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Editorial

Guest Editorial

Changing of the Guard and ANNA President's Address

Linda Nichols
Editor

Stepping into big shoes is never easy, as I can attest. Since I have taken over as editor I have tried to continue on where Vicki left off and to maintain the high standards she set.

I am sure that I am not alone in feeling like this, however like the other roles I have fulfilled on the ANNA committee my transition to editor was seamless and incredibly well supported.

Catherine's award winning presentation on mentoring at the ANNA conference in Wellington encapsulated what so many of us have experienced informally though ANNA and I am looking forward to seeing this process formalised so that we can enable the next generation of nurses to engage in leadership positions. I have been so privileged to have been a part of ANNA and would not have achieved what I have without the support of the committee members past and present.

With this in mind I wish to introduce our two new committee members. Leigh McCarthy will be taking up the role of Vice President and I look forward to seeing her skills, vibrant personality and can do approach applied in this role. Diane Lear is also joining us as president. Diane's skills and familiarity with ANNA having been a long term active member will bring a wealth of new ideas and collaborative partnerships.

Debbie and Jeanne will not be travelling far with Debbie continuing as the WA delegate and Jeanne staying to guide and assist, particularly with the preparations for 2021.

Diane Lear
President

It is an honour to be elected as the Australasian Neuroscience Nurses Association President at the annual conference in Wellington, New Zealand thus giving me the opportunity to lead ANNA over the next 3 years. I assure you I am dedicated to neuroscience nursing and will be committed to the role of ANNA President.

I have been a neuroscience nurse for over 30 years, and have been working in the role of Clinical Nurse Consultant at Westmead Hospital for the majority of that time. Those of you from NSW would know I am also currently the Neurosurgical Nurses Professional Development Scholarship Committee (NNPDSC) Chairperson.

I would like to take this opportunity to thank the outgoing President Jeanne Barr for her exceptional hard work, dedication and passionate and inclusive leadership of ANNA over the past 3 years.

I would like to reflect on the vision of ANNA. ANNA has a great history spanning over 45 years. The World Federation Neuroscience Nurses (WFNN) was established in 1968 with the first ANNA conference being held in the nation's capital, Canberra in 1974 with 30 nurses in attendance. ANNA is the peak body for neuroscience nurses to facilitate and foster the advancement of neuroscience nursing thus enabling optimal patient centred care. Although neurosciences is a relatively small specialty, as nurses we have the power to influence and drive change by working together. Together we can continually strive to build a better and safer environment and provide the best standard of care to our patients whilst advancing our organisation and profession.

A huge thank you to both Jeanne and Debbie for their work, commitment and contributions over the last three years.

It is an exciting time ahead with a symposium in Sydney next year, the conference in Melbourne and the WFNN Congress in Darwin 2021 and I look forward to working with both the members and committee to see ANNA continue to grow.

Next year we also celebrate the 'Year of the Nurse and Midwife" and ANNA is looking forward to celebrating this time and continuing to network and share our knowledge and skills both at the annual conference and through the AJON.

Linda

Linda Nichols
Editor

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One of my key areas of focus over the next 3 years is to increase the relevance of ANNA to our neuroscience nurses so that we can continue to foster growth, collegiality and learning whilst continuing to grow our membership. As a professional organisation we need to connect our members with each other to learn from one another and develop skills and opportunities as well as foster networking and discussion. Our Treasurer Catherine Hardman will be implementing a mentor program in 2020 to provide an opportunity to early career neuroscience nurses as well as an opportunity for more experienced neuroscience nurses looking to give back. The committee are also looking to seek other ways to strengthen the connections we have with our members.

The World Health Assembly has officially designated 2020 as the "Year of the Nurse and Midwife" in recognition of the 200th anniversary of the birth of Florence Nightingale. I look forward to sharing this wonderful celebration with you all at the next ANNA conference in Melbourne, Australia.

I would like to once again thank you for your support and I look forward to working with the committee and members in guiding the association over the next 3 years.

Diane

Diane Lear
President

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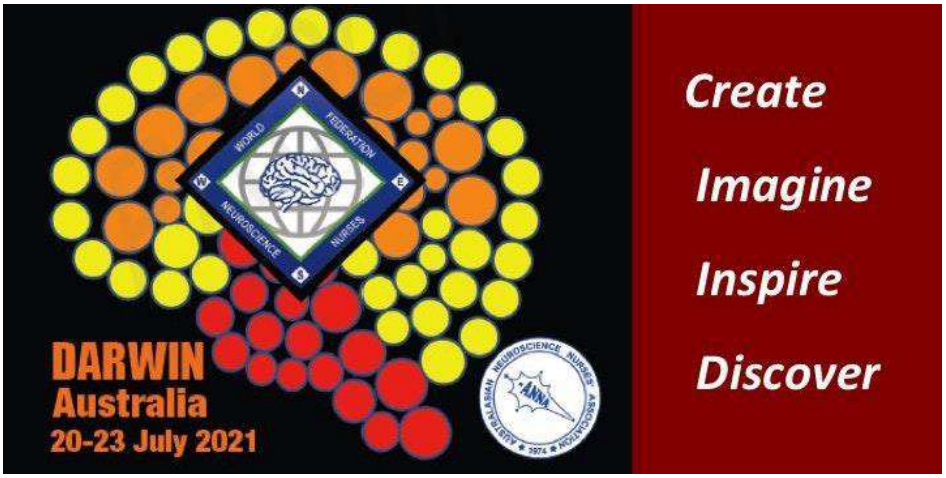

Intuition & the Expert Neuroscience Nurse

Vicki Evans [1].

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Abstract

Personal knowledge is a process whereby practice and research evolve simultaneously. Therefore, knowledge evolves with practice. It is a personal process, thus it creates a difficulty when identifying appropriate research methods of objectivity and analysis. Many researchers discount intuition as it is not an analytical process and cannot be studied. Rather, it is associated and absorbed through experience. Expert nurses integrate both intuitive knowledge and scientific development of intuitive skills, thereby enhancing the quality of practice. Today, scholars are beginning to understand the importance and value of expert intuition, especially in the neuroscience arena. It is this personal knowledge and intuition of expert neuroscience nurses that is the focus of this paper.

Key Words

Intuition, expert nurses, advanced practice nurse, neuroscience

Introduction:

Foreknowledge is formed by theory, principles and prior experience. Expert nurses or advanced practice nurses, foster intuitive knowledge, an understanding without rationale. It is based on background understanding, skilled clinical observation and is related to the theoretical structure of nursing through the concept of pattern. Pattern involves consideration of the total person–environment interaction. It is central to several theorists including Rogers, Newman and Parse.

Intuition, in the past, has rarely been given legitimacy as a sound approach to clinical judgement. Instead, it has been viewed as guess-work, unfounded knowledge or irrational acts. Expert nurses often speak of 'gut feelings' or a 'feeling that things are not quite right'. These feelings are unexplained on paper – perhaps a perfect score on the Glasgow Coma Scale, but the 'gut' tells the expert nurse otherwise. This makes quantitative researchers uneasy, as these perceptual ideas must move to conclusive statistical evidence. However, it is through experience and anecdotal evidence that the expert nurse has shown time and again that intuition and 'gut feelings' are real and should not be dismissed.

Today, there is the move towards advanced practice nurses, clinical nurse specialists, clinical nurse consultants and nurse practitioners. These positions possess skills far beyond text book knowledge. Advanced practice nurses are recognised as registered nurses who have acquired the expert knowledge base, complex decision making skills, and clinical competencies for expanded practice (Tymianski, Sarro & Green, 2012). Skills through experience, critical thinking and volunteering add great value to their knowledge base. Intuition, also, is an essential component of complex decision-making for the expert nurse.

In differentiating the novice nurse from the expert in clinical practice, the intuitive grasp is acknowledged (Lyneham, Parkinson, Denholm 2008). Ethical dilemmas, expert nursing and the ability to recognise and predict behaviour based on ambiguous signs, require applications of intuitive knowledge. Nursing practice involves multiple ways of knowing patients. There is a need to accept more than one mode of thought and emphasise the value of intuition in nursing. Clinical knowledge is gained over time and clinicians are often unaware of these gains. Interpretive description of actual practice uncovers this clinical insight (Ruth-Sahd, 2014; Rew & Barrow, 1987).

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Neuroscience:

Neuroscience is a specialised area of practice. Neurological illness often influences behaviour, either as a result of trauma, or due to pathophysiological changes within the brain itself. Patients with neurological illness present unique challenges to neuroscience nurses. Making sense of nursing observations and neurological assessments are key factors in determining the best care for the patient. The ability to recognise and comprehend subtle signs before they manifest into morbid outcomes, is the skill of the expert neuroscience nurse. Prioritisation of events is particularly important. The expert nurse will prioritise actions, events and observations, thus permitting a fluent performance in patient care. Skilled observation is noted as an expert appraisal. In neuroscience, the subtle changes give valuable information about the level of brain involvement, nature of involvement and the direction of the disease process. It is a pattern to be recognised. The expert neuroscience nurse is able to assess and interpret these findings and plan an appropriate course of action.

Expertise had not been adequately described in nursing until theorists such as Benner, Parse and Rogers commented in the 1980's. Their views acknowledged and supported the notion that expert nurses utilise intuition in daily patient care. This fosters the idea that expert neuroscience nurses are pivotal in both teaching and caring for the patient and family.

Nursing observations, like measurements, involve construction as a process of knowing. By observing and noting phenomena, the neuroscience nurse is constructing patterns and variables (Rogers, 1970; Newman, 1986). It is through this observation that the expert nurse becomes aware of the construction process, which involves separating variables from their unity. Explained further, this means that observations (vital signs and Glasgow Coma Scale) are taken from the patient and analysed together to form a picture in time. Valuing the observations taken, the nurse forms a picture of how that patient is progressing or deteriorating. Cowling (1993), suggests that the process of profiling the phenomena, rather than assessing the person, is more congruent as a constructing process. Variables are compared with one another. There is a search for an overriding theme. Rogers (1990) and Parse (1987), suggest that pattern recognition, or clusters of behaviour, are important; yet, eventually must be interrelated with the whole. The assumptions of the skilled nurse are that these variables are in unity and have significance for nursing in their unity, as well in their separateness. The construction of observations is what becomes critical in neuroscience nursing practice. The ability to recognise subtle changes, as in degrees of consciousness, before more devastating signs appear, is of utmost importance (Hickey, 2014).

Theorists:

Nursing practice has been theory driven. Several nurse theorists acknowledge nursing's knowledge base, using a specific form of the nursing process (Speziale, Streubert & Carpenter, 2011; Rogers, 1970, 1994; Parse, 1981, 1987; Roy, 1984; Orem, 1985, Barrett, 1988; Taylor, 1991). The framework of such theories has led to specific modes of practice within the knowledge-base of nursing (Mitchell, 1992). It can be acknowledged that when nurses enter a practice situation, fusion of knowledge from life-long learning experiences, as a well as the structure of knowledge of the discipline of nursing learnt through education and training, is utilised.

Rogers' *Science of Unitary Human Beings,* is a particular lens through which to view the universe. Rogerian ontology supports holism, in that the human and the environment are integral and in mutual, forward processes at all times. It is therefore assumed that humans can never go backwards. That is, learning through experience takes place and one never walks the same path twice (Lutjens, 1991). Nursing as an art and a science gained popularity in the 1980's (Pearson, 2013). Nursing care has both an aesthetic and scientific component (Tettero, Jackson & Wilson, 1993). Parse (1992), compares nursing to the performing arts - the nurse is the artist who "...unfolds the meaning of the moment with a person or family consistent with personal knowledge and cherished beliefs." (Parse, 1992. p.147). It is this personal knowledge that enables each individual nurse to practice and synthesise care in a unique way.

Neuroscience nursing has largely been led by the Americans. The founders of the American Association of Neuroscience Nurses (AANN) Agnes Marshall-Walker and Barbara Therrien were strong leaders in neuroscience. In the late 1960's, they led by example and were visionaries for neuroscience nursing, stating "Our future is determined by the attitude we take" and "Tomorrow will be an era born of today and yesterday". Agnes stayed a strong encouraging voice for neuroscience nurses and was active in the AANN and World Federation of Neuroscience Nursing (of which she also founded in 1969), until

her death in 2010. Since then, the AANN and many other neuroscience professional associations, including the Australasian Association of Neuroscience Nurses (ANNA), have led the way, improving neuroscience nurse education and facilitating a supportive platform for the specialty to grow.

Intuition debate:

Intuition is defined as an irrational unconscious type of knowing. Negative responses have been evoked when referring to intuition (Benner & Tanner, 1987; Rew & Barrow, 1987; Young, 1987). Intuition has been viewed as irrational acts, guesses or hunches. It is the "black-market version of knowledge" (Benner & Tanner, 1987, p.30). Rational data gathering is seen as the principle way to gain knowledge (Young, 1987; Correnti, 1992). Therefore, intuitive perceptions have been seen as opposing this empirical factual knowledge base. Benner & Tanner (1987) suggest that intuitive knowledge and analytic reasoning are not in opposition, rather, they work together. Lester (1993), surmises that intuition is not a mystical sense without foundation. It is a

> *"... means of higher cognition which can be used to improve personal and professional performance…*" (Lester,1993. p.7).

In trying to give more credence to nursing intuition, a descriptive phenomenological study was undertaken by Hassani, Abdi, Jalali & Salari (2016). It looked at a limited number of Intensive Care Nurses and their understanding of intuition. The findings revealed that the more interested the nurses were in their patients and their conditions, the more their intuition flowed. It gave the opportunity to discuss their experiences and reaffirmed that their intuition should be followed.

Personal Knowing:

Components of personal knowing include experiential knowing, interpersonal knowing and intuitive knowing (Moch, 1990). Personal knowing is related to the theoretical structure of nursing through the concept of pattern (Moch, 1990). Pattern, a central theme also to Rogers (1970), Newman (1979, 1986) and Parse (1981), involves consideration of the total person-environment interaction. Each nurse-patient encounter influences and enriches both participants and brings about a pattern for knowing each-other.

> "*Objective information can be transferred; personal knowledge can only be evoked."* (Moch, 1990. p.169).

Personal knowing is described as the discovery of self-and-other arrived at through reflection and synthesis of perceptions and connecting with what is known (Moch, 1990). There is an unavoidable act of personal participation in the nurses' individual knowledge. Knowing may be tacit or verbally inexpressible, but articulated through the nurses' practice. It is this personal knowing that is essential to the development of the practice of expert nursing.

Moch (1990), describes intuition as an act of indwelling, something from within the self. Perceptual awareness is pivotal to nursing judgement that

> *"…begins with vague hunches and global assessments that initially bypass critical analysis; conceptual clarity follows more often that it precedes."* (Benner, 1984. p.xviii).

Benner (1984) suggests that experts do not stop at hunches or vague feelings. Neither are they ignored. Vague feelings are the medium by which early identification of deterioration and the search for confirmatory evidence are expedited.

Experienced-based skill acquisition is safer and quicker when it rests upon a sound educational base from which to build (Rogers, 1970; Benner, 1984). The Dreyfus Model of Skill Acquisition, which Benner attests to, states that the student passes through five levels of proficiency: novice, advanced beginner, competent, proficient and expert. However, expertise may not be attained by all, and that is reasonable. Kuhn (1962; 1970) observed that "knowing that" and "knowing how" are two separate kinds of knowledge. Experience does not necessarily refer to longevity in a position. Rather, it is an active process of refining and changing preconceived ideas when applied to specific situations. Notwithstanding, experience is a requisite for expertise. An expert nurse would problem-solve differently from that of a beginner. This can be attributed to the know-how acquired through experience. The expert nurse

> *"… perceives the situation as a whole, uses past concrete situations as paradigms, and moves to the accurate regions of the problem without wasteful consideration of a large number of irrelevant options ..*" (Benner, 1984. p.3).

Expert neuroscience nurses:

"*Neuroscience nursing is in constant evolution, as research, science, and experiential knowledge add to our practice base as neuroscience nurses"* (Tymianski, Sarro & Green, 2012 p. iv).

Expert neuroscience nurses recognise subtle physiological changes. It might be a subtle change to conscious state, a little more vague than previously, yet still scoring 15/15 on their GCS. The expert neuroscience nurse knows that this subtlety is a mark of concern. Similarly, 'crow's feet' are a great sign of age, yet when one side disappears the expert nurse knows that this is a sign of a facial weakness. These finely tuned abilities come from many hours of direct patient observation and continual assessment.

"...Descriptive and interpretative recording of this connoisseurship uncovers clinical knowledge…" (Benner, 1984. p.5).

Benner (1984; 1987), addresses knowledge embedded in clinical practice. Each nursing encounter provides opportunities to acquire knowledge about self-and-other. Learning is achieved through self-observation, observing others, through feeling and sensing. Perspective is acquired through intense interaction with others. This interpersonal process is the cornerstone of nursing.

A characteristic of expert nurses is that time is spent thinking about the future course of the patient. Experts will anticipate what may arise and the course of action that maybe required (Sheer & Wong, 2008). Benner (1984) surmises that the expert no longer relies on an analytical principle, rule or guideline to interrelate the patient and current situation with appropriate action. The expert has an intuitive grasp and zeroes in on the accurate region of the problem (Lyneham, Parkinson & Denholm, 2008).

Capturing the descriptions of expert behaviour is difficult, as the expert functions from a deep understanding of the whole situation. When expert nurses intervene in patient care *"...some of the knowledge embedded in their practice becomes visible. And with visibility, enhancement and recognition of expertise becomes possible."* (Benner, 1984. p.36). The expert is able to create order amidst the chaos, manage well in crisis, be aware of the total picture and recognise the team as an integral part of their effectiveness. People who have a gift for gardening are sometimes described as having a 'green-thumb'. Likewise, as outlined by Jensen, Back-Pettersson & Segesten (1993), some nurses possess a 'green-thumb' for nursing. They are a role model to look up to and to emulate.

Throughout history, the nurses' role as observer and assessor was emphasised. An excellent and innovative example of neuroscience authorship in the modern era is the work of Professor Joanne V. Hickey. Hickey operationalized the role and knowledge-base of the neuroscience nurse (Strength, 1993). Today, she remains involved in neuroscience university teaching in Texas. Her books continue to be utilised in neuroscience nursing education and are a great current resource, having been revised many times.

Recovery from neurological impairment hinges on meaningful acts of connection. Looking at life through the patient's or family's eyes. This gives empathy towards the patient and how the relatives may be feeling. It also encourages personal empathy within the nurse. Expert nurses often gauge a patients' response by reading bodily cues, seeing the nuances of expressions. Recording baseline and frequent observations is critical in evaluation of patents and change over time (Hickey, 1986; 2016). The ability to observe, without machines and to make sense of what is seen, is a skill that expert neuroscience nurses possess. Continuous comparison of current to preceding findings is essential in neuroscience, since the degree of change can be rapid and dramatic or subtle and innocuous (Hickey, 1986; 2014). Oedema and rebleeding in the neuroscience setting cannot be compared with oedema or rebleeding in other body systems. The Monro-Kellie Hypothesis confirms that the skull is a rigid box in which the brain, cerebrospinal fluid and blood exists. There is only one "exit" from this box - through the foramen magnum. Therefore, if oedema or bleeding occurs, intracranial pressure increases and mortality concerns are real.

"…perhaps in no branch of medicine can a nurse be so helpful…as in the care of brain cases. I want to impress upon my readers, the absolute necessity of observing carefully each patient, in order that no transient incident may be lost …" (Dwyer, 1920 p.163).

Although this quote was written almost 100 years ago, the skill of observation is just as important then as it is now, and it is the foundation for neuroscience nurses to build upon (Hickey, 1986; 2014).

Conclusion:

Nursing theorists of the 1980's encouraged the validation of intuition in expert nurses. Intuition is recognised as a component of the perceived view of science and a legitimate way of knowing in nursing. Most sound nursing judgements are grounded in intuition. It is important to recognise it as a process of synthesis and to avoid the mistake of devaluing intuitive judgement. Nurses bring with them to each situation, their life-long experiences as well as the structure of the discipline of and knowledge-base of neuroscience. As nurses reflect on intuitive knowing, they will individually and collectively, come to appreciate its value and express it in daily practice.

Patients present patterns of responses that expert nurses learn to recognise. Neuroscience nurses are the first to detect early changes in the patient's condition. This is based on thorough knowledge of the patient, specialty and clinical expertise. The nervous system is the most central to our functioning as human beings. Therefore, evaluation of nervous system functioning underpins all aspects of nursing assessment. It requires no tools, apart from the knowledgeable observations of the nurse. Expert nurses are able to identify problems early, set priorities quickly and delegate responsibility where appropriate. Keeping up-to-date with advances in technology and current treatment is paramount in neuroscience nursing. Professionalism and belonging to professional groups will cultivate 'cross-pollination' and will expose nurses to best practice scenarios. Learning from others in local, national and international arenas will expose the nurse to other opportunities and experiences, building upon knowledge and moulding their expertise.

Previous concrete experiences guide the expert in recognition and action. Commitment to the future roles of nurses can develop only in an atmosphere of mutual respect. The organisational framework required to support professional nursing practice and promote expert neuroscience nursing services, must be tightly bound by a shared culture, yet loose enough to promote innovation.

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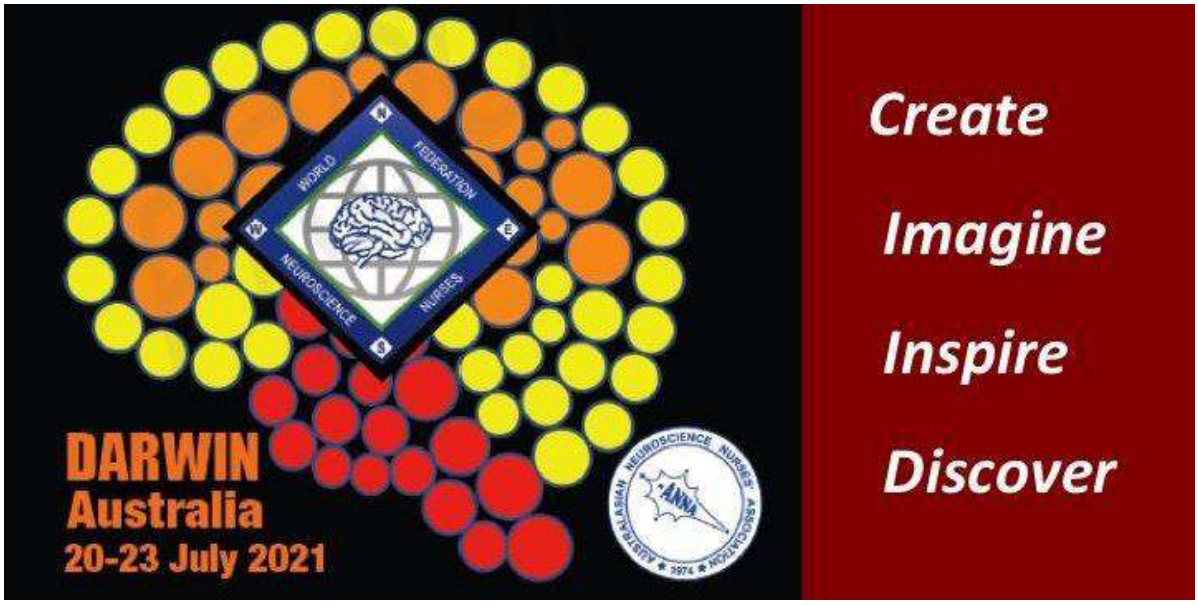

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The Circle of Willis, Aneurysms and Subarachnoid Haemorrhages: a Historical Narrative of Parallels from Observation to Intervention.

Linda Nichols

School of Nursing, University of Tasmania,

Abstract

The history of aneurysmal subarachnoid haemorrhage (aSAH) is far from modern, spanning close to 5000 years. There are many parallels and references to epidemiological principles that remain current today and are central to modern nursing research techniques. The importance of epidemiology in nursing cannot be overestimated, nursing practice closely aligns with the ultimate goals of epidemiological principle in the promotion of health and reduction of disease related risk factors. Despite nursing holding the conceptual key to enriching epidemiological research, nursing has historically distanced itself from front line epidemiological research, often hesitant about both capability and clinical expertise in leading epidemiological research. The following historical narrative serves as a reminder of how far we have come in the diagnosis, treatment and care of individuals post aSAH as well as serving as inspiration for future nursing research.

Key Words

Circle of Willis, Aneurysm, History, Subarachnoid Haemorrhage, Nursing

Introduction:

Early descriptions of cerebral aneurysms can be found by an Egyptian chancellor, who was glorified and deified to that of the God of medicine healing only to be rewritten in history as an evil mummy. The Old Testament and the writing of Hippocrates in the Greco-Roman period provide further evidence, with the medical observations and writing of a Greek physician becoming the mainstay of medieval medical practice. The 17th century saw the English civil war and a physician whose resilience and dedication in seeking to understand function of the basal arterial circle would have his name immortalised forever.

In the 18th century, autopsy observations and descriptions of the moments proceeding the ictus of aSAH's provided clear evidence of the mortal nature of aSAH. This included a trio of early and sudden deaths included a Duke, a Prince and the untimely death of the Crown Prince that would change the course of the Swedish Royal family forever. It was not until 1931 that a cerebral aneurysm was first successfully secured using ether anaesthesia and muscle taken from the patient's leg. Six years later at Johns Hopkins Hospital in America, the first successful surgical clipping of a cerebral aneurysm occurred. Surgical clipping continued to evolve however it was not until the late 20th century that the second major innovative development in intervention post aSAH occurred that would change practice thereafter. Rich in parallels from the early observational studies and describing the journey to current practice, this historical preamble demonstrates the resilience and determination of previous researchers and also the links to the core conceptual frameworks and epidemiological observations that are still applied to this day.

Questions or comments about this article should be directed to Linda Nichols
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Antiquity:

It is impossible to trace the understanding of cerebral aneurysms and subsequent aSAH, with exact certainly. As noted by Thomas Sydenham

'*can no investigator point out the origin of Medicine- mysterious as the source of the Nile. There has never been a time when it was not*'
(Sydenham, Medical Observations cited in, Sydenham et al., 1848)

Subarachnoid Haemorrhage is a disease of great antiquity with many references in classical literature and ancient writings (Walton, 1955). Whilst the origin medicine is unknown, the Nile is linked to what is perhaps the first description of a cerebral aneurysm that dates back to 3000 years BC. Imhotep, who in life was an Egyptian chancellor is described by some as being the founder of Egyptian medicine. However, it was not until 1,200 years after his death that he was deified to the status of the God of medicine and became the centre of a popular cult (Short, 2009). Despite there being little evidence to support his practice as a physician, he is believed to be the author of section 872, column 108/3-9, found in the Ebers papyrus that describes a globular and firm pulsating swelling of a vessel and the treatment employed using cautery (De Mouliln, 1961). It is perhaps ironic that the image of Imhotep was again rewritten by the motion picture industry to be an evil mummy.

A number of references to neurological function and disorders are contained within the Hippocratic Corpus (Pearce, 2006). Whilst it is impossible to determine the authorship of specific sections with any certainty, as the collection includes around 70 medical treatises (Freed, 2011), Hippocrates is cited as having authored several key neurological observations. The description of people in good health suddenly seized with pains in the head, fatality succumbing to their illness within seven days (Aphorisms of Hippocrates cited in, McHenry & Garrison, 1969), is suggestive of a subarachnoid haemorrhage (Iniesta, 2011), perhaps more significant is the language and tense that is indicative of this being a common observation. Some note this as only suggestive of a subarachnoid haemorrhage (Milinis et al., 2017). However the emphasis in the Hippocratic Corpus on clinical observations, prognostic indicators and epidemiological conclusions are still supported by the literature to this day. In his aphorisms on apoplexy, Hippocrates notes that apoplexy was most common between 40 and 60 years of age, identifying numbness as an impending symptom, and describing sudden and spontaneous headaches and a loss of consciousness as being associated with a poor prognosis (Aphorisms of Hippocrates cited in, Pearce, 2006).

Written around 550 BC during the Babylonian Exile, the Second Book of Kings presents another reference in history to a subarachnoid haemorrhage, with a description typical of the onset of symptoms and rapid demise.

'*And when the child was grown, it fell on a day, that he went out to his father to the reapers. And he said unto his father: "My head! My head!" And he said to a lad, carry him to his mother. And when he had taken him, and brought him to his mother, he sat on her knees till noon, and then died*'
(Second Book of Kings 4: 18-20).

This text represents a complex and cryptic script that is contradictory in describing a male child grown, yet sat on his mother's knees. Applying contemporary knowledge of age and sex characteristics of subarachnoid haemorrhages, this reference is arguably suggestive of a ruptured arteriovenous malformation. However, despite the description being typical of a subarachnoid haemorrhage some dispute it as being unlikely (Milinis, Thapar, O'Neill, & Davies, 2017), while others accept it as a likely reference (Pearce, 2006; Walton, 1955).

Six centuries after the birth of Hippocrates, the writings of Galen of Pergamon would provide another milestone in the evolution of neurosurgery (Caplan, 2015). Galen wrote numerous treatises on human anatomy (Missios, 2007) and whilst many of Galen's writings were lost in the great fire of 191 AD, samples of his works survived (Ustun,

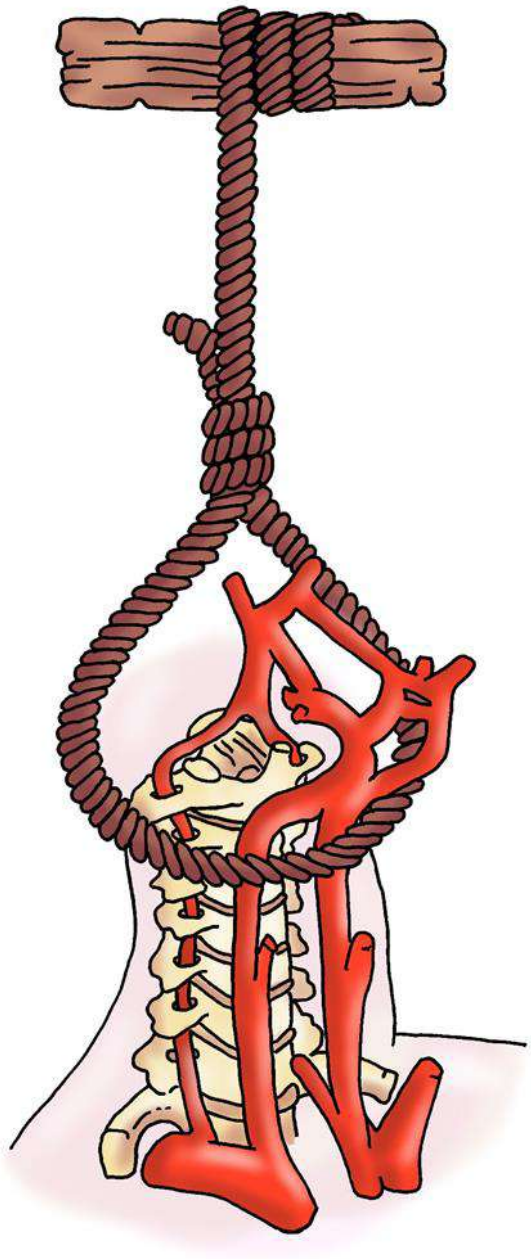
2004b). Considered an authority on anatomy, Galen wrote of an artery that has become anastomosed and named the affection an aneurysm (Milinis et al., 2017), (Greek aneurysma, a widening; from anu, across; and eurys, broad) and importantly he recognised the two distinct entities of arterial aneurysms (Missios, 2007). Galen advocated for evidenced based practice and the use of proven principles and logical progression in the gain of new medical knowledge (Magnus, 1927). What is valuable to note about both Hippocrates and Galen is that they studied and documented geographic, demographic and epidemiological features (Missios, 2007), many of which remain the focus of modern research. Whilst little was known about the nature and the conditions they described, their writings demonstrate an awareness of preventative and general health measures.

17th Century and a New Era of Understanding:

The 17th century saw medicine in its infancy and the beginning of the establishment of medical specialities. With this new era of modern history of aSAH paralleling that of the history and development of neurosurgery (Swash & Wilden, 2006). It also saw a distinct separation in the practice of medicine, with physicians such as Thomas Sydenhan advocating for clinical descriptions and bedside observation of individual diseases (Bhattacharyya, 2011). At the same time the introduction of autopsies into England was gaining social acceptance (Harley, 1994). One physician who was to utilise this practice to increase the knowledge of others was Thomas Willis. Born in 1621, Willis was educated in Oxford, at Christ Church College (Caplan, 2015), with his studies interrupted by the English Civil War of 1641–1647 and the siege of Oxford (Uston, 2005). It was during this time, and his service as a volunteer with the Royalist army, that he first became exposed to experiential science. The civil war affected medicine profoundly and the study of anatomy benefited from the end of censorship and the retreat of intellectuals to post-war Oxford (Harley, 1994). Willis was practicing autopsies as early as 1650, although his most famous case did not involve an autopsy at all.

Figure 1: Diagram depicting the potential for the vertebrobasilar system to provide collateral circulation when the anterior (internal carotid) system is occluded through ligature from a noose during hanging, as described by Thomas Willis 1664.

(Rigozzi & Nichols, 2019)



'*… there may be a manifold way for the blood to go into diverse regions of the brain that if by chance one or two should be stopped there might easily be found another passage instead of them …*' (Willis 1664 cited in, Ljunggren et al., 1994).

Hanging remains one of the oldest methods of execution. Unfortunately early hangings were plagued by technical failures, horrific decapitations, survivals and most cases slow, and graphic strangulation and death by asphyxiation (Rayes, Mittal, Rengachary, & Mittal, 2011). In 1650 Willis and his colleagues received the body of Anne Green, which had hung for 30 minutes post execution. Anne Green had been convicted of killing her illegitimate stillborn child. Her execution was a public event taking place in a cattle yard and several attempts were made to ease her agony including jerking her downwards (Hughes, 1982). However when the coffin was opened the young woman remarkably showed signs of life and following resuscitation she survived without complication (Caplan, 2000; Ljunggren, Sharma, & Fodstad, 1994). Given the horrific descriptions of her slow suffocation, It is perhaps a blessing to Anne that she remained amnesic to the hanging event, revival and recovery (Molnár, 2004). Following her recovery she was fully pardoned, eventually marrying and having three more children (Hughes, 1982). It was not until 133 years later in 1783 that judicial hangings were transferred to Newgate prison and the use the 'New Drop' gallows was adopted (Rayes et al., 2011).

At the time of Anne Green's failed execution the basal arterial circle had been described by Gabriele Fallopio almost a century earlier (Mortazavi et al., 2013) and was a well known anatomical feature. However the flow of blood and the importance of the connection between the internal carotid arteries and vertebral arteries was unknown. In the case of Anne Green, where her carotid arteries were occluded through the process of ligature from the noose during her hanging, the blood entering the vertebral arteries was remarkably able to compensate (Figure 1).

Regardless of whether this was the result of a unique anatomical variation or a very incompetent executioner, her story and the chance that it was Thomas Willis who was to receive her body was destined to change the direction of anatomical observation towards the study of function and the mind (Caron, 2015). Willis' subsequent descriptions of the function and adaptability of the basal arterial circle that now bears his name is one of the greatest contributions to medicine. However, it was his student Richard Lower who actually described this structure for first time in 1660 and named it in honour of Willis (Harrigan & Deveikis, 2012; Scatliff & Johnston, 2014; Wells, 1949).

With the assistance of Lower and the artist Christopher Wren, Willis' 1664 work entitled *Cerebri Anatome* went beyond previous unelaborated and detached anatomical descriptions (Caron, 2015) to give the most detailed description and demonstrate the function of the brain including the arterial circle that now bears his name (Ustun, 2004a). Willis describes a number of cases that demonstrate the function of the arterial circle in providing compensatory collateral blood flow (Vrselja, Brkic, Mrdenovic, Radic, & Curic, 2014). One case report noted that the right internal carotid artery was almost totally occluded and that the contralateral vessel was enlarged, thus providing sufficient blood supply (Willis 1664 cited in, Cassels, 1998). Willis described the arteries as communicating with one other reciprocally in various ways (Willis 1664 cited in, Feindel, 1965), an anatomical feature that we now refer to as collateral pathways. Sadly, Willis died at the age of 54 from pleurisy in 1675. While his pioneering work was honoured by burial in Westminster Abbey, following his death there was a relative lull in activity concerning brain anatomy and function (Caplan, 2000).

18th and 19th Century Royal Links:

Advancements in anatomy and surgery in 18th century Europe was led by France in part due to the work of Pierre Dionis (Tubbs et al., 2009). France had a long history of royal autopsies as far back as 1536, where autopsies were undertaken often in search of poison (Harley, 1994). In his early 20's Dionis was already considered a master surgeon and in 1673 was a key member of Louis XIV court, often performing public anatomical demonstrations (Tubbs et al., 2009). Dionis is attributed with elucidating the pathology of subarachnoid haemorrhage (Caplan, 2015) and describing in case reports what may have been ruptured cerebral aneurysms (Longstreth, Koepsell, Yerby, & van Belle,

1985). Dionis' case reports include two sudden Royal deaths, with the autopsy of the Duke of Aurelia and the Prince of Espinoy both revealing distended cerebral ventricles and a sanguineous extravasation of blood (Ljunggren et al., 1987). However, it is unknown if Dionis made the important link between ruptured cerebral aneurysms and subarachnoid haemorrhage.

Nearly 150 years after the work of Dionis it was English Surgeon, John Blackall, who made the link between the clinical features of a subarachnoid hemorrhage and a ruptured intracranial aneurysm (Engelhardt, 2017). It was Blackall's observations that led him to note the similarities between the deaths of the Swedish Crown Prince and a local young woman. In May 1810, the 41 year-old Crown Prince, Karl August of Augustenborg was inspecting a regiment when he suddenly experienced an unbearable headache and fell from his horse, dying within the hour (Ask-Upmark & Ingvar, 1950). An autopsy revealed a subarachnoid haemorrhage that extended all the way down the spinal canal, with a clear pronouncement at the base of the brain (Milinis et al., 2017). In the chaos following the Prince's untimely death a French Marshall was appointed to the throne with the current seventh descendant a direct line of this dynasty and a Royal Patronage linked to the rupture of an intracranial aneurysm some 177 years ago (Ljunggren et al., 1987).

Three years after the death of Prince Karl, Blackall described the clinical presentation and anatomical features of a ruptured basilar artery of a young and healthy woman. The clinical presentation was described as a headache of the most excruciating kind associated with violent vomiting and intolerance to light (Blackall 1813 cited in, Ljunggren et al., 1994). The detailed description of the anatomical features of a subarachnoid haemorrhage were traced to the basilar artery, where at its bifurcation a ruptured aneurysmal sac was noted (Blackall 1813 cited in, Walton, 1956). With the similarities between the two cases noted Blackall attributed a ruptured aneurysm as the cause of sudden death in the Swedish Crown Prince three years previously (Ljunggren et al., 1987).

20th Century Developments:

The 20th century saw a number of advancements in the diagnosis and treatment of aSAH, including the use of lumbar puncture and understanding of the chemistry of cerebrospinal fluid and its diagnostic significance (Sakula, 1991). Despite this many believed that the treatment of cerebral aneurysms was unachievable. Harvey Cushing described a cerebral aneurysms as

> '*a lesion having such remote surgical bearings … whether there are surgical indications such as ligation of the internal carotid, further experience alone can tell*' (Cushing & Symonds, 1923).

In 1927 Egas Moniz, a professor of neurology at the University of Lisbon, produced the first cerebral angiography images following the injection of a radioactive contrast medium (thorium dioxide) directly into the carotid artery followed by three x-ray images (Doby, 1992; Ljunggren et al., 1994). The risk of stroke initially outweighed the benefits for most physicians, however Norman Dott was fundamental in establishing the practice, through his refinement and use of routine cerebral angiograms to aid surgical planning for cerebral aneurysms (Milinis et al., 2017).

Dott was a neurosurgical surgical pioneer; he was one of Harvey Cushing's residents and it was during his residency that he was first exposed to the technique of wrapping an aneurysm. This was a distinct difference in approach to attempting to secure ruptured aneurysms using ligation (Louw, Asfora, & Sutherland, 2001) that more often resulted in the intraoperative and fatal rupture of the fragile aneurysm.

In 1931 Colin Black, a 53 year old Edinburgh solicitor and hospital governor, presented to Dott's care following an episode of sudden and severe pain chiefly affecting the back of his head with associated vomiting. Sixteen days later risking both his career and reputation, using only ether anaesthesia, Dott exposed the brain and was able to wrap the aneurysm with muscle obtained from Black's leg (Todd, Howie, & Miller, 1990). Black recovered and Dott managed a further 39 sus-

pected aSAH cases, operating on eleven individuals (Ljunggren et al., 1987). Dott never denied fear

> '*Sometimes courage is required. Courage implies an appreciation of risk – in fact it implies fear under control. He who knows no fear is not courageous but reckless*' (Dott nd cited in, Rush & Shaw, 1990).

Dott also made a number of key observations about the natural history of ruptured aneurysms including the reasonable possibility of spontaneous fibrosis and cure as the clot around the aneurysm becomes organised, as well as noting that further haemorrhage was often more serious than the initial bleed, with the second haemorrhage often being rapidly fatal (Dott 1926 cited in, Pearce, 2006).

In 1937, six years after Dott first successfully wrapped an aneurysm in Edinburgh, an American surgeon Walter Dandy successfully clipped an aneurysm using a clip originally designed by Harvey Cushing and modified by Kenneth George McKenzie (Pearce, 2006). Dandy's patient was a contrast to Dott's in that he was described as a frail, sallow man aged 43, with a stomach that had gone bad from drinking (Ljunggren et al., 1987). He had presented six days earlier with a history of severe frontal headache and third cranial nerve palsy (Milinis et al., 2017). The risk of rebleeding post the initial rupture was well known and in attempts to improve outcomes surgical intervention was routinely delayed (Louw et al., 2001) and Dandy himself noted that one would not dare operate in the immediate period after and aSAH (Ljunggren et al., 1994).

The aneurysm was described as having a narrow neck, which then expanded to the size of a pea (Milinis et al., 2017). This afforded a surgical approach obliterating the aneurysm using a flat clip, '*where after the aneurysm became much softer and also ceased to pulsate*' (Dandy, 1938). The procedure marked the birth of modern neurosurgery and shifted the treatment of subarachnoid haemorrhage to a curable condition. Remarkably it was also undertaken and accomplished without using angiography, despite this having been developed ten years earlier (Louw et al., 2001).

In the following decades substantial modifications to the original flat clips was undertaken including resigning the clips so they could be opened and repositioned as well as changing the aperture, together with configuration and rounding of the blades (Louw et al., 2001). However, the development and refinement of aneurysm clips was not singularly triumphal but often one of tragedy due to the experimental nature of clip evolution (Dujovny, Dujovny, & Slavin, 1994). With a reported the in-hospital mortality rate of 73% (Rosenørn et al., 1987), despite the advancements made overall outcomes had not significantly improved in the 50 years since surgery was first attempted. The timing of surgical intervention was also a subject of considerable debate (Phillips, Dowling, Yan, Laidlaw, & Mitchell, 2011).

Whilst delaying surgery was associated with improved surgical outcomes, the incidence of rebleeding was a significant cause of early mortality (Broderick, Brott, Duldner, Tomsick, & Leach, 1994; Ljunggren et al., 1994). With improved surgical approaches the timing of intervention has shifted towards early (within one to three days) if not ultra early (within 24 hours) (Siddiq, Chaudhry, Tummala, Suri, & Qureshi, 2012). This time also saw the introduction of the calcium channel blocker Nimodipine, validated as a pharmaceutical intervention to reduce the risk of cerebral infarction post aSAH (Pickard et al., 1989). Nimodipine has since become acknowledged in international guidelines as evidenced based practice post aSAH (Connolly et al., 2012). Whilst clip design, surgical approaches, treatment timing and pharmaceuticals evolved, there were no significant changes in the treatment of cerebral aneurysms between 1937 when that first clip was applied until the early 1970's.

The first CT machine was installed in 1971 and within 10 years there were an estimated 2000 machines in operation around the world (Ljunggren et al., 1994). Whilst this development in technology improved the diagnosis of aSAH, it was re-evaluating angiography and developing an endovascular approach to the treatment of ruptured cerebral aneurysms that revolutionised intervention post aSAH.

Initial attempts in the 1960's of thrombolysis using injected horse hair and a projection gun developed under the auspices of the Office of Naval Research (Gallagher, 1964), were not unsurprisingly unsuccessful. Serbinenko (1974) published the results of 300 individuals with arteriovenous malformations and cerebral aneurysms treated via an endovascular approach using micro-catheter balloons.

At the same time in Rome, Guido Guglielmi was experimenting with the concept of fine stainless steel wire to coil and occlude aneurysms, although the hurdle of overcoming electrolysis and the erosion of the wires would take years to perfect (Milinis et al., 2017). By attaching electrolysis-resistant platinum coil to the wires, Guglielmi had invented the detachable coil. His first patient was successfully treated in 1990 and the preliminary results were published in 1991, linking the success of his work to the timing of intervention (Guglielmi, Vinuela, Dion, & Duckwiler, 1991). Since its conception, endovascular coiling quickly gained popularity (Milinis et al., 2017) and has become a primary treatment option in the management of ruptured and unruptured cerebral aneurysms (Loewenstein, Gayle, Duffis, Prestigiacomo, & Gandhi, 2012). The use of endovascular coiling has continued to develop and is now used in conjunction with a range of supportive interventions, such as stenting, as well as microsurgical approaches to aneurysm clipping (Prestigiacomo, 2006).

Conclusion:

The history of the observation and treatment of cerebral aneurysms is rich in parallels. From the early observational studies to the fledgling surgical and endovascular approaches, and the growing field of evidenced based practice, the history of cerebral aneurysms has demonstrated the courage, resilience and determination of medical and epidemiological studies. There are many individuals who have played a role in the progression and the philosophy towards treatment of aSAH. This overview provides a brief capture of those most pertinent to the core of our current nursing practice. Nursing practice has been continuously challenged and developed as a consequence of epidemiological research (Jenicek, 1997). From the epidemiological observations of Hippocrates and Galen to the sociodemographic differences in the first patients treated by Dott and Dandy, the history of cerebral aneurysm treatment has not been limited to technological advancements (Prestigiacomo, 2006). Current and future research is in many ways built on both the failures and successes of previous work and it here that nursing holds the key to enriching research and improving patient outcomes. It has been over 350 years since Thomas Willis first described the circle of arteries that now bears his name. Despite the success of treatments and interventions, the overall mortality post aSAH remains high and in a parallel nature of research, a return to epidemiological observations is warranted to gain a better understanding of the incidence, treatment and outcomes post aSAH. In the words of the pioneering neurosurgeon Percival Pott,

> '*Many and great are the improvements which the chirurgic art has received within these last fifty years; and much thanks are due to those who have contributed to them; but when we reflect how much still remains to be done, it should rather excite our industry than inflame our vanity*' (Pott, 1790)

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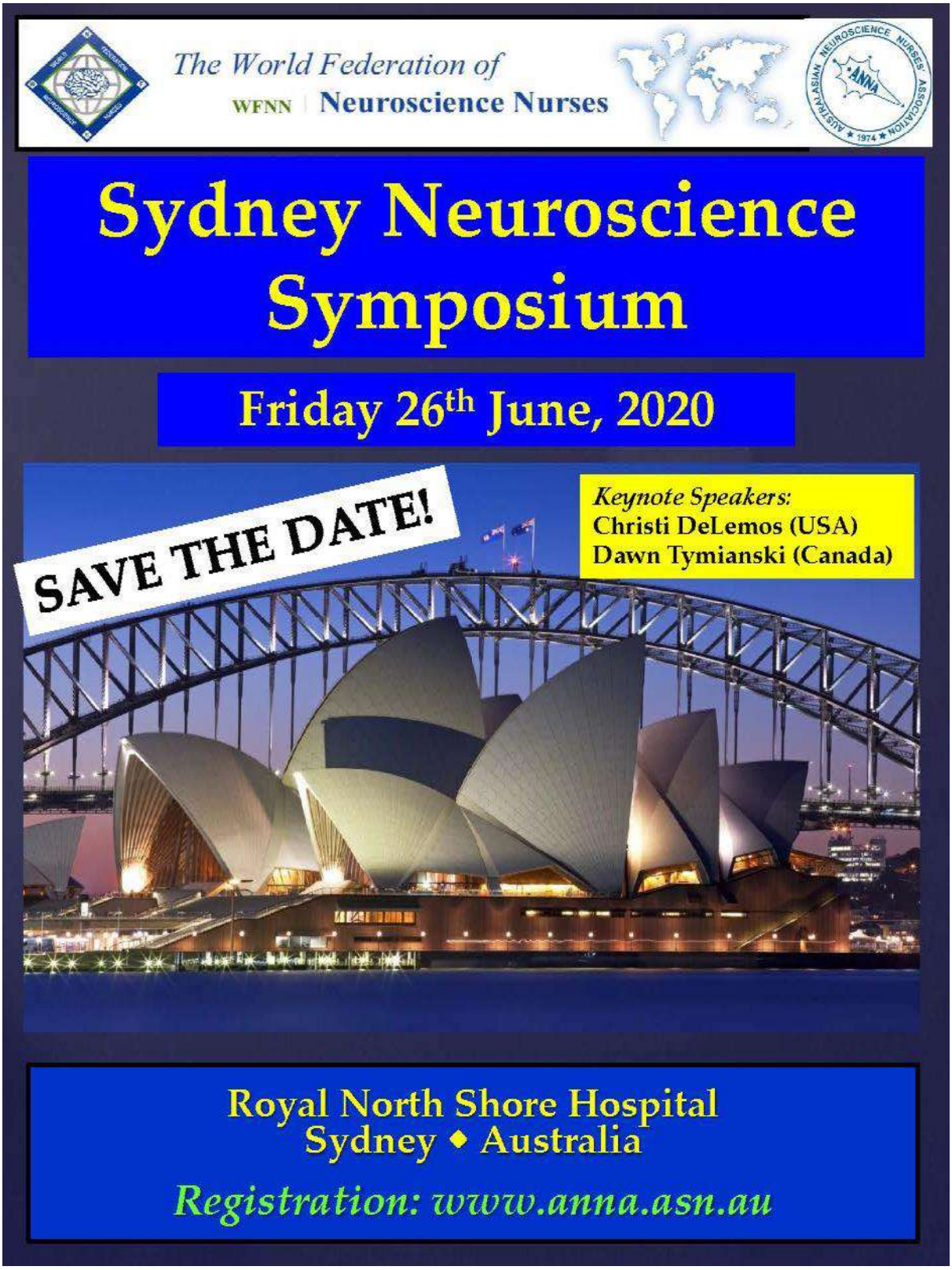
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2019 Australasian Neuroscience Nurses' Association Annual Conference Abstracts

On behalf of the Executive of the Australasian Neuroscience Nurses' Association (ANNA) it was my pleasure to welcome the delegates, presenters and sponsors to the 2019 ANNA Annual Conference at the Intercontinental Hotel, Wellington New Zealand.

The Annual Conference provides an opportunity to promote the exchange of scientific ideas and knowledge, and to strengthen relationships with colleagues and this year the quality of the presentations were again outstanding. This year saw the inaugural awarding of the Sharryn Byers Prize for the best original nursing research presentation presented at the ANNA scientific program. As well as some incredibly inspiring guest speakers.

We would like to extend our sincere appreciation to our sponsors for their support of the conference. Also thanking our local hosts for ensuring we were prepared with our earthquake drill. Luckily for us the only shaking we felt was the dance floor at the dinner where many a delegate danced the night away.

We hope you enjoyed to the 2019 Annual Conference and look forward to seeing you in Melbourne 2020, then in 2021 we will be heading north to Darwin for the WFNN Congress.

With kind regards

Linda Nichols and Leigh McCarthy
Australasian Neuroscience Nurses' Association

DOI: 10.21307/ajon-2017-019

The extinction of encephaloceles – a first world problem

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DOI: 10.21307/ajon-2017-019a

Neural tube defects (NTDs), including Spina Bifida and Encephaloceles have been linked to many causative factors one of which being the deficiency of maternal folic acid levels during conception and foetal growth (1). With the fortification of folic acid into Australian commercial bread in 2007 there has been a 14% - 74% decrease in recorded NTDs in children (2), leading to encephaloceles becoming a rare sight in Australian Paediatric or Neurosurgical units (particularly in isolation to any underlying congenital disorder). The precedence of adding folate to commercial breads and cereal products to reduce the occurrence of NTDs was most famously and successfully promoted in the United States commencing in 1992 and showed a 28% reduction in births affected by a NTD (3). These statistics are hugely significant, but what about low median income countries, particularly in developing nations, where mothers are not consistently consuming commercial food products and health promotion is limited? Cross to the other side of the world, to a small port in a West African Country most people would not have heard of. Here there is a non government, not for profit hospital ship providing free surgeries and care to those who have not felt the effect of these dramatic reductions in preventable medical conditions. Here, mothers, fathers and grandparents travel days or even weeks with children affected by encephaloceles at birth, to visit this 'nomadic' hospital with the hope of having their lives changed and the length of their children's lives significantly extended. Their stories are those of love, commitment and tragic circumstance where a combination of poor health promotion/ disease prevention, suboptimal nutrition and lack of access to acute healthcare mean most if not all of these children would not otherwise make it past 1 year of age. As a clinician with a passion for and specialisation in Neurosurgery, it is almost impossible to find a non government (NGO) or not for profit (NFP) organisation servicing those in developing countries in which your skills can be utilised to their full potential. This floating hospital ship in a small port of a West African Country most people would not have heard of is the exception.

Implementation of a telehealth follow-up clinic improves access to stroke specialists for people living in regional NSW

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DOI: 10.21307/ajon-2017-019b

Background: Accessing stroke specialists is challenging for people living in regional areas. Telehealth has enabled access to acute stroke thrombolysis, however outpatient follow-up appointments still require travel to metropolitan-based neurologist clinics or care is provided by local General Practitioners.

Aim: To improve access to follow-up appointments with stroke specialists for outpatients living in the Lower Mid North Coast, NSW.

Methods: Telehealth appointments are scheduled into existing stroke neurology clinics. Outpatients (±carer) attend the stroke nurse-led clinic at Manning Hospital (regional) and link via videoconference to the neurologist at John Hunter Hospital (JHH-(tertiary referral hospital). Joint consultations provide assessment and ongoing management. Data including attendance outcomes, travel and telehealth acceptability has been collected. Descriptive analyses are presented.

Results: Since commencing in December 2018, 13 people [male: 46%, mean age: 69 (12) years] have attended 15 telehealth appointments (2 patients have had 2 appointments each). Nine people had a stroke. Four people initially diagnosed as TIA had a change in diagnosis (seizures=2, pre-syncope=1, non-specific=1) and 11/13 people had medication changes. For 10/15 appointments, a carer attended, and a friend drove a patient for 2 appointments. The mean return travel distance for outpatients to each hospital was Manning=46(42) km, and JHH=323(36) km. If attending JHH, the outpatient (±carer) would have travelled an additional 4-5 travel hours for a 20-30min appointment, equating to an extra 4153km at $277/visit (current Australian Tax Office rate: 68c/km). Telehealth audio and visual quality has been excellent for all appointments. Outpatients have reported the service is "fantastic", "very convenient" and "worthwhile".

Discussion: Using telehealth, the stroke nurse and neurologist now provide access to specialist follow-up appointments for regional people in the Lower Mid North Coast, NSW.

Bstreetsmart road safety forum

Stephanie Wilson
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DOI: 10.21307/ajon-2017-019c

Bstreetsmart is the inspiring initiative of the Trauma Service at Westmead Hospital. Westmead's Trauma Service is constantly reminded through their hands on work that young people aged between 15–30 are disproportionally represented in road trauma. As a result they have a strong commitment to Road Safety Education. The purpose of bstreetsmart is to reduce the fatality and injury rates of young people by promoting safe behaviour as drivers, riders and passengers. Attendance at the bstreetsmart event grows every year which means more students and teachers are experiencing and learning about the impact of dangerous/distracted driving and the consequences for those directly and indirectly involved in a crash. Going into its 15th year, the bstreetsmart forum is Australia's largest educational event on road safety with over 185,000 year 10, 11 and 12 students having participated from 435 schools. bstreetsmart continues to grow with 22,000 students attending in 2018 from government and non-government schools across NSW and the ACT. To date (April) 23,000 students are booked for 2019. The feedback continues to be positive with students, teachers and parents reporting they have come away feeling more aware of the consequences of taking risks on our roads and are more likely to modify their driving behaviour. bstreetsmart provides students with first hand experiences and: •An understanding of their responsibilities as a driver and as a responsible passenger •Information and strategies to avoid serious injuries and death •Information on how to reduce risk taking behaviour through greater awareness of the consequences of distracted driving, inattention, speeding, drink and drug driving and driver fatigue. This successful initiative receives support from the NSW government and our generous partners to ensure bstreetsmart can continue to be offered to all schools, as they recognize the important role it plays in the community.

The impact of AIRO on neurosurgical nursing and patient outcomes

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DOI: 10.21307/ajon-2017-019d

In January 2018, at the request of our Neurosurgeons, St Vincent's Private Hospital Melbourne invested in the purchase of AIRO; a mobile intra-operative CT system allowing on -table navigation and CT imaging. Such imaging enables the surgeon to gain a real time CT image of the patient, allowing greater accuracy when visualizing the field of surgery (for example pedicle screws in lumbar surgery). AIRO was considered to be ideal for cranial and spinal procedures with expected improvements in patient outcomes through seamless integration and accurate navigation of neurosurgical implants. This would in turn lead to a decrease in operative time, reduced reoperation rates, improved theatre utilization figures and potentially the recruitment of new neurosurgeons to the hospital. The impact of the AIRO for the operating suite was well recognized with all the focus on the theatre staff education and the work practices. However there was no consideration how this would have a positive impact on the nursing care and patient outcomes on the neurosurgical ward. The aim of this study is to compare data and to investigate the benefits of the intraoperative CT on patients' recovery from a nursing perspective.

Constructing the meaning of personhood for people with traumatic brain injury

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DOI: 10.21307/ajon-2017-019e

A recent integrative review suggested that for people with a Traumatic Brain Injury (TBI), their sense of personhood can be eroded by their experience of injury as well as their experience of hospital care. To understand this issue, and to better meet the needs of people with TBI it is necessary to have clarity about the meaning of personhood for people receiving illness and injury management. The discussion will draw from contemporary literature sources to provide a practical understanding of personhood that might inform the application of this concept for TBI care and research. People with TBI present as a rather complex cohort for neuroscience nurses. They are a diverse group of people, many are young, some may be caring for others or raising a family, many have significant work and financial obligations. Due to this complexity, I argue that the concept of supporting "personhood" in TBI care has broad considerations and requires comprehensive exploration. Early findings from the literature suggest that themes of social dignity, respect for relational autonomy and lived relationships are important. Using an integrative review methodology (Whittemore & Knafl, 2005), diverse literature sources including scholarly and grey literature will be examined in a process of data reduction, display, and comparison. This critical synthesis will assist construction of a practical meaning of the concept of personhood in illness and injury contexts. This may provide a stronger foundation for care for people affected by TBI in a way that constructs and protects personhood.

Cortrak for the insertion of nasogastric tubes amongst neuroscience patients – how effective is it?

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DOI: 10.21307/ajon-2017-019f

Nasogastric tube feeding is common amongst neuroscience patients and are placed blindly at the bedside. However the procedure for inserting feeding tubes has remained time consuming and misplacement or complications can occur. Methods for checking nasogastric tubes have evolved over time but complications remain. The Cortrak 2 insertion system uses an electromagnetic approach to avoid the complications of blind tube insertion. A trial was commenced to determine whether the Cortrak 2 is accurate for nasogastric tube placement and whether this prevents the use of x-ray. The trial also examined whether the Corgrip bridle system would prevent the need for reinsertion of nasogastric tubes and the need for a one on one watch to prevent removal. Superusers were trained to insert the Cortrak nasogastric tubes and the Corgrip bridles. The trial demonstrated favourable results and these will be presented.

Why was it so hard to implement practice changes for management of stroke in ED? Results of a process evaluation from the T3 trial

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DOI: 10.21307/ajon-2017-019g

Background: Rapidly commencing evidence-based care for acute stroke in the emergency department (ED) improves outcomes. The T3 Trial, a nurse-initiated, multidisciplinary intervention was implemented in 26 Australian EDs to improve stroke care. Despite a robust process for identifying barriers and behaviour change strategies and an evidence-based implementation strategy, there were no significant improvements in 90-day patient outcomes or nursing processes of emergency care.

Aims: To identify organisational and clinician-level factors that influenced uptake of the T3 clinical protocols.

Method: Qualitative face-to-face semi-structured interviews based on the TDF were conducted with a purposive sample of 25 ED and stroke clinicians (n=21 nurses, n=4 doctors) at intervention sites who were involved in implementation, and with 3 site co-ordinators responsible for supporting clinical champions at each intervention site. Data were thematically analysed and checked by two researchers.

Results: ED staff reported that the protocols were difficult to implement within the complex ED setting. Professional boundaries, medical staff rotation, staff turn-over and beliefs about the evidence for thrombolysis, fever and glycaemia monitoring, mitigated against practice change. Nurse clinical champions responsible for driving change felt that their influence in facilitating practice change was limited because of these factors.

Conclusion: System and workplace factors that fell outside the control of the clinical teams and the site clinical champions influenced the ability to change practice in EDs. Alternative models of improving ED care for patients presenting to hospital with stroke need to be investigated.

Continence Assessment and Management Plan (I-SCAMP) Scampering across Northern NSW –the study protocol.

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DOI: 10.21307/ajon-2017-019h

Background: Urinary incontinence is common after stroke and has negative effects for patients, carers and health systems. In recent Stroke Foundation national audits, up to 41% of inpatients after stroke had urinary incontinence, but only half of these people had a continence management plan created or implemented. Clinical guidelines provide evi-

dence-based recommendations for urinary continence assessment and management. However, translating these recommendations into routine clinical practice can be challenging.

Aim: To determine if broader implementation (ie multiple Health Districts, across phases of care) of our previously-piloted multidisciplinary Structured urinary Continence Assessment and Management Plan (SCAMP) interventions (including clinically-applicable tools, processes and education; audit and feedback) improves inpatient post-stroke urinary incontinence assessment, diagnosis and management.

Methods: We are conducting a before- and after-implementation study at six acute stroke/ medical units, two comprehensive stroke and five rehabilitation services in three New South Wales Local Health Districts.

Our primary outcome is the change in the proportion of incontinent patients who have a continence management plan. Secondary outcomes include the change in the proportion of patients who have a urinary continence assessment, a documented urinary incontinence diagnosis and receive continence education. We will also determine the intervention effect on clinician knowledge, skills and confidence, and potential cost-effectiveness (hospital perspective).

Data will be collected for 3 months before and after the 7-month implementation period using medical record audits, clinician questionnaires and site-specific teams identifying local barriers and enablers to continence management. Sustainability will be evaluated 16 months after implementation commences.

Results: Ethics is approved. Before-implementation data collection commenced February 2019. The project will be completed by July 2020.

Discussion: Our SCAMP interventions have the potential to operationalise high-level concepts outlined in the Australian stroke guidelines into effective evidence-based, best practice clinical care across hospitals and phases of care. If successful, SCAMP can be readily-adopted nationally .

How I changed my practice: an end-of-life journey of a patient with a severe stroke

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DOI: 10.21307/ajon-2017-019i

Severe stroke is a life-threatening condition often resulting in early death due to a rapid increase of intracranial pressure from ischaemic brain oedema or haemorrhage. At several points critical decisions have to be made regarding ongoing treatment. Studies have shown that surgical intervention may benefit patients 60 years of age or younger. For patients older than 60 the focus shifts more to end-of-life care. We present the case of a patient with severe stroke on the background of advanced dementia. Mrs TN, a 93-year-old lady of Vietnamese descent, presented to our hospital with dense left sided hemiplegia and aphasia with unknown time onset. Her brain Computed Tomography (CT) and CT Angiography (CTA) showed an established right middle cerebral artery (MCA) infarct and a correlating right M1 occlusion. This was explained to the family and a decision was made for end-of-life care. Palliative care team review was sought at an early stage of the patient hospital admission. The case presentation will focus on the complexities of Mrs TN's journey and, in particular, the difficulties regarding evidence-based medicine versus individual patient care needs when it comes to palliative care nasogastric feeding. The experience of Mrs TN's case changed my practice since it taught me the importance of understanding the patient's previous life experiences and cultural background in palliative nursing care planning. In addition, it highlighted to me the significance of involving the palliative care team (early on) in the care of patients with severe stroke for whom withdrawal of life-sustaining treatment is considered.

Direct admission and transfer for treatment of Aneurysmal Subarachnoid Haemorrhage – effects on time to treatment and intervention

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DOI: 10.21307/ajon-2017-019j

Background and aim: Little known about the time to treatment or patient pathways from onset of symptoms of aSAH to intervention following an aSAH. This lack of knowledge may be contributing to less then optimal care for people with aSAH.

Methods: A statewide retrospective cohort study of confirmed or probable aSAH was undertaken within Tasmania (population ~500,000), Australia from 2010-2014. Data

were collected from administrative records, medical records and the death registry. We calculated the median (IQR) times from symptom onset to intervention and the proportion of time spent pre-hospital, before diagnosis and to intervention for directly admissions and transfers to the neurosurgical centre.

Results: From a cohort of 205 aSAH admissions, n=175 (85.4%) received endovascular or neurosurgical treatment and n=101 (81.5%) of the 124 regional admissions were transferred. The median (IQR) time to treatment was 17.17 (IQR 7.82, 24.47) hours for direct admissions and 24.52 (IQR 18.40, 40.29) hours for transfers ($p<0.05$). Prehospital time was similar for direct admissions and transfers while transfers spent 28% of their time being transferred.

Conclusion: The time to intervention was negatively influenced by inter-hospital transfers, which are necessary in a large proportion of people with aSAH due to their need for specialized treatment and management. Efforts to improve workflow in aSAH, including through regional clinical pathways, should be explored.

Amantadine – the new wonder drug that awakens patients from a persistent vegetative state

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DOI: 10.21307/ajon-2017-019k

We will report the case study of a patient who had a sub arachnoid (SAH). He remained in a persistent vegetative state for many months unable to participate in therapy and was on the verge of nursing home placement. The introduction of the drug Amantadine showed a stunning awakening in this patient. The patient started talking, eating and participating in therapy within days and was able to be transferred to a rehabilitation facility within weeks. We are now introducing Amantidine to all patients in a persistent vegetative state from a wide variety of conditions and seeing great improvements in their wakefulness. Amantadine is a Parkinson drug known to increase indirectly dopamine synthesis and dopamine release in the striatum. This report will outline the indications for Amantadine, the doses and possible side effects of the medications, including sudden cessation of the drug which can lead to a sudden decrease in the patient's level of consciousness. Amantadine has successfully been fully evaluated for use as a neuro stimulant in traumatic brain injury and is regularly used in brain injury units. However, it is an unknown drug in the acute care setting and an unknown drug for patients after a SAH and other neurological conditions. More trials are needed to investigate the use of Amantidine in the acute care setting.

Let's reflect on a fall!

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DOI: 10.21307/ajon-2017-019l

Introduction: Falls contribute to 40% of injuries in acute care and despite the use of multiple prevention strategies continue to be a major challenge in hospitals. Evidence suggests that many health professionals fail to reflect on their practice which can contribute to errors. There is paucity of research around utilising a reflective model to prevent falls. This projects aims to investigate whether reflection by staff and patients post-fall has an influence on falls reduction in the acute care setting.

Method: This action research study uses a Plan-Do-Study-Act model (Carr and Kemmis, 2003). The aim is to minimise falls by involving staff and patients in critical reflection of what has occurred, developing ideas about how things could be safer, implementing a number of potential solutions and evaluating them to see what works in reducing falls. A reflection template is completed by staff and patient stories are collected after a fall or near-miss fall. The reflection includes questions about how the incident could have been prevented and ideas staff or patients have to reduce future incidents. The data from the reflections is themed and fed-back to the staff in focus groups. Action(s) are then developed, implemented and evaluated. This cycle is repeated. This research is conducted on three wards in an acute hospital.

Results: Cycle one results of the action research project included the following themes - predisposition for falls, impact of the fall and potential solutions. These themes will be presented and discussed incorporating any influence on practice change and the decrease in falls rates.

Conclusion: This research is aimed at culture change for which an action-orientated approach is used and through staff engagement, they are able to find solutions to help change their own practice and improve falls rates on their wards.

Cognitive Function Training – Brain fitness in neuroscience

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DOI: 10.21307/ajon-2017-019m

With the continuous development of neurosurgery, the focus of surgery is not limited to resect lesions and treat diseases, but more of protect the nerve anatomy and the "traditional" brain function area. The continuous development and application of new technologies and the continued understanding of the functional divisions of the cortex will help people identify more clearly the relevant mechanisms of brain processing for cognitive processes. The available evidence suggests that the brain is a flexible organ that can regenerate, that, regardless of age, can maintain or even improve its current performance levels, through brain fitness. The term brain fitness has become more widely known, due to more scientists have realized that how important it is to maintain our brains and our bodies in good shape. This terminology is still controversial where some people believe that a well-designed intellectual brain fitness program can improve cognitive ability and improve the quality of lives; while the other side believes that this improvement is only short-term and cannot be passed on to other cognitive areas. Following this, we want to hypothesise that the cognitive functions can also be re-trained and exercised following traumatic brain injury or brain operation. Current brain fitness programs may able to optimize the patient outcome through the early rehabilitation. This article will review the current literature around cognitive function training and various brain fitness programs that currently exist. These programs will be critically analysed to assess if such programs can be recommended for, and implemented in, to a neurosurgical setting, as a result to promote better recovery following brain injuries and operations.

Epilepsy surgery: a paediatric perspective

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DOI: 10.21307/ajon-2017-019n

More than 250,000 people in Australia live with Epilepsy and more than 40% of those are children. Medication is a first line, effective treatment however, not all patients have the desired outcome for seizure reduction or cessation. In fact, 1 in 3 do not gain full seizure control with medication alone. Epilepsy surgery, while not a new concept of treatment for seizure management, has gained significant traction in the past decade and has become a particular focus of the Neurology Department at The Children's Hospital, Westmead. This is evident by the expansion of the Neuroscience ward for the precise purpose of surgical intervention for the treatment of Epilepsy and other seizure conditions. The paediatric patient journey to surgery is a complex and intricate one. It involves a collaborative approach of the multidisciplinary teams from diagnosis and beyond, whilst maintaining a high standard of holistic, family centred care. This presentation aims to discuss this journey and the impact it has on the patients, families and the nurses involved.

Mentorship in neuroscience nursing

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DOI: 10.21307/ajon-2017-019o

Mentorship is a relationship of reciprocal and collaborative learning which is formed between two individuals with common goals and shared accountability for the success of that relationship (Hnaituk, 2012). Mentoring can occur as a formal or informal process. In nursing, mentorship can also occur in a variety of settings and in a variety of ways. The mentor is usually a nurse with specific clinical experience who is in the position of an expert to guide and be a role model, while the mentee is a newer or less experienced nurse. The role of mentors in the graduate nurse's development as a clinician, including impacts on nursing retention and nursing satisfaction has been discussed in a number of research papers (Block et al., 2005). This integrative review will examine the impact of nursing mentorship and the potential benefits and pitfalls described in the literature, including anecdotal experience of mentors and mentees. Recommendations will be presented regarding the commencement of a mentorship program for neuroscience nurses for the Australasian Neuroscience Nurses' Association.

Does the implementation of NIHSS (National Institute of Stroke Scale) in monitoring post-thrombolysis patients improve early recognition of neurological deterioration?

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DOI: 10.21307/ajon-2017-019p

Background: Recognising worsening changes in acute stroke is crucial in order to ad-

dress the reversible causes of post-thrombolysis neurological deterioration and to provide urgent treatment. We implemented the use of NIHSS in monitoring patients post-thrombolysis in the acute stroke unit to recognise early signs of deterioration.

Aim: To determine if the use of NIHSS in monitoring patients post-thrombolysis, compared with Glasgow Coma Scale (GCS), improves early recognition of neurological deterioration.

Methods: An observational study was undertaken of patients admitted in the acute stroke unit 24 hours post-thrombolysis from 2013 to 2014 (pre-NIHSS group) and 2016 to 2017 (post-NIHSS group). Patients admitted during the NIHSS training period (2015) were excluded. During this period the NIHSS tool was not consistently used.

Results: A total of 398 patients were included in the observational study. The pre-NIHSS group included 161 patients (51% females, median age 78) and the post-NIHSS group included 237 patients (42% females, median age 77). Both groups had moderate strokes with a median NIHSS score of 7, and premorbid function (Rankin) score of 1 in 88% of patients in pre-NIHSS group and 86% of patients in post-NIHSS group respectively. In the pre-NIHSS group, 21 patients (13%) experienced neurological deterioration and only 9 patients (5%) (detected using GCS) had urgent imaging and 1 patient had decompressive craniectomy. In the post-NIHSS group, 17 patients (7%) (detected using NIHSS) had urgent imaging; 3 had endovascular clot retrieval (ECR) and 1 had decompressive craniectomy. There was no difference in the length of stay (both groups median = 6 days); and in-hospital deaths in both groups.

Conclusion: The NIHSS is a more accurate tool, compared with GCS, in early recognition of neurological deterioration in patients post-thrombolysis. Early recognition of deterioration is essential to ensure urgent treatment and management.

Nurse-led stroke education for secondary stroke prevention (NURSED)

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DOI: 10.21307/ajon-2017-019q

Background: Stroke is a leading cause of preventable death and disability in Australia. The risk of recurrent stroke is high among stroke survivors, with subsequent strokes often being more severe and disabling. They account for 20 – 30% of all preventable strokes. This rate could be reduced by improved evidence-based strategies in secondary stroke prevention during hospital admission. In 2017, the National Stroke Audit showed that only 53 and 56 per cent of our patients are discharged on a statin, antihypertensive medication, and antiplatelets or anticoagulation, respectively. In addition, it revealed an inadequate multidisciplinary input into the discharge summary.

Aim: The aim of this initiative is to strengthen our secondary stroke prevention, with this analysis
we want to assess patients' acceptance and the feasibility of a nurse-led stroke education discharge care plan (NURSED).

Methods: A review of 20 stroke patients' investigation results, initiated secondary prevention management and relevant documentation. Three stroke champions were trained as stroke educators/facilitators. The role of the champion is to support the patient in developing their own discharge care plan by identifying present risk factors, setting goals, planning activities and monitoring strategies. Allied health members were consulted in the development of this initiative.

Results: One month after implementation, 20 stroke patients were screened for NURSED participation. One third of these patients had language or cognitive problems. Five patients provided verbal consent to participate in the NURSED project. They all stated that the process increased their awareness and confidence to control their risk factors.

Conclusion: NURSED is an ongoing project in our hospital. Despite a low number of participants so far, we could show that NURSED empowered them to control their risk factors. Our team experienced the time investment for education and discharge plan development as feasible.

Poster Abstracts

eXtreme Lateral Interbody Fusion (XLIF)

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DOI: 10.21307/ajon-2017-019r

eXtreme Lateral Interbody Fusion (XLIF) is a relatively new surgical procedure in the treatment of extensive degenerative lumbar spinal diseases. Since being developed in the 1990's by spinal surgeon Luiz Pimenta, the XLIF procedure has become globally recognised as a minimally invasive approach for lumbar fusions by providing surgeons with the ability to dissect, remove and fuse the disc space through a smaller incision site. This is accomplished via a lateral retroperitoneal trans-psoas approach meaning it has the ability to preserve the posterior muscles, bones and ligaments. Other advantages of an XLIF are that it is minimally invasive, can be performed at multiple levels and has an excellent disc height restoration due to the larger sized cages. This poster identifies indications and surgical approaches for lumbar surgery and a general surgical overview of the positioning and technique used during an XLIF. The main focus of this poster was to provide nursing staff with the knowledge and education on nursing rationale behind the care provided to patient's after an XLIF procedure and to individualise patient care to minimise specific post operative complications.

Identifying nurses perceived enablers and barriers to providing evidence-based, best practice urinary continence assessment and management: a cross-sectional study.

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Background: In Australia, 35% of people admitted to hospital with acute stroke are incontinent of urine, however only 18% of these people have a urinary continence management plan.

Aim: To identify the perceived enablers and barriers to urinary incontinence (UI) assessment, diagnosis and the development of management plans from nurses who regularly care for patients after stroke.
Methods: Nurses from 13 wards that admit patients following an acute stroke at 9 hospitals in NSW completed an online questionnaire investigating their perceptions on UI assessment, diagnosis and management. The 58 questions (5-point Likert scale) were aligned to 13/14 domains of the Theoretical Domains Framework. Reponses were dichotomised to "strongly agree/agree" and "unsure/disagree/ strongly disagree". Descriptive analyses are presented.

Results: The 162 respondents were predominantly female (79%), had mixed clinical experience (0-1yrs=14%, 1-10 years=45%, >10yrs=41%) and on ≥ "some days of your working week" were involved in UI assessment (78%), diagnosis (61%) or management (90%).

Nurses perceived that accurate assessment (Ax) and individualised management plans (IMP) for UI were beneficial to themselves (Ax=95%, IMP=96%), their patients (Ax=100%, IMP=99%) and their wards (Ax=98%, IMP=99%). Regarding performing UI care, approximately half reported not having the time (Ax=53%, IMP=55%), personnel (Ax=57%, IMP=43%), equipment (Ax=45%, IMP=42%), knowledge (Diagnosis=46%, IMP=44%) or skills (Diagnosis=49%, IMP=39%). Respondents perceived UI assessment (57%) and developing management plans (54%) were something they did well. Regarding how well their ward did, this

perception reduced to 39% for both assessment and management.

Discussion: In a large cohort of nurse from different health services, we identified important enablers (Beliefs about Consequences and Goals domains) and barriers (Environmental Context and Resources, Skills, Knowledge, Behavioural Regulation, and Beliefs about Capabilities domains) to current nursing assessment, diagnosis and management of UI. Strategies to improve UI care need to harness the enablers and target the barriers.

Oral care for neuroscience patients in New Zealand: A survey.
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Introduction: Oral care is a pertinent issue in neuroscience nursing although often based on tradition or experience rather than evidence based.

Aim: To understand the experience and knowledge of neuroscience nurses working in acute ward settings in New Zealand and to determine what educational requirements were needed to standardize oral care.

Design: An online survey using qualitative and quantitative data was developed with three out of the five New Zealand units participating from the north and south island. The response rate was 34% (n=34). Quantitative data was exported into the Statistical Package for Social Sciences (SPSS) and analyzed using descriptive statistics and frequencies. Qualitative data was analyzed using a content analysis approach.

Results: Oral hygiene education was provided to the majority of respondents during their nursing training, but most did not receive any education within their nursing career. There was a lack of oral care assessment tools, guidelines and evidence based practice. Inconsistencies over product choice and frequency of care existed. Barriers to effective oral care included the uncooperative patient, lack of access to the mouth and a lack of time to provide oral care.

Conclusion: The experience and knowledge of neuroscience nurses varied. An oral assessment tool and guideline would improve the oral care of the neuroscience patient and standardize care throughout New Zealand. Oral hygiene education is fundamental for nursing students, registered nurses, health care assistants, patients and family.

Impact: Following this study, a guideline and assessment flowchart were created with an online e-learning experience and distributed nationwide.

Congratulations to our 2019 Prize Winners:

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Oral care for neuroscience patients in New Zealand: A survey.
Caroline Woon, *Wellington Hospital, CCDHB, New Zealand*

Barriers and Facilitators to End of Life Care in Huntington's Disease – A review of the literature.

Ruth Hosken

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Abstract

Background: The advanced stage of Huntington's Disease has been a secondary focus to support and treatment interventions, resulting in limited knowledge about best practice end of life care for both individuals and their families. This article analyses the current state of knowledge about late stage Huntington's Disease and end of life planning for people with the disease.

Methods: A literature search was conducted in the electronic databases using the following search terms: 'Huntington's Disease' AND 'end of life OR palliative care OR late stage OR advanced'. Forty two articles were identified for review.

Discussion: People with Huntington's Disease think about their end of life wishes, but often do not discuss these with their doctors. Incorporation of an early palliative approach into a multidisciplinary neurology service is widely regarded as best practice and should include the early introduction of end of life planning, however many clinicians are not comfortable with discussing end of life care. This paper synthesises the available information and makes recommendations regarding advance care plans for people with HD.

Conclusion: Initiation of a palliative approach early in Huntington's Disease has the potential to improve management of symptoms, increase the likelihood of advance care plans being developed and improve the overall quality of life throughout the duration of the illness; therefore, all clinicians working with people with Huntington's Disease should have an understanding of palliative approaches.

Key Words

Huntington's Disease, Palliative Care, Advance Care Planning, End-of-Life care

Introduction:

While palliative care has long been considered an essential component of care for people with cancer, there has also been exploration of the role it might play for people with disabling and life limiting progressive neurological diseases (PND) (Travers, Jones, & Nicol, 2007). Despite much rhetoric and many reports suggesting that palliative care should be accessible and available for all people with life limiting illnesses there has been little evidence of change in practice (Booth, Fallon, & Hollis, 2016). People with PNDs, including Huntington's Disease (HD), which will be the focus of this report, frequently live for many years, progressively becoming more physically and cognitively disabled and enduring a decreasing quality of life (Gofton, Jog, & Schulz, 2009). While there is little written specifically about end stage HD, an improved understanding of this stage is essential to ensure existing health services are able to support people with HD in preparing for their end of life (EoL), earlier in their disease trajectory. Recent literature demonstrates a growing interest and awareness of incorporating a palliative approach into neurological care (Oliver et al., 2016). This paper will explore EoL issues and provide recommendations regarding Advance Care Plans (ACP) for people with HD.

Method:

A literature search was conducted, initially using the terms "end of life" OR "terminal

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care" AND "Huntington's disease", in the electronic databases PubMed, CINAHL and Wiley on-line. When this failed to produce any results the term "palliative care" was added. To narrow the results on palliative care it was combined with each of the terms "neurodegenerative", "Huntington's disease" and "neurology". A further search was done using the terms "late stage" and "advanced" in combination with Huntington's disease. Given the dearth of results, papers were included if they covered the subject areas and were published this century. One seminal article was also included.

Further relevant articles were found from the reference lists of selected papers. Article titles and abstracts were reviewed and papers were included if they made reference to palliative care and PND, including HD, even if these were not the main focus of the article. Articles were excluded if their focus was Juvenile HD or another PND such as Motor Neurone Disease, because of their vastly different disease trajectories to HD.

A total of forty-two articles have been included, 39 from scholarly journals, one report from a working party, one fact sheet retrieved from an HD organisation's website and one chapter from a management guideline available on the internet. Of the 39 journal articles, 15 related broadly to palliative care in neurodegenerative disorders, 16 to HD and palliative care, five were general articles on HD that mentioned terminal or end of life care and three were primarily focussed on euthanasia and HD. The majority of articles (22) were 'expert opinion' review pieces, there were three literature reviews, one book review, seven retrospective cohort studies, one report on a current cohort of patients and eight papers with mixed method qualitative research. The expert opinion articles were written from the perspective of neurology (13), palliative care (4), gastroenterology (1), neuro-palliative services (3) and other (3). Major themes arising from the literature that will be explored in this paper include; definitions of palliative care, service delivery models for HD, barriers to accessing palliative care, advance care directives, tube feeding and end of life care.

Background: Huntington's disease:

Huntington's disease is a rare, genetic, neurodegenerative disorder that clinically presents as a triad of symptoms occurring in the motor, cognitive and psychiatric domains (Nance et al., 2011). Internationally, prevalence of HD is estimated at 6/100,000 (Oliver et al., 2016). First symptoms commonly appear between 35-50 years of age with slow and insidious deterioration culminating in severe incapacity prior to death, which is usually 10 -20 years after symptom onset (Nance et al., 2011). Despite differences in age of death and length of illness reported in the literature, HD does consistently result in a reduced life span. The advanced stage of HD has not been extensively studied, resulting in limited knowledge regarding best practice EoL care for people with HD and their families (Rodrigues et al., 2017).

Late Stage/Advanced HD:

The disease trajectory in HD is complex and varies strikingly, even between affected people in the same family (Macleod et al., 2017), making it difficult to know when to instigate an EoL approach (Gofton et al., 2009). Some suggest that the beginning of the 'end of life' in HD is the time when the individual is no longer capable of independent living (Dubinsky, 2004), a stage also referred to as 'late stage HD' or 'advanced HD', which may last more than 10 years . Others, however, suggest EoL is further into the late stage, when a person is bedbound, unable to communicate, eat or drink on their own and display severe chorea or extreme dystonia (Dellefield & Ferrini, 2011; Huntington Society Canada, 2016).

Terminal stage in HD:

There is very little written about the terminal stage of HD and how to recognise it. The lack of evidence based criteria for determining the terminal phase and specifically the six month prognosis in HD (Johnson, Frank, Mendlik, & Casarett, 2018), is a significant factor in people with HD having difficulties accessing palliative care services. Tarolli, Chesire, and Biglan (2017) suggest the terminal phase in HD tends to be unpredictable, with significant variation and fluctuation between patients. Some people with HD can appear to be in a terminal phase, but then recover and they may do this several times (Tarolli et al., 2017). While there remains difficulty in identifying the terminal phase of the disease, people with HD may also die unexpectedly, leaving families unprepared (Hussain, Adams, Allgar, & Campbell, 2014).

Symptoms that might indicate the approach of the terminal stage include; inability to walk, speak and eat, weight loss (Huntington Society Canada, 2016; Klager et al., 2008), new-onset screaming occurring in an otherwise mute and bed bound individual (Nance, 2012;

Nance et al., 2011), isolated episodic fevers and deep sleeping for most of a 24 hour period (Huntington Society Canada, 2016; Moskowitz & Marder, 2001). Identified triggers have been suggested for the recognition of end of life for patients with PND generally in a retrospective cohort study (Hussain et al., 2014); however, these require further validation and it should be noted that only four people with HD were included in the study (Hussain et al., 2014; Oliver et al., 2016). This could be a useful area of further research. Johnson et al. (2018) identified that the most common reported symptom for people with HD accessing a hospice service was pain, which is not otherwise a commonly reported symptom associated with HD, while Mestre and Shannon (2017) report that pain was present in less than 10% of a cohort of people with advanced HD living in a residential facility. Pain is otherwise scarcely mentioned in the literature reviewed.

Causes of Death:

Cause of death in HD is typically due to medical complications (Huntington Society Canada, 2016; Nance et al., 2011), most commonly pneumonia due to aspiration (Huntington Society Canada, 2016; Macleod et al., 2017), but possibly including dehydration, malnutrition or choking (Huntington Society Canada, 2016). Rodrigues et al. (2017) found that the most frequent cause of death was pneumonia (19 %), followed by other infections, then suicide and cancer, with cause of death being undetermined in 23% of deaths. Solberg et al. (2018) similarly found respiratory diseases, including pneumonia, were the most common cause of death (44%), followed by cardiovascular disease, HD itself, injuries and suicide, while Booij, Rödig, Engberts, Tibben, and Roos (2013) report pneumonia as the primary cause, followed by suicide.

People with late stage HD may have a series of sudden deteriorations or acute illnesses such as aspiration and it can be difficult to predict if and when they will respond to treatment and therefore to accurately identify the dying phase (Hussain et al., 2014; Wilson, Seymour, & Aubeeluck, 2011). This can inadvertently lead to someone's end of life wishes being breached, particularly if a decision is made to seek hospital care (Wilson et al., 2011). The majority of people with HD admitted to hospitals via emergency departments are discharged to long term care facilities (Simpson, 2007). A good death is widely considered to be pain free, calm and peaceful, in a familiar place, surrounded by familiar people, whether staff or family and where individual preferences are known and respected (Huntington Society Canada, 2016; McClinton, 2010; Wilson et al., 2011). People with HD typically spend their final years in care facilities, most commonly residential aged care (Tarolli et al., 2017) and the literature shows that the most common place of death is hospital or care facility, which differs from other hospice patients who are more likely to die at home (Johnson et al., 2018; Rodrigues et al., 2017). Mestre and Shannon (2017) suggest that stronger models of palliative care focussing on community support may enable people with HD to remain at home longer as their condition advances.

There are no published guidelines regarding specific treatments to be used in the terminal stage of HD; however, Nance et al. (2011) recommend the following: consider ceasing prophylactic medications and treatments for conditions other than HD except those used for comfort, but continue any psychotropic medications which may be necessary for psychological comfort and control of chorea. In addition they advise the use of long term narcotics, muscle relaxants and anti-anxiety medications, along with anti-cholinergic agents if drooling is excessive (Nance et al., 2011).

Care Delivery in Late Stage HD:

It can be argued that all management for HD, from diagnosis to death, is palliative because there are currently no disease altering treatments available (Dellefield & Ferrini, 2011). However there is a common misconception that palliative care is synonymous with end of life care and is primarily related to diagnoses of cancer (Boersma, Miyasaki, Kutner, & Kluger, 2014; Provinciali et al., 2016). It is surprising to note many of the articles reviewed that were related to palliative care contained no definitions of palliative care.

The most commonly cited definition in the remaining papers is that of the World Health Organisation.

> An approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation cited in Dawson, Kristjanson, Toye, & Flett, 2004, p. 124)

There is widespread agreement within the literature identifying barriers to people with PND accessing specialist palliative care services leading to their significant under-representation in these services (Rosenwax, Spilsbury, McNamara, & Semmens, 2016). Palliative care services are generally not funded or equipped to provide support to someone throughout a 20 year illness, so alternative care delivery models must be considered. The therapeutic goals of management for HD align with those of palliative care; mitigating symptoms, enhancing quality of life and responding to the often complex needs of patients and their families (Klager et al., 2008; Wilson et al., 2011). This can be extrapolated as the 'palliative approach' which has the support of many (Gadoud & Johnson, 2015; Oliver et al., 2016; Provinciali et al., 2016); combining active treatments specific to the disease with the holistic assessment and response to patients' needs while providing support to carers, within a philosophy of an open attitude towards death and dying. The effectiveness of the palliative approach in HD will depend on the skills and expertise of clinicians in adapting the concept of palliative care to the idiosyncrasies of HD (Provinciali et al., 2016) and this takes on additional importance in the late stage. Vaughan and Kluger (2018) suggest that a palliative approach may in fact improve quality of life for people with HD; however, they suggest this approach remains in early developmental stages and requires significantly more work to address the barriers. Tarolli et al. (2017) highlight the challenges of specialist neurology services not necessarily being well equipped to manage the non-neurological end of life issues, including advance care planning and psychosocial support, while palliative care services are generally unfamiliar with the specific needs of people with HD. The most effective care may be offered by a multi-disciplinary team, including both neurology and palliative care specialists (Mestre & Shannon, 2017).

Onset of late stage is the time where some consider palliative care should commence (Klager et al., 2008). Others argue it should commence much earlier, for example soon after the time of diagnosis (Dubinsky, 2004; Provinciali et al., 2016), while some, moreover, implore for the incorporation of a palliative approach in the early stages to relieve physical and psychological distress emanating from diagnosis (Kristjanson, Toye, & Dawson, 2003; Provinciali et al., 2016). What is clear is the need to commence a palliative approach early enough in the disease to ensure the person has capacity to make decisions and choices regarding their end of life care (Nance et al., 2011; Travers et al., 2007). If implementation of palliative care is left until the terminal phase, the period of greatest suffering for the patient may be over and with it the opportunity of palliative care to reduce suffering (Booth et al., 2016).

It is interesting to note that while the articles reviewed that were specific to management of HD (Nance, 2012; Nance et al., 2011; Novak & Tabrizi, 2010) did not mention palliative care or a palliative approach, their overarching philosophy and tone indicate that they apply a palliative approach to their management. 'The aim of treatment is to manage symptoms and improve quality of life' (Novak & Tabrizi, 2010 p.5). 'Thoughtful care can reduce discomfort and improve the experience of the patient and family confronting this difficult neurodegenerative disorder' (Nance, 2012, p. 364) 'Goals of care remain the same....: reduce the burden of symptoms, maximise function and optimize quality of life' (Nance et al., 2011, p. 111). Oliver et al. (2016) concur that most guidelines for care of specific neurodegenerative disorders do not provide an overt description of the role of palliative care, perhaps reflecting a level of discomfort with addressing EoL concerns.

In contrast to most medical conditions, where the burden of symptoms increases as the disease progresses, HD can present with severely debilitating physical and psychiatric symptoms early in the disease, thus highlighting the need for an early palliative approach (Tarolli et al., 2017). Whether these symptoms are best managed through a palliative care service or a multi-disciplinary neurology or specialist HD service remains unclear in the literature. Existing models of care generally result in few people with HD accessing specialist palliative care services even as they approach EoL (Vaughan & Kluger, 2018). Care throughout the disease, up to and including EoL is therefore largely provided by multi-disciplinary neurology teams using a palliative approach. Although there is limited supporting evidence, Oliver et al. (2016) conclude that a palliative approach is desirable during the progression of the disease and that specialist palliative care may have less contribution until the condition advances. Specialist palliative care is provided by services who assume responsibility for physical, psychological, social and spiritual care of a dying person (Boersma et al., 2014; Travers et al., 2007) and should be referred to when patients or carers have complicated needs beyond the capabilities of their treating team (Boersma et al., 2014; Brown & Sutton,

2009; Gadoud & Johnson, 2015). It must be accepted, however, that the application of traditional specialist palliative care approaches may not always be what is required by people with HD (Booth et al., 2016) and there is no consensus as to which symptoms, or what stage of the illness, should trigger a referral to palliative care (Tarolli et al., 2017). While the barriers to accessing palliative care are clearly stated, there was no evidence in the reviewed literature of anything being done, or service innovations described, to address the barriers. It is possible that including palliative care clinician/s or enhancing the palliative care skills of other members of the multi-disciplinary team, typically involved in managing the care of people with HD within a palliative approach, would be the simplest and perhaps most widely accepted solution.

Impact of the familial nature of HD:

Memories of how relatives lived their final days and months and how they died will increase the likelihood of people with HD having thoughts about EoL decisions and will often result in individuals not wanting to prolong the advanced stage of the disease (Booij, Tibben, Engberts, Marinus, & Roos, 2014; Hubers et al., 2016). Booij et al. (2014) concluded that although people affected by HD do not think about EoL issues any more or less than other people, their EoL thoughts are more detailed because of their familiarity with their own anticipated future as seen through the journey of relatives. Macleod et al. (2017) reflect that families may be scarred by generations of witnessing debilitating disease and difficult deaths. Regan, Preston, Eccles, and Simpson (2018), in a qualitative study on views of people with HD on assisted dying, report that most people's views were strongly influenced by having witnessed the effect of HD on their family members; although, this did not mean there was a consensus viewpoint amongst family members. The anticipated loss of dignity in the future is a major instigator of EoL thinking (Booij et al., 2014).

The familial nature of HD increases the need to ensure that EoL planning results in effective and respectful care as this can have a long term influence on how caregivers make decisions about their own end of life care (Booij et al., 2014; Kavanaugh, Noh, & Zhang, 2016). Many individuals and families affected by HD experience stigma and secrecy around the diagnosis and illness itself, both within their families and in the broader community (Kavanaugh et al., 2016). It is therefore vital for clinicians to facilitate open discussions around EoL issues to try and minimise the distress and reduce the burden of potentially having to make EoL decisions for a family member without ever having had a discussion about their wishes (Kavanaugh et al., 2016).

End of Life Planning:

Advance Care Plans- In Victoria the term Advance Care Plan is used to cover a variety of documents that people may use to express their values and preferences for care and treatment (The Victorian Department of Health, 2014) whereas others may be more familiar with the term Advanced Care Directive. Advance Care Planning is identified in The Victorian Health Priorities Framework 2012–2022 as an essential growth area in order to enhance the health experience of every Victorian (The Victorian Department of Health, 2014) and involves discussion and documentation of an individual's values, beliefs and preferences in relation to their future health and care needs to guide clinical decision making. It also involves the appointment of a substitute decision maker in case they are unable to make those decisions for themselves in the future (Hagen et al., 2015; The Victorian Department of Health, 2014).

Early incorporation of a palliative approach has the potential to improve EoL planning, promote the development of ACP and improve the quality of life for people with HD (Oliver et al., 2016; Provinciali et al., 2016). Given the long illness trajectory and the inevitability of the terminal phase there is ample opportunity for ACP to be made (Dawson et al., 2004; Nance et al., 2011). There is some contention in the literature as to when EoL planning should commence for people with HD. There is general consensus that it should be initiated prior to cognitive decline and loss of communication skills and the phrase 'as early as possible' is frequently used (Oliver et al., 2016; Provinciali et al., 2016). Others suggest it should be at the commencement of late stage or before institutionalisation occurs (Gadoud & Johnson, 2015; Wilson et al., 2011), while Booth et al. (2016) suggest planning should occur when good symptom control has been achieved. Ideally it should be initiated as early as possible in the illness and certainly before cognitive decline and deterioration of communication; however with predictive gene testing, many people with HD may receive a 'diagnosis' years before symptom onset and initiating EoL planning at this stage is contentious (Tarolli et al., 2017).

Thoughtfully prepared ACP can enhance quality of life during late stage HD and provide reassurance to relatives (Simpson, 2007). Written ACP tend to result in less aggressive treatments (Boersma et al., 2014; Gadoud & Johnson, 2015; The Victorian Department of Health, 2014) which could otherwise prolong dying and diminish quality of life (Huntington Society Canada, 2016). Autonomy is promoted through ACP and the individual may feel reassured by the knowledge that their preferences for EoL care will be followed and that the burden for decision making will not be placed on their families (Booij, Engberts, Rödig, Tibben, & Roos, 2013; Huntington Society Canada, 2016; Regan et al., 2018), leading to greater satisfaction with their care overall (Boersma et al., 2014; The Victorian Department of Health, 2014). Given that advance care planning is a dynamic process, once embedded as part of routine clinical practice, people with HD should be encouraged to discuss and review their preferences at identified points along their illness trajectory , perhaps annually in conjunction with functional changes (Vaughan & Kluger, 2018).

Talking about EoL wishes with an HD patient is part of the legal, professional and moral responsibility of the physician (Booij, Engberts, et al., 2013) and is desired by most people affected by HD; however, they often do not know how, or when, to discuss this, or even what options are available for EoL planning (Regan et al., 2018). Only 31-38% of people with HD have documented ACP (Booij et al., 2014; Downing et al., 2018), which is low given the prolonged and severe disease trajectory.

Barriers to EoL Planning- Many barriers to EoL planning have been identified in the literature. Reluctance to undertake ACP is a significant barrier, with Boersma et al. (2014) suggesting that neurologists have a propensity to broach the subject too late in the illness, or not initiate the conversations at all (Booij et al., 2014), while Tarolli et al. (2017) suggest a lack of comfort, time constraints and lack of a defined process contribute to this. Booij et al. (2014) found that less than half the people with HD who had EoL wishes had discussed these with their doctor, potentially leading to their wishes not being heard and treatment being provided that is not in keeping with their wishes, with a significant number not being aware that an ACP could be drawn up (Booij, Rödig, et al., 2013). Other barriers to ACP include lack of engagement or understanding of the process in the community (Hagen et al., 2015), patients' denial and fear of the future (Dawson et al., 2004; Klager et al., 2008), a sense that planning EoL is equated with giving up hope (Booij, Rödig, et al., 2013), family conflict possibly arising from feelings of guilt (Klager et al., 2008), and cognitive and communication decline resulting in reduced capacity to participate (Klager et al., 2008). Systemic barriers include insufficient time and competing priorities, inexperience or personal discomfort (Blackford & Street, 2013; Hagen et al., 2015), insufficient training and the belief that it is the responsibility of another health professional (Blackford & Street, 2013). Clinicians may feel that ACP discussions may lead to patient distress by forcing them to confront their inevitable mortality (Tarolli et al., 2017) However Booij, Engberts, et al. (2013) suggest that the discussions can result in peace of mind and reduce time spent worrying about it, while Hubers et al. (2016) found it may actually reduce suicidal ideation, although this was in a context where euthanasia is legally permissible.

People with HD have tended to feel excluded from current debates regarding assisted dying as they recognise that in most jurisdictions it does not (or will not) allow for the complexities of conditions such as HD where the final stages involve severe cognitive impairment and difficulty in identifying a six month prognosis (Regan et al., 2018). They, however, may view euthanasia as desirable or necessary to relieve suffering and where it is not legally available, suicide by other means is considered a rational option by some (Regan et al., 2018) and may occur earlier in the disease trajectory, due to fear of being physically unable to complete this when they most desire it. As one of the few conditions that can be identified before its onset and where individuals have a clear understanding and experience of what their future with the disease will be like, people with HD tend to have a significant interest in assisted dying (Booij, Engberts, et al., 2013; Booij et al., 2014; Regan et al., 2018).

F**acilitators of EoL Planning-** Education regarding ACP, along with resources to increase skills and confidence of clinicians, are critical strategies (Blackford & Street, 2013) to embed EoL planning in practice. Triggers for starting conversations about ACP can be identified and shared with all clinicians as a prompt to assist in initiating conversations and further develop required communication skills (Blackford & Street, 2013). Whilst the majority of the articles reviewed were written by physicians and discussed the responsibilities of physicians for initiating EoL discus-

sions, it has also been identified that care for people with HD is best managed in a multi-disciplinary team (MDT). All clinicians in the MDT could be involved in contributing to EoL discussions, particularly around their specific area of expertise (The Victorian Department of Health, 2014), thus reducing the expectation on the physician to initiate the discussion. The role of a care co-ordinator in the MDT for people with HD has been well established (Macleod et al., 2017) and perhaps responsibility for initiation of EoL discussions sits within this role. Booij et al. (2014) recommend that every person with HD should be asked early in the course of their disease 'their fears, their wishes and thoughts for the future' and given that ACP is best viewed as a process not an event (Hagen et al., 2015), these questions should be repeated at regular intervals. In a qualitative study, people with HD were found to be aware of the possibility of changing their views regarding EoL decisions (Booij, Rödig, et al., 2013) and confidence in knowing they would be asked to review their ACP regularly may overcome a reluctance to plan due to sensitivity to their possible response shift.

Two additional papers reviewed, that were not included in this report, presented tools developed to examine the end of life concerns and end of life planning for people with HD (Carllozzi et al., 2018; Carlozzi et al., 2016). The use of these tools may assist in addressing clinicians reported difficulties in initiating conversations about EoL planning.

Recommended Considerations for ACP and Implications for Practice:

Ideally ACP for a person with HD should include; appointing substitute decision makers and powers of attorney, decisions regarding resuscitation, types of treatment desired or refusal of treatment (such as antibiotics, ventilation, intensive care interventions), decisions regarding hospitalisation and preferred place of death, tube feeding and brain donation (Hussain, Adams, & Campbell, 2013; Klager et al., 2008) as well as concerns, goals and fears of both the individual with HD and their family (Tarolli et al., 2017). Discussions and documentation should include treatments both now and into the future, with clearly identified stages a person may like to refuse specific treatments. It is important that ACP stating the individual's wishes in relation to tube feeding be completed earlier in the illness when they have decision making capacity (Gadoud & Johnson, 2015; Simpson, 2007) and discussions should be had regarding indications for withdrawal of tube feeding if one is to be inserted (Macleod et al., 2017). Refer to discussion box.

Loss of the sense of self, rather than the severity of the disease symptoms was found to be a significant factor in anticipated reduced quality of life and fears for EoL (Booij et al., 2014; Regan et al., 2018) and may be partially addressed through the development of 'booklets' that describe the person and reflect their life and their values before and after onset of HD symptoms (Simpson, 2007). These 'booklets' can be powerful reminders of personhood, conversation starters and memory prompts to assist in developing rapport between the person with HD and carers thereby enhancing quality of life.

Conclusion:

The current literature on EoL planning in HD primarily reflects expert opinion, although more recently has included reports on the thoughts and feelings of people with HD and describes an increasing interest in the early introduction of a palliative approach into multi-disciplinary neurological care (Gofton et al., 2009; Oliver et al., 2016). Discussion regarding palliative care in broader PND literature continues to develop, however palliative care in HD remains under studied. HD provides a unique opportunity to investigate long term palliative care support for a younger cohort who tend to be institutionalised earlier and for longer periods of time than other people (Moskowitz & Marder, 2001; Nance & Sanders, 1996). Initiation of a palliative approach early in HD has the potential to improve management of symptoms, increase the likelihood of ACP being developed and improve the overall quality of life throughout the duration of the illness (Boersma et al., 2014; Dawson et al., 2004; Gofton et al., 2009; Hussain et al., 2013; Kristjanson et al., 2003; Oliver et al., 2016) and therefore all clinicians in a MDT working with people with HD should have an understanding of palliative approaches (Travers et al., 2007).

Further research is required to see if this has a direct impact on patient care and to produce evidence based data to support this approach (Gofton et al., 2009; Oliver et al., 2016). Additional research is recommended into the development and validation of prognostic predictors and outcome measures (Boersma et al., 2014; Dubinsky, 2004) as well as into the EoL concerns and wishes for people with HD. This paper has synthesised the available literature and concluded that implementing a palliative approach early in the management of Huntington's Disease is

recommended. All clinicians working with people with Huntington's Disease should have an understanding of palliative approaches, and the care co-ordinator might be best placed to initiate EoL discussions. Recommendations regarding required components in an ACP for a person with HD have been identified as: appointing substitute decision makers, decisions regarding resuscitation, types of treatment desired or refusal of treatment (such as antibiotics, ventilation, intensive care interventions), decisions regarding hospitalisation and preferred place of death, tube feeding and brain donation as well as concerns, goals and fears of both the individual with HD and their family.

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Practice Point – Tube Feeding in HD

Dysphagia, or swallowing difficulties, is a significant problem in HD, resulting in difficulty ensuring adequate nutritional intake to maintain weight (Novak & Tabrizi, 2010) and can have serious sequelae. Dysphagia is the most common cause of aspiration pneumonia in people with HD (Nance, Paulsen, Rosenblatt, & Wheelock, 2011). Consequently, the question of tube feeding may be raised and should be considered as a potentially life prolonging treatment. Expert opinion is divided on the merits and conclude it should be an individual decision. Indications for tube feeding may include: 10% weight loss over a month, inadequate hydration, repeated aspiration and severe swallowing difficulties (Moskowitz & Marder, 2001). Contraindications include: lack of informed consent, lack of capacity for communication and comprehension, or documented refusal (Moskowitz & Marder, 2001), while poorly controlled truncal chorea and behavioural disturbance should also be taken into account. Some suggest that tube feeding may prolong the life of an individual for whom quality of life is already dramatically reduced (Jones, 2010; Klager, Duckett, Sandler, & Moskowitz, 2008), while the reduced personal interaction people in residential care with feeding tubes receive, compared to those who are orally fed may reduce quality of life further (Jones, 2010; Moskowitz & Marder, 2001). While a person with late stage HD will generally meet all the commonly acknowledged indicators for tube feeding (Huntington Society Canada, 2016; Macleod, Jury, & Anderson, 2017) it does not eliminate the risk of choking, or the potential aspiration of colonised oro-pharyngeal material or aspiration of gastric contents. At end stage HD, the body no longer has a requirement for nutrition and loss of appetite is the body starting to shut down naturally (Gadoud & Johnson, 2015; Huntington Society Canada, 2016; Jones, 2010). Dellefield and Ferrini (2011) report that while they advise patients against tube feeding, 23% of their cohort chose to be tube fed. Swallowing can remain safe even in the event of significant cognitive decline when close attention is paid to appropriate food modifications, feeding techniques and environmental factors (Dellefield & Ferrini, 2011; Jones, 2010). When the person has advanced dementia, residential facilities and families should be encouraged to accept the increased risk associated with oral feeding rather than requesting tube feeding (Jones, 2010) and it is conceivable that some people with HD may document a wish to continue eating preferred foods, rather than have modified textures, if they place a higher value on enjoyment of eating over safety (Vaughan & Kluger, 2018). Clear guidelines on the risks and benefits of tube feeding in advanced HD would be beneficial (Simpson, 2007).

Calendar of Events

2019:

- **7th National Brain injury conference** at Melbourne University 28/29th October 2019
- **Movement disorder conference,** Adelaide convention centre 14th November

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- **52nd Annual Educational Meeting Illuminating Opportunities in a Time of Change**, 18-21st April 2020, Orlando Florida
- **ANNA Annual Conference**. https://www.anna.asn.au/

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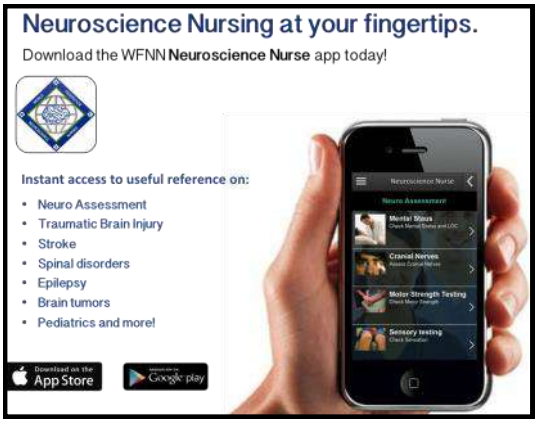
- **WFNN Congress** 20-23rd July, Darwin Australia**. www.wfnn.org**



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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.

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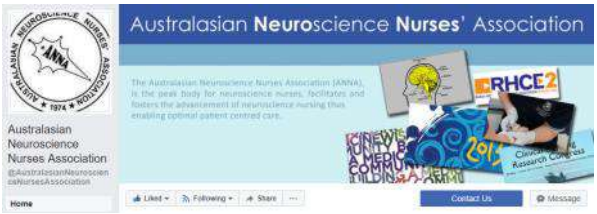

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