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## Brain Neoplasm and the Potential Impact on Self-Identity

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### Abstract

Cancers of the brain can cause alterations in a person's neurocognitive abilities, and in some patients can even challenge their concept of self and self-identity. Cancer treatment may offer some hope for longer survival, but residual neurocognitive alterations generally remain. Individualized care for these patients should include information related to anticipated effects of their disease or treatments affecting their perception or expression of self. At present, the concepts of self and self-identity are largely unexplored in neuro-oncology, but we will discuss this clinical population in order to highlight the need for further clinical evaluation of these phenomena among patients with brain neoplasm. Finally, we will briefly note the need for a clinical tool to assess self and self-identity changes in brain tumor patients.

### Keywords

Ethics; Brain Tumor; Self; Self Identity

### Introduction

Self-awareness is one of the elements of our self and involves the integration of information from many sources. Self-awareness, i.e., my recognition of my self as "me," begins with a comprehensive picture of the state of my body and its surroundings. These pictures are representations which are constantly changing and facilitate higher-order cognitions about my self and my environment to drive behavior. Low-level representations of my bodily states are always at the core of self-awareness. However, at higher levels, one or more specialized sets of self-representations come into play such as cognitive elaborations that inform my self notions or comprehensions.

This article is particularly interested in the interplay between self and self-identity. Of the two, the "self" is the much broader term, encompassing the essential properties by which we and others recognize ourselves as the persons we are. "Self" is an untidy concept in that it might refer to the coherence and continuity of my self-structure over time, i.e., the relative sameness of my behaviors, interests, beliefs, desires; or to my self as embodied, i.e., as my recognition of me in this body or as this body as mine; or to my self as the originative source of thoughts, feelings and actions, i.e., as intentional products proceeding from me. (Glannon, 2007) Brain function can be altered for many reasons including illness, medications, and injury which may in turn alter the essence of one's self.

Self-identity, meaning those properties of my brain-behavior that I and others recognize as constitutive of me is possible thanks to the brain's remarkable ability to integrate different aspects of self-awareness. Thus, Viamontes offers the following as components of one's self-architecture that, when integrated, provide a comprehensive picture of one's self and enable my self-identity: the protoself (a nonconscious collection of representations of the current state of the organism), the emotional self, the spatial self, the automatic self, the appetitive self, the social self, the remembered self and the neocortical observing self (Viamontes *et al.* 2004).

Damasio (1999) emphasizes that the persistence of an integrated or coherent self (i.e., a "self-same" me that endures over time and which I and others recognize as me) requires autobiographical memory. To Damasio, autobiographical memory is the organized record of past experiences of an individual organism. That sense of identity that endures through autobiographical memory is dually dependent on both continuous pulses of core consciousness (defined by the transient but conscious reference to the individual organism in which events are happening) and continuous reactivations of autobiographical memories. In other words, the interactions that living organisms engage in physically, humanly, and culturally get recorded in autobiographical memory and constitute the bases for the autobiographical self and our sense of identity.

If individuals, because of disease and/or treatment, have an alteration in the different neurocognitive abilities and representations of the self and can no longer view themselves as being in a certain place and time; or if they are unable to interact with others through communication and action in a certain or expected way; or if their current experience cannot be integrated into their past experiences or projected future, have they lost a part of themselves and/or their self-identity? Although some parts of the self might be constantly changing, the integration of the mind, brain and bodily components of the self creates a continuity that is manifested as our self-identity. What happens when this integration is broken because one or more of its components is lost? What does this mean to them and their loved ones?

Patients having cancer can experience alterations in consciousness or other neurocognitive domains that may in a transient or longer lasting manner affect their self-identity. These alterations may result from their brain disease, its treatment, or a combination of both. For some patients, tumor-related neuropsychiatric symptoms may be the first manifestation of the tumor, as was the case for 18% of the patients examined by Keschner *et al.* (1938). Some alterations in neuropsychiatric status due to brain tumor-related processes (such as seizures, excess analgesic medication, recovery from a surgical procedure) might cause alterations in the sense or expression of self that are transient, so their impact upon self-identity is not permanent. However, the destructive effect of the tumor or lasting effects from treatment, which regularly includes multi-modal therapy of surgery, radiation therapy, and chemotherapy, can have long-lasting effects on the different dimensions that constitute a patient's self-identity—such as his or her personality. At other times more circumscribed neurocognitive domains might be affected such as memory, language or perception. For instance, a patient's perceptual abilities might be altered as in the case of visual hallucinations altering a sensory or behavioral aspect of the self; or, a patient may develop problems with impulse control as in the case of someone becoming more disinhibited or violent as a result of his or her illness or treatment, impacting a relational aspect of the self. It is the usually taken-for-granted integration of these changed aspects of the self into a more comprehensive picture that explain a wide range of alterations in one's self and perceptions of self-identity sometimes observed in these patients.

The clinical population of patients with brain neoplasm offers ethicists a very unique group from both the disease and the treatment side of the issues related to the characteristics of self. Currently there are no evaluation tools to help guide clinicians in the care of such patients who might have an alteration of their self-identity or sense of self. We will discuss three brain tumor patients encountered in our institution with substantial alterations of self. These cases illustrate how neurocognitive symptoms influence a change in personality and self-identity and highlight the dilemma clinicians are faced with when discussing treatment options or explaining disease progression. Finally, we will pose the question whether or not a self-identity assessment tool might be useful in specific clinical situations

## Case History 1

A 75-year-old woman presented to our clinic with worsening right frontal headache, generalized body weakness, and a slight left facial droop in July 2008. Imaging studies demonstrated a large mass in the right medial frontal lobe. She soon had a surgical gross total resection and the pathology demonstrated glioblastoma (GBM). She recovered to near her baseline mental and physical status. Socially, she lived with her husband, daughter, and grandson, had a business degree and retired from the banking field in 1992, but went on to work initially part-time and then full-time in a local department store. She was known to enjoy being around people, attending church, and being a fastidious home-maker.

Four weeks following her surgery she began receiving concurrent fractionated external beam radiation therapy with temozolomide (as per EORTC-22981/2698-NCIC-CE.3 trial) (Stupp, *et al.* 2005). She also received maintenance temozolomide after initial concurrent treatment. Her medical course was complicated by a deep venous thromboembolism in her left leg, which limited her ambulation. Neurologically, she had no significant deficits, however, on questioning the daughter that lived and cared for her, she stated that since the time of the diagnosis, the patient had complained of a sensation of ants and spiders crawling on her (a symptom labeled 'formication') and of associated visual hallucinations of the same insects in various areas of her house and in our medical office. She had developed the delusional idea that a flood in the basement had led the spiders and ants to come inside the home. The fixation on these hallucinatory experiences and secondary delusions caused significant frustration in the people living with her. This resulted in social isolation, as she did not continue her involvement with church and friends; she also changed the way she interacted with her family and cared for her home. On neurologic examination her speech was intact, had good insight, and was able to provide a detailed history, but the visual hallucinations remained and she stated that spiders were in the corner of the examination room. Her family slowly perceived changes in her interpersonal style and also noticed that many characteristics that previously made her who she was were no longer present. The patient herself recognized that the focus of her daily preoccupations was different than before and sensed that she had 'changed'.

## Case History 2

A 58 year-old woman who works as an artist from her home presented to our clinic with a ten-day history of right-sided headaches and balance problems from postural dizziness and weakness in her left leg. Imaging studies demonstrated a large intracranial mass in the right fronto-temporal ( $6 \times 4 \times 3.7$  cm) lobes with midline shift. She underwent surgery with total resection of the lesion, which was diagnosed as GBM. Upon recovery from surgery she and her husband were optimistic and her functional status was improving. Although physically not at her baseline and unable to resume her art work, she was able to prepare simple meals and care for herself independently. She started concurrent chemo and radiation therapy per standard treatment, and received radiation therapy over a seven week period. During

treatment she did relatively well, but had feelings of hopelessness and depression for which she began to take an antidepressant.

She then received one cycle of maintenance temozolomide, which began four weeks from completing the concurrent chemo-radiation therapy, but was unable to continue because of worsening clinical status consistent with disease progression. As she was requiring more physical assistance, her husband took medical leave from work because she started complaining of visual hallucinations (seeing unwanted people breaking into her home). She no longer engaged in activities outside of her home, and she was no longer able to care for her home or prepare simple meals. Although she was weakening she could still ambulate, but spent most of her waking hours lying on her couch or bed. On her last clinic visit two months following the completion of concurrent chemo/radiotherapy, she was in a wheelchair and her physical appearance was unkempt. She exhibited psychomotor slowing with slow, but comprehensible speech. She was unable to provide a detailed history and was only oriented to herself and year. When asked to calculate the number of quarters in a dollar, she stated “I should know the answer” and she was unable to provide the right answer.

On imaging her tumor demonstrated evidence of progression, and for further management two options were offered: treatment with another chemotherapy regimen or palliative care. This chemotherapy regimen was offered as it demonstrated a survival benefit in patients with similar disease status, and although her performance status was lower than those on the same investigational study therapy, her age and minimal prior treatment status persuaded us to offer this option. When the logistics of receiving treatment were discussed, which included intravenous administration every two weeks; it was clear that due to her cognitive deterioration she could not participate in the decision making process. Relying on her husband as her surrogate decision maker, a decision for palliative care was made. Her husband did not want to prolong her disease process and did not believe she would want to continue, as he stated “she was no longer the person she was”. The patient had limited awareness of these changes, but still realized that many of the neurocognitive abilities that she usually relied on had markedly deteriorated or were no longer present. In essence, she had lost much of her identity - her person or self - from her advancing disease. She enrolled into Hospice and passed away eight weeks later.

### Case History 3

We have previously presented a patient with glioblastoma who committed a violent act against his wife post treatment, although he had no past history of aggression (Villano, *et al.* 2009). We discussed the clinical features associated with violence and the ethical steps that may have prevented this tragedy. We would like to presently discuss the loss of personhood in this patient. He was a 55 year old man who presented with a one week history of moderately severe right hemiparesis. He had been experiencing headaches, aphasia and moderate cognitive impairment. His radiographic studies revealed multiple large lesions involving multiple lobes of his left hemisphere. A biopsy revealed GBM and he received concomitant chemotherapy and radiation therapy. The treatment improved his hemiparesis, but he insidiously developed paranoia.

He neither had a previous history of psychiatric illness nor exhibited aggressive or abusive physical behavior towards family members or medical team. His paranoia, which included the belief that family and neighbors were plotting against him and stealing from him caused him to replace the locks to his home. Six months into his treatment he accused clinic staff of also plotting against him and spreading lies about him. The family denied feeling afraid or threatened by his behavior and assured staff they felt safe around him. However, they were distressed that he was having these abnormal symptoms and when we suggested he see a

psychiatrist on several occasions he repeatedly denied abnormal behavior and refused to see a psychiatrist. Upon insisting that he follow up with psychiatry, he stopped coming to our clinic for care. Eight months after his last visit, several local newspapers reported that he harmed his wife while she was sleeping with repeated hammer blows to her head. (Villano, *et al.* 2009).

During his clinic visits his wife would often cry as she wanted to provide details of his paranoia, but with her husband in the same room, she was cautious. His adult son was more forthcoming and supported that his father was not the same person as he was prior to his diagnosis and treatment. He previously was a good patriarch of the family without a history of psychiatric symptoms, but all this changed after treatment. The patient, however, had no insight into his paranoia and the effect his behavior had on his family. In essence, his self had drastically changed, but without insight, he denied changes to self and refused psychiatric treatment recommendations.

## Self-Identity

Do we lose our self if we no longer can remember our past or the ability to project for our own future or if our present experience is dissonant to our previous concept of ourselves?

As the above has shown, patients with brain tumors can exhibit a wide array of neuropsychiatric manifestations. One study reported that cognitive changes are common in brain tumor patients, with a majority of patients complaining of memory deficits and a near majority complaining of a loss in higher executive function (Meyers and Brown 2006). Regarding tumor location, frontal lobe tumors are usually associated with behavioral symptoms. The frontal lobes are involved in higher-level executive and cognitive functions and their different sub regions are involved in several tasks such as the mediation of problem-solving behavior, the regulation of intentional processing, the temporal organization of behavior and the modulation of affective states (McAllister and Price, 1987). All of these functions contribute to different components of our sense of self although they might depend from input from other remote brain regions. We need to remember that the physical and cognitive aspects of the self are mapped throughout different brain regions and even a region not directly involved in the cognitive elaboration of the self can contribute to the physical or sensory aspects of the self that will ultimately be an essential building block to self-identity. Furthermore, lesions in certain areas of the brain can produce changes similar to the ones expected in lesions in more distant areas of the brain through diaschisis or disconnection syndromes. Lastly, at an advanced stage, large lesions cause a global decrease in a person's cognitive abilities and this eventually will affect their awareness of and interaction with their environment. In conclusion, as tempting as it might be to anatomically 'localize', our self-identity is dependent on different elements that contribute to our sense of self (i.e. perceptions, memories, emotions), with some areas of the brain playing a more crucial role in integrating this information (such as the prefrontal cortex) but ultimately depending on input from various regions as their substrates.

As we mentioned earlier there are different dimensions of the self, with the low-level dimensions mapping physical sensations in the brain and the higher-level dimensions mapping functions considered more abstract or 'cognitive' (Viamontes *et al.* 2004). This argument does draw a line between a purely physical self and a cognitive self. Ultimately it is the harmonious integration of these aspects of the self in the past, present and projected future that gives meaning to our sense of self-identity and it is through our cognitive states, which are fluid and continuous, that we find meaning in our own self and the world around us.

Our cases might, at initial review, show three patients with brain tumor-related or treatment-related neuropsychiatric symptoms. When we examine how these symptoms impacted the lives and senses of self of the patients, it is clear that while they experienced a ‘symptom’, their whole sense of who they were was changed, as perceived either by themselves or their loved ones. Although clinically speaking the symptoms might differ from case to case [distressing visual hallucinations and secondary delusions in the first case, severe cognitive decline in the second case or loss of impulse control and paranoia in the third case] a significant building element of their self was lost and hence, the way these patients viewed themselves or their loved ones viewed them changed from the past. In these cases then, when trying to integrate past experiences into the present, a sense of continuity cannot be achieved. This sense of continuity is essential for the development of a sense of self-identity.

If one does lose his or her previous identity, is it possible to find meaning in one’s “new” self despite this changed sense of identity? If we lose a brain function that defines ourselves, our physical body might remain the same, but what about our own self-identity? Some people may argue that integrating experiences that are too dissonant with our previous self-identity could be very difficult to do while still preserving an ongoing meaning in the current self. The debate between having meaning from a physical life without a continuing sense of self-identity is a complicated one that may never find consensus. However, our point here is to look at how modern medicine may prolong biological lives even when much of what makes that person who he or she is, is no longer active or it is dramatically changed, and how modern care providers, at least those who work with brain tumor patients, may assist such patients with specific decisions about the treatment of their disease through disclosure of case based information related to the potential for loss of self-identity.

Similar to those persons with progressive dementia, once neurological abilities are lost in patients with brain tumors they are rarely regained. Although it is often the case that such abilities are lost far more quickly in brain tumor patients as opposed to the slower progression of such seen in dementia patients, the symptoms and course of dementia are extremely variable “and progression from mild to severe symptoms may take anywhere from a year to more than a decade” (McCance *et al.* 1990). In both conditions, there might be a loss of one or more essential neurocognitive functions, many of which are building blocks of the patient’s self. It is very distressing to persons with dementia and their loved ones when the ability to communicate in a meaningful way and to remember close family members deteriorates (Jenkins and Price 1996). Dementia, in essence, undermines self-identity in that it often seriously compromises the characteristics of self (Neisser 1988). However, it appears that the characteristics of self are the same for brain tumor patients and dementia patients alike and preserving one’s self-identity is an essential principle for the person, themselves, but perhaps more importantly for the family and care givers as this appears to benefit both (Perry and O’Connor 2002).

## Discussion

Neuroethics is a recent term that reflects a study of ethical issues related to the brain, neuroscience and neurotechnology (Alpert 2008). Neuroethics has been further defined by Glannon (2007) as “A branch of bioethics concerned with the ethical issues arising from different measures of and interventions in the brain or central nervous system” (p.4). People who are being treated for a brain tumor often have interventions that cause variable changes in the very structure of their brain.

With specific location and tumor type, clinicians can predict with some certainty the physical and mental changes that will result with or without therapy. In some instances as with low grade gliomas or meningiomas, the prognosis may include complete eradication of

the tumor disease, but the result of this cure may leave the person with specific neuropsychiatric or physical deficits. Oncology in general is advancing and we now have second, third, and even fourth line therapies to offer cancer patients. However, should such salvage chemotherapies be offered by clinicians on the outside chance that some tumor response will result but also with the chance that they will lose important aspects of their self? Such aspects generally include but are not limited to those cognitive functions that allow an individual to experience and interact with their physical and emotional environment in meaningful ways. It is the individual who decides what is meaningful to him or her, but this decision should be made prior to treatment and requires some form of discussion related to the concept of self. This potential loss of self and self-identity is not often brought up by neuro-oncologists when discussing treatment options with patients who have brain tumors, as the focus is to provide hope by offering the available treatment options and in discussing the many other side-effects from their disease, such as seizures, rehabilitation, and driving. In addition, there is scant literature that focuses on the clinical assessment of issues around the concept of self and self-identity. Because tumor- or treatment-related deficits can affect an individual's neurocognitive function, the very sense of self could be altered in such a way that he or she may not resemble the person he or she was prior to the treatment. In essence, patients may be cured of their disease only to lose their previous personal identity.

Our case examples appear to reinforce the obligation to disclose the potential for loss of aspects of self in those cases of brain tumor where there is a strong prognosis of such loss (Fuchs 2006). In addition to this obligation of disclosure, there may be an equal obligation by providers to place emphasis on palliative care rather than aggressive care to help those patients who might choose a shorter physical life but perhaps a longer life with their previous identity. This is perhaps important information that patients may need in order to provide informed consent for or against a specific treatment or intervention. We must always be mindful of "the fact that we do not treat brains, but persons"(Fuchs 2006).

Current literature does not appear to offer brain tumor patients a clinical assessment tool to effectively assess the concept of self and self-identity, either from the clinician, the patient, or the patient's loved one's point of view. There is a plethora of information related to the assessment and measurement of quality of life indicators, but research is needed on the concept of self and self-identity in the neuro-oncology clinical setting. In our experience, the assessment of the concepts related to self has important clinical salience for clinicians, patients, and their loved ones. To this end, we believe that a framework for assessment of self and self-identity for brain tumor patients merits serious bioethical attention. To develop such a framework, there is a need to speak to both patient's with brain tumors as well as their family and loved ones in order to clearly identify the important concepts they relate to self. Focus groups with these individuals will be imperative to framework development. From this framework, a specific assessment tool for self or self-identity might emerge for evaluation in the clinical setting.

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