the New Approaches to Brain Tumor Therapy (NABTT) consortium. We could plan and deliver her treatments, we could try to provide hope to her and her family, and we ourselves could hope.

Neuro-oncologists and neurosurgeons have long faced patients and families seeking alternate opinions on prognoses. Physicians often struggle with what information to impart and when [1–4]. How to deliver necessary information with compassion and honesty to the patient with brain cancer is a challenge worth pondering. Physicians are well trained in the science and art of differential diagnosis and therapeutics, but not in the phenomenon of hope as a therapeutic elixir for helping patients and families cope with life-threatening diseases like brain cancer.

Important insights into the experience of patients with brain tumors can be gained by qualitative studies using structured interviews [5]. Several reports have highlighted the value of hope in managing chronic or terminal illness [6–14]. In one study of 17 patients within 6 months of a cancer diagnosis, hope was identified as an essential coping

strategy, indispensable for survival from the patient's point-of-view [6]. Positivity, one of 12 measures in the Herth Hope Index, was found to be a component for quality-of-life in advanced cancer patients [15]. Salander et al. [11–13] have studied the issue extensively in patients with brain tumors, and have described a number of features of patient cognitive strategies [12, 13], family support functions, and characteristics or behavior of health care providers [11] that provide hope. An excellent summary of research on this issue for patients with gliomas was recently published by Catt et al. [16]. We believe hope, in its various forms, belongs in clinician's messages to patients at diagnosis and throughout the continuum of care.

Since the 1990s, our multidisciplinary team has treated brain tumor patients who, with their families, have taught us how to improve the elements of the care process and to maintain an atmosphere of hope even in the face of a grim prognosis. Our lessons, those we have learned from our own observations and those taught to us by our patients and their families, are provided as a template for physicians and others who share this journey of caring for brain tumor patients.

### Patient and family interviews

In the fall of 2008, we conducted structured telephone interviews with 14 patients or relatives of deceased patients. The goal of this project was to obtain some additional information on issues related to the importance of hope, factors contributing to the presence or absence of hope, and the effects of hope on patients, family members, and clinicians. The project also aimed to identify the "crisis points" as perceived by the brain tumor patients and their families, those time-points they are most psychologically vulnerable and need most support. Ten interviews were with patients; four interviews were with relatives of deceased patients. Most interview questions were open-ended (e.g., "When since your initial diagnosis have you experienced the greatest amount of hope?"), and thus data analysis was qualitative. There were 31 main questions in the interview and some had probe questions to follow specific initial responses (see interview outline in Appendix). The study was approved by the Henry Ford Institutional Review Board. We use the results of the interviews to illustrate some of the observations and recommendations that follow.

### Delivering diagnosis and prognosis

*This was truly the most frightening medical issue our family has ever experienced. Because of the kindness shown to us by staff and the confidence gained through the experience, our fears were lessened.*  
—Parent of Brain Tumor Patient, February 2004

Our patients, reeling from the shock and fear instigated by the brain tumor diagnosis, prefer incremental doses of information that respect both the patient's vulnerability and urgent need for an effective plan of action. A brain tumor diagnosis creates a crisis for which no one can be adequately prepared. This challenge to one's coping mechanisms often leads to "cognitive confusion" [17, 18] marked by panic, with patients unable to think clearly [17]. The physician's manner and word selection are critical to delivery of messages that will affect how patients and families receive difficult information and also how they remember what they heard [19–21].

The team's preparation for first clinic consultation requires support staff to obtain from the patient and/or referring physician(s) complete documentation of medical, surgical, pathologic, and radiologic reports and images. Images should be reviewed outside the clinic room to provide time to consider diagnostic and therapeutic alternatives and the best approach for communicating with the patient and family. In complex cases we often consult colleagues, with the neurosurgeon, neuro-oncologist, neuroradiologist, and neuropathologist exchanging points of view before the first patient/family meeting. We have heard stories from patients about physicians, caught up in long clinic hours or surgeries, arriving at the new patient consult unprepared and rushed. The body language and dialogue of a physician rushing through a consult cannot convey the nuanced analysis and genuinely hopeful outlook generated so naturally through a deliberate, thorough, patient-centered work-up with adequate time to clarify alternatives and to answer questions.

For the initial consultation with patients and families, we schedule time for the neurosurgeon and/or neuro-oncologist with additional time for the neuro-oncology nurse. The following steps are a guideline to core elements of the consultative interaction.

#### Step 1: calm fears

Discussion begins with first calming the patient's and family's fears. We advise patients, both in first and second opinion consultations, not to dogmatically believe everything heard or read about the disease since every patient is different and tumors are not all alike. We review the diagnostic findings with the patient, discuss differential diagnosis with newly diagnosed patients, and review any treatments undergone and/or presently being received by the patient. As expressed by a patient:

The first doctor I was referred to told me that because of the tumor location they couldn't do surgery or radiation therapy. The second doctor I saw said 'you have to die of something' and left the room. My

family doctor called the tumor center. Now, instead of being told that my tumor was inoperable, I was calmly told ‘treatment for brain tumors is what we do here.’ The doctor looked me in the eyes, put his hand on my arm, and said ‘I’ll take good care of you.’ Instead of feeling helpless, I was part of a team that had a direction and goal. At that moment, I began to feel safe. (Brain Tumor Patient, April 2007)

#### Step 2: discuss the science

We present the facts. Common knowledge of brain tumors in the physician community at large does not necessarily include awareness of recent advances in science and research therapies. We explain what we know scientifically in laymen’s terms, highlight the timeline of recent advances in knowledge, and describe how this new evidence has led and can continue to lead to improved therapies. We briefly outline our basic science and translational efforts as well as our clinical trials to demonstrate our commitment to fighting the disease and to deliver advanced therapies to our patients.

#### Step 3: address prognosis

We address the issue of prognosis as a nuanced concept, not as a simple number like time of life left measured in weeks or months. This is critical to help shape the cancer experience confronting the patient, reducing the influence of negativity [22]. Without being evasive, we use calming factual phrases to help patients and families cope with the shock of the diagnosis. Common statements from physicians include:

- We don’t know exactly what we’re dealing with yet.
- Prognoses are based on an average of survival statistics, and averages are just that, a mathematical figure. Every patient is different.
- Prognosis is dynamic. We know that subtypes of certain tumors respond better than others. Molecular analyses of tumors give us hints at new roadmaps for treatments.

Any discussion of prognosis must address the severity of the individual patient’s disease state at first consultation. Brain tumor centers often receive consultation requests near or at end-stage from patients treated elsewhere. Our approach to these patients and families sometimes relies more on palliative support discussions than on instilling hope for remission or cure.

In the interview study, respondents were asked about whether it is possible to deliver bad news (e.g., poor prognosis or initial diagnosis) and still allow patients to maintain hope. Patients reported wanting to have

information, and to know both good and bad news. However, several mentioned that they then chose to focus on the positive, or that they appreciated that the physician or nurse focused on the positive. Information on prognosis seemed to be a good specific example of this balance. Even if the mean or median survival duration is short, some patients live a long time. Even if most patients have recurrences, some don’t. Most of the respondents seemed to want to have a presentation of information that included the typical (e.g., median survival), something about bad things that *could* happen (e.g., treatment side effects or tumor recurrence), but plenty of examples of how things could go well (e.g., long survival, complete remission, experimental treatment in case of recurrence). An example:

I think they have to frame [bad news] in terms of the unknown and that is how [the doctor] did it with our family. There is a way you tell the family that the end result is a very high probability ... but saying that ‘in our experience in most cases we see outcomes as this ... but we can’t say that something else wouldn’t be possible.’ You can uphold hope by focusing and framing it on quality of life. Focusing on the unknown and the quality of life is key. [The doctor] did it in a way that didn’t destroy us. He was gracious. It is not delivering the information like it is data or like you are reading from some text.

#### Step 4: build the relationship between the team and the patient and family

The first patient/family consultation is the beginning of the health care team’s professional relationship with the patient. We demonstrate, at this first contact and throughout the patient’s illness, a multidisciplinary, patient-focused system of care. We describe the elements of the team approach, each team member’s function, and how the team members serve to support the patient and family. We provide each patient a packet with educational materials general to brain tumor patients and specific to the patient’s type of tumor (if known), and a list of community resources for brain tumor patients and families. We describe the multidisciplinary tumor board, its process and function. For patients first diagnosed at our center, we share our understanding of their potential need to seek alternate opinions and encourage them to do so. We provide team members’ telephone and email contact information, and identify the neuro-oncology nurse as the primary point person. We continually emphasize to the patient and family that we’re in this battle together.

Interview respondents confirmed our sense of the importance of a stable and trusting relationship with members of a treatment team. Patients clearly view their

physicians and nurses as more than just technicians or trained professionals. Example:

I will never forget the pats on the knee from [the doctor], along with him looking right into [the patient's] eyes with his words of encouragement, no matter how bad the news, gave him so much to hold on to. With [the doctor] ... his words 'it is what it is, but we still have hope' will be with me forever, and I know that was huge for [the patient]. The ICU nurse ... with her sense of humor, gift of affection, and profound professionalism gave him what he needed to get out of that bed, and go home. I would go on and on, about [the nurse] and her kind voice, and always making us feel that everything was under control and would be taken care of, and it was.

#### Step 5: focus on the patient's and family's responses

Patients and families are more than passive recipients of authoritative information. They come to us with viewpoints, preferences, styles of interaction, past histories and current agendas that matter [20, 23]. We cannot begin to know our patients unless we provide opportunities for dialogue and invite questioning at every interaction. It is especially important to encourage questions from the patient/family just prior to concluding the first consultation. Distress may cloud the patient's and family's thought processes, but the clinician who provides genuine encouragement and a few moments of silence will usually be rewarded with poignant and personally meaningful queries that help us to learn about, comfort, and guide the patient and family we're treating. This time also allows for patients and family members to convey a sense of how much information they're ready to receive, and at what level of detail. Patients differ in terms of their readiness to accept information, and individual patients differ over the course of disease in terms of readiness [2, 24]. As expressed by one of our interview respondents:

Doctors need to be intuitive to know how much the patient can hear at that time. They need to recognize that sometimes only the barest amount of information should be given and not elaborate; they need to know what stage the patient is at. Sometimes too much information at one time is not good.

The fear and anxiety evoked by a brain tumor diagnosis can be eased when patients and families perceive their physician to be truly engaged with them. Critical elements of engagement are attention, demeanor, and time. Physicians must take time to listen, share information, answer questions—appearing calm and relaxed without distraction, throughout the interview. Physicians must focus 100% on

the clinical interaction. Cell phones and pagers should be muted and glances at watches resisted. Anecdotal reports to members of our team repeatedly expressed gratitude and relief that a physician cared enough to spend unhurried time with the patient and family, as if there were no other important work to be done. This helps the patient to feel valued as a person. Recognition of an individual's value supports both the process of feeling hopeful and well cared for. "Patients don't care how much you know until they know how much you care" [25].

#### Developing and discussing treatment planning

We utilize various team members to discuss specific portions of the treatment plan, although the neurosurgeon and neuro-oncologist can provide each other's summaries at the outset. Neurosurgeons describe the surgical alternatives, with each option's associated risks, alternatives, limitations, and benefits, including the surgeon's recommended approaches for preserving or improving function. Medical neuro-oncologists describe the medical therapies to patients and families, recommending the treatment plan design for each patient. The neuro-oncologist and medical oncologist provide historical results of advanced therapies available as well as potential side effects of planned therapies. Molecular diagnostics are explained in relation to the design of a patient's clinical treatment plan. The range of standard therapies and research alternatives along the entire surgical—radiation oncology—medical oncology—neuro-oncology continuum are addressed. We provide a general description of research advances in the field, as well as local investigative efforts, emphasizing clinical trials as an addition to best standard of care.

For surgical candidates, neuro-oncology nurses help patients and families understand what to expect before, during, and after hospitalization. The nurse introduces other vital members of the care team such as hospital nurses, social workers, oncology nurses, and clinical trials nurses. Discharge planning is extensive and done preoperatively; patient and family needs for in-home care or rehabilitation are detailed at this time. Neuro-oncology nurses serve as a critical link between patients and families and the attending physicians. Our neuro-oncology nurses often know more details about a patient's physical and emotional state than any other team member throughout the entire process of care.

#### Delivering ongoing care

*It is wonderful to know that the MRI looks great and that he is doing well. That is what everyone says, but they don't know that some mornings he doesn't know he has to put his pants on first.*  
—Wife of Brain Tumor Patient, June 2004

The care of the brain tumor patient is a chronic disease management process, requiring the team to help patients and families not only with medical issues but also with daily life changes including the physical, cognitive, and inevitable cascade of emotions that usually involve fear, anxiety, and depression. After diagnosis, moving through the treatment phases of surgery, radiation, chemotherapy, and investigative therapies instills hope in patients and families that these interventions will result in cancer abeyance. Many adapt surprisingly well to this new life of ongoing therapies. Focusing on action may help keep emotional ruminations at bay, but fear lies close to the surface, easily evoked with any new symptom or looming imaging study. Our interview respondents identified the times of scheduled imaging tests as periods of particular vulnerability and potential loss of hope; they also identified the initiation of treatment and the receipt of good news (e.g., tumor shrinkage) from imaging tests as a time of greatest hope.

Neuro-oncology nurses become the umbilical cord for patients and families, especially for therapy side effects and ongoing physical and emotional symptom management. Revolving medical faces could overwhelm already exhausted patients and families, and lead to fragmented care. Instead, the neuro-oncology nurse integrates each referral into the fabric of the patient's care. This valued relationship, however, cannot serve as a surrogate for the physician–patient association. Anecdotal reports from our patients have expressed frustration and a feeling of abandonment when physicians no longer spend the time and attention expected and desired by patients throughout the long course of management.

Patients want to be “seen” by their physicians and treatment team. They reject being treated as theoretical possibilities, and yearn for honest responses to their very real circumstances. This desire for understanding requires the physician to provide treatment recommendations based on the “truth” of the individual patient's desires and medical condition while still maintaining hope [1, 23, 24, 26, 27].

The possibility of bad news is on patients' minds. One patient in our interviews pointed out an aspect of the testing process that inadvertently added to her experience of anxiety:

I get nervous about getting the [brain] scan. What makes me the least hopeful is seeing ‘residual tumor’ written on the [scan] order. It makes you think, what if [the tumor is back]. I also don't like the wait for the results – I really don't share my feelings when I am waiting but I am very relieved when the results come back.

There are effective ways to allay some fears even as the health care team shares the patient's anguish at having to grapple with unwelcome news. For example, we arrange

imaging studies to be followed by a same-day clinic visit or physician phone call within 24 h to spare patients and families the agony of waiting and wondering. We counsel patients that an observed change on an imaging study may require a new process of differential diagnosis: tissue necrosis versus tumor recurrence. We also discuss with our patients that the distress accompanying diagnostic uncertainty, disease progression, and changes in the treatment plan is difficult, natural, and usually manageable with help. We offer such assistance through our team of physicians and nurses, and by selectively referring patients and families to specialists in psychiatry experienced in working with cancer patients. At our institution's cancer center, a psychiatric nurse practitioner and psycho-oncology fellow are available to evaluate and treat patients/families, connect patients/families to psychiatric resources in the community, and help guide staff searching for the best way to respond to troubled individuals. Patients in our interviews generally reported that staff members were appropriately sensitive in picking up anxiety and depression, and that the subsequent referrals and supportive therapies were helpful.

Relaying news of a change in the brain scan can be a dreaded task. In fact, delivering news of disease progression after treatment is even harder than at first consultation because we now know the people facing us. The aforementioned elements of sensitivity, calmness, and kindness required at first diagnostic consultation are even more critical when delivering a diagnosis of possible tumor recurrence. In the face of human tragedy, it is tempting to frame an alternative diagnosis of tissue necrosis as almost positive in comparison to tumor progression. It is true that treatment can sometimes alleviate the necrotic process, relieve symptoms, and even be a good prognostic factor. However, brain tissue necrosis can produce devastating consequences such as permanent neurological deficits and severe cognitive impairment [18, 28]. Physician sensitivity to these very real risks can help formulate messages that are both compassionate and informative. Grief can be acknowledged and new treatment plans presented.

The physician–patient–family relationship at this stage may weaken. Disappointment, even blame for failed therapies may be directed at the physician. Physicians need to take the lead, without being defensive, to acknowledge disappointment, anger, and blame as natural reactions. Physicians must also explain the powerful biological factors that allow tumors and cancer cells to persist despite multiple therapies. Such physician–patient–family discussions at the time of tumor recurrence or radiation necrosis should evolve from validating the patient's and family's current negative feelings to promoting positive feelings by identifying the desires of the patient in a quality-of-life-focused treatment plan.

Quality of life should be distinguished as separate from end of life. While always important, quality of life becomes a central focus in treatment planning at tumor recurrence or progression. At these points of crises, we offer available clinical trials and describe our history of experience with these therapies. In this way the physician helps the patient and family transition from disappointment, anger, and sadness at failed therapies to realistic hope for achieving newly defined goals. These next steps are designed by the physicians and patient–family as a team. The medical oncologist, neuro-oncologist, and neurosurgeon should be involved with this decision-making interaction because these specialists each play a role in diagnosis and treatment, and together should be perceived as a team providing ongoing support. Consistent with findings by others [9, 21, 23, 26, 29], patients in our interviews reported that there can still be hope in the presence of recurrent or progressing disease if goals are re-set to focus on maintenance of function and maximizing quality of life. For example:

If you are working with a situation when you know about the end result, it is all about quality of life. They need to recognize that squeezing extra time out of one's life goes hand in hand with quality of life. Treatment of cancer is two things ... the actual treatment and the actual hope.

Support staff from nursing, social work, and psychiatry can provide a helpful sounding board as patients and families confront new realities and weigh treatment options. These exploratory discussions involve helping patients and families to (1) understand their strengths as well as vulnerabilities, (2) challenge and expand their definitions of quality of life, (3) foster development of flexible rather than rigid responses to problems, and (4) search for adaptation to illness consistent with the patient–family coping style.

As treatment progresses along the continuum of care, physicians should avoid offering potentially toxic treatments, one after another, without including the patient–family in the benefit/burden analysis. Patients and family members, no matter how well-informed during the previous phases of treatment, have their own concepts and beliefs about the meaning of recurrence or progression and what range of treatment options might be appropriate. Patients in our interview series frequently brought up the term “terminal” as a distinguishing label for a situation with no hope of cure or control of disease. The term “terminal” came up as a major focus in several of our patient/family interviews. In all instances, the term was used to suggest a major shift in disease status as well as personal identity. A tumor with a grave prognosis could still be “fought” or dealt with hopefully, as long as it didn't mean the patient was “terminal.” Becoming “terminal,”

though, meant a distinctly different (lower) level of hope, at least in terms of the prospects for extended survival.

Physicians must review, with patients, how prior treatments have affected a patient's quality of life, and predict the likely sequelae if patients continue to opt for life-prolonging therapy. Treatment planning should never be presented as a choice between treatment and no treatment, but rather as a search for the plan which best fits current attainable treatment goals. Palliative care, with its focus on symptom relief, *is* treatment. Stopping life-prolonging interventions is not a cessation of all therapy, but a change in the focus of care. According to our palliative specialists, hope at this juncture is hope for relief and hope for non-abandonment.

Whether the outlook is bleak or the prognosis excellent, many patients avail themselves of complementary or alternative medicine approaches, with few revealing this information to health care providers unless we probe in a non-judgmental way [30–32]. Complementary and alternative therapies need to be discussed in terms of science with attention to the source of therapy outcome claims. If safe complementary therapies are available in an organized institutional center, then a consultation can be arranged. It is important, however, that a positive and collaborative relationship be developed between the neuro-oncology service and the center for complementary approaches. Each group, the traditional and the complementary, attempts to promote hope and patient well-being. One group should not undo the work of the other.

### Identification and delivery of support

*I am not a tumor, I am a person.*  
—Interview Respondent, November 2008

Brain tumor patients and families require support services at all phases of care, at first diagnosis through recovery in benign cases, and for malignant tumors through end-stage processes of hospice and family bereavement. Patients and families are traumatized not only by fear of a shortened life but also by the loss of the self as known [3, 28]. Our mind, with its quirks and blessings of individual personality is the wellspring for our thoughts, feelings and behavior. Brain tumor patients survive in a changed form whether subtle or extreme. These changes in thinking, feeling, and behavior may occur gradually or rapidly, but they always occur—over and over again as part of the disease or treatment process. Clinicians foster hope by predicting, identifying, and interpreting these changes to patients and families. Hope in the face of changing “personhood” means helping patients and families to develop strategies for adapting to impaired cognitive function,

interpersonal communication, and motor performance. Support services such as speech, physical, and occupational therapies, neuropsychological testing, psychotherapy, and psychopharmacologic therapy help patients and families address problems of everyday living.

Our neuro-oncology nurses work with other professionals to provide critical emotional support to patients and families along with local community organizations and support groups. Many of our patients and their family members have been gracious enough to offer opportunities for those just starting the treatment process to speak with these “veterans” face-to-face or via phone. Approximately half of the patients in our interview series mentioned a conversation with another patient who was doing well or had at least been through what the patient was about to go through as an important source of hope.

Physicians must also play an integral role in supporting the patient and family. Aside from clinic or hospital bedside visits, telephone discussions, and maybe even the rare home visit, we have discovered several effective avenues for physician participation in supportive care activities. One such event brings together physicians and the patients and families they treat for a luncheon to recognize the special spirit required of patients with brain tumors. Patients and families sit side by side with physicians and other team members as awards are publicly bestowed on patients by their physicians. Community-wide annual events, such as golf outings or more formal special events, focus on philanthropic fundraising but include patients and families as well, with patient honorees selected each year. We have patients who have developed fundraising events on their own; our physicians attend these events, which bring much goodwill to all parties involved.

These social community events provide our team with crucial feedback on the physician–patient relationship. In the hospital or clinic, the patient–physician relationship is more formal, physician-directed, task-oriented, and restrained. Outside the medical setting, patients (even when severely disabled) and family members can be “regular people,” chatting with their physicians and other team members. This sense of normalcy, of social acceptance, is a balm to patients and families living with cancer, and is an ongoing source of valuable lessons for our health care team. Social gatherings attended by families of deceased patients may also provide learning opportunities for physicians. Because they are released from the professional medical relationship, such family members more readily provide information on where and how communication and support processes misfired, as well as the elements of care most appreciated.

As the brain tumor patient’s journey from diagnosis through treatment through recurrence and additional treatment enters into the palliative care and hospice phase,

families and patients desire time and attention from the neurosurgeon and neuro-oncologist. A phone call, a bedside visit, or a handwritten note speaks volumes to our patients and their families who have often been transferred to the capable hands of palliative medicine specialists. We physicians who began the journey with our patients and family members need to try harder and more regularly to offer closure to them and to ourselves. Families of our patients have recommended several points:

- Provide opportunities for both patients and family members to speak with the physician alone. Patients may hesitate to discuss sensitive topics in front of family members, and family members may hesitate to ask certain questions in front of the dying patient as each seeks to protect the other from burdensome information.
- Let patients and family members know that physicians and other team members are available to discuss what to expect during the dying process *if* they want to know.
- Provide an opportunity for closure during the bereavement period. Many families form a close bond with hospital caregivers and the brain tumor team. When patients die at home, family members say they regret the lack of opportunity to say goodbye in person to staff members who have held a critically important role in the family’s life for months or years.

### Physician and team sustenance

*Most of the important things in the world have been accomplished by people who have kept on trying when there seemed to be no hope at all.*  
—Dale Carnegie

Burnout is a problem among clinicians treating brain tumor patients. Sustaining hope among clinicians means nurturing the ideal of serving humanity and promoting the understanding of and support for research [19, 27]. We can and do help our patients. We can and do contribute to science through the pursuit of basic, preclinical, translational, and/or clinical research. Passion for service and discovery can renew physicians and team members doing the difficult work in which many patients do die on our watch.

Scientific investigators may nurture hope by creating successes—measured in new discoveries, publications, grants, and patient outcomes. Like clinicians, scientists can find sustenance through interacting with brain tumor patients and philanthropic community leaders. Meetings between scientists and patients and family members produce hope for both. Researchers see the faces of those who may benefit from their efforts; patients and families learn about extensive behind-the-scenes work to battle their

disease—a validation of the importance of life for all participants.

### Ongoing service to the general community of physicians and patients

#### Communication

A source of frustration for brain tumor center physicians occurs when patients receive incomplete or overly pessimistic information from generalists or delayed referral to brain tumor specialty centers. Generalists know some prognostic statistics for brain tumor patients. Neuroscience specialists know the most recent scientific and clinical advancements. Between the generalists and specialists sits the patient receiving a brain tumor diagnosis. A few patients in our interview series mentioned a comment by a non-specialist clinician about the inevitability of death or the difficulty of treatment as a point of “low ebb” in hope. Interviewees followed this critical comment with reports of positive outcomes both in function and emotional outlook after referral to the brain tumor specialty center. Neurosurgeons and neuro-oncologists must educate community physicians and the public about scientific advances and new therapies for brain tumor patients. An informed physician community and general public must rely on brain tumor center teams to provide regular vehicles of communication including: scientific and marketing publications; presentations to physicians, other health care professionals, patients, and the public; website materials; networking with professional and community organizations; and media opportunities.

#### Consultation availability

Patients with suspicious or identified tumor on brain imaging require immediate consultation, as do physicians calling on their behalf. Physician to physician communication must be made available 24/7, and patient clinic consultation within 24 h. Many patients accept the same- or next-day appointments, others select an appointment for a few days later: all receive the hope desired, a consultation time set by their terms.

Any type of clinical dilemma qualifies for initial consultation, from patients awaiting diagnosis, to post-surgical patients seeking therapeutic options, to patients treated elsewhere seeking second, third, or fourth opinions, to patients with recurrent disease receiving treatment elsewhere now searching for new therapies. Patients and families benefit from professionals willing to seriously consider their cases and who are committed to providing each consultee with a referral to a helpful resource no matter the stage of disease.

### The focus on hope

The patients we interviewed emphasized their impression on the relationship between hope, quality of life, and longevity in answer to the question, “Do you think that being hopeful can help you live longer?” All respondents said yes. Those who went on to describe a mechanism or reason for their answer often mentioned “less stress” leading to better strength and ability to fight disease as the mediating concept between hope and longer survival. Our patients’ suggestions are consistent with the impression of Jerome Groopman as stated in his book *The Anatomy of Hope* [33]: “I see hope as the very heart of healing. For those who have hope, it may help some to live longer, and it will help all to live better.”

Rabbi Harold Kushner stated at a national neurosurgery meeting several years ago that patients with cancer are most afraid of pain and abandonment (M. L. Rosenblum, personal observation). Patients with malignant brain tumors rarely suffer from significant physical pain, but all too often they struggle with real or perceived abandonment as they live more and more in a world where they can no longer fully participate. We, the patients’ health care professionals, must guard against this preventable form of destroying hope.

Our patient and family interviews have taught us much about their vulnerabilities and the odyssey of hope. They have clearly described four distinct crises:

- The crisis of “shock and the unknown” with the initial diagnosis.
- The crisis of “anticipation” with every new brain scan evaluation.
- The crisis of “defeat and limitations” upon the failure of the initial course of treatment.
- The crisis of “terminal expectation and limited legacy” with eventual failure of second-line therapies and significant disease progression.

They have also taught us how to approach helping them. To the interview question, “If you had the opportunity, what are the five most important things that you would teach doctors, nurses, and other health care professionals about what they can do to maintain hope among patients with brain tumors?” the most consistent suggestions included:

- Be honest.
- Be compassionate and caring.
- Tailor information and discussion to a patient’s willingness to hear and ability to assimilate.
- Take more time to explain and answer questions.
- Include family members in discussions and decisions.
- Highlight those aspects of the situation that are positive.

As physicians and patients alike transition from hope for a cure, to hope for therapeutic response or stabilization, to hope for quality of life and eventually to hope for a dignified death and sustained family integrity, we all remain appreciative of our nursing and other colleagues who provide invaluable assistance. Brain tumor centers must provide help and hope, through clinical care, clinical trials, and research. We must do better, we can do better. With the appropriate support and understanding, there is always new hope. The young mother who called us in 1993 stated that her goal was to see her children grow. We helped her through a battery of therapies and with learning how to live with brain cancer. The patient says we gave her hope, but she, like our other patients, gave us hope in return.

**Acknowledgements** We are grateful to all our patients and their families, and thank those whose letters, comments, and interview participation made this manuscript possible. We thank Bridget O'Connor, Amy Schultz, Lisa Pietrantoni, and Kelly Ciach for assistance with the patient-family interviews. Our Tumor Board team deserves thanks for their input in clinical care including Drs. Kost Elisevich, Samuel Ryu, Benjamin Movsas, Samir Patel, Thomas Doyle, Joseph Anderson, Haitham Ali, Jorge Guitierrez, Norman Lehman, Suresh Patel, Rajan Jain, and Roy Torcuator. Special thanks are due to our neuro-oncology and clinical trials nurses who are the heart and soul of our patient care focus: Sandy Remer, Jodie Honsowetz, Susan Finn, Amy Williamson, Jill Drouillard, and Rita Avedissian. We acknowledge the financial support of the founders of the Hermelin Brain Tumor Center including Eugene and Marcia Applebaum, William and Karen Davidson, David (Deceased) and Doreen Hermelin, Ed and Julie (Deceased) Levy, Mark and Gayle (Deceased) Kahn, Art and Mary Ann Van Elslander, Jay and Maryanne (Deceased) Alix, Harold and Penny Blumenstein, James and Nancy Grosfeld, Joseph and Suzanne Orley, William and Barbara Belzberg, Martin Goldman, Graham and Sally Orley, and Joseph and Rosalie Vicari.

## Appendix: patient and family interview questions on elements of hope

### Meaning of hope

Would you agree that it's important to have hope when you have a serious illness?

What do you mean when you talk about having hope?

### Time line of hope

Since the time that you first heard about your brain tumor diagnosis, when did you have the greatest amount of hope? What was going on then?

When did you have the least amount of hope? What was going on then?

Has your level of hope stayed fairly steady, or has it gone way up and way down?

Was there a time when you specifically needed or wanted someone or something to help you feel more hopeful? Did that someone or something come through for you at that time?

### Circumstances surrounding or promoting hope

Is feeling hopeful a stable characteristic for you as a person, or does it come and go depending on circumstances?

What sorts of things make you most hopeful about your illness?

What sorts of things make you least hopeful about your illness?

Has there ever been a time since your diagnosis when you felt abandoned—meaning that people who should or did care about you didn't any more? (If yes) How did that affect your feelings of hopefulness?

### Consequences of hope

Do you think that being hopeful can help you live longer?

Do you think that being hopeful will help your physical health during whatever period of time you're alive? In what ways?

Do you think that being hopeful will affect other aspects of your emotional or mental state? How? In what ways?

Do you think that your being hopeful has an effect on your family and friends? How?

Do you think that your being hopeful has an effect on the doctors and nurses who take care of you? Why?

Have you felt seriously depressed at times since diagnosis? (If yes) Have any of the doctors, nurses, or other health care staff recognized those feelings? (If yes) Have they done something about it? What have they done? How have they responded?

### Family/friends and hope

Are there things that family or friends do or say that help you feel hopeful?

Are there things that family or friends do or say that contribute to your feeling hopeless?

### Religion/spirituality and hope

Do you consider yourself a religious or spiritual person?

Does your religious faith or spiritual beliefs help you feel more hopeful about your illness?

If you do *not* consider yourself a religious or spiritual person, what are your sources of hope? (Where does your hope come from?)

## Doctors/nurses and hope

Of the various doctors, nurses, and other health care staff you've seen recently, has there been one who made you feel the most hopeful? What did that person do or say to make you feel that way?

Of the various doctors, nurses, and other health care staff you've seen recently, has there been one who made you feel the least hopeful? What did that person do or say to make you feel that way?

What suggestions would you give to doctors about the importance of hope, or what they can do to give hope to their patients?

## Information and hope

Do you seek out specific kinds of information to help you feel hopeful about your illness? (If yes) What information is that? Where do you go to look for it?

Do you think it is possible for health care professionals to deliver bad news without destroying hope? How?

Are you someone who wants to know what the doctor/health care team knows about your illness even if the news isn't all good?

Are you someone who prefers that the doctor/health care team just share certain types of information with you, focusing on the positive and avoiding information that might be negative?

Other than information specifically about brain tumors, are there other kinds of information that help you feel more or less hopeful about your illness?

What sorts of information should be available to patients as they go through the process of diagnosis and treatment to help them feel hopeful?

## Summary

If you had the opportunity, what are the five most important things that you would teach doctors, nurses, and other health care professionals about what they can do to maintain hope among patients with brain tumors?

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