The Australian Journal of Cancer Nursing

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In this issue

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Editorial
The *AJCN* aims to provide a forum where debate and the exchange of views can take place. We welcome papers on contemporary professional policy or practice issues of concern and interest to cancer nurses.

Notes for contributors
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The Cancer Nurses Society of Australia (CNSA)

Our mission

The CNSA is committed to achieving and promoting excellence in cancer care through the professional contribution of nurses.

To achieve our mission of promoting excellence in cancer care, the CNSA will act as a resource to cancer nurses around Australia, no matter what their geographical location or area of practice.
The CNSA will be the link between cancer nurses in Australia, the consumers of cancer nursing services and other health professionals involved in cancer care.

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Editorial

A 'haem theme' but a commonality of practice

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This issue of our journal has a haematological theme but our four papers report findings and engage in discussion that resonates with all cancer nurses. The threads that link the four papers are those of living with cancer and haematological malignancies and how best to support individuals doing this. Survivorship has been characterised as living on after a cancer diagnosis, as being a life-changing experience and as having both positive and negative aspects. The concept of survivorship has also been used as a tool to frame a survivor's experience and to describe the meaning making, skill building 'craftwork'[1] required by survival. A key consideration, therefore, for us as cancer and haematology nurses, is how to work with individuals affected by cancer and haematological malignancies and our fellow health professionals to enable individuals to survive well at all times across the trajectory of survival.

We start in an area of practice that is paramount for the support of many, if not all, cancer treatment modalities. Bev Quested's paper examines some of the significant changes that have occurred in the standards, guidelines and governance of blood and blood components in Australia. Transfusion practice has moved from the idea of numerical transfusion thresholds triggers to more qualitative and person-centred patient blood management principles.

I have used Fitzhugh Mullan's words before as he likened surviving cancer to being saved from drowning but then abandoned on the beach[2]. This remains pertinent as Yvonne Panek-Hudson's paper describes attempts at one institution to provide a cancer survivor care through a health promotion lens. Yvonne's paper elegantly orientates us to the gaps in survivorship guidelines and how to best serve these members of our population and then offers a useful and effective way of working.

Nicole Loft's paper provides us with an insightful opportunity to consider an important but sometimes forgotten (or at least not prioritised) late effect of cancer treatment — that of a secondary malignancy. The very idea of the treatment causing the condition that the individual is being treated for in the first place seems counterintuitive for some patients. Nicole's paper frames this adverse effect of treatment in a way that contextualises it and provides us as cancer nurses with information to enable us to discuss it but also contextualise it for those we care for.

Patricia Morris' paper takes on a journey to understand the experience of living with a haematological malignancy through the eyes of the autobiographer and *The Age* reporter, Pamela Bone. This paper deconstructs Pamela's biography and provides us with an analysis of her story through the lens of three key illness experience theories. This reflective paper is a little different from the usual *AJCN* manuscript and provides us with some valuable insights into ways of understanding one individual's experience of living with cancer.

These four papers provide a varied look at how we, as cancer nurses, can respond to changes not only in practice but also in knowing and understanding the experiences of those individuals who come into our care. We hope you enjoy reading this edition and find these papers useful in your own practice.

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Cancer Nurses Society of Australia

Patient blood management and care for chemotherapy and haematopoietic stem cell transplant patients

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Abstract

Without blood component support chemotherapy and haematopoietic stem cell transplant (HSCT) patients could not be properly treated. In the last two years significant change has occurred in the standards, guidelines and governance of blood and blood components in Australia. The paradigm in transfusion medicine has moved from transfusion thresholds triggers to patient blood management principles. This article reviews the current Australian guidelines and standards that relate to blood transfusion for patients undergoing chemotherapy and HSCT and the impact upon their care.

Blood transfusions are an integral part of supportive care for chemotherapy and haematopoietic stem cell transplant (HSCT) patients. Without blood component support these patients could not be properly treated[1]. Patients with cancer and blood diseases use 34% of the red cells produced by the Australian Red Cross Blood Service[2]. Cancer and blood diseases also require platelet transfusion support. However, like all treatments, transfusion is not without risk. Transfusion decisions need to consider the individual patient and their physiological status, treatment trajectory, the patient's preferences and circumstances.

Patient blood management (PBM) is a new paradigm in transfusion. PBM is the management and preservation of patients' own blood to reduce or avoid the need for a blood transfusion[3]. Blood component therapy involves supporting the patient with the specific blood component they require to correct their clinical problem[4]. Components include red cells, platelets, fresh, frozen plasma and cryoprecipitate. Plasma is fractionated into albumen, clotting factors and antibody products. These all have specific indications. PBM principles and guidelines aims to improve clinical outcomes by avoiding unnecessary exposure to blood components by:

- optimising blood volume and red cells mass
- minimising blood loss
- optimising the patients' tolerance of anaemia[4].

The National Blood Authority has released Patient Blood Management Guidelines to inform transfusion practice. Module 3 — Medical guidelines[5] has specific recommendations for chemotherapy and HSCT patients. Furthermore, the second edition of *Guidelines for the Administration of Blood Products* were released in 2011 by the Australian and New Zealand Society of Blood Transfusion Ltd and the Royal College of Nursing[6]. Haematology and oncology nurses will recognise aspects of PBM within routine patient care. This article reviews the Australian guidelines and standards that relate to blood transfusion for patients undergoing chemotherapy and HSCT.

Why shouldn't you transfuse

In the last 10 years there have been changes to the funding and organisation of blood in Australia with the establishment of the National Blood Authority. Funding for blood is borne by commonwealth and state and territory governments. In 2010–11 over $900 million was spent to manage the blood supply on behalf of all Australians by the National Blood Authority[7]. Patient blood management optimises the use of donated blood which can be in short supply at times, with the added benefit of containing costs associated with collecting, processing and administration of blood components. The clinical aim is to reduce transfusion-associated risk. The risk of transfusion-transmitted infection has reduced significantly with testing, processing measures, and the effectiveness of blood donor education and selection processes[8]. "Australia has one of the safest blood supplies in the world in terms of viral safety"[9]. However, there is a potential for new viruses and infectious agents to emerge.

Transfusion can have untoward effects. Blood components are biological products; blood cells are living human tissue. Transfusion of blood cells can cause recipient immune responses that can lead to development of antibodies[10]. These can make further cross-matching difficult and mean supply of matched blood components may take longer. Transfusion-related acute lung injury (TRALI) also involves an immune-mediated response

between donor and recipient that can result in acute respiratory distress. Transfusion-associated circulatory overload occurs when the recipient has a problem dealing with the volume of the transfused component. Clinical error can lead to a patient receiving the wrong component, which can have fatal consequences, with at least five deaths in Australia since 2002. For long-term transfusion-dependent patients, iron overload with iron deposition in organs can be a long-term complication of repeated red cell transfusions.

Platelet recipients are at risk of developing Human Leucocyte Antigens (HLA) antibodies[11]. These are part of the protective mechanism of our immune system. The immune system uses HLA to distinguish between "self" and foreign antigens that may enter the body. The immune cells look for foreign HLA types and make antibodies to destroy the cells which show these foreign HLA types. Platelets express a lot of HLA. The more platelet transfusions a patient receives, the more exposure to foreign HLA they have and thus increased risk of developing HLA antibodies. If a patient has HLA antibodies, transfused platelets are destroyed instead of increasing the recipient's platelet count. If the patient is refractory to platelets they require platelets that are HLA-compatible. Once immune refractoriness is confirmed, HLA matched platelet support is needed for all subsequent transfusion. Finding compatible donors may be difficult. Only 1 in 30 Australians donate blood. From the small donor pool there could be a very limited number of donors in all of Australia who are suitable. HLA-compatible blood may be collected interstate and shipped specifically for the recipient. The recipient's clinical response is assessed by comparing platelet counts before and after the transfusion to determine the best donors for them. Transfusion nurse consultants are employed by the blood service to liaise with the hospitals about individual patient requirements.

Why do patients need transfusion support?

Haematology patients experience dysfunction of their bone marrow as a result of their underlying diagnosis, and also as a result of chemotherapy-induced suppression of haematopoisesis. Anaemia can also be caused by pre-existing iron deficiency. Chemotherapy drugs interrupt cellular metabolism or division. Bone marrow contains fast dividing haematopoietic cells so patients receiving chemotherapy can develop thrombocytopenia, myelosuppression and anaemia (low platelet counts, white count and low red cells). Chemotherapy is given in cycles or as an induction and consolidation protocol. Therefore, patients' blood counts recover and they are then retreated and will require blood component support again. The average lifespan of a platelet is 8–12 days so are quite sensitive to chemotherapy. Red cells have a longer life span but are affected by the cycles of chemotherapy. While all blood cell lines can be affected, this article will focus on the acute support of anaemia and thrombocytopenia. White cell transfusions are a not a routine part of care.

Red cells carry haemoglobin, an iron-containing protein. Oxygen moves into the red blood cell and binds to haemoglobin, which allows oxygen to be transported around the body to enable metabolism to occur. When a patient is anaemic they are less energetic and more fatigued. A lower level haemoglobin is aimed for in chemotherapy and HSCT patients, with transfusions above 100 g/L likely to be unnecessary. Patients can tolerate the lower level as they are not engaging in vigorous exercise or activities; however, additional support may be required if they have a chest infection.

Red cell transfusions for chemotherapy and HSCT recipients need to be based on clinical signs and symptoms as well as haemoglobin levels. A single unit may be sufficient to provide symptomatic relief. A pack of red cells will raise the haemoglobin level by 10 g/L in an adult. After one unit the patient should be reassessed to determine if further transfusion is required. Blood loss should be minimised and this may include considering iatrogenic blood loss through sampling. If 30–40 ml of blood is taken from a patient each day in the course of two weeks, over 500 ml of blood could be lost to sampling. Routine care includes observation for minor bleeding as well as educating patients to report any blood loss. Minor bleeding should be treated promptly. Major bleeding may require intensive medical support.

Thrombocytopenia

Platelets are normally disc-shaped. When body tissue is damaged they become activated, change shape, become sticky and clump together. The activated platelets join together to form plugs to stop bleeding and clotting factors interact to form fibrin strands that bind together to form a clot. A normal platelet count is between 150 and 400 $x10^9$/L. The risk for a patient with a low platelet count is that they may have a life-threatening haemorrhage by bleeding that cannot be stopped, or a cerebral bleed with subsequent morbidity.

Platelet transfusions are used therapeutically for the treatment of haemorrhage. They are also used preventatively for chemotherapy and HSCT patients with counts <10 $x10^9$/L who are not actively bleeding as at this level they can bleed very easily with only a very minor trauma. For patients who are febrile, have minor bleeding or at risk of bleeding the platelet count threshold of 20 $x10^9$/L is recommended[12]

Petechiae looks like a fine, red rash but are micro bleeds under the skin (hickeys/love bites are a version of these) and is symptomatic of a low platelet count. The thrombocytopenic patient can develop petechiae on their shins just from the pressure of walking or on their arm from where they have had their blood pressure taken. A thrombocytopenic patient can have bruising anywhere on their body. Petechiael bruising is not life-threatening but it is a very visual reminder that such bleeding can also be occurring unseen within the tissues that could be significant.

Patients need to be regularly observed for signs of bleeding and bruising, including a skin assessment for bruising or petechiae; an oral assessment and urinalysis can detect any occult haematuria. As part of their daily care, thrombocytopenic patients need to minimise the possibility of bleeding or impairing their platelet function. This means avoiding oral trauma by careful use of toothbrushes to not traumatise gums or not brushing the teeth at all. Dental floss is avoided as it leads to gum trauma and bleeding. Skin care includes avoidance of shaving with a wet razor to prevent accidental skin nicks and scratching of any skin irritations. Daily activities need to be considered so that accidental trauma is prevented. Intramuscular injections should be avoided. Venous catheters are used for blood taking to avoid frequent venepunctures. Platelet transfusion may be required prior to some invasive procedures because of the risk of bleeding.

Pharmacological interventions to reduce bleeding may include suppression of menstruation for female patients, not using aspirin or ibuprofen as they impair platelet function and the use of protein pump inhibitors to minimise gastrointestinal irritation.

Administering red cell and platelet components

The Blood Service produces pooled and apheresis platelets components. Four donors are pooled to make an adult dose. Apheresis platelets are derived from one donor for an adult dose[4]. For paediatric patients an apheresis platelet component is divided into four to make smaller packs. In Australia all platelets are leucocyte-depleted by the Blood Service so further leucocyte filters are not required[4]. However, a standard blood administration set that incorporates a 170–200 micron filter to remove debris that may have accumulated during storage is required[6]. A new blood line is preferred primed with normal saline. An existing line may have medications or IV fluids that are incompatible with the blood component or the anticoagulant in the pack.

Platelets are usually given over 15–30 minutes. Each bag of red cells or platelets has the volume of the specific component printed on the label[4]. One unit of red cells contains the separated red cells form one whole blood donation. Red cells can be given in an emergency as quickly as the giving set and patient can tolerate. In non-urgent situations, they are usually given over two hours.

While the use of blood and blood products can be lifesaving, there are also risks associated with their administration. The final bedside check is a vital step to ensure the right person receives the right product[13]. Prior to the administration of any blood component, it is the responsibility of the person hanging the blood component to ensure it is appropriate to undertake the transfusion at this time. Flushing lines after a transfusion with a small volume of normal saline ensures the patient receives the entire component they required but also needs to take into account the patient's fluid status. Further information on administration of blood components can be found in *Flippin Blood*[13], Australian and New Zealand Society of Blood Transfusion Ltd and Royal College of Nursing 2011 *Guidelines for the Administration of Blood Products*[6] and *Blood Component Information. Circular of Information. An extension of Blood component labels*, 2012[4].

Special requirements

Chemotherapy and HSCT recipients may require further modifications and considerations to the type of blood components they are to receive. Blood components represent a snapshot of the donors' blood collected at that time and may contain donor lymphocytes. Leucodepletion removes most white cells. However, a small number of lymphocytes could remain, which can engraft into the recipient. The engraftment of donor lymphocytes can cause an almost universally fatal disease called transfusion-associated graft-versus-host disease (TA-GVHD) in some recipients[13]. Irradiation of cellular blood components inactivates donor lymphocytes, which can reproduce and grow in the recipient[4]. The risk of developing TA-GVHD depends on the number and the viability of lymphocytes in a pack, susceptibility of the recipient's immune system and degree of immunological difference or similarity between recipient and donor. The ANZSBT *Guidelines for Prevention of Transfusion-Associated Graft-Versus-Host Disease* (TA-GVHD)[14] provides the indications for all patients who require irradiated products. Patients with weakened immune systems such as HSCT recipients and some chemotherapy recipients are at risk of developing TA-GVHD. Materials to inform patients about irradiated blood products have been developed by the Queensland Blood management Program[15].

Cytomegalovirus (CMV) is a common virus typically carried by leucocytes. CMV infection may lead to severe or fatal disease in immunosuppressed patients such as those undergoing chemotherapy or HSCT recipients[16]. The Blood Service provides some CMV-negative blood components. CMV-negative blood components should be considered for use in immunosuppressed patients. The need maybe dependent on the patient's CMV status (evidence of their past infection or not). In Australia the Blood Service leucodepletes all red cells and platelets. Leucodepletion reduces both the white cell content and any CMV present but it does not eliminate the risk of CMV transmission. There is variability between clinicians as to whether leucodepleted components are acceptable if CMV-sero-negative components are unavailable.

Which patients should receive CMV-negative blood is currently being debated in Australia following the release of the UK Department of Health's Advisory Committee on the Safety of Blood, Tissues and Organs position statement and report about CMV tested blood components.

Patients

Within the last two years there have been significant changes to the governance, guidelines and standards in regard to blood and blood products in Australia.

In November 2010 the *Stewardship Statement: The Australian Health Ministers' Conference Statement on National Stewardship Expectations for the Supply of Blood and Blood Products*[17] was endorsed by Australian health ministers. The statement outlines the expectation for the responsible, sustainable and appropriate use of blood and blood products and how to minimise wastage. Hospitals, doctors, laboratories and other health providers serve a vital role in ensuring that blood reaches patients in need and are used in a clinically appropriate manner in accordance with relevant professional guidelines and standards. The other key outline of the stewardship document is that informed patient consent procedures are implemented for all patients.

In September 2012 the Australian Commission on Safety and Quality in Healthcare released 10 standards that all health service organisations are required to address. The standards aim to improve the quality of care provided by health services and provide a nationally consistent statement of the level of care consumers should be able to expect from health services. Standard seven[18] addresses blood and blood products, with the intention of ensuring patients receive blood and blood products appropriately and safely. Standard seven aims to ensure that patients (and carers) are engaged in the decisions about their management and that they are informed about the risks and benefits of using blood, and alternatives that are suitable for them when a plan for treatment is developed. Where consent is documented varies according to the health care institution's policy but it is required to be present.

PBM places the patient at the centre of transfusion decision making. The stewardship and governance standards reinforce that patients need to be informed and consent obtained for administration of blood. Blood components are biological products and blood cells are living human tissue intended for use in the treatment of patients. Materials to support patients have been developed by the Blood Service (www.mytransfusion.com.au) and by the state-based quality improvement program for blood. These include *Have all your questions been answered?*: available in English, Dinka, Serbian and Macedonian languages from Blood Matters[19]. New South Wales Health Blood Watch program has produced *Blood transfusion: Answers to some common questions for you and your family*[20] which is available in multiple languages.

Without blood component support chemotherapy and HSCT patients could not be properly treated. In the last two years significant change has occurred in the standards, guidelines and governance of blood and blood components in Australia. The paradigm in transfusion medicine has also moved from transfusion thresholds triggers to PBM principles. Nursing care of chemotherapy and HSCT patients has incorporated many of these aspects as part of the routine care for patients. The standards, guidelines and governance structures reinforces the ongoing nursing role of patient-focused care.

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Survivorship care — time for innovation?

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Abstract

Effective cancer treatment is continuing to improve survival for people diagnosed with cancers in recent years. The latest data on cancer survival has seen the cancer survival rate increase from 47% to 66% in just 20 years[1]. Cancer is increasingly being viewed as chronic illness and people with cancer are increasingly expected to take at least some responsibility for managing their own care[2]. Cancer nurses have to engage in cancer survival work in addition to cancer treatment work. This has demanded change and has led to cancer nurses having to change the way in which they work. Implementing survivorship care strategies into patient management has become a key component of cancer nursing. There is an increasing body of literature and a number of guidelines aiming to optimise and advise how to care for cancer survivors into the future in an attempt to improve the longer term outcomes for cancer patients.

This paper will provide an overview of current accepted definitions of survivorship and its relevance to Australian population. It will discuss survivorship strategy recommendations and their limitations and present an innovative model of nurse-led survivorship care in the care of patients post allogeneic bone marrow transplant (aBMT).

Keywords: Survivorship, model of care, survivorship recommendations, nurse practitioners.

The meaning of survivorship

There is a lack of consensus in the survivorship literature as to who is a cancer survivor and when they become one. Survivor definitions that require completion of treatment and an absence of symptoms clearly do not work for many individuals. Over time the definition of cancer survivor has shifted. It was once a common (mis) conception that to be called a cancer survivor you were required to accumulate five years of disease-free time[3]. Patients often felt in limbo: they could not get on with their lives nor make major decisions or changes until they had reached that milestone. The Western and Central Integrated Cancer Service (WCMICS)[3] in Melbourne, Australia, has included a priority area addressing survivorship issues as part of the strategic plan. Their vision is that survivorship care begins with completion of active treatment and includes "living with or beyond cancer"[4].

The 2005 seminal report by the Institute of Medicine (IOM) *From Cancer Patient to Cancer Survivor: Lost in Transition*[5] represents an effort on the part of the American Society of Clinical Oncology (ASCO), the National Coalition for Cancer Survivorship (NCCS), and the Institute of Medicine (IOM) to disseminate the findings and recommendations from a symposium in which over 100 stakeholders in the cancer community — survivors, advocates, health care providers, government officials and researchers — participated. This report considers that survivorship begins from diagnosis and continues throughout the lifespan[5]. The National Coalition for Cancer Survivorship (NCCS)[5], based in Washington DC, USA, has gone a step further and includes caregivers, friends and family in their definition of a cancer survivor "from the time of diagnosis and for the balance of life"[6]. This report is in parallel with the Victorian Cancer Action Plan (VCAP), and as such, prioritises supporting and empowering patients and their carers throughout their cancer journey[4].

Disenfranchised caregivers

The addition of caregivers, friends and family to the definition of survivor is timely and in keeping with the increasing work directed towards impact on lay caregivers. It is impossible to

dispute and is highlighted in studies that caregivers can feel exhausted and overburdened, leading to increased levels of depression and anxiety due to the multitude of physical and emotional responsibilities faced from diagnosis[7]. With the exponential increase in cancer survivors it can only be anticipated that dependence on caregivers will persist throughout the continuum.

Wulff-Burchfield *et al*[8] undertook a systematic review examining the long-term follow-up of caregivers following allogeneic stem cell transplant. Key findings described the "chronic burden" and the stress on caregivers of allogeneic bone marrow transplant (aBMT) recipients and the risk of developing post-traumatic stress disorder. They also note the paucity of literature examining this and the general movement towards management in the outpatient environment[8]. This is relevant given the broadening transition of care into the community and a growing expectation that caregivers will be involved in motivating patients to perform activities that may decrease their risk of developing long-term effects associated with cancer and its treatment.

Relevance to the Australian population

The Australian Institute of Health and Welfare's (AIHW) report *Cancer in Australia*[1], highlights many key ideas relevant to our population. These include the fact that cancer survival rates are improving; however, overall it was the second most common cause of death in 2010 and accounted for approximately 30% of all deaths; cancers that had the largest survival gains were prostate, kidney and non-Hodgkin's lymphoma; survival rates are not consistent among all cancer types, socio-economic status, between metropolitan and rural settings and between Indigenous and non-Indigenous groups[1].

At this point in time Australia does not have a national cancer action plan[3]. Different cancer councils have identified strategies. The Victorian groups have identified strategic priorities in survivorship care and are working on developing policy and models of care. The Victorian Cancer Survivorship Program (VCSP) has funded six projects from a variety of tumour streams addressing innovative models of survivorship care, risk assessment and streamlining care as well as measures to empower and educate patients in self-management[3]. In addition, NSW has a cancer plan[9] with a priority area to increase survival with cancer; however, the focus is on screening and early detection to improve cancer survival rates.

Other states and territories in Australia have survivorship support services for their community, many through their local cancer councils and disease specific support services. The Australian Cancer Survivorship Centre (ACSC) maintains a list of these services as well as information on national and international projects on survivorship care[10].

Factors affecting health, wellbeing and survivorship

Ganz[11] has suggested that, in addition to symptom management (palliation), prevention and health promotion in cancer survival are key components of any cancer survival plan.

> *The cancer may be gone, but patients still can suffer from pain, fatigue or depression, for which palliative care approaches become central. Prevention of the late effects means monitoring and preventing common late effects such as osteoporosis, screening for second cancers. Health promotion is often overlooked because everyone is concentrating on monitoring for cancer recurrence, when in fact many adults are at risk for and will die from cardiovascular disease, stroke or diabetes complications*[11 (p. 1)].

There are a number of complex and interrelated health issues that affect both the general population and cancer survivors.

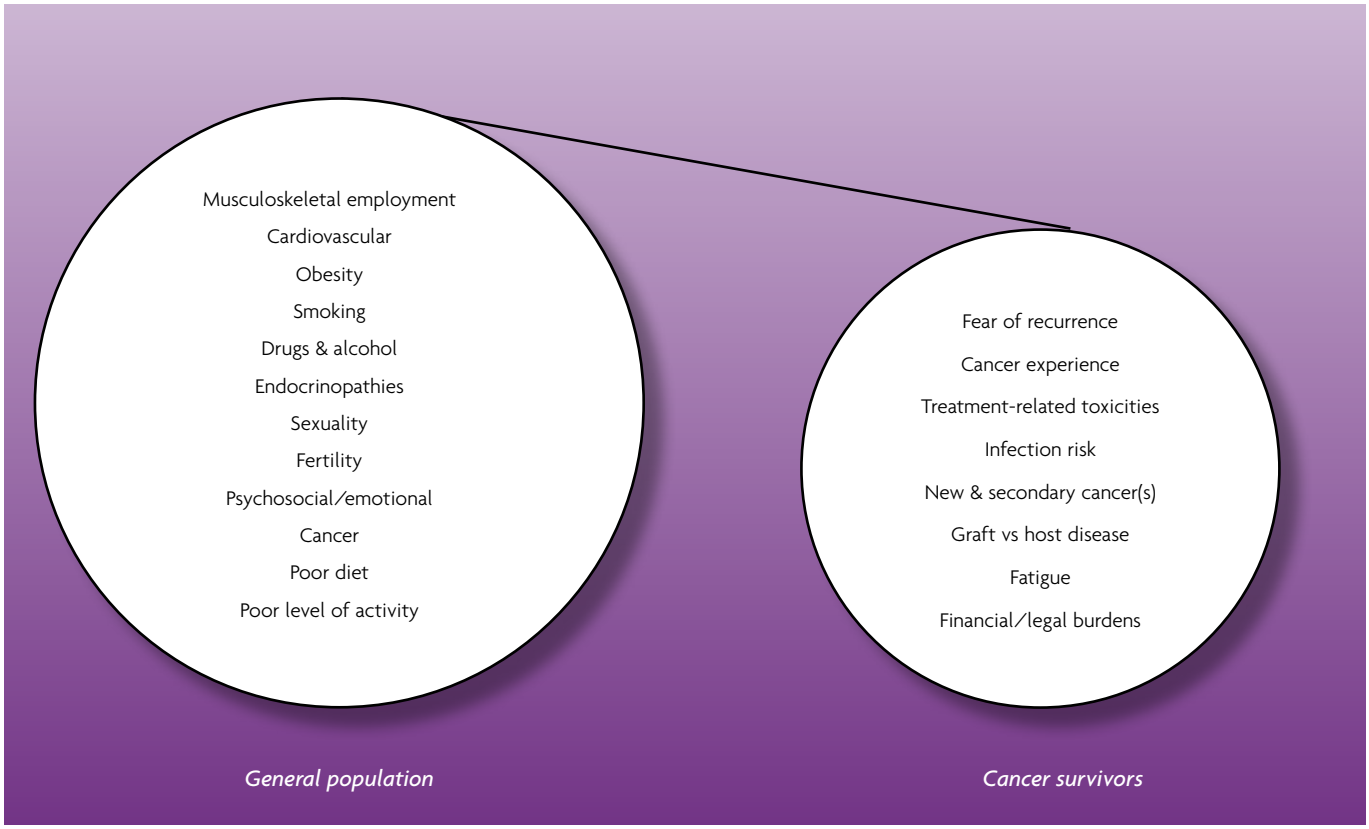
The compounding factor is that many of the challenges cancer survivors face are not unique to that population[11]. Cancer survivors frequently experience multiple health problems simultaneously, much earlier than the general population. Sometimes they occur regardless of best efforts to minimise the risk compounded by the emotional impact of cancer and its treatment.

Australian and international recommendations regarding survivorship care: the real and the ideal

Historically survivorship care focused on surveillance for disease recurrence[3]. More recently there has been a shift towards surveillance for and management of late effects, and education regarding prevention, early identification and self-management preventative strategies[11]. Early work on late effects surveillance and associated guidelines have come via the paediatric groups. This has occurred as a result of the knowledge that up to 74% of survivors of childhood cancers develop chronic health issues[12].

Although there have been improvements there continues to be little evidence supporting late effects surveillance and most recommendations are based on expert opinion rather than evidence[13,14].

Figure 1. Complex & interrelated health issues



The 2006 seminal report by the Institute of Medicine (IOM), *From Cancer Patient to Cancer Survivor: Lost in Transition*[5] presents a series of four essential components of survivorship care and 10 recommendations aimed at cancer survivors, caregivers, health professionals and a number of other groups. The recommendations relate to raising awareness of the needs of cancer survivors including care delivery; development and implementation of treatment summaries (TSs); survivorship care plans (SCPs); the development and implementation of evidence-based surveillance guidelines in survivorship care; and the development of methods to measure the effectiveness of survivorship care as a strategy to improve survivorship. A number of recommendations addressing the need for additional financial resources to service survivorship care initiatives and research have been identified as important in this report.

The publication of this report stimulated enormous debate and provided a platform for the addition of survivorship care to the cancer experience. Recent publications have described the challenges to providing survivorship care and in the provision of TSs and SCPs according to IOM recommendations[14,15,16,17,18].

In order to evaluate the content and use of SCPs against IOM recommendations, Salz *et al.*[15] surveyed all National Cancer Institute USA cancer centres on the use of SCPs for breast and colorectal cancer survivors. In summary, the findings suggested that only 43% of the designated centres deliver SCPs and none of the centres applied all IOM recommended elements of SCPs.

Stricker *et al.*[16] evaluated the use of TSs and SCPs using IOM recommendations at LIVESTRONG™ network of survivorship centres. The group evaluated TSs and SCPs delivered to survivors of breast cancer. Results were similar to those of the Salz *et al* study[15] with recommendations being met 46% of the time for TSs and 59% of the time for SCPs.

Both studies recognise the limitations of their results including: only examining specific tumour group SCPs; and that delivery may vary with other cancer survivor groups; and that application of TSs and SCPs delivery may differ according to level of resource allocation per institution[15,16].

Earle and Ganz[14] suggest that SCP recommendations are more likely to be adhered to if kept uncomplicated. The ACSC provide a succinct series of recommended SCP inclusions based on IOM recommendations[10].

In 2011 LIVESTRONG™ organised and hosted a meeting of experts to discuss the essential elements of survivorship care[14]. The working group suggested a three-tier system of survivorship care with the first tier representing consensus elements that are recommended goals for minimum standard. It includes

surveillance, screening, care coordination between referrers and GPs, education and health promotion and symptom management and palliative care[14].

Tier two constitutes high-need elements that should be included in survivorship care including late effects education, psychosocial assessment and education about survivorship and programs, and tier three contains elements to strive for[19].

Creating a model of cancer survivorship follow-up

Traditional models have primarily been applied within the treating institution or by referral to another institution that has a dedicated, long-term, follow-up service. The sustainability of this model has been questioned given the increasing numbers of cancer survivors.

Brennan and Jefford[20] have suggested that alternative models of survivorship care must be developed to manage changing landscape related to workforce and increasing numbers of cancer survivors. Given the commonality of some health issues affecting the general community and cancer survivors there may be a place for using general medicine guidelines for management of cancer-related late effects such as cardiovascular disease, bone health, decreased functional ability and poor nutrition[14].

In a study by Greenfield *et al*[13], cancer experts (medical and nursing) together with GPs, were surveyed and asked their opinion about follow up care for younger adult cancer survivors. The study focused on a number of domains. Sixty-nine per cent of cancer expert respondents agreed that GP survivorship follow-up would enable them to focus on acute cancer care, whereas GP respondents viewed maintaining existing relationships with patients as an advantageous aspect of survivorship care. In addition, both groups identified financial advantages. Most impressively, 91% of respondents believed that specialist nursing support was the crucial resource in survivorship care, followed by finance allocation and long-term follow-up guidelines[13].

A systematic review of the literature by Lewis *et al*[21] examining effectiveness and cost-effectiveness of nurse-led versus conventional physician-led follow-up for patients with cancer found patients to be satisfied with nurse-led follow-up. In particular, a lung cancer group was more satisfied with nurse-led telephone follow-up while a breast cancer group found nurse-led care convenient but also wanted regular hospital review. This systematic review also identified the decreased cost associated with nurse-led care but acknowledged that a statistical analysis was not performed on this factor[21].

Gates and Krishnasamy[22] highlight parallels between the philosophy of nurse-led care with recommendations from the IOM report *From Cancer Patient to Cancer Survivor — Lost in Transition*[5], including evidence-based practice, patient-centred outcomes and the importance of caregivers in survivorship care. Presenting a successful model of nurse-led survivorship care that incorporates supportive care needs screening, education focusing on self-management, early detection and prevention, and optimising survivor functionality.

Both community-based and nurse-led models of survivorship care are practical and achievable and warrant further investigation[13,21]. However, issues to be considered include: adequate funding of survivorship consultations that are typically a minimum of one hour in duration excluding preparation, collation and dissemination of results, and documentation of letters and SCPs. The broadening of access to include telehealth and videoconferencing for nurses in survivorship care allows improved care for rural and remote cancer survivors. Strategies to improve communication between community-based providers and specialists such as a centralised health information systems have been highlighted as important in survivorship models. Provision of education and support to community-based providers together with processes for re-referral to cancer specialists in the event of disease recurrence are also important aspects of care[3,13,14]. This further emphasises the urgent need for additional allocation of resources to delivery of survivorship care and the timely development of an innovative survivorship workforce.

Innovative nurse-led models of survivorship care

An increasing number of patients are surviving long-term post-treatment for haematological malignancies and bone marrow transplantation (BMT). This is due to significant improvements in early acute supportive care. With long-term survival, many patients are living with chronic illness and some experiencing late effects associated with the toxicity of prior treatment both pre-, during and post-transplant[23]. The assessment and management of patients within a dedicated late effects clinic (LEC) is well established internationally and the increasing need is being recognised in Australia[24].

In 2009 the Peter MacCallum Cancer Centre (Peter Mac) in Melbourne, Australia, developed and implemented a nurse practitioner (NP) position to manage the growing population of survivors post-aBMT. The role was filled initially by an NP candidate who went on to achieve NP endorsement. It was developed to function autonomously and collaboratively in dedicated allograft clinics to manage mid- to long-term (including late effects) issues post-aBMT. In addition, the scope includes patient and caregiver education, preventative health care initiatives, liaison with GP, specialist and community health care providers and health care professional education.

This model has been developed to address the long-term care requirements of patients attending Peter Mac following aBMT at the Royal Melbourne Hospital (RMH). The NP is employed by Peter Mac but works collaboratively with the transplant service at the RMH to ensure patients receive streamlined, integrative care irrespective of the stage of their illness and treatment.

This innovative model was developed with the vision of the Victorian Comprehensive Cancer Centre (VCCC), which is a fit-for-purpose, world-class, patient-centred cancer service delivering best possible patient outcomes (due for completion in 2015).

The focus of the NP service is on early identification and evidence-based management of post-transplant issues and patient-reported needs including referral to multidisciplinary services with improved access to psycho-oncology, pain services, dermatology, respiratory, gynaecology and rehabilitation services.

The NP works collaboratively within a multidisciplinary team but also autonomously with a defined cohort of patients, within a clearly defined scope of practice. Patients are educated regarding the model of care at referral and informed of the scope of NP practice. The aBMT service at Peter Mac aims for patient care to move fluidly between all health care providers depending on complexity of care needs.

Diagram of innovative, collaborative model of aBMT survivorship care

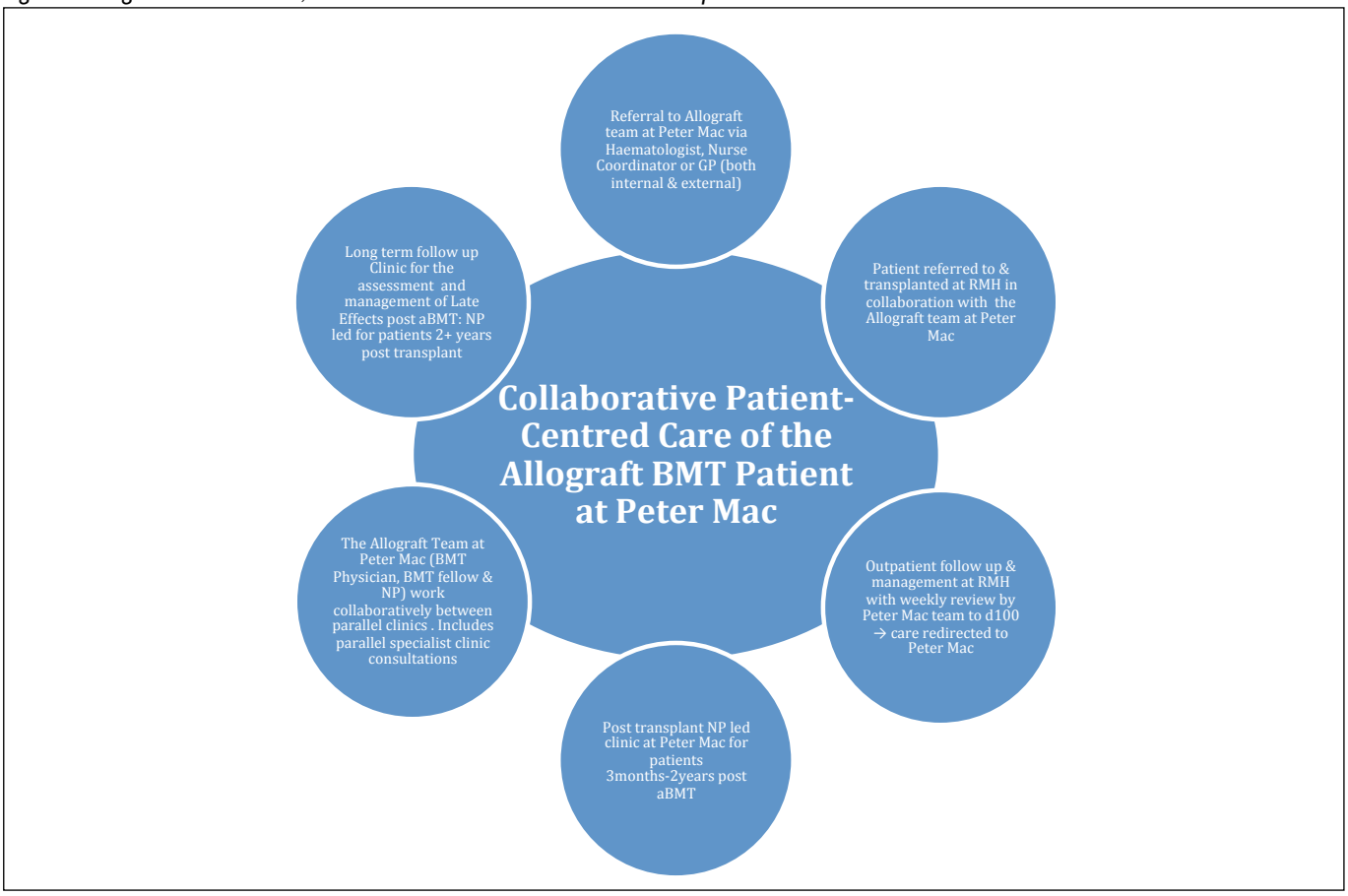
This innovative model of care has been operational for four years with an exponential growth in patient numbers. The service model is due for formal evaluation; however, in this time has become part of standard care within Peter Mac.

Where to from here?

Despite the need for more evidence examining the impact of survivorship care and recommendations, the quantity and quality of discourse and general consensus on the importance of survivorship care must act as a driver for implementing models that are patient-centred, user-friendly, cost-effective and applicable to the setting in which delivery is taking place.

A way of beginning conversations about survivorship care is at the point of discharge education and within the ambulatory follow-up environment. Cancer nurses, despite already providing survivorship care and recommendations as part of discharge planning, may be better placed if provided with focused

Figure 2. Diagram of innovative, collaborative model of aBMT survivorship care.



education regarding strategies. In addition, community-based providers require more education about survivorship care[14]. Grant *et al*[25] have suggested a model of survivorship curriculum for a multidisciplinary audience. The course included a diverse range of topics including specific survivorship issues, typical late effects and psychological, social and spiritual issues just to identify a snapshot. Data were collected at specific time-points and evaluated against seven care domains. The participants were able to demonstrate changes to survivorship care within their health care environments following course completion.

A number of authors identify the need for better patient and caregiver education to enhance empowerment and arm patients and caregivers with the knowledge and skills to ask for specific resources, implement risk-reducing strategies and self-surveillance, and to voice preference in regard to survivorship care planning, including place of implementation[3,14].

Summary

Cancer nurses are intrinsically wired to embrace and implement survivorship strategies as part of long-term cancer care. They are also perfectly positioned in various roles along the continuum to integrate education and recommendations, either as part of a formal survivorship program or as part of standard care.

There are a variety of options available and strategies to implementing survivorship care. Well-resourced, purpose-built institutions and philanthropically funded programs may appear optimally placed to provide survivorship care but is this what cancer survivors and caregivers prefer? Is this practical for cancer survivors living in rural and remote areas?

The way into the future of cancer survivorship care in Australia starts with using the experience of our international colleagues. We then need to ask patients and caregivers what they want as part of survivorship care and transpose this accordingly onto the background of resource availability and workforce issues applicable in our climate. The next step is to develop education programs for hospital- and community-based health care providers and broaden implementation of innovative models of care and then evaluate it in the Australian context.

Not easy by any measure but possible!

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Second primary cancers: A focus on Australian survivors of haematological cancers

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Abstract

An increasing number of Australians are now living as cancer survivors[1]. Survivors of haematological cancer are recognised to be at increased risk of developing a second primary cancer[2]. A second primary cancer may present as a solid cancer or a haematological cancer. Second primary haematological cancer may occur as a therapy-related myeloid cancer or a post-transplant lymphoproliferative disorder.

Nurses can engage with cancer survivors to educate and provide resources that will assist them to reduce avoidable risk factors and maintain a healthy lifestyle. Australia has national screening programs and healthy lifestyle recommendations for the general population. Behavioural changes, early detection and secondary cancer prevention are associated with improved cancer survival and may assist to identify and manage late effects[3,4]. Educating and empowering cancer survivors to participate in healthy lifestyle behaviours and engage with population screening programs may assist to optimise long-term health for cancer survivors.

Introduction

Cancer remains a leading cause of death in Australia; however, more than 60% of cancer patients are now expected to survive more than five years after a diagnosis[1]. As technological and medical advances lead to early detection and increased treatment success, more individuals will be living their lives as a cancer survivor.

Haematological cancers represent approximately 8% of the tumours reported in Australia and are associated with almost twice the risk for developing a second primary cancer when compared to the general population[2]. A haematological cancer can present as a second primary cancer, which may or may not be associated with treatment received for the initial primary cancer. Cancer survivors treated for a haematological cancer initially are also at increased risk of developing a second primary cancer. As such, haematological cancers can be a result of treatment, as well as an indication for treatment.

A number of risk factors for developing a second primary cancer are avoidable and Australia has national screening programs for the general population that could be incorporated when educating survivors, designing survivorship programs and implementing survivorship practices. It is essential to offer cancer survivors optimal long-term supportive care, by increasing awareness and information, aiming to optimise the future health of cancer survivors.

This paper reviews the incidence of second cancers with a focus on the Australian population. Haematological cancers associated with an increased risk of second primary cancers will be explored, as well as those haematological cancers that present as a second primary cancer. The preventative risk factors and Australian screening programs will be explored along with the key roles that nurses have in providing advice and referral to supportive services.

What are second primary cancers?

The International Association of Cancer Registries defines multiple primary cancers as those where each cancer originates in a separate primary site and is neither an extension, recurrence nor metastasis[5]. Multiple primary cancers can be considered to include both those diagnosed at the same time as the primary cancer (two separate primary cancers diagnosed within a short time frame) and those diagnosed at least two months following the initial primary diagnosis (including cancers that may have developed as a result of treatment received for the initial primary)[6].

A second primary cancer may be diagnosed as a result of investigations for an initial primary cancer. An example of this could be identifying a breast lesion on a computed tomography (CT) scan which was ordered for staging of a newly diagnosed lymphoma. The CT scan may reveal a lesion in the breast, which is then investigated and determined to be a breast cancer. This means the patient has had two primary cancers diagnosed within a short time frame. This can then lead to difficulty surrounding

which treatment regimen choice and timing to initiate, in order to control both primary cancers with maximum benefit at minimal toxicity. For the patient, it is perceivable that the fear and uncertainty associated with a diagnosis of cancer could be further compounded by a second diagnosis.

Treatment-related outcomes, including second cancers, are now incorporated in the National Cancer Institute definition of survivorship[7]. There is an increasing body of evidence exploring the late effects of cancer and treatments. As follow-up period post-treatment increases, there is increasing exploration of post-treatment effects, including the incidence of second primary cancers. This increases exploration of risk factors, aiming to minimise where possible, and ensure appropriate screening and preventative practices are initiated.

What is the incidence of second primary cancers?

Cancer survivors are recognised as being at an increased risk of developing a second primary cancer when compared to the general population, reported as having a 14% increased risk of developing a second cancer[8,9]. In the United States, one in six cancers diagnosed is a second primary cancer, highlighting the need for both patients and health care professionals to be vigilant for screening and early detection[10].

Australian studies have also reflected an increased risk for development of a second primary cancer. A study of the Victorian Cancer Registry by Karahilios *et al.* revealed that 10 years post-diagnosis of a primary cancer, the cumulative risk for development of a second primary cancer was identified as 1 in 10 for men, and 1 in 13 for women[11]. Youlden and Baade analysis of data from the Queensland Cancer Registry also revealed a significantly greater incidence for cancer survivors to be diagnosed with a second primary cancer when compared to the general population[12].

The risk of developing a second primary cancer for childhood cancer survivors is greater than six times higher than for the general population[13]. However, the occurrence of second primary cancers is greatest for patients who were diagnosed with their initial primary cancer between 50 and 69 years of age[9]. This highlights the need for health promotion and vigilance with cancer screening programs to be adopted by all cancer survivors, irrespective of age at diagnosis.

Initial haematological cancers and subsequent second primary cancers

Where a person has a haematological cancer diagnosed initially, they may subsequently develop a second primary cancer, which may or may not be of haematological origin. Royle *et al.* reported Australian survivors with an initial diagnosis of a haematological cancer are nearly twice as likely to develop a second primary cancer[2]. A study of survivors of childhood cancer in New South Wales revealed second cancers were most common after an initial primary diagnosis of leukaemia, Hodgkin's lymphoma or sarcoma[14].

The long-term follow-up of haematopoietic cell (HPC) transplant recipients has enabled researchers to evaluate long-term outcomes, including second primary cancers. In this population, Majhail *et al.* investigated the incidence of second solid cancers for HPC transplant recipients who received busulfan and cyclophosphamide as conditioning chemotherapy pre-transplant. It was found when compared to expected rates these recipients had a 1.4 times greater rate for the development of invasive solid cancers[15]. This risk was demonstrated to increase as the time post-transplant increased, with transplant recipients three times as likely to develop a solid cancer at 15 years post-transplantation, with a latency period in the initial 3–5 years post-transplant[16,17]. Risk factors for developing a solid cancer post-HPC transplant includes younger age, use of total body irradiation and experiencing chronic graft-versus-host disease[17]. Further, the most common solid cancer diagnosed post-transplant was lung cancer[15]. A strong smoking history was recognised to be evident pre-transplant for the majority of those diagnosed with lung cancer.

The effects of autologous transplantation on development of second primary cancers have also been explored. Forrest *et al.* compared treatments received and the risk for development of a second cancer for patients treated for Hodgkin's lymphoma[18]. An increased but similar level of risk for both treatment groups (conventional and high-dose therapy with subsequent autologous HPC transplantation) was reported, implicating autologous HPC transplantation is not a risk factor for second primary malignancy development when compared to conventional therapy.

There is a lack of evidence to investigate the prevalence of second primary cancer for people with multiple myeloma[19]. For patients undergoing treatment for multiple myeloma, Palumbo *et al.* found second primary solid cancers to be consistent amongst those receiving lenalidomide and those not; however, the incidence of second haematological primary cancers was increased for patients receiving lenalidomide maintenance[20]. During an investigation of lenalidomide administration during induction treatment for multiple myeloma, Ormerod *et al.* did not find patients receiving immunomodulatory therapy to be at an increased risk of second primary cancers[21]. Thomas *et al.* highlight that despite the risk of second primary cancers, multiple myeloma is generally incurable, with the risk of death greater than that of developing a second primary cancer[19].

The potential association between lenalidomide maintenance therapy and increased risk of second primary malignancy should be explored with patients prior to commencing lenalidomide and requires further investigation, with the potential risks and benefits of treatment requiring careful consideration for both patient and clinician.

Survivors of an initial haematological cancer:

- Almost twice as likely to develop second primary cancer.
- Transplant survivors who received busulfan and cyclophosphamide in pre-transplant conditioning regimen have approximately a threefold risk of developing a solid cancer at 15 years post-transplant.
- Risk factors for developing a second primary solid cancer post-transplant include: younger age, total body irradiation conditioning, experiencing graft-versus-host disease.

Haematological cancers occurring as a second primary cancer

Haematological cancers can be diagnosed as a second primary cancer, which may or may not be related to previous therapy received to treat the primary cancer. As the follow-up period of survivors of cancers increases, the availability of data and exploration of second primary cancers increases. Haematological cancers can occur as a result of the primary treatment utilised to treat the initial cancer, or potentially be unrelated.

A potential late complication of cytotoxic administration is the development of therapy-related myeloid cancer, including acute myeloid leukaemia and myelodysplastic syndrome[22]. Alkylating agents are recognised to have an effect on inducing therapy-related myeloid cancer[23]. Whilst alkylating agents and topoisomerase II inhibitors are associated with an increased risk for development of a therapy-related myeloid cancer, antimetabolites have also been implicated[23]. Many treatments utilised to treat an initial primary cancer may be associated with an increased risk of developing a second primary cancer. Whilst late effects, including second primary cancers, may be taken into account when discussing treatment choices and making treatment decisions, the initial focus is on achieving remission.

Radiotherapy-related malignancy has been investigated in several primary cancers[10]. The use of radiotherapy to treat non-Hodgkin's lymphoma is recognised as a risk factor for developing acute leukaemia, bladder cancer, kidney cancer and mesothelioma[24]. Similarly, men treated with large-field radiotherapy for testicular cancer were also found to have an increased risk for developing leukaemia[24]. Radiation and chemotherapy given in combination is reported to increase the risk of developing secondary leukaemia[23].

Female survivors of breast cancer were found to be at increased risk of being diagnosed with acute myeloid leukaemia when compared to the general Australian and North American female populations[25,26]. Risk factors for development of acute myeloid leukaemia after breast cancer are not clear[26].

Therapy-related myeloid cancers are associated with poor prognosis, and are often more aggressive and less responsive to treatment[9,22,27]. Approximately 10% of acute myeloid leukaemias diagnosed are subsequent to treatment with chemotherapy and/or radiation for an initial primary cancer or autoimmune disease[28]. Therapy-related acute myeloid leukaemia is associated with abnormal cytogenetics and an increased prevalence of adverse-risk karyotypes[28]. More women are affected than men, which is attributed to the incidence of therapy-related acute myeloid leukaemia that develops after treatment for breast cancer. In order of prevalence, therapy-related acute myeloid leukaemia developed most commonly after an initial primary cancer diagnosis of breast, non-Hodgkin's lymphoma and Hodgkin's lymphoma[28]. The median latency of diagnosis of therapy-related acute myeloid leukaemia was four years, with younger age associated with shorter latency periods[28].

The incidence of secondary myelodysplastic syndrome and acute myeloid leukaemia post-autologous transplantation is reported as 5–15% at 2–5 years post-transplant[17]. This highlights the potential for haematological cancers to recur as a second primary haematological cancer. For example, a patient initially treated for a non-Hodgkin's lymphoma may later develop acute myeloid leukaemia. The incidence of therapy-related myeloid cancers post-allogeneic transplantation is extremely rare[17].

Post-transplant lymphoproliferative disorders can occur after solid organ or allogeneic HPC transplantation. Whilst this is reported to occur in less than 1% of allogeneic transplant recipients, this second primary malignancy can be an outcome of the transplant utilised aiming to treat the primary haematological disorder[29]. The use of T-cell depleted HPC sources and recipient age over 50 are associated with an increased risk of developing post-transplant lymphoproliferative disorders[30]. Administration of rituximab may be utilised in the treatment for post-transplant lymphoproliferative disorders[31]. Rituximab has also been implicated as a potential risk factor for developing a solid tumour post-treatment incorporating autologous HPC transplantation for lymphoma[10]. This highlights the difficulties faced when balancing benefits and risks of treatment choices.

Summary of haematological cancers occurring as a second primary cancer:

- May be related or unrelated to therapy received to treat the primary cancer.
- Therapy-related myeloid cancers are associated with poor prognosis.
- Administration of alkylating agents, topoisomerase II inhibitors and antimetabolites may increase risk of developing therapy-related myeloid cancer.
- Radiotherapy is recognised to be risk factor to developing cancer in radiotherapy-treated areas, including haematological cancers.

Optimising detection and knowledge of second cancers for Australian cancer survivors

One of the aims of the implementation and utilisation of survivorship care plans is to promote healthy lifestyles to prevent and reduce the risk of recurrence and comorbid conditions, and to assist early detection where possible[32]. With the exception of screening for breast cancer, Syrjala *et al.* recommend general population cancer screening methods for HPC transplant recipients[33]. Despite evidence that transplant recipients may partake in less high-risk behaviour, transplant recipients should be encouraged to adopt and maintain healthy lifestyle practices[33]. In a study of HPC transplant recipients transplanted at the Fred Hutchinson Cancer Research Center in Seattle, Khera *et al.* reported 75% of HPC transplant recipients adhere to recommended preventative care guidelines, suggesting greater adherence by transplant recipients than that of the general population[34]. The majority of the transplant recipients reported being interested in additional health maintenance information. The implementation of survivorship care plans may provide cancer survivors with the desired additional information regarding long-term health preventative behaviours and screening recommendations.

As survivorship care plans are early in their implementation, the long-term outcomes of such plans are yet to be measured and reported. The impact these have on increasing early detection of second primary cancers is not yet known; however, it is recognised that providing additional information and support will aim to optimise early detection and risk avoidance, ultimately aiming to optimise outcomes.

Australian cancer screening programs

In Australia, national screening programs have been implemented to detect breast, bowel and cervical cancers. The BreastScreen Australia program offers initial mammogram imaging with additional follow-up, if required, via assessment centres[35]. The program targets women aged 50–69; however, it is accessible for women aged 40 and above. Cancer survivors should adhere to the general population recommendations. All HPC transplant recipients should commence screening mammograms at age 40, if not prior[36]. For patients who were exposed to total body irradiation or chest irradiation during treatment, screening mammograms are recommended to be commenced for women at age 25 or 8 years post the irradiation, whichever occurs later[37]. For patients under the age of 40, mammograms are not accessible via the BreastScreen Program, although these patients can be referred to imaging services by their health care provider. The BreastScreen Program guides women to practise breast awareness and monitor for changes including changes in size or skin, new lumps, pain or discharge from the nipple[35,37]. Adherence to screening and self-check practices can assist to lead to earlier detection of breast cancer, which can assist to increase survival, treatment options and quality of life[35].

The National Cervical Screening Program recommends women commence Pap smear screening for cervical cancer, at age 18–20 or 1–2 years after becoming sexually active, whichever is the latter, and continue until age 70, or longer if results have been abnormal[38]. Pap smears are recommended to be performed every two years, and are recognised to be protective against cervical cancer, preventing the most common form in up to 90% of cases[38]. Female cancer survivors should ensure they abide to the recommendations for screening for cervical cancer.

The National Bowel Cancer Screening Program currently offers testing for faecal occult blood for Australians at age 50, 55, 60 and 65 years of age[39]. Approximately 98% of the Australian population are considered to be at average or slightly above average risk of developing colorectal cancer, with the recommendation that faecal occult blood testing should be performed at least every two years at this level of risk[40]. The presence of symptoms or a positive family history of colorectal cancer must be taken into account when stratifying the patients risk and determining the optimal screening practices for the individual[40].

Healthy lifestyle practices

The populations of Australia and New Zealand have an increased incidence of melanoma when compared to other populations worldwide[41]. There is currently no population-based screening program for melanoma in Australia; however, the Cancer Council recommends adults aged 40 and above check all areas of their skin regularly and report any changes to a medical practitioner[42]. Royle *et al.* highlight the importance of considering the Australian population, and the increased incidence of melanoma, when interpreting second primary cancer data obtained from international studies[2]. Melanoma prevention recommendations include minimising moderate or greater ultraviolet exposure

(that is, ultraviolet index ≥3), physical protection (wearing sunglasses and tightly woven clothing that covers the limbs) and utilising sunscreen correctly as a complementary measure[41].

Wood *et al.* report that cancer survivors who continue to smoke are placing themselves at high risk for additional cancers[10]. Tobacco smoking is recognised as a leading cause of cancer and the National Tobacco Strategy aims include encouraging smoking cessation and prevention of smoking commencement[43]. Cancer survivors should be aware of the risk of smoking, and are encouraged to remain a non-smoker or to quit smoking. All health care professionals can contribute to smoking cessation by educating, motivating and providing assistance to quit smoking[44].

The Cancer Council has developed a position statement specifically for cancer survivors, entitled *Benefits of healthy diet and physical activity for cancer survivors*[45]. This correlates with recommendations for general population guidelines, incorporating healthy body weight, optimal nutritional intake and physical activity[10,33,45].

The Cancer Council reports evidence that alcohol is associated as a risk factor for six cancers, including mouth, oesophageal, breast, and male colon-rectum[43]. The Australian guidelines to reduce health risks from drinking alcohol recommend healthy men and women should not drink more than two standard drinks on any day to reduce the lifetime risk of alcohol-related disease or injury[46]. The Cancer Council recommends cancer survivors limit or avoid alcohol, recommending men drink no more than two standard drinks daily, and women limit to one standard drink per day[45].

The Cancer Council recommendation for cancer survivors to aim to exercise moderately for at least 30 minutes daily aligns with the National Physical Activity Guidelines for the general population. Being overweight or obese can be a risk factor for some cancers, including the colon, rectum, kidney, pancreas and endometrium[47]. Dietary restrictions are recognised to have potential to decrease the risk of recurrence for breast cancer; however, this has not yet been demonstrated as an intervention to reduce the risk of secondary breast cancer[10]. The Cancer Council Australia recommends adults abide with the *Dietary Guidelines for Adults*[47]. This guideline further explores the relationship between fruit and vegetables and cancer risk and provides advice regarding nutritional intake, energy consumption and expenditure.

Nursing implication

With an increasing population of cancer survivors, the majority of nurses are likely to interact with a cancer survivor, whether this is to address their cancer-related needs, or in other contexts. As such, all nurses are likely to have an opportunity to engage with a cancer survivor, provide information and support the individual along their survivorship journey. All nurses should be able to initiate conversations about second primary cancer risk, and direct the patient to appropriate resources.

Survivors with a primary diagnosis of breast, prostate or colorectal cancers report a similar level of fear towards recurrence of their primary disease and developing another form of cancer[48]. Discussing the increased risk of cancer returning is important to assist the cancer survivor to make informed choices about their current and future health. Nurses can discuss risk factors with the individual, who may wish to be referred to other resources, such as smoking cessation resources or dietician services.

Early identification of second primary cancers may assist to optimise outcomes[3]. Whilst the responsibility to participate with recommended programs and behaviours remains largely with the cancer survivor, these recommendations must be clearly communicated to the cancer survivor to inform decision making. Nurses can assist by providing information about healthy lifestyles, cancer screening programs and risk factors aiming to empower cancer survivors, by enabling the individual to make choices to reduce their risk factors where possible and enable early detection. Nurses may be ideally placed to initiate conversations about lifestyle behaviours and assist by providing information, resources and referrals to appropriate services.

There are many clinics in practice across Australia addressing the needs of cancer survivors. The Australian Cancer Survivorship Centre provides links to resources, including information regarding long-term follow-up and late effects clinics around Australia and how to cancer survivors can access these[49].

Gates *et al.* reported on the implementation of a nurse-led survivorship intervention for survivors of Hodgkin's lymphoma clinic in place at the Peter MacCallum Cancer Centre[50]. This demonstrates that nurses are in the frontline of implementing and excelling in survivorship care in Australia.

As survivorship care plans become integrated and embedded into practice, nurses may have an increasing role with assisting to personalise survivorship care plans, and giving this plan and discussing it with the cancer survivor. All nurses should aim to be aware of the resources available to provide to cancer survivors to assist them in meeting their needs.

Conclusion

In correlation with international findings, Australian cancer survivors are at an increased risk of developing a second primary cancer. With increasing cancer survival rates, implementation of survivorship care plans and increasing awareness of risk factors and risk reduction behaviours, there is hope that secondary primary cancers will be associated with improved outcomes in the future. As the population of cancer survivors increases,

maximising long-term health has beneficial implications for the individual, whilst also potentially decreasing future demand on the health care system.

The journey of a cancer survivor is well recognised to continue beyond treatment completion. Initial treatment focus may be on short-term benefit; however, it is imperative that long-term health is addressed, and cancer survivors are aware of what health care behaviours they can act upon to maximise their long-term health. Participating in general population cancer screening programs may assist to optimise outcomes by enabling early diagnosis of a second primary cancer, and nurses can assist by providing information about recommended healthy lifestyle guidelines and screening practices.

By increasing information, potentially via the implementation of survivorship care plans and empowering individuals, it is optimistic that cancer survivors will adhere to recommended preventative care guidelines and healthy lifestyle behaviours, aiming to maximise long-term health.

Nurses may engage with cancer survivors in a variety of settings, providing opportunities to inform and educate cancer survivors, and provide access to other resources (such as smoking cessation support services, healthy lifestyle guidelines or referral to a long-term survivors' clinic). Nurse-led survivorship initiatives are being explored in Australia. Whilst these are still early in their implementation and evaluation, such programs are aiming to assist to meet the health care needs of the increasing cancer survivor population.

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Understanding the experience of a cancer diagnosis and illness — A patient perspective of the biographical disruption of multiple myeloma

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Abstract

Developing an understanding of the experience and tensions associated with a cancer diagnosis and illness from a patient perspective presents a difficult and absorbing challenge for cancer nurses. There are three key theoretical concepts which can inform the nurse regarding the subjective experience of illness[1]. These concepts include: biographical disruption of illness[2]; narrative reconstruction[3]; and loss of self[4]. The relevance of these theories is to enable the nurse to understand the interface of the patient cancer journey as related to the health care delivery system and to a broader social context. These theories address issues of loss, uncertainty, stigmatisation of illness and the individual ability to recreate sense and order after a cancer diagnosis. The combination of the key theoretical concepts of illness and a humanities-based approach will help develop an understanding of the experience of a cancer diagnosis and illness beyond either a clinical or biomedical model. The humanities, which are associated with the medium of written texts, artefacts and cultural practices, can enable the patient to relate their cancer journey. The humanities attempt to understand the human experience by acknowledging and relaying the human aspiration, achievements and expressions[5].

Introduction

This reflective paper will demonstrate how key understandings of the illness experience created tensions and opportunities which facilitated the understanding of the experience of illness as related to a diagnosis of multiple myeloma. The theories of illness identified included postmodernism, biographical disruption[2] and narrative reconstruction[3].

Modernity is the theorising of social life in the modern era characterised by the replacement of superstition and tradition with science and rationality. The postmodern theory "reflects people's differences in terms of their culture, lifestyle, and vested interests"[6] (p. 37) and permits diversity with the resultant narrative.

Biographical disruption and narrative reconstruction are characteristics of "reflexivity, local knowledge replacing grand narratives and patient empowerment which favours self as a construction"[7] (p. 176). Consequently, the narrative allows the author a dimension to reflect on the illness experience and make a contribution with regard to the impact of the experience of symptoms[8]. The reflection on the illness experience allows an opportunity to rewrite the patient narrative.

The biography of *Bad Hair Days*[9] by Pamela Bone is an insightful example of how well the humanity of her experience translated her experience of illness. As a print media journalist employed by *The Age* for 23 years, Pamela Bone had the creative ability to write a unique narrative. Her book was in essence part autobiography, but principally a deconstruction of her cancer illness experience. This narrative was an example of the movement towards postmodern theory of illness and the impact on clinical practice. The biography gave Pamela's experience a voice outside that of the biomedical model[10]. Pamela's throwaway lines were attention-snagging. She lamented that "the reason I was thirsty and dizzy was that my bones were melting into my bloodstream"[9] (p. 9).

The transcript of her illness from diagnosis to the eventual withdrawal from treatment elicited both emotional and spiritual responses. From the point of view of a health care worker (that is, a nurse) her pragmatic descriptions of the impact of her cancer were totally engaging and encouraged investigation of the lived experience of multiple myeloma, such as a patient's perspective of the biographical disruption of multiple myeloma.

Key understandings of the experience of illness — a biographical disruption[2]

The book began in 2004 when Pamela's cancer first manifested itself whilst she was on an assignment in a refugee camp in Africa. She had travelled to Chad (a landlocked country in central Africa) with Oxfam to write a story about the refugee crisis on the Chad-Sudan Border. At the time there were over 200,000 people who had fled the mass killings in the Darfur region of Sudan and were sheltering in the refugee camps set up by international aid organisations. The complex story behind the conflict in Darfur (western region of Sudan) goes back to the history of Sudanese independence. However, this recent conflict she was reporting on had begun in 2003 and continues till this day.

Physical changes — an insidious onset

Pamela returned home to Melbourne extremely unwell and dehydrated and her husband was distressed by her appearance. She aptly described the clinical features of hypercalcaemia and hyperviscosity syndrome often associated with a diagnosis of multiple myeloma. She thought she had contracted a viral illness in the camps in Darfur. She had no idea that the insidious onset of her symptoms which she regarded as "a last insult to youth and beauty" would create a biographical disruption to her own and the lives surrounding her[2] (p. 170). She could not reconcile her lethargy, aching bones, mouth ulcers and the indignity of constipation with a serious anomaly.

Practical consciousness

Pamela's husband insisted on her admission to hospital. She was deeply affected by the trip and she steadfastly refused to go before she wrote up her story, because without it she felt the trip would have been wasted. She believed it would be of enormous impact on the retelling of the refugees' crisis. She had a story to tell and she wanted the Australian public to hear it. The practical consciousness of her actions demonstrated an unconsciousness dependency on the future she had no reason not to trust in the future. She had a shared assumption about time, her space and identity and she felt secure in these assumptions[11]. Pamela walked out of the Melbourne *The Age* office where she had worked for 22 years, not realising that it would be for the last time. She had no reason to believe that she would not be going back to that ugly, brown building in the city which she aptly described with vivid affection.

Similarly, patients who arrive into the chemotherapy suite armed with laptops, iPhones and with earpieces dangling are attempting to maintain their practical consciousness. Those who come ready to continue their small business operations whilst having chemotherapy do not want one treatment to interrupt their existential security.

Patients who continue to live passionately and sincerely in spite of their cancer diagnosis find it difficult to allow themselves to participate in the Parsons' "patterning of sickness role"[2](p. 168). These patients may not permit you to assess their symptoms adequately, which can be life-threatening, particularly in the instance of febrile neutropenia. Patients sometimes need to be given permission to take the 'sick-role' and that it is okay to access sick-role behaviour to ensure recovery from deterioration of their health.

Fateful moments

Pamela was diagnosed with the haematological cancer multiple myeloma (MM). She didn't feel shattered, angry or grief-stricken; she just felt sad. Her principal reaction was that it's "bad luck". She rationalised that to die in her sixties was "bad luck" but it's not a tragedy. She won't compare it to the death of a young child or mother. She won't be able to discover her favourite things in retirement but maybe she wasn't going to retire anyway. She recognised that her work would have kept her immobilised and separated from her family. She doesn't cry for a whole year, she remained dry-eyed and she can't explain why[9] (p. 23).

She researched her diagnosis extensively and discovered that MM was at the malignant end of the spectrum of haematological malignancies and the most elusive in terms of cure. She learned to live with a chronic illness which had a median survival of three years. Her natural instinct was to protect her adult children but quickly realised that they are strong, loving and supportive women who know more about the disease than she herself. Her treating haematologist explains the treatment regimen/option of chemotherapy and an autologous blood stem cell transplant. She asked, "Will I lose my hair?" and when the answer was "Yes", she finally began to question the treatment options and the prognosis. This was really the first time the situation impacted on her; this was her fateful moment. It was the knowledge that her external deterioration would signal cues that her identity would become disrupted. She experienced the beginnings of her social disruption as her shared identity of self was to be altered and that alteration would become public knowledge[12]. She felt it was simply taken for granted by the medical and nursing staff and her family that she would agree to treatment, but it wasn't what she necessarily wanted. She went along with it because she was a law-abiding citizen. She described being diagnosed with cancer as though a "giant hand came and slapped her on the face and told her to get out of the human race"[9](p .37).

Stigma

Pamela described walking along the street and being amongst those whom she thought were so "carelessly healthy". She felt that in the world of the well she was an imposter, a fraud. Her alopecia forces the disclosure of her illness and changed her

ability to interact socially. The treatment not the disease had taken away her citizenship and she was forced to participate in a different manner[2]. The world of illness was a different one for Pamela; it was the night side of life. One she described as an onerous citizenship and sooner or late if only for a spell we would all have to identify ourselves with that other place. The forced disclosure which the alopecia caused rendered a change in the construction of Pamela's identity. It reinforced the biological impact of the tension created to her self by the cancer and its treatment.

Sexuality

Pamela no longer saw herself as an object of desire. Her rapid weigh loss of 13 kilograms in three months in combination with a bald head and a few stray wisps of hair elsewhere, she rendered herself as a poor, diminished creature. She had a "pathetically flat bottom". Yet she quite liked it and talked about buying clothes off the rack. This one aspect of her disease she now found empowering. She found that there was a community of scarf and beanie wearers whom she had never noticed before. Pamela's husband and her children were her "supportive intimates" who helped sustain her through the transplant with their unconditional love and kindness. She described her husband as her rock. He caught her vomit, wiped away the diarrhoea and scoffed at her talk of dying. He was her "super hero" and reassured her, with "We'll beat this". Her family was at the core of coping with the physical problems her transplant induced.

Uncertainty

Pamela found the uncertainty of the timing of her death frustrating. She understood that she would eventually die. She was an educated person who had not shied away from the inevitability of her death. The uncertainties of her illness led her to consider "voluntarily restricting her life"[4] (p. 174). She ruminated about the plane crashing on the way home from Africa and questioned her husband about the unfair burden she felt that she had placed him under. Her sense of "becoming a burden" created images of dependence, immobilisation and lost past positive self images[4]. She thought "if I'm going to die let's get it over with "[9] (p. 34).

Biographical disruption of self

She talked of the debilitation associated with the transplant and her dependence on the nursing and medical staff. Her self image changed with the "induction" chemotherapy. Her life was reduced to series of tablets: taking them, breaking them in half and the importance of veins: "beautiful veins". She was empathetic with the nurses as they continued to try and find her veins; the only problem was she didn't know they were lost. She felt a great need to be polite and respectful to the nurses and, importantly, the doctors, because they held her life in their hands. At this point she did not care whether she died or not. She needed to fawn and placate those responsible for keeping her alive. She was reduced, diminished, with no status, no authority. She had become craven. How she could describe herself in such a manner was incredulous. She was someone who in the previous six months had travelled to a war-torn country and relayed the story of a diminished group of people, yet her life was reduced to "finding a vein".

Loss

Pamela sustained so many losses in her biographical disruption. The erosion and losses of her images were almost palpable. She identified herself as a busy, efficient person. She loved juggling multiple activities: working, shopping, cleaning and babysitting. It gave her a sense of purpose. She thought that if she could control her outside habitus through cleanliness and tidiness she might be able to control the "uncleanliness" of the cancer coursing through her veins. Slowly, her ability to maintain this level of activity and involvement was decreased. Over time and without a substitute experience for her "bustling identity" her self concept became diminished and she became glum and grumpy[4]. Pamela was fortunate to be surrounded by a fantastic support network of family and friends which is summed up by a "chocolate cake". The chocolate cake was made for her during a period when her taste buds were affected by the chemotherapy. Her wonderful sense of "taste" was severely diminished and she viewed this as the last insult. The smell, taste and sensation and the act of kindness associated with that cake, she linked with "what being normal felt like"[9](p. 83). It was a tangible memory of her past, her normal life before diagnosis and before the chemotherapy (the enforced taste changer). The cake eventually came to represent two main aspects of her life. Firstly, the constant strong community of family and friends and, secondly, that people strive collectively to do good things.

Key understandings of the experience of illness narrative reconstruction[3]

The diagnosis of MM had ruptured Pamela's life and taken away her freedom. She always felt a great sense of discord until she explored the issue of euthanasia fully[3]. She would only renew her driver's licence for three years instead of 10. She was not really reconciled to her future until she felt she had a semblance of control over her death[9] (p. 56). She described the cancer as a sniper, one she didn't have time for, but that had time for her.

She explored the option of euthanasia and assisted suicide. Once she had the knowledge she seemed reconciled to her prognosis. She goes on to plan her funeral as she sees this as a way of having control over her destiny. When she relapsed after the autologous transplant she declined further chemotherapy. She could not see the point of going through endless painful

treatment to prolong her life. She felt that it was a futile exercise. She rightly expressed that the world and its terrors and wars continue even though you are fighting a battle of your own. One might express the euphemisms of "Lose the battle, win the war", "Putting on a brave front" and "We'll fight and beat this together", but for her the cancer trajectory of MM continued to rage underneath. She continued to live passionately and sincerely in spite of her cancer diagnosis and found it difficult to allow herself to participate in the Parsons' "patterning of sickness role"[2] (p. 168). Despite all of the physical suffering from chemotherapy Pamela recognised the recurring themes of the fundamental goodness and kindness of people. She was able to continue writing a column for *The Age* until close to her death, which helped her reconstruct her narrative. Her employers were empathetic and did not pressure her at any time. She was able to continue participating in a fundamental aspect of her biography, which connected her present and past and her own self with society[3]. Pamela managed to recreate for herself a "sense of coherence, stability and order in the aftermath of the 'biographically disruptive' event of illness"[1] (p. 27). Pamela effectively rewrote her biographical map.

The biomedical model

The biomedical model is arguably a reductionist framework whereby disease is reduced to organic, cellular or genetic levels. The specific benefit was that this model made prior fatal conditions treatable (that is, pneumonia, appendicitis). It enabled us to rationalise medical practices, which make some episodes of illness treatable or untreatable. The difficulty is the reliability on biomedicine to continue with the discovery of new technology to direct care. This model does not necessarily consider the role of "social, psychological or emotional factors"[6] (p. 438) which may play an important part in the treatment trajectory of incurable illnesses.

Sociological theory models are beneficial in dealing with the reflexive practice of understanding the impact of illness on the patient and enabling patients to narrate their story. The potential conflict can be the omission of important physical attributes of illness with a negative outcome for the patient[7]. It would be the combination of both these models which will enhance a better understanding of the cancer process.

Pamela described her varying stages of illness eloquently and with a great deal of insight. Her account portrayed her biographical disruption and the consequent narrative reconstruction she experienced during the process of illness. It was a biography which created tensions and opportunities to facilitate the understanding of the experience illness, which can be translated into clinical experience.

I have a professional interest in the specialty of apheresis nursing. I provide ongoing clinical training and supervision for registered nurses conducting therapeutic apheresis procedures within a cancer services environment. Consequently, during the last decade I have nursed a large number of patients at varying stages of diagnosis, treatment, remission, relapse and palliation for the diagnosis of MM.

My current clinical perspective with MM patients mobilising for autologous stem cell collections has been driven by chemotherapy mobilisation protocols, growth stimulating factors and rising CD 34 counts. Consequently, my nursing practice has been motivated by a "biomedical model" due to the acuity of the varying phases of this particular disease trajectory and the correct use of limited resources to manage stem cell collections.

Hyden stated that:

> *One of our most powerful forms for expressing suffering and experiences related to suffering is the narrative. Patients' narratives give voice to suffering in a way that lies outside the domain of the biomedical voice*[10]*(p. 50).*

I have read and then reread Pamela's narrative: It was compelling. Like the "giant hand … which … came and slapped her and told her to get out of the human race"[9] (p. 37), I will continue to feel the sting and echo of her words as they continue to effect change in my clinical practice for the years ahead.

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