Nursing Working Group  
May 22, 2011

Summary

The Nursing Program provides a forum for nurses internationally to share practice related (translational) knowledge pertaining to disorders of haemostasis and thrombosis in both pediatric and adult populations. The goal is to promote evidenced based findings and practice through knowledge translation, standardization and systematic evaluation in clinical practice settings. The primary aim reflects the ISTH Nursing Workgroup’s commitment to advancing the promotion of both original research conducted by nurses and the uptake of evidence into practice within the nursing profession. To support this aim, the committee proposes a distinct session devoted to “Nursing Research”. Secondary aims include knowledge translation as applied to clinical patient challenges, optimizing health and health advocacy with a focus on optimizing adherence of patients with disorders of thrombosis or haemostasis, consistent with the World Health Organization recommendations.

To meet the objectives for the workgroup the following agenda is intended for this meeting:

Nursing Research

Presenter: Fiona Newall, PhD, RN  
*Nurse Led Research: Raising the ‘Voice’ of Nursing*  
The contribution of Nursing to health care delivery is recognised and highly appreciated in terms of optimising patient outcomes within the field of Haemostasis and Thrombosis. Nurses have made particular contributions to advancing practice in the fields of education, self-management and supportive care interventions. Frequently however, those contributions have been made only at an institutional level, limiting the scope and generalisability of these contributions. This presentation will explore the mechanisms by which Nurses engaging in education, patient management or supportive care interventions could employ a collaborative research framework in order to better promote the significance and generalisability of their initiatives. In undertaking such an approach, the ‘voice’ of nurses promoting strategies to optimise patient outcomes will become more compelling, powerful and reproducible.

Presenter: Debi Smith RN  
*Lower Than Expected Clot Rates In The Absence Of Effective Thromboprophylaxis*  
VTE is associated with significant morbidity and lower quality of life than other chronic diseases e.g. chronic lung disease. Post thrombotic syndrome occurs in 20-50 % of patients. Chronic pulmonary hypertension affects 2-4% of patient who develop PE. Studies have demonstrated that thromboprophylaxis reduces the risk of DVT/PE by 60% with a very low risk of adverse events. The objective of this study was to obtain data
about the (1) use of the risk assessment tool and thromboprophylaxis in everyday hospital practice (2) VTE rate for patients who have been recently admitted to CMDHB and from this data to estimate the number of preventable events. A retrospective audit undertaken on all patients readmitted with VTE within 3 months of hospital admissions recording demographic data and the level of VTE risk, reason for admission and whether risk assessment was performed. A letter was sent to the original consultants caring for patients during their initial admission to draw attention to the need for risk assessment. There were 223 patient admissions for VTE in the 6 month period. 73 patients met the criteria for having had a medical or surgical admission within the previous 3 months. < 60% did not receive appropriate thromboprophylaxis. Assuming a 10% fatality rate previously postulated in studies, an estimated 3 deaths and 36 cases of VTE annually could have been prevented in our patient population at CMDHB. A significant number of VTE's were prevented without a concomitant increase in other adverse outcomes by delivering prophylaxis to a a greater number of at risk patients

Presenter: Bunis Packham RN

Initiation Of Warfarin Therapy For Patients With Atrial Fibrillation

Initiation of warfarin therapy for patients with atrial fibrillation comparison 5mg vs. 3mg Patients who were diagnosed with AF requiring anticoagulation therapy for prevention of stroke were randomly selected. New patients with AF who were commenced on Warfarin, their details were collected from June to Oct 2010. 60 of 80 and 20 of 80 patients were initiated with 5mg and 3 mg warfarin respectively. Tait’s Model - commence patients on 5mg and check INR on day 5 and day 8. If patient unable to attend clinic on day 5 or are prescribed antibiotics, amiodarone the 3mg dose is initiated with INR day 7. In 3mg group 4/20 had elevated INRs due to Amiodarone during the initiation. Their Warfarin dose was adjusted accordingly and monitored before leaving them on less frequent follow up intervals In 5mg group 4 of 60, had elevated INRs secondary to antibiotic therapy with their Warfarin dose adjusted accordingly and monitored before leaving them on less frequent follow up intervals. The 5-mg warfarin initiation is superior to the 3-mg because it allows more rapid achievement of a therapeutic INR. Warfarin has been identified as one of the high risk medicine that can cause preventable harm. Risk assessment of patient before commencement of the treatment is important. Management of anticoagulant therapy by medical and non-medical health professionals is viewed professionally and legally as an advanced area of clinical practice. Only a trained competent health professional should undertake the assessment, consultation, titration, and prescribe treatment for patients.

Presenters: Fiona Newall PhD, RN and Mary Bauman, MN, PNP, RN

Concept Paper

Within the International Society of Thrombosis and Haemostasis, there are 20 Scientific Subcommittees. These subcommittee’s serve to support and promote the aim of ISTH to generate evidence via consensus and research into “...practical issues related to thrombosis, disorders of hemostasis and their underlying vascular biology...” 1 To date, the unique contribution of the discipline of Nursing has not been promoted.
Notwithstanding this, Nurses have made a contribution to the generation of evidence via the Scientific Subcommittee pathway within specific areas of practice. This concept paper explores the opportunity for Nursing to make a unique contribution to the generation of consensus and evidence supporting best practice Nursing care of patients presenting with haemostasis and thrombosis related disorders. Through the facilitation of discussion during the presentation, Nurses will be engaged to consider and comment on the scope and content of contribution Nursing could make to the generation of such evidence internationally. The content of this session and ensuing discussions are hoped to complement the session on “Clinical Challenges”, within which potential areas for collaborative research endeavors will be explored.

Selected Oral Presentations
Selected abstracts from online submission

Janine Furmedge: Examining the education needs of parents learning to use an infusaport in their child with haemophilia

Liesbeth Schrijvers : The learning process of self infusion in haemophilia: Finally some numbers we could give to our patients

Mary Bauman: An Innovative Clinic Approach to Increase Patient Participation in Their Health Care

Abstract Poster Presentations
Selected abstracts from online submission

Knowledge Translation: Women’s Health

Presenter: Maura Malone Dumas MSN RN
The Impact of a New Diagnosis: Striking a Balance

The diagnosis of a chronic illness can be devastating to an individual and/or family, even when the condition is labeled as a ‘mild disorder’ or ‘risk factor’. Initially, there are often misconceptions surrounding a diagnosis and the negative impact it may have on one’s quality of life. Correcting these misconceptions is essential, especially for children and adolescents, who can develop a sense of learned helpless, fragility, and poor self-esteem. Although many families follow a learning curve of concerns and questions, arriving at a sense of calm understanding, there are some that don’t. It’s important to try to help these families overcome unconscious behavioral traps they may have to keep themselves or their children overprotected and ‘stuck’ in an illness frame of mind. Working with patients and families to find the correct balance in managing their stress while better understanding their diagnoses, through education, support, and planning, allow the opportunity for them to live their lives to the fullest.
Presenter: Ann O’Sullivan RN
*Evaluation And Treatment Options For Menorrhagia With Clotting Disorders*
Menorrhagia or heavy menstrual loss (>80 ml/7 days) is common in women with bleeding and clotting disorders during their reproductive life. Menorrhagia is a debilitating condition that interferes with normal lifestyle and can result in chronic fatigue, iron deficiency anaemia and regular absences from school or work, is the main presenting complaint in gynaecological referrals and accounts for 2/3s of all hysterectomies. Primary coagulation defects account for menorrhagia in 17-20% of women investigated. The use of oral anticoagulants results in women seeking investigation and treatment for menorrhagia. The assessment and investigation of women with menorrhagia should be carried out in a Specialist Coagulation Centre and included a detailed personal and family bleeding history, completion and analysis of a pictorial blood loss assessment chart and laboratory analysis of relevant blood tests. Treatment options for menorrhagia include the combined oral contraceptive pill, cyclical 21 days oral progesterone, oral tranexamic acid, desmopressin, levonorgestre-releasing intrauterine device, clotting factor replacement. Unfortunately not all options are suitable for women with a history of venous thromboembolism and these women will have a higher rate of surgical intervention including uterine ablation and hysterectomy. Menorrhagia is a common and major problem in women with bleeding and clotting disorders. Appropriate assessment and haemostatic control during menstruation is essential to diminish any risk of haemorrhagic complications and to enhance quality of life in these women.

Presenter: Regina Butler RN
*Guidelines for Carrier for Neonate with Haemophilia*
Review of the Children’s Hospital of Philadelphia Guidelines for carriers for neonates with haemophilia

**Optimizing Health and Health Advocacy**

Presenter: Karen R. Baker, BSN RN
*Pearls Of The New Anticoagulants*
Warfarin and heparin have been well studied and documented for more than 50 years. The low molecular weight heparins are also now well established to those working with thrombophilia treatment or prophylaxis. Now we have several new and emerging oral anticoagulants. Following the experience with ximelagatran and the safety concerns with liver toxicity associated with prolonged (>35 day) administration with this drug, the new medications need to be used with education and caution. These new medications have been shown to be safe and effective in several clinical settings, including prevention of venous thromboembolism after orthopedic surgery, prevention of stroke in atrial fibrillation, and the treatment of acute venous thromboembolic disease. The absorption and metabolism of the new oral anticoagulants, and the resulting
pharmacokinetic and pharmacodynamic responses in the presence of other clinical conditions, including renal insufficiency and liver disease, are important considerations for the safety of special patient populations.

Presenter: Carolin Baglin RN  
*Obesity And Thrombosis Risk*  
Venous Thromboembolism (VTE) is a disease which has many causes. It is the result of the coincidence of several risk factors, some of which may be inherent to the individual whilst some are acquired. One of these risk factors is obesity, Excess body weight increases the risk of venous thromboembolism (VTE). The incidence of recurrence of VTE is also higher in obese patients, (3). There is a positive correlation between raised body mass index (BMI) and the risk of development of Post Thrombotic Syndrome (PTS). PTS can cause impairment of quality of life. The clinical significance of this promotes discussion relating to effective ways of preventing PTS. Obesity is a chronic disorder which is a growing public health issue globally. How anticoagulant services address the issue of sedentary lifestyle, obesity and reduced mobility is open to debate and discussion. How can the nursing profession strengthen their role as education lists and the issues that cause challenges to this group of patients?. Do obese patients require different treatment plans and care? How do anticoagulant services communicate with these patients to allow the patient the opportunity to be involved in decisions about their care? The presentation will share innovations in nursing practice that will benefit patient care, build solidarity in the profession and promote practical solutions.

Presenter: Bunis Packham RGN, BSc RN  
*Developing University Accredited Degree Module In Anticoagulation And VTE Prevention*  
It is estimated that 25,000 people in the UK die from preventable hospital-acquired venous thromboembolism (VTE) every year. The inconsistent use of prophylactic measures for VTE in hospital patients has been widely reported. A UK survey suggested that 71% of patients assessed to be at medium or high risk of developing deep vein thrombosis did not receive any form of mechanical or pharmacological VTE prophylaxis. Any patient admitted to hospital is potentially at risk of developing a blood clot. Therefore it is recommended that all health care professionals involved in caring for patients admitted to hospitals have the adequate skill and knowledge to provide a safe and effective VTE prevention. Currently there are conferences and study days on VTE but there is no accredited VTE course in the UK, this is the first accredited course. Aim: To develop VTE Link nurse /pharmacist/doctor who have adequate skill and knowledge. To enable the development of holistic, patient focused care based on the philosophies of VTE and prevention care. At the end of the course, successful candidates will receive a certificate 20 credits at level 6, and portfolio with evidence of practice or Certificate 10 credits at level 6 following completion of learning activity 3. Conclusions:
Previous course has been a huge success and feedback from the students has lead to the development of the VTE and anticoagulation course

Presenter: Jennifer Maahs MSN PNP

*General Aging Health issues: The Impact on the Haemophilia Population*

Persons with hemophilia have increased life expectancy related to advances in treatment. Age related co-morbidity is becoming common in this population. The aim of this review is to summarize available data regarding the impact of general aging issues in the hemophilia population. In the past, lifespans were shortened due to bleeding complication, HIV and Hepatitis. Patients are now developing cardiovascular disease, renal complications and cancer. General health maintenance is also more complex related to increase bleeding risks. Studies suggest that co-morbidity can lead to functional limitations, psychosocial issues and a decreased quality of life.

Presenter: James Munn MS, RN and Mary Bauman MN, PNP, RN

*What is Your Game Plan: Risk vs. Benefit?*

Objectives: Discuss why sports/physical activities are important to patients with bleeding disorders (BDs). Provide a tool to assist with decision-making for pediatric patients with BDs. Introduce “My Game Plan” developed for use with patients, families and HTC providers to assess risk/benefit of sports/activities participation. Educate the audience on how to effectively use the tool. Explore ways to adapt the tool for individual use. Methods: Using evidence-based research on risks/benefits to sport participation in BD patients, will discuss the need for a tool to assist with the open dialogue needed by patients, families and providers. Introduction of a tool developed physical therapist that addresses this need. Using a case study approach, outline how the tool can be used in any HT. Results: Initial anecdotal information has been positive at establishing an open dialogue between patient, families and providers on this sometimes delicate issue. The tool is easily adaptable to “motivational interviewing” techniques, older patients, and even those with thrombophilia concerns. Conclusions: “My Game Plan” has been used in different settings with pediatric patients and families. Initial results have been quite positive and the tool is now available through the National Hemophilia Foundation.

Modification of the tool for use in patients requiring anticoagulation therapy will be described.

Presenter: Regina Butler RN

*Influence of Patient Education on Adherence: Is Teaching Enough?*

Advances in medical care create the potential for individuals with chronic illness to minimize complications and attain optimal health. Many individuals find adherence to prescribed regimens challenging, with estimates of 50% adherence in chronic illness. For patients with hemophilia, poor adherence results in increased joint disease, limitations of activities of daily living and decreased quality of life. Treatment of hemophilia, by its nature, requires significant time and effort on the part of the patient and family and includes factors that have been shown to predict poor adherence. Providers often rely
on information to increase adherence. However, lack of information is only one of the factors negatively impacting adherence to medical advice. For each plan of care prescribed, multi-dimensional strategies must be developed with the patient and family to support their ability to adhere to the plan. While patient education is a critical component of comprehensive care, education alone is not sufficient to ensure adherence to treatment recommendations. Teaching can influence adherence if the educational plan is individualized, including recognition and attention to behavioral, cultural and social factors and plans of care are developed with patient and family participation from the beginning. Health care providers can assist families in identification of barriers to adherence and in developing successful strategies to promote optimal health.

Presenter: Sophie Jones RN  
*Outcomes of Clinical Practice: The Role of Quality of Life Assessments in Pediatric Anticoagulation Management*  
The absence of robust evidence for anticoagulant management in children, combined with a limited amount of reliable safety and efficacy outcome data of interventions challenges the clinicians’ ability to weigh up the risks and benefits of anticoagulation therapy for children. The increased survival of children with chronic diseases has led to an increase in the number of children requiring anticoagulation to minimize the risk of thromboembolism. Due to their underlying illness, mortality and morbidity rates for these children are not an accurate measure specifically of anticoagulation therapy success. Similarly the low incidence of anticoagulant-related adverse events in children limits the sensitivity of this outcome as a measure of efficacy. Our current clinical practice is obviously contributing to improved survival for our patients, but at what cost? Quality of life (QoL) assessments are outcome measures that provide information about the burden of treatment for the child and family and help clinicians tailor the goals of treatment to the individual child. QoL can be an indicator of symptom severity, levels of ability or physical, social and psychological function and the overall success of a specific treatment as measured by the child’s perception of the impact of treatment on their QoL. The core elements of evidence-based practice are the use of clinical expertise, best available research evidence and consideration of patient values. The application of QoL assessments as an outcome measure of anticoagulation therapy in children ensures children’s and families’ values are integrated with the current evidence for best clinical practice.

Presenter: Frederica Cassis Psychologist / Psychotherapist  
*Education and prevention using flashcards in the treatment of people with bleeding disorders*  
For people with a bleeding disorder internationally the treatment situation varies. While in severe hemophilia, prophylaxis is used as a normal standard treatment, in most countries only few patients receive it because the treatment is usually on-demand. On-demand treatment requires adaption since the moment of diagnosis to live with the fact they have to manage life according to the early detection of a bleed, infusion of factor,
choosing suitable activities. The situation resembles the others cases of moderate, mild hemophiliacs, Von Willebrand's and other rare blood clotting disorders, or patients with side effects of anti-coagulant treatment in thrombotic events. The objective of this presentation is to demonstrate the importance of early educational intervention through the use of flashcards for children, careers and professionals of the treatment center. The HEMOACTION and P-TET (Pediatric-Thrombosis Educational Tool) are educational, age-appropriate tools based on flash cards. Different domains of importance in treatment such as vascular anatomy, medication, side effects, activities, recognition of different bleeds are approached. Conclusion: Living well with a bleeding disorder requires knowing early and as clear as possible about the condition to cope with unnecessary fears or beliefs. Images are an accessible way of teaching difficult concepts by memorizing in a playful way.

Clinical Challenges

Knowledge Translation: Putting Evidence into Practice
Case Study presentations, care pathways and protocols

Summary
In summary, the Nursing workgroup is embarking on an ambitious program to support nurses in translational research focusing on a framework of clinical challenges, adherence and knowledge translation to the patient / family, locally within their institution and to the medical community as a whole. The Nursing workgroup provides a collaborative environment where knowledge and practice patterns are shared and systematic evaluation of each are supported to promote the significance and generalizability of initiatives. A future direction being explored during the 2011 ISTH Congress is the feasibility of the Nursing discipline to generate novel evidence and clinical recommendations through development of a collaborative research agenda.