Ongoing transitions: 
The impact of a malignant brain tumour on patient and family

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Abstract
Although primary malignant brain tumours represent only 1.4% of all cancers, it is considered one of the most devastating types of cancers in adults. From the time of diagnosis, the patient and family embark on a "rollercoaster" ride of uncertainty, fear, and hope. Despite improved medical outcomes, patients often experience severe functional impairment, as well as behavioural and cognitive dysfunction. Subsequently, they suffer from greater dependency and hopelessness than other cancer patients. The family caregivers are faced with multiple demands such as taking on new roles within the family and caring for their loved one while grieving the loss of the person they knew. The role of the nurse is to support the patient and the family throughout the illness trajectory, identify and promote their strengths and mobilize the necessary resources to facilitate patient and family coping. The purpose of this paper is to present, via a detailed case study, the impact of a malignant brain tumour on the patient and the family. The nursing strategies used to help them make the necessary transitions throughout the illness trajectory are discussed.

Introduction
The impact that brain tumours have on patients' function, quality of life and the lives of their families is tremendous. This impact continues today with recent studies indicating that only 18% of patients with primary brain tumours were able to return to work as a consequence of their ongoing symptoms (Armstrong, 2004). The incidence of primary tumours in the United States is 14 per 100,000 with a slightly higher incidence in males than in females (Doolittle, 2004). Although primary malignant brain tumours represent only 1.4% of all cancers diagnosed in the United States (Armstrong, 2004), they are one of the most aggressive cancers to treat and most challenging for patients and their family members (Graham & Cloughesy, 2004). More than half of the 18,400 primary malignant brain tumours diagnosed each year in the United States are malignant gliomas that not only confer high risk for death and severe disability, but also threaten to steal what is held so highly as the essence of human life: the mind and spirit (Fisher & Buffler, 2005). Gliomas are the most common form of primary brain tumours in adults and they occur most frequently in persons aged 45 to 55 years (Fisher & Buffler, 2005). Amongst the gliomas, glioblastoma multiforme (GBM) is the most common and most malignant type of tumour. The treatment of malignant gliomas has traditionally been maximal resection of the tumour, if feasible, followed by radiation therapy and adjuvant chemotherapy (Fisher & Buffler, 2005). Despite these treatments, however, the median survival is less than one year from time of diagnosis and, even in the most favourable situations, most patients die within two years (DeAngelis, 2001; Gupta & Sarin, 2002). More recently, there is great optimism around the new oral chemotherapy, Temozolamide (temodal). Temozolamide is generally well-tolerated (Graham, & Cloughesy, 2004) and is given concurrently with radiation therapy, as well as an adjuvant thereafter. It has shown an increase in median survival from 12 to almost 15 months in GBM patients, as well as an increase in their two-year survival rate, from 10.4% to 26.5% (Stupp, Mason, van den Bent, Weller, Fisher, Taphoorn, et al., 2005). Despite this medical advancement, however, patients living with a brain tumour suffer from the complications related to the brain tumour and its treatments, such as deep vein thrombosis, seizures, confusion and side effects related to steroids, which can have a negative impact on their quality of life (Taillibert, Laigle-Donadey, & Sanson, 2004).

Impact on the family
From the time of diagnosis and throughout the illness trajectory, the patient, along with the family faces with many confounding issues such as fear, uncertainty and hope (Hickey, 1997). What makes the brain tumour experience unique compared to other types of cancer is that not only is the family dealing with the diagnosis of cancer of their loved one, but also the neurological changes that accompany the brain tumour. Family members need to come to grips with the personality and cognitive changes of their loved one and grieve the loss of the person they once knew. From family systems perspective, the change in one member of the family brings on changes in all the other family members and the whole system (Carter & McGoldrick, 2005). Depending on the location of the tumour and symptom presentation, the patient may be dealing with multiple losses such as loss of independence as a result of inability to drive, work, speak, walk and continue with the usual activities of daily living. These losses bring along other changes within the family that may disrupt its equilibrium and normal functioning. Often, the spouse or a family member needs to adopt the new role of a caregiver while maintaining prior roles and responsibilities within the family. Family centred-care is essential in the care of malignant brain tumour patients as it is in palliative care. The patient's illness affects the whole family and, in turn, the family's responses affect the patient (Ferrell & Coyle, 2001). The role of the nurse then becomes
to assist the family in its struggle to adapt to the new demands of the disease and help the family develop new ways of functioning.

**Transitions**

The word *transition* is defined by *Merriam Webster’s Dictionary* as “the passage of one state, stage, subject, or place to another”; and “change” as defined by “a movement, development, or evolution from one form, stage, or style to another”; and also as “an abrupt change in energy or level (as of an atomic nucleus or a molecule) usually accompanied by loss or gain of a single quantum of energy”. Throughout our life span, we experience transitions, development and movement as we go through the life cycle, as in transitioning from adolescence to adulthood or from being parents to becoming grandparents. Although we may not be aware of it, each transition brings with it changes that are accompanied by losses and gains to which we need to adapt. When it comes to life-altering circumstances such as terminal disease, however, these transitions may not be as desirable and as easy to make.

The concept of transition is not a new one in the literature. Parkes (1975) proposed the concept of psychological transition, which meant that in order for the individual to cope with a newly altered space, he needs to change, that is to abandon one set of assumptions and develop new ones. The common view is that transitions are initiated by changes, by the start of something new. However, Olsson and Ek (2002) describe transitions as ongoing processes characterized by change for an individual. Bridges (1980) was first to suggest that most transitions actually begin with endings followed by a period of confusion and distress, leading to new beginnings. This was true for the families of terminally ill cancer patients in a study that examined their experience at home and in the hospital (Davies, Chekryn Reimer, & Martens, 1990; Ferrell & Coyle, 2001). Findings from that study generated a theoretic scheme, which conceptualized families’ experiences as a transition – a transition that families themselves labelled as “fading away”. The transition of fading away for families facing terminal illness began with the ending of life as they knew it. They came to realize that the ill family member was no longer living with cancer, but was now dying from it.

When it comes to terminally ill patients and their families, these transitions can be, at times, confusing and traumatic (Duggleby & Berry, 2005). Examples of such transitions experienced by palliative patients and their families include transitions from cure to comfort care, transitions related to loss, changes in care settings and psychosocial and spiritual transitions (Davies, Chekryn Reimer, Brown, & Martens, 1995; Ronaldson & Devery, 2001). Amongst these, the transitions from curative treatment options to a palliative approach have been recognized as the most difficult process for individuals (Ronaldson & Devery, 2001). Facilitating this challenging transition is an important part of the nurse’s role, and various strategies have been recognized as important in this process (Thompson, McClement, & Daeninck, 2006). Seizing opportunities to provide information and support family caregivers during the palliative stage of the patient’s illness are amongst the key interventions to help with this transition (Waldrop, Kramer, Skretny, Milch, & Finn, 2005; Thompson, McClement, & Daeninck, 2006).

Given the ongoing changes that may occur in the treatment plan due to brain tumour resistance, progression and recurrence, brain tumour patients and their families always seem to be in stages of transition as they try to cope with the disease and its impact on their lives. Families describe how they often feel like they are on a “roller coaster ride”; never knowing what to expect next. These ongoing transitions are not limited to the palliative stage of the illness, but also refer to the daily adjustments that patients and their families make to cope with their deficits and learn new ways of living their lives throughout the illness trajectory. The Victoria Hospice Society and Cairns, Thompson and Wainwright (2003) developed a framework looking at the journey of patients and their families from diagnosis to death and through bereavement. By using the Palliative Performance Scale, version 2 (PPSv2), they linked the physical changes experienced by the patient to the key psychosocial issues that frequently occur at particular transitions in a patient’s disease process. Their framework identifies significant transitions that patients and their families may go through, defines the psychosocial issues that each patient and family may face and suggests interventions that can be used by those who work with these individuals. These transitions are the following: 1) beginning the journey: early diagnosis and treatment, 2) the path not chosen: recurrence, 3) entering the unknown: the shift towards hospice and palliative care, 4) the long and winding road: illness predominates, 5) watching and waiting: as death approaches, 6) the parting of the ways: time of death, and 7) transitions in bereavement: phases model of grief. Although transitions can be traumatic for patients and their families, nursing actions can be geared toward understanding and supporting people through them (Duggleby, & Berry, 2005). The role of the nurse then becomes to recognize the needs of the family at each point of transition and help the patient and family cope with the changes that are imposed on them.

The purpose of this paper is to tell the story and describe the experience of a patient and his family as they moved through the active treatment phase of the illness to the palliative stage while struggling to maintain hope and quality of life. The Victoria Hospice Society and Cairns and colleague’s framework of transitions (2003), as mentioned above, was partly used to guide work with the family throughout the illness trajectory. As well, the McGill Model of Nursing was used with its focus on strengths, resources, learning, development and collaboration with the family (Gottlieb & Rowat, 1987).

**Beginning the journey:**

**The case of Mr. Joe Smith**

Joe was an active, pleasant 58-year-old man who had his own business. He lived with his common-law wife, Lynn, of 12 years. He enjoyed outdoor activities such as walking his dog, skiing.

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Joe was an active, pleasant 58-year-old man who had his own business. He lived with his common-law wife, Lynn, of 12 years. He enjoyed outdoor activities such as walking his dog, skiing.
growing, woodwork and water sports with his family. He was previously married and had two children from that marriage. His daughter Caroline was married with a five-year-old daughter and lived in Vancouver; his son James lived in Montreal with his wife and his eight- and 10-year-old boys. His common-law wife Lynn was also married previously and her daughter Sarah, 18 years of age, lived with them in Montreal. Lynn was also an energetic, capable woman who worked full-time in the fashion industry. The couple had a full life together and enjoyed going out and inviting family and friends to their house.

Joe started to have headaches for about two months, which were not relieved by Tylenol. Early November, he went to Vancouver to visit his daughter and he noticed having difficulty walking and was bumping into things. On his flight back to Montreal, he had some urinary incontinence and some left hand numbness. Upon arrival, Lynn took him immediately to the emergency room for further investigation and this was the beginning of their brain tumour journey. The CT scan and MRI showed two solid necrotic lesions, one in the left frontal and another in the right temporal/parietal regions, and significant cerebral edema. Immediately after being seen by the neurosurgeon, a meeting was held with the patient and his partner to describe the need for surgery. Within two weeks, Joe underwent two craniotomies, one week apart. The first craniotomy was on November 19 for the complete resection of the frontal lesion and the second craniotomy was on November 26 for a partial resection of the temporal lesion. The final pathologies revealed a GBM. After the surgeries, Joe was no longer bumping into things and his gait was back to normal. The numbness in his left hand also disappeared. He was put on steroids and plans began for four weeks of radiation therapy and chemotherapy.

Beginning the journey describes the impact of the life-threatening disease on the lives of patients and their families (Victoria Hospice Society & Cairns, Thompson & Wainwright, 2003). Receiving the diagnosis is an especially critical part of this transition, at which point people begin to have a tangible sense of what lies ahead. In a qualitative study of brain tumour patients’ experience before and after surgery, it was found that patients’ reactions to diagnosis of a tumour varied from calm, fearless attitude to shock, fear and disbelief (Lepola, Toljamo, Aho, & Louet, 2001). While some became depressed, others felt an awakening and a pause in their life. In the case of Joe, he had always thought of himself as an active, healthy person since he had never been seriously ill before in his life. To be told that he had two brain tumours and that he not only needed surgery, but most likely also radiation and chemotherapy, was a real shock to him. This was a time of great uncertainty, confusion and fear for both Lynn and Joe, especially while waiting for the pathology report. They had many questions related to the diagnosis, possible treatments and their outcomes. On the one hand they were struggling to learn a new medical language and navigate the medical system, while on the other hand they were faced with the diagnosis and needed to make critical decisions in a short period of time. As indicated by the Victoria Hospice Society and Cairns et al. (2003), while there is a great need for information during this transition, people are often overwhelmed with all the information that is provided to them. Many feel powerless to alter the outcome. Others, however, become determined to fight and survive the crisis.

The key nursing interventions used with the couple at this stage were providing, clarifying, repeating information and offering support by providing consistent opportunities for them to talk and express their thoughts and feelings (Hickey, 1997). Giving information and providing opportunities for the patient and family to talk about the illness experience are found by Lepola et al. (2001) to be important nursing interventions in the experience of brain tumour patients, particularly in the post-operative stage. Information was given at different intervals; the pre-operative stage followed by post-surgery and upon discharge and follow-up visit to the brain tumour clinic. Information was given both verbally and in a written format (example: The Brain Tumour Handbook by Brain Tumour Foundation of Canada) about the type of tumour, location and medications, as well as the types of treatments that were to follow. Efforts were made to match the learning needs of the couple based on their readiness. Although both Joe and Lynn wanted information, Lynn wanted more details and coped better with the information given and Joe preferred for her to get the details rather than him. Post-operatively, the need to talk about the illness experience, which was present before surgery, was found to be more pronounced. In conversations with Joe, he often reflected and searched for meaning as to how this could have occurred. This event was indeed like a pause in his life. Although he felt quite well after the surgeries and his symptoms diminished, he questioned that maybe he had been working too hard in his life and needed to slow down the pace. He was relieved that the cause of his symptoms was found and was determined to “fight the tumours”. At this point, the main focus for the couple was to recover from the surgeries and gather enough information to make their decisions about radiation and chemotherapy.

“The path not chosen”: The first progression

Following four weeks of radiation therapy and concurrent chemotherapy, Joe developed focal seizures and was put on antiepileptic medications. He continued with adjuvant chemotherapy until five months after his initial diagnosis, when he began to have weakness in his left arm and numbness in his left hand. His MRI showed that his tumour on the right side had progressed. He subsequently underwent a re-opening and a right temporal-parietal craniotomy for tumour resection in April. Post-operatively, his gait improved and his left arm regained strength. Overall, he felt better, however, he started to have subtle cognitive deficits. He started his new chemotherapy regimen for a period of eight months during which time his functional status gradually started to deteriorate.

Recurrence is a traumatic event for both the patient and the family, as it generates fear, anxiety related to loss of control and suffering, uncertainty and, often, dashed hopes (Herth, 2000). People are shaken that despite their best efforts the dis-
ease is progressing. During this transition, the patient re-evaluates his goals and priorities while having concerns about becoming a burden to the family. The family may take on more responsibilities while their own needs become secondary and communication can become impaired in wanting to protect their loved one. Hope must be maintained throughout this transition (Victoria Hospice Society & Cairns et al., 2003) since it is defined as one of the most essential elements in the lives of people with cancer (Cutcliffe & Herth, 2002). Hopes shift as people try to make sense of what is happening and it is incumbent upon nurses to promote hope in patients and their families knowing that the nature of hope can change with the illness trajectory from hope for cure, to hope for remission, to hope for comfort and, finally, to hope for a good death (Ferrell & Coyle, 2001; Herth & Cutcliffe, 2002; Parker-Oliver, 2002).

From the time of diagnosis, Joe and his family remained positive about the outcomes and believed that they were going to beat the odds. For this reason, the first sign of tumour progression was difficult for them and Joe became quite upset at the news. This is consistent with reports indicating that many patients say adjusting to recurrence is harder than adjusting to the diagnosis because recurrence is more damaging to their sense of hope and belief that they can beat the disease (Victoria Hospice Society & Cairns et al., 2003). For Lynn, it felt like a wake-up call, that this tumour was more aggressive than expected. Joe still wanted to “fight the tumour”, but was afraid of yet another surgery. He expressed that although he still wanted to fight the disease, he did not want to be in a vegetative state. This was a cue to begin end-of-life discussions with Joe and his family and to encourage them to have their own discussions in this regard.

Initiating end-of-life discussions early allows patients to make informed choices and achieve better palliation of symptoms and to have more opportunities to work on issues of life closure (Quill, 2000; Norton & Talerico, 2000; Larson & Tobin, 2000). Clinical indications for discussing end of life care include when the patient is expressing hopes and fears, when disease progression occurs and when there is discussion about the prognosis and treatment success (Quill, 2000). In light of the recent cognitive deficits (short-term memory deficits and decreased concentration) noted in Joe, it was even more important, before his status further deteriorated, to get a sense of what his wishes were in relation to his care and assess the family’s readiness to engage in these discussions. In collaboration with the neurosurgeon, I organized a meeting with the family to discuss the treatment options and answer their questions about the tumour. Efforts were made to present the information in a clear, empathic and simple manner, with as much opportunity as possible for the family to discuss their concerns (Reimer et al., 1991; Norton & Talerico, 2000). The family had understood that the tumours were malignant and not curable, and that the proposed surgery and subsequent chemotherapy were ways of containing the disease. Patient and family expressed their shock and disappointment at how fast-growing this type of tumour was. They were also relieved that another surgery with minimal risk was possible, and that chemotherapy was still an option. However, in discussion with the family, Joe began to realize that what was important to him was to remain autonomous and not be bed-bound and completely dependent. He remained hopeful about this surgery and wanted to continue with his chemotherapy as long as it maintained a certain level of functioning and quality of life.

Although the discussion with the family at this stage did not cover the whole scope of the disease and prognosis, it was an important step to “lay the ground work” as described by Norton and Bowers (2001). These authors describe laying the groundwork as an important step in establishing trust with patients and their families, especially when a patient has a life-threatening illness. “Laying the ground work” involves teaching the patients and families and helping them get a better understanding of the disease process. It also involves planting seeds, that is, opening up the door for future discussions with the family regarding end of life wishes in order to facilitate the transition to palliative care (Norton & Bowers, 2001).

Throughout this transition, while Joe was in the hospital and upon his discharge, ongoing opportunities were provided for the couple to verbalize their fears and concerns. Other key nursing interventions put in place were active listening via follow-up telephone calls and clinic visits, helping family manage symptoms by teaching them about medications and what signs and symptoms might signal deterioration, arranging for homecare services, providing information and support, involving the rehabilitation team and encouraging the couple to attend support groups, which are ways to promote hope and quality of life (Lovely, 1998; Herth & Cutcliffe, 2002; Victoria Hospice Society & Cairns et al., 2003).

**Grieving the losses**

As the couple continued their journey after Joe’s third surgery and subsequent chemotherapy, they were struggling to adapt to the ongoing changes brought on by the disease. Joe developed increased fatigue, which has been found to be one of the leading symptoms decreasing quality of life (Lovely, 2004; Taillibert et al., 2004). He also developed weakness in his legs, a common complication of steroid therapy in brain tumour patients (Wen & Marks, 2002; Kaal & Vecht, 2004). His cognitive deficits persisted, such as poor short-term memory. These changes may be related to the tumour itself, but also to the treatments such as radiotherapy, chemotherapy and anti-epileptic drugs (Taillibert et al., 2004). Similar to 70% of brain tumour patients, Joe was faced with the uncertainty related to treatment duration, efficacy and the fear of another recurrence (Taillibert et al., 2004). Joe began to realize that he was not going to go back to work and this was very difficult for him to accept. He also missed spending time and doing outdoor activities with his family. In addition, his inability to drive and feelings of being a burden on Lynn were very troubling to him. At this stage, I gave Joe and his family opportunities to express their thoughts and feelings and find meaning in their suffering (Ferrell & Coyle, 2001). It was evident that they needed to talk about the ill-
ness and share their experience. Joe expressed not feeling like himself anymore since he could not do half of the activities he used to do. He subsequently was found to be increasingly depressed, unmotivated and unhappy. At this point, we arranged for a psychiatric evaluation and he was put on an anti-depressant.

Lynn, on the other hand, was noticing subtle personality changes in Joe that others, or friends would not necessarily notice right away. For example, Joe was known in the family as a joker and having a great sense of humour. However, at times he would be slightly inappropriate or he would be unusually quiet and passive. She realized that the personality changes were due to the tumour and was doing her best to continue as “normal”. She did not feel burdened by the care and felt it was her role to care for Joe. She had learned to reassure him continuously of that in order to decrease his sense of being a burden. Lynn was slowly, however, beginning to grieve the person she had known over the years and was trying to adapt and get to know the new aspects of Joe’s personality.

The couple felt that over the past few months, their focus had been so much on the brain tumour and its treatments that they had not had any intimate moments together. This was difficult for both of them. Joe was trying to adapt to his new image. For 42% of brain tumour patients, the changes in body image cause suffering and affect their self-esteem (Taillibert et al., 2004). He felt that he was not the man he used to be, with his hair loss and weight gain. Lynn did not want to “make a big deal” out of this and would “pretend” that things were okay when they were not. As Joe became slower and weaker physically and cognitively, he was no longer able to carry out his regular daily activities and chores around the house. He had difficulty taking out the garbage, but he wanted to continue doing it. Lynn, wanting to be helpful, would not allow him to do it and would do it herself instead. By doing this, however, she had more chores on her shoulders and he, in turn, felt that he was inadequate and a burden to his family. This often occurs in patients who can no longer continue in their roles and tasks due to their deficits (Taillibert et al., 2004).

**Living and managing the illness**

At every encounter with the family during this transition, efforts were made to tease out the existing strengths in the family and empower them to problem-solve based on their strengths. In subsequent contacts with the family, they had been able to reframe and report that they were trying to cope as best as they could with the disease. Lynn had decided to take time off work to spend more quality time with Joe. Joe also was attending the support groups, which he now saw as a way of encouraging the newly diagnosed patients and providing support to them. This was an important role for Joe, which Lynn valued and encouraged. It gave him a sense of purpose and meaning in his life. He expressed feeling new again when talking to people about his experience. Knowing this about Joe, I asked him to participate in a workshop on brain tumours for nurses, and share his personal experience with them. By doing so, he felt happy to have contributed to the learning of others.

Taking the time to explore how the couple was coping was also an important intervention. I asked them what had been helpful to them at this time. After some thought, Lynn reported drawing from her previous cancer experiences in her family with both her mother and aunt who had died of gastric cancer. These experiences taught her to live one day at a time and enjoy the moments she had with Joe and continue with their usual lives as much as possible. For example, they celebrated their anniversaries together even if it meant only doing something small. Both Lynn and Joe expressed that they were trying to shift their expectations from wondering about the next month or even the next week to just today and maybe tomorrow. As a couple, they stopped planning trips too far in advance, but rather planned each day as it came and enjoyed what they could together. This was a key strategy for the family to help them cope with the uncertainty in their day-to-day life.

Following ongoing meetings and discussions with Joe and Lynn, they had the chance to discuss his end-of-life wishes and put their affairs in order. So, while Joe was not imminently dying, the couple recognized that these issues needed to be addressed early. At this point, I explored if they had had discussions with their children and, if not, what was holding them back. The couple reported having vaguely discussed the disease with the children since they did not want them to worry. However, when probed further, they both had noticed that Sarah was becoming rebellious and uncommunicative in the past few months, the grandchildren who visited seemed scared of Joe and would withdraw from him. The couple recognized that the children were also very much affected by the tumour despite efforts to protect them. Time was set aside to acknowledge the couple’s struggle to protect their family and encourage them to use the open communication style that they had with each other towards the rest of the family. I explained how this would help the family to cope with the impact of the disease on their lives. Joe was not sure how he would approach his grandchildren given their young age. Information and rationale was given to the couple as to how to approach young children in an age-appropriate language. It was at this point that Joe disclosed how his relationship with his son had been characterized by conflict over the past few years. He chose not to discuss it any further other than expressing his wish that his son could be more present in his care and in his life. I empathized with Joe in this regard and commended the couple for their openness to learn new ways of dealing with the disease and their ability to reflect on their actions vis-à-vis the rest of the family.

The issue of intimacy was explored since it had been a concern for the couple over the past few months. The couple appreciated having someone to speak to in this regard. Although they had difficulty being sexually intimate, more recently they had been able to rekindle that intimacy. This had meant a lot to them. They had learned to take some time away for themselves, and get away from the disease to recreate their romance. Their ongoing communication and ability to try to focus on one thing at a time seemed to have been helpful.
As I worked with this family, it was important to recognize and reflect their strengths as they dealt with the different challenges throughout the illness trajectory. Communication skills were an obvious strength for this couple. Despite the difficulties imposed by the disease, both were able to share with each other how certain aspects of the disease experience were affecting them. For example, Joe was able to verbalize to Lynn that he felt “useless” and wanted to do more at home and when she fussed over him, it really made him feel bad. When I encouraged the couple to discuss this openly, we were able to look at what chores and activities Joe could do on his own, as well as those he agreed he needed help with. This strategy gave him a sense of control, which is found to be important in patients with cancer and in palliative care (Duggleby & Berry, 2005). It also gave Lynn the security that Joe was safe to do a few things around the house (Ferrell & Coyle, 2001).

Resourcefulness was another strength this couple possessed. Once they learned about the support group meetings, they attended them regularly. Lynn also explored other existing resources in the community to help them cope with the disease. These included counselling to allow them to express their thoughts and feelings, and support from friends and family when necessary. They always remained hopeful that things would get better and they were able to reframe situations that were more difficult. They used humour at all stages of the illness when they could. For example, as difficult as it was to cope with the side effects of steroids and the body image changes, they were able to laugh and have fun with it. In the support group meetings, Joe would describe how everyone stared at him in the street due to his cushionoid-look ing face and his strategy was to stare them right back with a smile. This not only brought laughter to him and his wife, but also those around him. Therefore, one important nursing strategy was to highlight the strengths within this family and offer commendations for their efforts to cope with this disease (Wright & Leahey, 2005).

**Entering the unknown: The shift towards palliative care**

Joe’s last admission to the hospital was in December, after eight months of chemotherapy following his third surgery. Three weeks before his admission, Joe had begun to gradually deteriorate at home. He had started to have increased difficulty sleeping at night, and was experiencing fluctuating periods of confusion and agitation. This was terribly worrisome for Lynn and their daughter Sarah. He was on high doses of steroids to decrease the cerebral edema and the side effects of the steroids were preventing him from sleeping at nights. For example, Lynn described how one night, as she was getting ready for bed, she realized that Joe was not in the house. After many searches, she realized that he had gone out wandering with the dog and had gotten lost. Lynn had to go out in the neighbourhood looking for him with the car for several hours. He also had begun having left-sided weakness, decreased coordination, and was at risk for falls. He required supervision when walking and needed a cane, but he did not always use it. As these deficits persisted, plans were made to admit him to the hospital and perform an MRI. Upon admission to the hospital, Joe had a generalized seizure requiring a short stay in the intensive care unit (ICU). He became quite agitated and delirious and developed decadron psychosis. Psychiatric and palliative care consults were put forward. Joe subsequently became calmer, however, he had difficulty swallowing, was slow to react and was sleeping a lot more. The MRI at this point showed once again disease progression of both the left frontal and the right parietal lesions. Joe and Lynn were faced with decisions related to the possibility of another surgery, further chemotherapy and palliative care.

All this was very stressful to Lynn and Sarah, as well as Caroline who was in Vancouver. Joe had gradually become more communicative and less drowsy with fluctuating periods of confusion. He still had difficulty ambulating due to his overall weakness and a minor left hemiparesis. The need for a family meeting became evident because of disease progression, Joe’s impending death and the family’s unanswered questions (Shah & Lloyd-Williams, 2003). Joe was beginning to inquire about further chemotherapy and Lynn wanted to know what the next step was going to be. The team felt there were no other surgical options available and the next possible treatment would be experimental chemotherapy. Once again the family was faced with a crisis and it required quick responses.

“Entering the unknown, the shift toward hospice and palliative care” is the transition that begins when the disease is advanced and a cure is not possible (Victoria Hospice Society & Cairns et al., 2003). This change of focus is a painful shift for everyone involved, particularly for the patient and the family. Communication with the family can be difficult at this time since everyone is trying to protect each other from the harsh reality. The family may have fears of being abandoned and rejected by a treating team they have come to trust. Norton and Bowers (2001) describe three strategies in helping families shift from a curative to palliative treatment choices. These strategies are laying the groundwork, shifting the picture and accepting the new picture. We had previously begun one of these strategies, laying the groundwork when the tumour had initially recurred. To help the patient and family “shift the picture”, the team had to reconnect with the family and review their current expectations and understanding of the situation. This was followed by summarizing and explaining the status of the tumours and treatment efficacy. It was important at this stage for the team to work together and give consistent and clear information to avoid giving mixed messages. Mixed messages can lead to distress and frustration in patients and their families (Blatt, 1999).

Joe’s family had noticed that his level of consciousness had improved over the week and they were wondering if this meant that he could go back on the same chemotherapy regimen or perhaps have another surgery. It was important that they all understand that his tumours had progressed despite receiving standard chemotherapy treatments, and what remained was the possibility of experimental chemotherapy. However, the oncologist did not recommend that option given Joe’s poor functional status. The neurosurgeon and I also discussed issues related to levels of intervention (such as DNR status) and Joe strongly felt that he did not want to be resuscitated in the event of a cardiopulmonary arrest. It was
important, at this point, to raise the value of palliative care, and reassure the patient and family that the goal was to continue to care for him while focusing more on comfort measures rather than curative measures. Clear and simple language that was easily understood by Joe and his family were also key facilitators in this process. The nurse’s comfort level in these discussions also conveyed a new type of hope and reassurance to the family. Words that conveyed hopelessness such as “there is nothing that can be done” or “there is not any hope” were avoided and focus was put on what can be done to make the patient comfortable (Norton & Bowers, 2001; Norton & Talerico, 2000). Working with the family to “shift the picture” and “create a new picture” involved more than one meeting. An important role for the CNS was to repeat and reiterate the information given, clarify misunderstandings while providing hope in the new picture (Norton & Bowers, 2001).

During these meetings with the patient and family, I explored their thoughts and feelings, their understanding, their beliefs and what was helpful to them at this time. Lynn was concerned about how Joe would deteriorate, what that would look like, whether he would have any pain and what signs to look for and, finally, what to do for him. Information regarding symptoms and their management was given to Lynn with the assurance that Joe’s comfort and quality of life were the goals of care. Issues of feeding and hydration were also discussed with Lynn with emphasis on comfort care. It was again important to promote hope for Joe and his family and help them to redirect their hope towards newly identified goals (Sullivan, 2003). Offering hope at this stage was to assure that everything was going to be done to promote Joe’s comfort.

The couple, although disappointed and sad, felt that they had been preparing for this and were not terribly surprised at arriving at this point. Joe was able to express how he did not want to spend the rest of his life in a hospital or on chemotherapy feeling ill. He was quite aware that he was palliative, but wanted to continue having hope. He expressed being tired and wanting to rest. His hope was to return home. He also expressed that he was not afraid to die. His strong faith in God had helped him throughout the illness. At this point, I asked Joe what were the most important things that he wanted to do in whatever time that he had left. He paused for a moment and said that his only worry or regret was that he had not completed the past with his son as he had hoped. He also hoped to see his daughter once again. Most important, however, for Joe was his wish to marry his partner of 12 years before he died. This brought Lynn to tears. She, too, was hoping that they could have an official wedding with their immediate family members present.

Joe was aware that his being at home had been difficult for both him and his family. He was at risk for falls and required 24-hour supervision. Lynn expressed how concerned she was for his safety at home since the last couple of months had been quite difficult. However, she felt comfortable taking him home if there was help available from home services. I explored with Lynn what her main concerns were. Together with the rest of the team who had assessed Joe, a request was sent to the community home services for occupational and physiotherapy home safety evaluation and homecare nursing follow-ups. I also discussed with Joe whether he wanted to stay at home until his death or be transferred to a palliative care residence. The couple decided that he would stay at home for as long as possible, but that an application was to be sent to the palliative care hospice near their home as a second plan. Therefore, plans were made to apply to the palliative care residence in case Joe’s needs increased at home.

As both Joe and Lynn were preparing for the discharge home, Lynn began to have struggles that needed to be addressed. On the one hand, the couple was trying to take advantage of the time they had with each other, but on the other hand, Lynn was trying to prepare for the worst. She had begun to do some anticipatory grieving and preparing herself for Joe no longer being there. Lynn was also struggling with what is referred to in the literature as the paradox of living while dying. This stems from the fact that the patient is both living and dying and the family is having to deal with a paradox of their own: they want to care for their loved one and spend time with the patient, but also hope for a “normal life” (Ferrell & Coyle, 2001; Reimer et al., 1991). In discussing this, Lynn expressed her guilt regarding her feelings. I normalized how she was feeling and pointed out to her that this is a normal reaction in the family and we discussed how children can also feel the struggle of hanging on and letting go (Ferrell & Coyle, 2001) in relation to their dying parent. I pointed out to her that those spouses who find ways to manage the demands while attending to their own needs tend to cope best with this paradox (Ferrell & Coyle, 2001) and that this was what she was trying to do at this time. I discussed with her relaxation and distraction strategies to prevent burnout such as yoga, meditation and taking respite time for her with the help of the community resources put in place.

After arrangements were made for Joe to go home with the help of the home care services, a follow-up phone call was made to Lynn to explore how they were managing. Lynn expressed how they have many good moments together, but that Joe had become incontinent, increasingly weak in his extremities and falling at home. He was already on 16mg of dexamethasone (Decadron) per day and it could not be increased due to his past experience with drug-induced psychosis and current steroid-related muscle weakness. In line with the established plan, arrangements were made, in collaboration with the community partners, to transfer Joe to the community palliative care centre. Once at the palliative care centre, I remained in contact with the palliative care team as a liaison and also continued to support Lynn via telephone calls. Joe’s short-term memory and his level of alertness continued to fluctuate and he developed increased difficulty ambulating. At this point, as I had discussed Joe’s end-of-life wishes with the treating team, their focus became to follow-up on Joe’s goal of marrying Lynn, his partner of 12 years. The wedding ceremony took place at the palliative care centre with Joe giving a small speech saying he’s “the luckiest man in the world”. The new Mrs. Smith described the ceremony as beautiful and quite meaningful to her and the rest of the family. Lynn was grateful that Joe did quite well during the ceremony.
and even managed to dance with his new bride for a short while. Joe’s daughter and grandchildren were able to attend the wedding from Vancouver, which gave Joe his wish to see his daughter again. One last important closure in Joe’s journey was that his son James and his grandchildren were present at the wedding. This had meant a whole lot to Joe given that their past relationship had been full of struggles.

Following the wedding, I made a phone call to Lynn as a follow-up to the end-of-life discussions we had had. She expressed having mixed feelings of happiness and sadness regarding the impending death of Joe. She also felt exhausted from the emotional intensity of the past weeks. Overall, however, she felt at peace with her marriage and their choices. She reported that other family members were more supportive now than ever before. At that point, the couple wanted to continue taking things one step at a time, which, by now, had become their “mantra” and to enjoy the time they had together. Over the next three weeks, Joe gradually became more confused and somnolent. Exactly three weeks after their wedding, Joe died peacefully at the palliative care residence. His wife described him as having been comfortable and pain-free, surrounded by his family and loved ones, having achieved all his end-of-life goals. He had had a good death. Lynn was at peace, yet still trying to cope with the loss of her husband. She attended the memorial service organized by the brain tumour program as a gesture of keeping Joe’s memory alive.

The names of the patient and his family and certain details were modified to preserve their anonymity.

Discussion

The journey of living with a brain tumour is a tumultuous one both for the patient and the family. It involves facing uncertainty and fear while struggling to maintain hope in adversity. From the time of diagnosis to the palliative stage, the family is dealing with multiple losses and constant adjustments and ongoing transitions. Given the rapid and aggressive nature of malignant gliomas, end-of-life discussions must be initiated as early in care as possible to allow the patient and family time to grieve, time to plan and make the necessary closures in their life.

Nurses are often in the ideal position to assess the need to initiate end-of-life discussions (Norton & Talerico, 2000). However, they must develop a level of comfort to have these conversations about death with the patient and family (Ferrell & Coyle, 2001). Establishing a trusting relationship and identifying the need for end-of-life discussions are strategies to allow the family to express their thoughts and feelings comfortably. This, in turn, eases their transition into palliative stage. The role of the nurse involves viewing the family as a unit, but also giving consideration to the individuals who make up that unit and attending to the needs of the individual and the family as a whole. Active listening, highlighting strengths, promoting hope and providing and clarifying information are strategies that the nurse must repeatedly use over the illness continuum based on the needs of the patient and family.

Conclusion

Caring for patients with brain tumours involves dealing with the cancer diagnosis, as well as the neurological effects of the tumour itself. Despite the inherent uncertainty and ongoing losses with this disease, patients and families have the potential to cope and make the necessary adjustments to the disease and maintain quality of life. Joe and Lynn showed tremendous strength and resilience in dealing with Joe’s malignant brain tumours. In collaboration with the team, they were able to make the necessary transitions that enabled them to live a day at a time with this disease, give meaning to their experience and achieve their goals.

Appendix One. Genogram.
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