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HAA 2017

David Collins
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Sydney looks forward to welcoming you to the annual conference, HAA, in October. The conference is being held at the new Sydney conference centre in Darling Harbour and brings together the Haematology Society of Australia and New Zealand, the Australian & New Zealand Society of Blood Transfusion and the Thrombosis and Haemostasis Society of Australia and New Zealand, with each society bringing many international experts to the conference.

The NSW Nurses group is busy organising a program that we hope will be informative, thought-provoking and educational.

Our international speaker this year is Dr Beth Faiman from Cleveland, Ohio. Beth works as an Adult Nurse Practitioner at the Cleveland Clinic and specialises in multiple myeloma, amyloidosis, plasma cell dyscrasias, general cancer diagnosis and treatment, as well as management of skeletal and other cancer complications. She has many publications to her name and has been involved in education for many years, presenting at many international conferences.

We will also be welcoming several Australian speakers to the conference; these experts will be sharing their wealth of knowledge with us.

Now is the time to work on your abstracts if you would like to be part of the conference, please see the HAA website for details on how to submit your abstract.

If you are a first-time presenter and would like to be linked to a mentor, please let us know by emailing us on nurses@hsanz.org.au and we will put you in touch with one. If you have always wanted to put an abstract in for a poster but have had concerns about the printing of it, have no fear! This year posters will be printed by HAA at no cost to you.

Please visit the website http://www.haa2017.com where you can find out more about the conference, and register for further updates.

HAA 2017 Abstract Submission is now open and will close on 6 July 2017.

You are invited to submit informative and relevant abstracts in a word document using the approved template.

Mini-Orals

The 2017 Meeting will be introducing mini oral sessions which will take place on Monday 31 October as part of the poster-viewing session. A select number of poster presenters will be offered the opportunity to present their abstract in this format.

Poster Printing

If you are accepted as a poster presenter your poster will be printed by the Meeting. Delegates must send their poster artwork files to haa@tcc.co.nz by Friday 6 October in order to meet the printing deadline.

Delegates cannot bring their own posters and this will be strictly enforced. Failure to supply your poster by this date will result in the withdrawal of your abstract from the program.

For more information see: http://www.haa2017.com

Travel grants and awards

Remember you may be eligible for a travel grant to attend HAA 2017. See the website for details and apply early.

Registration

Early Bird registrations closes: 14th September

Cost of a nurse member registration for the meeting : $635.00 (full registration)

Full registration covers:

- Attendance at all Meeting sessions
- Name badge and Meeting documentation
- Morning and afternoon teas
- Lunches
- A ticket to the Welcome Function and Gala Dinner
- Attendance at exhibition

Beth Faiman
Invited international speaker

Other news from NSW

David Collins

The group has already held several meetings this year, not only are we holding them in Sydney, but our members are branching out and organising meetings out of the metropolitan area. Thanks go to Jacqui Jagger who has held the annual meeting in Gosford, and to Casey Hutchison who has held meetings in Newcastle. We have further meetings planned for the year both in Sydney and Wollongong.

If you are an NSW member, how about joining the organising committee? We are looking for members to help with the organisation of the meetings. Please contact us if you are interested.

EBMT REPORT 2017

Jodie Marsh

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EBMT 2017, Marseille France, marked EMBT's 60th year, 43rd congress and its largest number of delegates ever at over 5000 attendees. These delegates came, not only from Europe but it was estimated that more than 40% came from further afield - North and South America, Asia and of course 2.2% of us came from Australia.

Australia was well represented and it was a pleasure to watch Dr Monica Slaven chair and present her session looking at evidenced based strategies in the treatment of Invasive Aspergillosis. This session reinforced our current practice of using Posaconazole as both prophylaxis and treatment and introduced us as to how and when Isavuconazole may be utilised.

What I particularly enjoyed about EBMT is that it tended to move away from didactic lectures and instead had a focus on participation and interaction of delegates; it also showcased how multi-disciplinary collaboration leads to best outcomes for the transplant patient cohort. This was particularly evident in the nursing stream where there was a focus on practical clinical guidance.

Practical approaches to managing GVHD were showcased in the nursing program. The guidelines presented for oral GVHD focused on a move away from the traditional grading system and instead pointed us to listening to the patient's report of symptoms and effect on quality of life as the cornerstone to managing oral GVHD effectively.

Vaginal GVHD was also showcased as the silent symptom. The take home messages from this session were firstly; vaginal GVHD should be suspected in any woman that exhibit signs of oral, ocular or skin GVHD and that as clinicians we must begin to have greater discussions about this issue. Secondly, interventions to prevent or decrease the impacts of vaginal GVHD should begin prior to 100 days for all women including the use of oestrogen cream to the vulvar and oestrogen pessaries to the vaginal vault, as well as initiation of HRT in younger transplant recipients.

One of the best sessions that I attended was an extended debate covering both sides of the equation into the need to transplant MRD negative ALL. The delegation was polled pre- and post-debate with a 70% majority opting to proceed to transplant pre-debate. Dr Josep Ribera presented the evidence for not transplanting. Surprisingly in a room full of transplant nurses and physicians his argument swung the audience to a majority that would opt not to transplant. Citing amongst other evidence a PETHEMA trial that showed better overall survival in MRD negative patients that were not transplanted than those who were (73% vs 58%) and rationalising for those patients that were Philadelphia Chromosome positive outcomes were more favourable with prolonged TKI drugs than with allografting.

This conference was practical and clinically relevant. I found myself making notations throughout my lecture notes in reference to specific patients that could benefit from what I had learned. I have begun now to incorporate the information from my lecture notes into updating the content for our graduate nurse transition to Oncology / Haematology program. I would like to thank HSANZ for awarding me the EBMT scholarship for 2017. This made my long journey from Townsville to Marseille possible. EBMT 2018 is being hosted in Portugal I urge all members to attend this conference at least once; it was a truly worthwhile experience.

ARE WE THE BEST LEUKAEMIA UNIT EVER?

Mingdi Xie and Peter Haywood

Clinical Haematology/BMT Service, Royal Melbourne Hospital

Quality performance indicators (QPIs) are increasingly used as a method of measuring and maintaining improvements in medical and nursing care. Hospital nurses will be aware of the many indicators used nationwide – such as hand hygiene compliance and falls. Of course, these are important measures in their own right, and it is true that they are relevant to leukaemia patients. But we wonder if they really capture the quality of the specialist haematology care we provide.

We had expected to find many appropriate quality measures that someone else had already developed. But we were a little disappointed as it appears very little published data of leukaemia specific quality measures exist.

The only specific quality measures that we did find are those of the Scottish Cancer Taskforce, comprising of 12 evidence-based QPIs for the use in units treating acute leukaemia. All QPIs are clearly measurable as a percentage of patients diagnosed and with a nominated target level.

Out of our own interest, we conducted a clinical audit, by looking into our database of leukaemia patients, trying to have a glimpse of how well, as a large haematology/bone marrow transplant we look after leukaemia patients.

We went through the files and looked at 112 patients treated for acute leukaemia in the last 2 years, and applied those QPIs. In 2016, we attended the HAA annual scientific meeting, and we presented this data with a poster titled "Quality performance indicators for the clinical management of acute leukaemia; a single centre experience".

The Royal Melbourne Hospital

The QPIs are:

QPI 1

Proportion of patients with acute leukaemia undergoing treatment with curative intent who have complete diagnostic panel undertaken.

QPI 2

Proportion of patients with acute leukaemia who have World Health Organisation (WHO) classification assigned and recorded (either by multi-disciplinary team (MDT) or reporting haematologist/haematopathologist).

QPI 3

Proportion of patients with acute leukaemia who are discussed at MDT meeting within 6 weeks of diagnosis.

QPI 4

Proportion of patients with acute leukaemia being treated with curative intent who die within 30/35 days of treatment (aim to be below target).

QPI 5

Proportion of patients with APL who receive ATRA within 24 hours (1 day) of diagnosis.

QPI 6

Proportion of patients with acute leukaemia undergoing treatment with curative intent who die in first complete remission, within 1 year of diagnosis (aim is to be below the target).

QPI 7

Proportion of patients with acute leukaemia being treated with curative intent who are enrolled in a clinical trial.

QPI 8

Proportion of patients with acute leukaemia eligible for transplant (i.e. over 16 years of age and under 65 years of age) being treated with curative intent should have a specimen sent to the lab for tissue typing at diagnosis.

QPI 9

Proportion of patients with acute leukaemia over 60 years of age with performance status (PS) 0-1 who receive intensive chemotherapy.

QPI 10

Proportion of patients with acute leukaemia being treated with non-curative intent who are enrolled in a clinical trial.

QPI 11

Proportion of patients with AML who are suitable only for treatment with non-curative intent who receive an appropriate palliative chemotherapy regimen.

Overall we made the provided target, with except in enrolling in clinical trials. Although it is really reassuring that we meet the target of the QPIs, we doubt their relevance.

Our plan for this year's HAA is to submit an abstract with our own QPIs that we think are more relevant at measuring our performance within the unit.

Some of the examples of our QPIs are:

QPI 1

Rate of blood culture contamination;

QPI 2

Average time from diagnosis to donor identification in transplant eligible patients;

QPI 3

Average number of inpatient bed days per cycle of consolidation;

QPI 4

Average time from bone marrow biopsy to when patient is informed of the results.

We think if we demonstrate improvements in these measures, it will correspond with an improvement in the quality of leukaemia care we provide. We don't feel that is the case with other quality measures.

We look forward to seeing you in Sydney!

A WORD FROM THE PRESIDENT

Welcome to this newsletter. It is amazing to think that we are already a third of the way through the year, and winter will soon be upon us. Now is the time to get your flu shot. It is also our responsibility to ensure that our patients and their families are made aware of the importance of being vaccinated. I make this point every year, as I still come across people who forget to get it done or choose not to, but I believe it is our responsibility to ensure the safety of our patients and families, and ourselves. I have already seen in my practice several patients with respiratory viruses, so they are out there!

It also seems to be that time of year when people want money from us, yes, it is time to renew your nurse registration, it will also be time soon to renew your HSANZ Nurses Group membership. Membership fees are due on July 31 and can be paid online through the website. You will find that there has been a slight rise in the membership fee this year, the first increase in a long time. Membership to HSANZ NG gives you access to journals online, communication with other haematology nurses, local groups, reduced fees to attend HAA and much more.

I would also ask you, do you know what's going on in your local group? Have you ever thought about helping in the arranging of group meetings? If so, I am sure the local chair of your local group would love to hear from you. You can find the details of your local group in this newsletter.

I would like to thank all the contributors to the newsletter. Rosie, our editor is always happy to receive articles for publication. The newsletter is a method of communicating with your colleagues across Australia and New Zealand. You may like to tell us about a project you are running, or you may be seeking advice, whatever it is, contact us.

David Collins
President HSANZ NG
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CHANCE TO WIN YOUR MEMBERSHIP FEES BACK

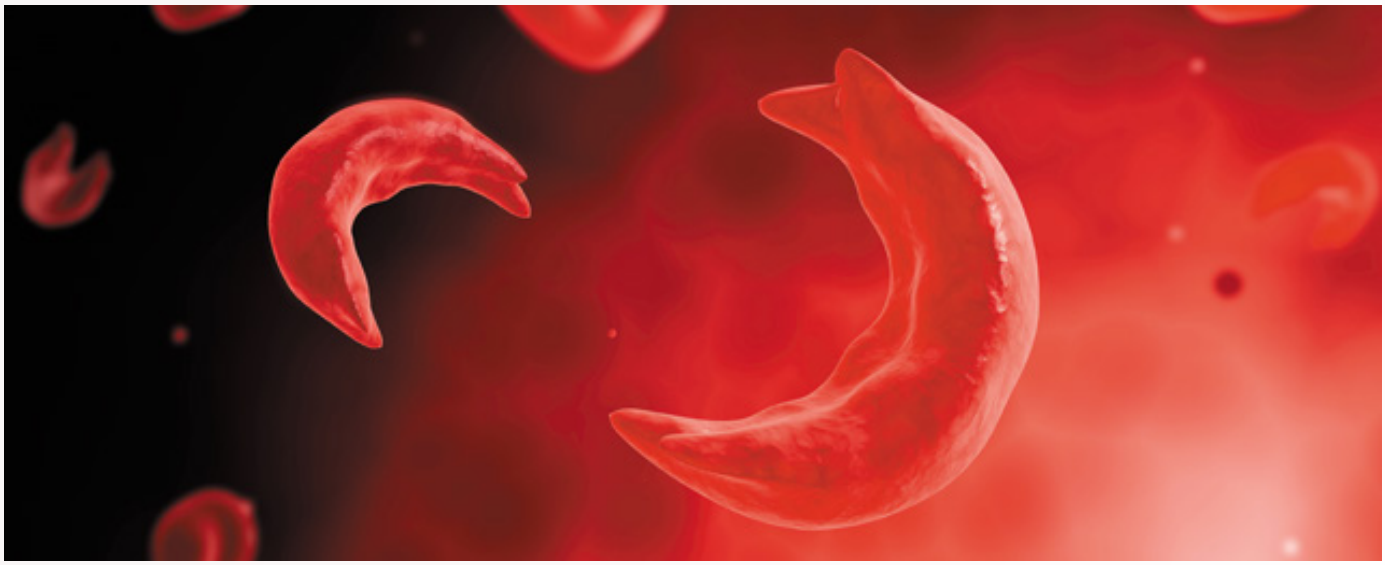
To encourage nurses to join HSANZ and renew their membership each year, the Nursing executive will reimburse one lucky member their yearly membership costs.

To win this back you must be a current financial member, having renewed your membership by the due date, which will be the end of July 2017.

SICKLE CELL DISEASE: IMPLICATIONS FOR CARE

Claire Dowsing

Apheresis Nurse Practitioner

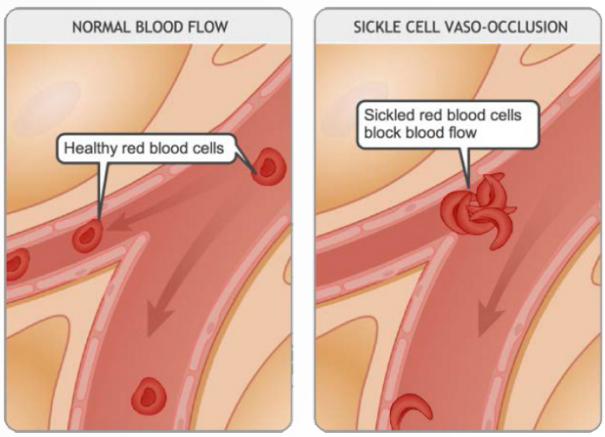


The term sickle cell disease encompasses a range of disorders characterised by a single point mutation in the beta globin gene resulting in the synthesis of sickle haemoglobin (HbS).[1] An autosomal recessive inherited disorder homozygous HbS or sickle cell anaemia (SCA) is considered to be the most severe form of the disease but compound heterozygotes for HbS with beta thalassaemia (HbSß°thal, HbSß⁺thal) haemoglobin C (HbSC) or other beta globin chain variants may also be severely affected.1 The significant pathophysiology associated with SCD relates to the polymerization of HbS in deoxy states which decreases solubility and deformability of red cells, and distorts the red blood cell into the classic sickle shape.[1, 2] A cascade of interactions between the sickled red cell, vascular endothelium and leucocytes results in vaso-occlusion, pain and ischaemia.[3] Injury to affected organs may occur and include severe, acute adverse sequelae such as stroke and myocardial infarction, or contribute to chronic organ dysfunction such as pulmonary hypertension, renal disease and osteonecrosis.[4]

SCD was first discovered in 1910 and was the first disease to have a specific genetic defect identified for which screening can be performed.1,6 It is now the most common genetic disease identified as a result of newborn screening in the US.6 Exact numbers of people affected by SCD in Australia are not known despite attempts to launch a Haemoglobinopathy registry. However, as immigration increases from countries where SCD is prevalent nurses will see more patients presenting for treatment with this disease. This article aims to highlight some of the common acute health problems patients affected by SCD will present to hospital with and the associated implications for nursing care.

Vaso-occlusive crisis

The vaso-occlusive crisis (VOC) or pain crisis is the most common reason for patients to present to the emergency department.[3,5] Occlusion of the microvasculature caused by sickling of red blood cells and increased red cell adhesion to the vascular endothelium results in ischaemia, and tissue damage, and the stimulation of pain receptors by the release of inflammatory cytokines.[2,3,6] Pain is characteristically extremely intense, progressive and continuous in nature.[3]



Typical focal areas for sickle pain include the back, chest and extremities and feature a symmetric presentation.[3] Pain crises are acute, unpredictable and require rapid assessment to ensure the early initiation of appropriate analgesia – within 30 minutes of presenting to hospital is recommended.[3] History taking will ascertain which medications are used at home to control pain and what works best for the individual.[3] Patients who present to ED with a VOC will likely have exhausted all options for pain management at home and therefore parenteral or oral opioids are usually required.[3,6]

Referral to the acute pain service for severe episodes is recommended so that a structured plan for analgesia can be implemented to ensure an adequate and safe strategy for opioid administration.[6] Intramuscular administration of opioids is not recommended for the management of painful crises as absorption rates are unpredictable.[3,6] Evaluation of analgesia 15 - 30 minutes post administration using pain scores is necessary to ensure patients receive appropriate, timely and effective doses of medication with dose titration occurring as needed to ensure relief.[6] A pain chart should be initiated to monitor pain levels and response to medication.[6] Clock-watching by patients is more likely to be an indication of poorly managed pain relief rather than drug-seeking behaviour therefore careful assessment of pain and response to analgesia will help to determine scheduling.[6] Nurses should also be aware that patients may not display "typical" responses to pain, for example moaning, however the intensity of pain should not be underestimated nor should requests for specific analgesia be seen as drug-seeking behaviour.[6] Patients often know what works best for them and this should be considered in their treatment plan.[6]

Other therapies which can assist in the amelioration of sickle related pain include oxygen therapy if Sa02 is less than 95% and intravenous hydration for the correction of dehydration and hypovolaemia.[3]

Patients on chronic transfusion programmes will benefit from red cell exchange transfusion if they present with a VOC.[7,8,9] VOC events often occur just prior to a scheduled exchange, when HbS levels are at their highest, making the facilitation of this treatment easier to arrange and effective in outcome.[8] However simple transfusions are not recommended in uncomplicated VOC unless the patient is severely anaemic.[6]

Anaemia and Transfusion

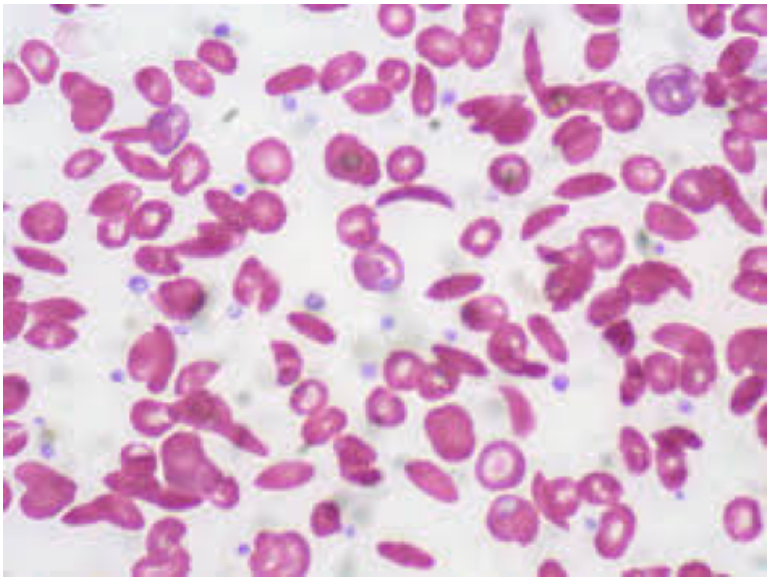
Chronic haemolysis and anaemia are the "hallmarks" of sickle cell disease.[10] Sickle red cells have a considerably shorter life span than normal HbA red cells (10 – 30 days compared with 120 days) resulting in chronic anaemia with average baseline Hb levels around 60-90g/L.[1,6,10] Blood transfusion in SCD has two purposes, firstly to increase haemoglobin and oxygenation and secondly to dilute the number of circulating sickle red cells.[6,10,11] Thresholds for transfusion are lower in patients with SCD and should only be used if the patient is suffering adverse effects of a low Hb (for example, dyspnoea, heart failure, hypotension) or to ameliorate organ dysfunction resulting from a sickle crisis.[6,10] Pre-operative transfusions to Hb 100g/L are recommended to reduce the likelihood of adverse events during anaesthesia and surgery.[6,8]

Transfusions may be given to treat acute, emergent crises or prophylactically as in a chronic transfusion programme. Additionally, the transfusion may be given as a simple transfusion or as an exchange transfusion whereby a portion of the patient's own red cells are removed either manually or by apheresis.[10] The removal of autologous red cells helps to offset the effects of iron overload which occurs with chronic transfusion and is achieved more effectively with apheresis (erthrocytapheresis, red cell exchange) than manual exchange techniques.[10]

Erythrocytapheresis involves the removal of a large portion of the patient's HbS cells and replacing with an equivalent volume of donor HbA blood with the aim of reducing HbS levels < 30% and haematocrit ≥ 30% post procedure.[12] Generally six units of phenotyped, packed red cells are transfused at intervals of 4-6 weekly.[8] Red cell exchange is recommended for the treatment of acute complications of SCD however enrolment onto a chronic red cell exchange schedule is recommended in the context of existing end organ dysfunction (e.g., stroke, silent cortical infarct or pulmonary hypertension) and for the management of frequent VOC involving >3 hospital admissions per year.[8,12]

Complications of transfusion include allo-immunisation to donor red cell antigens and the potential for iron overload.[10,12] Regular monitoring of iron levels is recommended and commencement of iron chelation therapy as indicated.[6,10] Blood transfusions can cause

hyperviscosity which, particularly affects this cohort of patients as an increased haematocrit can slow transit of blood through the microvasculature and lead to sickling.[10] A target Hb 100g/L is recommended post transfusion for patients who are not chronically transfused.[10]



Immune mediated haemolysis can present as a delayed haemolytic transfusion reaction (DHTR) up to three weeks post-transfusion.[10,12] Hyperhaemolytic transfusion reaction (HTR) is a life-threatening syndrome involving the destruction of donor and recipient red cells resulting in severe anaemia and reticulocytopenia.[10,12] Further transfusions can exacerbate HTR and worsen anaemia to below pre-transfusion levels. Treatment with intravenous immunoglobulin and corticosteroids can switch off haemolysis.[10,12] Close observation of patients during and after transfusion is recommended to monitor for potential haemolytic reactions. Patient's need to be aware of possibility of delayed reactions and importance of reporting generalised musculoskeletal pain, dark urine or lethargy post transfusion.[10]

Infection

Patients with SCD will often be functionally asplenic as a result of splenic sequestration crises and splenic infarction during early childhood and be further immunocompromised due to increased bone marrow activity and abnormal complement activation.[2,3] This makes them particularly susceptible to infections from encapsulated organisms and a comprehensive immunisation programme is recommended.[2,3,6] The Spleen Registry provides guidelines on immunisation protocols (https://spleen.org.au) however at a minimum patients should be vaccinated against pneumococcal and meningococcal infections. [2,3,6] Prophylactic antibiotic therapy, usually Penicillin, is strongly recommended for children up to 5 years of age, but there is little data regarding efficacy in adults and is an area which warrants further study.[13]

The most frequent trigger of VOC is infection and is thought to be related to an increase in activated leucocytes which secrete inflammatory cytokines and contribute to the cycle of endothelial adhesion, inflammation and subsequent sickling.[13] Hospital admission is indicated for any patient with SCD presenting with fever in the setting of asplenia.[3,6]

Chest x-rays, urinalysis, full blood count and blood cultures are essential diagnostic tests if no focus for infection is readily identifiable.[3,6] Fever may precede life threatening conditions such as Acute Chest syndrome (ACS) and empiric antibiotic therapy should be considered in patients with temperature >39.5°C or evidence of ACS.[6,10]

Infection with Parvovirus B19 can trigger an aplastic crisis in patients with SCD as the virus attacks erythroid precursors in the bone marrow which in the setting of chronic haemolysis contributes to profound anaemia. Duration of infection is approximately ten days.[6] Symptoms include fever, reticulocytopenia, headaches and signs of upper respiratory infection.[6] Monitoring of haemoglobin levels is required with transfusion support if needed.[6]

Acute Chest Syndrome

ACS is a serious, acute complication of SCD and is the leading cause of mortality in children and adults.[2,10,15] Diagnosed by the appearance of a new segmental pulmonary infiltrate on x-ray, with sudden onset of symptoms similar to pneumonia including fever, hypoxia and dyspnoea.[2,10] Aetiology is not always known but ACS has been linked to bacterial and viral infections, fat embolism (often as a result of bone fracture and trauma), pulmonary oedema and the accumulation of sickle cell aggregates in the pulmonary microvasculature.[2,10,15] Treatment includes blood transfusion (exchange transfusion preferable), antibiotics and supplemental O2 therapy and incentive spirometry.[2,10,15]

Hydroxyurea

Hydroxyurea (HU) is an S-phase cytotoxic drug which is used as a myelosuppressive agent for a number of haematological diseases, melanoma and ovarian cancer.[2,5]

It was first trialled in SCD in the early 1980s and was found to increase foetal haemoglobin (HbF) production and reduce HbS levels in the circulation.[5] The effect of increased HbF levels is a reduction in pain crises by reducing HbS polymerisation and vaso-occlusion.[5,10] Additional benefits of HU are thought to be related to the reduction in circulating leucocytes, increasing RBC volume and improving red cell deformability and rheology.[2,5,10] Due to it's myelosuppressive properties careful monitoring for cytopenias is required. [5] Counselling for patients of child-bearing capacity is recommended and discontinuation of therapy prior to pregnancy is advised.[2,10]

Health maintenance and education

People with sickle cell disease are at risk of systemic acute and chronic health complications, which start in early childhood. A multidisciplinary team approach to ensure appropriate management of complications and timely health screening to minimise multisystem effects are required to help mitigate the effects of this chronic illness.[2,6,10] Patient and family education is important for ensuring a good understanding of sickle cell disease, common complications and the importance of seeking medical attention for persistent fevers, chest pain, productive cough or respiratory distress, abdominal pain, signs of infection (urinary, chest) or severe headaches.[6]

Patients should be aware of strategies to reduce the likelihood of pain crises with an emphasis on avoiding triggers for VOC such as dehydration, extremes in temperature, excessive stress and alcohol.[6] Education should also focus on the importance of continuing medications such as iron-chelating agents, antibiotics, Hydroxyurea and Folic Acid. Education regarding the use of analgesia for chronic and acute pain should include non-opioid and non-pharmaceutical strategies.[2,6]

Psychological support is vital component of health maintenance and referral to psychologists, social workers or mental health teams can help patients cope with the impact of chronic disease, pain and social stigma.[6,16] The therapeutic relationships which nurses develop with their patients are an integral component of this support. [6]

Conclusion

SCD is a complex, multifactorial and multisystem disease. This article has briefly touched on a few acute complications of SCD which nurses may encounter with these patients and the relevant factors to consider in monitoring and treatment of SCD presentations. Nurses are well placed to ensure appropriate care is provided, championing patients' needs for effective analgesia, recognising acute deterioration or the development of serious complications whilst providing education and support to assist patients with managing their illness. Effective care of these patients must be within the context of a multidisciplinary team for the promotion of health maintenance, to minimise the potential for adverse sequelae and end-organ dysfunction

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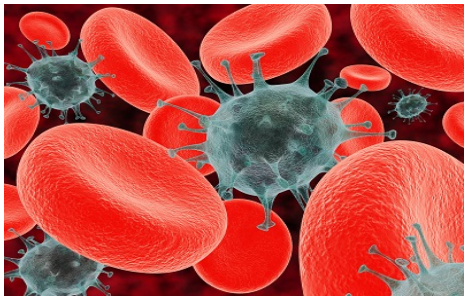


HAEMATOLOGY STUDY DAY

FOR NURSES/ALLIED HEALTH
AND OTHER INTERESTED HEALTH PROFESSIONALS

Topics include:

Allogeneic stem cell transplants
Non-malignant haematological disorders
Myeloma
Sexuality & cancer
What goes on in the lab
Palliative care and the haematology patient

Saturday July 1st 2017
8.30 am to 4.30 pm
(Registrations from 8am)

Barnett Lecture Theatre, Level One
Dunedin Hospital

Registrations close 21st June
No cost to attend

Enrolments and queries to:
Val Waugh - Val.Waugh@southerndhb.govt.nz
Rosie Hoyt - Rosemary.Hoyt@southerndhb.govt.nz
C/o Oncology Outpatients, Dunedin Hospital

DISCOURSE ANALYSIS

Considerations about the language used to describe chronic haematological malignancies- thoughts and discourses.

Rosemary Hoyt

What is discourse analysis?

Discourse analysis (DA) examines the use of language within society, be it written text, spoken words, non-verbal interactions or symbols *(Shaw & Bailey, 2009, p.413)*. Language is used universally to communicate and ascribe meaning to everyday activities. What DA can do is alert us to the different meanings language can have and how this may influence our understanding and knowledge of what is occurring *(Parker, 1999, p.4)*. This knowledge is frequently based on dominant understandings or common truths within the world *(Ballinger & Payne, 2000, p.566)*. These truths are socially constructed and most often politically based. If such truths are seen as absolute they may be rarely questioned or challenged *(Shaw & Bailey, 2009, p. 415)*. Consequently, the power of such knowledge and the 'common view' persists, even if at times it is not credible or is perceived inaccurately. Discourse analysis assumes that there will always be a connection between the uses of language and how it supports power relationships within society *(Parker, 1999, p.415)*.

DA may reveal who benefits from holding such power and how it may have originated. By exposing the power relationships, alternate ways of meaning may be considered leading to new knowledge and understanding *(Shaw & Bailey, 2009, p. 418)*.

Cancer has been portrayed extensively within wider society with a variety of discourses describing or positioning what it means and how it may be managed *(Willig 2011, p.897-903; Harrington 2012, 408-412)*. Metaphors exist that describe how cancer can be fought, how one presenting with a diagnosis should 'think positively' with common phrases such as 'You can beat this' being uttered. Within the media, a 'search for a cure' and 'the battle against cancer' are commonly occurring themes. Scientists are often perceived as being busy trying to solve the cancer problem *(Willig, 2011, p.898-899)*.

How is this relevant to chronic haematological malignancies?

For patients diagnosed with conditions such as chronic lymphocytic leukaemia (CLL) and follicular lymphoma (NHL-FL) who are well and asymptomatic they often enter a 'watch and wait' period *(Hiddemann & Cheson, 2014, p.1388-1395; Evans et al, 2012, p. 67-77)*. This means they will be observed for symptoms or worsening of their condition. The ability of physicians to communicate this management course effectively to patients is a considerable challenge *(Hiddemann & Cheson, 2014, p.1388-1395; Evans et al, 2012, p. 67-77; Caldwell, 2013)*.

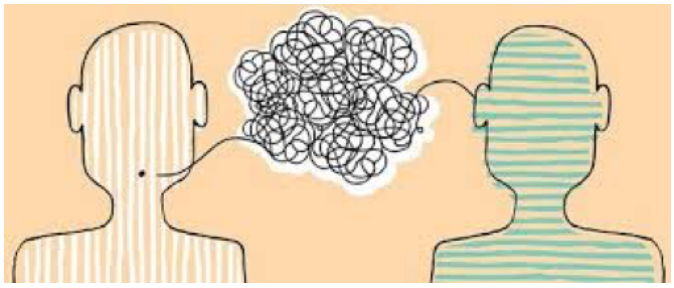
In some patient information materials and within on-line resources, conditions such as CLL and NHL-FL are sometimes termed incurable. Within media incurable cancers are often linked with language such as; advanced cancer, palliative care and end of life care *(Kazimierczak & Skea, 2015, p 340-354; O'Connor 2010, p.68)*. These associations can influence what patients and carers understand about what an incurable cancer means in their situation.

For haematology patients diagnosed with an 'incurable cancer' the implications from the above discourses have the potential to be profound. If no treatment is being offered at time of diagnosis how can they 'fight' the cancer? For many with an incurable cancer they may wonder why a cure has not been found when others with cancer appear to be receiving curative therapy *(Evans, 2011, p.69)*.

How patients diagnosed with CLL and NHL-FL cope with the diagnosis and its future implications is influenced by what they comprehend about their condition.

Importance

Patients diagnosed with CLL and NHL-FL often express confusion about being diagnosed with an incurable cancer that does not need treatment *(Evans et al, 2012, p. 67-77; Caldwell, 2013, p. 36)*. Some feel abandoned by haematologists as patients perceive they are considered 'uninteresting' cases *(Evans et al, 2012, p. 75)*. Cheeson *(2012, p. 3781)* suggests some NHL-FL patients instead



of adopting the 'watch and wait' care plan as advised by their haematologists, adopt instead a 'watch and worry' focus with concurrent feelings of anxiety and distress. Recognising how an incurable cancer in this context may be perceived by patients and providing relevant information about prognosis and treatment implications is vital *(Cheeson 2012, p.3781; Horn & Campbell, 2010, p.34-37)*.

In addition, communicating accurately to other health professionals, whom those diagnosed with CLL/NHL-FL may interact with or be referred to, is essential.

If patients access counselling or other supportive care, health professionals should have some understanding about the patient's condition and its expected course. The health professional without expert haematological knowledge may be influenced by the discourses around terms such as incurable cancers and palliative chemotherapy *(Nappa, 2014, p.591-597; Kazimierczak & Skea, 2015, p.340-354)*. Their supportive care advice may vary as a result and could distress the patients and family.

What we can do?

Haematology nurses may not always meet or encounter asymptomatic patients with CLL or NHL-FL. However the following may be helpful:

- Check that the written information available in clinics is clear about the diagnosis, the role of 'Watch and Wait' or 'Active Monitoring'.
- Highlight where further resources and expert support can be obtained (e.g. Leukaemia Foundation, Lymphoma Australia or Leukaemia and Blood Cancer NZ).
- When referring patients to other health professionals include information about the diagnosis and its expected course. If words such as incurable, palliative are in the patient notes explain what they actually mean for the specific haematological malignancy.
- Lastly scrutinise language being used in everyday practice and what different meanings it might have to people. It is very interesting when you start thinking about it.

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THE HSANZ NG MYELOMA SPECIAL PRACTICE NETWORK 'M-SPN'

HSANZ NG | myeNURSE

It's been a busy start to the year with the International Myeloma Workshop (IMW) in Delhi; continued work on our educational projects; collaborative publications and HAA later in the year. I enclose some of the highlights for your reading pleasure.

Following on from the success of our inaugural annual seminar 2016, we've been approached to collaborate with our medical colleagues and co-host a combined medical and nursing seminar. MSAG will co-host the event with the HSANZ M-SPN. The date and venue has been established and the program is being planned. Excitingly, Myeloma Australia will also host a concurrent patient & family seminar to make use of medical and nursing faculty that will be onsite. Members will be notified directly, once program is finalised and registration opens.

3rd International Nursing Program held in conjunction with the 16th International Myeloma Workshop, Delhi, India 2017

The IMW is a biannual event that brings together myeloma experts from around the world. This year represented the 3rd Nursing Program within this prestigious IMW meeting and was arguably the most successful to date. I have the privilege of leading an international nurse organising committee to bring together a faculty of myeloma nurse and medical experts to present a comprehensive clinical program. A few of the highlights this year included:

- Dr Thomas Osborne, Consultant in Palliative Medicine from King's College London who opened the program with a presentation of his work on developing of the patient reported outcome measure (PROM), 'MyPOS'. The MyPOS instrument has been developed specifically for use in the clinical setting to assess for aspects relating to HRQOL in a MM population.[1,2,3] MyPOS tool can be accessed at www.pos-pal.org
- Charise Gleason, Nurse Practitioner, Emory, USA, presented an overview of nurse side effect management with a focus on newer drug combinations. Charise and her US nursing colleagues, have developed expertise in managing patients on the newer targeted therapies and was able to share this experience with nurses from regions only just beginning to access these agents.
- Monica Morris, Healthcare Professional Programme Manager, Myeloma UK presented the recently published guidelines on the 'Screening and Management of Late and Long-term Consequences of Myeloma and its Treatment'.[4] This important clinical update provides health professionals from a range of primary health care, as well as cancer and haematology services, with clear guidance on how best to screen and manage for the range of health conditions that can occur as a consequence of a diagnosis of myeloma and its treatment.

A range of other presentations included a an overview of extramedullary disease; a study on carer needs; real world data on the impact of daratumumab administration & nursing implications for patients on daratumumab and lenalidomide; patient reported symptom concerns & provider interventions; development of an advanced practice nurse role in myeloma; patients perceptions of being involved in a clinical trial; creating a QOL clinic; decision aids utilized during treatment decision making; physical exercise habits of patients with MM & symptom management and adherence in MM.

To read more about these topics, access the IMW 2017 abstract book via the International Myeloma Society website (www.myelomasociety.org) or follow this link https://cms.cws.net/content/beta.myelomasociety.org/files/2017IMWAbstractBook.pdf

myeNURSE was presented as an oral abstract during IMW and we were able to utilise the App to deliver slides from the meeting in addition to the content for the local Indian nurse's seminars held in the days running up to the IMW meeting.

FREE access to IMW meeting slides: If you are a member of M-SPN and would like to access slides from the talks mentioned from IMW 2017, please get in touch. You need to be a M-SPN member to access - why not consider joining if not already a member?

Tracy.king@sswahs.nsw.gov.au

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OF COURSE, WE DID GET TO HAVE SOME FUN! L-R: MAX, BETH & MATT FAIMAN; TRACY KING; TIFFANY RICHARDS; CARMEL WOODROW; PATRICK SPENCER; DONNA CATAMERO

In addition to hosting the IMW Nursing Program, we were able to collaborate with our friends from the Oncology Nursing Association of India (ONAI) to host educational meetings at hospitals in Mumbai and New Delhi. Several members of the International Nursing Faculty for IMW were kind enough make travel arrangements to arrive in India in time to join us at these events.

Tata Memorial Hospital, Mumbai in conjunction with ONAI, Mumbai chapter

In collaboration with Mrs Pratheepa Jagdish and her nursing colleagues at Tata Memorial in Mumbai, Tiffany Richards (Nurse Practitioner, MD Anderson Houston USA) and I took an early flight down to Mumbai from Delhi to participate in an amazing day which started with setting the fire alarm off as we lit ceremonial candles to open the event! Over 200 nurses from the Mumbai region came together for a program of myeloma clinical updates, disease and treatment side effect management and even Yoga, which ended the day with a bit of fun. The nurses were so welcoming and engaging and Tiffany and I very thankful for their friendship and hospitality. We learnt that myeloma and nursing, in India as in our own countries, has more in common than not. Although the incidence of myeloma is much lower in India, there is a larger number of people living with myeloma due to the large population size. Autologous transplants are undertaken with good outcomes, and patients have similar challenges with side effect management and accessing high cost drugs in what is a mixed public and private healthcare system. Thanks to the support from Diane Moran at the International Myeloma Foundation (IMF) we were able to leave the nurses with flash drives packed full of myeloma nursing resources. Thanks also to Janssen India for their support of flights for Tracy & Tiffany to fly down from Delhi, and to their driver for getting us back to the airport with seconds to spare for our flight back up to Delhi!

All India Institute of Medical Sciences (AIIMS), New Delhi

Having visited AIIMS hospital to teach about MM in the past, it was clear to me that I wanted to go back and collaborate on a larger nursing event pre IMW 2017 and endorsed by the International Myeloma Society. As Prof Lalit Kumar mentioned on the day, "Tracy King hounded me by email from Australia until I agreed to support a nursing seminar at AIIMS"! Be that true, Prof Kumar, Mrs Baby Rani Debnath, Mrs Nileema Shingade with their team of nursing colleagues at AIIMS, gracefully set to the challenge and hosted an amazing day of learning. Utilising the IMW nursing faculty to present and engage with local nurses, over 130 nurses attended a full day of myeloma lectures from clinical disease updates to better understanding how to manage some of the side effects of treatment. Those attending were able to engage with each others during breaks but also their International nursing colleagues. Again, we had brought a range of MM nursing educational resources to give to the local nurses including the IMF flash drives; text books, access to a fully loaded myeNURSE App (India) and even some clippie and chocolate Koalas found their way over in my luggage!

The Delhi nurses, under the leadership of Nileema Shingade, continue to work with us to produce some local myeloma resources including a patient guide translated into Hindi. We look forward to one day welcoming the Indian nurses to visit us in Australia.

L-R PHOTO MRS NILEEMA SHINGADE; TRACY KING

I would particularly like to thank Mrs Nileema Shingade who has stayed in touch with me since my first visit to India (2015) and was the key local collaborator for all the meetings in India, including joining our faculty during IMW. Also to my international nursing colleagues who so generously supported these extra meetings by flying in early and giving so generously of their time and energy. Dr Beth Faiman (USA); Dr Tiffany Richards (USA); Charise Gleason (USA); Donna Catamero (USA); Monica Morris (UK).

INTERNATIONAL MYELOMA WORKSHOP AIIMS NEW DELHI

L-R: TIFFANY RICHARDS; PATRICK SPENCER; DONNA CATAMERO; CHARISE GLEASON; BETH FAIMAN; TRACY KING; MONICA MORRIS; GOVINDI CHAUHAN.

The International Myeloma Foundation (IMF) Nurse Leadership Board (NLB) is publishing new Best-Practice Guidelines in Symptom Management and Adherence in upcoming Clinical Journal of Oncology Nursing

As the management and treatment of multiple myeloma continues to evolve, the IMF NLB recognises the critical need to improve education for nurses who in turn educate patients and caregivers. Lead Editor, Beth Faiman, PhD, MSN, APRN-BC, AOCN, says "This publication will provide concise, easy-to understand recommendations that will set the standard for future nursing care of myeloma patients." As an active affiliate member of the NLB I have been lucky enough to contribute to these publications and look forward to bringing them to you in due course. Beth Faiman and some of the other authors, were able to present the work at the recent IMW in Delhi.

L-R: NLB MEMBERS TIFFANY RICHARDS, CHARISE GLEASON, TRACY KING, BETH FAIMAN, AND DONNA D. CATAMERO POSE IN FRONT OF THEIR POSTER PRESENTATION AT THE IMW IN NEW DELHI, INDIA

A wide range of MM nursing publications and resources are readily available on the NLB pages of the IMF website. https://www.myeloma.org/nurse-leadership-board

Most recently:

Steroid-Associated Side Effects: A symptom management update on multiple myeloma treatment.

King & Faiman 2017. CJON 21(2):240-249.

One constant and relatively unchanged aspect of treatment of multiple myeloma (MM) is the use of steroids, which can cause a wide range of adverse side effects and harm patients' quality of life. The NLB recently updated recommendations on the management of steroid-associated side effects in patients with MM.

Available at: https://cjon.ons.org/cjon/21/2-0/steroid-associated-side-effects-symptom-management-update-multiple-myeloma-treatment

Slide set from recent symposium at Oncology Nursing Society (ONS) Annual Conference. 'Case Studies in Multiple Myeloma: Best Practice in Patient Care and Symptom Management'

NLB members, co-chairs Beth Faiman and Joseph Tariman with Faculty Charise Gleason and Sandra Rome hosted a successful symposium with over 900 nursing delegates.

Slides available for free download at: http://imf-ons.myeloma.org/ONS_2017.pdf

An invitation to all members to join us at HAA 2017 Sydney

The M-SPN will be hosting its annual meeting at lunchtime during HAA this year. Beth Faiman is known to most of you as a myeloma expert clinician. As our guest at HAA this year she will be talking on a range of subject areas and I'm delighted to say she will be joining the lunchtime M-SPN meeting as our guest speaker.

The educational projects we've reported on previously are coming to fruition. We have engaged InspireHCP to work with us on these projects and aim to deliver our completed work at HAA.

DO YOU CARE FOR THOSE WITH MM?

Not yet a member of our MM group? Then please consider joining, it's easy and FREE to HSANZ members

Why not consider joining the M-SPN so you can access the full content of myeNURSE App giving you a comprehensive range of MM resources available on your hand-held device or desktop PC.

Application forms can be found at the hsanz.org.au website or by emailing us at nurses@hsanz.org.au or email me directly.

Tracy King
Chair HSANZ NG MM-Special Practice Network
Tracy.king@sswahs.nsw.gov.au

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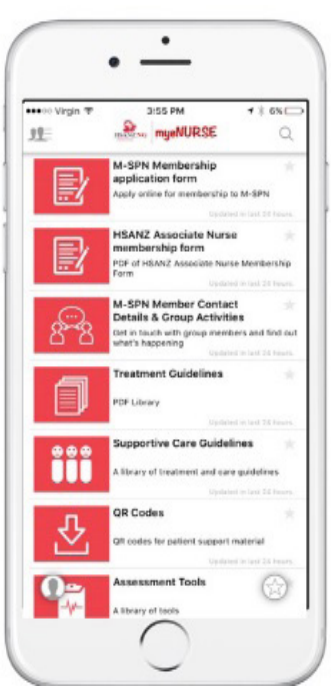
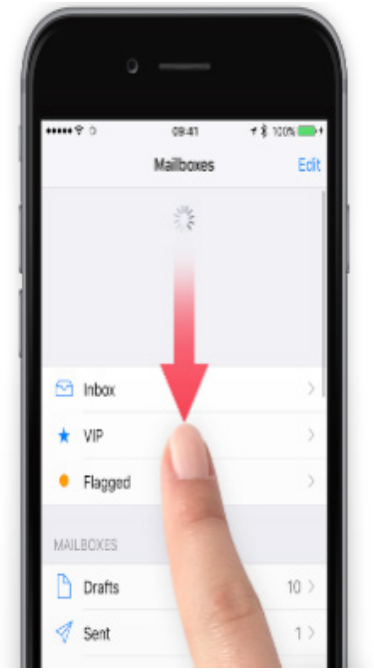




DO YOU RUN A MEN'S HEALTH GROUP?

I am interested in looking at men's health post-treatment for haematological disease or Blood and Marrow Transplant. I would like to hear from anyone who is running a male-specific health support program, or have such a group operating within their hospital. If you are running anything like this or are interested in discussing the subject, please contact me.

David Collins
Nurse Practitioner Acute BMT
David.Collins@health.nsw.gov.au

MYELOMA AUSTRALIA

Myeloma Australia is a not-for profit organisation dedicated to providing support and information to those living with myeloma and their carers. Myeloma Australia also provides advocacy services for our community particularly in the area of drug/ treatment access and aids research through the support of clinicians, scientists and researchers through our Medical Scientific Advisory Group, (MSAG). We are passionate about assisting and improving the quality of life of Australians living with myeloma and we do this through our nurse led services. These include our 1800MYELOMA telephone support line, patient and carer support groups and information seminars as well as health professional education and publication of written resources.

You may be familiar with our 'Myeloma: A Comprehensive Guide', a thorough and detailed resource for patients and nurses regarding all aspects of the myeloma experience. There is information about myeloma the disease, tests for diagnosis, current and upcoming treatments, self help checklist and a guide to communicating with the medical team. Another useful resource is our 'Managing Peripheral Neuropathy' book which is now available in hard copy and has information on the different types of peripheral neuropathy, common symptoms, management strategies, a self assessment tool and safety considerations. Myeloma Australia also circulate a quarterly magazine the 'MyeNews', a monthly e-newsletter the 'Myeloma Muster' and a number of fact sheets on topics such as steroid management, bisphosphonates, FISH test, nutrition, exercise, chronic disease management plan. If you would like any of our resources, please contact your local Myeloma Support Nurse (details below).

Specifically for health professionals, Myeloma Australia publishes the Clinical Practice Guideline for Myeloma, AL Amyloidosis and Waldenstrom Macroglobulinaemia. These guidelines are written by our MSAG, a group of leading myeloma clinicians and researchers from Australia and NZ and outline clinical guidelines for diagnosis, staging and treatment of each disease specific to the current Australian health care environment; they are updated regularly and can be downloaded from our website (www.myeloma.org .au). The MSAG also convene a myeloma specific education event each year; last year was the scientific meeting in the Yarra Valley and this year will be a collaborative event with the HSANZ Myeloma SPN on Saturday September 16th at the Victorian Comprehensive Cancer Centre (VCCC) in Melbourne. The event is an education day for clinicians, nurses and patients and will host a number of leading myeloma clinicians as speakers. Myeloma Australia will have a number of travel grants available to health professionals attending from interstate, save the dates will be circulated shortly followed by a final program and grant details.

Currently we have a team of six nurses to deliver services to people living with myeloma and their carers. We are currently going through a period of expansion and are looking to employ more nurses in NSW, WA and Qld. It is an ideal role to match with a part time clinical role, so if you are interested in providing supportive care and education to myeloma patients and carers keep an eye out for the ads or feel free to contact us if you would like any further information about our expansion by emailing nella.combe@myeloma.org.au

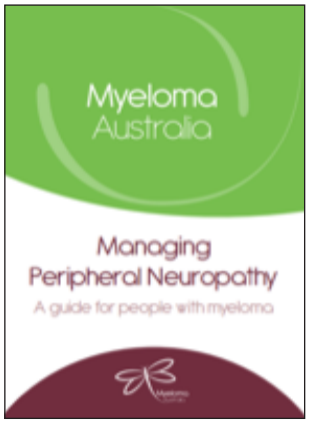
Lastly, if you would like to order any resources or arrange any myeloma education in your clinical setting please contact your local Myeloma Support Nurse

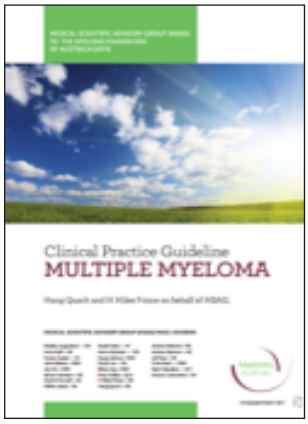
Tas, WA, Qld, ACT: Nella Combe and Hayley Beer – nella.combe@myeloma.org.au or hayley.beer@myeloma.org.au

SA & NT : Jo Gardiner – jo.gardiner@myeloma.org.au

NSW: Jacqui Keogh – jacqui.keogh@myeloma.org.au

Vic: Elli Foley and Laura Jones – elli.foley@myeloma.org.au or laura.jones@myeloma.org.au





Introduction to the Lymphoma and Related Diseases Registry

MONASH University
Medicine, Nursing and Health Sciences

OVERVIEW AND AIMS

The Lymphoma and Related Diseases Registry (LaRDR) was established in 2016 and is administered by Monash University in Melbourne. LaRDR a registry of patients (≥ 18 years) diagnosed with all forms of lymphoma and related disease such as B and T/NK cell non-Hodgkin Lymphoma and Hodgkin Lymphoma

The aim of the LaRDR is to monitor access to care, benchmark outcomes nationally and internationally, monitor trends in incidence and survival, explore factors that influence outcomes including survival and quality of life and act as a resource for clinical trials. It will also enable clinicians to benchmark against national and international standards and allow evaluation of the translation of therapy such as the introduction of new target therapies.

RECRUITMENT

In the short time that LaRDR has been active a milestone was reached in May with the 100th patient registered. The research team thanks all of the patients, data managers and clinicians for their support. Five sites now contribute to the data registry.

ACTIVE SITES

QLD
- **Princess Alexandra Hospital**

NSW
- **Concord Hospital**

VIC
- **Monash Medical Centre**
- **Austin Hospital**

WA
- **Fiona Stanley Hospital**

HOW PATIENTS CAN BE INVOLVED

Patients (≥ 18 years and recently diagnosed with lymphoma) are invited to join the registry by clinical staff at participating hospitals. Inclusion on the LaRDR does not involve any procedure or change in treatment and participants can opt-off the registry at any time.

If you would like to know more about the LaRDR:
Visit our website: www.lardr.org
Call: 1800 811 326
Email: SPHPM-Lymphoma@monash.edu

MEET OUR DATA CONTRIBUTORS

Tania Cushion is a Lymphoma Clinical Nurse Consultant who works on the LaRDR registry at Austin Hospital.

What does your role involve on a day-to-day basis?

The most important part of my role is to act as a primary point of contact for patients. This involves seeing patients either in clinics, day oncology or when they are inpatients.

For someone who has just received a diagnosis of cancer, taking the next steps can be confusing and overwhelming and this can be a barrier to accessing care. I ensure that patients understand their diagnosis and treatment plan, and co-ordinate their care. This can range from chemotherapy education, psychological support, fertility counselling and referrals to community care and various allied health services.

Throughout a patient's treatment plan I am available to provide reassurance, support, or to organise review as needed. In addition to this, I provide support and education for nursing staff.

And, you find time to enter patients into the registry. What do you see as the benefits of tracking lymphoma cases?

I've been involved in data collection for many years in past roles, and as such I can see the benefits in patient outcomes that this can bring.

Having a nationwide database of lymphoma will allow us to identify what treatments are working and to learn from each other to provide the best possible therapy for patients.

Keeping track of what we're doing now will allow future clinicians and researchers to follow the trajectory of the registry, hopefully resulting in a greater understand of lymphoma and how to treat it.

SPONSORS

The LaRDR is supported by funding provided by Bristol-Myers Squibb, Celgene, Novartis, Roche,Takeda Pharmaceuticals and Janssen

UPDATE FROM THE LEUKAEMIA FOUNDATION

Ally Tutkaluk
Communications Officer

New blood cancer survivorship resource

The Leukaemia Foundation has partnered with Queensland University of Technology and the Royal Brisbane and Women's Hospital to produce a new book on survivorship for blood cancer patients. 'Living well after treatment' covers a range of issues that patients and their families may experience post-treatment, including dealing with fatigue and a changed body image; sexuality and intimacy; returning to work; staying healthy; and dealing with the fear of a cancer recurrence.

Contact the Leukaemia Foundation to order a copy for your patients or hospital: phone 1800 620 420, email qldsupport@leukaemia.org.au, or download a copy from the website at leukaemiaqld.org.au.

New program for CLL patients

SHEILA SHEILA DEUCHARS - QLD CLL MY WAY COORDINATOR

A pilot program to provide personalised information and support to people with chronic lymphocytic leukaemia has been rolled out in Queensland and New South Wales.

CLL My Way is wellness program that highlights the issues of a CLL diagnosis and its treatment, and provides strategies on how to live well with CLL.

The program gives patients access to a designated CLL My Way Coordinator to offer personalised support; telephone forums; a moderated closed Facebook group; and seminars and support groups.

Topics covered in CLL My Way include adhering to therapy; managing side-effects, relationships, and financial health; and personal reflection/growth.

Once the pilot has been evaluated, the program may be rolled out across Australia.

CLL My Way is a collaboration between the Leukaemia Foundation, Janssen and the CLL Australian Research Consortium.

For information about CLL My Way call 1800 002 244 or visit leukaemia.org.au/cllmyway.

$5,000 QLD nursing and allied health bursary

CARLIE NIELSEN RECIPIENT OF THE 2016 ESA INTERNATIONAL DOROTHY BANKS BURSARY PRESENTED BY BARBARA HARTIGAN, DIRECTOR OF SUPPORT SERVICES (L) AND VAL FILES, ESA PAST PRESIDENT 2015-2016

Queensland nurses and allied health professionals are invited to apply for a $5,000 bursary to further their professional development.

The 2017 ESA International Dorothy Banks Bursary is designed to improve the services and care provided to patients being treated in the haematology setting. It provides an opportunity for a Registered Allied Health Professional/Registered Nurse practicing in this field in Queensland, who has a keen interest and passion in the care of their patients to undertake further professional development or to attend either a national or international conference.

Applications will open in May; visit leukaemiaqld.org.au/dorothy.

Leukaemia Foundation BLOOD BUDDIES

Blood Buddies: peer support for patients

The Leukaemia Foundation runs Blood Buddies, a phone-based peer support program that matches and connects those diagnosed with blood cancer (or those caring for a person with blood cancer) with a trained volunteer who has had blood cancer (or cared for somebody with blood cancer).

Blood Buddies volunteers offer non-judgmental reassurance, support, encouragement and hope. No aspect of the Blood Buddies program is intended to guide medical treatment decision-making. People who are referred to this service are matched, according to several key indicators, with a trained volunteer – known as a 'Buddy'. As a mentor, a Buddy shares their personal experience of how life changed for them, what treatment was like, and strategies they used to help them get through a difficult circumstance with a positive attitude. Simply talking to someone else who has 'been there and done that', can mean you feel less alone and more able to manage your health. Blood Buddies volunteers are in a unique position – one that is quite different from health professionals and support agencies – in the sort of support and assistance they can provide to others.

For more information, including how your patients can be matched with a Buddy or how they can register their interest in becoming a Buddy, email bloodbuddies@leukaemia.org.au or call 1800 007 343.

Upcoming blood cancer telephone forums

Hosted by Leukaemia Foundation support staff, these free forums are a chance for blood cancer patients to connect with others across Australia, as well as hear from health professional guest speakers.

- 6 June – Myeloma
- 13 Sept – Waldenstrom's Macroglobulinaemia
- 25 July – Cutaneous lymphoma
- 6 June, 19 Sept – Hodgkin lymphoma
- 14 June, 2 August – General lymphoma

To register and find out more information on upcoming forums, phone 1800 620 420.

Upcoming blood cancer seminars and support groups

- 5 June – Bendigo Blood Cancer Support Group, 9.30 – 11:00 am, Kangaroo Flat VIC
- 6 June – Women's Blood Cancer Support Group, 10:00 am – 12:00 pm, Adelaide SA
- 7 June – Wollongong Blood Cancer Education and Support Group, 10.30 am – 12.30 pm, Figtree NSW
- 9 June – Men's Blood Cancer Support Group, 10:00 – 11.30 am, Melbourne VIC
- 10 June – Grief Support Brunch, 9.30 am – 12.30 pm, Brisbane QLD
- 21 June – Armidale Blood Cancer Education and Support Group, 2:00 – 3.30 pm, Armidale NSW
- 21 June – Lymphoma Support Group, 10.30 am, Brisbane QLD
- 29 June – Alice Springs Blood Cancer Support Group, 10:00 – 11.30 am, Alice Springs NT
- 5 July – Blood Cancer Support Group, 5.30 – 6.30 pm, Mount Gambier, SA
- 14 July – Post-BMT Support Group, 10.30 am, Sunshine Coast QLD
- 19 July – Blood Cancer Support Group, 2:00 – 4:00 pm, Sydney NSW

Support groups and educational seminars are run throughout the year across Australia. For more listings, visit leukaemia.org.au/events or phone 1800 620 420.

SPECIAL PRACTICE NETWORKS- EXPRESSIONS OF INTEREST

SPNs are communities of members who share ideas, information and experiences with others in the same sub specialist field. Each SPN will comprise associate nurse members who establish networks to address professional and educational issues relating to specific areas of haematology nursing practice. This networking may be achieved in the following ways:

1. Communication between SPN members through means such as the HSANZ NG newsletter, HSANZ NG website and email correspondence.

2. Provision of education through special interest sessions at HAA or other appropriate cancer nursing forums

3. National activities in the area of interest.

Lymphoma SPN- Karen Matoga

Expressions of Interest are being sought from nurse members who are interested in forming a steering group to establish a Lymphoma SPN.

Potential areas for development could include:

- Establishing educational guidelines and resources for nurses providing education and support to new diagnosed Lymphoma patients
- Collaboration opportunities for research activities
- Formulating a discussion forum on clinical practice updates

If you are interested in being part of a steering group to develop the aims and activities of such a group please contact Karen Matoga at: karen.matoga@mh.org.au

Myleodysplasia/Myeloproliferative Neoplasms SPN

Sam Soggee

Sam is still keen to hear from anyone interested in being part of the MDS/MPN SPN. Please make contact if you wish to be involved:

Sam Soggee at: Sam.Soggee@epworth.org.au

CNSA UPDATE

CNSA Congress 2017

The theme of the CNSA 20th Annual Congress is "Evolving Cancer Care: Enhancing Quality – Embracing Innovation". This year's CNSA Congress offers you a diverse program supported by experts in e-health, health reform, symptom management, nursing research, professional skills and palliative care. Whether you are new to cancer nursing or an experienced cancer nurse, Congress 2017 has targeted content to meet your professional development needs. It is also a wonderful opportunity to network with like-minded colleagues from around the country and update yourself on what industry and the not-for-profit sector has to offer. To view the full Congress program on offer - Please visit the website: http://www.cnsacongress.com.au/home

Keynotes speakers for this year's congress include Professor Roma Maguire, Associate Professor Alexandre Chan, Professor Dorothy Keefe, Professor Patsy Yates, Ms Carrie Marr and many more. Early bird registration closes on 30 April 2017. To register, please click here: http://www.cnsacongress.com.au/registration-submission-details

New CEO Apointment

MS SAM GIBSON

CNSA recently announced the appointment of Ms Sam Gibson RN, MN, NP as its inaugural Chief Executive Officer. Sam has an impressive career spanning close to 30 years in cancer care. Sam has worked as a clinician and educator in oncology, haematology, bone marrow transplantation and palliative care across the public, private and community settings. Sam's experience has seen her sought out to provide nursing expertise and contribute to a number of forums, including senate committees, advisory boards and state-based cancer collaborative groups. In 2008, Sam was awarded the HESTA Australian Nurse of the Year award in recognition of her contribution to the nursing profession. Sam has held a number of leadership roles within the CNSA over the past 11 years. These include Chair of the Western Australian Regional Group, a member of the National Executive Committee, Secretary of the Cancer Nurse Practitioner Specialist Practice Network, and more recently Chair of the Annual Congress Committee.

As the peak cancer nursing body in Australia, Sam has a vision for the CNSA to position itself as a key representative body, where consultation is sought in service planning, policy development and establishment of models of service in cancer control. She is passionate about the provision of networking and professional development opportunities for all cancer nurses independent of cancer specialty, discipline or geographical location.

Sam is looking forward to working with the HSANZ and all national and international cancer professional societies to advance our collective efforts in cancer control across the globe.

CONFERENCE UPDATE 2017

Compiled by Peter Haywood

DATE	CONFERENCE	DETAILS
JUNE 2017		
2-6 June	**ASCO 2017:** American Society of Clinical Oncology Annual Meeting	Chicago, USA **am.asco.org**
14-17 June	**14-ICML:** International Conference on Malignant Lymphoma	Lugano, Switzerland **www.lymphcon.ch/icml/website/index.php**
15-17 June	**ANZCHOG:** Australian and New Zealand Children's Oncology Group Annual Scientific Meeting	Adelaide, Australia **http://www.anzchog.org/**
15-17 June	**CNSA:** Cancer Nurses Society of Australia Winter Congress	Adelaide, Australia **https://www.cnsa.org.au**
22-24 June	**MASCC/ISOO:** Annual Meeting on Supportive Care in Cancer	Washington, USA **mascc2017.com**
22-25 June	**EHA:** European Hematology Association Congress	Madrid, Spain **https://www.ehaweb.org/**
JULY 2017		
9-12 July	**ICCN:** International Conference on Cancer Nursing	Anaheim, USA **isncc.org/page/iccn2017**
OCTOBER 2017		
29 Oct – 1 No	**HAA 2017**	Sydney, Australia **www.haa2017.com**
NOVEMBER 2017		
13-15 Nov	**COSA:** Clinical Oncology Society of Australia Annual Scientific Meeting	Sydney, Australia **https://www.cosa.org.au**
14-17 Nov	**ALLG Scientific Meeting**	Sydney, Australia **http://www.allg.org.au/events.html**
DECEMBER 2017		
9-12 Dec	**59th ASH Annual Meeting:** American Society of Haematolog	Atlanta, USA **http://www.hematology.org/Annual-Meeting/**

CONFERENCE UPDATE 2018

DATE	CONFERENCE	DETAILS
JANUARY 2018		
FEBRUARY 2018		
21-25 Feb	**BMT Tandem Meetings** American Society for Blood and Marrow Transplantation	Salt Lake City, USA **http://asbmt.org/event/2018-bmt-tandem-meetings**
MARCH 2018		
18-21 Mar	**EBMT:** European Society for Blood and Marrow Transplantation Annual Meeting	Lisbon, Portugal **http://www.pr-medicalevents.com/congress/ebmt-2018/**
APRIL 2018		
MAY 2018		
17-20 May	**ONS:** Oncology Nursing Society Annual Congress	Washington, USA **https://www.ons.org/congress**

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Jane Worsfold: ***Retiring, replacement to be advised.***

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EDITOR'S NOTE

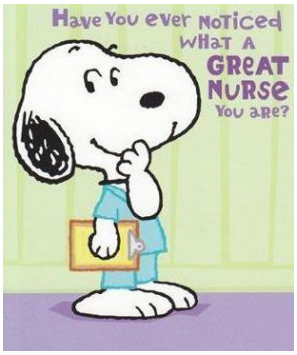
Rosemary Hoyt
Dunedin Hospital, New Zealand

My struggle and search for content for the HSANZ nurse's newsletter continues. Thank you to the people who do make such great contributions to it and answer my pleas for updates, articles and information. But to everyone else, please do not wait to be invited, take the initiative tell us what you are doing, have learnt, have seen or think others should know about. Over winter especially when you are snuggled up inside and scared to venture out due to rain, snow and ice, sit quietly for an hour or so and write a little article about what you have been doing, an interesting case study, an article you have read and thought should be shared with others, a new patient resource you have come across, a conference or meeting you have attended and found interesting. Gosh so many ideas….

It was International Nurses Day recently and I reflected on the wonderful work that nurses do in their everyday practice. We have recently been confronted with a restructuring document at our work place and many nurses feel it does not recognise the work nurses do. So I elected to write down a few of the things nurses might do on a daily basis. The list could go on and on but I think we sometimes forget or underestimate the roles we take on. The following were some of my thoughts:

- Provide education to patients and care-givers about their condition, its treatment, ways to manage side effects and empower them to optimally use medicines and access supportive care resources
- Listen to and counsel patients/families who are distressed, worried or scared
- Administer chemotherapy in a safe, efficient and efficacious way
- Address supportive care needs for both patients and their families. This includes advice about financial, psychosocial supports, counselling options, nutrition, navigation of government agencies, transport support, accessing disability supports, discuss sexual health issues and optimise safety in the home.
- Complete referrals to allied health professionals and non-government organisations
- Coordinate inpatient care, provide support 24 hour a day care to patients and families having either potentially curative or palliative treatment as well as end of life care
- Support families and friends of patients with decision making, accessing resources and trouble-shooting of side effects and obstacles they encounter when caring for someone with a haematological disorder
- Address side effects and establish management plans
- Provide care in acute assessment units, day centres, outpatient clinics or home based community settings thereby reducing acute admission rates, length of in-patient hospital stays, readmission rates and reducing side effects by intervening early
- Act as a resource for junior (and often senior) medical and allied staff, other wards in the hospital, district nurses, practice nurses and GPs
- Run nurse-led clinics or other outpatient activities where patients receive additional counselling and education about their diagnosis, its implications and treatment options
- Provide ongoing follow up regarding toxicities, end of treatment care planning, survivorship counselling or end of life care and support
- Liaise with various health care providers, educational institutions and community groups
- Participate in educational programmes for either patients, other nurses or other health professionals thereby sharing knowledge and skills
- Represent speciality nursing on national advisory boards, international groups and at conferences both locally and overseas
- Establish educational standards, supporting junior nursing staff in their advancement of knowledge and skills in caring for haematological patients

Happy Belated Nurses Day and thank you to those colleagues who have taught me, inspired me, comforted me, laughed with and at me, shown be better ways to do things and offered me advice (apologies as sometimes it did take me awhile to recognise it was good advice).



Edition deadlines for rest of 2017

Monday 14th August

Monday 27th November