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In This Issue:

Editorial

Editor - Vicki Evans

The 2015 Hollywood movie awards has highlighted two movies most notable to neuroscience nurses —

1. *'Still Alice'* - based on the novel by Lisa Genova. The film stars 2015 Oscar winner, Julianne Moore as Alice, a Columbia linguistics professor diagnosed with early-onset Alzheimer's disease. After discovering it was genetically inherited, the movie follows Alice's struggles and progression of the disease— concerned and afraid for her future and how that will affect those around her.

2. *'The Theory of Everything'* - is a biographical film about the British theoretical physicist Stephen Hawking (a notable presence also to those of you who watch 'The Big Bang Theory'!) It portrays the life of a remarkable man, the scientist, family life and his struggle with an incurable neurological illness — amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's Disease or Motor Neuron Disease. The film's primary source is Jane Hawking's memoir, *"Traveling to Infinity: My Life With Stephen".*

It is therefore poignant to begin this years' AJoN with a Western Australian article discussing the role and function of the WA MND Association.

Then follows several interesting manuscripts from the 2014 ANNA Conference (held in Canberra), beginning with a discussion through case study of Central Pontine Myelinolysis; and a moving recount of a situation where the neuroscience nurse became the neuroscience patient, coinciding with the 2011 Christchurch earthquake in the article "Both Sides of the Counter".

We are also fortunate to have a number of manuscripts from an array of countries — a phenomenological study from New Zealand portraying the experience of living with myasthenia gravis; an article from the USA highlighting the importance of the multidisciplinary team approach for improved patient outcome; and from Japan, the effectiveness of the sitting position without back support, improving patient care. *Enjoy!*

Guest Editorial

Miriam Priglinger MD, Stroke Fellow.
Martin Krause MD, A/Prof. Neurology & Stroke Medicine. Royal North Shore Hospital, Sydney, Australia.

About 2 million Australians suffer from migraines, with women being affected three times more frequently. They can be associated with a significant disability and are underlying cause to a relevant amount of sick leave. Migraine headache is typically one sided, moderate to severe, throbbing headache which is aggravated by movement and usually lasts from 4 up to 72 hours. Often it is accompanied by nausea, vomiting, photophobia or phonophobia.

Acute migraine attacks account for up to three per cent of presentations to ED and are common with inpatients as well. The main focus of acute migraine management should be on a rapid delivery of effective medication. This includes Aspirin PO or Sumatriptan SC/ PO in combination with Metoclopramide IV or Prochlorperazine IV. Corresponding recommendations are made by Headache Australia (Brain Foundation) and Emergency care – evidence in practice series. Despite clear Australian guidelines, 50% of patients presenting to public hospital emergency departments with acute migraine are treated with opioids which were demonstrated to be ineffective.

The use of triptans in ED patients and inpatients is very low despite being the current gold standard for acute migraine treatment. Several studies showed their superior effect over other treatments including Aspirin and Ergotamine. The contraindications for the use of triptans are coronary artery disease and cerebrovascular disease due to potential vasoconstrictive effects. The main side effects of this class of medication are chest tightness or chest pain. Otherwise they are well tolerated and constitute the treatment of choice, preferably applied subcutaneously. The following triptans are available in Australia: Sumatriptan 6mg SC or 50-100mg PO or 20-40mg via nasal spray. Naratriptan 2.5-5mg PO. Rizatriptan 10-30mg as wafers. Eletriptan 40-80mg PO. Zolmitriptan 2.5-10mg PO. They can be administered in combination with Prochlorperazine IV or Metoclopramide IV.

Alternatively, Aspirin 900mg PO combined with Prochlorperazine IV or Metoclopramide IV has been repeatedly proven to deliver rapid and reliable pain relief. If aspirin cannot be administered due to intolerance or vomiting, Paracetamol 1g IV should be considered.

It seems reasonable to initiate a paradigm shift in the real-life management of acute migraine attacks in Australian hospitals since besides helping to avoid hospital admissions, an effective management means that patients can benefit faster from the superior treatment.

Further information — Brain Foundation:

www.headacheaustralia.org.au

Marmura MJ, Silberstein SD, Schwedt TJ. The acute treatment of migraine in adults: the american headache society evidence assessment of migraine pharmacotherapies. Headache. 2015 Jan;55(1):3-20.

Describing the role and function of Care Advisors in the Motor Neurone Disease Association of West Australia.

Gilly Smith

Abstract

Background: The Motor Neurone Disease (MND) Association of Western Australia provides information, education and advocacy for people living with MND. The role and function of the personnel who provide this service has not been described in the literature and is therefore poorly understood by both healthcare professionals and the public.

Purpose: To describe the role and function of the West Australian Motor Neurone Disease Association (MNDA [WA]) Care Advisors (CAs).

Method: Ethnographic observation of seven MNDA (WA) CAs in their normal daily setting. Interviews with end users of CA service (people living with MND and their carers). Analysis of the observations and interview transcripts was undertaken to identify themes.

Findings: The CAs were observed to undertake their supportive role with passion. Clarity around the role and function was ambiguous, even amongst the people in the roles. It is suggested this is due to limited formalised processes and procedures in an organisation that has moved from originally being run by volunteers through to a professional not-for-profit organisation. This in turn led to issues in recruitment and retention, clinical knowledge versus clinical care and demonstrating capabilities against Key Performance Indicators (KPI's) for reporting to funding bodies.

Conclusion: Multiple opportunities were highlighted during this study for these service providers to develop robust procedures to record the nature of their work, develop resilience in their work place, and ensure ongoing professional develop processes are engaged.

Keywords: *motor neurone disease, Care Advisor, case management.*

Introduction

Motor Neurone Disease (MND) is an aggressive, degenerative neurological disease with no known cause or cure. It is indiscriminate in the age cohort in which individuals are affected; and no particular race is more or less prone to the impact or incidence of this disease (Craft, Tiziani, & Gordon, 2011). MND is a "fatal neuromuscular condition that afflicts as many as 1 of 350 males and 420 females over the age of 18" (Kiernan, 2007, p 2). The disease is most commonly diagnosed after the age of 40 years and is usually slowly progressive over 3-4 years. The incidence of MND globally is 1.5 – 2 patients diagnosed per 100,000 per year (Doyle, Hanks, Cherny, & Calman, 2005) with an approximate lifetime risk of developing the disease of 1 in 800 (Phukan & Hardiman, 2009). The MND Association of Western Australia (MNDA WA), has approximately 140 MND patients and their families registered to receive support at any given time. The volume of clients fluctuates as new clients register with the Association and others succumb to the disease. The support the Care Advisors supply may include approximately six months' grief support (Department of Health, 2008).

Questions or comments about this article should be directed to Dr Gilly Smith, Senior Lecturer School of Nursing and Midwifery, Edith Cowan University Western Australia. Email: gilly.smith@ecu.edu.au

The clinical presentation in MND is one of muscle weakness which may involve all muscles, or a paresis (partial paralysis) which corresponds to a single muscle group, with possible hyperreflexia (over responsive reflexes) and neurone degeneration affecting both the upper and lower neurological pathways. Muscle wasting and weakness of the limbs become evident, with eventual progressive involvement of motor neurones controlling speech, swallowing and respiration (Gent, 2012). Due to the devastating implications of the disease, and with no single diagnostic test presently available, there may be a long period of symptoms, often up to a year, with exhaustive testing to eliminate alternative diseases prior to a definitive diagnosis (Oliver et al., 2006). It is at the point of diagnosis a per-

son living with MND, their family and significant others, may access the support of the MND Association.

The MND Association provides the primary source of advocacy, social, physical and emotional support to people living with MND and their families and carers across Australia (Kiernan, 2007). The key contacts who provide this service are the Care Advisors (CA). The role of the CA developed from its inception in Western Australia some twenty years ago as a group of volunteers, to the present situation where the Association, as well as case coordination the Care Advisors has moved from that of a supportive friend to a professional service.

To date, the work of the Care Advisors has been poorly described in the Australian context and not at all in West Australia. A needs analysis of patients and carers living with MND conducted by Colyer (2009) indicated the MNDA (WA) Care Advisors are highly regarded however what CAs actually do, what supports they require as individual healthcare professionals, and what risks the organisation faces if their corporate knowledge is lost through attrition, has not previously been analysed. This paper reflects the key learnings from an internal research study to observe, question and document the work, role, function and processes of incumbent and past Care Advisors from MNDA (WA).

Methodology

The theoretical framework for this study is set in social research, with grounding in the qualitative research method and logic of thematic analysis. Ethnography challenges quantitative research by observing interactions, behaviours, and written reflections, asking questions of the inhabitants (informal interviews), then taking this data and eliciting themes to develop a rich depiction of the culture. Ethnographic research stresses discovery and takes the position human behaviour and the ways in which people form and make meaning of their worlds and their lives are variable and locally specific (LeCompte & Schensul, 1999).

In this case, the ethnographic study included a combination of non-participant observation, review of organisational processes, record-keeping and staff interaction, as well as semi-structured interviews with incumbent and former Care Advisors, clients of the service, current and former carers of people living with MND, and some members of the public who were identified as bereaved from the loss of a partner to MND.

Ethical Considerations

This research was supported by the Motor Neurone Disease Association of Western Australia Board of Directors and was conducted under ethics approval of the Edith Cowan University Human Ethics Research Committee. Participants were informed about the nature of the project, their right to withdraw at any time and that ultimately the findings would be presented to both the MND Association of Western Australia Board of Directors, and be submitted for publication. In order to provide a level of anonymity to the participants, comments are attributed to either a patient (P 1), family member (F 2), bereaved (B 3) or Care Advisor (CA 4).

Sample

The sample for the observation was purposive as there was a finite number of Care Advisors working for the organisation at the time of the research. A total of four CAs were observed in their daily workplace, including during telephone, face-to-face and home interviews with people living with MND. Consent was gained from all CAs to observe their work. Consent was obtained from all clients, families and carers where their interaction with the Care Advisors was observed by the non-participant researcher.

The sample for the interviews included two separate groups:

- Current and former Care Advisors (N=7); and
- People living with MND who were supported by Care Advisors (N=6), and current carers (N=17). This second group included bereaved family members (B=5) or carers who were willing to talk of their experiences with Care Advisors.

The review of organisational processes and record-keeping was undertaken over a period of one week and consisted of documented administrative processes related to the work undertaken by Care Advisors, organisational job descriptions, and the organisational Operational Plan, with associated policies and procedures.

Data Collection

Research was undertaken over a three month period. This included a period of observation and interviews. The Motor Neurone Disease Association of Western Australia

(MNDA WA) was keen to support this research and thus agreed to use their website as the primary recruitment location for people living with MND and/or their carers to volunteer to be interviewed.

An additional group of interviews came unexpectedly through word of mouth, with several carers and people living with MND contacting the researcher through their individual Care Advisors requesting to be involved in the research. Care Advisors were either interviewed, or interviewed and observed in the carriage of their daily duties. Interviews were conducted with 17 carers (both current and bereaved) and six current clients.

Data Analysis

The interviews and observation notes were transcribed verbatim and this data was entered into a computer program which picks up similar words or phrases to identify nodes that are consistent across all (or most) of the data (Nvivo). These nodes were then linked together in similar groupings or themes. The themes identified through this process included understanding the service, recruitment and retention, development of data collection capability to support describing the service, clinical knowledge versus clinical care, and the nature of supportive resources.

Findings

Role Ambiguity

When asked, all the CAs described their role as "*providing education, advocacy and information*"… to people living with MND and "*their families or carers*", and "*healthcare professionals who worked with these clients*" (CA 1, 2, 3, 4). Consistency, however, was absent when the CAs were asked specifically how they provided this service. Some CAs described their role as to support the clients by providing knowledge and information, others suggested they journeyed through the disease progression with the clients, and a third group of CAs spoke of advocating for services, equipment and clinical care for their clients.

Understanding the Service

MNDA WA has approximately 140 clients registered with the organisation. As people living with MND are in various stages of their disease progression, some require more interaction than others, and others require no support. The complexity of understanding when to engage with a client, their family or carer comes to the CAs only through time and experience in the role. It is suggested key to understanding the role and function of the Care Advisors, is gaining an understanding of the interaction which may be required

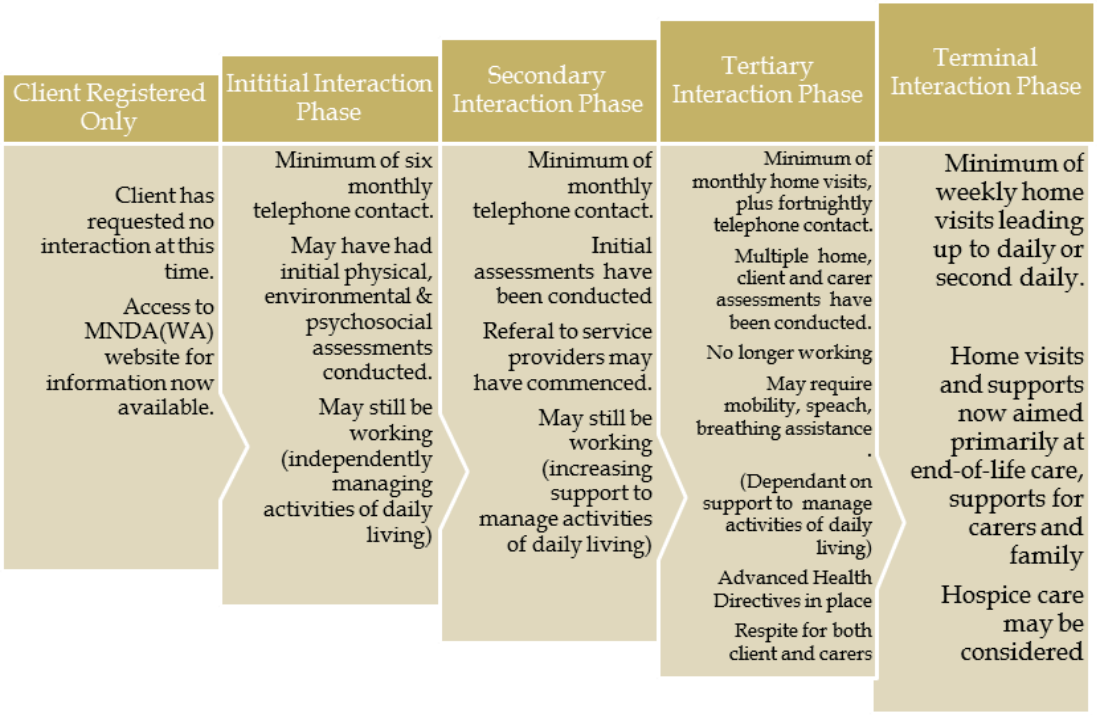

Figure 1 (Above): *Phases of MND client interaction (Developed for this study).*

at various different stages through the disease. A short descriptor of five different phases of client interaction is offered in Figure 1.

Recruitment and Retention

By 2013 the Association had moved from a volunteer basis to a service provided by personnel with professional healthcare backgrounds, and it recognised that in order to recruit and retain the right people to be Care Advisors, they needed to be able to describe the processes associated with the role. Having come from a volunteer service where the records were handwritten, there was an inconsistent approach to assessment. There was no standardised assessment, filing system or computer filing processes, thus the processes to capture the actual work associated with the support and advocacy roles of the Care Advisors was less than clear or simple. This was found to result from a lack of policies and procedures, inconsistent staff induction, inconsistent mentoring and a lack of professional development structures.

Some staff reported they had received excellent induction experiences from supportive mentors, while others reported their experiences indicated the level of induction and mentoring was personality-based. Those staff who had not received positive experiences in their induction or mentoring articulated this was one of the primary reasons they ultimately left the Association.

Electronic and manual folders of information and process mapping were provided to each CA and these were updated annually (or on an "as needed" basis) by the senior CA. The Association moved from individual staff networks of healthcare service providers to a generic listing available to, and updated by all, staff working in the Association. Protocols for interaction with service providers outside the Association were mapped and a consistent approach adopted by all CAs. The Association recognised the impact of not having these processes clearly mapped and quarantined time for each of the CAs to map one process. They then added time to the weekly staff meetings to review these maps in order to deliver a consistent approach to any given process. The process engaged the staff rather than imposing a top down set of rules. The following quotes exemplify this experience,

> *"In the past I've either done it the way I was shown when I first started here, or developed my own way of doing things. Looking at the different ways we all did the same thing was a real eye opener" (CA 1).*

> *"Initially I thought this whole mapping thing was a complete waste of time I didn't have. Because we've developed set plans for how to do things and we are all doing it the same, we save so much time and it's forced us to work together rather than independently" (CA 5).*

Induction also included a review of the interprofessional set of guidelines for the office setting, including communication, access to client information (electronic and manual filing systems), and administrative processes such as notification of death.

Induction and mentoring also included a period of "shadowing" where the new CA did not take on a full case load initially; instead they worked alongside and experienced CA for a period of two weeks, gradually taking on their own client load. On the occasion of a first home visit or new client intake, the experienced CA was observed to take the lead in interactions. On the following two or three occasions, the experienced CA supported the new CA, allowing them to take the lead, then provide feedback to the new staff member on ways to improve on their interaction and/or assessment.

Meeting the professional development needs (PD) of the Care Advisors commenced at the time of their employment with the induction and mentoring processes, but were felt by all interviewees to be limited. They wanted opportunities to develop their skills and knowledge around the care of people living with MND, and implementing evidence of best practice in the support of people who care for people living with MND.

> *"Part of the problem is the lack of research published about caring for people living with MND. There's lots of publications about the science of the disease, but very little evidence of best practice for care" (CA 4).*

In the absence of any formalised PD, staff determined to develop other capabilities to ensure the smooth functioning of their workplace. Inclusive in these capabilities was data collection.

Development of Data Collection Capability

Opportunities to improve the manner in which statistics for reporting day–to–day business were identified as a result of the CA task process mapping, as a potential way to gain time

for CAs to spend less time on documentation tasks. The development of electronic assessment tool(s) and an electronic client database which links to each client's electronic file, has had an immediate impact on the calculation of statistics required for monthly reporting to the Department of Health. These included data sets for how many hours per client per day per CA for home visits, telephone contact, interviews with clients, carers and families; clinic attendance, interaction with member of the interdisciplinary team, coordinating support services and respite.

This study identified further opportunities for the Association to develop robust processes upon which data collection capabilities may be enhanced to articulate how much time intake, registration, allocation of services, provision of education, developing educational programs and administration of equipment allocation takes.

Clinical Knowledge vs Clinical Care

It was made clear to the researcher on several occasions that the role of a Care Advisor is not clinically based and they do not provide any clinical intervention. This is sourced within the Perth metropolitan area primarily through the neurological nurse employed by the Multiple Sclerosis (MS) Society. At this point there is only one neurological nurse and this presents an immense risk to the Association in terms of succession planning, sick leave, annual leave and age of the incumbent. The current incumbent is an extremely experienced nurse, however they are working toward the end of their nursing career and the members of the Association who rely upon her clinical skills and knowledge would be poorly supported in the event she leaves or is unable to continue in her role.

A similar situation was noted to exist with the clinic nurse at the State rehabilitation clinic. This person has an enormous amount of corporate clinical knowledge about the care required for people living with MND, yet no processes have been put in place to ensure their knowledge is captured prior to retirement. Succession planning and development of clinical practice guidelines are required.

A third group of clinician nurses the Care Advisors interact with are the rural and remote community nurses. Observation and interviews with several Neuroscience Council-funded rural community nurses indicate an overlap of services provided by the MS Society nurse, the MNDA WA Care Advisors and the community nurses who have developed a therapeutic relationship with clients in their community. Several carers interviewed indicated their frustration with *"too many fingers in the pie*" *(F2)* and *"too many people giving different information*" *(F7).* This may be one of many reasons articulated in the needs analysis survey as to why individual clients registered with the Association and then chose not to use the services, or of more concern, elect not to join the Association initially. Word-of-mouth in small rural communities will always provide "evidence" where an Association has not shown itself to be a functional organisation working together with all the components of the health care team.

The need to have a background in clinical healthcare was noted to be a major theme, when considering the capacity of the CAs to perform their primary function of assessment. Whether the first interaction with a person living with MND was by telephone, in the Association office building, or in the client's family home, all CAs performed assessments which could be clearly observed to fall into three discrete categories: psychosocial, physical and environmental.

Psychosocial assessments documented less consistently than physical and environmental assessments. The CAs interviewed suggested this was a result of the subjective nature of psychosocial assessments and the fact these were most often based on conversations not formalised assessments using psychometrically tested tools. These assessments looked at how well or poorly the person living with MND, as well as their family and primary carer, were coping with the change in their health and wellbeing.

> *"Simply put, we look at how they are coping with dying" (CA 4).*

CAs were seen to suggest respite when either the person living with MND or their carer needed time out or time away from each other. The CAs noted a move away from respite being provided by facilities, instead moving toward a preference for service providers to come into their home to provide respite.

> *"It's hard enough trusting someone else to look after him the way I do, but asking him to go to some place that isn't familiar with what MND is…that'd be too much for both of us to cope with" (F4).*

The CAs also suggested interactions with other people who had the disease and other carers, not only for the social interaction with people who understood the situation the cli-

ents and carers were experiencing, but also to learn how others coped. Learning strategies from others who were "living" the same life was seen to be of greater value to the carers interviewed than "reading it from a book".

> *"I think we were really fortunate to have CA3 as our Care Advisor. We met many other people with MND over the three years of [husband's name] illness. We needed someone to be really professional and that's what we got. I wouldn't have liked someone who was just there for a social chat. I have family for that" (B2*).

> *"When CA 1 came the first time she brought a book along written by someone who had MND. I thought it was a nice book but there was too much information all in words. I only read the beginning bit and then bits when things changed, but then she left and CA5 came instead. She gave me a smaller pamphlet of information and a website to look at. That was easier for me as it was in smaller snippets of information "(B5).*

Physical assessments followed a more prescribed, subjective process looking at mobility, speech, swallow, communication, cognition and physical capabilities related to strength and gait. Interventions and referrals resulted from changes to physical assessment, for example a Speech Pathologist, Respiratory Physician or for mobility or communication aids.

Finally, the CAs were circumspect in their assessments of the client's environment. Carers and clients both insisted remaining in their home where they felt "safe" was paramount to living with the disease for as long as possible. In order for them to be able to achieve this, the CAs introduced the concept of minor alterations to the home in such a way as the client and carers did not feel the change was imposed. Such interventions or alterations included the change of stairs to include ramps, risers over entries, handles in showers, removal of mats and other trip/fall hazards.

> *"CA3 brought the shower chair one day. I didn't even know what one was. It made it so much easier in the mornings that he could sit down. Neither of us had realised he was that weak, but she must've just seen the changes from her last visit" (C4.)*

> *"CA3 was amazing for dad. She'd arrive with bits of equipment that made mum's life much easier. First it was a sort of extension clip to lift things off the ground. That was great because his balance went really early and he had lots of falls trying to pick things he had dropped up off the floor. Later a chair arrived with a delivery van, then it was the lifter. I don't remember mum ever saying she did an assessment or snooped through the house, but she must've done to know what he needed. Or more correctly what mum needed to care for dad" (F7).*

Supportive Resource

Interviews with current and former clients of the CA service provision were unanimous in their description of the Care Advisors being "*angels*" who helped them to navigate through the minefield of available health care services and provided information and education about the disease both in a timely manner relative to their physical, psychosocial or financial needs. They were also seen as "*partners in the journey*" from diagnosis through the disease trajectory and into the first months of bereavement.

Patients, carers, family members and bereaved listed similar support services provided by CAs. These included information about the disease and prognosis regarding physical deterioration; information about services for people living with MND, how to access financial support for people living with MND, how to access equipment, completion of forms relating to accessing equipment or services, and provision of equipment; knowing when the patient needed physical aids or the service of home care or nursing support; knowing when the carer or family needed support; and most often cited, someone who would listen to them and share a cup of tea.

> *"Even though [husband's name] has been gone for five years, I still miss my cups of tea with CA1. She rang every week and then started visiting more often. She would always stay for a coffee while I had a cup of tea. We wouldn't necessarily talk about MND, but she was a good listener" (C1).*

> *"It's only a couple of months since [patient's name] died. CA2 drops in once a week to check on me* "(C7).

Discussion

This study has provided a description of the previously unpublished role and function of

the Care Advisor Service provided to people living with Motor Neurone Disease in Western Australia. Similar titles for MND staff exist across Australia with nomenclature differences (Regional Advisors in New South Wales, Victoria and Tasmania). However to date, no studies have been undertaken to determine if the role and function is the same for each of these positions. The MND Associations for each state have briefly described these positions on their organisational websites. However these are insufficient for people external to the organisation to understand fully the complexity of the role.

Part of the lack of understanding about the role may be attributed to the role title. The title "Care Advisor" may imply a level of clinical care not commensurate with the actual role function. For this reason, discussion about the appropriateness of the role title may be due, not only in Western Australia, but more widely across the country. The role is more aligned with the broad title of "case coordinator" which is defined throughout literature as "providing a continuum of healthcare services for a defined group of clients" (White & Hall, 2006, p E99). The emphasis for case coordinators is on the word "services" rather than on "care".

Based on the findings of this study, the Association would provide a more consistent approach to their service delivery, developing a process for induction - A "buddy" mentoring system, whereby an experienced CA is appointed as the mentor for new CAs which would be beneficial. Development of clear relationship parameters are also important, particularly where CAs interact with community nursing staff. Development of clear processes will avoid duplication of effort and reduce confusion for clients. Leading on from these professional development processes, is the need to clearly articulate reporting processes and robust data collection processes with infrastructure to support the CAs to collect and collate this information.

Conclusion

The role of the MND Care Advisor developed from its inception in Western Australia to the present situation where the Association and the service the Care Advisors provide has moved from a supportive friend to a professional service. The growth in service delivery for Care Advisors has not been supported by growth in documentation of this service, electronic records, consistency in service delivery,consistency in information being provided clients, and moderation of service delivery amongst the various Care Advisors.

Development of mentoring programs and processes for new staff, along with the development of key practice guidelines based on evi-dence of best practice as is the industry standard for all health care service delivery are fundamental to the ongoing professional development and professional image of the Care Advisor. The current incumbent Care Advisors and supportive Executive are mov-ing to address these issues, bringing the ad-ministration of the service into line with the professional clinical application of knowledge to the role of MND Care Advisor.

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Central Pontine Myelinolysis: A Case Study

Leigh Arrowsmith, Christopher Tolar

Abstract
Central Pontine Myelinolysis (CPM) commonly presents as a complication of treatment in patients with profound life threatening hyponatraemia. It occurs when the sodium level is corrected too rapidly. Hyponatraemia should never be corrected at a rate greater than 8-10mmol/L of sodium per day. Rapid correction causes extracellular tonicity and will continue to drive water out of the brain's cells leading to cellular dysfunction.

Frequent clinical signs include dysphagia, dysarthria, diplopia and acute para/quadraparesis. Patients can also experience locked in syndrome, where cognitive function is intact but all muscles are paralysed with the exception of eye blinking.

CPM gets its name as it occurs when cell dysfunction causes destruction of the myelin sheath of nerve cells in the brain stem, more specifically the pons. It is associated with poor prognosis and prevention is of primary importance.

Freddy is a 35 year old freelance graphic designer, fitness instructor and ultra-marathon runner. In October 2011 he competed in the Sahara Marathon in Morocco, a 6 day 255km ultra-marathon. At the end of the third day Freddy was found collapsed and vomiting. He was confused and was suffering severe leg cramps. The next morning Freddy suffered a single convulsive episode and was subsequently transferred to a hospital in Egypt.

Key Words: *Central pontine myelinolysis, myelin, pons, hyponatraemia*

Introduction

Central pontine myelinolysis (CPM) is also referred to as Osmotic Demyelination Syndrome. It was first identified approximately 50 years ago. Pontine refers to the stem of the brain. Myelin is a covering that protects the pontine nerve cells. CPM is a neurological disorder defined as a demyelination of the nerve cells, in the pontine area and in extreme cases it can extend into the extra-pontine area. CPM can occur from various reasons, but the most common cause is from osmotically induced demyelination, due to overly rapid correction of serum sodium in a hyponatraemic patient (Medline Plus, 2013).

Hyponatraemia

This is a common electrolyte imbalance. Sodium is one of the most important elements in the body that accounts for 90% of extracellular fluid cations. Hyponatraemia refers to a sodium deficiency in relation to the amount of water in the body (Pradhan, Jha, Singh, Gupta, Phadke & Kher,1995). The normal serum level of sodium is 135-145mmol/L. Common diagnostic tests in patients with hyponatraemia include:

- Serum osmolality less than 280mmol/L
- Serum sodium level less than 135mmol/L
- Urine specific gravity less than 1.010

Hypernatraemia

This is a less common problem and refers to an excess of sodium relative to the amount of water in the body. A patient is considered to have hypernatraemia if their serum sodium is above 145mmol/L. Sodium balance is maintained by Anti Diuretic Hormone (ADH) which is secreted from the pituitary gland into the blood stream. It can be corrected by lowering sodium or increasing body water (Stöppler, 2013).

Clinical presentation

According to the National Institute of Neurological Disorders and Stroke (2013), the typical symptoms of CPM usually begin 2-3 days after the over-correction of hyponatraemia

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has occurred. The most commonly observed symptoms of CPM are:

- acute quadraparesis
- dysphagia
- dysarthria
- diplopia
- loss of consciousness

The key features of the neurological exam include confusion, horizontal gaze paralysis and spastic quadriplegia. Increased limb tone, weakness, hyperactive reflexes and Babinski sign are all typical of lesions involving upper motor neurons.

In some instances, brain damage to the pons from rapid myelinolysis of the corticobulbar and corticospinal tracts in the brainstem leading to "Locked in Syndrome" or death. "Locked in Syndrome" is when an individual has full consciousness and cognitive function intact, but has severe paralysis of the voluntary motor system where movement and communication is not possible, however patients are able to blink or move their eyes vertically. Delerium and coma are extremely common in CPM (Hickey, 2003). This results from lesions in the pontine tegmentum and/or thalamus. Magnetic Resonance Imaging (MRI) is the modality of choice. MRI images demonstrate hyperintense or bright areas where demyelination has occurred (Hromanik, 2010).

Treatment of CPM

Once demyelination of the pons has started there is no cure or very little treatment that can be offered (Abbott, Silber, Felber & Ekpo, 2005). The only treatment is that of the symptoms alone.

These include:

- physical therapy, to improve balance and retain range of motion in limbs.
- a dopagenic medication such as Levodopa to increase dopamine and control tremors and the difficulties with swallowing and speech.

Nurses can assist in the treatment, mainly by keeping the patient comfortable. It is imperative to source an effective communication tool, to allow a patient to be involved in their care and keep some "normality" in their life. Nurses can provide family support and refer the patient to the necessary Allied Health teams for ongoing management.

Prognosis

Although CPM was considered to have the mortality rate of 50% or more, early diagnosis has led to better prognosis for many. Most individuals improve gradually but continue to live with significant deficits.

Case Study

Freddy (not his real name) is a 35 year old freelance Graphic Designer and a fitness enthusiast. In his spare time he is a fitness instructor and ultra-marathon runner. In 2011 Freddy went to Morocco to compete in the Marathon des Sables or the Marathon of the Sands which is a 6 day stage race which covers 250 km through the Sahara Desert. This multiday event is held every year and is considered the toughest foot race on Earth.

On day 3 of the event Freddy was acting normally and interacting with friends. Late in the evening Freddy was found near his tent suffering leg cramps, he was confused and it was evident that he had been vomiting. He was assessed by race doctors and given fluids, and it was recommended that he be transferred to the closest major hospital.

Whilst travelling to the base camp the next day Freddy had a single convulsive episode, and became more confused and agitated. Subsequently he was rushed by ambulance to a major hospital in Egypt. On arrival to the hospital it was reported that two other athletes were admitted to the same hospital with similar conditions. Freddy was admitted on 8th October 2011, his blood profile was:

- Serum Na^+ was 108mmol/L
- Rest of electrolytes were normal
- Creatinine Kinase (CK) was 30,000u/L(<1,000u/L)

Elevated levels of the enzyme CK indicate muscle damage or muscle strain such as in the case of a heart attack or the muscles being overworked (Medical Health Tests, 2011). In this case the excessive running in the marathon done by Freddy could have contributed to his high CK levels.

Freddy's vital signs were as follows BP 125/53, HR 92bpm, RR 25bpm, central temperature was 42.9℃, and Sp02 99% on RA. His GCS was 13 (E4 V4 M5).

There was nothing obvious reported on both his CT and MRI. It was decided that treatment would start focusing on, the correction of electrolyte imbalance, treatment of rhabdomyolysis, the management of disturbed level of consciousness, and the treatment of fever. It was recommended that Freddy

stay in the ICU for closer monitoring.

An unknown IVF was infused at 200ml/hr and hypertonic saline was given at a rate of 20ml/hr to correct symptomatic hyponatraemia. Freddy was administered antipyretics to control fever and he was also started on antimicrobial and anti-viral medication to control possible infection, as well as anticonvulsants for his reported seizures.

On 9th October 2011, approximately around 36 hours after treatment had started it was documented that Freddy's CK levels had significantly declined but were still slightly elevated and his Na+ levels had started to rise *'gradually'* reaching 138mmol/L. However Freddy's LOC did not improve, the medical staff mentioned he had become 'locked in', with no eye fixation, increased motor tone and spasticity, and an inability to walk or sit independently. He also had 2 or 3 generalised seizures around this time. The team decided that if Freddy's LOC didn't improve in the next few days they would do a spinal tap/lumbar puncture.
A MRI of the brain (Figure 1) was performed to exclude central causes, but showed that no abnormalities were detected. On October 10th 2011, Freddy's vital signs were - BP 110/50, HR 89bpm, RR 21bpm, Sp02 99% on RA, temperature 38.2°C, and urine output 200mls/hr.

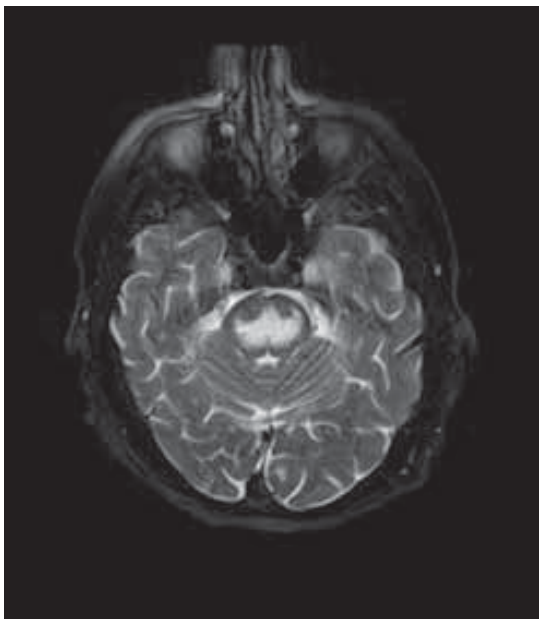

Figure 1 (Above): *Freddy's MRI on presentation at Westmead Hospital.*

It was documented that Freddy's current diagnosis was symptomatic hyponatraemia, heat stroke, and rhabdomyolysis. The team were unsure of what was happening to Freddy, a reporting medical officer said... "*I cannot explain his elevated enzymes...and although they have dropped, they still remain in the thousands.....I am unclear of what is going on. The low Na+ and the dehydration have been corrected, and there is nothing obvious in the brain neither on his CT or MRI. There are no signs of infection, his breathing is normal, his chest is clear, and his abdomen is soft.....I am treating him conservatively without any specific diagnosis at hand."* The medical staff decided that Freddy had treatment to the level of care able to be provided and that it would be beneficial for him to travel to a higher level of care for re-evaluation and second opinion. A German hospital answered the call and agreed to accept Freddy under their care.

Freddy arrived in Germany 12th October 2011, ninety-six hours after initial onset. Primary reports state that *"the patient is awake but unresponsive with present mutism, the general muscle tone of his extremities and torso are increased, his neural tension tests were positive, and he showed negative Babinski signs bilaterally."*

Initial MRI showed abnormalities in the left corpus callosum, para-hippocampal gyrus and left occipital lobe, his EEG was abnormal and suggestive of subcortical dysfunction, without potentials for epilepsy, and CSF results from spinal tap/lumbar puncture showed only a minor disturbance of the barrier function, and no indications for an inflammatory infection of the CNS. Given these results and the patient history the medical staff in Germany decided to initiate anti-epileptic therapy in the form of Levetiracetam. Freddy tolerated this and the dose was gradually increased to 2000mg daily with no further seizures occurring. Freddy was also prescribed a dopagenic medication to help facilitate activation of his muscles, and a muscle relaxant to reduce his increased limb tone.

After thirty-six hours, Freddy's limb tone decreased with right sided emphasis, and there was a positive right-sided Babinski sign. With these medications and intensive physio and occupational therapy Freddy progressively began to communicate more and became more aware of his surroundings. He also began tracking and his eyes started to fixate on persons speaking when he was addressed. Although Freddy was becoming more responsive, he still suffered from mutism or being 'locked in'. This proved difficult for

communication. Also difficult was swallowing and due to his dysphagia, a PEG tube was inserted without complications, to help with nutritional support.

A repeat MRI was attended and showed generalised changes consistent with metabolic or hypoxic brain injury. However the team recorded that 'the reason for the patient's actual status could not be clarified at this time.' It was decided that Freddy's 'brain damage' is likely due to him suffering from major fluctuations of electrolyte balance at an early stage, where his severe hyponatraemia was promptly corrected. It was decided that Freddy would require long term neurological rehabilitation, preferably in his home country Australia. This could be done immediately as Freddy was safe to fly on a commercial flight as long as he had a medical escort with him.

Freddy arrived at Westmead Hospital in Australia 1st November, 2011. The medical teams' initial plan for Freddy on admission was for a physiotherapy and occupational therapy assessment, a speech pathology assessment re: speech and diet, rehabilitation referral, social worker review, and dietitian review.

Initial assessments included-

- Physiotherapy (PT):
  - Freddy refused to cooperate and wanted to return to bed to sleep
  - Able to stand and walk independently Freddy was not compliant with the PT staff.
  - Freddy showed no strength deficits
  - Throughout the exchange he was unable to communicate verbally and showed inconsistent eye contact.
- Dietitian:
  - Commence on bolus feeds through the PEG tube
  - 6 times a day with 4 hourly water flushes of 150ml.
- Speech Pathology (SP):
  - Communication: *Auditory comprehension* - Freddy was not following commands, not responding to yes/no questions, and not looking at objects. *Verbal expression*- Freddy was only making minimal eye contact. He had no facial expressions, made no gestures and gave no verbal output.
  - Functional impression: Patient presents with significant cognitive impairment, including severe communication impairment. He is unable to understand simple commands.
  - It was documented Freddy suffered from severe global aphasia, and would benefit from intensive communication rehabilitation.
- Occupational Therapy (OT):
  - Freddy has non-purposeful upper limb active movement.
  - He reaches out, grasps, seeks stimuli but not to command.
  - Patient inconsistently fixing on OT's initial entry to room and he is fixed on the OT's face mimicking their gestures eg: smile.
- Social Work (SW):
  - Noticed the family had been through a 'roller coaster ride' of emotions to which the SW provided supportive counselling and education.
  - Freddy's mum is the primary carer for her husband and has applied to be Freddy's carer.

It was confirmed by the neurology team 2nd November 2011, that Freddy's condition was due to the rapid correction of hyponatraemia hence giving the diagnosis of central pontine myelinolysis. Despite the new diagnosis, Freddy continued to improve. Within 1 week of arriving at Westmead he was making eye contact and smiling at the staff, mobilising up to 300m independently only requiring directional assistance, tolerating an oral puree diet with pudding and thickened fluids, attempting some yes/no responses, and speaking in jumbled sentences with some coherent words.

Freddy was seen by the Rehabilitation Team as a 2 week trial to see if he would be suitable for rehabilitation in the Brain Injury Unit (BIU). Initially Freddy was unable to complete simple tasks such as combing his hair. It was noted whenever Freddy became tired he became increasingly agitated. So it was decided short sessions would be most beneficial for Freddy. At the end of the 2 week rehabilitation trial Freddy significantly improved cognitively. After 10 weeks and 3 hospitals, it was decided that Freddy would be transferred to the BIU 14th December 2011, to continue his extensive rehabilitation.

Freddy spent 16 weeks in the BIU at Westmead Hospital he was discharged home under the care of his parents 5th April 2012, after several successful home trials. On discharge Freddy was able to reliably indicate yes/no using a non-verbal thumbs up or down in response to direct questions, use an increased portion of real and non-real words, and he was able to understand and follow simple routine spoken commands such as 'sit down'. Freddy was able to use some routine gestures in a functional manner such as pointing to a comb and gesturing brushing his hair, understand the spoken function of most daily objects, reliably follow conversations with staff and family, demonstrate active listening skills such as looking at the other person, nodding his head and using fillers such as 'yeah' or 'okay'.

Conclusion

Freddy now lives at home with his parents who are his guardians. Although he will never be able to live independently by himself reports from his family are that his sense of humour remains the same, as he constantly is playing tricks on his family which he finds amusing. He does have good and bad days but his family report that he is a pleasure to be around and most pleasing of all for Freddy is that he has joined a running club which he attends three times a week which he is enjoys immensely.

From the case study and the demonstrated evidence, it is clear that patients presenting with hyponatraemia should be closely monitored whilst sodium correction is taking place. CPM symptoms can mask other neurological conditions so it is imperative that the 'over correction' of sodium does not take place, and that the replacement of sodium does not exceed 8-10mmol/l in a 24 hour period, which is the recommended rate of replacement. It is also advised to consider CPM as a diagnosis when patients display signs and symptoms, such as diplopia and a decreased level of consciousness. This early detection can ensure that the patient receives adequate treatment and that appropriate rehabilitation can take place.

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Both Sides of the Counter

Colin Woodhouse

Abstract:
Colin is a neuroscience Registered Nurse originally from the United Kingdom (UK). He had his first seizure in the UK. He and his family emigrated to Christchurch, New Zealand in 2007. Whilst at work on the neuroscience unit, Colin had another seizure resulting in a significant head injury. He was in rehab when the deadly Christchurch earthquake hit. *Both Sides of the Counter* covers his experience as a neuroscience nurse caring for others and then how things can quickly change - as a neuroscience patient with a head injury. This is his story.

Keywords: *Neuroscience nursing, head injury, epilepsy, rehabilitation*

Introduction: the UK
Unlike most nurses I have a degree in geology. I graduated in 1987 and spent most of the next 8 years working in the oil industry. This I grew to hate and decided to do something very different. Nursing appeared promising. It is part scientific and involves meeting lots of people. I thought I'd find it interesting.

It seemed a good idea to get some experience in the health service prior to starting my training. I was living in Edinburgh and got a job as a hospital aide in the Scottish Brain Injury Rehabilitation Unit. I have to admit I spent a fair part of the first two weeks thinking I'd made an enormous mistake. However, I got used to wiping bottoms and started to feel I was heading in the right direction.

I trained in Leeds. I did my medical placement in the Neurosciences Rehabilitation Unit at Chapel Allerton Hospital. I enjoyed it so much that I did my final elective placement there too.

During my training and the time as a hospital aide, I met patients with all sorts of neurosciences issues. Frontal head injuries with personality changes, expressive and receptive dysphasia, strokes, hemiplegia, neglect, multiple sclerosis, motor neuron disease, Guillane Barre Syndrome and many more neurological illnesses. All of these went onto my list of things I didn't want to get, but I found them fascinating. Just before qualifying, I felt rehabilitation was where I should be. I also thought it would be good to get some acute experience to have an idea of what patients had been through prior to arriving in rehabilitation. I got a job in acute neurosciences and really enjoyed it. There was no way I was going to leave the acute area and go to rehabilitation!

I spent my first year on one of the surgical wards followed by 6 months in neurology and 6 months in the neurosciences high dependency unit (NHDU). I then went back to working on the neurosurgical ward. The 6 months in NHDU were fantastic and left me feeling I could cope with pretty much anything. I had dealt with significant head injuries, sub arachnoid haemorrhages, tumours, vasospasm, tracheostomy patients on CPAP, status epilepticus, diabetes insipidus and all sorts of other things neurosurgical.

As soon as I started in neurosciences I knew that one thing we simply cannot do is forecast how soon and how well someone will recover from a brain injury. We have to be very careful about what we tell patients' families as we could easily give them false hope or expectations.

October 2003 I was working nights. They were extremely demanding, in that we had several patients with tracheostomies and for some nights I was the only nurse competent to look after these patients and give intravenous medications. I had worked six shifts and got up to work the last of the set of seven. I was in our lounge room having a cup of tea. My wife was in the kitchen and heard an odd noise. She came in to find me having a tonic-

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clonic seizure which lasted for a couple of minutes. My wife, Helen, phoned 999 (the emergency number in the UK).

I was postictal for about 20 minutes. The first thing I remember is being in an ambulance outside our house. I had a cannula in my right arm. I was told that I had walked out to the ambulance, but I don't remember that part. On arriving at hospital, I called in sick for the night shift from the Emergency Department (ED). I was seen in the ED by one of the general medical team. He said I should ask my GP to refer me to neurology and discharged me.

I went up to the ward to say hello to my colleagues. Fortunately one of the neurosurgical registrars was there. When he heard what I had been told to do in ED, he was not impressed. He organised a CT scan straight away which was good, considering it was Sunday evening. By then I was starting to think I had something horrible going on – something like a GBM. I had met patients with tumours whose presenting symptom was a seizure. Having a CT that was spectacularly normal was a great relief! I had also started to feel very uncomfortable. In having a tonic-clonic seizure, a person uses every muscle they have and uses them a lot. After my seizure I was off work for 3 weeks. This was due to back pain following the seizure.

I had an EEG and saw a neurologist a few weeks later. He told me that the seizure was probably triggered by fatigue. He told me he would not start me on anticonvulsants and I was not classed as having epilepsy as in his words "everyone is allowed one seizure". However in the UK, I was not allowed to drive for 12 months.

Having been through that, I wanted to move away from working shifts. In April 2004 I went to work in outpatient oncology. In 2005 I got a post as a research nurse for a large prostate cancer project.

Christchurch, New Zealand

In 2007 my wife, son and I emigrated to Christchurch, New Zealand and I returned to working in the neurosciences. In August 2009, I was promoted to charge nurse. I can assure you that being a charge nurse is tiring and stressful even though it doesn't involve working shifts. I often woke up during the night and lay thinking about work-related issues. Frequently I was tired when I got up to go to work.

On **January 28th 2011**, I went to work early. This was to meet with one of the staff who always worked nights. I'd said I would go in early rather than her having to come in during her own time.

At about 8:30am I was on a ward round with a consultant neurosurgeon. I had a tonic-clonic seizure. I'm told I went down like a tree. Falling backwards, my head hit the concrete floor and people all over the ward heard a loud crack. My injuries included: - a fractured skull, cerebral bleed with mid-line shift, contra-coup injury and lacerated scalp. This was my second seizure so I was now formally diagnosed with epilepsy.

Initially I was in Intensive Care (ICU). After that I was transferred to the Stroke Unit, not because I'd had a stroke, but it was felt that it would be odd for me to be looked after on my own ward. It would have been odd for the staff too.

I remember very little of the following 2 ½ weeks. I do remember:

- Asking for my catheter to be removed (but thankfully not the removal!)
- A visit by the clinical director who described it as a friendly visit.
- A visit by the consultant looking after me, but do not remember anything that was said.
- A neurologist explaining my switch from Phenytoin to Epilim. I recognised him but could not remember his name. I knew what he did, knew how long I had known him, understood what he was talking about, but had no idea why he was sitting on my bed talking to me! Putting it simply, I did not realise that I was in hospital.
- A visit to my home ward. I do not know who took me there in a wheel-chair but I do remember seeing a couple of the staff.
- I remember a visit by a colleague who had a serious head injury about 7 years before me. I found out several weeks later that this visit lasted about 20 minutes, yet I remember only one sentence from the conversation. This being "You will get better Colin"

The first time I remember being told I was in hospital with a head injury was on 15th February. I asked Helen if I had been knocked off my bike on the way in to work. She said no. I

then thought that I must have been assaulted. The idea of having a seizure certainly didn't pop into my mind.

I transferred to the Rehabilitation Unit at Burwood Hospital. I thought that I didn't need to go to rehab as I was safely mobile and able to dress myself. I could also put on the eye patch which was helping me cope with the dreadful diplopia I had developed.

On arrival in rehab, I recognised five of the patients. They had been on my ward over the previous couple of months. Generally I could remember what had happened to them but not their names. In fact the only name I had been getting right up to then was Helen - my wife's name. I had been calling our son 'Alex'. Our son's name is Tom. Alex is my nephew, 13 years older than Tom and was at university in Scotland.

On my first morning in rehab, I had a supervised shower. The nurse who watched me was someone I had spoken with on the phone many times prior to ending up there as a patient. My second day made me recognise I needed rehabilitation. I had my first Speech and Language Therapy session. I was given a difficult test to do. The therapist gave me a piece of paper and a pen and asked me to write my name. I misspelt my surname for the first time in 40 years.

Looking back, I recognise that really I was illiterate at that time. I think I could read individual words but I couldn't put them together to understand sentences. On day 3, I wrote something (Figure 1). It is legible but if anyone can explain to me what I meant I will be most grateful.

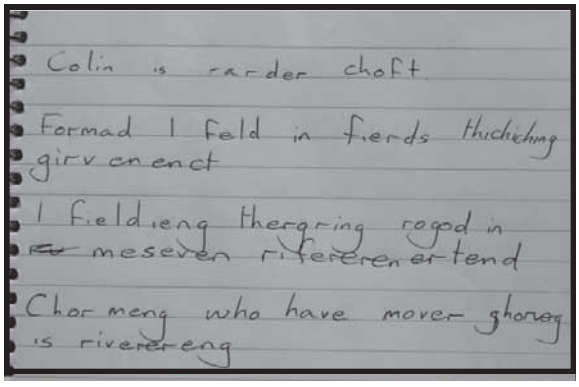

Figure 1: (Above) *My first writing.*

Remembering names was a real challenge. Prior to the injury I had been good at this skill. I knew I had to remember names for the post-traumatic amnesia test. I was cheating a bit by writing the names in my note book and doing a bit of revision before seeing the Occupational Therapist (OT).

Physiotherapy was generally straight forward as, by the time I was at rehab, I did not have any limb weakness or balance problems. The physio looking after me often took me for walks outside.

Another big issue was fatigue. I could sleep after any therapy session. Most nights I was asleep shortly after 9pm and would sleep for about 10 hours.

Christchurch Earthquake

February 22nd 2011, was the day of the fatal Christchurch earthquake. My wife was at work in the city centre. She didn't get through on the phone until 6pm. I cried openly when we finally got to speak. I am more emotional since my head injury. A week after the earthquake was the formal 2 minutes silence which I watched on TV. This showed film from the hospital. I got very upset and cried thinking I should be there, at work, helping. Eventually I got a grip as I knew I couldn't do anything for 45 minutes without needing a sleep!

I was doing the neuropsychology tests and thinking I was doing quite well … which I wasn't. Once again remembering names was an issue. Quite often, when shown a picture, I could say what something did, or what letter its name began with, but not name the object. One of the tests involved moving discs around on wooden pegs. The discs are different sizes. The therapist sets the discs up and gives you a picture of what she would like you to replicate. You can move one disc at a time and bigger discs can't go on top of smaller ones. These tests progressively get harder and include more discs. The last test was very difficult. In fact I gave up - convinced that it was impossible. A year later I re-sat all the tests to see if I had improved. When I repeated the "impossible test" I completed it correctly in under a minute. I had improved a lot.

Getting better is a long, slow process. It needs to be. I think there is real risk involved in trying to take big steps forward. This could easily end up with a patient taking steps backwards and feeling as if they were getting nowhere. I kept wondering how much I would recover before I plateaued.

I began going back to work in late June. I started doing 2 hours, 2 days per week. The plan was to build this up gradually. I spent some time as a staff nurse on another ward. This was partly to prove that I was safe to do things such as give patients paracetamol. I then worked parallel to a charge nurse in another area to get used to that role again.

About 2 years after my head injury I was back on my home ward working alongside the acting charge nurse. I was all but back in my position. However, I decided that I didn't want to be doing paperwork most of the time. I wanted to look after patients, so I reverted to being a staff nurse. When I first chose to be a staff nurse I spent a couple of weeks thinking I had made a big mistake. I then knew I had made a great decision. I was asked by one of the consultants if I felt I had taken a load off my shoulders. I told him I felt I had taken off a rucksack full of rocks.

Conclusion

I do have what can be described as a degree of paranoia. It is widely believed that anyone can make a mistake but I am concerned that if I made a mistake that a question would be raised. Was it a mistake or was it because I'd had a head injury? The odd thing is looking after head injury patients. I knew early in my career that we can't say how well the patient will get. You definitely can't say "been there, done that".

The last 3 ½ years have been hard at times. I certainly feel that I lost 2 ½ weeks of my life. I can have word finding difficulties – especially when I am tired. As far as fatigue is concerned I think there are two aspects. I do get tired more easily but I also think that I am better at recognising when I am tired and doing the right thing – going to have a sleep.

Overall I am enjoying working as a staff nurse. I still cannot think that any other area would be more interesting and varied to work in than the neurosciences. I'm not just saying that because I had a smack on the head!

Importance of a Multidisciplinary Team Approach for Optimizing Pituitary Surgery Outcomes

Amy A. Eisenberg, Nancy Mclaughlin, Pejman Cohan, Chester Griffiths, Garni Barkhoudarian, Daniel Kelly

Abstract

Pituitary tumors including pituitary adenomas and related lesions such as craniopharyngiomas and Rathke's cleft cysts present with a wide range of hormonal and neurological signs and symptoms resulting in a variety of referral pathways. A multidisciplinary approach to the diagnostic evaluation and treatment plan is essential to optimise outcomes. The patient is seen by each member of the team, including neurosurgeon, endocrinologist, head & neck surgeon, nurse practitioner and in some instances neuro-ophthalmologist, oncologist, radiation oncologist and interventional neuro-radiologist. Appropriate investigations are undertaken and a further meeting arranged at which all opinions are discussed. A reasoned treatment regimen is recommended, taking into consideration the patient's wishes and overall medical condition. This manuscript describes the team approach currently employed in the Brain Tumor Center and Pituitary Disorders Program at Providence Saint John's Health Center & John Wayne Cancer Institute. When referring pituitary patients to this centre, health care professionals and patients alike are experiencing the positive benefits received from a patient-centred, multidisciplinary approach.

Keywords: *Pituitary, tumor, pituitary adenoma, transsphenoidal surgery, multidisciplinary team.*

Introduction

Patients undergoing endonasal transsphenoidal surgery have complex needs that require expert care and the coordination of a multidisciplinary team of healthcare professionals. Collaboration among health care disciplines is assumed to be an effective solution to many problems, including the quest for cost-effective quality care. Collaboration is a process of shared planning with joint responsibility for outcomes. Interdisciplinary care also involves coordination, joint decision making, communication, shared responsibility, and shared authority (Lough, Schmidt, Swain, Naughton, LeShan, Blackburn & Mancuso, 1996). This article provides a literature review of the topic as it relates to patients undergoing endonasal endoscopic pituitary surgery and presents an illustrative case.

Pituitary adenomas are one of the most common intracranial neoplasm, making up about 15% -20% of such lesions. Prolactinomas are the most prevalent subtypes, representing 40% - 50% of pituitary adenomas, followed by non-functional adenomas accounting for about 30%, and other functional adenomas secreting growth hormone, adrenocorticotropic hormone, or other hormones making up the remainder (Kovacs & Horvath 1987; Kontogeorgos, 2005).

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Pituitary adenomas may be classified based on an anatomical approach which classifies pituitary tumours by size based on radiological findings. Tumours are divided into microadenomas (i.e.; the greatest dimension is <10 mm) and macroadenomas (i.e., the greatest dimension is > 10 mm. An MRI scan is now considered the imaging modality of choice for the diagnosis of pituitary disorders because of its multiplanar capability and good soft tissue contrast enhancement. Sagittal gadolinium enhanced T1-weighted images, clearly displaying the anterior and posterior lobes and the stalk on the same plane, and coronal gadolinium enhanced images, displaying the relation between the pituitary and cavernous sinuses, are optimal for identifying a pituitary adenoma. A 3mm thin slice typically is used to obtain optimal resolution.

The goals of treatment of pituitary adenomas include relief of compression of surrounding

Tumor Type	Primary Therapy	Second line Therapy	Adjuvant Medical Therapy	Adjuvant Radiation therapy	Additional therapies
Endocrine inactive Macroadenoma	Surgical resection	Radiation therapy	Temozolamide for malignant recurrent tumors	Fractionated Stereotactic Radiotherapy for invasive tumors	
Prolactinoma	Dopamine Agonists (cabergoline or bromocriptine)	Surgical resection (refractory or intolerant to medications)	Temozolamide for atypical or malignant recurrent tumors	Fractionated Stereotactic Radiotherapy for invasive tumors	
Growth Hormone (acromegaly)	Surgical resection	Somatostatin analogues (octreotide or pasireotide)	Dopamine agonists or growth hormone antagonists (pegvisomant)	Fractionated Stereotactic Radiotherapy for invasive tumors	
Adrenocorticotropic Hormone (ACTH) (Cushing disease)	Surgical resection	Steroidogenesis inhibitors, (mitotane, metyrapone, ketoconazole, aminoglutethimide)	mifepristone	Fractionated Stereotactic Radiotherapy for invasive tumors	Hypophysectomy or bilateral adrenalectomy
Thyroid–stimulating hormone (TSH) (rare)	Surgical resection	Thyroid hormome inhibitors	Somatosatin Analogues	Fractionated Stereotactic Radiotherapy for invasive tumors	
Gonadotroph secreting Ovarian Hypersecretion syndrome (rare)	Surgical resection	Radiation therapy	none	Fractionated Stereotactic Radiotherapy for invasive tumors	
Pituitary Carcinomas	Surgical resection	Radiation and Chemotherapy	Somatostatin analogues for GH and ACTH producing carcinomas	Dopamine agonists for PRL producing carcinomas	

Table 1 (Above): *Pituitary Tumour Subtypes and Treatment Option Overview.*

structures (e.g. optic chiasm or pituitary gland), normalisation of hormonal secretion (e.g. normalisation of hypersecretion or improvement in hypofunction) and improvement of progressive neurological deficits. Interventions may include surgery, medical therapy, radiation therapy, or a combination of these modalities. The treatment of choice must be individualised and is dictated by the type of tumour, the nature of the excessive hormonal expression, and whether or not the tumour extends into the brain or other critical structures around the pituitary.

The transsphenoidal microsurgical approach to a pituitary lesion is the most widely employed surgical approach to pituitary lesions and represents a major development in the safe surgical treatment of both hormonally active and non-functioning tumours. Rapid deterioration of vision is an immediate indication for surgery to relieve pressure produced by an expanding tumour mass, except in the case of macroprolactinomas (where intensive observation with a patient on dopaminergic agonists may be an acceptable alternative). Progressive deterioration of visual fields is often the primary neurological criterion on which surgical management decisions are based. Conventional radiation therapy is an effective adjunct to the treatment of pituitary tumours, and rarely used as a first-line therapy. The advantages of radiation therapy are that it is non-invasive and suitable for high-risk surgical patients. The clinical and biochemical response, however, is slow and may require from 2 years to 10 years for complete and sustained remission. In addition, radiation therapy carries a substantial risk of hypopituitarism (approximately 30% at 10 years), (Sheehan, Starke, Mathieu, Young, Sneed, Chiang, Lee, Kano, Park & Niranjan, 2013). Stereotactic radiosurgery (SRS) may be a treatment option for patients with recurrent or residual adenomas.

In acromegalic patients, impaired glucose tolerance, hypertension, and hyperlipidemia should be vigorously treated concurrently with definitive therapy. A multidisciplinary clinical approach may be required for the treatment of arthritis, carpal tunnel syndrome, obstructive sleep apnoea and prog-

nathism. Mortality is related primarily to cardiovascular and respiratory diseases.

Given the insidious and often non-specific symptoms with pituitary adenomas, there is a significant delay between symptom onset and definitive therapy. In some instances, the early clinical manifestations may even lead to erroneous diagnoses for patients with non-functional pituitary adenomas. In some cases, patients are only diagnosed once the tumour has enlarged to the point of causing pituitary dysfunction and/or altered visual fields and decreased visual acuity (Ebersold, Quast, Laws, Scheithauer & Randall, 1986; Berkmann, Schlaffer, Nimsky, Fahlbusch & Buchfelder, 2014). Making an appropriate diagnosis in a timely fashion and directing the patient towards an experienced team specialised in pituitary pathologies is essential for the patient's well-being. The multidisciplinary concept is important in the pre-operative, operative, in-patient and long-term follow-up care of patients with a pituitary lesions and offers the best chances of favourable outcome. We review the key elements that assure the success of a multidisciplinary team and present how this approach has been implemented in a centre dedicated to the management of pituitary lesions for optimal outcomes (McLaughlin, Laws, Oyesiku, Katznelson & Kelly, 2012).

Teamwork for Better Patient Outcome

In our current medical system, which encourages specialisation in specific fields of interest such as skull base endoscopic surgery, it is realistically impossible for one single physician to provide holistic care. The complex needs of patients, families, communities and populations are not usually amenable to the actions of single care providers in isolation from colleagues of other disciplines. Teamwork is recommended in order to pool skills, experience and knowledge to ultimately yield the best overall outcome for patients (Fagin 1992). In multidisciplinary teams, members coordinate their efforts to fulfil goals set forth by the team (Hamric, Hanson, Tracy & O'Grady, 2013). This type of teamwork assures greater flexibility and interchangeability between members. Multidisciplinary also serves to achieve greater resource efficiency by reducing duplication in a patient's care, by sealing potential gaps in care management and by decreasing the risk of errors with the use of protocols accepted by members of the team.

Implementation of a Multidisciplinary Approach

Multiple groups around the world have concentrated their efforts on the care of patients with pituitary pathologies. We present an overview of how members of a multidisciplinary team specifically designed for pituitary pathologies interact at various aspects of the patient's overall care (Figure 1).

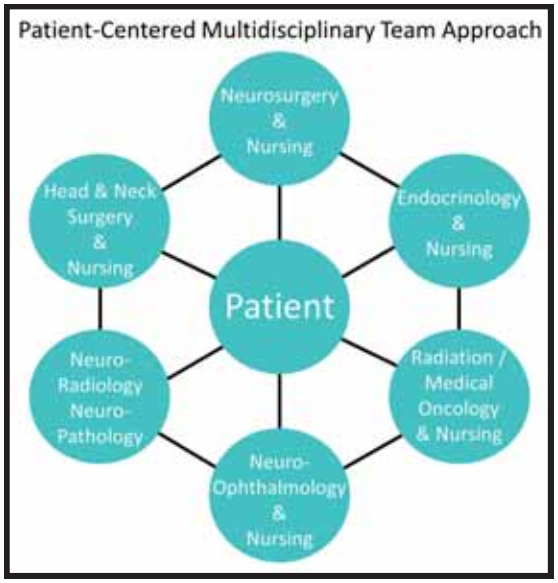

Figure 1 (Above): *Diagram demonstrating the patient-centric model of the multidisciplinary approach to the pituitary patient.*

Pre-Operative Care

The primary care physician is a central player in the pre-operative care of most patients. Primary care physicians coordinate the initial investigation, including endocrine work-up, ophthalmological assessment, neurological evaluation and radiological investigation. Referring physicians, including primary care physicians, endocrinologist, neuro-ophthalmologist, and neurosurgeons, should seek to refer their patients to a team specialised in pituitary lesions, capable of tailoring the surgical procedure and adjuvant therapy to each patient's specific situation.

The initial conversation with the team's nurse practitioner provides an opportunity for the patient to voice questions and concerns to which the practitioner can address. The nurse practitioner explains the consultation process to the patient and ensures that pertinent data such as pituitary hormonal blood evaluations, neuro-imaging and visual fields if indicated are available at the time of consultation.

During this initial consultation, a detailed clinical history and physical examination are performed. Images and hormonal test results are reviewed with the patient and their family, and the likely diagnosis is presented. In many instances, the diagnosis is clear-cut. However, in certain cases, the diagnosis may be uncertain due to ambiguous imaging or inconclusive hormonal test results. Thus, some patients may require additional evaluation before a recommendation regarding the optimal treatment can be made. Once this key data is available, definitive treatment options are discussed in detail including indications and alternatives to endonasal surgery, medical treatment options and the possible need for radiosurgery or radiotherapy. The need for hormonal replacement therapy is also discussed. Providing this data helps the patient process the information and understand the following steps. For those who ultimately require surgery, meeting the surgical team pre-operatively allows patients to direct specific questions to each team member. Once the surgical team has discussed the treatment management options, the nurse practitioner can go over key questions regarding the post-operative period from the patient's stay in recovery room to the first weeks after surgery to give the patient appropriate expectations. They will also help coordinate the pre-operative medical evaluation, including cardiac or pulmonary clearance if required as well as consultations with other medical specialists and complementary imaging.

In the 48 hours preceding surgery, the pre-operative work-up should be verified by the entire team and the patient is contacted if any further verification is required. As the patients are usually not admitted to the hospital the night before surgery, communication with the nurses in the pre-operative unit is essential to verify that the chart is complete and that all inquiries have been addressed. This is essential to prevent any delays on the morning of surgery.

In research institutions, contributing the tumour specimen to a tissue and/or blood bank should be offered on a voluntary basis to each patient prior to surgery. This is introduced by the surgical team and the consent may be obtained either by the research nurse, the investigator or the nurse practitioner.

Intra-Operative Care

Peri-operatively, the anaesthetist is an integral member of the care team. For some pituitary tumour patients, such as those with acromegaly or Cushing's disease, securing the airway may be a challenge and may require special intubation techniques. The pre-operative discussion with anaesthetist should include specific concerns, including blood pressure management and intra-operative medications. In particular, the necessity or contraindication for peri-operative steroids should be discussed. The operation is performed by a dedicated team, combining skull base neurosurgeons and head and neck surgeons, both versatile in endonasal approaches. Combining expertise on a regular basis optimises the surgical team's success in comparison with casual interaction. Intra-operative pathological assessment often confirms the presumed pre-operative diagnosis. Detailed analysis of the histological characteristics and molecular signature are important for the adjuvant treatments recommended after surgery.

Post-Operative Care

Following the endonasal transsphenoidal resection of pituitary tumour, close observation and monitoring in a skilled nursing unit is required for the initial 24 hours. Intensive care units are reserved for the unstable or high acuity patient (e.g. requiring vasopressor or insulin drips). The surgical team must inform the intensivist about the patient's clinical history, pre-operative neurological status, hormone deficiencies, intervention performed, occurrence of any intra-operative complication and total blood loss. In cases of pre-operative hypopituitarism, functional pituitary tumours or surgical procedures that might have altered the pituitary gland or pituitary stalk, an endocrinologist should manage the patient's hormone balance.

Standing orders and critical pathways are vital tools for nurses in anticipating complications and therefore improving patient outcomes. Serial neurological examinations and prompt reporting of any changes are critical in identifying neurological complications. Once identified, the treating physician must be advised. Complications such as diabetes insipidus and cerebrospinal rhinorrhoea (CSF leak) associated with endonasal surgery may result in prolonged hospitalisation and worsened functional outcome (Eisenberg & Redick, 1998). A dedicated, multidisciplinary clinical practice with large annual volume of

transsphenoidal surgery is important for safe, successful outcomes in patients with pituitary tumours (Shahlaie, McLaughlin, Kassam & Kelly, 2010). In conjunction with the surgical team, the hospital case manager initiates discharge planning as soon as the patient arrives to the ward, allowing for a thorough review of the patient's condition facilitating the discharge home or to other facilities when necessary.

The Patient's Support System

The patient's family is an important element in the pre-operative care period. Most patients have a family member that stays at bedside throughout their hospitalisation. It is crucial that they understand what is to be expected in the post-operative period. They should be informed on signs and symptoms to observe. The family members also play a key role in the patient's rehabilitation as they can stimulate progressive oral intake and mobilisation, when indicated. Early ambulation prevents the complications seen with immobility, such as atelectasis, pneumonia, deep vein thrombosis and pulmonary embolus (Prather, Forsyth, Russell & Wagner, 2003). Hence, family cooperation should be recognised and encouraged.

Discharge from the hospital is organised when the entire team believes the patient is stable. For typical patients undergoing endoscopic endonasal resection of a pituitary adenoma or Rathke's Cleft Cyst, this occurs on the second post-operative day. For patients with more complex operations, such as extended skull base approaches for craniopharyngiomas, chordomas or meningiomas, length of stay can range from three to seven days. The patient's family or immediate caregiver should always be involved in this process since they will be looking after the patient at home. Post-operative instructions specific to endonasal surgery are given to the patient prior to discharge and include recommendations for activities of daily living, medications to take and/or avoid, allowed physical activity, and appointments after hospital discharge. These discharge instructions also mention signs and symptoms that would be more worrisome and that should trigger a call to the treating team. The patients are also told that if they have permanent pituitary insufficiency (hypopitutiarism) and require long term steroids (prednisone or hydrocortisone) and/or DDAVP, they should carry a medic alert card in their wallet and wear a medic alert bracelet. This will alert medical personnel to the need for additional hormone administration in an emergency situation. A serum sodium level is evaluated on the 4th or 5th day after surgery. Delayed hyponatraemia, attributed to the syndrome of inappropriate secretion of antidiuretic hormone (SIADH), typically occurs in a delayed fashion following transsphenoidal resection of pituitary lesions. In a series of 99 consecutive patients who underwent transsphenoidal surgery for pituitary adenomas, nine patients developed delayed hyponatraemia, seven of whom were symptomatic. Of these seven patients, four had been discharged from the hospital and required readmission on postoperative Day 7 to 9. In the nine patients who developed hyponatraemia, on the average sodium levels began to fall on Day 4 and reached a nadir on Day 7 (Kelly, Laws & Fossett, 1995). Education at discharge about common symptoms of SIADH, such as nausea, confusion, fluid retention, and lethargy, is important for early recognition and prompt treatment. When left untreated, severe delayed hyponatraemia can result in coma or death.

Post-Operative and Long-term Follow-Up Care

Patients are typically seen by the surgical team 7-10 days after the surgery. After endonasal endoscopic surgery, the head and neck surgeon will perform outpatient sinonasal endoscopy and debridement at least 2-3 times over multiple months. The definitive pathology results are discussed with the patient usually at the first postoperative visit in the clinic. The possible needs for adjuvant treatments such as medical therapies for patients with acromegaly or radiosurgery for residual invasive adenomas are also discussed with the patient. In many patients, these decisions may need to be delayed for several months or years with frequent hormonal evaluation and pituitary imaging. The nurse practitioner is key in coordinating post-operative care and possible adjuvant therapy by the endocrinologist, medical oncologist and radiation oncologist. It is important that the treatment plan be communicated to the patient's primary physician to keep all caregivers informed. Patients should be referred back to their endocrinologist four to six weeks after surgery to assess the status of their pituitary function and determine if any hormonal replacement is needed or should be adjusted. Patients with macroadenomas undergo a follow-up pituitary MRI at three months after surgery. Patients with functional adenomas obtain an initial post-operative baseline MRI, but are subsequently monitored biochemically, based on their endocrinopathy. Patients with non-functional

inactive pituitary adenomas are followed with serial imaging, with progressively longer intervals between exams, with stable disease. Faithful adherence to a schedule of follow-up pituitary imaging allows for early detection of tumour recurrence and timely treatment, including either repeat surgery with or without radiation therapy and chemotherapy. Nurses who care for patients during the follow-up phase of pituitary management face the special challenge of ensuring that these individuals, who may no longer be symptomatic, return for evaluation at regular intervals. The nurse practitioner must emphasise the importance of maintaining follow-up appointments with all team members namely the endocrinologist, neuro-ophtalmologist, surgical team, radio-oncologist and medical oncologist.

Educational Opportunities

Education opportunities focusing on the care of patients with pituitary lesions is an ongoing experience. Ongoing lectures and review of journal articles continue to help nurses develop their knowledge and improve practice. A Neuroscience Nursing Symposium has been developed in our Center to keep nurses updated on state of the art treatments for pituitary pathologies and on future trends. Strategies that may further improve patient outcomes include establishing guidelines for pituitary tumour centres of excellence and more focused residency and fellowship training in endonasal endoscopic transsphenoidal surgery.

The impact of the internet on patient education and support is very vital. We correspond regularly with patients who research online for information and guidance. These patients are referred to online forums and patient associations that offer the possibility to discuss with other patients with similar pathologies. We offer a community outreach program where different specialties collaborate to educate the general population regarding pituitary tumours. Our Center offers a patient focused pituitary symposium including neurosurgeons, head and neck surgeons, endocrinologist, radiation oncologist, patient advocates, nurse practitioners and research nurses. As patients become increasingly involved in researching diagnoses and medical treatment options online, we must be able to provide the most up-to-date and comprehensive information via the internet. Our practice website is updated regularly to have the current information and publications for patient's references.

Case Study

A 40 year old man presented with a 7 year history of fatigue and low energy with a 20 year history of low testosterone treated with testosterone supplements. For over a year, the patient has noticed decreased libido, anxiety as well as worsening vision, predominantly in the right eye. His pre-operative total testosterone was 180 ng/dl (normal >250 ng/dl) with LH at 2.2m/iu/ml (low normal); prolactin was mildly elevated at 29.7ng/ml; IGF-1 was 230 ng/ml (age appropriate normal); thyroxin was 6.0 ng/ml and TSH was 1.5ng/ml (both normal); ACTH was 25 pg/ml and cortisol was 12 ug/dl (both normal). A radiographic image of the brain and pituitary demonstrated large pituitary macroadenoma with degenerative changes and subacute haemorrhage and severe chiasmal compression (figure 2).

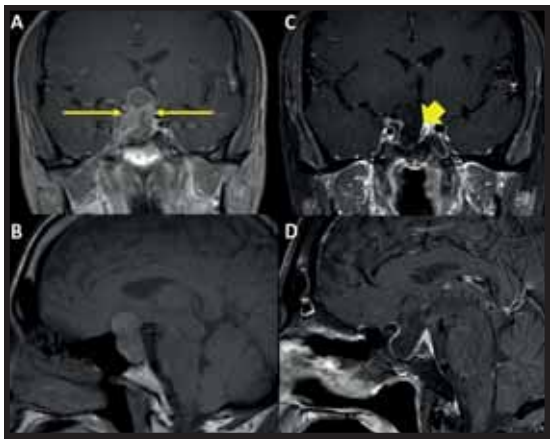

Figure 2 (Above): *Pre-operative (A&B) and post-operative (C&D) MRI images of the case study patient. Note the large macroadenoma with evidence of hemorrhage (arrow) and gross-total resection of this tumor. Note the normal, decompressed and preserved pituitary gland now visible in the post-operative images (arrowheads).*

On neurological examination visual acuity was diminished on the right (20/50) and normal on the left (20/20). There was mild bitemporal hemianopsia on confrontational examination, worse in the right eye. He was otherwise neurologically intact. He underwent endonasal endoscopic removal of an endocrine inactive macroadenoma and sellar reinforcement with an abdominal fat graft. The post-operative MRI showed gross total resection of the pituitary adenoma. His immediate post-operative prolactin level was 19.9ng/ml; cortisol 5.6ng/ml. His visual fields deficits resolved and visual acuity improved to 20/25 OD and 20/20 OS. Pathological evaluation confirmed pituitary adenoma, ACTH staining; no features of atypia or malignancy and Ki-67 is

<1% (pathological grading marker for neuroendocrine tumours). The patient was able to be discharged on the second post-operative day without complications. We saw him on follow-up 4 months after surgery and he has had an improvement in his vision. His visual acuity revealed 20/25 OD and 20/20 OS. His pituitary hormonal function was normal. It was recommended that he have a repeat hormonal function test within 2 months and follow-up visit with his endocrinologist. He was to have a follow-up appointment and repeat MRI in one year.

This case illustrates the importance of a multidisciplinary approach with members experienced in pituitary pathologies. The patient was seen by a medical physician, then referred to an endocrinologist, an ophthalmologist and neurosurgeon. The unfortunate situation in this case is that the diagnosis of pituitary tumour could have been investigated early on if an early MRI was performed. The patient had a pituitary apoplectic event due to the enlarged tumour.

Conclusion

Multidisciplinary team work is essential to optimally manage patients with pituitary adenomas and related lesions, resulting in improved quality of care and patient outcomes. As illustrated, throughout the process of pre-operative, peri-operative and post-operative care, numerous specialists and team members must be carefully integrated in this process. At pituitary centres of excellence, practitioners should demonstrate that endonasal surgery patients can be cared for safely, effectively and efficiently through multidisciplinary treatment paradigm. In order to administer excellence in nursing care, key contribution of the neuroscience nurses include maintaining a holistic view of the patient, maintaining the patient and family central to care and decision making, advocating for the patient and family interests, and educating the patient and family. The foundation for implementation of these and other aspects of care is critical thinking and highly developed clinical reasoning skills. These skills are necessary for both independent decisions by the nurse practitioner and participation in multidisciplinary settings.

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Effectiveness of the Sitting Position Without Back Support

Nobuko Okubo

Abstract

Purpose: In the field of neuroscience nursing in Japan, the "sitting position without back support" (SB) has promoted earlier ambulation, improved level of consciousness, and prevented disuse syndrome in patients with disturbance of consciousness and impaired mobility. This research was conducted with the aim of examining if respiratory function improved using SB on acute patients on ventilation in ICU.

Method: The research design involved daily administration of SB to 10 participants in a controlled trial to compare respiratory function before, during, and after implementation. The measurement indexes were respiratory functions such as tidal volume and lung compliance value and the number of incidences that occurred during implementation, and tools such as APACHE II were used to measure deteriorations of physical condition. Analysis used non-parametric and parametric methods and an alpha level of 0.05 was used for all statistical tests.

Results: Tidal volume and lung compliance value during SB implementation significantly increased, compared to before and after implementation. There were no incidents such as decannulation during implementation, and APACHE II scores were seen to significantly drop after the commencement of SB until discharge from ICU. However, a decline in pulse rate and blood pressure were seen during implementation of SB (4.8%).

Conclusion: The sitting position without back support administered to acutely ill patients on a ventilator was effective in improving respiratory function. In the future, there is a need to create a nurse's assessment guide for implementation of SB and test the SB on a larger population.

Key words: *Backless sitting chair, respiratory function, ICU, ventilator.*

Background

In the field of neuroscience nursing in Japan, the nursing intervention called the "sitting position without back support" (SB) is used with patients to promote early ambulation, improve level of consciousness, and prevent disuse syndrome. This nursing intervention, created in the early 1990s, emerged from the nurses' experience in the clinical setting. It is used with patients with altered level of consciousness as well as dementia, and has been recognized as improving level of consciousness and daily activities (Kawashima, Hiramatsu, Taki, & Murota, 1991; Kamiya, Shiro, & Hayashi, 1993). This particular sitting position has the following characteristics: stimulates the cerebral cortex, requires a posture that preserves that natural curvature of the spine, has no back support, and engages the proprioception of the soles of the feet by planting them firmly on the floor (Kawashima, Hiramatsu, & Ohyoshi, 1993).

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Even amid a shortage of nurses, SB has been used for patients with persistent disturbance of consciousness and dementia with the goal of increasing stimulation to the cerebral cortex. To more easily and safely administer this posture, an apparatus for maintaining the sitting position without back support referred to as 'the backless chair', was devised (Kawashima, et al. 1991). Consequently the SB technique spread throughout Japan. Currently, a total of three types of backless chairs (see Figure 1), have been commercialized through collaboration with emergency physicians and physical therapists, and further joint research was conducted to establish its effectiveness (Okubo, Nagatani, Kawabe, Kishimoto, Inoue & Shinaji 2012).

Initially, the results of SB were mainly pre-

Figure 1 (Above): *Three types of backless chairs for sitting position without back support.*

sented as case reports, many of which involved patients with persistent disturbance of consciousness (Amemiya & Hishinuma, 2001) and dementia (Kawashima, et al. 1991; Nakajima, Adachi & Takeuchi, 2006). Later, systematic studies utilizing physiological indexes were carried out to verify results presented in the case studies (Okubo & Hishinuma, 1998; Okubo et al., 2012; Okubo, Eguchi, Shinaji & Hishinuma, 2005; Okubo, Kohgo, Mizusawa & Hishinuma , 2002). Currently, there is research reported on SB for example with acutely ill patients (Tamura, Sugano, Watanabe & Okawa), patients with acute cerebrovascular disease (Okubo, 2012) and head trauma patients (Kishibe et al, 2011;Okubo & Hishinuma, 2005). Patients on ventilators, and patients that have undergone a thoracotomy procedure (Abe, Okubo & Ueno, 2014) represent a newer group of patients that may benefit from SB related to their prolonged recovery time.

Common to all patients with prolonged bed rest are the negative effects on respiratory functioning (Knight, Nigam, & Jones, 2009). While clinical nurses have noticed an improved respiratory function among acutely ill patients using SB, another technique that effectively improves respiratory function is prone positioning. Its efficacy has been indicated in many papers, but a systematic review of improved respiratory function due to prone positioning pointed out that, while it is effective for respiratory function, the technique is difficult to implement, requires nurses to provide the care, and can involve difficulty with decannulation and bending of the line when it becomes sandwiched between the stomach and bed Curley, 1999). Thus, it can be conjectured that compared to prone positioning, SB is easier to administer in terms of decannulation, manpower and difficulty. However, without health insurance reimbursement for SB care it will be difficult to expand its use and develop SB as a standardized nursing practice.

In the nationalized Japanese medical care remuneration system, when patients receive medical treatment covered by medical insurance the insurance pays the fees to the medical facility. Every two years, Japan reviews the medical treatments that will be covered. There are questions as to the extent to which nursing care can be included in these medical treatments and specialized nursing fields have petitioned for the inclusion of nursing care that is backed by a wealth of evidence. The Japanese Society of Nursing Art and Science recommended that this SB technique be included in the petition for care covered under the medical care remuneration system. Research is being promoted to strengthen evidence through the receipt of research grants (Social Insurance Union of Societies Related to Nursing Grants in Aid) related to the medical care remuneration system.

This study was conducted as a part of the research being carried out to accumulate evidence to determine the efficacy of SB. It examines if there was improved respiratory function in acute patients on ventilation through the administration of SB, which has previously been said to be effective in the clinical setting. The results of this research will document the impact of SB on respiratory function of acute patients and will provide data to aid in decision-making regarding the status of including SB in the revised medical care remuneration system in Japan.

Methods

Research Questions

The following research questions address the effectiveness of SB carried out with acute

patients on ventilation, in terms of improved respiratory function.

a. Is respiratory functioning improved when SB is administered to acute patients on a ventilator in ICU, compared to when SB is not administered?
   - Is improved respiratory function achieved during daily implementation of SB, compared to before and after implementation?

b. Does the administration of SB for acute patients on a ventilator in an ICU endanger their physical condition, compared to when SB is not administered?
   - Does the daily implementation of SB create a risk to their physical condition, compared to before and after implementation?

Design and sample

This was a before/after controlled trial implementing daily SB with participants and comparing respiratory function before, during, and after implementation. The researcher in collaboration with the unit staff nurses and attending physicians used purposive sampling to identify 10 patients who were on ventilators in the intensive care unit (ICU) and whose scope of permitted activity allowed them to sit upright on the bed.

Intervention

After admission to the ICU and when the patients were permitted to sit upright in bed, SB was administered at the bedside once a day using a backless chair. At least two nurses conducted an assessment of functioning particularly screening for abnormalities that included taking vital signs and an EKG. SB was administered during the period the participating patients were in the ICU. During that period, if it became possible for a patient to sit up independently then SB was determined to be unnecessary and discontinued.

Measurements and Instruments

Participants' attributes of gender, age, illness, medical history, history of smoking, and history of present illness were noted upon admission. During the study the following variables were documented: (1) period of stay in ICU, (2) number of days from admission to ICU until commencement of physical therapy, and (3) number of days from admission to ICU until commencement of SB.

The assessment of respiratory function included the following: tidal volume, lung compliance value, PaO_2/FiO_2 contrast (contrast between oxygen partial pressure/intake oxygen concentration in arterial blood; hereafter, P/F contrast), airway pressure, percutaneous oxygen saturation level, and the existence of ventilator-associated pneumonia (VAP). Participants' physical condition other than respiratory functions were also recorded before and during the intervention: blood pressure, heart rate, respiratory rate, and body temperature. Measurements were taken at the same time each day and before the implementation of SB and during implementation averages were taken.

In order to quickly assess the participant's level of consciousness during the intervention the Japanese Coma Scale (JCS) (Shigematsu, Nakano & Watanabe, 2013) was used. If the level of consciousness decreased then the nurse would stop the intervention.

Other data collected throughout the study period were the number of cannulation accidents/removals, number of incidents such as tumbling/falling over, number of times SB implementation was discontinued and reasons, estimated mortality rate (as a measure of risk), and the amount of sedatives/ catecholamine used during implementation.

There were two widely used valid and reliable instruments: Acute Physiology and Chronic Health Evaluation II (APACHE II) and the Ramsay Sedation Score (RASS). These are commonly used in ICU settings and in this study were used at admission, every three days thereafter, and at discharge from the ICU; (1) APACHE II scores range from 0-71. The higher the score meant the higher and the more severe the disease and risk of death. (2) Ramsay sedation score (RASS) rates patients on a scale of 1-6 for rousability. The higher the score the less arousal and 1-3 indicate states of wakefulness and 4-6 levels of somnolence with 6 meaning unresponsive to stimuli. It is used frequently in ICU settings to support appropriate sedation management. A research nurse trained to validly use both tools administered the two instruments.

Data Analysis

A simple tabulation was conducted for the attributes. After examining normality, a t-test, a Mann-Whitney test or one-way analysis of variance, a Kruskal-Wallis test, and multiple comparisons (Tukey's test) were carried out on the assessment of respiratory functions that merited dependent variables, other physical conditions, estimated death rate, and the APACHE II score from admission to ICU until

discharge. If the p value was less than 5% ($p < 0.05$), then significant differences were analyzed. The statistical software, SPSS Statistics version 19 (IBM) was used.

The number of cannulation accidents/removals, number of incidents such as tumbles/falling over, and the number of times SB was implementation and discontinued was calculated from the time SB commenced. Furthermore, the amount of sedatives/catecholamines used during implementation and RASS were noted, and the number of incidents and noted contents were analyzed in relation to SB in terms of safety.

Ethical Considerations

Since this clinical research was conducted on acutely ill patients in the ICU, explanations were given to the patients' families at the time of hospitalization and intervention began after obtaining consent from the legal representatives and attending physicians. Once a patient regained consciousness, the research was explained to the patient, and the intervention was continued when consent was received. Because the patients were in ICU, each day a doctor would judge whether the intervention posed a risk to life and implementation would be halted if it were judged that risk existed. Approval was obtained from the research ethical review board at the facility where the research was conducted (approval no. H2507-3).

Results

Participants included five men and five women with an average age of 66.8±16.4. Participant attributes are shown in Table 1. SB was implemented for an average of 18.5±6.3min. The number of implementations averaged 8.5±7.8 times. Implementation was discontinued six times (4.8%) out of the 73 implementations conducted on 10 patients. Refer to Table 2 for the number of times implementation was discontinued for each participant.

Indexes for respiratory function assessment

Tidal volume was 467.0±100.8ml before, 508.5±122.7ml during and 462.2±105.7ml after SB implementation (Figure 2). Tidal volume was significantly increased during implementation, compared to before and after implementation ($F = 11.696$, $df = 2$, $P = 0.01$). Lung compliance value was 48.7±17.9 ml/cmH_2O before, 53.2±29.1 ml/cmH_2O during, and 50.2±19.5 ml/cmH_2O after SB implementation, indicating it was significantly higher during implementation, compared to before and after implementation ($F=2.872$, $df=2$, $P=0.023$) (Figure 3). PaO_2/FiO_2 contrast was 244.8±47.9 before, 245.4±59.5 during, and 236.7±38.2 after SB implementation with no significant changes before, during, or after implementation. Airway pressure was 16.4±5.7 before, 19.03±6.3 during, and 17.7±5.2 cmH_2O after SB implementation. Thus, no significant differences were noted. Percutaneous oxygen saturation was 99.1±1.4% before, 99.2±1.9% during, and 99.0±2.4% after SB implementation, so there was no significant difference. There was no incidence of VAP in any of the patients. Indexes for physical conditions other than respiration.

There were no significant differences in heart rate, respiratory rate, blood pressure, or body temperature before, during, or after SB implementation (see Table 3). However, heart rates and respiratory rates rose during SB implementation, and on some days blood pressure was seen to increase and decrease in both the systolic phase and diastolic phase during implementation, compared to before and after implementation. If the nurse conducting the assessment found that a participant's blood pressure rapidly rose or dropped, then the nurse using the facility's criteria for discontinuation of a patient's getting out of bed would halt the implementation. As noted earlier, implementation was halted on six occasions (4.8%). SB implementation was halted on one occasion for one of the two patients given catecholamine drug preparations. SB implementation was halted on 1–2 occasions for four of the six patients administered a combination of propofol, benzodiazepine, or other hypnotic/analgesic drugs. During implementation, one participant's RASS showed a change in wakefulness between 1–2 levels, but was still within the range of the deepest RASS (4-6). Implementation of SB was continued later since the doctor did not judge it to be an adverse event (Table 4). One patient (#1) was assessed as having a decrease in the Japan Coma Scale (JCS) and implementation for that day was halted (see Table 2).

There were no accidents/removals of cannula during SB implementation or incidents such as tumbling/falling over. Both the APACHE II scores, from the time of ICU admission until discharge, and the estimated mortality rates after the SB intervention, showed a significant decrease (see Table 4).

Discussion

As a result of implementing SB for patients on

Table 1: Participant Attributes

№	Gender	Age	Illness	Period of ICU stay (days)	Complications		Medical history	History of alcohol consumption	History of smoking	APACHE at admission	No. of days from admission to start of rehabilitation	No. of days from start of rehabilitation to sitting position	FIM score		Ventilator setting in ICU
					Yes/ No	Details							At ad-mission	At start of rehabilitation	
①	Male	60s	Sigmoid colon perforation, septicemia	76	No		Gastric ulcer	No	No	35	7	20	18	18	BIPAP
②	Female	30s	Limbic encephalitis	50	Yes	herpes zoster	Gastric polyp, herpes zoster	No	Yes	21	1	4	18	18	BIPAP
③	Male	70s	Postoperative pneumonia, CO2 narcosis	21	No		Gastric cancer, left upper lobectomy	Yes	No	21	2	3	18	18	BIPAP
④	Female	50s	Brainstem hemorrhage	15	No		Appendicitis	Yes	Yes	16	3	5	18	18	SIMV
⑤	Male	60s	Cardio-pulmonary arrest on arrival, acute myocardial infarction	39	Yes	hypoxic-ischemic encephalopathy	Duodenal ulcer	No	Yes	29	5	6	18	18	BIPAP, CIPAP
⑥	Male	80s	Hypoxemia, pneumonia	42	Yes	Lung cancer	Cerebral infarction, emphysema, thyroid mass	Yes	Yes; currently non-smoker	29	0	3	18	18	SIMV CPAP BIPAP
⑦	Female	80s	Perforative peritonitis of the gastrointestinal tract, septicemia	19	Yes	Pneumonia	Appendicitis, gallstone, femoral head replacement	No	No	27	3	4	18	18	SIMV
⑧	Female	80s	Cerebral infarction	15	Yes	Pneumonia	Valvular disease	No	No	23	1	13	18	18	SIMV
⑨	Female	40s	Malignant lymphoma	20	No		None	No	No	42	2	5	18	18	SIMV
⑩	Male	80s	Acute myocardial infarction	47	Yes	hypokalemia	Cerebral infarction, diabetes, hypertension	No	Yes; currently non-smoker	64	4	25	30	30	BIPAP
Avg. value		66.8		34.4						30.7	2.8	8.8	19.2	19.2	

*BIPAP: Biphasic intermittent positive air pressure *SIMV: Synchronized intermittent m andatory ventilation *CIPAP: Continuous positive airway pressure FIM: Functional Independenc

Patient	Avg. implementation time (min.)	No. of implementation days	Implementation (no. of times)	Discontinuation of implementation (no. of times)	Reason for discontinuation	Use of sedatives during implementation	Use of catecholamine drug preparations during implementation	RASS[1] changes during implementation	Deepest RASS during ICU
(1)	16.5	19	19	2	BP & JCS decrease	Midazolam 4ml/h, ***Propofol*** 4ml/h, Precedex 2ml/h,	None	0~-1	-3
(2)	15.6	9	9	1	Increased involuntary movement	Midazolam 4ml/h,	None	-1	-4
(3)	13.6	7	7	1	Rise in pulse	Precedex 1.4ml/h,	None	0~-1	-4
(4)	12.3	3	3	1	Rise in BP	None	None	None	
(5)	23.8	25	25	0	None	None	None	None	
(6)	15.0	3	3	1	Rise in BP	Precedex 1.2ml/h,	Dopamine hydrochloride 2γ/h	-1	
(7)	15.0	1	1	0	None	Precedex 1.5ml/h,	None	-2	
(8)	10.0	10	10	0	None	None	None	None	
(9)	21.7	3	3	0	None	***Propofol*** 10ml/h,	None	0	-1
(10)	17.0	5	5	0	None	None	Dopamine hydrochloride 4γ/h, Dobutamine hydrochloride 4γ/h,	-2	-2
Avg.	**18.5±6.3**	**8.5±7.8**	**8.5±7.8**	**0.6±0.7**					
Total			**85**	**6**		**6**	**2**		

Note: RASS=Ramsey Sedation Scale (range 1-6); JCS=Japan Coma Scale

Table 2 (Above): *Implementation of sitting in backless chair—variables for each patient.*

	Before implementation	During implementation	After implementation	One way ANOVA
Body temperature ℃	37±0.5	37±0.5	37±0.5	F= 0.00 , df=2 P=1.00
BP systole mmHg	103±24	103±26	104±21	F=5.15, df=2 P=0.62
BP diastole mmHg	62±14	65±15	62±14	F=7.23, df=2 P=0.93
Pulse rate times/min.	86±15	88±17	88±16	F=1.70, df=2 P=0.56
Respiratory rate times/min.	23±10	25±11	24±11	F=3.39, df=2 P=0.44

Table 3 (Above): *Changes in vital signs before, during and after implementation of sitting in backless chair.*

Patient	Maximum number of lines	Number of incidents	APACHE I score		Estimated death rate	
			1st SB	At discharge from ICU	1st SB	At discharge from ICU
1	9	0	35	30	83	70
2	6	0	21	13	39	17
3	6	0	21	21	39	39
4	6	0	16	14	23	19
5	8	0	29	16	67	23
6	9	0	29	20	67	36
7	12	0	27	25	60	17
8	6	0	23	-	46	-
9	7	0	42	14	93	19
10	7	0	28	-	64	-
Average	7.6	0	27.1	19.125	58.1	30
SD	1.95505044	0	7.50481327	6.057758	21.45512112	18.30691
Mann-Whitney test			U=15.5, P=0.028		U= 11.5, P=0.011	

Table 4 (Above): *Number of cannulations, incidents, APACHE II scores and estimated death rate during backless sitting intervention.*

ventilators in the ICU, the tidal volumes and lung compliance values significantly increased during implementation, compared to before and after implementation. Therefore, it is conceivable that SB is effective in improving respiratory function. It is surmised that this phenomenon occurred because the sitting position without back support lowered the diaphragm, enabling tidal volume to increase. Furthermore, even in consideration of the calculation formula for lung compliance value, it is conceivable that the lung compliance value also significantly increased due to the increase in tidal volume, since the majority of ventilator settings for the patients during SB were pressure limited. Given the circumstances in the improvement in tidal volume and lung compliance value, it is possible that SB has the effect of encouraging lung ventilation and elasticity, which are both a part of respiratory function.

In addition, regarding the safety of administering SB for acute patients on ventilators, it is believed that SB presents a low risk for the occurrence of negative incidents when compared to those said to arise from prone positioning. There were no accidental removals or incidents such as tumbling/falling over, despite the fact that the average number of cannulation times was as high as 7.6. Prone positioning is a complex advanced care-procedure and there are reports about the tendency for concurrent incidents (Petrucci & Iacovelli, 2007; Rossetti, Machado, Valiatti & Amaral, 2006; Wong, 1999). On the other hand, SB care is not as complicated as prone positioning and can be more simply implemented using a backless chair. For these reasons, it is conjectured that incidents could be prevented, and SB should be considered a type of care that can be safely carried out. Even viewed from the perspective of sedation, it was demonstrated that there was no particular adverse outcome due to SB. Regarding adverse events on physical condition such as cyclical fluctuation, there were six instances of discontinuing the implementation of SB out of the total 124 implementations, but the discontinuation was carried out prior to the deterioration of condition because nurses assessed the patients' physical condition, and at no time did it escalate to an adverse event. In fact, the APACHE II scores and estimated mortality rate significantly dropped with each day after admission to ICU. Based on this, it can be judged that SB can be safely administered to acutely ill patients as long as it includes the nurses assessments linked to a discontinuation policy that allows the nurses to act immediately.

Because SB must be administered with an assurance of safety that rests on the nurses' assessment of the patients' physical condition, there is a need to create a physical condition assessment guide for SB in the future. Even in previous research on the implemen-

tation of SB on post-surgery patients with cerebrovascular disorder in the ICU, and the adoption of an SB care program that included an assessment guide for nurses there was no worsening of the APACHE II score, and the acquisition rate for daily activities rose (Okubo, 2012). From this research as well, there is a strong possibility that the administration of SB for acutely ill patients, along with a nurse's assessment, is safe.

Limitations and Future Issues

The outcomes of this research may carry a bias due to the fact that the number of participants was limited to 10 patients. There is a need to greatly increase the number of participants and instituted randomized controlled trials with broadened research base outside of Japan to accumulate evidence.

In addition, changes in blood pressure and pulse were seen several times when implementing SB, leading to the discontinuation of implementation. In the future, assessment indexes for the patient's condition during implementation must be created in order to bring safe SB to many medical facilities.

Summary

SB was administered on a daily basis to 10 patients on ventilators in an ICU, and respiratory function was measured before, during, and after implementation. As a result, tidal volume and lung compliance values increased during implementation, compared to before and after implementation. Furthermore, decannulation, incidents such as falling over, or worsening of physical condition did not occur during SB implementation. However, at times slight changes in pulse and blood pressure were seen. Therefore, SB administered to acutely ill patients on ventilators effectively improves respiratory function and can be safely implemented. The task going forward is the creation of a nursing guide that provides both safe parameters for assessment of the patient's physical condition during implementation of SB and also immediate discontinuation parameters.

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The lived experience of adults with myasthenia gravis: A phenomenological study

Trudy Keer-Keer

Abstract
Myasthenia gravis (MG) is a disorder of the neuromuscular junction (NMJ) that causes fatigue and fluctuating muscle weakness (Hickey, 2009). The physiology of this disease is well understood and there are numerous medically focused articles that outline historical data, randomized controlled trials of treatment options and unusual case studies. The nursing literature about MG is limited and dated.

The aim of this study was to examine and understand the lived experiences of adults with MG. An interpretive phenomenological approach has been used that applies the research methodology of van Manen (1990). Seven people living with MG were interviewed and their experiences of the disease recorded. Questions were broadly worded about various topics related to MG and were guided by individual experiences. Thematic analysis revealed that MG affects every aspect of a person's 'lifeworld': their sense of time, body, space and their relationships with others.

The findings of this study highlight three main themes embedded in the data that a person with MG experiences: living with uncertainty, living with weakness and living with change. These experiences have been interpreted and discussed to gain a deep understanding of the meaning of the disease. This study raises awareness of MG for neuroscience nurses and provides a unique view of this disease.

Key words: *myasthenia gravis, lived experience, phenomenology.*

Introduction

MG is a rare, chronic disease of neuromuscular transmission characterised by fatigue and fluctuating muscle weakness (Hickey, 2009; Lindsay, Bone, & Fuller, 2010). MG can be classified by change of function and is often referred to as ocular, bulbar or generalised myasthenia.

The aim of this study was to examine and understand the lived experiences of adults with MG. To date there is no published nursing research on this in Australasia. An interpretive phenomenological approach has been used that applies the research methodology of van Manen (1990). Seven people living with MG were interviewed and their individual experiences of the disease recorded. A 'highlighting' approach, developed by van Manen (1990), was used to identify important thematic statements which were further analyzed through the dimensions of lived time, lived body, lived space and lived other. The findings of this study highlight three major themes embedded in the data that a person with MG experiences: living with uncertainty, living with weakness and living with change. In conjunction with an extensive literature review, these experiences have been interpreted and discussed to gain a deep understanding of the meaning of this disease.

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Literature Review

The key words 'myasthenia gravis' and 'lived experience' were used when searching electronic databases. These terms were searched separately because, at the time of this literature review, no research about the lived experiences of people with MG was located. This was also a significant finding of LaDonna (2011). Phenomenological studies addressing the concept of lived experience were widely searched. Due to the limited nursing research, medical and allied health studies have been included. Despite a lack of primary nurse-led research about the lived experiences of people with MG, the search

strategy was effective because it yielded a vast amount of information that addresses all aspects of MG and has provided a sound literary background for this study.

Definition and pathophysiology

In MG the main muscles affected are skeletal (Alshekhlee, Miles, Katirji, Preston, & Kaminski, 2009), in particular the voluntary muscles innervated by motor nuclei of the brainstem (Ropper & Samuels, 2009). Ineffective neuromuscular transmission occurs because of the destruction of nicotinic post synaptic acetylcholine receptors (AChRs) by acetylcholine receptor antibodies (Lindsay, et al., 2010). This results in decreased strength of muscle contractions and, with repetition, there is less acetylcholine (ACh) available which causes the muscle to become fatigued (Abbott, 2010). Acetylcholine receptor antibodies are found in up to 90% of people with MG (Cavel-Greant, 2008).

Classification and presenting symptoms

Ocular symptoms can occur in up to 90% of people with MG (Ropper & Samuels, 2009). Ptosis can be unilateral or bilateral (Barker, 2008) and occurs because the extra ocular muscles are weak (Hickey, 2009). Ptosis can consequentially cause blurred or double vision (Barker, 2008). Lindsay, Bone and Fuller (2010) suggested up to 40% of people with ocular myasthenia will develop generalised myasthenia. Bulbar weakness can result in facial weakness, dysarthria and dysphagia (Kaminski, 2009). Facial weakness can produce an expressionless mask-like appearance that makes it difficult for a person to smile, causing a characteristic 'myasthenic snarl' (Lindsay, et al., 2010). Dysphagia associated with MG can account for weight loss of 5-10kg for a person in the months prior to diagnosis (Kaminski, 2009). Progression to generalised weakness involves the diaphragm, intercostal and neck muscles which can result in breathlessness and dyspnoea (Hickey, 2009). Limb weakness is usually bilateral in the muscles closer to the torso, especially the hips, shoulders, upper arms and legs (Cavel-Greant, 2008). Fatigue is also a symptom of MG (Hickey, 2009) which may increase during the day and improve with rest.

Thymus involvement

A thymoma is a rare tumour of the thymus gland caused by epithelial neoplasms (Kaminski, 2009). These can occur in 10-15% of patients with MG (Chaudhuri & Behan, 2009) and is an indication for thymectomy (Armstrong & Schumann, 2003). Hyperplasia of the thymus gland can occur in up to 65% of patients with MG (Ropper & Samuels, 2009). It is thought that these thymic abnormalities in people with MG may be responsible for causing the immune attack on the AChRs (Barker, 2008).

Prevalence, Gender and Ethnic differences

Kaminski (2009) states the prevalence of people with MG is 0.5-20.4 people per 100 000, which is consistent with all the literature reviewed in for this study. This is supported by Barker (2008) who suggested prevalence rates have increased over recent decades due to better recognition of MG, resulting in earlier diagnosis and treatment of the disease.

Hickey (2009) and Lindsay et al. (2010) suggested MG is more common in women than men, with the peak age of diagnosis for women being between 20 and 30 years and men between 50 and 60 years. Thymomas are more common in men between the ages of 50 and 60 years (Ropper & Samuels, 2009).

Matsui et al. (2009) found that MG is unrelated to ethnicity, however Kaminski (2009) suggested there is a higher incidence of the disease among African-Americans. MG with thymoma occurs more frequently among Māori or Pacific Island people and presents at a younger age in these populations (Fink, Wallis, & Haydock, 2001).

Older adult considerations

There is a higher incidence of MG in adults over 65 years of age (Casetta, et al., 2010; Matsui, et al., 2009; Vincent, Clover, Buckley, Evans, & Rothwell, 2003) and may be underdiagnosed in older adults. Vincent et al. (2003) believed this may be due to co-existing morbidities older people have that may mask the symptoms of MG, while Matsui et al. (2009) suggested increasing incidence could be the result of the ageing population in general, improvements in diagnostic tests or an increased awareness of MG. Thymoma is more common with late onset patients, as is an increase incidence of bulbar symptoms and progression to more severe disease (Kaminski, 2009).

Pregnancy considerations

Pregnancy can unpredictably alter the course of MG (Gurjar & Jagia, 2005; Kaminski, 2009). Complete remission, clinical improvement, acute exacerbation and change in symptoms of MG have been documented with

pregnancy (Gurjar & Jagia, 2005). While most women can have a successful pregnancy and delivery (Cavel-Greant, 2008), it is important to note that the treatments for maternal MG can affect the foetus (Kaminski, 2009).

Myasthenic crisis

Myasthenic crisis involves a sudden onset of severe muscle weakness that can cause respiratory failure leading to the patient requiring intubation and ventilation (Alshekhlee, et al., 2009). It can be caused by a lack of anticholinesterase medication or precipitating factors such as infection, surgery or stress (Hickey, 2009). Myasthenic crisis should be diagnosed and treated promptly and it is important that nurses are able to identify this medical emergency (Chaudhuri & Behan, 2009; Kutzin, 2011). A rare cholinergic crisis can also occur due to the toxic effects, or overmedication, of anticholinesterase drugs (Ropper & Samuels, 2009).

Diagnosis

The Tensilon test involves administering intravenous edrophonium, a short-acting anticholinesterase inhibitor (Moore & Shepard, 2014). Edrophonium works by inhibiting enzyme action, which prevents the breakdown of ACh molecules and improves muscle weakness (Cavel-Greant, 2008). The diagnosis is considered positive if there is an improvement in muscle strength lasting approximately five minutes (Moore & Shepard, 2014). Nerve conduction studies (Hickey, 2009), Immunological tests to determine elevated AChR antibodies MG (Heldal, Owe, Gilhus, & Romi, 2009) and a CT of the mediastinum to detect thymoma (Barker, 2008) may also be used to diagnose MG.

Treatment options

Because there is no cure, treatment options are aimed at managing the symptoms of MG and can include medication, plasmapheresis, intravenous immunoglobulin (IVIG) and thymectomy (Fowler, 2013). Anticholinesterase drugs are the first line approach for managing the symptoms of MG (Barker, 2008). They work by inhibiting cholinesterase, the enzyme that breaks down ACh (Lindsay, et al., 2010). Anticholinesterase drugs allow larger amounts of ACh in the synapse for a longer time resulting in more effective nerve transmission (Woodward & Waterhouse, 2009). Pyridostigmine bromide (Mestinon) is the most common anticholinesterase drug used to treat the symptoms of MG (Kumar & Kaminski, 2011). Doses are individualised and improvement in muscle weakness can occur within 15-30 minutes after oral administration (Hickey, 2009). Some people may require additional immunosuppressive drugs, such as the corticosteroid prednisone, which is most commonly used and can provide significant improvement in patients (Kumar & Kaminski, 2011). Other immunosuppressant drugs that can be used include Cyclosporine, Azathioprine (Imuran), Mycophenlate mofetil, Tacrolimus, Cyclophosphamide, Methotrexate and Rituximab (Kumar & Kaminski, 2011).

Plasmapheresis is used as an option for patients in myasthenic crisis and prior to thymectomy (Kaminski, 2009; Lindsay, et al., 2010). The benefits of plasmapheresis can last up to six weeks (Barker, 2008), but there can be complications and side effects (Kumar & Kaminski, 2011). IVIG can also be used as a short-term treatment for worsening symptoms (Ropper & Samuels, 2009). Thymectomy can result in an improvement in patients with generalised MG by inducing remission (Costello, 2006).

Lived Experience

Van Manen (1990) built on the work of early 20th Century European philosophers by developing a modern extension of traditional phenomenological methods. Van Manen (1990) advocated a 'human science' approach to researching the lived experience and used this term interchangeably with the terms 'phenomenology' and 'hermeneutics'. Van Manen (1990) believed phenomenology is the study of essences and descriptions of meanings as they are lived; lived experience is the explication of phenomena as they present themselves to consciousness.

There is limited literature on the lived experiences of people with neurological conditions, especially neuromuscular disorders (LaDonna, 2011). Chen, Shih, Hayter, Hou & Yeh (2013), found patients with MG experienced physical and emotional difficulties that impacted on quality of life. For this study, the experiences of people with other neurological conditions with similar symptoms to MG such as Guillain-Barré Syndrome, stroke, multiple sclerosis, motor neuron disease, muscular dystrophy and cerebral palsy were explored. Some people have published books about their individual experiences with MG (Atkins, 2010; Byars, 2007; Gray, 2011; Hill-Putnam, 2010; Smart, 2006). The focus of these publications are stories, journeys and reflections on life events, and they all include specific examples of how they have experienced MG.

Method

An interpretive phenomenological approach developed by van Manen (1990) was used for this study. This method aims to understand thorough interpretation and identify common themes of the lived experience. The purpose of this qualitative study was to develop detailed, insightful perspectives to understand the lived experiences of adults with MG. This study was approved by the Canterbury District Health Board (CDHB), the Upper South B Regional Ethics Committee and the Research Manager of Māori Health. Seven adults with generalised MG aged between 31-86 years volunteered to participate in this study. Each person was interviewed once on a broad range of topics related to MG. The transcribed interviews were sent to the participants to review before they were returned to the researcher for data analysis.

Relevant text was analysed using van Manen's (1990) 'highlighting' approach. Identified themes were clustered into four 'existentials' that represent a person's 'lifeworld': lived time, lived body, lived space and lived other. Lived time (temporality) is subjective time and involves the "temporal way of being in the world" (van Manen, 1990, p.104). Lived body (corporeality) refers to the way "we are always bodily in the world" (van Manen, 1990, p.103) and means our physical or bodily presence reveals something about us. Lived space (spatiality) is 'felt' space and "refers us to the world or landscape in which human beings move and find themselves at home" (van Manen, 1990, p.102). The concept of lived other (relationality) involves the lived relations maintained with others in shared interpersonal space (van Manen, 1990).

Results

Thematic analysis revealed that MG affects every aspect of a person's 'lifeworld': their sense of time, body, space and their relationships with others. The 'existentials' were used as major headings and examples from the transcripts have been included to illuminate the essence of each dimension. It is essential that these dimensions are considered, as a whole to truly reflect the lived experience.

Lived time: past, present and future time

Each person interviewed in this study recalled where they were in relation to time when they first noticed symptoms "What is happening to me?" and when they were diagnosed "It was he who picked it, he put all those symptoms together". This was significant and had meaning for them. Present time was dominated by medication "I counted twenty pills a day!" and fatigue "I have to have my sleep in the afternoon". There was also a fear of what may happen by some of the participants in this study "I just don't want to go backwards". MG is intrusive and alters a person's sense of time regularly along the disease continuum.

Lived body: physical and psychological effects

The physical symptoms of MG can subtly or severely invade a person's body. The people in this study described difficulty with swallowing "I just couldn't swallow" and communicating "I couldn't speak, I was talking all funny". The effects of visual disturbances "I thought I was going blind" and fatigue "I would spend most of my time sleeping" were also significant. MG is unpredictable and a person may have little or no control during acute exacerbations. Experiences also included an array of emotions including fear "I was scared about the breathing" and anxiety "I just wanted to hide away, actually" in addition to grief due to loss of body function.

Lived space: restricted, improved and home space

The experience of MG restricts a person's dimensions of space, both mentally "I wasn't with it really, I was in just another kind of world" and physically "I wasn't allowed out of bed". A person's landscape can become cluttered with equipment and have limits set by health professionals in the acute phase of illness. Some of the people in this study reported feeling more positive "I've turned the corner" when they improved and developed a sense of determination "It's not going to defy me". Within home space, MG can intrude on everyday activities "It's a shame how you give things up" resulting in isolation "I can't drive anymore" and financial concerns "I could not work".

Lived other: relationships with family, friends, health professionals and faith

Relationships with others was significant in this study at every stage of illness. Family concern "My son, he seems a bit worried" and support "I could not have done without them" were acknowledged, in addition to strained relationships "We do have our words of course" the disease caused. Friendships changed and were either altered "I can't relate to people in the same way that I could" or strengthened as a direct result of the disease

"It was a wonderful experience with the patients". Despite often getting conflicting information from health professionals "But even doctors will all say different things", having doctors and nurses that were trustworthy "To have someone I was able to trust" was a significant finding. Medical and nursing students were spoken about often positively throughout this study "Students have got to learn too". Whether it was the support of family and friends, the importance of faith "I had a lot of people praying for me" or the trust they placed in health professionals, it was essential people with MG have relationships with others. This appeared to be a method of coping with the disease.

The findings of this study highlighted the many different ways a person experiences MG. In viewing the results through the dimensions of lived time, lived body, lived space and lived other, clear embedded themes related to the phenomenon of MG emerged. The themes of uncertainty, weakness and change are illustrated in the following diagram (Figure 1).

Figure 1 (Above): *The interrelated experiences in adults with myasthenia gravis.*

Living with uncertainty, weakness and change are all meaningful experiences in people with MG and, when interlinked represent the lived experience of this disease. At different stages of the disease, these intertwined circles expand and contract with a sense of fluidity, but are always present to some degree in a person living with MG.

Discussion

It is important to note that these findings are the researcher's interpretation of the experience of MG from the data obtained. More participants may have represented the MG population in a different way and collection of structured quantitative data may have enhanced the results of this small study.

Living with uncertainty: altered life equilibrium

People with MG experienced symptoms that are constantly changing, which can result in varying degrees of uncertainty that can occur at any time along the disease continuum. Throughout the duration of chronic illness, Hickey (2009) suggested a sense of uncertainty can occur as the level of disability waxes and wanes. Uncertainty is a characteristic of chronic illness (Kaminski, 2009), and this dynamic experience can have a major impact on a person (Hansen, Rortveit, Leiknes, Morken, Testad & Joa 2012). A sense of uncertainty is always present in some people with MG.

Living with weakness: altered physical strength and energy

The experience of weakness can occur at any stage in people with MG and was often the first sign that something was wrong. MG is essentially an invisible disease unless a person exhibits signs of muscle weakness or fatigue. The weakness associated with MG has been well described in the autobiographical literature (Atkins, 2010; Cavel-Greant, 2008; Gray, 2011; Hill-Putnam, 2010; Smart, 2006) but the meaning of weakness has been elusive. Muscle weakness was found to be subtle or severe, acute or chronic and had a profound effect on each individual that was interviewed in this study and therefore a significant experience of MG.

Living with change: altered control, outlook and daily life

The people in this study made significant changes to their daily lives as a result of their experiences of MG, although, it was not perceived or viewed in a negative manner. There were three main areas of change which illuminated the lived experience. Having control or lack of control and autonomy was significant and similar to people with cerebral palsy (Sandström, 2007) and amyotrophic lateral sclerosis (King, Duke & O'Connor, 2009). A positive outlook and determination were all experienced by people in this study which was also found in people with Guillian Barré Syndrome (Forsberg, Ahlström & Holmqvist, 2008) and muscular dystrophy (Boström & Ahlström, 2004). Daily life change highlighted the alteration and adaptation people with MG have made in relation to self-care, hobbies, employment and driving.

Conclusion

The pathophysiology of MG is well established in the literature and the results of this literature review provide a broad understanding of the aspects of this disease. The nursing literature available is limited, dated and highlights the need for quality nursing research within this specialist area. The literature review draws attention to the lack of information on the lived experiences of people with MG, a lack of nursing research and a lack of New Zealand led research. However, there is emerging literature which examines MG from a cultural viewpoint (Chen, et al., 2013) which supports some of the findings in this study.

What is the meaning of this disease?

The experiences in people with MG tell us that it is an individual experience with similar aspects that are shared by others with the disease. MG is an intrusive disease that causes physical and psychological challenges differently for each individual affected. The meaning of MG is multifaceted. The experiences of the people interviewed in this study are unique to their 'lifeworld'. This study has identified that people who have the same diagnosis of MG experience the disease in different ways, but do have common elements that are similar to other types of neurological disease. A person with MG lives in a dynamic equilibrium in their world where the experiences of uncertainty, weakness and change are interlinked and always present in some shape or form. These experiences serve as a constant reminder that disease is present, even if a person is in remission.

Relevance to Clinical Practice

MG, as a chronic health condition, can be severe and debilitating. The disruptions it causes to the physicality of one's body, to lifestyle, and to one's self-image make it imperative that gaining understanding into patient experience is essential. Nurses are in a unique position to understand the disease process and its meaning for the patient (Benner & Wrubel, 1989) and have a significant role when helping patients with MG adapt and cope with their illness. This study raises awareness of MG for nurses and other health professionals. It provides a unique view of the disease by exploring the meaning of MG and fills a gap in the nursing literature. The findings support existing studies in the area of neurological illness and add to the existing body of neuroscience knowledge. Despite its small sample size, this study may enhance clinical practice for nurses caring for people with MG, in particular ensuring accurate assessment, care planning, and collaboration with allied health, patient education and future research.

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Calendar of Events

2015:

- **European Association of Neuroscience Nurses Congress**
  Belgrade, Serbia.
  Dates: 13-16 May
  www.eann2015.rs

- **Neurosurgical Nursing Professional Development Scholarship Committee (NNPDSC) 12th Annual Conference.**
  Kirribilli Club, Lavender Bay. Sydney.
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  www.aci.health.nsw.gov.au

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

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

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

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

For further details and criteria guidelines please visit the ANNA website at **www.anna.asn.au**

Correction Notice

In the article by M.L. King, *Trauma and the Elderly: The Real Picture of Their Health May Be Blurred*, AJoN 2014, 24 (2) a reference citation was listed incorrectly. The author's name was listed as Sheetz when it should correctly have read Scheetz. Apologies for any inconvenience.

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