DESIGN OF A PATIENT EDUCATION BOOKLET DESCRIBING GLIOMAS AT THE CELLULAR LEVEL

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DEDICATION

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DESIGN OF A PATIENT EDUCATION BOOKLET APPROACHING GLIOMAS AT THE CELLULAR LEVEL

by

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The most common brain tumors originating in the cells of the brain are a family of tumors known as gliomas that are incurable and usually require some combination of surgery, radiation, and chemotherapy to manage tumor growth and prolong the life of the patient. The central difficulty in curing gliomas lies in the motility of the tumor cells that migrate throughout the spongy tissue of the brain, invading healthy areas beyond the reach of standard treatment, and seeding the beginning of another tumor. This process continues until treatment options are exhausted. The length of the process is determined by the malignancy of the tumor cells, and gliomas can mutate into more malignant forms over the course of the disease. There are many newsletters, brochures, and websites available to patients that explain gliomas by describing tumor symptoms and treatment procedures. This is comforting to the patient because it tells him/her what to expect. However, most glioma patient collaterals rarely describe gliomas at the cellular level or explain the basic science behind radiation or chemotherapy; consequently, the patient doesn't have a grasp of the crucial disease processes going on at the cellular level, doesn't understand why his/her diagnosis might change, and doesn't understand why the treatments available have limited

effectiveness against the tumor. The purpose of this thesis was to produce patient educational collateral for recently diagnosed adult patients and their caregivers to explain the concept of gliomas and their treatment options from a cellular perspective. Patients were polled to establish the relevance, scope, and form of the information included in the final product; then based on their input copy and illustrations were created and assembled into booklet form, selected as a more accessible and convenient format for fostering a better understanding of gliomas and better communication between patients and the medical staff involved in their treatment.

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CHAPTER ONE
Introduction

OBJECTIVE

The purpose of this thesis was to produce educational material to improve patients' understanding of the most common primary brain tumors and facilitate communication between patients, their families, and the medical staff involved in their treatment. A patient poll was done to establish the relevance, scope, and form of the information included in the final product. Based on the patients' input, copy and illustrations were created and assembled into booklet form, considered the best method of delivery for its accessibility and convenience. The booklet is intended to introduce recently diagnosed adult patients and their caregivers to the concepts of gliomas and their treatment options from a cellular perspective. This thesis discusses gliomas in general and addresses the educational materials currently available to glioma patients and their caregivers. The advantages of writing about and illustrating gliomas at the cellular level are examined. The results of the patient and caregiver poll and how they shaped the final product are included in this thesis, as well as an account of the creation of the final product. Finally, there is an overview of patient and caregiver reactions to the booklet and speculation on future improvements, plus possible future expansion of the booklet's information into different media.

BACKGROUND INFORMATION

The cells of the brain can be divided into two groups: neurons and glial cells. By weight, half the brain is made of glial cells while the other half is neurons (Weiss, 1988, p. 306). Neurons are the cells commonly associated with the brain; they are specialized to coordinate all thought, all voluntary and involuntary muscle movement, and all sensory input, as well as some hormone output. They are supported in their tasks by glial cells. (Weiss, 1988)

There are three kinds of glial cells addressed in the booklet: astrocytes, oligodendrocytes, and ependymal cells. The glial cells are produced by the glioblasts. A glioblast is a precursor cell that does no work, but has the potential to divide and produce many mature functioning glial cells. There are a few glioblasts in the adult brain, ready to become astrocytes or oligodendrocytes when there is need. However, occasionally a glioblast mutates and produces a glioma instead of normal cells. (Holland, 2001, pp. 121-122)

There are seven common glioma diagnoses described and explained in the booklet. Three are grouped as well-differentiated: astrocytoma, oligodendroglioma, and mixed gliomas, which have the best prognosis as many of these patients live for ten years or more after diagnosis. Well-differentiated tumor cells still resemble the normal cells they should have become because they have relatively few mutations. These gliomas grow relatively slowly. (Perry, 2003)

There are three gliomas grouped as anaplastic: anaplastic astrocytoma, anaplastic oligodendroglioma, and anaplastic mixed glioma. Anaplastic glioma cells look more like glioblasts and less like mature cells because their DNA has more mutations that cause these

tumor cells to be more malignant. Researchers believe that some anaplastic gliomas were once low-grade gliomas in which the tumor DNA mutated further. Anaplastic gliomas are must be treated more vigorously than low-grade gliomas for the patients to survive a few years. (Kleihues & Cavenee, 2000)

The last glioma diagnosis to be addressed in the booklet is glioblastoma multiforme. According to Kay and Laws, "glioblastomas represent 15-20% of all intracranial tumors and 50% of tumors in adults" (1995, p.197). Unfortunately, it is also the most malignant, due to the greatest number of DNA mutations. It is believed that any of the anaplastic gliomas can become glioblastoma multiforme given enough time for the tumor DNA to accumulate mutations. These tumors require the most aggressive treatment plan, and the patient's survival time is often spoken of in months. (Salcman, 1995)

There are many treatments available to glioma patients that are designed to remove or kill as much of the tumor as possible and prolong the life of the patient. A physician takes into account the patient's age and health, the location of the tumor, and the type of glioma then creates a treatment plan that is usually some combination of surgery, observation, radiation, and chemotherapy. Surgery must be done to obtain a sample for biopsy to establish a diagnosis, while, at the same time, removing as much of the tumor as possible. This means recently diagnosed patients, the booklet's intended readers, have already had one surgery. After surgery, a patient-specific regimen of observation, radiation, and chemotherapy is followed to prolong life until the patient's capacity for undergoing treatment is exhausted. (Schold., Burger, Mendelsohn, Glatstein, Mickey, & Minna, 1997)

SIGNIFICANCE OF PROJECT

Glioma patients and their caregivers have many resources available to them that will explain the symptoms of the tumor in terms of gross anatomy and will prepare patients for treatment by telling them what they can expect to happen during and after any procedures. Such resources also educate the patient about different radiation and chemotherapy treatments, as well as about advances in imaging that may make treatment more effective.

Such resources can provide great comfort to patients and caregivers who learn they are not alone and they have some choice in the method of treatment. However, understanding of the names used to describe gliomas and comprehension of why treatment works (or fails) is incomplete without a histological description of the tumor. Description at the cellular level should also include how radiation and chemotherapy work to kill cells—basic concepts that are usually left out of patient educational materials.

This thesis was designed to produce a booklet that would introduce a lay audience of recently diagnosed adult patients and their caregivers to the classifications and terminology used to describe gliomas. These important concepts incorporate medical jargon which is largely incomprehensible to a lay audience. Although an understanding of this new vocabulary aids communication between medical professionals and patients regarding treatment options and prognosis, the available patient education resources inadequately represent these concepts. In a departure from previous patient education efforts, the booklet produced in the course of this thesis illustrates the terminology and classification of gliomas in full color to give a lay audience a cellular map of different gliomas and their relationships to one another. Combined with the text, these illustrations provide patients and caregivers

with a knowledge base that will enable them to better navigate their communication with medical professionals as well as their independent research of gliomas.

The booklet begins with cells and how they reproduce normally; it then proceeds to a description of normal brain cells. From there it explains how normal glial cells and gliomas develop from the same rare cells, glioblasts, but that mutated DNA in single glioblast produced the tumor cells. Then the booklet describes and explains the different diagnoses and how some gliomas are more malignant or mobile than others. Segueing into treatment options, the brochure briefly covers surgery (which the patient has already had) and observation before explaining how radiation and chemotherapy work to kill tumor cells. Finally, patients and their caregivers are provided contacts and references for gathering further information. All of the cells and the different disease and treatment processes are illustrated in a non-realistic style reminiscent of children's book illustrations. The final product is a printed booklet that is easily accessible in a reliable medium while giving the patient the chance to absorb information at his/her own pace.

LIMITATIONS

Although the cellular approach could be adapted to explaining many brain tumors, the scope of this project was limited to gliomas, and then narrowed to the seven most commonly diagnosed. Discussion of the tumors avoided mention of gross structures, except for a small

graphic of the brain provided for orientation. In the treatment section, particular methods of surgery, radiation, and chemotherapy were not named or defined; instead, information was confined to the general workings of each. In the interest of brevity, the procedures involved in treatment were largely left out or generalized.

Due to the threatening nature of the disease, great care was taken to avoid distressing the patient with negative concepts. Illustrations of the tumors were confined to static endpoints of the disease process in order to circumvent the ideas of progression or growth wherever possible. Within the text, the poor prognosis of the disease was downplayed, while possible outcomes, such as personality changes from tumor growth or lasting, negative, side effects from treatment, were only hinted at or left out in order to avoid robbing the patient of hope. The harsher aspects of the disease and treatment are best told to patients in a personal way by their doctor, rather than published.

The target audience was limited to adult patients and their caregivers because gliomas progress differently in children. In children, there is a chance of a cure; also, children require a more conservative treatment plan to avoid damaging their developing brains.

Various media, such as a video, a CD-ROM, a website, and a booklet, were considered when developing this project. Video and CD-ROM were determined to be impractical for the target audience. Animation would be counterproductive in explaining the progression of these tumors because visualizing growth of an incurable cancer is unavoidably depressing to the patient. Therefore, the strengths of video or CD-ROM to portray animation would be underutilized. Also, the audience might not have access to the equipment necessary to view the materials in those formats. While compiling the information in website

form is a possible future project, most patients prefer print media for its portability, ease of access, and reliability. Thus, a printed booklet was decided upon as the best format for this project at this time.

PRESENTATION METHODS

The final product is a twenty-page, printed booklet that incorporates illustrations, text, and graphic elements describing what a glioma diagnosis is at a cellular level and how it is managed (on a cellular level) by treatment. A rough outline of the information to be included guided the concepts in the text. The copy was written and rewritten and revised—balancing the need to impart information with the need to spare the patient's emotions. Information within the text was reduced in order to stay firmly on the subject and remain within the constraints of the space. The illustrations were sketched first in pencil; then their outlines were rendered in ink after the content was approved. The outlines were scanned and colored on the computer using Adobe Photoshop®. A storyboard was created to relate the visual and verbal elements and to provide a format to determine the number of illustrations and amount of text necessary to create a comprehensive booklet.

All the elements of the booklet were digitized and brought into Quark Xpress®, where they were structured according to the storyboard. The appropriate font size and style was chosen in order to present the information in an intuitively organized fashion. Graphic elements and colors were chosen to unify the booklet into a pleasing, ordered whole. A cover design was chosen, and the booklet was readied for print. It was decided that the first printing of this booklet should be no more than one hundred copies, an ample amount to

submit for patient evaluation over the course of one year. Digital printing, rather than offset printing, was chosen as the most inexpensive option in a print run of such small size.

CHAPTER TWO
Review of the Literature

MEDICAL BACKGROUND

Biology of Gliomas

Normal Brain Cells

The adult brain is made up of two types of cells—neurons and glial cells. Neurons make up the thinking and acting part of the brain. Glial cells provide protection and support for the neurons. By weight, glial cells make up half the brain, and nerve cells make up the other half. Neurons use electrical impulses combined with chemical transmitters to communicate with one another. Each neuron has three parts: a cell body, an axon, and dendrites. Neurons are so specialized for their task of communication that they need glial cells to help them survive. 'Glial' means glue, and these cells are the glue supporting the neurons. (Weiss, 1988)

Most of the glial cells in the brain originated from glioblasts, precursor cells that did no work, but had the potential to divide and produce many mature functioning astrocytes or oligodendrocytes. The adult brain has a few glioblasts waiting to become astrocytes or oligodendrocytes if necessary. (Weiss, 1988)

Mature astrocytes and oligodendrocytes have different functions in the brain. Atrocyte means 'star cell', which is what these cells look like. An astrocyte's many arms support the nerve cells and blood vessels in the brain like scaffolding. Astrocytes bring oxygen and nutrients from the blood to the neurons. They also clean up after our neurons by removing waste. (Duffy, 1983)

Oligodendrocytes (whose means ‘few arm cells’) send out arms like the astrocytes, but their arms wrap around the neuron in sheets to make insulation. As electric signals travel from neuron to neuron, the insulation provided by oligodendrocytes makes the signals travel faster. Oligodendrocyte insulation also keeps the neuron-to-neuron communication from becoming confused. (Weiss, 1988)

A third type of glial cell is mentioned in the booklet: the ependymal cells which line the ventricles of the brain and have hair-like cilia plus microvilli on the surface facing the inside of the ventricle. This type of glial cell originates with the embryonic neuroepithelium instead of the glioblast. (Weiss, 1988)

How a Glioma Begins

When the DNA in a cell mutates in a certain way, the cell becomes cancerous. Then, the mutated cells multiply beyond normal limits, becoming a tumor. There are two kinds of brain tumors—primary or metastatic. Metastatic brain tumors happen when cancerous cells from another source in the body appear in the brain. Most brain tumors are metastatic, most commonly from lung, breast, colon, or skin cancers. Primary tumors originate with brain cells. Gliomas are the most common primary brain tumors. (American Brain Tumor Association [ABTA],1998)

Popular theory once held that a glioma began when a mature astrocyte or oligodendrocyte mutated and regressed to become a tumor cell. Current research indicates that a glioma likely occurs when the DNA inside a glioblast mutates. A normal glioblast can become normal glial cells, but the mutated DNA causes the glioblast to become non-functional cells that continue to divide and overrun cellular boundaries. Although these

tumor cells share characteristics with normal astrocytes and oligodendrocytes, most likely they were never functional cells. (Holland, 2001)

Even tumor cells continue to mutate, and these mutations may cause the glioma to become more malignant, grow faster and have greater mobility. Mobility in particular makes gliomas especially difficult to treat because cells from the main tumor mass often migrate into nearby healthy tissue, making it impossible to catch and treat every cancerous cell. (Perry, 2003)

Well-Differentiated Gliomas

Astrocytoma, oligodendroglioma, and mixed glioma are the three well-differentiated gliomas included in the booklet, grouped together because of "the substantial clinicopathologic overlap among these glioma subtypes" (Perry, 2003, p.169). Well-differentiated means that these tumor cells somewhat resemble normal cells because they are organized similarly and with equal sizes. These gliomas grow relatively slowly.

Astrocytoma: The cells of an astrocytoma still look like normal astrocytes, except that their shorter, fewer arms serve no purpose. The nuclei of the astrocytoma cells are slightly irregular in shape. Mitotic figures are rarely seen, because astrocytomas grow slowly. The tumor cells can grow around healthy nerve cells and blood vessels, but are generally distinct from the healthy cells. Still, a few cells can infiltrate into the surrounding, healthy cells. (Kleihues & Cavenee, 2000) An astrocytoma may develop anywhere in the brain and spinal cord, but most are located in the cerebrum, especially in the frontal or temporal lobes. The tumor may cause seizures, headaches, or subtle changes such as

difficulty in speaking or moving. It can also cause changes in sensation, vision, and behavior. (Morantz,1995)

Oligodendroglioma: Oligodendrogliomas are composed of cells with uniform, round or oval nuclei and no arms. Since oligodendrogliomas grow slowly, there are few blood vessels to the tumor and mitotic figures are seldom seen. A few tumor cells will infiltrate the surrounding healthy cells. (Kleihues & Cavenee, 2000) Oligodendrogliomas most commonly occur in the white matter of the cerebrum, especially in the frontal lobe, although they may arise anywhere in the brain or spine. This tumor commonly causes seizures and headaches, and patients may have a long history of these symptoms before being diagnosed with an oligodendroglioma. (Couldwell & Hinton, 1995)

Mixed Glioma: This kind of low-grade glioma is called of a mixed glioma because some of the tumor cells look like oligodendroglioma, while some tumor cells resemble astrocytoma. There are small, armless tumor cells with round nuclei next to larger tumor cells with small arms and irregular nuclei. These tumors grow slowly, so there is little growth in the surrounding blood vessels, and mitotic figures are rarely seen. A few cells of the tumor mass will migrate into the surrounding healthy cells. (Kleihues & Cavenee, 2000) Mixed gliomas usually occur in the cerebral hemispheres, commonly in the frontal or temporal lobes. They cause the same symptoms as astrocytomas and oligodendrogliomas. The most common symptoms are seizures, headaches, personality changes, and difficulty in motor control. (Kaye & Laws, 1995)

Anaplastic Gliomas

'Anaplastic' means the cells in a tumor look more like a glioblast and less like a mature cell. This occurs because the DNA of anaplastic tumor cells has more mutations, causing these tumors to be more malignant. In some cases, anaplastic gliomas were once low-grade gliomas in which the tumor DNA mutated further; in others, the anaplastic glioma was the initial diagnosis. Anaplastic gliomas are treated more vigorously than low-grade gliomas. (Kleihues & Cavenee, 2000)

Anaplastic Astrocytoma: The cells of an anaplastic astrocytoma have short, nearly absent arms and come in various sizes. Unlike astrocytoma cells, the anaplastic astrocytoma cells are disorganized and dense with atypical nuclei. Mitotic figures are always found in the biopsies of these tumors. This means the tumor cells are reproducing faster than a low-grade astrocytoma. The reproducing tumor cells stimulate more blood vessels to branch out into the area. The new blood vessels feed the tumor, allowing new growth. These tumor cells migrate into our surrounding tissues with greater ease, making them harder to treat. (Kleihues & Cavenee, 2000) Anaplastic astrocytomas occur in the same places as astrocytomas and have the same symptoms. Anaplastic astrocytoma may be a patient's initial diagnosis, or it may become the diagnosis after a recurring low-grade astrocytoma has become more malignant. (Salcman, 1995)

Anaplastic Oligodendroglioma: Anaplastic oligodendroglioma cells have oddly shaped nuclei. Compared to a low-grade oligodendroglioma, there are more tumor cells packed into a small space. The cells show less organization than an oligodendroglioma and slightly varying sizes. These tumors grow faster than low-grade oligodendrogliomas, and

there are more blood vessels supplying the anaplastic oligodendroglioma. Mitotic figures are always present. More of the tumor cells migrate into the healthy tissue than in a low-grade oligodendroglioma. (Kleihues & Cavenee, 2000) Anaplastic oligodendrogliomas have the same symptoms and occur in the same places as oligodendroglioma. Anaplastic oligodendroglioma may be a patient's initial diagnosis, or it may become the diagnosis after a recurring low-grade oligodendroglioma has become more malignant. (Couldwell & Hinton, 1995)

Anaplastic Mixed Glioma: Anaplastic mixed gliomas have traits of both anaplastic astrocytoma and anaplastic oligodendroglioma. These tumor cells come in various sizes, with more irregularly shaped nuclei than a low-grade mixed glioma. Anaplastic mixed gliomas are dense and always show mitotic figures because they are growing faster than a low-grade tumor. There are more blood vessels growing to the tumor site. These tumor cells migrate into the surrounding healthy brain in greater numbers than the low-grade mixed glioma. (Kleihues & Cavenee, 2000) Anaplastic mixed gliomas have the same symptoms and occur in the same places as low-grade mixed gliomas. Anaplastic mixed glioma may be a patient's initial diagnosis, or it may become the diagnosis after a recurring low-grade mixed glioma has become more malignant. (Kaye & Laws, 1995)

Glioblastoma Multiforme: Glioblastoma multiforme is the most commonly diagnosed glioma. Unfortunately, it is also the most malignant, due to the greatest number of DNA mutations. It is believed that any of the anaplastic gliomas can become glioblastoma multiforme given enough time for the tumor DNA to accumulate mutations. Most of the cells in a glioblastoma multiforme appear similar to a glioblast (therefore the 'glioblastoma' part

of the name) but some of the tumor cells have features like other cells in the body (therefore the 'multiforme' part of the name). There are often giant cells with multiple nuclei. Because these tumor cells spend less time differentiating, they reproduce quickly and show several mitotic figures. These tumors are very dense, so dense they often outgrow their blood supply and have areas of necrosis (dead cells), even though blood vessels proliferate around the site. (Kleihues & Cavenee, 2000) Glioblastoma multiforme tumors don't have defined borders. Instead, islands of tumor cells spread between healthy cells. There can also be migratory tumor cells far away from the main tumor masses. These tumors require the most aggressive treatment plan. (Salcman, 1995)

Diagnosis of Brain Tumors

There are many signs and symptoms of brain tumors. According to Schold, Burger, Mendelsohn, Glatstein, Mickey, & Minna, brain tumors "produce three general categories of signs and symptoms: (1) nonlocalizing symptoms related to increased intracranial pressure (ICP), such as headache, nausea, and altered mental status; (2) signs and symptoms related to localized brain dysfunction, such as hemiparesis, visual field defects, and dysphagia; and (3) seizures" (1997). The presentation of signs and symptoms varies widely from patient to patient and depends more on location of the tumor and the tumor's speed of growth, rather than the kind of tumor. The onset of these symptoms occurs over a relatively extended period of time, from weeks to years, although a more abrupt onset can occur due to seizures or hemorrhage. The most common symptoms of brain tumor patients are headache and seizures. (Schold, et al, 1997)

The size of a brain tumor at diagnosis depends on its ability to produce symptoms. Brain tumors that grow large before detection "(1) grow slowly, (2) affect a relatively silent part of the brain, and (3) do not produce seizures" (Schold, et al, 1997). The converse is true of brain tumors that are still small when detected: they grow quickly, affect a critical part of the brain, or cause seizures. However, thanks to the widespread use of CTs and MRIs , more tumors are diagnosed while small and producing mild symptoms than ever before. These neuroimaging techniques are indispensable in diagnosing brain tumors, and all patients undergo a CT or MRI or both before surgical biopsy of the tumor. (Schold, et al, 1997)

Surgery to obtain a tumor sample for pathologic diagnosis is mandated in nearly all cases. According to Schold, et al, "when no therapeutic intervention is planned, it is reasonable to defer biopsy, but there are very few settings in which the clinical and radiographic findings justify treatment without a histologic diagnosis" (1997). This surgical biopsy can be via a needle biopsy, a craniotomy, or CT- or MRI-directed stereotactic craniotomy: these procedures are described below in the treatment section. The main goals of surgery are to obtain the largest sample possible for histologic evaluation and to remove as much of the tumor as possible. Further treatment of the tumor requires diagnosis by the pathologist. (Schold, et al, 1997)

The pathologist looks at the characteristics of biopsied tumor cells under a microscope and utilizes differential staining techniques to diagnose the brain tumor according to the classification standards of The World Health Organization (Gonzales, 1995). Some brain tumors share many features, and their diagnosis may require outside consultation if the pathologist cannot decide between possible diagnoses with significantly different forms

of treatment. Even so, experienced pathologists may have minor disagreements about the specific diagnosis of a tumor due to differences in interpretation. (Schold, et al, 1997) According to Schold, et al,

"Before the coordinating physician initiates a treatment plan, it is essential in each case to synthesize all available data, without taking any single component necessarily at face value—even the histologic diagnosis." (1997, p.24)

All the clues to the identity of the tumor, including the clinical and radiographic evidence, are taken into account before the coordinating physician creates an appropriate treatment plan. In this way, tumors are not over-treated or under-treated.

Treatment Options

There are many treatments available to glioma patients. These treatments are designed to remove or kill as much of the tumor as possible and prolong the life of the patient. A doctor creates a treatment plan that takes into account the patient's age and health, the location of the tumor, and the type of glioma. The treatment plan is usually some combination of surgery, radiation, chemotherapy, observation, and prescription medication.

Surgery

The goals of surgery are "(1) to establish a diagnosis, (2) to relieve symptoms, and (3) to improve outcome" (Schold, et al, 1997, p.37). Removal of the majority of a glioma reduces pressure the brain. This allows the clinical symptoms of the tumor to recede,

because the tumor is no longer crowding the surrounding brain. Surgery also allows for a specific diagnosis because the pathologist can examine samples from the tumor. Surgical removal of as much of the tumor as possible is the best option for gliomas in areas that can be operated on without causing the patient permanent loss of ability. However, a surgical cure is impossible due to the infiltrative nature of these gliomas. (Schold, et al, 1997)

Types of Surgery

Needle Biopsy: A needle is inserted into the tumor through a small opening made in the skull. A sample of the tumor is sent to a pathologist for diagnosis. This is a conservative procedure, used when it may not be safe to operate and remove more of the tumor. (ABTA, 1998)

Craniotomy: Any brain surgery where the skull is opened is called a craniotomy. A craniotomy performed on a glioma patient usually means the surgeon goes into the brain and removes a majority of the tumor and gets a sample for the pathologist at the same time. Since a doctor can confidently diagnose a brain tumor using MRIs and CT scans, the doctor may decide that performing a craniotomy is safe without doing a needle biopsy first. During a craniotomy, the surgeon makes an incision in the scalp and exposes the skull. Then a window to the brain is cut into the skull. After that, a flap is cut in the dura mater, the tough outer covering of the brain. While the brain is exposed the surgeon finds the tumor and removes it. After removal, the parts of the tumor go immediately to a pathologist, who makes a preliminary diagnosis. The flap of dura mater is replaced and sutured closed. The

piece of skull is replaced and sewn into position with nylon or wire sutures. Then the scalp is closed. (ABTA, 1998)

Stereotactic Craniotomy: During a stereotactic craniotomy, the surgeon performs the same steps as a craniotomy described above. The only difference—a stereotactic imaging device is used during surgery to locate the tumor and ensure a greater percentage of tumor removal. Stereotactic imaging also allows the surgeon to plan a more direct route to the tumor. This way, less healthy brain is disturbed, the surgery takes less time, and patient recovery time is faster. (ABTA, 1998)

With gliomas, there is always the chance the tumor may recur. Depending on the patient's ability to cope with the stress of surgery, some patients have multiple surgeries to reduce the bulk of the tumor. (Schold, et al, 1997)

Radiation

The goal of radiation therapy is to kill tumor cells and to halt their reproduction. Radiation treatment is used after surgery to kill tumor cells left behind. It is also used instead of surgery for inoperable tumors. Some kinds of gliomas are known to be particularly responsive to radiation, so radiation is the usual treatment in those cases. (ABTA, 1998)

How Radiation Works

Radiation breaks DNA. Human cells experience radiation from the sun everyday and have adapted to it. Normal cells easily repair the damage caused by the sun and can even repair radiation damage in higher doses. Tumor cells, however, can't make repairs quickly.

Their DNA repair mechanisms are usually shut down or slowed by the mutations required for cells to become tumor cells. In radiation therapy, measured doses of radiation are beamed on the tumor, usually multiple times with rests in between doses. The radiation breaks the DNA in the tumor cells and any normal cells also exposed. In the rest between doses, normal cells are able to repair the damage. The tumor cells have a much harder time recovering, and are treated with radiation again and again until their DNA is useless for growth. Then, the tumor cells die. (ABTA, 1998)

Types of Radiation Therapy

External Beam Radiation: This is the most common type of radiation therapy. For this procedure, a customized helmet is made with the patient's cooperation so the radiation technicians can be sure of treating the same area each time he or she returns for radiation therapy. After putting on the helmet, the patient is immobilized on a table and a beam of radiation is sent to the tumor for a few minutes. The immobility of the patient maximizes the radiation on the tumor and minimizes the impact to healthy tissue. The entire series of radiation doses usually occurs over a period of six weeks, five days a week. The angle of the beam pointed at the tumor may change each session in order to minimize radiation contact with normal tissue. Radiation is measured in Grays [Gy] or rads [rad]. 1 Gray = 100 rads. The maximum amount of radiation given to a patient during treatment is usually around 60 Grays, or 6000 rads. (ABTA, 1998)

Stereotactic External Beam Radiation: All steps of external beam radiation, explained above, are followed plus a stereotactic imaging device is used to improve the

accuracy of the beam treating the tumor. This helps minimize radiation contact with healthy brain. (ABTA, 1998)

Stereotactic Radiosurgery, or "Gamma Knife": In this treatment, the patient is immobilized in a stereotactic imaging device so the edges of the tumor can be accurately defined. Then, the doctor finely focuses 201 tiny, low-power radiation cannons on the tumor using a computer. When activated, the beams are weak until they meet at the focal point in the center of the tumor. There, the rays deliver a combined high dose of radiation to break the DNA of the tumor cells while doing little damage to the normal brain DNA along the way. This is a one-time treatment that works well for small tumors. The drawbacks are the expense and the scarcity of the equipment. (ABTA, 1998)

Stereotactic Interstitial Radiation, or Brachytherapy: In this radiation treatment, stereotactic imaging is used to find the tumor. Then, tiny beads made of radioactive metal are surgically implanted in the tumor. These beads provide a radiation dose field fitted to the size of the tumor, so only the tumor gets a lethal amount of radiation while the normal brain gets very little thanks to fall-off. This technique requires a stereotactic craniotomy, previously discussed in the surgery section, to place the radioactive beads and another surgery to remove them once they have delivered the required dose. (ABTA, 1998)

After Radiation

Possible side effects of radiation include hair loss, skin irritation, nausea or vomiting, drowsiness and fatigue, hearing problems (if the inner ear is involved in radiation therapy), or other neurological effects. Most people will experience only a few side effects as minor

nuisances; fortunately, major complications are rare. Radiation can also cause late effects, which occur months or years after treatment. Late effects are caused by damage to blood vessels or myelin in the path of the radiation, and are a considered risk in therapy. (ABTA, 1998)

Chemotherapy

The goal of chemotherapy is to reduce the tumor cells by using drugs that target rapidly reproducing cells to stop cell division. Chemotherapy also affects healthy cells that naturally divide at a higher rate, stopping their reproduction and causing the temporary side effects of treatment. Chemotherapy is less toxic to healthy cells now than even a few years ago. New drugs are just as effective at killing tumor cells but are less harmful to healthy cells.

Kinds of Chemotherapy

There are many chemotherapy drugs. Each drug employs a slightly different method of disrupting cell production. Some chemotherapy drugs break DNA by chemical methods, while some drugs stop production of proteins necessary to dividing cells. Other chemotherapy drugs make radiation therapy more effective. Different drugs may be given in combination to decrease the tumor's tendency to become resistant to a single drug over time. Some combinations of drugs even reduce each other's side effects. Chemotherapy drugs can be given orally or injected into a blood vessel. Dosage amount and length of treatment depend on the chemotherapy drug chosen and the patient's overall health. (ABTA, 1998)

Advances In Chemotherapy

High Dose Chemotherapy: In this treatment, a radically high dose of chemotherapy is given in order to kill as many tumor cells as possible. The patient is given the antidote to the drug or receives a bone marrow or stem cell transplant on the same day of treatment. The bone marrow or stem cells for this procedure are usually harvested from the patient before chemotherapy. (ABTA, 1998)

Hormone Therapy: This is essentially a variation on chemotherapy. Tumor cells are very sensitive to any growth promoting hormones that may be naturally present in the bloodstream. Hormone therapy blocks the tumor's recognition of the hormones. (ABTA, 1998)

Blood-Brain Barrier Disruption: The blood-brain barrier normally surrounds the blood vessels that go to the brain. Its job is to keep out harmful chemicals and only allow nutrients to pass into the brain. The blood vessels in gliomas are not surrounded by the blood-brain barrier; tumor cells surround them instead. The tumor cells don't stop chemotherapy drugs from reaching the main mass of the tumor, while the blood-brain barrier keeps chemotherapy drugs out of the rest of the brain. However, tumor cells often infiltrate healthy brain surrounding the main tumor mass, and chemotherapy never reaches these tumor cells. However, there are new drugs that make the blood-brain barrier leaky for a short period of time. This allows chemotherapy to reach the infiltrating tumor cells, after which the blood-brain barrier is restored. (ABTA, 1998)

Intrathecal Chemotherapy: The brain makes a watery liquid, called cerebrospinal fluid. This fluid flows around and through the brain and spinal cord in fluid-filled spaces to cushion the nervous system. Intrathecal refers to the fluid-filled space between the membranes that cover the brain and spinal cord. Cerebrospinal fluid in the intrathecal space can be reached by needle in the spine. Injecting chemotherapy into the intrathecal space allows chemotherapy to bypass the blood-brain barrier entirely. (ABTA, 1998)

Chemosensitivity Testing: Many chemotherapy drugs are tested for their effectiveness against samples of the patient's biopsied tumor cells. The doctor then prescribes the chemotherapy drug or drugs that proved most effective at slowing tumor growth. So far, the testing has not proven to be reliable, but new research may improve the success of chemosensitivity testing. (ABTA, 1998)

Side Effects of Chemotherapy

While chemotherapy targets tumor cells, it also affects dividing healthy cells. Areas in the body that are sites of regular cell division are: bone marrow, lining of the mouth, esophagus, stomach, intestines, skin, and hair. The effects of chemotherapy on these areas are temporary and end with treatment. Chemotherapy also affects the testicles and ovaries; the effect on one's fertility may be permanent. (ABTA, 1998)

Bone Marrow: Chemotherapy affects bone marrow by slowing manufacture of blood cells. Patients having chemotherapy are given frequent blood tests to check the number of red blood cells, white blood cells, and platelets. A low red blood cell count results in anemia, tiredness, shortness of breath, and chilled extremities. A low white blood cell

count results in increased risk of infection by common ailments like colds and flu. A low platelet count means patients may bruise easily, heal more slowly, have bleeding gums, and menstruating women may bleed more. (ABTA, 1998)

Hair, Skin, Digestive System: Some chemotherapy drugs cause hair to fall out; others do not. Possible side effects of chemotherapy on the skin include rash, dryness, and itching While receiving chemotherapy, patients may experience dry mouth, oral sores, a burning or tingling in the mouth, diarrhea, constipation, nausea or vomiting. (ABTA, 1998)

Reproductive Organs: It is crucial for patients to not become pregnant or father a child while undergoing chemotherapy because these drugs are harmful to the development of the fetus. Depending upon the drug, chemotherapy can reduce or eliminate sperm count in men. This is usually reversible, but it may take years for sperm counts to return to normal. Some drugs may halt menstruation in women, but menstruation should return after chemotherapy ends. Also, some chemotherapy drugs can slow or halt egg production, with greater effects in older women. (The Musella Foundation, 2001)

PATIENT EDUCATION EFFORTS

Current Patient Education

There are many sources of information about gliomas available to newly diagnosed patients and caregivers. Physicians, support groups, government agencies, non-profit organizations, and pharmaceutical companies all add to the pool of available information. This researcher reviewed many of the patient education collaterals provided by these sources

in the course of this thesis project. Often, these collaterals describe the symptoms of brain tumors, then readers are shown parts of the brain and given an idea of the functions controlled by different areas of the brain. Therefore, patients have an idea of how a tumor is causing their symptoms and what other functions may be affected by their tumor. Brief descriptions of the glioma diagnoses are included in the body of these patient education collaterals in order to give a persona to the patient's diagnosis. Such information resources also educate the patient about different surgery, radiation, and chemotherapy treatments, as well as about advances in imaging that may make treatment more effective and less draining. They prepare patients for treatment by telling them what they can expect to happen during and after any procedures. Information about clinical trials and medications may also be included in these education materials.

Media

Brochures and websites make up the preponderance of the patient education collaterals available. The National Brain Tumor Foundation sells audiotapes, which appear to cover the same topics as are widely found in brochures and websites; this researcher did not review them due to the cost. Also, this researcher found nothing in the form of videotapes, DVDs, or CD-ROMs on the subject of gliomas and their treatment intended for patient viewing.

Analysis and Findings

The patient education collaterals currently available can provide great comfort to patients and caregivers who learn they are not alone and they have some choice in the

method of treatment. However, understanding of the disease process and comprehension of why treatment works (or fails) is incomplete without a histological description of their tumor. Without the concept of a glioma as a mass of mobile cells, patients remain ignorant of the central difficulty of glioma treatment. Other concepts that are usually left out of patient educational collaterals include descriptions at the cellular level of how radiation and chemotherapy work to kill tumor cells.

Nine brochures and thirty-five websites were reviewed by this researcher, who used a seven-question rubric to discover what information about gliomas they contained and whether quality illustrations of gliomas existed. All available brochures were included in the review. Websites were included in the review if they were written for patients and included information about more than one type of glioma as well as some description of treatment options. The entire results of this literature review are contained in Appendices A and B; the results are summarized in Table 2.1.

	Brochure n=9 Yes	Websites n=35 Yes	Brochure n=9 Somewhat	Websites n=35 Somewhat	Brochure n=9 No	Websites n=35 No
Discussion of how gliomas develop?	3	7	0	0	6	28
Discussion of glioblast as glioma cell-of-origin?	0	0	0	0	9	35
Discussion of relationships between gliomas?	3	19	3	2	3	14
Illustrations of gliomas and normal glial cells?	0	1	3	2	6	32
Explanations of how radiation and chemotherapy kill tumor cells?	1	1	2	3	6	31
Illustrations of how radiation and chemotherapy kill tumor cells?	0	0	0	0	9	35
Color drawings or photos?	0	5	1	1	8	29

Table 2.1 Review of current patient education brochures and websites: summary of results.

Discussion of how gliomas develop? The brochures and websites were reviewed to see if they described the difference between normal glial cells and glioma tumor cells—in other words, if they said mutated DNA causes gliomas. Three of nine brochures included this fact—a definite minority; and only seven of thirty-five websites educated readers about the proximal cause of gliomas.

Discussion of glioblast as glioma cell-of-origin? Although research indicates that gliomas originate with mutated glioblasts, none of the patient education collaterals reviewed included that fact. If an originating cell for gliomas was mentioned at all, it was said that mature glial

cells regressed to form a tumor mass. None of the brochures mentioned a cell of origin—only websites.

Discussion of relationships between gliomas? This question was designed to find out whether the reviewed collaterals educated readers about the propensity of lower grade tumors to mutate into a more malignant grade so that tumor diagnoses may be related by the kind of cell the tumor cells resemble but differentiated by grade. For example, well-differentiated astrocytoma and anaplastic astrocytoma have similar looking cells, but the anaplastic astrocytoma has more malignant characteristics. Only three of nine brochures imparted this to readers. However, just over half of the reviewed websites described relationships between gliomas.

Illustrations of gliomas and normal glial cells? Most of the reviewed patient education collaterals had no illustrations of glioma cells or normal glial cells. Three brochures and two websites had illustrations of single glial cells. None of the brochures or websites showed normal cells interacting with glial cells, but for one exception. This exception was a website written by Patrick J, Kelly, MD, FACS called *A simple explanation of gliomas: Growth patterns and imaging studies*. (n.d.) This website included "cartoons" of neurons and glial cells, and successive illustrations showed the effects of the developing glioma on the normal cells. These were the only illustrations of gliomas interacting with healthy cells anywhere; unfortunately, their quality is rather dubious, leading one to believe they were not created by a professional illustrator with access to advanced graphics software.

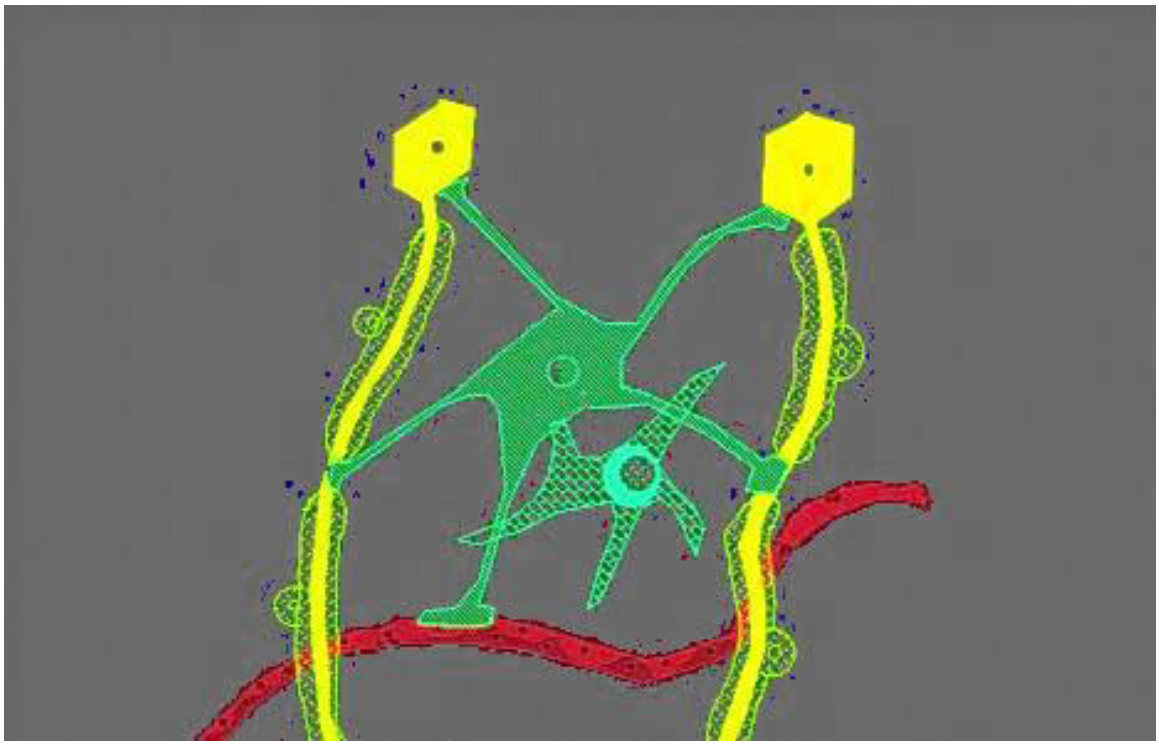

Figure 2.1 Illustration from *A simple explanation of gliomas: Growth patterns and imaging studies* (Kelly, n.d.). Original caption: *Transformed astrocyte pulls in its processes and detaches itself from neuron and blood vessel.*

Explanations of how radiation and chemotherapy kill tumor cells? One brochure and one website adequately described the mechanisms working at the subcellular level in radiation and chemotherapy treatment while two brochures and three websites described the workings of one or the other. The majority, six brochures and thirty-two websites, included no information about how radiation and chemotherapy worked to kill tumor cells.

Illustrations of how radiation and chemotherapy kill tumor cells? There were no illustrations of the mechanisms of radiation or chemotherapy in any patient education collaterals reviewed by this researcher.

Color drawings or photos? There were no full-color illustrations or photos in any of the brochures; only a spot color used as accent in one brochure, therefore the single “somewhat”.

Even though there is no extra cost to publishing illustrations or photographs on a website in full color rather than black and white, only five of the thirty-five websites reviewed had full color graphics. A "somewhat" was recorded for the single website whose illustrations used a spot color besides black.

Summary

None of the reviewed patient education collaterals provided all of the information necessary for patients and caregivers to have an adequate understanding of their glioma diagnosis. Several sources would need to be viewed in combination for the reader to learn how gliomas begin, how different glioma diagnoses are interrelated, and how common treatments such as radiation and chemotherapy work to kill tumor cells. Illustrations of these basic concepts were exceedingly rare, inadequate, or non-existent. Current research indicates that gliomas originate with mutated glioblasts; this was not included in any of the reviewed materials, even those published in the last two years. All of these facts lead to the conclusion that a need exists for patient education collaterals that explain, describe, and illustrate gliomas and their treatment at a cellular level.

CHAPTER THREE
Methodology

SURVEY

A patient survey was created to determine readers' response to the prospective information included in the proposed patient education material. The pilot survey (see Appendix C) asked fifteen questions, then refined to twelve in the final form (see Appendix D). There were three categories of questions: What do you know? How do you know that? What more would you like to know? Patients and caregivers were interviewed for at least fifteen minutes, often more, by this researcher, and their verbal responses recorded and later summarized (see Appendix E). Their answers documented their desires for further information, their level of knowledge about gliomas, resources they used to gain this knowledge, and their opinion of proposed methods of information delivery.

Survey Participants

This researcher interviewed fifteen patients during their follow-up visits to Dr. Bruce Mickey or Dr. Karen Fink. All patients were accompanied by at least one caregiver, whose responses were also recorded, although caregiver responses were not recorded on separate survey forms. The patients surveyed were not randomly sampled from the population of glioma patients in the area. For ease of access, all were patients of Dr. Mickey who chose which patients this researcher would approach for participation, using his rapport with the patients to determine which ones would be most communicative and willing to participate in

a survey. All of the patients agreed to be interviewed after they were approached for participation. Two of the patients included in the survey had diagnoses outside the scope of the booklet—a pituitary adenoma and a medulloblastoma, respectively—but were willing participants and were interviewed nonetheless.

Survey Results

The subjects' responses are recorded numerically in Appendix F. Most of the patients and caregivers were eager for more information about their disease, with a majority stating that they had desired information as soon as they learned the diagnosis: however, they had also been concerned with being overwhelmed. Five of the respondents emphasized keeping the information included in the booklet simple, while the patients who had wanted limited knowledge of their disease at the outset stated that they had been too emotionally overwhelmed to take in much information at the time of their diagnosis. This led to the conclusion that information about gliomas would be greatly appreciated by patients but should be as streamlined as possible in order to alienate fewer members of the audience (defined as newly diagnosed adult glioma patients).

Roughly two-thirds of the respondents had no idea what glial cells are or what they do, nor could these patients or caregivers define what glioma means. However, roughly half of the subjects thought knowledge of gliomas was important and a cellular approach to explaining their diagnosis would be useful. Of the other half, two participants were unsure of how helpful cell-level knowledge would be, while the remainder thought greater knowledge of tumor cells useless or frightening, patients who wanted limited knowledge due to the

emotional stress caused by thinking about their brain tumor, patients who might avoid education material anyway. These findings confirmed the idea that patient educational materials about gliomas on a cellular basis would be useful to patients and caregivers, if they are inclined to seek information.

All respondents agreed that any material about treatment would be welcome. This overwhelming response convinced this researcher that treatment information is an indispensable part of patient education. Some respondents wished for simplification of the available information into tables of treatment option comparisons, while others said that too much information at once would be overwhelming to the newly diagnosed. This eventually led to the decision to include treatment information in the booklet but to keep its scope conceptual—focusing on the goals of treatment and how different kinds of treatment generally work, rather than describing lists of treatment options. Thus, patients and caregivers would be prepared to understand descriptions of treatment options later but not be forced to consider them at once. However, this decision was reached in the latter stages of writing the copy for the booklet.

A clear majority of patients and caregivers wanted illustrations, both of gliomas and of how radiation, chemotherapy, and medications work. In one standout instance, one of the interviewees told of how he'd talked a nurse into giving him one of the posters from the clinic because those were the best illustrations he could find of the brain and glial cells. Thus illustrations would definitely be included in any form this project took. Of the few patients who did not want pictures, one woman aptly summed up her feelings by saying that she could forget text about gliomas and keep a positive attitude but that pictures of gliomas

would haunt and depress her. Further discussion revealed that she thought of her tumor as a black mass and she believed "pictures" referred to photographs of tumors instead of illustrations. Upon this evidence, that fear tends to cause patients to demonize the look of the tumor, it was decided that illustrations needed to be brightly colored and non-threatening (such as the illustrations on the coveted poster).

All respondents got information about their tumor from these sources: their physicians, booklets and brochures, websites, medical texts and journals. Subjects were questioned about their preferences for information sources: eight used the Internet and paper media together, two used paper media only, and the others preferred to depend on their doctor or have information passed to them through friends and family. Four were actively prejudiced against the Internet, characterizing websites as an unreliable source. After reviewing these answers, it was decided that a printed booklet would be the best media for delivery of the information.

WRITING THE TEXT

Preliminary Outline

The information to be included in the booklet was outlined, based on the conclusions drawn after the patient interviews (See Appendix G). Although few of the headings and subheadings in the outline remain in the final product, the flow of information is the same from start to finish, through seven versions of the text. Generally, the outline begins with normal cells, differentiates between neurons and glial cells, and explains how gliomas begin,

describes the gliomas, then the treatment options, and concludes with references and contacts for further research and support. This organization remains intact in the final product.

Although the flow of ideas is the same, some changes were made immediately in the text. A proposed subject, Facts and Statistics, was deemed irrelevant and excluded from the text. Numbers are a cold comfort to glioma patients; at best one can say that the statistics are improving all the time due to advances in imaging and treatment. However, there is still no cure for a glioma, which the statistics make obvious. This subject was left out entirely because it is well covered in other booklets and is of dubious value to the patient.

Writing and Editing

The text was written to be as simple, as concise and straight-forward, as possible while including all pertinent scientific information. Care was taken to define within the text any and all terms that might be unfamiliar to a lay audience. Simple pronunciations for these terms were provided as well. Inclusive language was used where possible, such as “our body” ,“our cells” , and “our neurons”, instead of “your body”. “your cells”, or “your neurons”, to avoid isolating the patient. The text can be loosely divided into two sections: information defining gliomas and information about treatment options for gliomas. Figures 3.1 and 3.2 summarize the subject matter included in each version of the text.

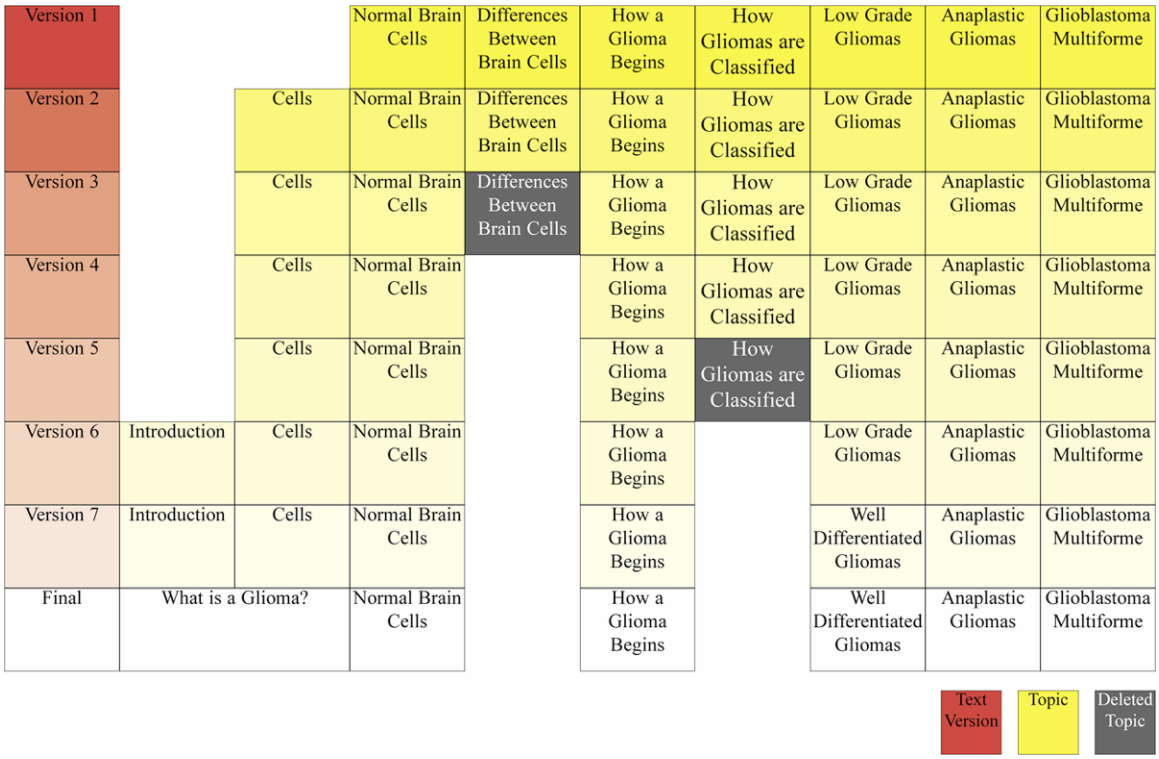

Figure 3.1 Changes made to information defining gliomas across all versions of the booklet text.

Figure 3.1 summarizes the changes to the information defining gliomas throughout seven versions of the text plus the final product. An introduction was written in version six of the text to provide patients and caregivers with an overview of the subjects to be covered within the booklet. In the second version of the copy a paragraph about cells was added to the beginning of the text in response to the concern that patients might not understand or have thought about their bodies as cellular entities. Since the booklet is written and illustrated from the cellular point of view, and its success hinges on that understanding, it was agreed that basic knowledge of cells could not be assumed and had to be included. This introductory paragraph and the basic information about cells were combined under the

heading “What is a Glioma?” (see Figure 3.1), which became the introduction to the booklet in the final version.

The descriptions of normal brain cells generally stayed the same throughout all versions, except that the information from “Differences Between Brain Cells” (see Figure 3.1) was added to the “Normal Brain Cells” section when the former heading was cut in version three. The description of “How a Glioma Begins” (see Figure 3.1) was also more or less the same throughout. Besides describing the differences between normal cells and gliomas, the first version of the copy gives details about pathology and the classification of gliomas in a rather dry section called “How Gliomas Are Classified” (see Figure 3.1), that was ultimately considered too confusing and possibly distasteful to the target [patient and caregiver] audience. Instead of making a section about pathology and what pathologists look for when making diagnoses, the important facts in this early section were revised into simpler ideas and included in other parts of the text in later versions.

The descriptions of each of the diagnoses, under the headings “Well Differentiated Gliomas”, “Anaplastic Gliomas”, and “Glioblastoma Multiforme” (see Figure 3.1), were more fully developed over the course of writing and editing the text. To reduce the emphasis on tumor “grade”, as grading is no longer used by pathologists in diagnosing these tumors, “Low Grade Gliomas” (see Figure 3.1) was revised to “Well Differentiated Gliomas” in the later versions. Since “low grade” is still used as descriptive terminology in most other patient education materials related to gliomas, it was retained in the body copy so the readers would be familiar with the term when encountering it later.

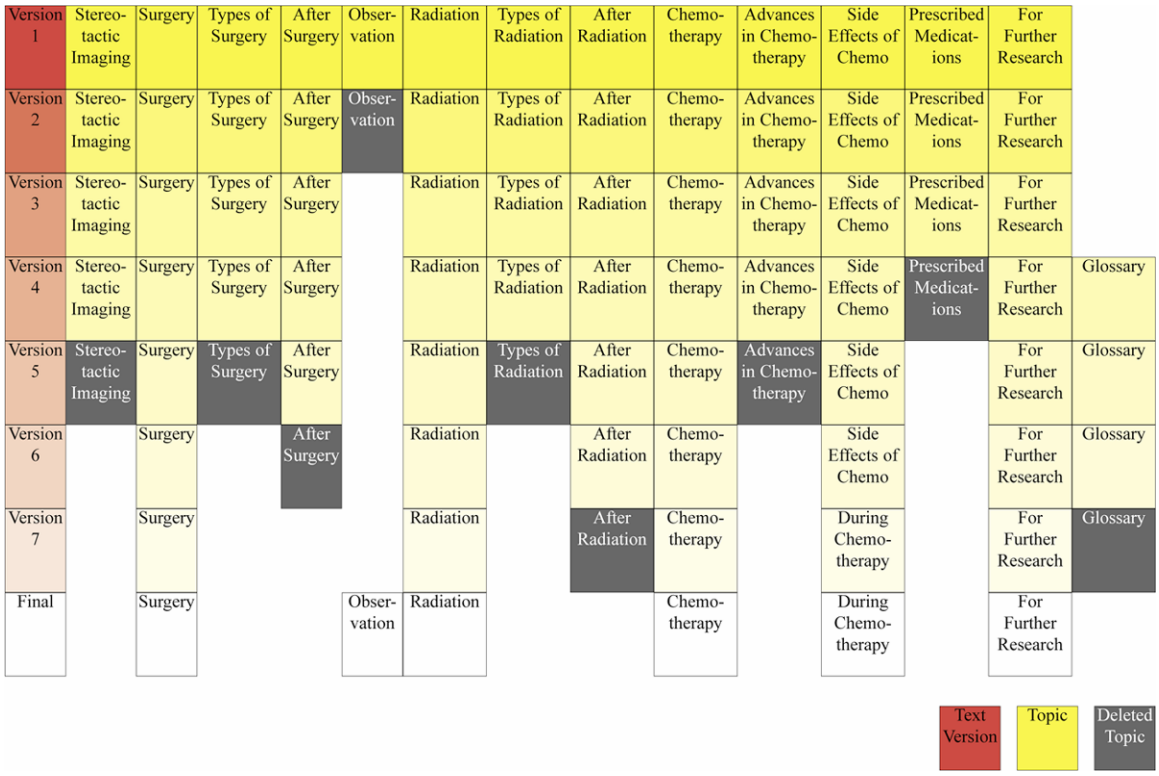

Figure 3.2 Changes made to information about treatment across all versions of the booklet text.

Figure 3.2 describes the revisions related to treatment options. In the first draft of the copy, there was uncertainty as to how much material about treatment options should be included. Keeping in mind the patients' enthusiasm for treatment information, it was decided to include as much as possible in the first version as long as it was in keeping with the tone of the rest of the text. Therefore, the first version describes every major type of surgery, radiation therapy, and chemotherapy in practice. It also includes facts about after-effects for each of the major therapies. There is a lengthy discussion of "stereotactic"-–what it means and why this imaging technique is an advantage—that would have been at least two pages in the final product had it been included.

However, all specific definitions of treatment options, such as “Stereotactic Imaging”, “Types of Surgery”, “Types of Radiation”, and “Advances in Chemotherapy” (see Figure 3.2), were deleted in the fifth version. These revisions were made for the purpose of streamlining the text and focusing the text on the patients’ needs at the time they are informed of their diagnosis. This booklet was never intended to be an exhaustive resource: instead, it is intended to be a beginning place for further research. Sections were edited with that in mind, as well as with the patients’ wish, recorded in the interviews, to keep the information simple. In the sixth version, the “After Surgery” section (see Figure 3.2) was removed because it contained details about timing and procedures that were too specific to apply in every case and could foster more questions than they answered. Recalling that the audience would be newly diagnosed patients, and that a definitive diagnosis of a glioma requires surgery, it was noted that patients and caregivers receiving this booklet would already have experienced surgery. Any information that conflicted with their recent experience of surgery could engender confusion. For a short time, it was argued that patients with recurring tumor masses eligible for subsequent surgeries would need additional information about surgery. However, the counterargument—that very little choice about the method of surgery, even for recurring tumors, is available to the patient—led to the deletion of most of the content about surgery. Surgery is better discussed on an individual basis between a patient and his or her doctor.

For the same reason, the “After Radiation” section (see Figure 3.2) was deleted from the seventh version. The after-effects of radiation vary individually and depend on the location of the tumor and the method of radiation delivery. Information about the side effects

of radiation therapy is best delivered to the individual by a doctor familiar with the details of his or her case. In contrast, the side effects of chemotherapy are widely experienced by patients undergoing that treatment and are probably known of to some degree by most of the booklet's audience. With that in mind, the section titled "Side Effects of Chemotherapy" (see Figure 3.2) was simplified and re-titled "During Chemotherapy", and the information therein was included as a sub-heading to "Chemotherapy" in the finished booklet.

"Observation" (see Figure 3.2) was included as a heading in the first version of the text, but copy for it was not written, and the heading was cut in the subsequent version. Compared to the welter of information about surgery, radiation, chemotherapy, and medications in early versions of the text, the fact that the patients' progress would be observed with MRIs and CT scans seemed uninteresting and unnecessary. Later, when most of the information about treatment was simplified to the essentials, "Observation" was reframed as a legitimate aspect of treatment and written into the final product.

From the survey, to the preliminary outline, and into the first versions of the text, information about commonly prescribed medications was intended to be a part of the final product. First called "Symptom Control" in the outline, "Commonly Prescribed Medications" (see Figure 3.2) was briefly attempted in the first versions but ultimately got left out because the subject was too complex. Although patients expressed interest in learning about the medications regularly prescribed to control the symptoms of brain tumors, there are too many medications, and their use and manner of prescribing depends on the individual. There was enough data to create a booklet on the medications alone, so it was

decided that medication as a subject was best left to the doctors and the pharmacists able to give specific information to individuals.

The section titled "For Further Research" (see Figure 3.2) did not change from concept to the final copy. This section was intended to provide the audience with leads to more information if they wished to pursue them, and as such includes contact information, website addresses, and book recommendations in the finished booklet. Another informational aid, a glossary, was included in the text while the number of specific treatments described in the copy was very high. The "Glossary" (see Figure 3.2) provided a quick reference for definitions for all these treatments as well as definitions for all the terms with pronunciations in the text. After these treatments were deleted from the text, and it was observed that the other terms were well defined within the body copy, the usefulness of the Glossary was debatable. Ultimately, it was cut from the copy before the final version of the booklet went to print in order to cut down the number of pages and conserve costs.

ILLUSTRATING THE TEXT

Preliminary Sketches

It was decided at the outset that the final product would include one illustration of normal brain cells in interaction with one another. The final product would also include seven illustrations, one for each diagnosis included in the booklet, showing each kind of tumor in interaction with the cells. Normal cell shapes and relationships were researched, as well as the shapes and appearances of the included tumors. Preliminary sketches were created which showed normal brain cells and their relationships to one another. From these

preliminary sketches, it was agreed that the illustrations would be done in a linear fashion with flat color. This way, the complicated relationships between cells would be illustrated in a simplified way and color coded so a lay audience would have the easiest time possible comprehending the scientific ideas in the text. A vertical format was chosen.

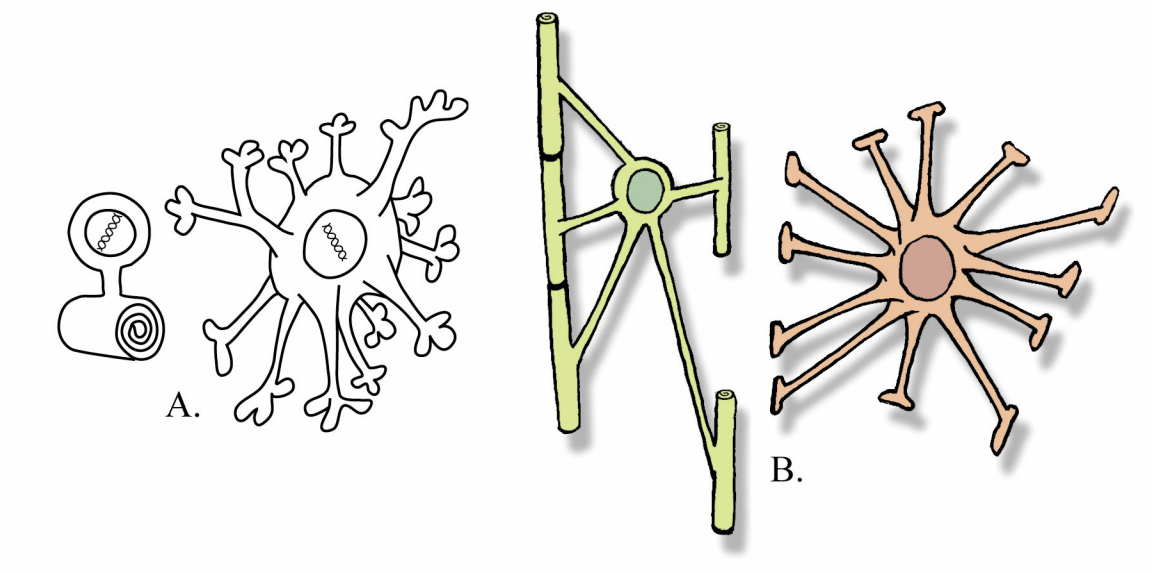

Figure 3.3 A. Preliminary versions of an oligodendrocyte and an astrocyte.
B. Final versions of an oligodendrocyte and an astrocyte.

Since it was a given that DNA would be mentioned in the text, and the tumor cells would be known to have mutated DNA, the preliminary sketches included short lengths of DNA in the nuclei of the cells. Thereby, normal DNA could be contrasted with mutated DNA in each cell throughout the main illustrations. This concept proved to be unfeasible in practice: the short lengths of DNA looked completely unrealistic and were too small to indicate mutated vs. normal. Instead, a larger illustration of DNA was proposed, that would be situated as a "magnified" image next to a cell. A DNA template made of simple shapes was created in 3D Studio Max®, a software tool capable of rendering and animating three-

dimensional graphics. This template was later used to create realistic two-dimensional images of DNA.

References and Advisor Input

After the illustration style and general composition were approved, further research was done to gather specific data on brain cell sizes and functions, in order to illustrate cells in their proper size proportions to one another. The results of this research are recorded in Table 3.1 and Table 3.2. An illustration of normal brain cells and their relationships to one another was composed using the measurements and descriptions in Table 3.1 to guide the look and relative size of the cells.

Cell or Structure	Size	Appearance	Sources
Pyramidal cell (neuron of the cerebral cortex)	Cell body is 10-20 μm across at nucleus; Apical dendrite 4-5 μm in diameter; Axon 2μm in diameter,	Pyramidal cell body, prominent apical dendrite, four or more branching basal dendrites, axon extends into the subcortical white matter	Bergman, Afifi, & Heidger, 1989, pp. 119-120; Weiss, 1988, pp. 286-287
Fibrocytic astrocyte	6-8 μm diameter at nucleus (slightly larger than oligodendrocytes)	Nuclei usually oval in shape, vesicular. Small, irregularly shaped cell soma gives rise to a number of processes of variable thickness, length, and branching pattern. Some processes are stout and lengthy but others are thin and sheetlike.	Bergman, Afifi, & Heidger, 1989, p. 165; Duffy, 1983, pp. 1-22; Weiss, 1988, pp. 306-312
Oligodendrocyte	6-8 μm diameter at nucleus (slightly smaller than astrocytes) Approx. one lamella for every 0.2 μm increase in axon diameter.	Nuclei are smaller, more irregular, and more deeply staining than astrocytes.	Bergman, Afifi, & Heidger, 1989, p. 166; Weiss, 1988, pp. 312-315
Ependymal Cell	5-9 μm wide, 10-16 μm tall	Many microvilli at luminal surface and commonly have one or more cilia, tall and columnar	Bergman, Afifi, & Heidger, 1989, pp. 167-168; Weiss, 1988, pp. 316-318
Capillary	5-10 μm inner diameter		Weiss, 1988, p. 377

Table 3.1 Description of Cells and Structures Included in Booklet Illustrations

Likewise, clusters of tumor cells were drawn for each glioma diagnosis included in the booklet. The look of these clusters of tumor cells was based on photographs of tumor sections and written descriptions of the tumor types, summarized in Table 3.2.

Glioma	Appearance	Sources
Astrocytoma	Increased cellularity on a prominent fibrous background. Variety of nuclear shapes. Expanded extracellular space. Marginated chromatin in nucleus. Mitotic figures rare. Plump cytoplasm. Fewer and shorter processes. Neurons separated by tumor cells.	Kleihues & Cavenee, 2000, pp. 22-26; Morantz, 1995
Oligodendroglioma	Monotonous sheets of tumor cells. Attenuated tumor cell processes. Calcification is common. Lack of nuclear pleomorphism. Minimal mitotic activity.	Couldwell & Hinton, 1995; Kleihues & Cavenee, 2000, pp. 56-61
Mixed Glioma	Distinct or diffuse areas of oligodendroglioma along with areas of astrocytoma.	Kaye & Laws, 1995, p. 138; Kleihues & Cavenee, 2000, pp. 65-67
Anaplastic Astrocytoma	Hypercellularity greater than astrocytoma. Nuclear pleomorphism mor marked. Mitotic figures present. Vascular endothelial proliferation. Plumper cytoplasm. Processes less prominent than astrocytoma.	Kleihues & Cavenee, 2000, pp. 27-28; Salcman,1995
Anaplastic Oligodendroglioma	Hypercellularity greater than oligodendroglioma. Increased nuclear pleomorphism. Developing vascular proliferation. Tumor cells show astrocytic features. Areas of focal tumor necrosis. Mitotic figures present.	Couldwell & Hinton, 1995; Kleihues & Cavenee, 2000, pp. 62-64
Anaplastic Mixed Glioma	Distinct or diffuse areas of anaplastic oligodendroglioma along with areas of anaplastic astrocytoma.	Kaye & Laws, 1995, pp. 138-139; Kleihues & Cavenee, 2000, pp. 68-69
Glioblastoma Multiforme	Many mitotic figures present. Multinucleated giant cells present. Tumor cells form palisaces around necrotic centers. Capillary proliferation with hyperlastic endothelium. Little free extracellular space. Irregular cell nuclei.	Kleihues & Cavenee, 2000, pp. 29-39; Salcman, 1995

Table 3.2 Description of Gliomas Included in Booklet Illustrations

These drawings were then taken to Dr. Kimmo Hatanpaa for review. Dr. Hatanpaa is a neuropathologist at UT Southwestern; he routinely analyzes glioma biopsies and makes differential diagnoses based on his knowledge of tumor cells. Dr. Hatanpaa identified changes that could be made to the tumor cell drawings to make the tumor cells more representative of each of their types. For example, Figure 3.4A shows a sketch of a well-differentiated oligodendroglioma based on written description and slide reproductions.

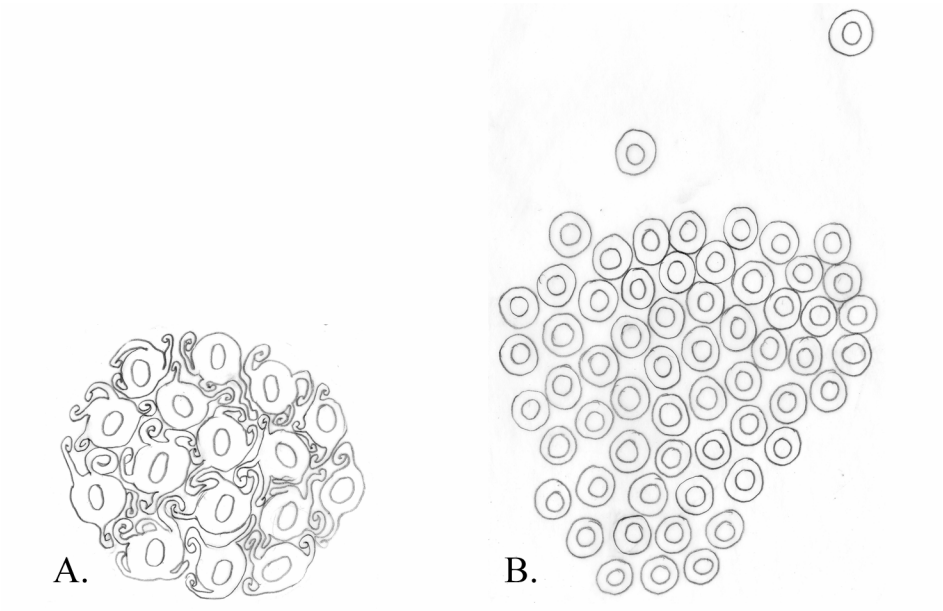

Figure 3.4 A. Oligodendroglioma sketch before review by Dr. Hatanpaa
B. Oligodendroglioma sketch with changes.

In reviewing this sketch, Dr. Hatanpaa suggested that the clumps of tumor cells be depicted in a fan shape rather than a circular mass, because the tumor cells typically spread in that pattern, and that the cells should be farther apart because the individual cells were too close together for a well-differentiated glioma. Inclusion of a few migratory tumor cells was also suggested. Speaking specifically of oligodendrogliomas, Dr. Hatanpaa recommended amending the cells' appearance to armless cell bodies with scanty cytoplasm and round, regular nuclei—traits which differentiate oligodendroglioma from astrocytoma. Figure 3.4B shows the sketch of oligodendroglioma following critique. Similar changes were suggested for each glioma diagnosis. Dr. Hatanpaa also identified features of each tumor type that would indicate a greater or lesser degree of malignancy to a pathologist, such as migratory cells, mitotic figures, necrosis, and evidence of vascular hyperplasia, and made recommendations as to how they might be included to simplistically show increased

malignancy to a lay audience. These changes were made, and the drawings were brought back for further review. At that time, the drawings received approval.

After approval, a background of normal cells affected by the mass of tumor cells was drawn for each tumor type. This background, combined with each tumor cluster, made an illustration of each tumor in relation to the normal cells, blood vessels, and ventricles of the brain. This way, it was possible to show progressive mass effect on healthy tissue and ventricles, progressive blood vessel infiltration, and progressive cell migration into the healthy surrounding cells as the tumors gain in malignancy.

Final Illustrations

The approved sketches were turned into ink line drawings and scanned into the computer at 1200 dpi. Each drawing was colored using Adobe® Photoshop®, a professional image editing program. A color was chosen for each of the cell types based on logical associations as well as design strategies. The vessels had to be red, to show that they convey blood, but the red was less saturated since the capillaries are not the focus of the story. The glioblast, a key player, was assigned the brightest color—yellow. The astrocytes were given orange, as they come from the glioblast (yellow) and are closely associated with the blood vessels (red). Orange is also a "warm" color which attracts the eye: the astrocytes were given this focal color to denote their integral role in the story. The oligodendrocytes were assigned a bright lime green because they also come from the glioblast and have the same status as the astrocytes. Cool colors were assigned to the cells with background roles: the

ependymal cells were blue because they are associated with the watery ventricles, while the neuron was given purple.

The tumor cells were assigned drab colors in the same scheme as the cells they resembled. Astrocytic tumor cells were muted orange, oligodendrocytic tumors were drab green, and mixed gliomas were drab tan from the mixture of orange and green. Glioblastoma multiforme, which most resembles the glioblast, was assigned a muted yellow.

After the full-page illustrations of cells were finished, a two-dimensional drawing of normal DNA was created using a rendered image of the previously created DNA model as a template. An outline of the DNA was inked, then scanned in at 1200 dpi and converted to an Adobe® Photoshop® document. The image was colored, then manipulated to create several versions of the DNA, including mutated DNA radiated DNA, and radiated, mutated DNA.

The DNA illustrations were combined with several cutouts of normal cells and groups of tumor cells (taken from the full-page illustrations of the cells) to create the graphics necessary to illustrate the rest of the text. Auxiliary images were created as necessary in the same manner (inked drawings, scanned then colored), such as cells undergoing mitosis, enzymes, and a sun providing natural radiation. These digital images were then combined with the text in a graphic design program called Quark XPress® Passport™.

FROM STORYBOARD TO FINISHED PRODUCT

Storyboard

A storyboard, or a sketched mock-up of the booklet, was created to integrate the text and illustrations in a fashion that might be translated to the final product. The purpose of the storyboard was to create a "rough draft" of the booklet by determining the placement of all the elements included in the booklet. The storyboard followed the outline of the text, so the flow of information proceeded from cells, to normal brain cells, to how a glioma is formed, to the different possible glioma diagnoses, to treatment options, then to further research and the glossary. Making a storyboard was useful in that it allowed one to visually plan where the text might go on a given page, estimate how much room the text would take up, and plan where to place the illustration on the page.

At that time, the intended dimensions of the booklet were 8.5 inches by 11 inches per page, long axis horizontal. It had been suggested by Dr. Mickey that the main illustrations might be turned to a horizontal format rather than vertical to indicate lateral spread of the tumor cells as was most common in his experience. So, the main illustrations, although intended to be viewed vertically, were sketched horizontally in the storyboard.

Design Issues

The illustrations and text were combined according to the storyboard in a graphic design program called Quark Xpress® Passport™, creating a preliminary version of the booklet which was then shown to the advisory committee. The preliminary booklet was found to be wanting in many respects.

First, the horizontal format was determined to be an inefficient and unwieldy way of presenting the material, besides robbing the main illustrations of some of their effect. A return to vertical format was deemed necessary, and the new dimensions of the booklet were agreed to be 10.75" vertical by 8" horizontal, in order to present the main illustrations to the best effect, as well as allow for better presentation of the text.

Second, the preliminary booklet used palantino font, a serif font which was found to be lacking in style and also difficult to read in the small size necessary for illustration labels. The font used throughout the booklet was changed to gill sans, a sans serif font which is stylistically more up-to-date as well as readable in 8 point type required for labeling graphic elements. Other fonts were considered for use as emphasis in headers and titles, but this was deemed an unnecessary overuse of design in a booklet of only 20 pages. Therefore, one font was adhered to throughout the booklet for a unified presentation of textual effect.

Third, the storyboard called for a separate spread for each glioma diagnosis: a total of seven spreads, or fourteen pages. This was determined to be an inefficient and expensive use of space. Upon consideration, the text and illustrations for the diagnoses were combined by type into three categories—well differentiated, anaplastic, and glioblastoma multiforme—with a spread for each category: a total of three spreads, or six pages.

After the three main flaws of the preliminary booklet were addressed, a new spread for the section on normal cells was designed in Quark Xpress® Passport™. This section included the most text and illustrations of any spread in the booklet and therefore presented the greatest challenge to graphically design. The design elements employed in this new spread in order to organize and present the information in a clear and attractive manner were

continued throughout the booklet for unification and professionalism. These design elements included (1) separation of the text and included illustrations into two columns; (2) a vertical dotted line between columns; (3) a light blue-purple box around the section header; (4) use of gill sans bold on section heads and subheads, in appropriate sizes and kernings; (5) use of gill sans light italic for pronunciations of unfamiliar words; (6) increased leading for paragraphs beneath section heads compared to paragraphs beneath subheads; (7) a 0.5" margin on all sides; and (8) an olive green backdrop to the full-page illustrations, filling the 0.5" margin and requiring a bleed on three sides. These design elements were incorporated in the rest of the booklet where possible, and mildly modified where impossible—such as dropping the two-column format for the glioma diagnoses spreads because the information was too dense to break it into columns.

After the main information was organized into a unified design and arranged in a clear and attractive manner in the judgment of this researcher and the advisory committee, several cover designs were created. The cover design chosen as the most appropriate was judged so by its adherence to the design elements within the body of the booklet, while combining images of DNA, cells, and views of the human brain in an attractive manner. The inside cover and the back cover were designed to be fully printed in dark shades of the blue-purple ink used to highlight the section heads, while the inside back cover was to be printed in a less intense shade of the olive green used as the border of the full-page illustrations inside the booklet. The copyright, acknowledgements, and dedication were placed on the inside back cover in the same font and type size used throughout the booklet.

Committee Approval and Printing

Several times during the course of the booklet's design, the booklet was printed on an inkjet printer and shown to the thesis committee members. Many changes were suggested and implemented during this process, including the design changes explained previously. The necessity of labels on the full-page illustrations was discussed; these labels were added as text on a box of appropriate contrasting color, after other options such as handwritten labels were tested and discarded. The text of the title was changed from "gliomas: diagnosis & treatment management" to "gliomas: diagnosis & management". Likewise, a heading in the interior was changed from "treatment management" to 'treatment". After these and a few other changes were made, the committee approved the final version of the booklet for printing.

Estimates of the cost for printing a twenty-page booklet in four color process with bleeds were obtained. Digital printing and offset printing were both considered. The estimates given by the printing services showed that offset printing was the most economical option for a print run of 500 copies or more, while digital printing was most economical for print runs of 200 copies or less, due to the technologies involved in the different processes. A small print run of 100 copies was decided upon for the first version of this booklet, and Digital Document Services was given the job.

CHAPTER FOUR
Results

READER REACTION TO FINAL PRODUCT

The finished booklet and a questionnaire (see Appendix H) designed to evaluate its effectiveness were distributed to more than sixty patients and caregivers. Fifteen patients and caregivers returned the survey in the stamped, self-addressed envelopes provided. The results of the post-production survey are summarized in Table 4.1.

	Strongly Agree	Agree	No Opinion	Disagree	Strongly Disagree
1) The written material is clear and well organized.	12	2	1	0	0
2) The relationships and tasks of normal brain cells are clearly shown and understandable.	10	5	0	0	0
3) How a glioma begins is plainly illustrated.	12	2	1	0	0
4) Your understanding of gliomas and diagnoses has increased.	9	6	0	0	0
5) The descriptions of the major treatment options were satisfactory.	7	5	1	2	0
6) The illustrations of how radiation and chemotherapy works with cells were helpful.	9	6	0	0	0
7) Use of color made the drawings easier to follow.	14	1	0	0	0
8) The graphic design of the brochure is aesthetically pleasing.	13	2	0	0	0
9) This booklet would be useful to adult patients who have been diagnosed with a glioma.	11	3	1	0	0
10) A printed brochure is the best way to present this material.	8	5	1	1	0
11) Overall, the information in the booklet adequately provides an overview of gliomas and basic treatment option	9	4	0	2	0

Table 4.1 Results of post-production reader survey.

The questionnaire included eleven statements, and readers were asked to choose whether they strongly agreed, agreed, had no opinion, disagreed, or strongly disagreed with

each statement. All fifteen respondents unanimously agreed with statements 2, 4, 6, 7, and 8. The relationships and functions of normal cells had been adequately described, and their understanding of gliomas and diagnoses had increased. The illustrations of treatment mechanisms in radiation and chemotherapy were helpful, as was the use of color in all illustrations. The overall look and feel of the booklet was pleasing to the eye.

Statements 1, 3, and 9 all received one "no opinion" selection. The other fourteen respondents agreed that the text was well-organized and easy to read, that the illustrations of how a glioma begins were easy to understand, and that the booklet would be useful to adult glioma patients.

Although most readers agreed with statements 5, 10, and 11, a few readers expressed slight dissatisfaction. Two respondents disagreed and one expressed no opinion related to statement 5, "The descriptions of the major treatment options were satisfactory." which means that some readers did not find the simplified information about treatment options adequate for their needs. This is probably the basis for the disagreement with statement 11, "Overall, the information in the booklet adequately provides an overview of gliomas and basic treatment options." Here as well as with statement 5, two respondents expressed slight dissatisfaction and disagreed with the statement. One respondent disagreed and one had no opinion about statement 11, "A printed brochure is the best way to present this material." More patients and caregivers are seeking information on the Internet than even two years ago, when patients and caregivers were initially interviewed about this project. As such, some readers may be more comfortable with a website than with a brochure. The steadily

increasing variety of media allows patients and caregivers access to information in a form that best matches their learning style and media preferences.

Impact to Readers

The survey incorporated a section for respondents' comments, some of which are included here:

> "Beautifully produced and illustrated. This is limited information but a good start. I wanted, and got, much more information when my husband was diagnosed. From—Booklet from doctor, doctors, surgeon, radiologist, chemotherapist, *Internet,* and friends." [respondent's emphasis]
>
> "The booklet needs more information treatment options for glioblastoma."
>
> "I've read everything I can find about glioblastoma multiforme so when I got to the last page of this material I was disappointed that there wasn't more. I felt there was something missing."
>
> "I thought it was clear and concise. Even after a year of treatment, it helped me to understand certain fundamentals better. I believe patients can benefit from this booklet. My only question here is any reference to heredity?"
>
> "As a patient, I would like to be able to understand how the chemotherapy knows "where" to go in the body to kill the bad cells (if possible to plainly explain), and is there any knowledge of what is causing these cells to mutate wrong, i.e. what a patient might be able to do "better" in life to keep this process at bay?"
>
> "This booklet will be a useful tool for patients and families of newly diagnosed tumors. I think now people want more information concerning their health."
>
> "This booklet is easy to understand. It would be an excellent starting point for a newly diagnosed patient in gathering information about his or her disease and understanding its nature. A great help when one is facing the unknown. It makes things less scary."

PRESENTATION OF FINAL PRODUCT

SEE APPENDIX I.

CHAPTER FIVE
Conclusions and Recommendations

SIGNIFICANCE OF FINAL PRODUCT

The purpose of this thesis was to produce a booklet designed to improve patients' and caregivers' understanding of gliomas, thus leading to better communication between the patients and the medical staff involved in their treatment. Available patient education materials failed to adequately describe the relationships of normal cells to tumor cells, to adequately describe the classification and terminology of gliomas, and to consistently describe the basic mechanisms of common treatments. Also, neither cellular relationships nor treatment mechanisms were effectively illustrated. After reviewing the available patient education materials on the subject of gliomas and their treatment, it was concluded that there was a need for patient education materials that explain and illustrate gliomas and their treatment at a cellular level, where the difficulty in treating gliomas lies and where patient understanding is most difficult but most crucial..

Patients and caregivers were interviewed to determine the scope of the information to be included in the prospective educational materials, as well as to determine the media best suited to their needs. A printed booklet was decided upon as the most accessible and convenient media. The final product is a twenty page digitally printed booklet that combines simply written text with colorful illustrations as the best means and media for understanding the basic concepts of gliomas and their treatment to interested readers—the newly diagnosed glioma patients and their caregivers.

The effectiveness of the final product was measured by a reader questionnaire distributed to patients and caregivers and was found to be useful and informative. There was only slight dissatisfaction with the streamlined descriptions of treatment options. It was concluded that the booklet provides necessary information for new patients and their caregivers, and achieves the goal of increasing the patients' and caregivers' knowledge about gliomas while aiding in the communication between patients and physicians, all of which was designed to make the disease less frightening.

FOLLOW-UP OPTIONS

The booklet produced as part of this thesis is the first edition of what could become a longer work or a series of booklets related to gliomas. For example, in subsequent editions, the content could include what is not known about gliomas, namely, what causes the DNA in the glioblast to mutate in the first place. A few gliomas can be traced to hereditary causes, but researchers are still uncertain as to what causes the majority of gliomas. Companion booklets and/or subsequent editions could describe what happens at a cellular level with various treatment options, et al., all contingent upon the identification of patient and caregiver needs for particular information, such as those revealed in the survey designed for this edition.

In this survey, readers showed they do, in fact, desire more information in the treatment sections. While this section might be expanded in subsequent editions of the booklet, the need to not overwhelm patients in the beginning with too much information might be better served by a second booklet solely about treatment options and common

medications, which could be given to patients and caregivers later in the treatment process when they have have adjusted (as much as possible) to the diagnosis and have indicated a desire for more information.

Consideration might also be given to how to make such information available in a variety of media, specifically via the Internet, perhaps a website focused on both the cognitive need for specific information related to cellular processes and treatment options, as well as on the affective need, with links to patient and caregiver support groups. Not only would this media reduce or eliminate printing costs, but it could be easily updated as advances are made in glioma research and treatment. For some patients and caregivers, generally those who are younger and have more fully integrated Internet media in their daily lives, accessing a website for information is easier than reading printed materials, notwithstanding the ease of access for friends and family who are not physically close to the patient but still want to be informed.

APPENDIX A
Rubric for Brochures

	Discussion of how gliomas develop?	**Discussion of glioblast as glioma cell-of-origin?**	**Discussion of relationships between gliomas?**	**Illustrations of gliomas and normal glial cells?**	**Explanations of how radiation and chemotherapy kill tumor cells?**	**Illustrations of how radiation and chemotherapy kill tumor cells?**	**Color drawings or photos?**
(1)	Yes, briefly.	No	Yes	Small line drawings of individual normal cells only.	No	No	No
(2)	No	No	No	No	No	No	No
(3)	Yes	No	Yes, but information is disorganized.	Small line drawings of individual normal cells only.	Yes	No	No
(4)	Yes, briefly.	No	Yes, but only different kinds of astrocytoma.	One small line drawing of an astrocyte.	No for radiation, yes for chemotherapy.	No	No
(5)	No	No	No	No	No	No	No
(6)	No	No	Yes	No	No for radiation, yes for chemotherapy	No	No
(7)	No	No	No	No	No	No	Yes
(8)	No	No	Yes, very sketchily.	No	No	No	No
(9)	No	No	Yes	No	No	No	One color plus black.

(1) American Brain Tumor Association. (1996a) *About oligodendroglioma and mixed glioma* (4th ed.) [Brochure]. Des Plaines, IL: Author.

(2) American Brain Tumor Association. (1996b) *Dictionary for brain tumor patients* (3rd ed.) [Brochure]. Des Plaines, IL: Author.

(3) American Brain Tumor Association. (1998) *A primer of brain tumors: A patient's reference manual* [Brochure]. (7th ed.). Des Plaines, IL: Author.

(4) American Brain Tumor Association. (2000a) *About glioblastoma multiforme and anaplastic astrocytoma* (7th ed.) [Brochure]. Des Plaines, IL: Author.

(5) American Brain Tumor Association. (2000b) *Living with a brain tumor* (3rd ed.) [Brochure]. Des Plaines, IL: Author.

(6) The Brain Tumor Society. (1997) *Color me hope* (3rd ed.) [Brochure]. Watertown, MA: Author.

(7) National Brain Tumor Foundation. (1998) *Brain tumors: Understanding your care* [Brochure]. San Bruno, CA: Krames Communications.

(8) National Brain Tumor Foundation. (1994) *Brain tumors: A guide* [Brochure]. Oakland, CA: Author.

(9) National Cancer Institute. (1995) *What You Need To Know About Brain Tumors* [Brochure]. Bethesda, MD: Author.

APPENDIX B
Rubric for Websites

	Discussion of how gliomas develop?	Discussion of glioblast as glioma cell-of-origin?	Discussion of relationships between gliomas?	Illustrations of gliomas and normal glial cells?	Explanations of how radiation and chemotherapy kill tumor cells?	Illustrations of how radiation and chemotherapy kill tumor cells?	Color drawings or photos?
(1)	No	No	No	No	Somewhat	No	Yes
(2)	Yes	No	Somewhat.	No	No	No	No
(3)	Yes	No-says astrocyte instead.	Somewhat	Occasional individual normal cell.	No	No	No
(4)	Yes	No-says astrocyte instead.	Yes	No	No	No	No
(5)	No	No	Yes	No	No	No	No
(6)	No	No	No	No	No	No	No
(7)	No	No	No	No	Somewhat	No	No
(8)	No	No	Yes	No	No	No	No
(9)	No	No	No	No	No	No	No
(10)	No	No-says astrocyte instead.	Yes	No	No	No	Yes, photos of tumors.

	Discussion of how gliomas develop?	**Discussion of glioblast as glioma cell-of-origin?**	**Discussion of relationships between gliomas?**	**Illustrations of gliomas and normal glial cells?**	**Explanations of how radiation and chemotherapy kill tumor cells?**	**Illustrations of how radiation and chemotherapy kill tumor cells?**	**Color drawings or photos?**
(11)	No	No	Yes	No	No	No	No
(12)	No	No	Yes	No	Yes	No	Yes, photos.
(13)	No	No	No	No	No	No	No
(14)	No	No	No	No	No	No	No
(15)	No	No	No	No	No	No	No
(16)	No	No-says astrocyte instead.	Yes	No	No	No	No
(17)	Yes	No-says astrocyte instead.	Yes	No	No	No	No
(18)	Yes	No	Yes	No	No	No	No
(19)	Yes	Alludes to possibility.	Yes	Yes	No	No	Yes
(20)	No	No.	Yes	No	No	No	No

	Discussion of how gliomas develop?	**Discussion of glioblast as glioma cell-of-origin?**	**Discussion of relationships between gliomas?**	**Illustrations of gliomas and normal glial cells?**	**Explanations of how radiation and chemotherapy kill tumor cells?**	**Illustrations of how radiation and chemotherapy kill tumor cells?**	**Color drawings or photos?**
(21)	No	No	Yes	No	No	No	No
(22)	No	No	No	No	No	No	No
(23)	No	No	No	No	No	No	No
(24)	No	No	Yes	No	No	No	No
(25)	No	No	Yes	No	No	No	No
(26)	No	No	No	No	No	No	No
(27)	No	No	Yes	No	No	No	Drawings one color plus black.
(28)	No	No	Yes	No	No	No	No
(29)	Yes	No	No	Yes-only individual cells.	No	No	Yes
(30)	No.	No-says astrocyte instead.	Yes	No	Yes for radiation only.	No	No

	Discussion of how gliomas develop?	Discussion of glioblast as glioma cell-of-origin?	Discussion of relationships between gliomas?	Illustrations of gliomas and normal glial cells?	Explanations of how radiation and chemotherapy kill tumor cells?	Illustrations of how radiation and chemotherapy kill tumor cells?	Color drawings or photos?
(31)	No	No	Yes	No	No	No	No
(32)	No	No	No	No	No	No	No
(33)	No	No	No	No	No	No	No
(34)	No	No	No	No	No	No	No
(35)	No	No	Yes	No	No	No	No
				TOTALS			
	7 of 35 Yes	**0 of 35 Yes**	**19 of 35 Yes 2 of 35 Somewhat**	**1 of 35 Yes 2 of 35 Somewhat**	**1 of 35 Yes 3 of 35 Somewhat**	**0 of 35 Yes**	**5 of 35 Yes 1 of 35 Somewhat**

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APPENDIX C
Pilot Patient Interview Questions

These are the questions asked of the three patients interviewed first.

Patient Survey Questions

How much do you know about the brain?

How much do you know about cells?

Do you know what glial cells are/do?

Do you know exactly what glioma means?

Would pictures of gliomas help you?

Would knowing about the cellular origins of gliomas help you

How much did you want to know after your diagnosis?

Do you rely on what the doctor tells you, or do you do research on your own?

How important to you is learning about the cancer?

How important is knowing about the cancer compared to knowing about the treatment options?

What media do you find most useful for learning about your cancer?

Would you want to see pictures of how radiation works to kill cancer?

Would you want to see pictures of how chemotherapy works to kill cancer?

Do you want to know how the anti-seizure medication works?

Do you want to know how the anti-inflammatory medication works?

APPENDIX D
Patient Interview Questions

These are the questions asked of the twelve patients interviewed last.

Patient Survey Questions

How much did you want to know after your diagnosis?

Do you rely on what the doctor tells you, or do you do research on your own?

Where do you go to find information about gliomas?

What is more important to you—knowing about gliomas or knowing how gliomas are treated? Are they equally important?

How much do you know about the cells in the brain?

Do you know what glial cells are and what they do?

Do you know exactly what glioma means?

Would knowing about the cellular origins of gliomas help you?

Would pictures of gliomas help you?

Would you want to see pictures of how radiation works to kill cancer?

Would you want to see pictures of how chemotherapy works to kill cancer?

Do you want to know how the medication you take works?

APPENDIX E
Patient Interview Summaries

J. T. –Pituitary Adenoma

Although J. T. did not have a glioma, Dr. Mickey felt it would be good to start the interviews with a talkative, well-educated patient. He was asked eight questions out of the fifteen survey questions included in the pilot patient survey. The seven others were not asked because the question did not apply to this patient or this researcher felt uncomfortable asking it.

Mr. T. knew a little bit about cells; it had been years since his last biology class. He did not know what glial cells are or what they do. When asked if pictures had helped him learn about his tumor, he replied that pictures had been useful and were the basis for learning, providing him with a map in his mind of where the pituitary was and what surrounded it. He thought that knowing some information about the cellular origins of cancer would be helpful to other patients, but stressed that the information shouldn't be too detailed. After his own diagnosis, Mr. T. had wanted to know general information about his tumor from the doctors. Details about pituitary adenomas came later, while he did research on the Internet (his main source of information) at his own speed. In Mr. T.'s opinion, patients should know general facts about their cancer, such as what it is and how it got there, but their treatment options should be of primary importance. Patients need to know *all* the treatments available to them, even little weird ones, because individuals differ and the little weird treatment may be the best for a given person. The pros and cons of each treatment should be made clear to the patient so that they can perform their own comparisons and make an informed choice. Mr. T.

emphasized throughout the interview that the information in the brochure should "stick to the point" and not become too detailed because too much information at the outset causes people to shut down. Details come later, after the idea of having a brain tumor has been dealt with somewhat.

K. C. – Low Grade Glioma

Mr. C. had been dealing with seizures for ten years or more; only recently had they been attributed to a low grade glioma instead of epilepsy. He seemed accustomed to the idea of a disease process taking place in his brain. He had done some research on his own, but relied mostly on what the doctors tell him. He said he is very distrustful of the information on the Internet. In Mr. C.'s opinion, the patient needs to understand the concept of the skull as a fixed box with the brain inside being squished by the tumor. He felt that information about the disease is more important than the treatment for the disease because treatment options change over time. However, when asked if knowing the reasons for gliomas existence would help patients he answered, "Not so much." He did not think that schematics of how radiation, chemotherapy, and anti-seizure medication work on cells would be useful, although his wife disagreed. All in all, Mr. C. seemed skeptical of cellular level drawings being much help to patients.

L. A. – Astrocytoma

After her diagnosis four years ago, Ms. A. didn't want to know much beyond how long she had to live; conversely, her husband wanted to know all he could find out. She still hadn't done much research on her own at the time of the interview; instead, she relied on Dr. Mickey for information and decision-making. She, too, was distrustful of the Internet, although her sister had found it a great source and had joined a listserve. Ms. A.'s sister brought information to her, as well as other family members; Ms. A. herself claimed to rely on books and other print media. She said she would have looked at a brochure given to her at the time of her diagnosis--maybe not at first, but later, as she felt ready to deal with the reality of the tumor.

Ms. A. was able to point out a glial cell on the chart hanging in the room, but did not know what glial cells did in the brain; she expressed a desire to find out. She did not know what glioma meant and wanted to know that as well. She said that knowing about the cellular origins of gliomas would help her; she knew that the DNA mutated to cause the tumor but wanted to know why that happened in the first place. Pictures of glial cells would have helped her, she said, especially a comparison of normal to cancerous. She thought that a chart showing the areas of function in the brain would be help patients understand what functions are affected by their tumor. She thought that pictures of how radiation and chemotherapy work to kill cancer would be informative, and the discussion of these treatments should include their pros and cons, as well as side effects, so that patients know what they can expect. She also thought that a breakdown of treatment options might include

a few outdated treatments to show patients that the technology for fighting brain tumors is constantly improving.

A. T. – Glioblastoma Multiforme

Mr. T. and his wife responded jointly throughout the interview. After his diagnosis, he didn't want to know a lot, whereas she wanted to know *everything*. He relies mainly on what the doctor tells him, then she does research on her own, feeding him the information she knows he can handle. To find information on gliomas, she goes to the Internet and looks for reliable sources, reads the *Primer of Brain Tumors* (American Brain Tumor Association,1998) and e-mails a neurosurgeon in Tyler, Texas when she has questions. When asked what was more important, knowing about gliomas or knowing how gliomas are treated, Mr. T. said that the treatment options were more important to him, while his spouse said she felt they were equally important. She felt she couldn't make informed choices without all the knowledge she could find. They agreed that the treatment options will probably be more important to the patient, while knowing about the disease will be more important to the family of the patient because that will help them understand what's happening to the patient.

When asked how much they knew about cells in the brain, the spouse knew some about neurons, but neither she nor her husband knew about glial cells, what they do, and how they differ from neurons. They didn't know what glioma meant. They said that knowing about the cellular origins of the tumor would help them, and that pictures of tumor cells would be great, although he might not want to look at them. She suggested a picture of very

basic brain anatomy showing ventricles, etc., to go along with the cells and give patients a way to relate the cells to the brain. They wanted to see pictures of how radiation and chemotherapy kill cancer cells, and wanted to know how medications commonly prescribed for brain tumor symptoms work on cells. They liked the idea of everything being shown at the cellular level.

W. M. – Oligodendroglioma

Mr. M. is a health professional and knew considerably more than the average patient before his diagnosis. Afterward, he wanted to know everything he could find out. He does plenty of research on his own, using the University of Colorado as his main resource for medical literature. He also finds information in brochures, pamphlets and the Internet. Knowing about gliomas is as important as knowing about their treatment, according to Mr. M., because knowing why the tumor occurs helps one to deal with it emotionally.

Mr. M. was well educated about glial cells and gliomas. He said knowing about the cellular origins of gliomas has helped him because he likes to know a lot about a problem, sometimes too much. Pictures of gliomas at a cellular level would be of use to him and to others, he said. He thought pictures of how radiation and chemotherapy kill cancer cells would be good for patients. He liked the idea of a "consumer report" of treatments, listing their pros, cons and side effects. He suggested that places to go for these treatments, or "Centers of Excellence" might be listed as well.

S. B. – Oligodendroglioma

Ms. B. wanted to know everything after being diagnosed with a glioma. She said she does as much research as she can on her own, but has limited comprehension due to her medications. Her friends and family give her excellent support and bring her articles and information as they find it in books and medical periodicals. Ms. B. said she and her supporters are wary of the Internet—too unreliable—and stick to proven sources such as the American Brain Tumor Association if they venture into it. She felt both knowledge of the disease and knowledge of its treatments are of equal importance to patients. She thought patients should comprehend the path from biopsy to treatment to follow-up to possible recurrence.

When asked what she knew about cells in the brain, Ms. B. laughingly replied, "More than I did before," and cited the *Primer of Brain Tumors* as her source for this information. She knew what glial cells are, what they do, and what glioma means. She answered with a definite no when asked if knowing about the cellular origins of gliomas would help her. She "wants to stay positive and pictures of cells and slides and how these alien cells are dividing is depressing." MRIs are graphic enough for Ms. B., and she responded with a no to every other idea of a picture. Verbal expression of ideas are less threatening to her, she said, because she can put them out of her mind when she needs to feel better. Pictures, however, are unforgettable, and can be an obstacle to thinking positively about beating the tumor.

C. H. —Glioblastoma Multiforme

Ms. H. was a little out of it, although very pleasant. Her daughter answered most of the questions for her. Ms. H. likes having reading material about gliomas around, mostly for the comfort of "doing the right thing" because her memory, especially short-term, doesn't work well anymore. She relies on what the doctors tell her, and has been impressed with the number of people involved in her case; overall she feels well taken care of. Her daughter, the caretaker, was more anxious on Ms. H.'s behalf.

As a caretaker, Ms. H.'s daughter had done some research on her own, looking on the Internet and in pamphlets she picked up in the office. She felt that knowing about gliomas and knowing about the treatment options were of equal importance. However, her only information on cells in the brain had come from the doctors involved with Ms. H.'s treatment. She did not know what glial cells are, what they do, or what glioma means. She couldn't say if knowing about the cellular origins of gliomas would be helpful, but was eager to see pictures of how chemotherapy and radiation work to kill cancer along with pictures of gliomas.

S. P. —Neurofibromatosis and Anaplastic Astrocytoma

Ms. P. had two diagnoses—neurofibromatosis, which led to an anaplastic astrocytoma. She had some difficulty focusing and answering verbally, so her husband gave more information. However, she stayed involved and nodded her head at what he said and volunteered information on occasion. After her diagnosis, they had wanted to know what happens next from the patient's point of view. They were interested in the process of dealing with a brain tumor and sought support groups, reliable resources on the web, and personal

experience from others in their church. In so doing, and by reading pamphlets given them by the doctors, they learned about the disease.

The P.s felt that being informed about the disease was more important than merely knowing treatment options, and that the choice of treatment depended on knowledge of the disease. However, they did not know about cells in the brain, and considered that information to be "too high level". They knew more about how brain tumors affect the rest of the body's processes: "how cancers and treatments affect hormones and such". They did not know about glial cells or gliomas, and seemed focused on the neurofibromatosis diagnosis. Whether they understood the anaplastic astrocytoma diagnosis or not was unclear, because they were unable to explain it comprehensively. Mr. P. was excited by the idea of pictures and stated that S. P. is a visual person who had worked as a graphic designer. Pictures of the cellular origins of cancer, before and after pictures of gliomas, the procedures involved in getting radiation therapy, and pictures of how radiation, chemotherapy, and medication work were all approved by this couple. They were especially keen on suggesting that a flowchart of medications be included somehow. Organizing her medication schedule is a confusing chore for the two of them, so they felt that a chart filled out by the doctor would make sense for patients and their caretakers.

J. P. —Oligodendroglioma

J. P. was an enthusiastic and well-informed interviewee. Mr. P. wanted to know everything about his disease, and characterizes the resources he's found as islands of information with no connecting areas. He had done research on his own, using Internet

searches to find medical texts and journals. He considered the disease and the treatment options to be of equal importance in his research. He had found no adequate pictures and exclaimed that the chart in the room with us had the best illustrations of brain areas plus cells; previous to the interview, he'd even talked one of the medical staff into letting him take a chart home.

He knew quite a bit about brain cells and gliomas, and seemed to think of the disease at the cellular level. In addition to the colorful pictures of cells, he wanted a picture of the brain with the different areas demarcated in color for the patient to refer to as they looked at cells. He was very keen on having the importance of tumor location explained to patients. Mr. P. suggested a chart of pros and cons for treatment options that could be related to tumor location and type. He illustrated his thoughts during the interview by drawing a chart that looked like this:

	Pros	Cons	Responsive tumor types	Sensitive brain areas
Radiation				
Chemotherapy				
Surgery				

Mr. P., based on his experience in support groups, asked that swelling and seizures be explicitly defined because some patients don't know what constitutes a seizure or what the symptoms of swelling are, and those patients don't keep their doctor adequately informed.

Mr. P. was adamant that bad side effects of any treatment should be disclosed to the patient so that they may make an informed choice.

A. D. —Oligodendroglioma

Ms. D. did not want to know much about her glioma. She had undergone treatments and observation for the past two years, and only recently had felt courageous enough to do a little research on her own. Dr. Mickey steered her away from the Internet, but her school librarian, her pastor, and other friends had helped her along in her print research. She focuses on the treatment options, or "the hopeful stuff". She finds the biology stuff boring and glosses over it. Ms. D. did not know what glial cells are and didn't know what gliomas were exactly, but she knew about the different grades of tumors. She thought that would be too much information for a new patient and best left out at first—same for the cellular origins of gliomas. She didn't want to see pictures of glioma cells for herself, but thought that her parents might be interested.

On the other hand, Ms. D. wanted to know all she could about how radiation and chemotherapy work to kill cancer, as long as it was in layman's terms. Pictures here would be fine. She also wanted to see how the medications work, and have seizures and other effects of the tumor specifically defined.

R. V. —Anaplastic Astrocytoma

Mr. V. didn't want to know a lot about the tumor when he was first diagnosed, just the facts about the immediate treatment options. He felt that the problem with too much

information about these tumors is that the numbers don't mean anything. The best treatment for a given tumor is a matter of opinion, and the best opinion comes from a trusted doctor. He is extremely confident in Dr. Mickey, and any auxiliary information comes from the *Primer of Brain Tumors* given to him by Dr. Fink. The treatment options were of utmost importance to Mr. V. He understood that treating brain cancer was different from other cancer because of the blood-brain barrier. He did not know what glial cells are, nor did he know what glioma meant.

He thought that knowing the cellular origins of gliomas might help patients understand what caused their cancer, how it's mutated DNA and luck of the draw. He supported illustrated explanation of treatment options, as long as it was kept schematic and simple. Mr. V. also requested more information about seizures.

H. M. —Medulloblastoma

Mr. M. said he wanted to know everything after his diagnosis. He listened to the doctor and did research on his own, attended support groups, searched the Internet and found information with the National Brain Tumor Association. He felt that knowing about the disease was just as important as the treatment options, but the quest for knowledge had not led him to much information at the cellular level. He was satisfied with his current level of knowledge, and felt that he didn't need information on a cellular level to make decisions. Mostly, he left it up to Dr. Mickey and did a little research to find out how others dealt with treatment. He was open to all knowledge, at any rate, and would like pictures and schematics in order to further understanding of his disease.

C. H. —Astrocytoma

Mr. H. was experiencing some long-term side effects of radiation therapy he'd had to reduce his tumor five years ago, and as a result couldn't speak very fluidly. After his diagnosis, he had wanted to know the affects of the tumor on his body and how much longer he could expect to live. He said he relies on what the doctors tell him, and he thinks that knowing how gliomas are treated is most important to the patient. Mr. H. said the cellular origins of gliomas were just details. More important to the patient is a grasp of what the tumor is going to do to his or her body and lifestyle. Yet despite this opinion, both he and his wife knew about glial cells, how they're different from neurons, and what glioma means.

He thought a chart of gliomas might be okay for a quick glance. Pictures of how radiation and chemotherapy work would be good too. He recommended including a few details, like white cell count limits and interdictions to chemotherapy such as hardware in a broken arm.

S. F. —Glioma

Ms. F. said she conceives of herself as sitting in a small box, where the walls of the box are protecting her from all the scary information about the disease. She still doesn't want to know a lot about the tumor; her box hasn't expanded to include much information. She came to the doctor's office with her husband, mother, and sister. During the interview, this researcher gathered that she is never this frank with them regarding her tumor, and they are banned from talking about it in her presence. Her father-in-law, a retired doctor, is doing

a ton of research, she said, and the important stuff trickles down to her through her husband. At that time, she was not aware of much beyond what the doctor told her, although she knew her family was keenly interested in her diagnosis and discussed it when she wasn't there to hear. She takes her medicine and works at getting through the next thing.

Ms. F. doesn't want to know about cells and the different kinds of gliomas. Nor does she want to see pictures of the tumor cells—her attitude is "What can I do about it?" Most information only aggravates her sense of helplessness at this point. Hopeful subjects such as how radiation, chemotherapy, and medication work will be acceptable to her at some time in the future, but she's not there yet.

M. M. —Glioblastoma Multiforme

Ms. M. had a very aggressive tumor with a very poor prognosis and had had radical surgery in both frontal lobes. She was unable to complete the interview since the surgery had left her incapable of concluding a narrative. Her husband did not answer questions on her behalf, and appeared to notice no difficulty in his wife's speech. However, it was obvious that Ms. M. thought faith in God and Dr. Mickey would cure her—all she had to do, she said, was pray on the Book of Jabez and God would miraculously heal her. She and her husband had a religious outlook on life that obviated the need for scientific fact. It is the opinion of this researcher that a patient education booklet about the origins of gliomas in mutated DNA would be of dubious benefit to people of this nature.

APPENDIX F
Patient Interview Analysis

The sample size varies from question to question, depending on whether caretakers answered as well as the patient.

	Yes	**No**	**Not Sure**
Knows what glial cells are/do	5	10	0
Knows what glioma means	4	11	0
Thinks the cellular approach to explaining a brain tumor useful	8	5	2
Thinks knowledge of treatment options of greatest importance	7	n/a	n/a
Thinks knowledge of disease of greatest importance	2	n/a	n/a
Thinks knowledge of disease and treatment of equal importance	6	n/a	n/a
Would like to see pictures of how radiation, chemotherapy, and medications work	15	2	0
Emphasized keeping it simple	5	n/a	n/a
Asked for a tabular comparison of treatment options	4	n/a	n/a
Asked for more and explicit information about seizures	3	n/a	n/a
Mentioned *A Primer of Brain Tumors* by name	2	n/a	n/a

APPENDIX G
Preliminary Outline of the Text

Title: Gliomas and Their Treatment

Headings:
About Gliomas
Symptom Control
Treatment Options
Facts and Statistics
For Further Information

About Gliomas:
Normal Brain Cells
Neurons vs. Glial Cells
What Causes Brain Cancer?
Primary vs. Metastatic
Low Grade and High Grade
What the Diagnosis Means

Symptom Control:
Anti-epileptics—Define seizures
Anti-inflammatory—Define symptoms of brain swelling
How they work—Illustrated

Treatment Options:
Surgery—List kinds
Radiation—Illustrated
Chemotherapy—Illustrated
Chart of Treatment Options—For doctor to fill out in presence of patient

Facts and Statistics:
Talk about the difference between the two.
Positive message: remain hopeful.

For Further Information:
Addresses and phone numbers of societies
Websites
Support group contact information

APPENDIX H
Booklet Questionnaire

Booklet Questionnaire

Gliomas: Diagnosis & Management

Instructions: Please color in the bubble to rate your level of agreement with the statements to the right.

Strongly Agree	Agree	No Opinion	Disagree	Strongly Disagree		
○	○	○	○	○	1)	The written material is clear and well organized.
○	○	○	○	○	2)	The relationships and tasks of normal brain cells are clearly shown and understandable.
○	○	○	○	○	3)	How a glioma begins is plainly illustrated.
○	○	○	○	○	4)	Your understanding of gliomas and diagnoses has increased.
○	○	○	○	○	5)	The descriptions of the major treatment options were satisfactory.
○	○	○	○	○	6)	The illustrations of how radiation and chemotherapy works with cells were helpful.
○	○	○	○	○	7)	Use of color made the drawings easier to follow.
○	○	○	○	○	8)	The graphic design of the brochure is aesthetically pleasing.
○	○	○	○	○	9)	This booklet would be useful to adult patients who have been diagnosed with a glioma.
○	○	○	○	○	10)	A printed brochure is the best way to present this material.
○	○	○	○	○	11)	Overall, the information in the booklet adequately provides an overview of gliomas and basic treatment options.

Comments or Suggestions:

_____

_____

_____

APPENDIX I
Presentation of Final Product

The completed booklet, *Gliomas: Diagnosis & Management,* is attached as a supplement to this thesis document. To view the booklet, navigate to the folder called "GliomaBooklet". In the folder, click on GliomaBooklet.pdf to open the booklet in Adobe® Acrobat®. You may also choose to open the booklet from within this document by clicking on the following link. *Gliomas: Diagnosis & Management*

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VITAE

Nicole Marie Hilborn was born in La Porte, Texas, on March 15, 1977, the daughter of Richard and Jerri Hilborn. She graduated as salutatorian from La Porte High School in 1995. On graduation, she accepted several four-year scholarships (National Merit Scholarship, Southwestern University Academic Scholarship, and Robert C. Byrd Honors Scholarship) as well as some one-time awards. That year she put them to good use upon entering Southwestern University in Georgetown, Texas. While enrolled there, she served on the Student Advisory Board of the School of Fine Arts by appointment of the Dean of the School of Fine Arts. Later, she was awarded an Art Department Award of Merit. She graduated cum laude in 1999 and received her Bachelor of Arts, having majored in fine arts with a minor in biology. Somewhere in all that she remained well rounded and retained a semblance of a life. In 2000, she joined the University of Texas Southwestern Medical Center's program to attain Master of Arts in Biomedical Communication. With her thesis complete, she anticipates her degree in May 2004. Strangely, she doesn't expect to leap back into academia, but rather intends to put all her effort in some form of employment-for-remuneration experience, which might be appropriate considering the loans coming due for repayment soon.

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