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HAEMATOLOGY SOCIETY OF AUSTRALIA AND NEW ZEALAND NURSES GROUP

HSANZ NG News

From the president

Dear members and colleagues,

I doing some research the other day with regard to POEMS syndrome, also known as Crow-Fukase syndrome, represents a rare multisystem syndrome characterized by polyneuropathy, organomegaly, endocrinopathy, M protein, and skin changes) and the lovely, ever efficient Google family delivered me this poem which I would like to share with you – it made me stop and think about smelling some roses instead of my usual practice of rushing past them and knocking half of the petals off!

This poem was written by a terminally ill young girl in a New York Hospital.

Have you ever watched kids on a merry-go-round?
Or listened to the rain slapping on the ground?
Ever followed a butterfly's erratic flight?
Or gazed at the sun into the fading night?
You better slow down, don't dance so fast.
Time is short, the music won't last.
Do you run through each day on the fly?
When you ask how are you, do you hear the reply?
When the day is done, do you lie in your bed?
With the next hundred chores running through your head?
You'd better slow down, don't dance so fast.
Time is short, the music won't last.
Ever told your child, we'll do it tomorrow?
And in your haste, not see his sorrow?
Ever lost touch, let a good friendship die?
Cause you never had time to call and say hi?
You'd better slow down, don't dance so fast.
Time is short, the music won't last.
When you run so fast to get somewhere
You miss half the fun of getting there.
When you worry and hurry through your day,
It is like an unopened gift.....thrown away.
Life is not a race, do take it slower
Hear the music before the song is over.

The annual conference in Adelaide was a huge success, with thanks to Bev Quested and her team. Rosie Howard and her team are hard at work putting together what promises to be an exceptional programme in Auckland this year. Once again, I am putting out a plea to you to think about sharing your practice with colleagues by presenting your work at the meeting.

If you have not yet got around to joining the HSANZ NG – pick up a membership form from the HSANZ stand or from the website – it really is great value for $55 a year, but more importantly, I believe that your membership of this, the only professional organisation for haematology nurses, says something about you as an expert and specialist and, by having a strong membership, says a lot about haematology nursing as a discrete specialty - so stand up and join up!!

Moira Stephens February 2010

Inside this edition

From the travel grant winners

The development of a Haematology Late Effects Nurse Consultant role with a national scope

Gates.P[1], Krishnasamy M[2], Wheeler.G[1], Seymour.JF[1], Ritchie D[1], Schembri.S[3].

[1]Haematology Late Effects Service. Peter MacCallum Cancer Centre. Melbourne Australia. [2]Department of Nursing and Supportive Care Research. Peter MacCallum Cancer Centre. Melbourne Australia. [3]Leukaemia Foundation of Australia.

Haematology Late Effects

Long-term survivors of childhood, adolescent and adult haematological malignancies are an important and expanding patient group with unique and wide ranging survivorship issues. With advances in multimodality therapy, survival rates from many haematological malignancies now exceed 80%. This results in a large cohort of survivors who are at risk of developing long term late effects (LE) related to treatment including secondary malignancies, cardiac and endocrine dysfunction, infertility and psychosocial sequelae. Many LE are avoidable or can be ameliorated by early detection and/or risk modification.

Nurse-led care in the context of a multidisciplinary, haematology LE clinic

The LE clinic at Peter Mac was established in 2000 and is one of three known LE units for adult survivors in Australia. Referrals come from all over Australia and include hospitals, advocacy groups, primary care physicians or survivors may self-refer. Patients are accepted into the unit five years after completion of curative treatment.

In 2008, a Haematology Late Effects Nurse Consultant (LE NC) was appointed to work specifically with survivors of haematological malignancies. The position is funded by the Leukaemia Foundation of Australia and was motivated by recognition of the considerable health deficits experienced by survivors of haematological malignancies.

Prior to each LE clinic, all patients are considered in detail by the multidisciplinary team in order to consider anticipated health risks, review relevant past disease and treatment issues and potential areas of risk. All relevant practitioners meet with the patient on the same day. Patients remain in one location throughout the visits and are not required to move from room to room for consultations with the relevant practitioners (Gates and Krishnasamy, 2009).

Health deficits

1) Emotional distress

Since the incidence of emotional distress is significant in cancer survivors (Aziz 2007) screening for emotional distress is undertaken by the haematology LE NC at every consultation, with timely referral for specialist support as needed.

2) Informational needs to promote healthy living

The nursing consultation focuses on six key domains informed by best-available evidence to indicate prominent health-related needs for cancer survivors: physical activity, healthy eating, smoking status, alcohol consumption, self examination and sun protection (Klosky et al 2008). The information is presented to each individual within the context of an education package directed specifically at their concerns, problems or health risks

3) Survivorship care plans

The Survivorship Care Plan (SCP) includes details of medical history, treatments received, potential for LEs, requirements for follow-up appointments, tests and reasons for them. It focuses on health promotion and highlights the need for and how to adopt healthy behaviours. It also addresses psychosocial issues, how to identify them and where to get help. A copy is sent to each person's primary care physician.

Conclusion

This innovative nurse-led model of survivorship follow up is in its infancy. Data is currently being gathered to evaluate its contribution to the outcomes of survivors of haematological malignancies and findings will be published in 2010. The interventions which are in-

From the travel grant winners (cont'd)

formed by patient-reported concerns are delivered by an advanced-practice haematology nurse, have been based on best-available evidence and endorsed by a multidisciplinary team of experts in the field. The NC role, situated within a multi-disciplinary, LE team offers a new model of cancer survivorship care that may prove to be applicable to other patient groups in future.

Acknowledgement

The Haematology Late Effects Nurse Consultant role is supported by funding from the Leukaemia Foundation of Australia.

References

Aziz NM. Cancer survivorship research: state of knowledge, challenges and opportunities. Acta Oncol.2007; 46:417-32.

Gates P, Krishnasamy M. Nurse-Led Survivorship Care. Cancer Forum. 2009; Nov; 33 (3): 175-179.

Klosky JL, Cash DK, Buscemi J, Lensing S, Garces-Webb DM, Zhao W, Wiard S, Hudson MM. Factors influencing long-term follow-up clinic attendance among survivors of childhood cancer. Journal of Cancer Survivorship. 2008; 2(4): 225-32.

Priscilla Gates, ***Peter MacCallum Cancer Centre***

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The Development and Implementation of a Nurse-Led Follow-Up Clinic for Patients who have Undergone an Autologous Stem Cell Transplant (ASCT)

The needs of individual patients following ASCT are highly varied. Patients commonly experience ongoing adverse effects such as fatigue, poor appetite, difficulties in resuming work, alterations in body image and sexuality issues. Evidence indicates that traditional medical models of follow-up care may fail to meet patients' psycho-social needs and are sub-optimally effective at managing late effects. An ASCT is a lengthy and complex journey for the patient and family. Follow-up care for this patent group has traditionally been delivered through a medical model. However, there is evidence to suggest that medical follow-up care may fail to, or not optimally address the patient's psychosocial needs following an ASCT.

Nurse-led clinics (NLCs) are a growing feature in our health care landscape. In the NLC model care is planned and led by advanced specialist nurses with site specific expertise. NLCs have demonstrated to offer patients increased continuity of care, more individualized follow-up and improved psychosocial outcomes (Cox & Wilson, 2003; Tonkin, 2007).

The Haematology Service at the Peter MacCallum Cancer Centre (PMCC) is the main Centre of referral in Victoria for patients who are planned for ASCT. In 2009 a total of 133 autologous stem cell transplants were performed. There was a consensus amongst the team that a more coordinated approach to post-transplant follow-care was necessary and with the increased specialisation of nursing roles within the Haematology Team this care could be led by specialist nurses.

In response to this, we obtained funding to undertake a pilot study to test a nurse-led follow-up clinic for patients who have undergone an ASCT. This study set out to test the acceptability, feasibility and safety of the NLC. A quasi-experimental pilot study was developed. Phase 1 involved the collection of baseline data to gain an appreciation of problems experienced by this group of patients at PMCC. Three well validated and internationally utilised instruments were used: the Hospital Anxiety and Depression Scale (HADS); the Chemotherapy Symptom Assessment Scale (C-SAS); and the European Organisation of Research and Treatment of Cancer Quality of Life Q-C30 Version 2 (EORTC-QOQ C-30). This data was used to inform evidence-based interventions to be delivered in the NLC. Algorithms were developed to support the specialist nurses working in the clinic to ensure safe and consistent practice. Standardised nursing assessment documentation was developed to record the issues presented by patients, the interventions delivered by nurses in the NLC and their efficacy. Phase 2 involves testing the acceptability, feasibility and safety of the NLC and this is now underway. Data collection is ongoing using the aforementioned questionnaires and we have also included a patient satisfaction questionnaire. The NLC commenced operation in October 2009. Since commencement a total of 41 face to face patient consultations have taken place. Activity in the NLC focuses on health assessment, psychosocial assessment, symptom management, referrals to allied health and general practitioners as needed, and patient and family education.

We believe this innovative model of care has the capacity to enhance the current model of follow-up for patients following an ASCT. We are testing this assumption using evidence, wherever possible, to inform the design, content and evaluation of our initiative.

References

Cox, K & Wilson, E. (2003). Follow-up for people with cancer: nurse-led services and telephone interventions. *Journal of Advanced Nursing* 43(1), 51-61.

Tonkin, J. (2007). Developing a telephone follow-up service for myeloproliferative disorders. *British Journal of Nursing, 16(17), 1090-1094.*

Trish Joyce, ***Peter MacCallum Cancer Centre***

Please note that our other travel grant winner, Liz Hayes, is on leave. Her article will appear in the next issue.

HAA 2010—Auckland, New Zealand

A reminder that this year's conference is to be held in Auckland. We have a fabulous guest speaker, Shelley Dolan, Chief Nurse at the Royal Marsden Hospital in London. It's never too early to start thinking about what you'd like to present and to avoid that last minute rush!

2010 dates for your diary

International Conferences

24-28 Feb: BMT Tandem Meetings, Orlando, Florida, USA

7-10 Mar: International Society of Nurses in Cancer Care, Atlana, Georgia, USA

21-24 Mar: European Group for Blood and Marrow Transplantation (EBMT), Vienna, AUSTRIA

19-21 Apr: British Society of Haematology, Edinburgh, SCOTLAND

13-16 May: Oncology Nursing Society Congress, San Diego, California, USA

22-25 May: International Society on Thrombosis and Haemostasis, Cairo, EGYPT

26-29 May: American Society for Apheresis, New Orleans, USA

10-13 Jun: European Haematology Association, Barcelona, SPAIN

26 Jun-1 Jul: International Congress of the International Society of Blood Transfusion, Berlin, GERMANY

10-14 Jul: World Federation of Haemophilia, Bueons Aires, ARGENTINA

1-4 Sep: World Apheresis Association Congress, Interlaken, SWITZERLAND

10-13 Oct: International Society of Haematology, Jerusalem, ISRAEL

4-7 Dec: American Society for Hematology, Orlando, Florida, USA

National/Trans-Tasman Conferences/Meetings

4-7 May: ALLG, Adelaide

29-31 Jul: CNSA 13th Winter Congress, Perth

17-20 Oct: HAA, Auckland

9-12 Nov: ALLG, Sydney

State/Regional Meetings

16 Apr—Gosford
17 Jun – Sydney
16 Sep – Wollongong
18 Nov – Sydney

For those of you who really like to plan ahead!

2011
Mar - EBMT, Paris, FRANCE

Paroxsymal Nocturnal Haemoglobinuria (PNH)

PNH is a rare, progressive, clonal disease that can cause thrombosis, end organ damage, and increased mortality. While the disease can present at any age, it most often affects patients in the prime of their lives with the typical age at diagnosis in the early 30s. It can occur in isolation (as classical PNH) or in the presence of a bone marrow dysfunction disorder, such as Aplastic Anemia and/ or Myelodysplastic syndrome. Patients with a history of (or active) AA and MDS, have been reported to be at higher risk for developing PNH. These conditions can also present with similar symptoms (eg, anaemia) and may complicate the early diagnosis and treatment intervention of PNH.

Signs and Symptoms

Chronic haemolysis, due to the PNH red blood cell (RBC) destruction, is central to the morbidities and mortality associated with PNH. This can be associated with a wide spectrum of presenting signs and symptoms including:

- Anaemia
- Arterial and venous thrombosis
- Fatigue - disproportionate to underlying anaemia
- Haemoglobinuria (haemosiderin in urine)
- Low or undetectable levels of haptoglobin
- Elevated lactate dehydrogenase (LDH) or aspartate amino-transferase
- Pulmonary hypertension
- Pain (e.g. abdominal)
- Erectile dysfunction in males
- Dysphagia
- Dyspnoea
- Renal insufficiency

Patients suffer from a poor quality of life from these symptoms and are at risk for life-threatening complications. 35% of PNH patients die within 5 years of diagnosis. Thrombosis, one of the most serious sequelae, has been documented in 40% of patients and is the leading cause of death in PNH. There is also growing evidence supporting an increased incidence of end organ damage involving lung, liver, kidney and brain in these patients. Nurses who are not fully aware of the full spectrum of symptoms associated with this disease may not fully appreciate the burden that these morbidities place on these patients. Failure to recognize the consequences of chronic haemolysis has contributed to the challenge of diagnosing and managing the disease. Historically, it has been recognized that intermittent acute haemolysis (paroxysms) leads to exacerbations of distinct PNH symptoms such as haemoglobinuria. However, many of the signs and symptoms, including fatigue, smooth muscle dystonias (e.g, dyspnoea, dysphagia, pain and erectile dysfunction), and thrombosis, do occur without haemolytic exacerbations. Indeed, only 26% of PNH patients present with haemoglobinuria.

Diagnosis

Diagnosis of PNH is generally confirmed by laboratory assessment. Important laboratory assessments to assist in this diagnosis are:

- lactate dehydrogenase (LDH) levels. LDH, long considered a useful clinical marker of intravascular haemolysis, is frequently elevated in patients with PNH

- flow cytometry (a measure of the PNH clone of GPI-deficient white and red blood cells).

Other laboratory measures that assist in the diagnosis of PNH or help to monitor disease burden, include **Hb**, **reticulocyte count** and **haptoblogin**

Treatment/Management

Red blood cells transfusions have historically been the main supportive therapy available to these patients. Transfusions have been primarily aimed at replacing RBC loss as a result of ongoing active haemolysis. However, transfusions alone do not address the underlying haemolysis that leads to other signs, symptoms, and risks in PNH patients. In fact, not all patients suffering from PNH require RBC transfusions. Patients who require minimal or no RBC transfusions may still demonstrate significant chronic haemolysis and suffer symptoms and risks associated with it, such as life-debilitating fatigue, dysphagia, pain, kidney disease and thrombosis.

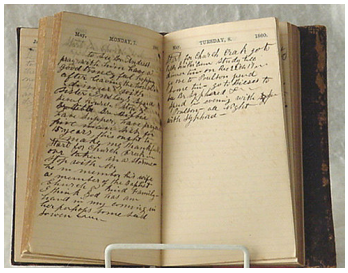
Corticosteroid and androgen therapy have also been used in an attempt to help control acute haemolytic exacerbations in classic hemolytic PNH, but no controlled data exists to suggest that the potential benefit outweighs the established risks of such therapies.

Patients with acute thrombosis are often treated with thrombolytic therapy and placed on long-term anticoagulants to help prevent further blood clots. However, the risk for haemorrhagic effects associated with long-term anticoagulant therapy also needs to be considered. Furthermore, evidence shows that some patients will continue to develop blood clots despite therapeutic anticoagulation.

Despite the availability of these supportive treatments, patients have continued to suffer from symptoms and disease progression associated with their PNH. A new humanized monoclonal antibody for the long-term management of PNH has been recently registered in Australia. Soliris® (eculizumab) is indicated for the treatment of patients with PNH to reduce the haemolysis which leads to the morbidities associated with PNH. Soliris® has been shown to reduce chronic haemolysis, improve anemia (as defined by stabilization of Hb concentrations and reduction or elimination of the need for transfusions), decrease disabling fatigue, and improve overall quality of life. Also, patients on Soliris® experienced fewer thrombotic events than during the same period of time prior to treatment.

We are looking at establishing a PNH special interest group within the Australian Haematology Nursing community. If you would like to become involved with this group, or would like to be informed about some upcoming educational opportunities, please contact Michael Brown (Royal Melbourne Hospital). Email: michael.brown@mh.org.au. Ph: (03) 9342 7954

Research News – a short trip around some recent journals



Bisphosphonate-related osteonecrosis of the jaw in cancer patients: Implications for nurses.

Morris M, Cruickshank S. Eur J Oncol Nurs. **2010 Feb 1. [Epub ahead of print]**

PURPOSE: This paper reports a review of the literature with a specific focus on osteonecrosis of the jaw. Bisphosphonate drugs are commonly used in the treatment of bone disease secondary to myeloma and solid tumours, such as breast and prostate cancer. In the past few years, an uncommon but distressing condition known as osteonecrosis of the jaw (ONJ) has been detected in patients who are having bisphosphonate treatment, particularly the intravenous (IV) preparations. Osteonecrosis of the jaw results from bone exposure in the oral cavity with subsequent death of bone tissue (necrosis). METHOD: The review searched key databases including Medline, British Nursing Index, Cochrane, and meeting abstracts to ascertain the extent of literature in this field. RESULTS: Fourty-two articles were reviewed which described the clinical manifestations of ONJ, the reported incidence and clinical cases. CONCLUSION: The results indicate there is an emerging body of evidence in this field and nurses delivering bisphosphonates need to familiarise themselves with the current guidance to ensure risks are minimised for patients

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Etoposide induces more severe mucositis than CY when added to TBI as conditioning in allograft recipients receiving CsA and MTX.

Hoyt R, Ritchie DS, Wirth A, Szer J, Grigg AP.Bone Marrow Transplant. 2010 Jan 11. [Epub ahead of print]

Department of Clinical Haematology & BMT Service, The Royal Melbourne Hospital, Victoria, Australia.

Fractionated TBI and etoposide (FTBI-VP16) conditioning is effective therapy for patients receiving allogeneic stem cell transplants for ALL. One of the major dose-limiting toxicities with this regimen is mucositis although its effect on patients and hospital resources is not well described. To determine the severity of mucositis (WHO grade 3-4) experienced and assess resource utilisation, we compared the non-haematological toxicities of 38 patients receiving FTBI-VP16 with 104 patients receiving CY and TBI (CYTBI). FTBI-VP16 patients were more likely to develop severe mucositis (odds ratio (OR) 6.0 (95% confidence interval (CI) 1.36, 54.42), P<0.01) and its duration was longer (11.5 vs 8 days, P<0.01). Resource utilisation was considerably higher especially in the use and duration of i.v. narcotics and parenteral nutrition, nursing care requirements and plt-transfusion support. Patients receiving FTBI-VP16 conditioning are ideal candidates for new therapies to prevent or reduce the severity of mucositis

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Facilitating needs based cancer care for people with a chronic disease: Evaluation of an intervention using a multi-centre interrupted time series design.

Waller A, Girgis A, Johnson C, Mitchell G, Yates P, Kristjanson L, Tattersall M, Lecathelinais C, Sibbritt D, Kelly B, Gorton E, Currow D.B MC Palliat Care. 2010 Jan 11;9:2.

Centre for Health Research & Psycho-oncology, The Cancer Council NSW, University of Newcastle, Hunter Medical Research Institute & Priority Research Centre in Health Behaviour, Callaghan, Australia.

BACKGROUND: Palliative care should be provided according to the individual needs of the patient, caregiver and family, so that the type and level of care provided, as well as the setting in which it is delivered, are dependent on the complexity and severity of individual needs, rather than prognosis or diagnosis [1]. This paper presents a study designed to assess the feasibility and efficacy of an intervention to assist in the allocation of palliative care resources according to need, within the context of a population of people with advanced cancer. METHODS/DESIGN: People with advanced cancer and their caregivers completed bi-monthly telephone interviews over a period of up to 18 months to assess unmet needs, anxiety and depression, quality of life, satisfaction with care and service utilisation. The intervention, introduced after at least two baseline phone interviews, involved a) training medical, nursing and allied health professionals at each recruitment site on the use of the Palliative Care Needs Assessment Guidelines and the Needs Assessment Tool: Progressive Disease - Cancer (NAT: PD-C); b) health professionals completing the NAT: PD-C with participating patients approximately monthly for the rest of the study period. Changes in outcomes will be compared pre-and post-intervention. DISCUSSION: The study will determine whether the routine, systematic and regular use of the Guidelines and NAT: PD-C in a range of clinical settings is a feasible and effective strategy for facilitating the timely provision of needs based care.

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Nurses' Perspectives on the Care Provided to Cancer Patients.

Watts R, Botti M, Hunter M.Cancer Nurs. 2010 Feb 5. [Epub ahead of print]

Authors' Affiliations: Centre for Clinical Nursing Research, Epworth/Deakin Nursing Research Centre, Victoria, Australia (Drs Watts and Botti); and Bone Marrow Transplant Unit, Royal Melbourne Hospital, Victoria, Australia (Ms Hunter).

BACKGROUND: Optimal care for patients with cancer involves the provision of effective physical and psychological care. Nurses are key providers of this care; however, the effectiveness of care is dependent on the nurses' training, skills, attitudes, and beliefs. OBJECTIVE: The study reported in this article explored cancer nurses' perceptions of their ability to provide psychosocial care to adults with cancer and their subsequent evaluation of the effectiveness of the care provided. This study was the first part of a larger project that evaluated the effectiveness of Proctor's model of clinical supervision in an acute care oncology environment. METHODS:: An exploratory qualitative design was used for this study. One focus group interview was conducted with 10 randomly selected registered nurses working within the oncology units at a major Melbourne tertiary referral hospital. Analytic themes were developed from the coded data using content analysis.

RESULTS: The 4 analytic themes to emerge from the data were frustration, difficult to look after yourself, inadequate communication processes, and anger. CONCLUSION:: The findings from this study indicate that, although informal mechanisms of support are available for oncology nurses, most of these services are not accessed. IMPLICATIONS FOR PRACTICE:: Leaders in cancer care hospital settings need to urgently develop and implement a model of support for their oncology nurses who are attempting to provide psychosocial support to oncology patients.

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Plasma exchange and immunoadsorption for autoimmune neurologic diseases - current guidelines and future perspectives.

Klingel R, Heibges A, Fassbender C.Atheroscler Suppl. 2009 Dec 29;10 (5):129-132.

Apheresis Research Institute, Cologne, Germany.

There is increasing interest from neurologists to use therapeutic apheresis in autoimmune neurologic diseases due to growing knowledge of pathogenic relevance of autoantibodies. Developments in that field have been summarized in this review focusing on German guidelines and recent results from clinical research. Therapeutic apheresis can offer a therapeutic armamentarium with rapid response for severe acute neurologic symptoms, and a drug-free option for clinical courses being refractory to drug based strategies or complicated by drug side effects. Plasma exchange (PE) as the classical method has become part of current guidelines within basic and escalating immunomodulatory treatments of autoimmune neurologic diseases, and in daily practice gets increasingly replaced by selective immunoadsorption (IA) due to its equivalent efficacy in combination with a superior safety profile. Therapeutic effects of PE and IA in autoantibody mediated diseases can be attributed to 3 major mechanisms: immediate intravascular reduction of (auto-) antibody concentration, pulsed induction of antibody redistribution, and subsequent immunomodulatory changes. 5 treatments over a period of 8-10 days seem to be an appropriate regimen to restore neurologic function in acute flares or relapses of autoimmune neuropathies, e.g. myasthenic crisis, Guillain-Barré-syndrome, and steroid refractory relapse of multiple sclerosis. Especially in MS a better understanding is needed, who are the best candidates for IA.

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Extracorporeal photopheresis for the prevention of acute GVHD in patients undergoing standard myeloablative conditioning and allogeneic hematopoietic stem cell transplantation.

Shaughnessy PJ, Bolwell BJ, van Besien K, Mistrik M, Grigg A, Dodds A, Prince HM, Durrant S, Ilhan O, Parenti D, Gallo J, Foss F, Apperley J, Zhang MJ, Horowitz MM, Abhyankar S. Bone Marrow Transplant. 2009 Nov 16. [Epub ahead of print]

Texas Transplant Institute, San Antonio, TX, USA.
GVHD is partly mediated by host APCs that activate donor T cells. Extracorporeal photopheresis (ECP) can modulate APC function and benefit some patients with GVHD. We report the results of a study using ECP administered before a standard myeloablative preparative regimen intended to prevent GVHD. Grades II-IV acute GVHD developed in 9 (30%) of 30 recipients of HLA-matched related transplants and 13 (41%) of 32 recipients of HLA-matched unrelated or HLA-mismatched related donor transplants. Actuarial estimates of overall survival (OS) at day 100 and 1-year post transplant were 89% (95% CI, 78-94%) and 77% (95% CI, 64-86%), respectively. There were no unexpected adverse effects of ECP. Historical controls receiving similar conditioning and GVHD prophylaxis regimens but no ECP were identified from the database of the Center for International Blood and Marrow Transplant Research and multivariate analysis indicated a lower risk of grades II-IV acute GVHD in patients receiving ECP (P=0.04). Adjusted OS at 1 year was 83% in the ECP study group and 67% in the historical control group (relative risk 0.44; 95% CI, 0.24-0.80) (P=0.007). These preliminary data may indicate a potential survival advantage with ECP for transplant recipients undergoing standard myeloablative hematopoietic cell transplantation.

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Outcomes of surgical and radiologic placed implantable central venous access ports.

Sticca RP, Dewing BD, Harris JD.Am J Surg. 2009 Dec;198(6):829-33.

Department of Surgery, University of North Dakota School of Medicine and Health Sciences, 501 North Columbia Road, Grand Forks, ND 58203, USA.
BACKGROUND: Recent literature suggests implantable central venous access ports (ICVAPs) can be placed by interventional radiologists with fewer complications and lower expenses when compared with surgeons. An analysis of outcomes and expenses of ICVAP placement by service was conducted. METHODS: Three hundred sixty-eight ICVAPs were placed over 3 years at a 230-bed community teaching hospital. A retrospective review of these procedures was conducted. Data recorded for each procedure included patient demographics, reason for placement, indwelling port days, complications, billed charges, and reimbursement. RESULTS: Two hundred seventy-six (75%) ICVAPs were placed by interventional radiologists, while surgeons placed the remaining 92 ports (25%). Short-term complications were identified in 7 interventional radiologist-placed ports (2.5%) and 1 surgically placed port (1.1%), P = .42. Billed charges were greater for interventional radiologist-placed ports ($5,301 vs $4,552, P = .0001). In contrast, reimbursement was greater for surgically placed ports: interventional radiologist 31.3% of charges, surgery 42.8%, P = .049. CONCLUSION: Reimbursement and charges demonstrated significant differences between surgeons and interventional radiologists. Prior assertions that ports placed by interventional radiologists are less expensive with fewer complications may no longer be valid.

Clinical Practice Corner

This is the space where you can share your practice, your bright ideas and innovative ways; everybody is at it, so why not share it?

If you would like to know more about any of the posted topics, please don't hesitate to contact the contributors.

Fast Forward- a post transplant fatigue and recovery intervention

Cancer related fatigue (CRF) can be an immobilising symptom, immersing the person with it in an all encompassing, intrusive, debilitating exhaustion. It is often described as being relentless and unrelieved by rest. Agnes Glaus has defined it as " a multidimensional experience that focuses not only on biochemical or pathophysiological causes, but also involves psychological and behavioural aspects" (Glaus, 1993). Patients have used metaphors of batteries being run down, of having finished a race and needing to be rewound. Another aspect of CRF is the incredulity of it – it is a very personal experience that has been described as being impossible to describe! The words don't exist to adequately explain and patients suggest that it seems ridiculous to be too fatigued to brush their hair or vacuum a small room. These conversations are familiar to you I am sure.

In one of my clinical roles I noticed that patients post transplant not only had profound fatigue but lacked confidence and felt insecure as they were discharged from the transplant unit. It seemed to make sense that having been cocooned in a single room on a transplant unit with fourth hourly observations and anything that flowed in or out being measured, that the joy and excitement of being discharged home might be tempered by a fear of the unknown, an uncertainty about being able to manage away from the bright lights and safety of the unit.

A physiotherapist and I got together and decided it might be valuable to offer a link between the transplant unit and the home; a sort of branch from the nest of the unit along which they could make their way and learn to fly again, to suggest a corny analogy!

We invited a dietician and an occupational therapist and created the Fast Forward rehabilitation programme. All patients who were post transplant were invited to attend the seven week programme and the only pre requisite was that they their haematologist was happy for them to take part. The first week involved an assessment by the dietician, an assessment (6 minute walking test) by the physiotherapist and a discussion about the programme. Each week for the next six weeks the participants enjoyed a thirty minute gym session (usually to the strains of Abba!), followed by a thirty minute relaxation therapy session and then an hour's talk and discussion. The gym session was comprised a circuit with participants spending two minutes at each station. The stations included a static bike, a short staircase, passing bean bags and other similar aerobic and resistance exercises. The occupational therapist then spent the next half hour teaching a different relaxation technique each week. The talk and discussion was focused on a different topic each week. For example, I spoke about transplant complications that might be lingering or expected and how to manage them; the OT spoke about fatigue management; and the physio about the benefits of exercise and how to integrate it into everyday life. The dietician's talk was always very lively as everyone always had a question or story. In the penultimate week we invited the pastoral care officer who led a discussion about the experience of transplant and some of the attendant emotions. The last week we always left open for participants to suggest a topic and we would do our best to get an appropriate speaker or, quite often, just chat, with the participants sharing experiences. Also in the final week, participants would be reassessed by the dietician and they would re-take the walking test.

We always evaluated the programme to make improvements and tinker where necessary. It was a fabulous experience to be a part of and I should note that the name of the programme came from one of our first participants who said that it 'fast forwarded' him to recovery.

Glaus A (1993) Assessment of fatigue in cancer and non-cancer patients and in healthy individual Support Care Cancer. 1993 Nov; (6):285-6.

Moira Stephens
moira.stephens@sydney.edu..au

Allograft late effects clinic at the Peter MacCallum Cancer Centre

With an increasing number of Allograft survivors there is a need to focus care on the potential late effects experienced by Allograft recipients. Contemporary literature suggests that the probability of long term disease free survival is high for patients who are disease free at 2 years. As well as physical issues, some patients experience emotional, psycho-social and sexuality issues post allogeneic BMT.

The Allograft late effects clinic at the Peter MacCallum Cancer Centre, commenced in November 2009, as part of the well established Haematology late effects clinic, coordinated by the Haematology late effects CNC. It is attended by a BMT physician/ Haematologist, Allograft CNC/ Nurse Practitioner candidate, specialist physicians and allied health staff.

Patients are invited to attend from 2 years post Allograft. Transplant related treatment; pre transplant treatment and co-morbidities are considered when performing a health assessment, arranging screening investigations and designing a survivorship plan.

Patients have initial consultations where a plan of care is discussed, and then a follow up consultation is booked to discuss the results of screening investigations. Appointments thereafter are yearly.

Health promotion and education is a major focus of the late effects clinic. This includes dietary and exercise advice, and management of weight, cholesterol, hypertension and blood glucose. Screening includes assessment for risk of secondary malignancy, thyroid dysfunction, metabolic syndrome, psychosocial issues, and sexual dysfunction, amongst others.

Future directions include increasing the number of clinics for 2010 and research projects focusing on male sexuality, relationship issues post allograft and carer issues. We look forward to presenting our Allograft late effects clinic experience at conferences and in peer reviewed publications.

Yvonne Panek-Hudson
Allograft Nurse Consultant/ Nurse Practitioner candidate
Yvonne.Panek-Hudson@petermac.org

A decade of Rituximab: improving survival outcomes in NHL

The anti-CD20 monoclonal antibody rituximab was first approved for clinical use in 1997. This has changed the standard of care for many patients with NHL. Prior to its introduction, there had been only modest improvement in the treatment outcome of diseases such as follicular and diffuse large B-cell lymphoma, the two most common subtypes of NHL. Recent data from large randomised clinical trials confirm that the use of rituximab, particularly in combination with various chemotherapy/radiotherapy regimes, has significantly improved both response rates and survival outcomes in patients.

Rituximab is also approved or being investigated for the treatment of many other haematological disorders. These range from other malignancies, such as CLL to autoimmune disorders such as TTP and rheumatoid arthritis.

Many studies conducted in patients with follicular lymphoma over the past three decades have demonstrated four-year overall survival estimates have improved from 69% with CHOP alone to 91% with CHOP plus monoclonal antibody therapy.

The results of recent phase III randomised trials further support an improving prognosis. In newly diagnosed follicular NHL patients, the combination of rituximab with chemotherapy increases response rates and prolongs progression-free and overall survival times. In patients with relapsed or refractory disease, the combination of rituximab given with CHOP or FCM has improved response rates and time to disease progression.

An increase in adverse events is always a concern with the addition of any new agent to an established regime. However, across these phase III trials, the addition of rituximab did not substantially increase adverse event rates in NHL patients. Most of the trials found the addition of rituximab to chemotherapy regimes to be well tolerated.

The PRIMA (Primary Rituximab and Maintenance) trial being conducted in Europe and Australia has just been completed. This trial is investigating the benefit of maintenance rituximab following chemo-immunotherapy for patients with previously untreated follicular lymphoma.

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Cassi Sprague
Cassi.Sprague@health.wa.gov.au

Clinical Practice Corner (cont'd)

Steroid toxicities in Multiple Myeloma: A challenge for patients

Steroids (dexamethasone, prednisolone) form the foundation of treatment regimens for myeloma. They are used as single agents but more commonly, as combination therapy alongside chemotherapy—eg Thalidomide Lenalidomide and Bortezomib (Dimopoulos et al 2007, Morgan et al 2008). A patient with myeloma is going to be exposed to multiple cycles of steroids throughout the course of their disease.

Often thought of as the less toxic of the drugs in a regimen, steroid toxicities can affect most body systems ranging from increased susceptibility of infection through to proximal myopathy. Not to mention the often distressing psychological affects of extreme high and crashing low moods. It is this author's experience that managing the unpleasant side effects of steroid therapy poses one of the greatest challenges to most patients with myeloma.

So why are steroids so commonly used to manage myeloma? How do steroids work?

The mechanisms of action of steroids are complex and include powerful anti-inflammatory effects and the ability to modify the body's immune responses (Hardman & Limbard 2001). Their activity in myeloma includes inhibiting a range of cytokines responsible for myeloma cell growth leading to myeloma cell death (Berenson et al 2002). The therapeutic rationale for steroids also extends beyond their anti-tumour affects, due to their ability to reduce nausea and vomiting, swelling associated with malignancy, inflammation and hypersensitivity reactions. Steroids are prescribed in various doses and schedules with high and low dose schedules being apparent. See **www.eviQ.org.au** for a selection of treatment protocols

What toxicities are associated with steroid use?

The severity and nature of toxicities related to steroids can vary, and is in part related to the dose and duration of therapy (Stanbury & Graham 1998; Faiman et al 2008). The incidence of toxicities increases with increased dose, duration and older age of patient (Stanbury & Graham 1998, Faiman et al 2008). Dose reductions are often applied in the event of undesirable side effects (Faiman et al 2008; Chou & Ippoliti 2008, Palumbo 2008) with a clear goal in treatment being to seek a balance between therapeutic efficacies of the steroid verses minimising any side effects so as to maximise quality of life for the patient.

Steroids influence the biochemical behaviour of most tissues of the body (Hardman & Limbard 2001). It is no surprise then, that steroids have the potential to cause a range of toxicities affecting most body functions (Stanbury & Graham 1998; Terao 2008). Below is a list of some of the more common toxicities:

Unstable blood glucose
- Hypokalaemia, Hypernatraemia
- Oedema
- Osteoporosis
- Proximal myopathy – muscle weakness
- Insomnia, fatigue
- Mood alterations, anxiety, depression, behavioural changes
- Increased susceptibility to infection
- Thin fragile skin, impaired wound healing
- Dyspepsia, risk of peptic ulcer

For a more comprehensive list of toxicities associated with steroids please see Faiman et al 2008 Stanbury & Graham 1998

Little evidence based literature exists that describes the specific incidence of steroid associated toxicities in myeloma. This may be partially explained as steroids are used concomitantly within multi-drug regimens and often administered in the presence of significant disease morbidities. Pam McGrath's' research into the psychological effects of steroid therapy in haematology patients is highly recommended and provides further evidence for the need for more research if we are to help patients manage the full range of physical and psychological toxicities that accompany steroid therapy (McGrath et al 2007 ; McGrath et al 2009).

How can nurses help manage the toxicities associated with steroid therapy?

Despite the complex nature of steroid toxicities, there are a range of interventions and strategies that can be applied to help patients live better with steroids:
- Be aware of the range of toxicities associated with steroid therapy
- Inform patients of the potential toxicities and encourage them to inform their health professionals should they experience any side effects
- Encourage patients to adapt their activities around steroid schedule - noting times of increased energy on the days they take steroids and periods of low energy, low mood on the 2 to 3 days following steroids
- Early and appropriate referral to allied health colleagues for the management of mood alterations
- Measure / grade and document any toxicities

> NCI Common Terminology Criteria for Adverse Events (CTCAE) provides a grading system commonly used in the context of clinical trials. You may also find other measurement tools such as the 'Anxiety Thermometer' or 'Hospital Anxiety and Depression Scale' (HADS) useful tools.

- Consider adapting schedule or dose in presence of toxicities
- Take steroids with food to avoid gastric irritation
- Monitor blood glucose as indicated
- Take steroids in morning to avoid insomnia

The International Myeloma Foundations' Nurse Leadership Board published a consensus statement on managing steroids-associated side effects in patient with multiple Myeloma (Faiman et al 2008). A patient information sheet is also available at www.myeloma.org

Authors observations

Anecdotally I find it is the side effects of steroids to be one of the most overlooked and under-managed toxicities associated with Myeloma treatment regimens. Perhaps it is the complex nature of steroid effects on all body areas that makes it so complex to manage? Perhaps it is the perception that steroids are the more 'gentle' of treatments? Perhaps it is the systemic nature of the toxicities or the complex range of co-existing morbidities that patients are often experiencing? Whatever the reason, I believe we do an injustice to our patients in not more pro actively managing toxicities associated with steroids.

In my own practice I find patients who are better informed to the potential side effects of steroids, are able to adapt lifestyles around pulsed steroid schedules and cope better with them. Common sense recommendation I know, but never the less worth mentioning.

For further information do not hesitate to get in touch with me:

Tracy King,
Myeloma Nurse Consultant, Royal Prince Alfred Hospital, Sydney Tracy.king@sswahs.nsw.gov.au Tel: 02 9515 7310

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News from the regional groups

New Zealand (North Island)

The North Island section of the HSANZ NG hosted its second education evening on the 25th November 2009. It was a very successful evening with 23 people attending from both the Wellington and Palmerston North areas. BJ Ramsay (Haemophilia CNS) gave an excellent talk entitled "A beginners guide to Haemophilia". The evening was sponsored by Bayer and the feedback on the education provided and the overall evening was very positive.

Negotiations are underway for the programme for the 2010 year. As mentioned in previous newsletters, there will be six education evenings run with three of these being run out of Wellington and three being run out of Palmerston North (approximately 2 hours drive north of Wellington). Some sponsorship has already been confirmed as have some ideas for topics to be presented. If anyone from this region has any topics that they would like to see discussed over the year, then please get in touch with me.

Catherine Wood

South Australia/Northern Territory

Hello from South Australia, where we are basking in the afterglow of the HAA2009 conference held here in sunny Adelaide… and trying to contain our excitement over the arrival of Panda Bears, Wang Wang and Funi to our State…

Firstly, thank you to everyone for their feedback from the conference and we are glad to report that evaluations of the conference were overwhelmingly positive! Suggestions will be passed on to the Auckland organising committee. We're very glad that people got a lot out of attending – whether it was new information to take back to their units, networking among peers or a chance to sample Haigh's chocolate or SA's fantastic wines. Hopefully everyone is fired up now for Auckland in October!

Allan Hayward

QLD

We are starting meetings in February. A flyer will be sent out to hospitals later this month with dates and times.

Robynne Morris

NSW

The NSW group recently held it's first meeting for 2010 – despite competing with the AC/DC concert a number of discerning nurses came along to enjoy a dinner together, with Dr Brenton Wylie presenting his take on the ASH meeting last December. There are certainly a wide variety of exciting developments both in diagnosis and understanding, particularly of molecular markers and, importantly, what they mean for prognosis and treatment options.

Risk Adapted Therapy with individualised therapy pathways is coming to a hospital near you!!

NSW has an exciting programme planned for 2010 with the next dinner meeting:

Thursday April 16th – Gosford – Dr Cecily Forsyth talking about CLL - did you know that this is the commonest leukaemia in the Western world with over 40% of leukaemia cases being CLL?

Moira Stephens

HSANZ – NG National Council Members

President **Moira Stephens**
Lecturer/Coordinator
Cancer and Haematology Nursing programme
Sydney Nursing School
University of Sydney
Phone: 02 93510542
Mobile: 014 22468233
Email: moira.stephens@sydney.edu.au

Secretary **Tracy King**
Myeloma CNC , RPAH
Support Services Manager, Myeloma Foundation Australia
Phone: 02 9515 7310
Email: tracy.king@sswahs.nsw.gov.au

VIC /TAS **Yvonne Panek-Hudson**
Allograft Nurse Consultant
Peter MacCallum Cancer Centre
Melbourne
Phone: 03 9656 1111 and page
Email: Yvonne.Panek-Hudson@petermac.org

WA **Cassi Sprague**
Cancer Nurse Coordinator
Malignant Haematology
WA Cancer and Palliative Care Network
Mob: 0448771453
Email: cassi.sprague@health.wa.gov.au

NZ North Island **Catherine Wood**
BMT Coordinator
Wellington Hospital
Phone + 64 4 806 2019
Email: catherine.wood@ccdhb.org.nz

Vice President/Editor **Angela Booth**
Area CNC Cancer Services
Greater Southern Area Health Service
Phone: 02 61289865
Mobile: 0438435428
E-mail angela.booth@gsahs.health.nsw.gov.au

SA /NT and Treasurer **Allan Hayward**
Clinical Operation Manager,
Division of Haematology
Royal Adelaide Hospital
Phone: (08) 8222 2804
Email: allan.hayward@health.sa.gov.au

QLD **Robynne Morris**
Clinical Nurse
Day Oncology Therapy Unit
Royal Brisbane and Women's Hospital
Herston, Brisbane
073636 8749
Email: Robynne_Morris@health.qld.gov.au

NZ South Island **Sharron Ellis**
CNC Haematology
Christchurch Hospital
Email: Sharronb@cdhb.govt.nz

ANZSBT Rep **Beverleigh Quested**
Transfusion Nurse Educator,
Transfusion Medicine Service,
ARCBS,Adelaide,
Ph 08 84221372
M 0439 30132
Email: BQuested@arcbs.redcross.org.au

HAA 2010 Rep **Rosie Howard**

BMT Nurse Specialist
Building 8, Blood and Cancer Services
Auckland City Hospital, Auckland, New Zealand