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The Australasian Journal of Neuroscience
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Editorial

The last decade of the last century was called the decade of the brain. Today, half way through another decade the technological and biological advances that have occurred since the beginning of that last decade have made many changes to the management of persons with neuroscience related problems. Similarly these present challenges in the areas of ethics and law as well as $80.00 care and education. At the same time the essence of care and support that people require in order to continue to live with the results of neurotrauma, cerebrovascular disease or the results of progressive disruption of the neurologic system remain a constant

Much of the work that neuroscience nurses do in these areas remains hidden or is only disseminated within the confines of a clinical area. If we are to demonstrate the worth of neuroscience nurses then the evidence underpinning our practice needs to be collected, presented in fora and published. Inquiry and research into all aspects of care and patient experience can only enrich our practice, and the outcomes for patients and their families.

Similarly we can advocate for patient groups, such as young persons with neurologic related disability who find themselves placed in residential care with people . from older generations. Research into the effects of this lack of policy for these young people may assist in persuading policy makers of the necessity for purpose built facilities. Facilities that provide adequate care within an age appropriate environment that allows some choice for the residents, not just physical care.

Finally, as neuroscience nurses working in a range of clinical fields we can unite to show our colleagues from nursing and other health fields that we have an important role to play based on solid evidence.

Jennifer Blundell

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Huntington Disease nursing education, as an evidence-based intervention for reducing the impact of the "Cuckoo in the nest" phenomenon in NSW aged care facilities

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Abstract

Huntington Disease (HD) is an incurable, neurodegenerative, genetic condition of younger adult onset. The ensuing need for long tem nursing care is usually provided by aged care facilities, who, in New South Wales (NSW), Australia, are supported by a multidisciplinary outreach team. A nursing study using a triangulated, exploratory design, consisted of a mailed, whole population survey. The respondents were a convenience sample of 90 nurses from a sample of NSW aged care facilities with HD affected residents. The aim was to investigate reported nursing problems, to identify any existing evidence-based strategies to overcome these, and to generate new solutions. An extensive literature search identified only one tangentially related HD nursing research study. High response rates (57%) by the sample of 90 nurses (including Registered Nurses, 88%; Enrolled Nurses, 6%, and Assistants in Nursing, 11%) from 59 state-wide, high and low care, facilities, strengthens the credibility of the findings. The findings indicated that :

- **nursing difficulties were attributed to the different medical, social and lifestyle needs of the "*Cuckoos in the Nest*" compared to their elderly peers**
- **The nurses' dissatisfaction with the situation was related to the amount of their nursing education**
- **HD specialist nursing contact was endorsed as facilitating better resident care.**

Amplification of the quantitative results by the nurses' written responses to the questions provided further insights into their HD educational experiences, their unmet educational needs, and the positive value they placed on HD education and support. The findings prompted several changes to the existing education sessions with positive outcomes.

Keywords: Huntington Disease, Aged Care facilities, Nursing Education, New South Wales, Australia

Introduction

The 'outreach' phone rings –the caller states that there is a problem with the care of X – "you know - the 45 year old with HD". The family of his roommate is threatening to take legal action because the younger man uses foul language when he is denied access to the phone to ring his estranged wife yet again. The Director of Nursing of the high care aged care facility also reports anxiety amongst the staff when allocated this resident to shower. Three staff have already had time off in the last week due to injuries incurred whilst busy with this task. There is an urgent request for help to manage this situation. In common with many others in similar situations, she has exhausted all her personal and professional resources attempting to provide care for a man with HD in an aged care facility. This man's children have dispersed, his father died in a strait jacket in the back wards of a psychiatric hospital when he was only fifty-eight years of age, and he can only communicate using incoherent, incomplete phrases accompanied by wild gestures and sometimes curses. Although this is an extreme scenario

selected to make the point, this type of crisis was common following the inception of the Sydney West Huntington Disease outreach service in November 1995. What does one do? What wise words do you use? What clever intervention do you introduce for a problem such as this?

In response, some answers derived from a New South Wales nursing research survey, are presented. This includes information on the following subjects:

- Basic information on Huntington Disease
- Problems with late stage care provision
- The generation of new research in response to the lack of solutions to these problems
- The description of the problem as "The Cuckoo in the nest" phenomenon
- The support of HD education as a solution to the problem as suggested by the research findings
- The translation of the findings into effective changes to practice
- Theoretical explanations

Huntington Disease (HD)

As an incurable, neurodegenerative, genetic condition of younger adult onset (Kovach & Stearns, 1993), HD represents a challenging condition which, in spite of intensive efforts, is not amenable to curative medical intervention for its solution, although there is rapid scientific progress underway. With the age of onset being typically 35 – 55 years, its prevalence in NSW is 6.25 / 100,000 (McCusker, Casse, Graham, Williams, & Lazarus, 2000). Therefore there are approximately 400 people affected in NSW. HD is an hereditary condition transmitted as an autosomal, dominant, genetic trait with increased CAG repeat numbers on chromosome 4. The signs and symptoms result from poorly understood cell death in the basal ganglia and frontal cortex (Turner & McCusker, 1997). These are a triad of physical, emotional and cognitive changes (Harper, 1996), which result in progressive, irreversible decline over more than twenty years. The goal of medical treatment is the reduction of the impact of these changes on quality of life and includes medical monitoring, medications, lifestyle and social interventions, risk reduction strategies, and nutritional supplementation (Chiu, 1990; Hardy, 1989; Kovach & Stearns, 1993).

Problems with residential care provision

The ensuing need for long tem nursing care is usually provided by aged care facilities, who in NSW, are supported by a specialist multidisciplinary HD outreach team (Williams, 2001). The progressive, degenerative nature of the disease means that increasing care needs necessitate early institutionalisation (Gelbart, 1998; Jolley,1990). However, there are only 15 specialist beds for the approximately 130 people requiring 24 hour residential care. Therefore, most live in high level (nursing home) and low level (hostel) aged care facilities with outreach support. However, as has already been described, aged care nurses describe many difficulties in providing care. HD families have been vocal for many years, in support of the preference for HD specialist accommodation (Kapp, 1985, 2002).

The generation of new research in response to the lack of solutions to these problems

A belief in evidence based practice provided an impetus for a search for best practice guidelines for this situation. However, an extensive literature search for such HD nursing guidelines was not fruitful. Other related work included the following publications.

- A HD study by Nance, & Sanders,(1996) describing a USA specialist facility.
- A HD study by Barczak et al (1987) was based in a psychiatric hospital in Birmingham, U.K.
- A tangentially related HD study by Skirton, & Glendinning, (1997), was community based.

On the other hand, the belief that HD education would improve patient outcomes was stated in some of the HD literature (Barczak, Pedlar, Hunter, & Betts,1987) and (Glendinning, & Skirton, 1994).

Aged care studies however, demonstrated the Importance of staff education to aged care resident outcomes.

- Pearson, Hocking, Mott & Riggs (1992a, 1992b, 1993a & 1993b) reported a statistically significant relationship between the level of in-service training and resident outcome measures of "Quality of Care" and "Quality of Life"
- Smith, Jepson & Perloff (1982) studied the impact of the educational preparation of nursing staff, and found that the most experienced & best educated staff had the most positive, and also the least negative attitudes to the residents
- Ryden, Bossenmaier & McLachlan (1991) reported that education of nursing assistants to reduce patient aggression, improved the quality of life for the residents and reduced caregiver burden.

Method

Based on these findings therefore, an inaugural nursing study to fill the knowledge gap was undertaken. The research goal was to increase understanding of HD and the nursing of people with HD in aged care facilities in NSW. This would assist in planning for their long-term accommodation needs. One way this could be achieved would be by describing evidence based strategies to overcome identified problems. The study design adopted was an exploratory, triangulated (Bull & Hart, 1995), mailed, whole population survey of nurses in all NSW aged care facilities with HD affected residents. The research was undertaken in 1997 by the HD Outreach Clinical Nurse Consultant with the short term assistance of an assistant who helped design the questionnaire. Ethics approval was granted by the relevant committee of the hospital sponsoring the research. Survey responses strengthened the credibility of the findings in the following ways.

- A sizeable group (90) of aged care nurses returned a valid questionnaire.
- 54% of NSW aged care facilities with an HD affected resident were represented.
- 57% of HD affected residents in aged care were reported on.
- Interrater consistency levels of 77% were considered an acceptable standard of reliability.
- The validity of the questionnaire was assessed by a criterion-related validity measure (Skodol-Wilson, 1989 p.357), by comparing responses with verifiable data from another source. The result was in the range of 70–94% considered an acceptable measure..

The description of the problem as "The Cuckoo in the nest" phenomenon

The analysis of the responses to the questionnaire (reported in more detail elsewhere) provided evidence of the "Cuckoo in the nest " (CIN) phenomenon. This metaphor, first used by British HD mental health nurse Frank Gardham (Gardham,1982), relates to the behavior of the cuckoo which lays its egg in the nest of another type of bird. On hatching, this chick is unlike the others, both in appearance and behaviour, causing great consternation to the mother and hardship to the other chicks. Likewise, an underlying cause of the nursing difficulties was the very different medical, social and lifestyle needs of the "Cuckoos in the Nest" compared to their elderly peers. The nursing home is also not a hospital for people with a disease but home to the frail elderly residents. Predictably, the staff generally have an interest in and expertise in aged care, and not necessarily in the behavior management of young disabled residents who tend to die prematurely of respiratory disease.

Further interpretation of the research findings indicated that the "Cuckoo in the nest phenomenon" has interacting components. These include firstly the residents, who are surrounded by and interact with, the various elements of their environment, representing both physical and social components. Secondly, the nurses constitute a component of the *social environment*. The outreach team, on the other hand, represents an external influence to the care facility also interacting with all of its components.

Aspects of the profile of the HD affected residents, particularly their relative *youth*, were shown to have a significant statistical relationship (r =- .51, p = .0001, N =46) with a view of the nurses regarding the *appropriateness* of the accommodation. The more *experienced and educated* the nurses (r = .50, p =.0001, N =46), the *more satisfied* (r =.31, p = .034, N =46) they were with the accommodation. In addition, a small group (n = 11), of predominantly the least

educated nurses, dissented from the majority view regarding the *adequacy of nursing care*. They all reported on the HD affected residents in low care, or hostel settings with lowest staff: resident ratios. Seventy percent of this group of residents were male; they were relatively more mobile than the rest of the sample, and without exception, were reported to exhibit behaviour problems.

Research findings support HD education as a solution to the problem

As part of the overall goal of improving the lives of the HD affected residents in aged care institutions in NSW the identification of evidence-based strategies to overcome identified problems was a major aim of the research under discussion. The following results of the quantitative and qualitative analysis of the nurses' responses indicate the weight placed on education as one of several possible solutions to the problems they had described.

Firstly, with respect to the responses to the fixed choice questions:

- HD nursing was endorsed as *requiring special skills* (95% n = 90)
- Of the 50 respondents who reported contact with the HD specialist nurse, this contact was overwhelmingly endorsed (98% n = 50) as *facilitating better care*.
- With respect to relationships between measures, a statistically significant relationship (χ^2 =6.65, ϕ = .28, p =.010 df =1) was demonstrated (using chi sq tables), between reports of *contact with HD nurse specialist,* and *having HD education subsequent to the admission of the resident.*

This applies to 73% of those who also reported having formal HD education and indicates that specialist nurse contact was associated with education provision to this group.

Secondly, with respect to the open ended questions, content analysis of the responses revealed the following:

- The themes of *HD educational experiences* and *unmet educational needs* were both present .
- A meta analysis of all the themes (n =49) for all open ended questions, indicated that 10% of all these themes dealt with the *need for specialist skills or other resources.*
- In response to the final, optional, question inviting "any other comments", 41% of responses (n = 110) by half the sample of nurses, described the presence of unmet needs for *HD specialist input, education and* (particularly in rural areas), *accommodation*. The number of respondents providing information to this question is above the average (n = 37, range = 17 -62) for the 16 open-ended questions in the survey indicating a significant interest in this topic.
- Evidence of the positive value the nurses placed on HD education and support is provided in their own words.

  One nurse wrote ;*"(We need education) when difficulties arise, if HD residents with severe, volatile aggression are to live with frail, confused elderly."*

  Another, reporting on her experience caring for a 44 year old nursing home resident with both Multiple Sclerosis and HD said : *"Due to frequent turnover of caring staff, ongoing education would be optimal in understanding* [the] *condition and special care needs"*

With respect to the value of these findings, as judged by the widely used Evidence Base Practice framework of the Joanna Briggs Institute (2003), they are presented for consideration as Category II evidence which are judged on the strength of the evidence as described : "Suggested for implementation and supported by suggestive clinical or epidemiological studies or theoretical rationale." On this basis it is argued that the evidence they represent should be considered superior as compared to anecdotal, or tangentially related, writing. The nurses' words direct attention to HD education as a means to reducing the impact of the "Cuckoo in the Nest" phenomenon. Education implies the facilitation of changes which could apply to both the nursing profile and to the care environment. These changes should reduce the impact of the social mismatch (CIN) on the HD affected resident. Therefore, on the strength of what the research described, changes to practice were made.

The translation of the findings into changed practice

Changes based on these findings were made in four areas of practice.

Changed policies included:

- The provision of written information on HD to aged care facilities at the time of the admission of an HD affected resident to the facility
- The conduct of a formal staff education session as soon as possible after the admission.

New education material included:

- The production of a peer reviewed handout : "The story of HD" & "The ABC of the care of the person with HD".
- The collation of articles on HD into a book for limited educational distribution.
- The distribution of HD booklets from the Australian Huntington Disease Association
- The ongoing search for additional material such as relevant videos.
-

Improved education resources included:

- The involvement of local education staff and the use of a data projector for Powerpoint presentations to facilitate the projection of easily
  edited, visually attractive, colored material to enhance learning.
- The use of a digital camera to enhance learning through visual images of best practice methods.
- The content revision of the current presentation following the input of specialist HD residential nurses and literature searches
- The analysis of participant feedback from all education sessions to ensure continuing relevance of content and presentation

Changed education techniques to increase the effectiveness of the specialist input were motivated by ideas from the Problem based learning literature of Freire, (Auerbach & Wallenstein, (1987). In essence, to maximise learning, the leader stimulates the emotional involvement of the participants in the topic. Commenced on a trial basis prior to the conduct of the research, this method was adopted as standard practice based on the research findings.

The aim of these educational sessions was to increase participants' knowledge, change any negative attitudes they held, and assist in the development of achievable nursing goals. This was seen as a way to reduce frustration for everyone, increase job satisfaction for the nurses, and, most importantly, improve the quality of life for the HD affected residents (Healey, & McKay, 1999).

There are indications that these innovations have produced positive outcomes. Firstly there was feedback from the research questionnaires. For example, one nurse said: *"Angela's visit was informative, educational and extremely helpful for our resident / staff/ and family,"* whilst another said: *"The most valuable part was knowing how to help .... more"*.

Then there is the ongoing feedback from the written evaluations to the changed sessions. A sample of responses to the question asking for "the most positive aspect" of the session included:

- 'Asking us the carers questions and personalizing the talk.
- Knowing that it (the situation) will get better and can be rewarding
- Insight into why people behave the way they do
- Being able to understand through the sufferer's eyes
- Understanding their point of view
- Problem solving discussion
- Question time to brainstorm ideas re the patient
- A clear explanation of understanding someone with HD
- Answered all doubts & questions

In the context of the overall positive ratings on the rest of the evaluation questionnaire, the examples are given as indicators of the effectiveness of the sessions in increasing both understanding of the resident, and a commitment to a compassionate search for solutions to the problems that the nurses describe. In short, this is viewed as further evidence of an effective strategy for improving the quality of life of these most vulnerable people.

Theoretical explanations

In addition to that already stated, another explanation for the success of the education format discussed above, is that it enables the HD affected resident to be understood as a human being whose illness, and not some personal failing, is

responsible for the antisocial tendencies and the intractable signs & symptoms. This concept is now developed further. As viewed against the background of the sociological field of deviance, the research findings support the proposition that this shift of attitude may be viewed as the redefinition of the HD affected resident as "accidental deviant" rather than "difficult patient" (Trexler, 1996). According to her theory, which redefines Deviance theory for nursing, this shift of attitude should reduce the stigma and negative treatment, which has been noted in other settings to be associated with being "different." (Breeze & Repper, 1998; Carveth, 1991; Johnson & Webb, 1995; Lorber 1975, Podrasky & Sexton, 1988 and Stockwell, 1972). Furthermore, it is proposed that this concept may also be applied to the "Cuckoo in the nest" phenomenon in aged care facilities in NSW, Australia, to explain the effectiveness of HD education in that setting over the last several years.

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A Fatal Reaction to Phenytoin-Toxic Epidermal Necrolysis (TEN)

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Abstract

Toxic epidermal necrolysis (TEN) is a rare disorder characterised by a blistering and peeling of the top layer of skin. Internationally, the average incidence of TEN is 0.5-1.4 cases per million population per year and mortality is estimated to be 25-70%. It is important for nursing and medical staff to be aware of the signs and symptoms of TEN, as early intervention is essential. This rare condition is explored by outlining the case of a 36 year old woman admitted to hospital with a head injury who died due to the development of TEN caused by a reaction to phenytoin. The causes, clinical features, diagnosis, treatment and complications of TEN are discussed in relation to this case study, and important issues highlighted

Key Words: Toxic Epidermal Necrolysis; Phenytoin; adverse drug reaction

Case Study

Lisa, a 36 year old female, presented to the emergency department with a three day history of headache, general malaise and vomiting. A physical examination revealed 4/5 power in her upper limbs and 3/5 power in her lower limbs. Otherwise no abnormalities were detected. Lisa was haemodynamically stable, with a Glasgow Coma Score (GCS) of 15. She denied any fever, cough, shortness of breath or recent head trauma. Except for a slightly raised white cell count her clinical chemistry and haematology workup were all normal. She had no known allergies.

Within two hours, whilst in the emergency department, Lisa's GCS deteriorated to a score of 10. She was intubated and a cerebral computer tomography (CT) scan revealed that she had bilateral acute on chronic subdural haematomas. A left and right craniotomy for evacuation of the subdural haematomas was performed. She remained haemodynamically stable intra-operatively and was admitted to the Intensive Care Unit (ICU) post-operatively.

Day 1 following surgery a repeat cerebral CT revealed recurrent bilateral subdural collections with associated mass effect and midline shift and she returned to the operating theatre for further evacuation and insertion of a subdural drain. It was at this point that she was commenced on prophylactic phenytoin 200mg twice daily via the intravenous route.

Post-operatively Lisa improved slightly, however on Day 4 her GCS deteriorated. At this stage this was thought to be due to seizures and her phenytoin dose was increased to 300mg twice daily.

Over the next two weeks Lisa slowly improved. She had a tracheostomy inserted on Day 9 and this was removed on Day 14. She was obeying commands and communicating by writing. On Day 15 she was transferred from ICU to the Neurosurgical Ward where she continued to improve.

Twenty-one days following surgery Lisa complained of 'being itchy'. On examination she had a rash over her trunk and limbs. Her temperature was recorded as 39.5^0 Celsius, all other vital observations were within normal limits. The rash was described as "measle-like" and the cause was thought to be a viral infection, drug

reaction or bacterial sepsis. She had not been prescribed any new medications since day 4. A routine septic workup was performed and the infectious diseases team consulted but a source of infection could not be detected despite an intensive investigation.

On Day 23 Lisa rapidly deteriorated. She became hypotensive with a systolic blood pressure of 60, and tachycardic with a weak and thready pulse of 160 beats per minute. These symptoms were thought to be due to sepsis possibly caused by a cerebral abscess or meningitis. The rash remained widespread and appeared to be getting worse and was becoming darker in some places. Lisa was administered intravenous fluids, was stabilised and remained on the neurosurgical ward. Five hours later the patient deteriorated again with a non-palpable blood pressure and whilst being assessed and treated by the medical emergency team, she had a cardiac arrest.

The resuscitation of Lisa at this point was very distressing for staff. Lisa's skin was visibly blistering as they administered treatment. The staff member performing cardiac compressions had layers of skin sloughing off the patient's sternum onto their hands. Skin was shedding off in large sheets whilst staff tried to insert intravenous lines and apply blood pressure cuffs and electrocardiogram (ECG) dots. When an endotracheal tube was passed a large proportion of the patient's bottom lip sloughed off. Every time Lisa was touched the skin from that area would just slide off its original site leaving raw, dark red, oozing areas which resembled burns.

After a review by the dermatology team a diagnosis of "toxic epidermal necrolysis (TEN) most likely secondary to the phenytoin" was made. Microscopic examination of a skin biopsy was consistent with this diagnosis. More than 70% of the patient's total body surface area was involved, in addition to the mucous membranes.

Lisa developed acute pulmonary oedema, metabolic acidosis (pH 6.8), coagulopathies and acute renal impairment. Lisa died seven hours later following two further cardiac arrests. The coroner reported that her death was the result of shock and the cardiac arrest the patient suffered due to TEN, that caused her to develop failure of multiple organ systems.

What is Toxic Epidermal Necrolysis?

Toxic epidermal necrolysis is the most severe cutaneous drug reaction. It was initially described in 1956 by Lyell in four case reports that compared the disease to a scald burn. TEN affects most organ systems of the body. The incidence internationally is between 0.5-1.4 people in every 1 million inhabitants per year with a reported mortality rate of 25-70% (Cohen & Schwartz, 2002). TEN may occur in people of any age, race or sex. For unknown reasons, TEN occurs more often in females than in males, the female to male ratio being 1.6 women to every man who develops TEN (Cohen, et al., 2002; Roujeau, Guillaume, Fabre, Penso, Flechet & Girre, 1990; Ngan, 2004).

What are the causes of Toxic Epidermal Necrolysis?

In approximately 90% of cases TEN is caused by an adverse drug reaction (Guillaume, Roujeau, Revuz, Penso & Touraine, 1987; Fritsch & Ruiz-Maldonado, 2003), although other non-drug causes have been determined. Less than 5% of cases are linked to other causes such as infection, vaccination or graft-versus-host disease (Fritsch, et al., 2003) and in some cases the cause is unknown. The most commonly implicated agents for TEN are antibiotics (especially sulfonamides), anticonvulsants (especially carbamazepine and phenytoin) and non-steroidal anti-inflammatory drugs (Fritsch, et al., 2003; Schummer, Schummer & Kuwert, 2002; Revuz, Penso, Roujeau,Guillaume, Payne, Wechsler & Touraine, 1987). Prophylactic phenytoin was the only drug prescribed for Lisa that was considered a causative agent. The risk of TEN is highest during the first eight weeks of treatment (Rzany, Correia, Kelly, Naildi, Auguier & Stern, 1999), with one report suggesting a mean time from drug intake to onset of TEN of 13.6 days (Guillaume, et al., 1987). Lisa had been taking phenytoin for 20 days before the first signs of the rash appeared, and 22 days before the blistered, sloughing lesions manifested. This scenario is consistent with the 8-week high risk period reported in the literature.

<u>What are the Clinical Features of Toxic Epidermal Necrolysis ?</u>

Two to three days before the actual onset of skin changes, at least half of the patients experience generalised flu-like complaints such as fever, malaise, anorexia, rhinitis, cough, and sore throat. Lisa's

temperature had been elevated and she experienced lethargy and anorexia, which are consistent with symptoms of TEN.

The primary skin manifestation includes a fine, red, tender, burning rash which is difficult to interpret (Schummer, et al., 2002). Rash is a known adverse reaction to phenytoin (MIMS Online Prescribing Information, 2004).

When the skin rash is at its worst it includes formation of large flaccid blisters with necrotic areas that rupture easily and leave large raw patches. The epidermis becomes loose and easily detached, following minimal frictional trauma (Fritsch, et al., 2003). This is called Nikolsky's sign, and is always present with TEN. When lateral pressure is applied the epidermis is seen to separate from the dermis (Cohen, et al., 2002; Schummer, et al., 2002). Lisa experienced a dramatic epidermal detachment to 70% of her body surface area which the literature acknowledges as a 'severe' case.

The oral cavity, lips and eyes are almost always effected (Fritsch, et al., 2003), one study reporting these features in 97% of cases (Revuz, et al., 1987). The oral mucosa especially is susceptible to inflammation, blistering and erosion. Haemorrhagic crusting of the lips is also a common finding (Cohen, et al., 2002) and this was evident in Lisa.

Diagnosis of Toxic Epidermal Necrolysis

It is crucial to acquire a detailed medical history that includes, besides clinical history, the development and time scale of the skin eruption and a list of all applied drugs. In addition to a detailed medical history it is important to confirm the diagnosis by skin biopsy because the skin eruptions are not always obvious. In TEN the skin biopsy is characterised by full thickness epidermal necrosis and detachment (Schummer, et al., 2002).

Treatment for Toxic Epidermal Necrolysis

There are no generally accepted treatment guidelines for active suppression of TEN and no reliable evidence on which to base treatment to slow down the natural progression of the disease (Fritsch, et al., 2003; Schummer, et al., 2002; Majumdar, Mockenhaupt, Roujeau & Townshend, 2003).

Steroids have been the mainstay of treatment in the past, however, several reviews have concluded that steroids do not shorten the disease course, and they produce more medical complications, namely secondary infections (Fritsch, et al., 2003).

Thalidomide is the only treatment that has been tested in a randomised, double blinded, placebo-controlled trial for TEN. This trial was stopped early because of the increased mortality rate in the treatment arm of the study (Majumdar, et al., 2003).

The role of other promising agents such as intravenous human immunoglobulins, cyclosporin, cyclophosphamide, and plasmapheresis remains to be established by controlled, prospective studies. With such rare incidences of the condition, gaining enough power within a study would require multiple sites over an extended period of time.

Withdrawal and discontinuation of the suspected offending drug or drugs is crucial. Other medications that are deemed able to be withdrawn should also be ceased (Schummer, et al., 2002). One study reports that prompt withdrawal of all non-life-sustaining drugs in patients with incipient TEN may reduce the death risk by approximately 30% per day (Kelemen, Cioffi, McManus, Mason & Pruitt, 1995).

The treatment of TEN is supportive (Schummer, et al., 2002) and must be varied to suit the individual's needs (Fritsch, et al., 2003). Impairment of the skin barrier results in massive loss of water and electrolytes and enhances the risk for infection and sepsis which are a major cause of death in patients (Rabito, Sultana, Konefal & Candido, 2001). Therapy includes fluid and electrolyte resuscitation, antibiotics and wound care, as well as aggressive nutritional support, maintenance of body temperature and pain management. Intubation and mechanical ventilation are often necessary (Schummer, et al., 2002).

Lisa required ventilatory support, dialysis, and maximal inotrope therapy to maintain her blood pressure. The dermatologist recommended silver sulphadiazine (SSD) cream for her skin lesions, prophylactic antibiotics and intravenous cyclophosphamide or

cyclosporine. Due to numerous lengthy resuscitations there was no opportunity to administer this treatment prior to her death.

What are the complications of Toxic Epidermal Necrolysis?

TEN can affect almost every system of the body. Internal organ involvement can be severe, most often affected are the respiratory and gastrointestinal tracts (Fritsch, et al., 2003). Pulmonary and gastrointestinal involvement results from mucosal sloughing anywhere along the tracheobronchial tree or mucous membranes in the mouth and digestive tract. Pneumonia is common.

Ocular involvement occurs in 78% of cases (Revuz, et al., 1987). Conjunctival sloughing and other eye problems lead to blindness and occur in 50% of TEN survivors (Haus, Paquet & Marechal-Courtois, 1993). Bacterial skin infections and systemic infections complicate the picture and a majority of patients (70%) develop these (Kelemen, et al., 1995). Genital tract epithelium involvement has been reported in 63% of cases (Haus, et al., 1993). Metabolic alterations, shock, and multiple organ failure are often major causes of death (Kelemen, et al., 1995).

Lessons to be learned

The team of clinicians caring for Lisa were traumatised by this event. Managing a totally unknown condition is always difficult, but one in which the skin came away in their hands became a real challenge. The following lessons were learnt:-

- Don't assume a patient is safely established on a drug treatment plan.
- Expect the unexpected in drug reactions.
- There should be a clear reason for the prescription of any drug.
- Prophylactic use of drugs should be restricted to where there is an immediate need.
- Patients must be observed closely for cutaneous manifestations or complaints within the first eight weeks of treatment by drugs known to cause TEN.
- Clinicians should be aware of the signs and symptoms of TEN, as early recognition and prompt intervention is essential.
- This could happen to any patient that is prescribed phenytoin or any other TEN - causative drug.

Most physicians consider anticonvulsant drug prophylaxis after neurosurgery an expected standard of care. Alternatively, other physicians may not offer prophylaxis routinely, choosing to treat seizures once they occur.

The literature supports the use of prophylactic anticonvulsants in reducing early seizures post head injury, that is seizures occurring within 7 days of the initial injury (Schierhout & Roberts, 2002; Temkin, Dikmen, Wilensky, Keihm, Chabel & Winn, 1990; Anonymous, 2000; Haltiner, Newell, Temkin, Dikmen & Winn, 1999), but there is no evidence that treatment with prophylactic anticonvulsants reduces the incidence of seizures that occur more than 7 days following injury (Schierhout, et al., 2002; Temkin, et al., 1990; Bullock, Chesnut, Clifton, Ghajar, Marion, Narayan, Newell, Pitts, Rosner, & Wilberger, 2000). Therefore it would appear that continuation of prophylactic anti convulsants more than 7 days following the initial injury needs to be considered.

Conclusion

Toxic Epidermal Necrolysis is a rare, life-threatening skin condition that can affect every system of the body.

- It is most often drug induced with phenytoin a known and common causative agent.
- TEN causes extensive blistering and shedding of skin and mucous membranes.
- A detailed medical history and skin biopsy is mandatory to make an accurate diagnosis and discontinuation of the causing agent is crucial.
- Currently there is no specific treatment for TEN and management is concentrated on intensive supportive treatment.

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Abstracts from the 2004 Scientific Meeting

'How far have we come' - changes in Neuro-imaging and the impact on nursing practice.
Lyn Wallace, Monash, Victoria

In the past 30 years enormous advances have been made in Neuro-Imaging. The Radiologist has moved from the reporter of diagnostic investigations to become an integral part of the treatment team. Specialist Neuro radiologists and interventional Neuro radiologists are increasingly treating the conditions our patients present with. This has had a major impact on nursing practice.

This paper explored some of the changes which nursing care and patient management have undergone.

A "then V now" approach was used to identify the quantum leaps made to nursing practice and to the effect on the patient of these newer modalities.

An overview of the impact of follow up and the new "team" structure was discussed. New members of the team include the nursing staff in the angiogram suite, their role and the collaborative approach needed to educate and empower all the members of the team to understand each aspect of the patient journey was explored.

A "where to next" discussion concluded the presentation

Cerebral Tumour Classification: Introduction to Histopathology/ Molecular Genetics
Rochelle Firth, Royal North Shore Hospital, NSW

Cerebral tumour classification historically has been based on systems relating to the presentation and histopathology of the tumour itself. Current classification and grading systems utilised are the St. Anne Mayo scale and most recently and commonly the World Health Organisation tumour classification. Classification of tumours allows the clinician to determine the appropriate treatment and can be used as an indicator for prognosis.

Major advances in neuro-oncology have been through the advances in molecular biology and the genetics of brain tumours. Investigations surrounding the alterations in a tumour genome are increasingly apparent. These advances will have an influence on prognosis of patients but will also be instrumental in planning and developing new treatment options for patients with cerebral tumours.

This presentation reviewed the historical development of current tumour classification scales. Future classification and tumour grading scales will include molecular genetic information. An overview and introduction to tumour molecular genetics was explored and current statistical findings discussed. The role of the neuroscience nurse is important to consider in these recent advances.

Trigeminal neuralgia - 'the worst pain known to man'
Jessy Welby and Fleur Hannett, Capitol Coast Hospital, Wellington, NZ

Trigeminal Neuralgia (TN) also known, as 'tic douloureux' is a disease of the 5th cranial nerve causing pain often described as 'the worst pain known to man'. Patients describe the pain as a sudden sharp, burning or stabbing sensation usually isolated to one side of the face.

The exact etiology still remains unknown, possible explanations are vascular compression, hyperactivity of the trigeminal nerve, trauma or nerve demyelination. Diagnosis is usually based on the patient's description of the symptoms and by complete neurological and dental examinations to rule out a compressive lesion or multiple sclerosis prior to treatment. Patients initially often go to the dentist then bounce from doctor to doctor and the problem may be mistaken for dental or sinus problems, cluster headaches or temporaomandibular joint disorder.

Once diagnosed medical treatment is the initial approach using anticonvulsants. Surgical treatment such as Microvascular decompression (MVD), Percutaneous microcompression, Glycerol injections, Radiofrequency Lesioning and balloon compression is usually reserved for those who find medical treatment unsuccessful. No single treatment is effective for all patients. The aim of treatment is to improve the patient's quality of life by effective pain relief with minimal side effects. TN can have tremendous impact on the patient emotionally and psychologically, hence can lead to depression, poor nutrition and oral hygiene, and work and relationship difficulties.

Understanding, emotional support and education by the nurse is an essential part to the treatment of this disease. In gaining insight and understanding of TN a case study was used to gain a personal perspective on trigeminal neuralgia.

SMASH - Supplemental Magnesium Administration in Subarachnoid Haemorrhage

Dr. Celia Bradford, Rochelle McKnight Royal North Shore Hospital, NSW

Vasospasm remains a significant source of neurological morbidity and mortality following subarachnoid haemorrhage (SAH) despite advances in current medical, surgical and endovascul;ar therapies. There are theoretical benefits in administering magnesium to neurosurgical patients.. Magnesium is thought to increase cerebral blood flow (CBF) and reduce the contraction of cerebral arteries caused by various stimuli. Currently, there is much interest in the use of magnesium (Mg++) as a neuroprotectant and antivasospastic agent.

To date little research has been performed to determine the effect of magnesium supplementation on cerebral vasospasm in humans with subarachnoid haemorrhage. There is minimal data to indicate if this treatment is beneficial.

Therefore a randomised controlled trial is planned at Royal North Shore Hospital to evaluate the clinical cause of patients with Aneurysmal subarachnoid haemorrhage who receive Magnesium supplements.

The aim is:

To determine if maintaining serum magnesium in the range of 1.6-2.5mmol/L as compared with the normal range of > 0.65mmol/L is associated with less angiographic vasospasm and fewer angioplastic procedures following aneurysmal subarachnoid haemorrhage.

Promoting Compliance versus Adherence in Immunomodulatory MS Medication Therapy

Tim O'Maley, Royal Brisbane Women's Hospital, Queensland

The disease-modifying therapies for multiple sclerosis (MS) - interferon beta (Rebif, Avonex and Betaferon) and glatiramer acetate (Copaxone)-are the therapy for managing treatment-related adverse events.

The Immunotherapy Support and Training Program at the MS Clinic Royal Brisbane and Women's Hospital uses a program that supports patient compliance with injectable medication regimes and has demonstrated significantly higher patient retention than those trained outside the clinic.

Extra-pontine neurolysis: A case report

Sharryn Byers, Nepean Hospital, NSW

Extra-pontine neurolysis and pontine neurolysis were not disease processes that were familiar until a young 26 yr old woman came into my care with this devastating diagnosis.

The disease process including pathophysiology, treatment and prognosis will be outlined with reference to a case study. The case study will also outline the difficulties in managing patients with devastating iatrogenic disease processes and the impact on family members.

Australia's first experience with Riluzole used in the treatment of motor neurone disease - the Riluzole early access program

Zoing M, Burke D, Pamphlett R, Kiernan M, Prince of Wales Hospital, NSW

Aim: To provide early access for Australian Motor Neuron Disease (MND) patients to Riluzole and thereby to expand the safety profile data of this therapy.

Methods: MND patients were referred to the program by neurologists covering the Sydney Metropolitan region. To be eligible to receive Riluzole, patients had to be aged between 18 and 75 years and have probable or definite MND with a disease duration of less than 5 years. In addition vital capacity had to be greater than 60% before study entry. Patients gave written informed consent and the study was approved by the Research and Ethics Committee of the South Eastern Sydney Area Health Service. Patients were prescribed Riluzole 50mg twice daily. Safety data were collected through documentation of adverse events in combination with laboratory results. Full blood count, haematocrit, differential white cell counts and serum liver transaminase levels were obtained monthly for 3 months, and then at each visit (every 3 months for 1 year).

Results: In total 25 MND patients (17 male, 8 female; age range 40-74; mean age 59 years) were commenced on Riluzole. Of these patients 28% had definite MND and the remaining 72% were diagnosed as probable. 16% had bulbar onset MND, and the remaining 84% had limb onset MND. At 12 months, 68% of patients continued on Riluzole, 16% had died from their disease and 16% ceased Riluzole related to side effects and for other reasons, including a perceived lack of efficacy. Progressive haematological and biochemical arrays showed no significant alteration during the

12-month period.

Conclusion: Riluzole was well tolerated by Australian MND patients and was listed by the Australian Pharmaceutical Benefits Advisory Scheme in June 2003

Poster Abstracts

Traumatic Brain Injury - A guide for staff, patients and their families.

Diane Lear, Judith O'Brien, Westmead Hospital, NSW

Traumatic brain injury (TBI) has the potential to impose devastating effects on the patient and their family; these may include physical, emotional, psychosocial and vocational impact. The information provided in this poster is to assist the health care team, the patient and their family with a clearer understanding of the causes and management of traumatic brain injury.

Traumatic brain injury results from a variety of physical stressors, including motor vehicle accidents, workplace accidents, falls, physical assaults, sporting accidents and penetrating trauma.

Each year in New South Wales there are more than 10,000 admissions to hospital with TBI. The highest incidence being in the 15 to 39 years age bracket with 70% of this population, male.

The past twelve months at Westmead Hospital saw over 2000 trauma admissions. Of this, 445 patients presented with a head injury, approximately half of this group were classified as having a severe head injury with a Glasgow Coma Score (GCS) of 8 or less (n=212). There were 11 TBI related patient deaths during this period.

The poster will provide staff, patients and their families with an understanding of the physics associated with mechanisms of injury, identification of critical traumatic findings, treatment modalities and brain injury rehabilitation including assessment of post traumatic amnesia.

Information in the poster is not intended to replace individualised discussion with the doctor, nurse or other members of the health care team.

A Pictorial Study of Deep Brain Stimulators in the treatment of Parkinson's disease

Cheryl Trudinger, St Vincents Hospital, Sydney

The majority of Parkinson patients require L-dopa therapy and over time many develop disabling dyskinesias and severe fluctuations that are unresponsive to medical therapy. Surgical therapies can offer properly selected patients hope for significant improvements in their activities when medical options become limited.

Studies have shown that subthalamic nucleus (STN) activity is increased in patients with Parkinson's disease. The STN is a popular target for deep brain stimulation (DBS) in surgical candidates who have severe motor fluctuations dose limiting dyskinesia and other severe medication side effects and or severe tremor. Long term follow up after bilateral placement of STN stimulators has shown significant improvement of motor symptoms.

In patients who respond to L-dopa but have intolerable adverse effects STN stimulators can decrease medication dosages and improve functional status.

Quality of life of caregivers post-stroke

Tracy Desborough, Denis Crimmins, Scott Whyte, Bradley Townend Mary Fitzgerald, Jonathan Sturm, Central Coast Health, NSW

Background: Health-related quality of life (HRQoL) research in stroke has focused on survivors with little attention to caregivers. The limited available data suggest that caregivers with poor physical health, increased strain and depression have worse HRQoL, however other studies demonstrate no change in HRQoL of partners of survivors. Previous studies are small (generally <10 subjects) and there is no HRQoL data on caregivers in Australia. The influence of service utilisation on carer outcomes in Australia is also uncertain.

Aims. To assess:

(a) the impact of stroke on caregiver HRQoL and social relationships.

(b) whether mood impairment in stroke survivors or carers affects carer HRQoL.

(c) the influence of service utilisation on carer HRQoL.

Methods: 120 caregivers of consecutive acute stroke patients admitted to Gosford Hospital assessed with a standardised questionnaire (addressing demographics, co-morbidities, mood, strain, social support, marital adjustment and HRQoL), during the acute hospital stay, and at 3 and 12 months post-stroke. Patient demographics, impairment, mood and cognition is also assessed. The study is linked with a concurrent study in the patient population investigating mood impairment post stroke.

Discussion: Information gained from this study will be used to plan

further interventional studies aimed at reducing burden and improving HRQoL in caregivers. Results of this study have the potential to impact upon the delivery and educational focus of nursing care and the educational tools and strategies used to educate this patient and caregiver population.

Tracheostomies - a guide for nursing care of the trachy patient.

Maureen Edgtton-Winn and Kylie Wright, Liverpool Hospital, NSW

Severe brain injury post trauma, cerebral bleeding and embolism and neurological diseases affecting cerebrospinal fluid flow and neurotransmission may mean that the patient will require an artificial airway. A long-term airway solution is the placement of a tracheostomy tube to either assist with ventilation or prevent airway damage from secretions entering the bronchi and lungs. Tracheostomy placement is hopefully a measure that is used during the acute phase of an illness and may be removed appropriately once the reason for use has been resolved. On occasion, however, tracheostomy placement will remain as a permanent need.

Whether the tracheostomy is for short or long term use this airway maintenance technique requires specialised nursing knowledge and care interventions. Currently, patients may be sent to specialised and non-specialised ward areas depending upon acute or chronic bed availability.

To address the knowledge and care needs of nursing staff, we identified the need for a one-page care resource that provides visual and verbal prompts regarding trachy care.

1. To produce a poster that highlights the basics of nursing care.
2. To identify patient care needs when there is an artificial airway initu .
3. To develop a comprehensive and practical visual aid that meets the knowledge needs of health care professionals and carers of patients with a tracheostomy insitu.

The Acute Stroke Nurses Role in Thrombolysis.

Malcolm Evans*, Michelle Russell*, Angela Royan*, Andrea Moore *John Hunter Hospital, Newcastle, Australia, + Newcastle Mater Misericordiae Hospital

Introduction:

In 2003, the Therapeutics Goods Administration (TGA) licensed the use of t-PA in acute ischaemic stroke. This poster describes the role of the acute stroke nurse in a tertiary level facility for the treatment of acute stroke patients with thrombolysis.

Method:

A team of four acute stroke nurses were trained in the National Institute of Health Stroke Scale (NIHSS) to assess patients presenting to the emergency department with an acute neurological deficit sub three hours since onset. The acute stroke nurses are paged by the triage nurse in the emergency department according to clearly defined criteria found on a decision algorithm. The stroke nurses provide a 24 hours a day, seven days a week on call service. The acute stroke nurse assesses the patient according to pre-determined thrombolytic eligibility criteria, and notifies the on call stroke physician of potentially eligible patients.

Results:

Effective pre-therapy screening of acute stroke patients can be carried out by appropriately trained and qualified stroke nurses.

Conclusions:

The acute stroke nurse is an integral part of the stroke team. They can provide a 24 hour on call service to assist in determining patient eligibility for thrombolysis in acute stroke patients.

"But we were left to cope all alone". Commencing a Brain Tumour Support Group.

K. Wright, S Langford, T Simpson,

The consequences of brain tumours are devastating and these patients and their family members are a vulnerable group requiring immense support and specific needs.

The aim of this project was to provide practical and emotional support to brain tumour patients and their family members. To achieve this goal a neurosurgical oncology team within Liverpool Health Service decided to inaugurate a brain tumour support group where educational sessions could be delivered and the necessary support provided.

A planning team was formed. Support was gained from medical colleagues and hospital administration. "Brainstorming" was used to look at the educational needs of brain tumour patients and their family members. Using the Delphi consensus technique, the team

identified topics and a 10-session program was devised. Participants were recruited via a mail out or on discharge from the neurosurgical ward. A multidimensional questionnaire was developed to monitor and evaluate the program's potential effectiveness to significantly improve the functional outcomes and quality of life of BT patients and their close others.

Well attended meetings are held on a fortnightly basis and cover the planned topics, generating fruitful discussion and question asking. Planning for the commencement of the group took 2 months and the group is currently ongoing due to its popularity. Participants have highlighted benefits gained from the meetings and have reinforced the necessity for continued support.

Objectives - The objectives of forming this brain tumour support group were:

To cater for the special needs of people with Brain Tumours and their families by:

- further developing a persons knowledge of brain tumour,
- providing a setting that encourages supportive discussions about brain tumour/cancer
- offering a forum for people to meet and learn from others who have similar experiences
- building on a persons coping skills and to provide this group at a local level, accessible to the people of South Western and Western Sydney Area Health Services.

COMING IN THE APRIL ISSUE !

Basics facts about neurons

Review of the literature: Treating head injured patients with induced hypothermia

Case study of a child with an arteriovenous malformation

Assessing comfort in the patient with altered consciousness

New neuroscience nursing research

Historical review: Intracranial pressure

Historical Review: Measurement of blood pressure and Cushing's Triad

Jennifer Blundell: RN B.App.Sci (Nursing), Grad.Dip.Ed., PhD

Hypertension is the medical term used to describe an above normal measurement of the pressure of blood on the walls of the arteries of the body. Today measurement of blood pressure for diagnostic and evaluative purposes is a normal component of medical and nursing care. Furthermore measurement of blood pressure may be included in assessments performed by others such as fitness trainers as well as people measuring their own blood pressure.

It is unclear exactly when the term hypertension came into general use in medicine. Tension as a descriptor was one of the characteristics, along with rate, rhythm and volume that were traditionally assessed by Palpation of the pulse prior to the development of instruments able to measure blood pressure.

Development of instruments to measure blood pressure

Early attempts to design an instrument that would measure pressure in arteries were related to measurement during research studies on animals. A number of devices, many too unwieldy for clinical use, started to come into being during the 1800s. These included the sphygmometer (Jules Herisson, 1833); the sphygmoscope (Scott-Allison 1938); the sphygmograph (Dudgeon 1882). Marey (1830-1904) was the first to design an instrument for use in clinical practice, the sphygmograph (Cameron & Hicks 1996).

This instrument was modified by a number of persons. Mahomed, while a student at Guy's Hospital in London, modified it further to allow him to measure the blood pressure in patients over a number of years (1870-1881). He established a relationship between an elevated blood pressure and renal damage, and gave the first description of essential hypertension (Cameron & Hicks 1996).

These measurements were of the systolic blood pressure through obliteration of the radial pulse. In 1901 Harvey Cushing returned to the United States of America from Italy bringing a version of what we know as the blood pressure cuff. He encouraged use of this by medical officers at John Hopkins Hospital in Baltimore (Crenner, 1998).

Henry Cook and John Briggs, two of these medical officers supported wider use of the cuff to measure blood pressure. However they tailored their championship of the new approach in different ways for different audiences. In a 1903 paper published in a journal whose readers were predominantly physicians working in the community the use of the blood pressure cuff was presented as an adjunct to the traditional method of pulse palpation. However in a 1903 report to John Hopkins Hospital Cook and Briggs argued for the replacement of the inaccurate palpation method by the blood pressure cuff (Crenner 1998).

In the same year Cushing in a talk to the Harvard Medical School in Boston proposed that use of the blood pressure cuff allowed the gathering of 'standardised quantitative data' in the same way that the watch and thermometer were used to measure pulse rate and temperature. He saw that measurement could be performed by persons other than medical officers, such as nurses, with the data then interpreted by the physician. This proposal raised concerns about how the measurement by nurses using the cuff might "reflect on the physician's practice of assessing the tension, size, force, and duration of the pulse"(Crenner 1998 p 491)

A clinical trial in three hospitals was commenced, with one of the sites using nurses to measure blood pressure using the cuff. The outcome demonstrated that the cuff measured blood pressure but as it validated information collected by the traditional methods, rather than providing new information about the patient was not accepted (Crenner 1998)..

However the report from the site at Massachusetts General Hospital noted that when the cuff had been used on patients with brain injury it had detected cases where there was a decrease in pulse rate and an increase in the blood pressure. This set of circumstances later became known as part of the Cushing Triad.

The widespread use of BP measurement by use of the cuff and pulse obliteration did not occur at this time. Special skill was required to perform and interpret such measurement, and some felt that it was dangerous to rely on this rather than the traditional palpation of the pulse.(Crenner 1998)

It was the introduction a few years later of the stethoscope, an instrument that allowed systolic and diastolic blood pressure to be measured by auscultation, that saw the marriage of the two instruments to measure blood pressure and by 1910 part of the physician's repertoire (Crenner 1998).

However although Cushing had seen measurement of blood pressure using the cuff as something nurses could do this skill remained the perogative of the physician until 1930 when it started to be incorporated into nursing practice, although not as a regular component of nursing assessment until the1960s. Crenner (1998) suggested that the use of lightweight and colourful materials in the manufacture of stethoscopes marketed for nurses was to ensure that they were distinguished from the more serious heavy, black stethoscopes physicians used.

Today neuroscience nurses are conversant with the observations that Cushing and his colleagues noted that are an indicator of increasing intracranial pressure. Modern technology allows much more specific measurement of varying vascular pressures in the body and nurses assess the trends of these measurements as a routine component of care.

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