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The Strength, Vision and Resilience of Workforces

Editor: Linda Nichols

It is great to see the research and rapid growth of Parkinson's Disease and Movement Disorder Nurse Specialist (PMDDNS) positions across Australia. The 2020 Annual Demographic Survey provides an important baseline, providing key details regarding the workforce in Australia. The results present a unique opportunity to track the growth and changes within the speciality and also address needs areas such as the underservicing of rural and remote areas.

As Covid-19 continues to disrupt the way we live, work, and interact organisations are scrambling to manage the fallout and to prepare for not only what is next but also a new norm of social distancing, remote and virtual communicating and working. Life has been a journey of existential challenges and it is impossible to overestimate the gravity of the pandemic. We might all wish that we had a crystal ball to have predicted the impact and devastation of Covid-19. What we have is strength in the structure of our organisations with vision and mission statements.

As Neuroscience Nurses we need to be leaders and we need to be reactive to the challenges that confront us. We also need vision and a strategic path towards it. We need to look beyond the dark horizon of Covid-19 and be guided, together with guiding those in our care. An essential part of this is understanding our workforce. It is only through measuring, monitoring and formally reviewing our workforce that we can adjust to meet the needs of individuals in our care.

Vision is especially urgent during a pandemic. Variations to our practice that we might have had even two years ago unfolded in a matter of weeks and months following the events of January 2019. Videoconferencing, phone consultations and building the skillsets of regional and rural practitioners is vitally important to meeting needs in this changing environment.

2020 Annual Demographic Survey of Parkinson’s Disease and Movement Disorder Nurse Specialists

Guest Editorial: Sue Williams, David Tsui

Reflection of the last 12 months.

Over the past 12 months, we have seen a rapid growth in the number of Parkinson’s Disease Movement Disorder Nurse Specialist (PMDDNS) positions across Australia. This is largely thanks to Federal funding of $6.3 million injected into the Primary Health Networks. The result is a creative diversification of the Parkinson’s disease nursing model as organisations seek to meet the needs of their local populations with the resources available.

Changes to the landscape diversification of models of care

Creative new models of care include using the funding to upskill a number of rural and remote nurses within their existing positions to provide specialised care to people with Parkinson’s disease. Another model has placed one nurse position within a private allied health business setting. A third model is the ongoing initiative from Parkinson’s NSW where they have continued to partner with Local Health Districts across New South Wales to insert PMDNS into public hospitals.

Timeliness of the Demographic survey – what the survey set out to achieve, advantages of tracking change and growth within the specialty
environment and the growth of these areas has been exponentially steep. Covid-19 has widened all our skillsets, we have all become more flexible in the way we network and meet the needs of clients. However, we need to be open to the fact that this is perhaps the new norm of health care delivery. Alternatively, when this pandemic does end, our healthcare models may be different again from what they were when the pandemic began. We need to begin planning now and have a longer-term vision that envisions beyond the pandemic.

Achieving geographical equity and meeting the needs of individuals residing in rural and remote areas is challenging and never more so than now. The Movement Disorder Chapter aims to reduce geographical isolation and promote professional identity. These key aspects in the Chapter’s Mission Statement marry perfectly with the aims and outcomes of the survey. It is often said that an organisation without a Mission Statement is like a ship without a compass and during a pandemic we need every compass bearing we can get. We must work through this pandemic, but we also need to be able to work towards a future and we should not be afraid of setting long-term goals and aspirations. It is all too easy to feel constrained by the pandemic and the restrictions that have resulted from it, but it has also provided us with opportunities. So many stories have been inspiring and imbued with purpose. We can only hope that the future is a little more stable than the current ship we are on and that our vision and Mission Statements continue to provide those compass bearings.

We will emerge from this stronger and more resilient than we were before, and I look forward to seeing this in the 2021 survey.

At a time of such rapid advancements, an annual demographic survey enables us to quantify and track the growth and changes within the specialty. Data collection provides clear evidence of the emerging trends and enables us to respond to changes appropriately.

What we are doing:
The publication of results from the first demographic survey highlighted that pharmaceutical companies are the second largest employer of PDMDNS at 21%. In response, the Movement Disorder Chapter (MDC) has focused to be inclusive of this cohort of PDMDNS with unique workplace needs, provide them with a supportive network and educational resources. The MDC is partnering with variety of organisations to provide expertise for co-design processes, clinical governance structures and evaluation of emerging service models.

COVID has widened our skillset to allow more flexible networking and minimised the impact of geographical challenges through video conferencing capabilities. We are now able to provide structured members’ meeting to keep everyone updated on our projects and activities and allow for a platform to provide mentoring and support for all PDMDNS.

Our aim as the ANNA MDC is to continue to cultivate a culture of clinical excellence, professionalism, mutual support and an environment of altruistic attitudes. It is truly an exciting time to be a Parkinson’s Disease Movement Disorder Nurse Specialist in Australia.

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The Effect of Bevacizumab on Vestibular Schwannoma Related to Neurofibromatosis Type 2

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Abstract

Introduction: We describe an Australian experience of infusional bevacizumab for vestibular schwannoma (VS) in neurofibromatosis type 2 patients, with specific focus on 3-dimensional tumour volume and audiometry.

Method: Data was pooled from patients with symptomatic or progressive VS from 2009 to April 2018. Tumours were assessed as total volume per patient. Bevacizumab infusions were administered every 2-4 weeks. 3-D volumetric response (cm³) was determined through serial magnetic resonance imaging, at baseline and at 3-6-month intervals, until cessation of infusions following progression or prior to surgery. Volumetric response was defined as a reduction of volume ≥ 20%, from baseline. Patients underwent interval pure tone audiometry. A decrease in the average pure tone analyses by 10dB indicated response.

Results: Twenty-one VS tumours were identified in eleven patients. Median age was 26 (range 13 – 67yr). Average baseline tumour volume was 14.17cm³ (range 1.45cm³ - 38.51cm³). Tumour volume reduction >20% was shown in 7/11 patients (64%), indicating partial response, 2/11 (18%) patients showed stable disease, and 2/11 (18%) progressed. Average percentage tumour volume change was +4.45% from baseline (range -57% to 241%). 16 individual ears were tested, 3/16 (19%) of ears showed an average decibel reduction of 10dB or more, indicating response (average change 2.5dB, range -36dB to 81dB). 10/16 (63%) showed stable hearing, and 3/16 (19%) showed hearing deterioration.

Conclusion: Bevacizumab is a useful agent for reducing tumour volume and improving hearing losses due to vestibular schwannoma in neurofibromatosis type 2 patients. These results reflect results described from the United Kingdom and United States.

Key Words: Bevacizumab, Vestibular Schwannoma, Neurofibromatosis Type 2, 3-D Volumetric Analysis, Audiometry

Introduction

Neurofibromatosis type 2 (NF2) is a rare, predominantly hereditary, genetic mutation of the NF2 suppressor gene on chromosome 22. It occurs as an autosomal dominant inherited mutation, or as a sporadic somatic mutation, with up to 50% of patients presenting with a de novo mutation (Evans, 2009; Evans et al., 2019). Individuals with NF2 are at high risk of developing tumours of the central nervous system; typically vestibular schwannomas (VS) of the eighth cranial nerve, but also meningiomas, ependymomas and gliomas (Evans, Sainio, & Baser, 2000).
The mean age of onset of symptomatic VS is 20-30 years (Parry et al., 1994). Patients who develop VS tumours in childhood are expected to live into their thirties, and this is improving with modern advancements (Evans et al., 2019). Larger tumours incur worse prognosis (Otsuka, Saito, Nagatani, & Yoshida, 2003). Diagnosis typically follows investigation of hearing loss or visual disturbance. VS tumours are usually bilateral, and associated with sensorineural hearing dysfunction, headaches, and, on occasion, cranial nerve neuropathy (Bell’s palsy or trigeminal disturbance), all of which can have significant impact on quality of life. Plotkin and colleagues suggests an average linear growth rate of 1.9mm/year (Plotkin et al., 2012; Slattery, Fisher, Iqbal, & Oppenhiemer, 2004).

Hearing loss is usually progressive, and has been traditionally managed with either surgical resection or radiation of the VS tumour (Halliday, Parry, & Evans, 2019; Kazim, Shamim, Enam, & Bari, 2011; Phi et al., 2009; Van Gompel et al., 2018). If left unattended, VS can cause increased intracranial pressure and even death (Evans et al., 2000). While the techniques on surgical resection and radiotherapy have been refined over many years, these modalities often leave patients with permanent deafness. There is a rare potential for benign tumours to undergo malignant transformation, thought to be related to previous irradiation (Evans, Birch, Ramsden, Sharif, & Baser, 2006). Therefore, while patients can achieve an extended prognosis, it is often at the expense of their quality of life (Otsuka et al., 2003).

There have been multiple studies investigating systemic options for NF2 related VS. Systemic treatment is complicated by the elusiveness of the blood-brain barrier, and multiple monoclonal antibody and small molecule inhibitor agents have been proposed (Evans et al., 2009; Goutagny & Kalamardes, 2018; Karajannis et al., 2012; Nigro et al., 2019).

Bevacizumab in Neurofibromatosis Type 2

VS tumours express vasculo-endothelial growth factor (VEGF) on immunohistochemical profiling (Li et al., 2016; Mautner et al., 2010; Plotkin, Stemmer-Rachamimov, et al., 2009). Several studies have investigated the effect bevacizumab, an antiangiogenic agent specifically targeting VEGF, to reduce the volume and associated hearing impairment related to VS tumours (Alanin et al., 2015; Hochart et al., 2015; Huang et al., 2018; Mautner et al., 2010; Morris et al., 2016; Nigro et al., 2019; Plotkin, Stemmer-Rachamimov, et al., 2009). In a cohort of ten patients with ten index tumours, nine tumours showed treatment effect, and four patients maintained response during 11-16 month follow up (Plotkin, Stemmer-Rachamimov, et al., 2009). Overall, a median volume reduction of 26% was observed. Of the seven patients who were eligible for audiometric analysis, four showed response, two had stable hearing and one deteriorated. This was followed up with a larger retrospective study looking at thirty-one patients, including the ten originals (Plotkin et al., 2012). Again, volumetric and hearing outcomes were favourable; seventeen of thirty-one lesions had a positive volume response, and seventeen of twenty-three showed a positive audiometric response. Results were durable beyond one year, and more than 50% of patients had maintained their response beyond three years. Toxicity was typically manageable. Alanin (2015) and colleagues conducted a 12 patient study and showed partial volumetric response in 50% of patients, and 11% response in hearing.

Morris (2016) and colleagues co-ordinated a similar study for NF2 VS patients based in the UK. Data from sixty-one patients receiving bevacizumab illustrated a partial response of tumour growth occurring in 39% of all tumours, and stable disease in 51%. 86% of patients had either a stabilisation or improvement of their hearing.

In Australia, bevacizumab is not currently funded by the Pharmaceutical Benefits Scheme for this indication, and patients are currently self-funding infusions. Access programmes established throughout public hospitals can assist with costs in the short term, however are unsustainable for ongoing infusions.

Audiometric Assessment

Plotkin and colleagues have provided recommendations for audiometric assessment in NF2 VS (Plotkin, Blakeley, et al., 2013; Plotkin, Haipin, et al., 2009). Pure Tone Audiometry (PTA) has a sensitivity of 92% and a
specificity of 94% in detecting sensorineural hearing impairment. Audiometric volumes are tested from 15-30 decibels (25-30 dB for adults, 15-20 dB for children), and aims to challenge patients with tones ranging from 500 to 4000Hz, which is reflective of the normal speech spectrum (Plotkin, Blakeley, et al., 2013; Plotkin, Halpin, et al., 2009). Word Recognition Score (WRS) assessment is the most accurate reflection of the speech spectrum, and is more widely utilised in NF2 (Dombi et al., 2013; Plotkin, Ardern-Holmes, et al., 2013)

Methods

This paper is a retrospective analysis describing the effect of bevacizumab on tumour volume and audiometry in VS in NF2 patients in Australia. The primary endpoint is change in tumour volume and the secondary endpoint is change in audiometry.

Study design and ethics

This analysis pools data from two periods of treatment, looking at a total of eleven NF2 patients. Seven patients were followed from 2009 through to 2013, and four patients were followed from 2013, through to April 2018. This study was approved by the local Human Research Ethics Committee (10CHW14). Patients were informed of the utilisation of their radiological and audiometric information for the purposes of this study. Patient information was de-identified and kept under password protected security. There was no interference with standard treatment procedures and no additional interactions with patients.

Patients

All patients met clinical criteria for NF2. Patients were identified over two time periods. Patients from 2009 to 2013 were evaluated at Westmead Children’s Hospital or Westmead Hospital. Patients were included from three sites in New South Wales (Prince of Wales Hospital, Liverpool Hospital and Royal Prince Alfred Hospital), Perth (Hollywood Private Hospital, Western Australia), Adelaide (Flinders Medical Centre, South Australia), and the Gold Coast (Gold Coast Cancer Centre and Day Hospital, Queensland). Patients from 2013 to 2018 were included from Westmead Hospital (New South Wales).

Patients were retrospectively analysed from the beginning of their treatment until February 2013 for the earlier cohort, and until April 2018 for the later. Patient information including age, gender and clinical response to treatment, was collected through the hospital-centered electronic databases - (PowerChart and ARIA) and paper records. MRIs were accessed through Inteleviewer, an electronic image viewing portal with secure access. Audiometry assessments were conducted through local audiometry services.

Assessment

Patients were screened for factors that would increase risk of bevacizumab side effects; including uncontrolled hypertension, prior stroke, vascular disease (both cardiac and peripheral vascular), previous or current deep vein thrombosis, personal or family history of coagulation disorders, hepatic dysfunction or renal dysfunction, or haematologic dysfunction (MacKeith et al., 2018; Morris et al., 2016). No patients were pregnant or breastfeeding during treatment. Advice was provided to patients of reproductive age to use contraception and avoid pregnancy during treatment. Fertility preservation was discussed with patients prior to commencing therapy. Patients were clinically reviewed in between bevacizumab cycles. Blood pressure and urinalysis was taken prior to every infusion. A quality of life questionnaire was incorporated into the earlier cohort assessment, however this was not conducted in the later cohort and as such has not been included in this analysis.

Bevacizumab infusions

Patients received bevacizumab infusions through the chemotherapy suites at Westmead Hospital, Westmead Children’s Hospital, Prince of Wales Hospital, Liverpool Hospital, Royal Prince Alfred Hospital, Hollywood Private Hospital, Flinders Medical Centre and the Gold Coast Cancer Centre and Day Hospital. Bevacizumab infusions were financed via a combination of self-funding, pharmaceutical special access schemes and compassionate access through the Hospital Drug Committee.
Dose adjustments were made based on clinically assessed adverse effects, such as hypertension, proteinuria, bleeding, clotting and general tolerability (Farschtschi, Kollmann, Dalchow, Stein, & Mautner, 2015; Morris et al., 2017; Slusarz, Merker, Muzikansky, Francis, & Plotkin, 2014). Infusions were withheld prior to any surgical procedures to allow for drug washout, and minimisation of bleeding and clotting risks, and delays in wound healing.

Radiological measurement of response

Magnetic Resonance Imaging (MRI) is the current gold standard for NF2 VS imaging (Dombi et al., 2013; MacKeith et al., 2018; Plotkin, Blakeley, et al., 2013). MRI brain series were collected at baseline and 3 month intervals throughout treatment duration. Various imaging facilities were utilised, based on patient preference and convenience. Attempts wherever possible to complete imaging at the same imaging centre was encouraged, for continuity of imaging quality. Three-dimensional (3-D) volumetric assessment is more sensitive and specific than two-dimensional (2-D) analysis and can detect changing volumes earlier than 2-D measurements. The Response Evaluation in Neurofibromatosis and Schwannomatosis (REINS) criteria are most reliable and have been accepted widely as the standard criteria for NF2 related lesions (Dombi et al., 2013; Plotkin, Halpin, et al., 2009). Significant clinical response is based upon a 20% change in 3-D volumetric analysis; a 20% decrease indicating partial response, a 20% increase indicating progression, and any measures within these parameters considered stable disease. Under this criterion, surgery for the target lesion also constitutes radiological progression.

For the earlier cohort, 3-D volumetric analysis was sought from an external company, NFTumormetrics Group, Medical Imaging Centre, Massachusetts General Hospital, Boston; and two local radiologists at Westmead Hospital. For the later cohort, volumetric measurements were recorded from two separate investigators; a medical oncology advanced trainee, and a radiology fellow. Measurements were taken under guidance from a senior radiologist and medical oncologist at Westmead Hospital. T1 gadolinium contrast images were analysed, with sliced series ranging 1mm-5mm in the axial plane. VS measurements were collected independently, and then collated for statistical analysis. 3-D Volumetric Analysis of tumour size was obtained using electronic Inteleviewer software (version 4-12-1-P115)

Figure 1. Scans conducted at alternative MRI sites could be imported to Inteleviewer, for standardised analysis. VS tumours were identified as target lesions, and other lesions (non-vestibular schwannoma, meningioma, optic nerve sheath tumours) were identified and measured where appropriate, though not included in our final analysis. Data from both time periods was combined as a single dataset.

Figure 1: Volumetric Measure of Bilateral VS Audiometric measurement of response

Patients underwent audiometric assessment, at baseline and then 3-6-month intervals. Various audiometric labs were used, based on patient preference and convenience. A combination of PTA and WRS results were collected. All patients underwent PTA testing, however, WRS testing was not routinely conducted, and thus was not included in the final analysis. PTA results were measured and analysed individually for each ear. A decrease in the average PTA by 10dB indicated response (Plotkin, Halpin, et al., 2009).

Statistical analysis

Statistical analysis was guided by a statistician. Simple descriptive statistics were calculated using Microsoft Excel Workbook, v16.25. NFTumormetrics volumes and local volumes were pooled and averaged for each patient for each scan. Absolute change in volume was expressed as a percentage for each patient.
Volume change percentage was measured from baseline through until last MRI on treatment. Serial PTA results were also calculated in the same manner. PTA readings were averaged across frequencies from 250Hz-8000Hz and expressed in decibels (dB).

Results

Twenty-one VS tumours were identified in eleven patients across both time periods. All patients had either clinical or radiological progression of VS tumours on commencement of bevacizumab infusions. The median patient age was 26 (range 13-67 years). Results are summarised in Table 1 below.

Seven patients were identified from 2009-2013, three females and four males. One patient only had a unilateral VS tumour. Five patients only had unilateral hearing intact at the time of commencement of infusions. Three patients also experienced symptoms of brainstem compression. One patient had significant NF2 related disability, with unilateral deafness and bilateral blindness. Four patients had other intracranial lesions, including meningiomas, trigeminal schwannoma and optic nerve sheath tumours.

One patient received prior small molecule therapy (imatinib) before commencing bevacizumab. Imatinib was ineffective in this patient and was ceased five months prior to the commencement of bevacizumab therapy. Patients with co-morbid meningiomas, who were included within the first time period were concurrently prescribed a somatostatin analogue, in light of data indicating potential benefit for meningiomas (Chamberlain, Glantz, & Fadul, 2007).

Four patients were analysed from 2013 to 2018, one female and three males. All patients had bilateral VS tumours. One patient developed brainstem compression prior to commencement of bevacizumab. One patient with hearing loss was also experiencing

Table 1: Results Summary for Tumour Volume and Audiometry Response

<table>
<thead>
<tr>
<th>Patient</th>
<th>Age (years)</th>
<th>Unilateral or Bilateral Tumour</th>
<th>Duration of Treatment (months)</th>
<th>Baseline Total Tumour Volume (cm3)</th>
<th>Best Volume Response % (response)</th>
<th>Best Hearing Response (right/ left ear)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>22</td>
<td>U</td>
<td>27</td>
<td>10.79</td>
<td>-53 (PR)</td>
<td>R: PR, L: not tested</td>
</tr>
<tr>
<td>2</td>
<td>23</td>
<td>B</td>
<td>24</td>
<td>5.55</td>
<td>-21 (PR)</td>
<td>R: SD**, L: PD**</td>
</tr>
<tr>
<td>3</td>
<td>33</td>
<td>B</td>
<td>12</td>
<td>16.26</td>
<td>-32 (PR)</td>
<td>R: PD, L: PD</td>
</tr>
<tr>
<td>4</td>
<td>22</td>
<td>B</td>
<td>9</td>
<td>18.51</td>
<td>-37 (PR)</td>
<td>R: PR, L: SD</td>
</tr>
<tr>
<td>5</td>
<td>31</td>
<td>B</td>
<td>9</td>
<td>38.51</td>
<td>-28 (PR)</td>
<td>R: not tested, L: NA*</td>
</tr>
<tr>
<td>6</td>
<td>33</td>
<td>B</td>
<td>15</td>
<td>3.76</td>
<td>-25 (PR)</td>
<td>R: SD, L: SD</td>
</tr>
<tr>
<td>7</td>
<td>13</td>
<td>B</td>
<td>9</td>
<td>1.77</td>
<td>+17 (SD)</td>
<td>R: SD, L: not tested</td>
</tr>
<tr>
<td>8</td>
<td>15</td>
<td>B</td>
<td>47</td>
<td>1.45</td>
<td>+241 (PD)</td>
<td>R: NA*, L: NA*</td>
</tr>
<tr>
<td>9</td>
<td>14</td>
<td>B</td>
<td>9</td>
<td>13.38</td>
<td>+14 (SD)</td>
<td>R: SD, L: SD</td>
</tr>
<tr>
<td>10</td>
<td>67</td>
<td>B</td>
<td>9</td>
<td>4.25</td>
<td>-57 (PR)</td>
<td>R: SD, L: SD</td>
</tr>
<tr>
<td>11</td>
<td>17</td>
<td>B</td>
<td>18</td>
<td>37.9</td>
<td>+30 (PD)</td>
<td>R: SD then PD, L: PR then PD</td>
</tr>
<tr>
<td>Mean:</td>
<td>26</td>
<td></td>
<td>17</td>
<td>14.17</td>
<td>+4.45</td>
<td>+2.5 (decibels)</td>
</tr>
</tbody>
</table>

PR: partial response, SD: stable disease, PD: progressive disease
* Patients had single data available, not included in analysis
** Patient did not have baseline data, however serial data available for analysis not tested: no data collected (baseline deafness)
neuralgia from trigeminal V3 trigeminal nerve compression of the VS tumour. One patient had a large tumour causing compression of the optic nerve and visual impairment of the right eye. This patient had complete vision loss in the left eye secondary to a prior left VS tumour. 

One patient had transferred from the children’s oncology service to the adult oncology service. They had been treated previously with bevacizumab in the Children’s Hospital and had ceased therapy for surgical resection. This patient was restarted on bevacizumab after a treatment break following surgery. 

Most patients were commenced on a dose of 5mg/kg given every fortnight. One patient (treated with concurrent imatinib) was commenced on 15mg/kg every 3 weeks, which was subsequently reduced following disease stabilisation, to 7.5mg/kg given every 3 weeks. There was variability in the frequency of cycles, ranging from two to four weeks. Median duration of therapy was 9 months (range 9-47 months), with an average of 17 months. 

Tumour Volume Response

The average baseline total tumour volume per patient was 14.17cm³ (range 1.45cm³ - 38.51cm³). Reduction in tumour volume of >20%, indicating a partial response was identified in seven out of eleven patients (64%) (Figure 2) (Dombi et al., 2013). The average volume change was an increase by 4.45%, ranging from a reduction of 57%, through to an increase of 241% from baseline measurement, however this patient had the smallest baseline volume. Of the four patients who did not achieve a partial response, two had stable disease (18%) and two had progression (18%) of disease. 

Figure 2: Volume Change in Unilateral VS

At 12 months, six patients were still receiving infusions. The longest treatment period was 47 months. The average length of treatment was 17 months. Reasons for stopping were progression of disease, progression to surgical resection or cessation of funding for infusions.

Pure Tone Audiometry Analysis

Results were available for 16 ears. Two patients only had a single ear tested from baseline. Two patients had a single result for each ear available, and as such were unable to be analysed for decibel change. One patient did not have a baseline data set available, however had serial PTA results available and as such was included in the analysis. Follow up for PTA analysis ranged from 6-30 months, with a median of 15 months. 

Of the sixteen ears tested, three responded, 19%. 10/16 ears maintained a decibel change between -10dB to 10dB. Three ears showed progression of hearing impairment. The average decibel change was 2.5dB, (range -36 to 81dB).

Toxicities

One patient was hospitalised with a viral illness and haematemesis, who also developed thrombosis around intravenous catheter. Bevacizumab was temporarily withheld, cautiously restarted after anticoagulation, with no recurrence of either bleeding or clotting events. No patients were documented to have suffered from stroke during their bevacizumab treatment period. 

The main toxicities documented were hypertension, proteinuria and fatigue, all grade 1-2 (National Cancer, 2010). Two patients developed both hypertension and proteinuria. Management for these toxicities included antihypertensives for management of blood
pressure, along with a dose and frequency reduction in the bevacizumab dosage for effected patients. No patients ceased therapy due to toxicity. Fatigue was an intermittent symptom for most patients and likely multifactorial.

On informal follow up, at least six patients ceased bevacizumab infusions due to cessation of compassionate funding, where self-funding was not a feasible option. One patient stopped infusions to proceed with surgery, another stopped to proceed with radiation. At least two patients continued to self-fund infusions.

Discussion

This study demonstrates a beneficial effect of bevacizumab in control of VS and hearing in patients with NF2. We believe this study represents the first published experience amongst Australian NF2 patients treated with bevacizumab and our results are reflective of those in international centres.

Plotkin (2009) showed evidence of radiological response in 6/10 (60%) of patients. Similarly, Alanin (2015) studied a cohort of 12 patients and found 6/12 (50%) of patients had a partial response.

Plotkin (2012) again collaborated and studied thirty-one patients who showed 53% of patients responding in a larger cohort of thirty-one patients, with fifty-one measurable lesions. Morris (2016) conducted the largest trial, looking at sixty-one patients, and found 39% of their cohort showed evidence of response.

Alanin (2015) reported a similar hearing stabilisation effect of bevacizumab in a total of 9 ears across their 12-patient cohort, and describe a response in 11%, stable hearing in 79% and deterioration of hearing in 22%. We recognise that WRS analysis is a more sensitive measure of hearing in NF2 patients, however, the paucity of available WRS results within our patient cohort prevented statistical analysis.

Bevacizumab toxicities were within the expected spectrum and manageable, with appropriate dose and frequency modifications (Morris et al., 2017). There was only one major grade 4 toxicity, and no treatment related deaths.

Limitations

The heterogeneity of volumetric assessment may have minor impact upon the accuracy of our results. Although both time periods cohort measurements were standardised within each separate time period, it would have been preferential to have a standardised assessment process across both time periods. Dombi (2013) and colleagues do not specify whether manual measurement is preferential over automated measurement, but simply comment that measurements should be consistent across the cohort and analysed centrally which we upheld within the confines of our study. Financial restraints posed a barrier to accessing off site automated analysis in the second cohort. While measurements were simple to obtain on manual measurement, manual techniques were time consuming and would prove inefficient in larger cohorts outside of a study environment.

Future direction

Given the durability and reproducibility of response rates, bevacizumab should be considered as part of the frontline management of VS tumours. It would offer a less invasive and generally more tolerable side effect profile to surgery or radiotherapy, without the risk of malignant transformation (Evans et al., 2006).

Bevacizumab may reduce the use of steroids to manage VS symptoms, which in turn would reduce steroid related morbidity in patients who survive for extended periods with VS tumours and are often prescribed protracted courses of steroids and incur many steroid related co-morbidities.

Li (2016) and colleagues have been investigating the use of biochemical characteristics and changes in serial ‘dynamic contrast enhanced’ scans to help identify a subgroup within VS tumours who are more likely to respond to VEGF inhibition with bevacizumab. This may help to further triage and streamline treatment modalities to offer the
most clinically and financially effective treatment option to NF2 patients.

Ideally, bevacizumab would be incorporated into the national funded registry (in Australia, the Pharmaceutical Benefits Scheme) of available treatment options for NF2 patients, thus alleviating the financial burden placed upon patients and their families in an attempt to access treatment.

**Conclusion**

Bevacizumab has been shown to be effective drug in helping to reduce tumour volume and improve hearing. The Australian experience is comparable to that illustrated in both the US and the UK, using standardised volumetric measurement techniques and response criteria, and acceptable appropriation of audiometric results.

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Australasian Neuroscience Nurses Day May 4th

On 4 May, 1974, Tonnie Koenen organised the first meeting of Australasian neuroscience nurses in Canberra, during the Neurosurgical Society of Australasia’s annual meeting.

About 30 nurses met to formally establish the Australasian Neurosurgical Nurses’ Association. Since that time, Neuroscience nurses have continued to promote collaboration with other nurses and other health professionals in a committed effort to the professional development and education of nurses within the specialty of neuroscience. We celebrate this and the beginning of our Association on our Australasian Neuroscience Nurses Day, every 4th of May.

The Covid-19 pandemic has shown the world the important role that nurses play within our healthcare systems.

During this past year we have been exposed to enormous pressures and challenges. Australasian Neuroscience Nurses day is a day to reset and take the opportunity to reflect.

We give thanks this year for the advancements that have led to improvements in the health of so many.

We work to support new breakthroughs in overcoming neurological diseases and disorders.

We hope for this pandemic to end and for no more lives to be lost.

We support our colleagues as we all work to provide the best care that we can, always embracing change and innovation.

We hope that we can have the wisdom, knowledge and vision to work together and support each other during the often long and lonely hours.

Linda
Introduction

In Australia, it is estimated that 80,000 people are living with Parkinson’s disease (Rossiter et al., 2019). The median time from disease onset to death is approximately 12.4 years, with many living with the disease for over 20 years (Deloitte, 2015). A significant proportion of people living with Parkinson’s disease suffer from disabilities that require long term care (Williams et al., 2017) with an estimated average lifetime financial cost of $161,300 per patient over the 12 years. In 2018, the estimated total economic cost was $12.3 billion (Deloitte, 2015).

A person living with Parkinson’s disease may experience a collection of motor and non-motor symptoms which are specific to the individual. The cardinal motor symptoms of PD include tremor, rigidity, akINESIA or bradykinesia and postural stability along with many others. However, the non-motor symptoms of Parkinson’s disease are often more troublesome as it is less visible and is often a neglected aspect of the condition. Common non-motor symptoms may include mood and sleep disturbances, autonomic dysfunction and cognitive impairment (Durcan et al., 2019).

The management of Parkinson’s disease and the varying combination of all its complex symptoms require expert titration of medications and psychosocial interventions to achieve a balance that will provide patients with quality of life. In order to execute this with precision, the need for Parkinson’s disease and movement disorder nurse specialists (PDMDNS) is warranted (Bramble et al., 2018).

Abstract:

Parkinson’s disease is the second most common neurological disorder after dementia in Australia (Deloitte, 2015). The complexities of caring for a person with Parkinson’s disease highlights the need for Parkinson’s disease and movement disorder nurse specialists (PDMDNS) (Bramble, Carroll, & Rossiter, 2018).

The Australasian Neuroscience Nurses Association’s (ANNA) Movement Disorder Chapter (MDC) aims to implement an annual demographic survey over the next 10 years to capture the characteristics of the PDMDNS cohort, identify gaps in service provision and aid the workforce planning through useful and influential data.

The results of this survey were able to highlight the geographical areas that are underserviced, the diverse employment opportunities available and the issues around financial funding for PDMDNS positions in Australia.

Keywords:

Parkinson Disease, Parkinson’s Disease, Movement Disorders, Nurse Specialist, Demographic survey, workforce demographics.
It has long been recognized that PDMDNS provide skilled clinical care, education and advice through communication with patients, carers and health care providers. These interventions reduce both physical and psychological morbidity and result in improved health outcomes (MacMahon & Thomas, 1998).

In Australia, the role of the PDMDNS is as diverse as the presentation of the condition itself. The employment of a Parkinson’s disease nurse by the Parkinson’s Association of Western Australia in 1998, was the first published reference recording the start of the specialty in Australia (Doherty, 1999). However, it is historically believed that the first PDMDNS role may have been in established as early as 1985 in the setting of a hospital based, industry funded, clinical trials nurse.

This study is the first of a series of annually recurring publications to progressively monitor the growth and development of the PDMDNS profession over the next ten years. This is to provide appropriate evidence to ensure the PDMDNS in Australia are supported with adequate resources, sufficient training and appropriate levels of qualifications. It will also assist in identifying the gaps in the profession as well as the provision of service to people living with Parkinson’s disease.

Study Objectives

The primary objective was to collect demographic information pertaining to PDMDNS positions in Australia including the population, the geographic location, the level of education and the clinical experience of the nurses. It was also aimed to explore the nature of work that the PDMDNS are engaged in and the long-term sustainability of this subspecialised nursing workforce.

The secondary objectives were to analyse data to identify gaps in service provision to people living with Parkinson’s disease in Australia. This information will aid in workforce planning related to funding, education and advocacy.

Study Design

The study and its design were initiated solely and independently by the Australasian Neuroscience Nurses Association (ANNA) Movement Disorder Chapter (MDC) with no financial funding and/or conflict of interests. The ethics application was submitted to and approved by Northern Sydney Local Health District Human Research Ethics Committee 2019/ETH12872: Parkinson’s Disease Movement Disorder Nurse Specialist Demographic Survey as a low or negligible risk project.

Data was collected through an anonymous online multiple choice survey produced using the website https://www.surveymonkey.com. The survey included a series of quantitative, multiple choice questions designed to sample a cohort of PDMDNS across all states in Australia, including years of service, employer types and levels of education. This survey was emailed to 100 PDMDNS contacts known to the ANNA MDC but only the recipients who were employed as a specialty nurse working directly with people with Parkinson’s in Australia were included.

Study Results

Between 21st April 2020 and 20th May 2020, we distributed a total of 100 surveys and received 70 responses. 87% (n=61) met the inclusion criteria and were analysed.

On examination of the 61 specialised PDMDNS positions, New South Wales and Victoria held the highest population with 31% (19) in New South Wales, 26% (16) in Victoria, 18% (11) in Queensland, 10% (6) in Western Australia, 8% (5) in South Australia, 5% (3) in Tasmania and 2% (1) in the Australian Capital Territory. There was no PDMDNS position employed in the Northern Territory (Figure 1).

New South Wales employed 12 metropolitan, 5 regional and 2 rural positions. Victoria had 12 metropolitan, 2 regional, 2 rural positions. Queensland had 7 metropolitan, 3 regional, 1 rural position. Western Australia had 5 metropolitan, and 1 rural position. South Australia had 4 metropolitan, 1 regional position, Tasmania had 1 metropolitan and 2 regional positions. The only position in Australian Capital Territory was employed in the metropolitan area (Figure 1).
Nationally across Australia, the majority of the PDMDNS positions were based in the metropolitan area at 69% (42) with the remaining 21% (13) and 10% (6) located in regional and rural areas respectively (Figure 2).

The largest employer of PDMDNS positions was the state Department of Health which employed 49% (30) of the positions across Australia seconded by the pharmaceutical industry with 21% (13) which employ nurses as product specialists or support nurses for device assisted therapies (Figure 3). Other employers include 8% (5) by consumer organisations, 7% (4) from private practices, 3% (2) in Primary Health Network, 3% (2) in Private Hospitals and 2% (1) in university or educational institutions. There were 20% (12) that did not specify their employer as their employer may not have been clearly represented (Figure 3).

### Workforce Stability

The permanency of funding indicates 59% (36) of PDMDNS are permanently funded with 31% (19) of PDMDNS positions without permanent funding. There were 10% (6) that answered ‘not applicable’ for various reasons possibly due to the contractual or performance based nature of their position (Figure 4).

### Levels of Experience

It was identified that 33% (20) of the PDMDNS nurses had 5-10 years’ experience in their positions with 26% (16) having held their positions for over 10 years. The third most prominent cohort with 25% (15) were the nurses with experience between 2-5 years.

Workforce stability forecasts fairly consistent workforce with 33% (20) intending to stay in their position for 6-10 years with 16% (10) intending to stay 11-15 years and 21% intending to stay for 16-20 years.

### Level of Education

Within our cohort, 23% (14) recorded a registered nursing degree as their highest level of education related to their nursing position. 25% (15) have completed a graduate certificate and the largest group at 30% (18) held a graduate diploma. Those who hold a master’s degree account for 21% (13) of the group and 2% (1) hold a doctorate.

### Discussion

The results of this survey were able to identify three key issues of the PDMDNS workforce.

Firstly, we were able to quantify that the rural and regional areas are underserviced. While the disparity in the number of nurse positions across states and regions was expected anecdotally, it was useful to objectively quantify the severity of this issue. This data may assist local service providers, con-
umer groups and professional bodies to advocate for changes in the health system to provide additional funding to ensure this significant Parkinson’s patient population in those geographical areas has access to this specialised nursing care.

Secondly, PDMDNS employed by pharmaceutical companies are an integral part of the PDMDNS ecosystem. Although these nurses are often viewed with a negative connotation due to fears of conflicts of interest, the pharmaceutical industry is the second largest employer of PDMDNS and partnership with these nurse specialists are an integral part of providing specialised nursing care for people with Parkinson’s and meeting the gaps in service.

Thirdly, and one of the most crucial observation that was extrapolated from the results of this year’s data is the lack of permanent funding for PDMDNS positions in Australia. Over 30% of these PDMDNS positions are currently operating without assurance of permanent funding. There is a high risk that the loss of these positions would lead to loss of clinical expertise and experience in an extremely subspecialised field if more secure funding is not sought. We aim to collect more detailed information regarding the temporary funding arrangements in future surveys to assist in identifying the current limitations in this area.

One limitation of the study included the inability to capture the characteristics of nurses who have a special interest in Parkinson’s disease and act as a champion in their workplace but are not employed specifically in a specialty position. These nurses may include nurse educators in an aged care or rehabilitation facility, a registered nurse in a ward environment or a community nurse providing nursing care in a home setting. Future design of the survey will maintain consistency in recapturing existing data for comparative purposes but will also refine the survey design to overcome this limitation.

On an encouraging note, in January 2019, the Liberal National Government announced $6.8 million over four years for Primary Health Networks to improve access to specialized nursing care in the community for people living with movement disorders, including Parkinson’s disease (Australian Minister of Health, 2019). Consequently, we anticipate a significant influx of PDMDNS in rural and regional areas over the next four years. Ultimately, this will improve access to specialized care for people living with Parkinson’s disease in these previously underserviced areas. With expected growth in PDMDNS positions, it is both essential that this new group of nurses are educated and supported to provide their patients with best practice nursing care. It is also crucial to challenge the existing and established group of PDMDNS to remain engaged with ongoing education, maintain currency of practice and be able to provide mentorship to these developing PDMDNS.

Conclusion

This Demographic survey is the first of its kind and captures a snapshot of the PDMDNS workforce in Australia. Collecting this information annually will provide information on trends and the changing nature of these positions over time.

The results of this survey highlighted three key issues in the PDMDNS cohort which included the underservicing of rural and regional areas, the integral role of the pharmaceutical industry PDMDNS and the significant percentage of PDMDNS positions that do not have the assurance of permanent funding.

There is a forecast that there will be an influx of PDMDNS positions over the next four years. Preparations to educate and upskill a growing workforce need to occur now. The nursing, medical and consumer groups need to collaboratively lobby for adequate resources from governing bodies to ensure resources are provided to address the needs of this growing and vulnerable Parkinson’s population and the group of specialised Parkinson’s nurses that care for them.
References:


Most of these talks will be available on the WFNN website www.wfnn.org in the coming month.

**Speakers:** As an international event, there were presentations from colleagues in the USA, Canada, UK and Iceland, as well as Australian speakers. All presentations were well-received and included:

Christi DeLemos (USA) – Fact or Fiction? How data impacts decisions. This began with a discussion of the NASA Challenger disaster and led into nursing decisions based on fact or fiction.

Lauren Hansen (AUS) – from CPA, explained the role as exercise physiologist for the Cerebral Palsy Alliance.

Stephen Cavanagh (USA) – Innovation in clinical practice and research. He challenged us to look for new strategies in our practice or perhaps not new but rather old ways and reinvent the way in which we look at them into the future.

Cindy Bautista (USA) – Visual aids to validate stroke nursing knowledge. Cindy’s talks are always lively and this was no exception! Her ability to explain things simplistically through drawings is appreciated.

Dawn Tymianski (Canada) – Shaping the landscape: NP-led clinics in Canada. Dawn’s session gave great insight and scope for NPs, not only in rural and remote areas, but also for city practitioners as well. Her Live Q&A session gave the opportunity to connect and there were many questions.

Vicki Evans (AUS) – Concussion & School Sport Update.

Linda Nichols (AUS) – Vaccination: Changing neurological disease course. This talk provided an excellent historical look and timeline of diseases and vaccinations in Australia and provided a great segue into the current vaccination offering. The live Q&A gave an opportunity for discussion.

Vicki Evans (AUS) – COVID-19 & Panel discussion (US, Canada, UK, AUS). This gave insight into the issues of the pandemic from a global perspective and described the emerging neurological complications of the virus.

Jeanne Barr (AUS) – Pain management in the neurosurgical patient. This session gave a look into the research behind managing pain in the neurosurgical population, through evidence, its impact, developing a protocol and other strategies.

Christi DeLemos (USA) – Neuroimaging. Whilst not recorded specifically for this symposium, this talk was requested as it gives a great introduction to neuroimaging.
Short International Sessions:

Ruth Trout & Fiona Chalk (UK) – Emerging understanding and interventions to promote Neuroplasticity.

Cindy Sullivan (USA) – The spinal fusion pathway to discharge: It takes a team!

Jenny Huffadine (UK) – Transition from hospital to home following stroke - the patient experience.

Marianne Klinke (Iceland) – Screening for spatial neglect in a ward-based environment within two weeks from stroke onset: preliminary results of a pilot study.

Sponsors - were very forthcoming and included the Northern Sydney Local health District and Royal North Shore Hospital, Cerebral Palsy Association, SEER Medical, University of Tasmania and University of Technology Sydney. We are extremely thankful for the continued support of these sponsors, as without this partnership, events such as this could not occur.
2021 Educational Webinars & Annual Conference

We have a fantastic line up of events for 2021, so invite your friends and look forward to the conference.

This year the conference will be joining with the Movement Disorder Chapter, to provide you with two days of quality education online with the event called 'Localized Connections'. More details on this to follow!

This is an exciting year to be part of ANNA. Amongst the uncertainty of travel, with our online education capabilities we can continue to provide quality education throughout the year to make membership great value for money!

Please see the program below for our educational webinars, workshops and conference.

A huge congratulations to Caroline, Catherine and the team for a great upcoming educational program

<table>
<thead>
<tr>
<th>Date</th>
<th>Branch</th>
<th>Title</th>
<th>Speaker</th>
<th>Cost</th>
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<tbody>
<tr>
<td>Monday 3 May</td>
<td>ANNA NZ</td>
<td>New Zealand Branch workshop – Bowel care in the neuroscience patient</td>
<td>Caroline Woon facilitating workshop</td>
<td>Free for ANNA members</td>
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<tr>
<td>Friday 14 May</td>
<td>Movement Disorder Chapter (MDC)</td>
<td>Parkinson's disease education day Movement Disorder Chapter (MDC)</td>
<td>Sue Williams / David Tsui</td>
<td>Free for ANNA members</td>
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<td>Tuesday 1 June</td>
<td>ANNA</td>
<td>What's new in neuro nursing education? 7.30pm (AEST)</td>
<td>Caroline Woon online</td>
<td>Free for ANNA members</td>
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<tr>
<td>Thursday 22 July</td>
<td>Movement Disorder Chapter (MDC)</td>
<td>Atypical parkinsonism</td>
<td>David Tsui / Sue Williams online</td>
<td>Free for ANNA members</td>
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<tr>
<td>Tuesday 7 September</td>
<td>ANNA</td>
<td>&quot;Multiple Sclerosis, an Update for Neuro Nurses – The Good, The Bad and The Hidden&quot;</td>
<td>Tim O'Malley online</td>
<td>Free for ANNA members</td>
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<tr>
<td>Thursday 16 September</td>
<td>Movement Disorder Chapter (MDC)</td>
<td>Nursing assessment of movement disorder</td>
<td>David Tsui/Sue Williams online</td>
<td>Free for ANNA members</td>
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<tr>
<td>Monday 11 October</td>
<td>ANNA NZ</td>
<td>New Zealand Branch workshop - Agitation in the neuroscience patient</td>
<td>Caroline Woon facilitating workshop online</td>
<td>Free for ANNA members</td>
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<tr>
<td>Thursday 11 &amp; Friday 12 November</td>
<td>ANNA and Movement disorder chapter</td>
<td>Movement Disorder Chapter (MDC) and ANNA conference combined ‘Localized connections’</td>
<td>Online</td>
<td>Price TBA Discounted members rates apply</td>
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<tr>
<td>Tuesday 7 December</td>
<td>ANNA</td>
<td>Clinical governance</td>
<td>Kylie Wright online</td>
<td>Free for ANNA members</td>
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The Louie Blundell Prize

This prize is in honour of our colleague Louie Blundell and will be awarded for the best neuroscience nursing paper by a student submitted to the Australasian Neuroscience Nurses Association (ANNA) for inclusion in the Australasian Journal of Neuroscience by the designated date each year. The monetary value of the prize is AUD$500.

Louie Blundell, was born in England, and although she wanted to be a nurse she had to wait until after World War II to start her training as a mature student in her late twenties. Later she and her family moved to Western Australia in 1959. She worked for a General Practice surgery in Perth until a move to the Eastern Goldfields in 1963. Subsequently, she worked at Southern Cross Hospital and then Meriden Hospital. During this time she undertook post basic education to maintain her currency of knowledge and practice, especially in coronary care.

Louie was also active in the community. She joined the Country Women’s Association and over the years held branch, division and state executive positions until shortly before her death in 2007. She was especially involved in supporting the welfare of students at secondary school, serving on a high school hostel board for some time.

She felt strongly that education was important for women and was a strong supporter and advocate of the move of nursing education to the tertiary sector, of post graduate study in nursing and the development of nursing scholarship and research, strongly defending this view to others over the years.

The Louie Blundell Prize

2021:

- Thursday 11th and Friday 12th of November Combined Movement Disorder Chapter and ANNA Conference ‘Localised Connections’.

- WFNN Congress
  July 2025, Darwin Australia.
  www.wfnn.org
The Australasian Journal of Neuroscience publishes original manuscripts on all aspects of neuroscience patient management, including nursing, medical and paramedical practice.

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All manuscripts are subject to blind review by a minimum of two reviewers. Following editorial revision, the order of publications is at the discretion of the Editor.

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A letter of submission must accompany each manuscript stating that the material has not been previously published, nor simultaneously submitted to another publication. The letter of submission must be signed by all authors. By submitting a manuscript the authors agree to transfer copyright to the Australasian Journal of Neuroscience. A statement on the ethical aspects of any research must be included where relevant and the Editorial Board reserves the right to judge the appropriateness of such studies. All accepted manuscripts become copyright of the Australasian Journal of Neuroscience unless otherwise specifically agreed prior to publication.

Manuscripts

Manuscripts should be typed using 10 font Arial in MS Word format. It should be double-spaced with 2cm margins. Number all pages. Manuscripts should be emailed to the AJON Editor at: editor@anna.asn.au

TITLE PAGE: Should include the title of the article; details of all authors: first name, middle initial, last name, qualifications, position, title, department name, institution: name, address, telephone numbers of corresponding author; and sources of support (e.g. funding, equipment supplied etc.).

ABSTRACT: The abstract should be no longer than 250 words.

KEY WORDS: 3 to 6 key words or short phrases should be provided, below the abstract, that will assist in indexing the paper.

TEXT: Use of headings within the text may enhance the readability of the text. Abbreviations are only to be used after the term has been used in full with the abbreviation in parentheses. Generic names of drugs are to be used.

REFERENCES: In the text, references should be cited using the APA 6th edition referencing style. The reference list, which appears at the end of the manuscript, should list alphabetically all authors. References should be quoted in full or by use of abbreviations conforming to Index Medicus or Cumulative Index to Nursing and Allied Health Literature. The sequence for a standard journal article is: author(s), year, title, journal, volume, number, first and last page numbers.

ILLUSTRATIONS: Digital art should be created/scanned, saved and submitted as a TIFF, EPS or PPT file. Figures and tables must be consecutively numbered and have a brief descriptor. Photographs must be of a high quality and suitable for reproduction. Authors are responsible for the cost of colour illustrations. Written permission must be obtained from subjects in identifiable photographs of patients (submit copy with manuscript). If illustrations are used, please reference the source for copyright purposes.

Proof Correction

Final proof corrections are the responsibility of the author(s) if requested by the Editor. Prompt return of proofs is essential. Galley proofs and page proofs are not routinely supplied to authors unless prior arrangement has been made with the Editor.

Discussion of Published Manuscripts

Questions, comments or criticisms concerning published papers may be sent to the Editor, who will forward same to authors. Reader’s letters, together with author’s responses, may subsequently be published in the Journal.

Checklist

Letter of submission; all text 10 font Arial typed double-spaced with 2cm margins; manuscript with title page, author(s) details, abstract, key words, text pages, references; illustrations (numbered and with captions); permission for the use of unpublished material, email manuscript to editor@anna.asn.au

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