Pseudoprogression: Patient experience and nursing in uncertainty

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Abstract

Glioblastoma Multiforme (GBM) is the most common primary brain malignancy in humans and has a limited survival (median of 14.6 months). The goal of treatment is supportive rather than curative. Patients with a GBM struggle with uncertainty related to the illness trajectory. This uncertainty is compounded when possible progression is noted on imaging. Pseudoprogression (PsP) is an early treatment-related effect where there are apparent imaging changes suggesting progression, which then improve or stabilize through time. This paper provides a review of the literature on PsP in patients with high-grade gliomas. Insights in the patient and family experience of PsP will be informed by Mishel's Uncertainty in Illness Theory, research on patients' and families' neuro-oncology experience, and the author's nursing practice. Nursing implications will be proposed.

Key words: pseudoprogression, neuro-oncology, glioblastoma multiforme, uncertainty, cancer nursing

Pseudoprogression : l’expérience des patients et les soins infirmiers en période d’incertitude

Résumé

Le glioblastome multiforme (GBM) est la tumeur maligne la plus commune, à laquelle on associe un pronostic limité (médiane de 14,6 mois). Dans le contexte des gliomes de haut grade, le traitement n’a pas un objectif thérapeutique mais palliatif. Les patients atteints de GBM sont confrontés à l’incertitude quant à la trajectoire de la maladie. Cette incertitude s’aggrave lorsque l’imagerie détecte une progression possible de cette maladie. La pseudoprogression (PsP) constitue un effet lié au traitement, par lequel une progression radiographique apparente fait suite à la radiothérapie, avant de pouvoir constater une amélioration ou une stabilisation au fil du temps. Pour les patients et patientes, cette période d’attente se caractérise par un état d’incertitude et la peur de récidive. Ce document de réflexion présentera un aperçu des connaissances actuelles sur la PsP en neuro-oncologie et reliera ce phénomène à la théorie de l’incertitude dans la maladie énoncée par Mishel. Nous discuterons également des conséquences de ceci pour le corps infirmier.

Mots-clés : pseudoprogression, neuro-oncologie, glioblastome multiforme, incertitude, soins du cancer

Glioblastoma Multiforme (GBM) is the most common primary brain malignancy and continues to have a grim prognosis. In Canada, it is estimated that there were 2,900 new cases of brain cancer in 2014 (Canadian Cancer Society, 2014). Based on the landmark study by Stupp et al. (2005), the current standard of care for high-grade gliomas is maximal safe resection followed by fractionated radiotherapy with concurrent chemotherapy over six weeks. This is followed by adjuvant chemotherapy given over five consecutive days per month for six to 12 months. Response to treatment is monitored by serial MRI imaging and clinical evaluation.

In the context of high-grade gliomas, the goal of treatment is supportive rather than curative. Despite progress in treatment modalities and understanding of cancer growth in the last decade, median progression-free survival remains at 6.9 months and the median prognosis is 14.6 months (Stupp et al., 2005). Progression is generally inevitable in the illness trajectory of patients faced with the diagnosis of a GBM. Nurses have a pivotal role in supporting these patients from diagnosis to end-of-life care, particularly at crisis points such as when progression is noted on imaging.

Radiation treatment-related changes that mimic progression on imaging have been documented in the past. Such reports have become even more frequent since the introduction of temozolomide as the standard of care for GBM. Pseudoprogression (PsP) is one of these changes and is the focus of this article. PsP is the radiological appearance of progression soon after combined radiotherapy and chemotherapy treatment, which stabilizes or improves over time (Taal et al., 2008). PsP thus complicates medical decision-making and underlines the ambiguity present in determining progression based on current imaging technologies.

Given the difficulty in interpreting early imaging changes, patients and their families are placed in a period of heightened uncertainty with an unknown outcome. Recent nursing literature highlighting unique aspects of uncertainty in primary brain tumours often cites PsP as a trigger of increased uncertainty (Lin et al., 2012; Lin et al., 2015). Uncertainty in cancer has been negatively correlated with quality of life (Suzuki, 2012; Shaha, Cox, Talman, & Kelly, 2008) and significantly related to anxiety (Lien, Lin, Kuo, & Chen, 2009). More than half of patients with brain tumours may have anxiety or depression (Arnold et al., 2008). Nurses have a pivotal role both in educating patients and families about the possibility of PsP and providing support during this period of uncertainty.

There is limited knowledge about the lived experience of patients and families faced with PsP, as there are no studies reported in the nursing literature that specifically explore the patient’s lived experience of PsP. However, there is some recent
medical literature exploring decision-making that occurs with patients and their caregivers in the context of PsP. This paper describes PsP and provides a review of the literature on PsP in high-grade glioma patients with a focus on lived experience. Nursing literature on uncertainty in neuro-oncology will better inform our understanding of PsP as a trigger of uncertainty. In addition to uncertainty-focused literature, literature on patient and family experience and needs in neuro-oncology will be reviewed in order to enhance understanding of the key theme of uncertainty, as it relates to PsP. The discussion will be informed by Mishel’s Uncertainty in Illness Theory and by the nursing practice of the author in a specialized quaternary care centre. Nursing implications will be proposed.

**Literature review**

**Pseudoprogression**

PsP is a sub-acute treatment-related reaction, usually occurring within three months of combined treatment, that mimics tumour progression on imaging and then stabilizes or improves over time without any intervention (Brandsma, Stalpers, Taal, Sminia, & Van den Bent, 2008). A comprehensive review of PsP after combined treatment (Kruser, Mehta, & Robins, 2013) found that approximately 50% of patients had indications of early progression within one to six months following combined radiation and chemotherapy. Forty per cent of these patients were identified as having PsP. Kruser et al. (2013) found the overall rate of PsP to be 6%–31% (2013), while most publications report a rate of 20%. It has also been suggested that the incidence of PsP may increase with new therapeutic agents and therapies (Yang, Huh, Smith, Han, & Parsa, 2010; Huang, Neagu, Reardon, & Wen, 2015).

PsP is thought to be secondary to edema and disruption to the blood-brain-barrier caused by radiation and potentiated by chemotherapy (Wen et al., 2010; Brandsma et al., 2008). Some suggest that PsP lies on a spectrum of post-treatment radiation effects: PsP is an earlier reversible occurrence whereas radiation necrosis occurs later (six months to several years) and is potentially devastating and irreversible (Brandsma et al., 2008; Kruser et al., 2013; Walker et al., 2014). While radiation necrosis is usually confirmed through surgery, PsP is confirmed retrospectively by evaluation of the clinical and radiological course through time (Walker et al., 2014).

Early progression has a significant impact on individual prognosis. In one study (Sanghera et al., 2010), median survival after progression was 8.3 months, whereas patients with PsP had significantly longer survival (median 28.7 months). Although this study had a limited number of patients (n=104), it highlights the difference in survival between these two groups of patients. Several other authors suggest that patients with confirmed PsP may have a better prognosis, even better than those with stable imaging. (Fabi et al., 2009; Knudsen-Baas, Moen, Fluge, & Storstein, 2013; Radbruch, et al., 2015). Imaging changes early on may be good news, indicating a more effective response to treatment, or maybe very bad news in that the patients’ lifespan is quite limited. Given the seriousness of early treatment failure, one study highlighted that patients misdiagnosed with early progression may themselves elect to abandon treatments, which may have devastating consequences on their lifespan (Fatterpekar, Galheigo, Narayana, Johnson, & Knopp, 2012).

In high-grade gliomas, response to treatment is typically assessed by clinical and radiologic assessments. Although there are clues, there is currently no radiological or clinical method proven to differentiate between PsP and true progression. The probable diagnosis of PsP involves an evaluation of the location of the suspected tumour on MRI, the timing of these changes, the presence of neurological symptoms, and the molecular markers analyzed from diagnostic surgery. This assessment process has recently been enhanced by the development of the Response Assessment in Neuro-Oncology (RANO) criteria, as a way to respond to the complexity related to the increased incidence of PsP (Wen et al., 2010). The criteria urge that, in the first three months after combined treatment, progression be diagnosed only if the majority of the enhancement is beyond the radiation field, or if there is surgical pathology confirming progressive disease. These criteria further suggest limiting patient recruitment into trials on recurrence after 12 weeks post combined treatment if they do not fulfill the above criteria for progression, thus limiting possible bias due to PsP (Neagu, Huang, Reardon, & Wen, 2015; Taal et al., 2008; Wen et al., 2010; Easaw et al., 2011; Kruser et al., 2013). The timing for PsP is recognized as being within three months of combined treatment in the RANO criteria (Wen et al., 2010). A recent study found that almost a third of patients with PsP presented beyond this time (Nasseri et al., 2014) and other studies defined PsP as occurring up to six months after combined treatment (Kruser et al., 2013). This suggests a longer timeframe when PsP is possible than in the RANO criteria. Better access to molecular and genetic markers in neuro-oncology has widened our understanding of brain malignancies. Response to temozolomide is improved when MGMT is methylated and median survival is almost doubled (21.7 months versus 12.7 months) (Hegi et al., 2005). MGMT methylation has also been found to increase the likelihood of having PsP, as compared to true progression (Brandes, Franceschi, et al., 2008). Also, 67% of patients with true progression have neurological symptoms, compared to 33% of patients with PsP (Taal et al., 2008). These patients with neurological symptoms may receive higher doses of steroids to counter possible edema related to PsP or progression (Sanghera et al., 2010). Given that deterioration, improvement and stabilization of clinical status can all accompany cases of PsP, clinical status alone is misleading when determining whether or not a patient has PsP (Brandes, Tosoni, et al., 2008; Taal et al., 2008).

**Uncertainty and PsP**

Currently, PsP is confirmed through repeat imaging. From the patient’s perspective, this means that true progression remains a possibility for weeks or months. Patients with PsP have a better prognosis than those with early true progression. Given this, it is not surprising that PsP and imaging ambiguities are highlighted as causes of significant uncertainty (Lin et al., 2012; Lin et al., 2015). Recent research offers a better understanding of uncertainty in primary brain tumours (Cahill, LoBiondo-Wood, Bergstrom, & Armstrong, 2012; Lin et al., 2012; Lin et al., 2013, Lin et al., 2015). Mishel’s Theory of Uncertainty in Illness can help to better understand the lived experience of PsP.
Mishel’s Theory of Uncertainty in Illness (UIT)
Uncertainty in illness is defined as a person's inability to determine the meaning of illness-related events (Mishel, 1988). There are three main components involved in the UIT: the antecedent theme (what precedes and characterizes uncertainty), appraisal of uncertainty (the process of evaluating the uncertainty) and coping with uncertainty (the response and strategies used to adapt or deal with the uncertainty) (Mishel & Clayton, 2003).

Given our interest in PsP as a trigger for uncertainty, Mishel's first theme—antecedents of uncertainty—is particularly relevant. There are three facets involved in the antecedent theme: stimuli frame, cognitive capacity, and structure providers. The stimuli frame includes symptom pattern (whether or not there is a distinguishable consistent pattern in symptoms), event familiarity (whether or not the event is repetitive, routine or has familiar cues), and event congruency (consistency between an expected outcome and the actual outcome in illness-related events) (Mishel & Clayton, 2003).

Uncertainty is higher when there is no clear pattern, given that there is a lack of ability to anticipate symptoms or a lesser degree of control of symptoms (Mishel, 1988). The second facet, cognitive capacity, directly impacts the stimuli frame and refers to the patient’s ability to process information and infer patterns. Finally, structure providers are the resources available to assist the person in interpreting the stimuli frame and their appraisal of uncertainty. These include credible authorities, social support and education. (Mishel & Clayton, 2013). The last two phases of Mishel’s theory are more straightforward. In the appraisal phase, the person judges uncertainty as an opportunity or a threat. In the final phase, the person then applies coping strategies based on their ability to adapt to the uncertainty.

In the revised uncertainty in illness theory (RUIT), Mishel suggests that in long-term illness and cancer survivorship, people can move from a perception of uncertainty as a danger to an opportunity. This adaptation phase may best be described as a restructuring, or as gaining a new perspective/acceptance of unpredictability (Mishel, 1990; Mishel & Clayton, 2003).

Uncertainty in neuro-oncology
In relation to PsP, no studies have looked at the experience of patients, although PsP has been mentioned as a trigger of higher levels of uncertainty in the brain tumour experience (Lin et al., 2012; Lin et al., 2015). The uncertainty literature in neuro-oncology provides insight into the brain tumour experience. Various studies that explore the experience of having a brain tumour have cited uncertainty as an important theme (Janda et al., 2008; Ownsworth, Chambers, Hawkes, Walker, & Shum, 2011; Cahill et al., 2012; Ford, Catt, Chalmers, & Fallowfield, 2012; Lin et al., 2012; Lin et al., 2013; Lin et al., 2015). In a survey-based evaluation of unmet supportive care needs of Australian patients with brain tumours and their caregivers, patients (n=75) highlighted requiring help in managing uncertainty about the future (43.1%), anxiety (36.2%), and fears about recurrence/progression (33.8%). The caregivers (n=70) highlighted decision-making in the context of uncertainty as an area where they needed help (36.2%) (Janda et al., 2008).

In a qualitative analysis of how patients with a brain tumour (n=18) and their caregivers (n=15) create meaning within their illness experience (Ownsworth, et al., 2011), uncertainty was an important theme in many discourses and existential issues and concerns related to death were more prominent for patients with malignant brain tumours. Some patients found new meaning and purpose in their life through their illness experience (Ownsworth et al., 2011), which may speak to the adaptation described in the RUIT where the constant unpredictability and uncertainty bring about a new perspective/goal in the illness experience (Mishel, 1990). Since no studies

Figure 1: Mishel’s Uncertainty in Illness Theory
have specifically examined the lived experience of patients with PsP; the remaining discussion will focus on uncertainty for patients with brain tumours more generally.

The recent development of the Mishel's Uncertainty in Illness Scale–Brain Tumour (MUIS-BT) offers a new measurement tool in the field of uncertainty in neuro-oncology (Lin et al., 2012). Patients with brain tumour are subjected to unrelenting uncertainty that differs from that experienced by survivors of cancer or other long-term illnesses, mostly given the incurable nature of the illness. In contrast to the Mishel's Uncertainty in Illness Scale (MUIS), the MUIS-BT contains more items related to unpredictability. In the MUIS-BT, the four fundamental factors involved are: ambiguity/inconsistency, unpredictability of disease progression, unpredictability of symptoms and other triggers, and complexity. High uncertainty levels result from patients' inability to predict illness outcomes and symptoms, and from a lack of clear and consistent information related to the disease. Even when treatment protocols were relatively straightforward, patients were found to be unable to predict their symptoms/function and the outcome of their disease. Furthermore, the inevitability of future recurrence or progression was highlighted as a constant trigger for uncertainty (Lin et al., 2012).

The study of uncertainty, particularly in relation to primary brain tumours, offers interesting insight into patients' illness experience. Lin et al. (2013) found that decreased functional status in patients with brain tumours was correlated with higher levels of uncertainty and with increased tension and anxiety. In another study, employment status was predictive of uncertainty levels (Lin et al., 2015), which can be another indication of functional status and symptom burden. Cognitive impairment, common in brain cancer, may increase uncertainty, as described in the antecedent theme of the UIT (Mishel, 1988). It was also found that uncertainty levels tended to be higher earlier in the treatment trajectory (Lin et al., 2013; Lin et al., 2015).

As highlighted in Mishel's stimuli frame, symptom pattern and predictability are important factors in uncertainty. In an integrative review of symptoms among patients with brain tumours, Cahill et al. (2012) found that symptoms such as fatigue, changes in mental capacities, and neurologic symptoms were inconsistent over time. They propose that the inconsistent nature of symptoms in the brain tumour population may predict increases in uncertainty, as described by Mishel's theory of uncertainty in illness (Cahill et al., 2012; Mishel & Clayton, 2003).

The clinical impact of uncertainty in patients with brain tumours is important. Uncertainty has been correlated with negative mood states and increased symptom distress. Higher levels of uncertainty are associated with negative mood states such as anger, tension, depression, fatigue, and confusion and increased symptom severity (Lin et al., 2013). A systematic review of supportive care needs in patients with malignant brain tumours confirmed that lack of information and uncertainty about treatment and prognosis were linked to anxiety (Ford, Catt, Chalmers, & Fallowfield, 2012). When characterizing mental health in patients with primary brain tumours (n=363), anxiety and/or depression were found in 56% of patients, although less than half were treated pharmacologically for these symptoms (Arnold et al., 2008).

Various authors point out that worry and anxiety levels may increase in patients with brain tumours who are waiting for imaging results (Newton & Mateo, 1994; Catt, Anderson, & Critchley, 2011; Lin et al., 2012; Rosenblum et al., 2009). Lin et al. (2012) hypothesized that patients waiting for imaging results would have more emotional responses such as anxiety related to uncertainty. Surprisingly, when these patterns were studied with the MUIS-BT, uncertainty scores were lower for patients being seen in clinic with imaging results compared to those being seen for clinical follow-up only. They hypothesized that patients waiting for MRI results felt a greater sense of control and were better able to foster positive coping skills given the impending results (Lin et al., 2015).

In summary, our review of relevant literature shows that uncertainty pervades the brain tumour illness experience and is particularly due to the inevitability of progression. Uncertainty has been found to be related to anxiety and negative mood states in the brain tumour population.

PsP: Patient experience

Drawing from our professional experience and the relevant literature reviewed, the experience of patients faced with PsP and implications for nursing practice will be discussed.

The suspicion of PsP is usually found in an MRI completed approximately one to three months after combined treatment. By this time, patients have generally begun the adjuvant phase of maintenance chemotherapy. This MRI is typically the first imaging evaluation since their post-operative MRI conducted 24–72 hours after surgery to provide the new baseline for comparing the treatment response imaging. The patient and family have invested time, energy and resources into an intensive six-week combined treatment regimen. Patients may have persistent fatigue related to the combined treatment, cited as the most significant symptom in the brain tumour experience (Cahill et al., 2012). Depending on the location of their tumour, they may have cognitive or functional impairments, which is associated with uncertainty (Lin et al., 2013). Patients and families are eager to know whether their combined treatment was effective.

In our context, nurses play a significant role in intervening with patients and families after receiving news of changes on imaging. The imaging results and a discussion of the probability of PsP related to genetic markers and presentation is provided by the medical team with the nurse present in clinic. Depending on the patient's and family's cognitive status and the desire for detailed information, statistics may be shared about current understanding of the probability of their results being PsP. When PsP is suspected, a repeat MRI is requested within four to six weeks to better understand the course of the disease and to clarify whether results reflect PsP or progression. The nurse then meets with the patient and family to review their needs and provide teaching and support.

At the first MRI evaluating treatment response, patients are not accustomed to these regular follow-ups. Given this lack of 'event familiarity', there may be a risk of increased uncertainty at the first treatment response-related evaluation. Through time, anxiety related to imaging may decrease with various sequential
tests. The unexpected result of lesser levels of uncertainty when patients were awaiting MRI results (Lin et al., 2015) may not reflect the reality of patients waiting for their first MRI after treatment, as the study included patients in all phases of illness and treatment. Levels of uncertainty in patients with primary brain tumours have already been found to be higher in earlier stages of diagnosis and treatment (Lin et al., 2013; Lin et al., 2015). Given that PsP is usually diagnosed early in the treatment phase, uncertainty levels are likely to be high at this time. In a descriptive cross-sectional study on the clinical follow-up patterns for patients with high grade gliomas (n=10), Catt et al. (2011) found that patients valued seeing their imaging scans and discussing these with their team, but for some, this desire waned over time, suggesting a change in their needs. During routine surveillance, the patient and family have already passed the resource-intensive phases of diagnosis and treatment and have entered a phase of chronicity. During this phase of stability, a return to normalcy may be more likely, but this may be too early only months after combined treatment and in adjuvant therapy when suspected PsP is suggested.

Four distinct crisis points have been proposed in the illness trajectory of patients with brain tumours: 1 – “shock and the unknown” with the initial diagnosis, 2 – “anticipation” with every imaging evaluation, 3 – “defeat and limitations” when treatment fails, and finally, 4 – the crisis of “terminal expectation and limited legacy” when second-line treatment fails and there is continued deterioration leading to end of life (Rosenblum et al., 2009). We suggest that patients who are faced with early imaging changes straddle two crisis points. They have the “anticipation” crisis in their expectant wait for the next imaging evaluation, but they are also more cognizant of the possibility of failure and defeat of the standard of care. These patients and families are living in a very vulnerable time when uncertainty is prominent.

Implications for practice

Education:
Given the links between uncertainty, symptom distress, and negative mood states in patients with brain tumours, it is important to develop strategies to address uncertainty, especially during vulnerable periods such as the time of uncertainty surrounding a potential diagnoses of PsP. Information and communication have been consistently highlighted, as key facilitators of coping with uncertainty in the cancer experience (Diaz et al., 2009; Knobf, 2013; Miller, 2012; Shaha et al., 2008; Ford et al., 2012). Patients with malignant brain tumours have also expressed a need for more information and the desire to have access to a dedicated health care provider (Ford, et al., 2012). In describing uncertainty in patients with brain tumours, Lin et al. (2013) suggest that improving patient-provider communication may not only decrease uncertainty, but may improve symptom distress. In relation to PsP, clear effective information exchange between the patient/family and the care team are essential to allay anxiety related to uncertainty. In our setting, the possibility of treatment-related changes on imaging is discussed with the patient and family prior to starting treatment. Treatment-related imaging changes are, thereby, already framed as possible outcomes after treatment for patients and families. Based on the UIT, this information may add to event congruence. By giving information ahead of time, we are changing patients’ expectations when early imaging changes occur.

Nurses have an important role in educating patients regarding the rationale for MRI scheduling. The timing for imaging is locally determined, and the patient’s illness trajectory often dictates when imaging is scheduled (Easaw et al., 2011). Given the difficulty in interpreting early imaging changes, the best time for the first MRI after treatment is unclear. In our setting, the first MRI is scheduled two to three months after combined treatment, in order to obtain a clearer picture of response and the possibility of PsP. Considering patients’ wishes to know their response to treatment as soon as possible, nurses provide reassurance and education as to the reasoning for the wait and provide support in coping with the uncertainty.

Social support and credible authority:
As described in the Uncertainty in Illness Theory (UIT), social support and credible authority are components that impact on uncertainty (Mishel, 1988; Mishel & Clayton, 2003). Although social support is often defined as family and community support, health care providers also serve as an important source of social support (Lien et al., 2009). Having one dedicated health care provider, such as a nurse specialist, is another important aspect of care for patients with brain tumours and their caregivers (Janda et al., 2008; Catt, Chalmers, & Fallowfield, 2008; Ford et al., 2012). In Canada, through a therapeutic relationship from diagnosis to remission or end-of-life, professional cancer navigators or “infirmières-pivot” (in Quebec) facilitate continuity of care and empower the patient and family in their cancer experience (Cook et al., 2013). These specialized nurses minimize uncertainty by offering a sense of predictability for care through availability and information, and by empowering patients and families in their coping through reinforcement of their strengths and resources (Cook et al., 2013).

There are several other support systems to which patients and their families can be referred during higher periods of uncertainty, such as support groups, individualized psychological support, and community services. The availability of support, whether accepted or not, was deemed important and was appreciated by patients with brain tumours (Ownsworth et al., 2011). In our experience, patients and families are often not receptive to referrals to structured supportive services, such as support groups, at diagnosis and during the first phase of treatment. Their willingness appears to increase after combined treatment, when time and energy commitments for treatment activities are lessened. This may coincide with the timing of the first MRI, the possibility of PsP and increased uncertainty. Given the unique timing of heightened uncertainty, nurses should reinforce the variety of resources available to support patients and families at this time.

Cancer research, primarily in breast, prostate and colon cancers, has underlined the pervasiveness of uncertainty throughout the oncology experience. Interventions proposed to limit the negative impact of uncertainty on cancer patients include education, information, and tailored psychological support interventions (Shaha et al., 2008). Another mid-range theory
developed in breast cancer. "Carrying On", provides insight into oncology patients’ responses during different phases of the cancer experience (Knobf, 2013). One of the main phases is “Dealing With Uncertainty” and is described as beginning during treatment, although the author notes that the phases may not be linear and may define various moments based on symptom profile, patient-provider communication and support. The patient behaviours described are seeking information, communicating with health care providers, and relying on oneself (Knobf, 2013). The first two of these strategies relate to our previous discussion about the importance of information and communication. Interventions that help patients ‘rely’ on themselves could strengthen and empower patients’ own coping abilities.

Coping with uncertainty:
Nurses have a privileged role in empowering patients and reinforcing strengths with the goal of enhancing coping in periods of uncertainty. Given the inherent uncertainty in PsP and given the fact that uncertainty is a constant reality in the brain tumour experience (Lin et al., 2013), nurses can take the diagnosis of PsP as a window of opportunity to intervene and strengthen the patient’s and family’s ability to cope. Given the privileged relationship developed between the neuro-oncology patient, their family and their primary nurse, nurses can play a key role in helping patients respond to uncertainty. In the context of PsP, the fear of recurrence and the underlying fears of functional deterioration and death are at the forefront. Stress and anxiety are often prominent. By engaging in meaningful conversations about their experience and the impact of the illness on their lives, the nurse can identify the beliefs, fears, and strengths present in the family unit (Wright, Watson, & Bell, 1996). By identifying and commending the patient and family on their strengths and the effective ways in which they have dealt with uncertainty in the past, patients and their family may feel more competent and may be better equipped to find their own ways of coping (Wright & Leahey, 2000). Through these therapeutic interventions, the nurse empowers the patient and family and provides a precedent in dealing with uncertainty that can be reflected upon at the inevitable next crisis point, when the specialized nurse will again be present to educate, support, and empower.

Conclusion
Pseudoprogression is an important phenomenon that impacts decision-making in high-grade glioma patients. Although there are studies on the medical aspects of PsP, there is a gap in terms of describing and exploring the patient’s experience when faced with this possible diagnosis. PsP is inherently related to uncertainty. Therefore, uncertainty research in cancer and the recently validated MUIS-BT are valuable tools to inform future investigations into patients’ experience of PsP and to propose nursing interventions to support them during this vulnerable time. As per Mishel’s Uncertainty in Illness Theory, providing information increases predictability and event congruence. Increasing social support and maintaining availability and presence of a credible health care provider may minimize the negative health outcomes of uncertainty. Finally, identifying and commending patients on their strengths may improve their ability to cope with this heightened uncertainty. Further research is needed to better understand patient and families’ experience of PsP and better define and support these interventions in the context of uncertainty.

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