Allies in the fight against brain tumours

Kathy Oliver explains why tackling the challenges of brain tumours requires an army of allies from within and without the scientific community

> Hope, not defeat, should always be the starting point, no matter someone's diagnosis.

When Spanish conquistadores first established missions and settlements in that huge tract of land which we now know as Texas, this southwestern area of North America was called 'Taysha'. Derived from the native American Caddoan language, Taysha means 'allies'. And of course, the word has since evolved into the name of Texas, as we call it today.

One might wonder at the connection between an ancient native American word and the field of neuro-oncology. It was only on the plane back to the UK after attending the 12th Annual Scientific Meeting of the Society for Neuro-Oncology (SNO) in Dallas, Texas (15–18 November 2007) that I realized the connection and symbolism of the location of this year's SNO meeting.

Attending the SNO meeting on behalf of the International Brain Tumour Alliance (IBTA), I became aware that tackling the challenges of brain tumours requires allies—indeed, an army of them from within and without the medical and scientific community.

Brain tumour patient and caregiver input is essential, as part of a successful working alliance, and the role of neuro-oncology and neuroscience nurse specialists is particularly vital. It is through this alliance of nurse specialist, patient, family, and caregiver that some of the strongest bonds are formed during the brain tumour journey.

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Challenges and complexities

As neuroscience nurses know, the supportive care requirements of brain tumour patients are varied, highly complex and often nightmarishly intense. There can be devastating changes to a patient's cognitive, emotional and physical abilities. Symptom management might include epilepsy, brain oedema, fatigue, anxiety and depression. And there are non-medical issues also. These might include the loss of a driving licence and independence; concerns about employment or the necessity to stop work altogether; lifestyle adjustments and coping with loss of control over one's future.

All of these aspects of a brain tumour diagnosis can significantly detract from a patient's quality of life. Some of these issues also affect the caregivers of brain tumour patients and, consequently, their quality of life too.

Dr Sherry Fox, Programme Director of the Cullather Brain Tumor Quality of Life Center in Richmond, Virginia said: 'Being diagnosed with a brain tumor is catastrophic as compared to many other cancer types. Not only are the patient and family dealing with the shock of a cancer diagnosis, but also dealing with the neurologic sequelae of the tumour that result in significant and permanent disability. The patient and family are immediately set on a rocky course of trying to learn to live "the new normal".'

These challenges were at the heart of the neuro-oncology and neuroscience nurses' breakout meeting at SNO.

The aims of 'battle'

The meeting was co-facilitated by neuro-oncology nurses Mary Lovely (Medical Information Specialist at the National Brain Tumor Foundation in the USA) and Mary Ellen Maher (Northwestern Neuro-Oncology Center, Chicago).

The meeting's goals were to encourage more and better networking among neuro-oncology/neuroscience nurses treating brain tumour patients, to provide collaborative support and to assist with the dissemination of information.

One of the ideas discussed was the hope that more nursing-specific content could be added to scientific meetings like SNO, particularly in relation to symptom control and quality of life issues for brain tumour patients.

Indeed, the following two posters were submitted to the general SNO conference from neuroscience nurse specialists.

A poster by Kathleen Mogensen, of Roswell Park Cancer Institute, Dent Neurologic Institute (Buffalo, New York), dealt with 'Fertility issues in adults treated with temozolomide' (Mogensen, 2007).

Temozolomide, a chemotherapy given concomitantly with radiotherapy and as an adjuvant therapy, is now standard treatment in most developed countries of the world for newly diagnosed glioblastoma multiforme (GBM) grade IV malignant brain tumours. In the late autumn of 2007, the National Institute for Health and Clinical Excellence (NICE) finally confirmed that this combined therapy would be endorsed for use on the NHS (NICE, 2007).

The manufacturer's product information says: 'There are no adequate and well-controlled studies in pregnant women. If this drug is used during pregnancy, or if the patient becomes pregnant while taking this drug, the patient should be apprised of the potential hazard to the fetus. Women of childbearing potential should be advised to avoid becoming pregnant during therapy with Temodar Capsules.' (Schering Plough, 2005).

Ms Mogensen related anecdotal exam-

ples of three case studies involving brain tumour patients and issues surrounding fertility while on, or shortly after, active treatment.

Another poster, submitted by Eva Lu Lee and Terri Armstrong, both of the UT MD Anderson Cancer Center in Houston was entitled 'The neuro-oncology advanced practice nurses' role and experience in the collaborative management of patients with primary brain tumor' (Lee and Armstrong, 2007).

> The degree of detriment to quality of life by a brain tumor for patients and that for their carers are similar and clinically significant

Ms Lee and Ms Armstrong stated: 'The collaborative practice model between the advanced practice nurse (APN) and the physician is a comprehensive approach to healthcare management that has particular application in complex disease processes, such as primary brain tumors.'

The authors added: 'Despite a concerted effort, tumors often recur quickly and life expectancy may be short … Management of these patients by the collaborative method and successful patient outcome demand a mutual understanding, agreement and communication between physician and APN … APNs, who are in continual contact with the patient, have the advantage of being able to educate, manage symptoms, and enforce health behaviors to enhance a positive patient experience and outcome.'

Other topics discussed at the special SNO nurses' meeting included palliative care for brain tumour patients, quality of life tools, advocacy, cognitive challenges and dealing with symptom management such as epilepsy.

The journey

The point was brought up that the journey is extremely daunting to patients, caregivers and families because of the very nature of the multi-modal treatment, the often devastating side effects of the brain tumour itself, and the overwhelming stresses and strains that can result, both for patient and caregiver.

It was suggested that what brain tumour patients, families and caregivers need is an expert 'system navigator', who could tie together all the disparate parts, including not only medical care and rehabilitation, but also aspects of social benefits and quality of life issues.

Although not part of the SNO proceedings or discussed at the SNO nurses' meeting, it is worth mentioning here two recent studies from Australia and one from Canada highlighting the challenges that specialist nurses working with brain tumour patients encounter.

In their paper entitled 'Quality of life among patients with a brain tumor and their carers', Monika Janda and colleagues (from Australia) concluded that 'The degree of detriment to quality of life by a brain tumor for patients and that for their carers are similar and clinically significant' (Janda et al, 2007).

In another paper by Janda et al (2006), 'Supportive care needs of people with brain tumours and their carers', five recommendations to improve service delivery were suggested:

- A dedicated case manager
- Proactive dissemination of information, education and psychosocial support
- Access to objective assessment of neuro-psychological functioning
- Facilitating easier access to welfare payments
- Facilitating communication about difficult illness-related topics.

A Canadian study by specialist neuro-oncology nurse Rosemary Cashman and colleagues (2007) entitled 'Evaluation of an educational program for the care-givers of persons diagnosed with a malignant glioma' showed that such a programme demonstrated 'effective knowledge transfer (recall of the information) immediately after the education program and four to six weeks later. Specific qualitative and quantitative data serve as a basis for understanding caregivers' needs and experiences.'

Allies

It would be thoughtless to end this meeting report without a reference to the importance of hope for those individuals who are dealing with a brain tumour diagnosis.

One of the world's most eminent head and neck cancer surgeons, Professor Chris O'Brien from Australia, was diagnosed with a grade IV malignant brain tumour. As first a clinician and then a brain tumour patient, Chris voiced his philosophy in a recent newspaper interview (Barrowclough, 2007):

> **hope, not defeat, should always be the starting point, no matter someone's diagnosis.**

For brain tumour patients and caregivers to know that there are strong allies in the specialist neuroscience and neuro-oncology nurses who will help them navigate their journey is also a vital part of that important starting point.

The recently released Cancer Reform Strategy (Department of Health, 2007) also acknowledges the importance of clinical nurse specialists and states: 'patients repeatedly told us of the vital role that the clinical nurse specialist (CNS) can play in improving the experience of people living with and surviving cancer', prompting the Cancer Reform Strategy to conclude:

> **Commissioners and providers should therefore give particular consideration to the role of the clinical nurse specialist.**

Table 1. Further information

Abstracts for the Twelfth Annual Meeting of the Society for Neuro-Oncology in Dallas, Texas (November 15–18, 2007): http://tinyurl.com/2c8pcg
Full report of the SNO conference for the International Brain Tumour Alliance (IBTA): http://tinyurl.com/2ec276
IBTA SNO 2007 speech on the challenges of brain tumour treatment in developing countries: http://tinyurl.com/ythy2p

Conflict of interest: The International Brain Tumour Alliance (IBTA), of which the author is a Director (on an unpaid basis) receives undirected funding grants from a number of industry sources, which are listed publicly on the IBTA's website under its sponsorship policy: www.theibta.org/SponsorshipPolicy.htm

KEY POINTS

- Tackling brain tumours requires nurse specialists to work in close contact with patients and carers
- The journey of care can be daunting, owing to issues of treatment, effects on quality of life and the resulting stresses and strains on daily life
- Consideration should be given to the role of the clinical nurse specialist by NHS commissioners and providers
- The goal of the Society for Neuro-Oncology nurses' discussion meeting was to provide collaborative support and networking opportunities for neuroscience nurses treating brain tumour patients

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Janda M, Steginga S, Langbecker D, Dunn J, Walker D, Eakin E (2007) Quality of life among patients with a brain tumor and their carers. *J Psychosom Res* **63**(6): 617–23

Janda M, Eakin EG, Bailey L, Walker D, Troy K (2006) Supportive care needs of people with brain tumours and their carers. *Support Care Cancer* **14**(11): 1094–103

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