

# The Australian Journal of Cancer Nursing

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References: 1. Herst Patries M, et al. Prophylactic use of Mepitel Film prevents radiation induced moist desquamation in an intra-patient randomised controlled clinical trial of 78 breast cancer patients. Radiotherapy and Oncology 2014.

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### Editorial

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# The Australian Journal of Cancer Nursing

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## Editorial

# What's happening to the role of the registered nurse?

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The question, *what's happening to the role of the registered nurse (RN)?* does not relate to the current shortage of RNs but to the role of the RNs who are at this moment providing patient care at the bedside. A considered thought, this question became prominent for me when I embarked on a two-year secondment in a state-based role at the Clinical Excellence Commission (CEC), one of the pillars of NSW Health. This temporary position involves supporting the implementation of a program aiming to build highly reliable health care teams. This role has given me the opportunity for a broader view of the NSW Health system away from my role as clinical nurse consultant (CNC) in a specialist area, which I have held for more than two decades. The question of the RN role then became urgent in my mind following a recent experience in a carer's role. Following a fall resulting in a fractured neck of femur, my 90-year-old mother received treatment in a NSW Health acute hospital facility. For the week that she was an inpatient I sat by my mother's side.

As an inpatient my mother was under the care of three medical teams, surgical, medical and subacute medical. The interdisciplinary team that I met during the 10 hours a day I spent with her included: RNs, enrolled nurses (EN), physiotherapists (PT), occupational therapists (OT), PT and OT assistants, a dietitian, a speech pathologist, a CNC, junior medical staff (JMO) and a staff specialist. It was my observation of the care provided by the nursing staff and allied health which occupied most of my attention.

The speech pathologist assessed my mother's ability to swallow and informed me that she would tell the nursing staff it was okay for my mother to eat in bed as long as she was sitting upright. The dietitian chose the meals for my mother while it was the OT who checked my mother's skin integrity and prescribed the interventions for pressure injury prevention. Post-operative mobilisation did not occur unless under the supervision of a PT

and a CNC made one visit to inform us of the plan for discharge. The EN assisted with hygiene but also measured and recorded vital signs.

As I sat in my carer's role and observed allied health professionals perform initial assessments and develop allied health-based care plans, it occurred to me that in the not too distant past it was the RN who made the initial assessment and referred to allied health when a patient had complex needs requiring specialist skills. Not so long ago it was the RN who developed a recovery plan with the patient, factoring in the necessary input and referring to allied health. This organisation of care has always been and remains especially important as, unlike the RN, most allied health professionals do not cover wards on a 24-hour basis.

However, as a carer my observation of the RN was a health professional trying to keep up with the demands of a busy surgical ward. This observation is echoed when, in my CEC role, I travel to Local Health Districts across NSW. The increased complexity of inpatients as well as shorter lengths of stay is likely to have an impact on the ways we deliver care, especially the care delivered by the RN who is involved in direct patient care. These ever-changing conditions in health care provision are placing increasing tension on the ability of the RN to perform the core aspects of their role. Specifically, the RN role is critical to planning and delivering complex care coordination which is holistic and patient-based.

There is a seismic shift in the scope of practice of health professionals rumbling away which is not necessarily based on evidence. In a measure to meet the predicted RN shortage and to meet the fiscal constraints experienced by most health care facilities, we are upskilling lesser qualified staff, such as ENs who, for example, are endorsed to deliver medications. In some



cases this endorsement extends to administering antineoplastic agents. Confounding this is the extended role skills of some RNs which were traditionally the domain of medical staff such as venepuncture, cannulation, ordering and reviewing pathology or reviewing medically initiated investigations. This does not refer to the extended role skills of the advanced practice nurse, but rather the bedside nurse, the RN involved in direct patient care.

So, if allied health is performing initial assessments and prescribing interventions and ENs are administering medications, and there are advanced practice nurses who are coordinating the discharge planning, then where is the RN? The person I was looking for as I sat by mother's side. The professional I hoped would pull together all of the messages we were receiving from the three medical teams. Where was the RN who sought background information to get to know the person in the bed and who would clarify or confirm the discharge arrangements?

The changing scope of practice of health professionals and the blurring of professional boundaries risks an unbalanced division

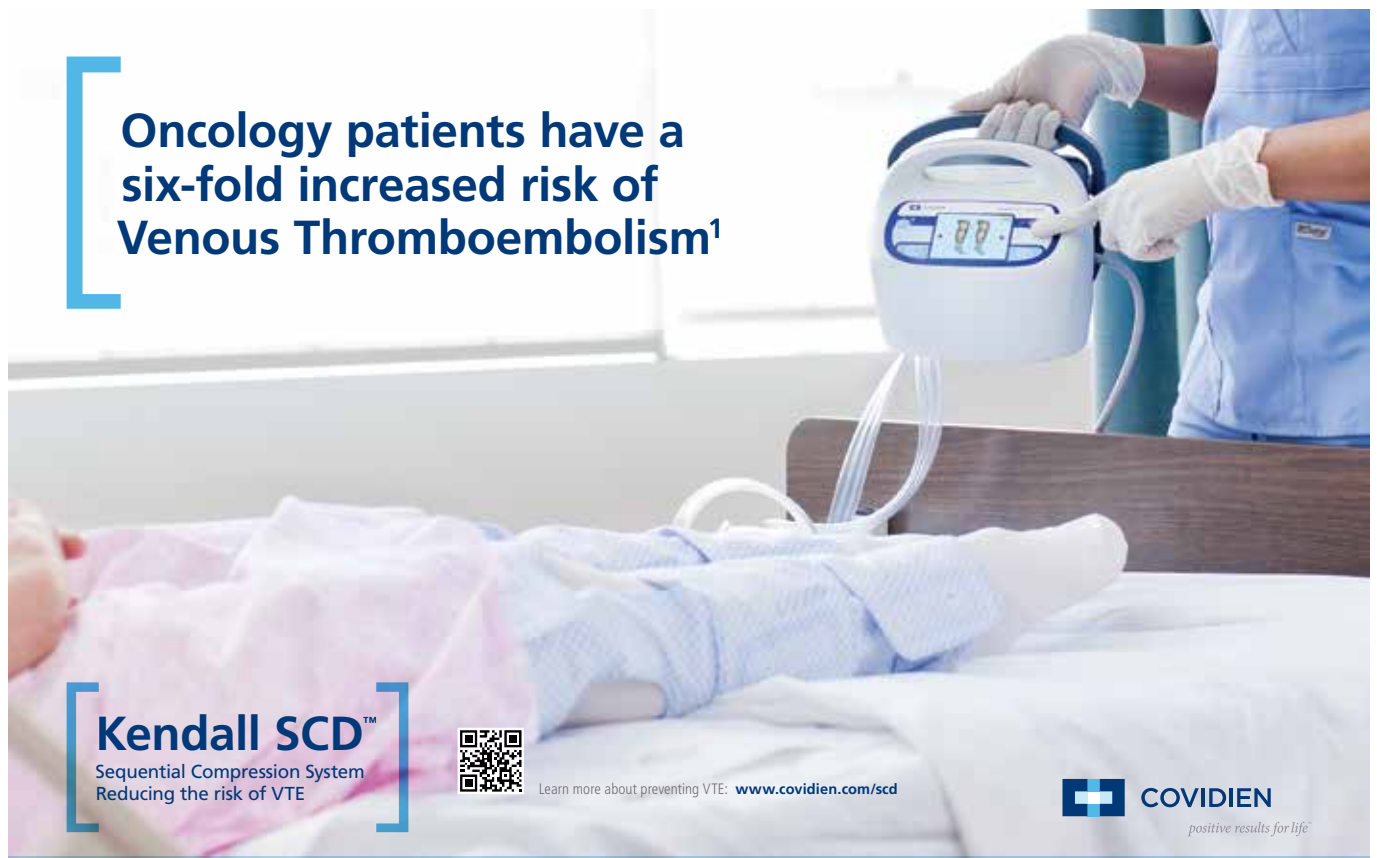
of health care provision and a potential risk to the quality and safety of patients. A more balanced and efficient approach to providing care is unlikely to happen until there is an agreed interdisciplinary approach to health professional education reform<sup>1</sup>.

Could the division of skills and changing scope of practice be at the expense of the bedside RN role? By the reallocation of aspects of the RN role vertically to lesser qualified staff and horizontally to allied health, for example, are we squeezing out the crucial role of the RN which is pivotal to providing quality, coordinated bedside care?

### Reference

1. Leggat SG. Changing health professionals' scope of practice: how do we continue to make progress? An issues brief prepared for the Australian Government National Lead Clinicians Group. Australian Healthcare and Hospitals Association 2014. Accessed 28 September 2015 from: <http://ahha.asn.au/publication/issue-briefs/changing-health-professionals%E2%80%99-scope-practice-how-do-we-continue-make>

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<sup>1</sup>. Geerts, et al. Prevention of Venous Thromboembolism: American College of Chest Physicians Evidence-Based Clinical Practice Guidelines (8th Ed). CHEST 2008; 133:381S-453S

# Cardiotoxicity related to anti-cancer drug treatment: a literature review

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## Abstract

### Introduction

New anti-cancer drug treatments have resulted in longer life expectancy for many patients; however, anti-cancer drug treatment-related cardiotoxicity can become an issue for those who have completed treatment. Anti-cancer drug treatment-induced cardiotoxicity is associated with high morbidity and mortality rates. However, there is limited research to indicate when cardiotoxicity develops and what preventative measures might be available for people with cancer who have received cardiotoxic anti-cancer drug treatment.

### Objectives

The review explores the potential risk factors for cardiotoxicity and examines their precise aetiology and pathophysiology.

### Methodology

A literature review was undertaken by searching online databases CINAHL, PubMed and Medline. The comprehensive review resulted in 17 articles meeting the inclusion criteria: English language articles from peer-reviewed journals dating from 2004 to 2014.

### Results

The published literature indicates an increased incidence of cardiotoxicity in people who have received anti-cancer drug treatment. In addition there is a dearth of understanding of the pathophysiology of cardiotoxicity.

### Conclusion

This literature review serves as a first step towards understanding the pathophysiology of cardiotoxicity. Further, before the health care needs of people who have received cancer treatment can be understood and addressed, it is crucial to have a clear understanding of the mechanism and risk factors associated with cardiotoxicity.

**Keywords:** Cardiotoxicity, anti-cancer drug treatment, antineoplastic agents, cardiomyopathy, heart failure and radiotherapy.

## Introduction

Cardiotoxicity can occur as an acute side effect of some anti-cancer drugs in the form of hypotension, tachycardia, arrhythmia, and transient depression of left ventricular function, or as a long-term side effect<sup>1,2</sup>. Acute decreases in left ventricular ejection fraction can occur, whereas delayed left ventricular dysfunction, which can develop over several years after completion of treatment, is reported to impair prognosis in 5% to 10% of patients<sup>3</sup>. The exact extent of cardiotoxicity is variable but largely dependent on the type of drug used, its combination with other drugs, prior mediastinal radiotherapy and the presence of cardiovascular risk factors or a history of heart disease such as coronary artery disease, hypertension and

rhythm disturbances<sup>4,6</sup>. Combined treatment with radiotherapy, anti-cancer drugs, and surgery are commonly used in the management of different cancer types. Combined therapies generally improve outcomes but tend to result in more acute and delayed side effects such as cardiotoxicity<sup>4</sup>.

## Methodology

A literature review was undertaken by searching online databases CINAHL, PubMed and Medline. The eligibility criteria included:

- i) articles published between 2004–2014
- ii) limiting the search to articles in the English language
- iii) using articles only from peer-reviewed journals.

The search terms cardiotoxicity, anti-cancer drug treatment, antineoplastic agents, cardiomyopathy, heart failure and radiotherapy were used to gather relevant articles. Other sources of literature were sought from reference lists contained in the articles obtained from the database searches. A comprehensive review of the articles resulted in 17 articles meeting the inclusion criteria. Following the analysis of the literature, the following themes emerged:

- Factors associated with anti-cancer drug treatment-induced cardiotoxicity.
- Detection of anti-cancer drug treatment-induced cardiotoxicity.
- Prevention and management of anti-cancer drug treatment-induced cardiotoxicity.

These themes shaped the discussion of the literature.

### Factors associated with anti-cancer drug treatment-induced cardiotoxicity

Some of the established factors associated with the development of anti-cancer drug treatment-induced cardiotoxicity include anti-cancer drugs, radiotherapy, lifestyle factors and non-modifiable risk factors<sup>7-9</sup>. Despite notable improvements in anti-cancer drug treatment and survival rates, this has resulted in a cohort of patients who could live longer but who go on to

develop longer term cardiac complications (or “cardiotoxicities”) of cancer treatment<sup>10</sup>. Cardiotoxicity is now understood to compromise the clinical effectiveness of some common anti-cancer drug treatments and to affect the patient’s survival outcomes<sup>10,11</sup>. These factors are discussed in the following subsections.

#### a) Anti-cancer drugs

It is widely acknowledged in the oncology literature that anti-cancer drugs, especially the earlier anti-cancer drugs, are non-discriminatory and can cause multiple organ damage<sup>7</sup>. It is important for clinicians and people with cancer to understand that even the contemporary “targeted” anti-cancer drug treatments can inflict collateral damage on the heart<sup>7</sup>. Unfortunately, because so many of these drugs are relatively recent in clinical practice, little is known about the extent of the damage or the mechanisms behind it.

The following anti-cancer drugs are known to contribute to cardiac risk: anthracyclines, humanised monoclonal antibodies (“targeted” therapies), taxanes, antimetabolites and alkylating agents<sup>3,12,13</sup>. See Table 1 for a list of commonly used anti-cancer drugs and their associated cardiac effects.

Anthracyclines are an important group of anti-cancer drugs widely used in the treatment of breast cancers, lymphomas, and leukaemias. Anthracyclines are known to have both acute

Table 1: Commonly used anti-cancer drugs and their associated cardiac effects

Drug class	Drug names	Cardiac manifestation	Reversibility
Anthracyclines	Doxorubicin Epirubicin Daunorubicin Idarubicin	Cardiomyopathy, congestive heart failure	Not reversible
Alkylating agents	Cyclophosphamide Ifosfamide Melphalan	Cardiac decompensation, cardiomyopathy	Not reversible
Humanised monoclonal antibodies (“targeted” therapies)	Trastuzumab Cetuximab	LVEF decrease or asymptomatic heart failure	Reversible
Taxanes	Paclitaxel Docetaxel	Sinus bradycardia, ventricular tachycardia, atrioventricular block, heart failure, ischaemia	Reversible
Antimetabolites	5-fluorouracil (5-FU) Capecitabine Cytarabine Gemcitabine	Angina pectoris myocardial infarction, left ventricular dysfunction, arrhythmias	Reversible
Small molecule tyrosine kinase inhibitors	Imatinib Sunitinib Sorafenib Lapatinib	Left ventricular dysfunction, myocardial ischaemia, heart failure, hypertension	Reversible

and long-term cardiac effects. Long-term anthracycline-related cardiac effects that manifest as left ventricular systolic dysfunction and heart failure were recognised from the introduction of anthracyclines in the 1960s<sup>12</sup>. According to Vejponga *et al.*<sup>6</sup>, patients who receive cumulative doses of doxorubicin of 400, 550 or 700 mg/m<sup>2</sup> have an incidence of heart failure of 3%, 7% and 18% respectively. As a result, guidelines discourage doxorubicin cumulative doses of more than 500–550 mg/m<sup>2</sup><sup>3</sup>. Left ventricular systolic dysfunction and heart failure secondary to anthracyclines are believed to result from free radical formation that damages the myocardium<sup>13</sup>. The formation of free radicals is thought to lead to oxidative stress resulting in the loss of the cardiac myocytes through cell death<sup>9</sup>. Acute heart failure, on the other hand, is an uncommon but severe cardiac complication of anthracycline-based regimens that predominantly affects children<sup>14</sup>. Risk factors for anthracycline-related cardiotoxicity include its dosing and schedule, age, sex and genetic factors<sup>5</sup>.

Monoclonal antibodies such as trastuzumab (Herceptin<sup>®</sup>) are now established as adjuvant treatment for patients with HER2-positive early breast cancer and for the treatment of patients with HER2-positive metastatic breast cancer<sup>15</sup>. However, their administration carries the risk of adverse effects including cardiotoxicity<sup>13,14</sup>. Some studies suggest that the mechanism behind trastuzumab-related cardiotoxicity is the disruption of the epidermal growth factor signalling-system located in the heart<sup>16–19</sup>. Risk factors for trastuzumab-induced cardiac toxicity include older age, use in conjunction with anthracyclines, chest wall irradiation and pre-existing cardiac co-morbidities. The incidence of trastuzumab-related heart failure is 2% to 7%, which increases to 27% when trastuzumab is used in combination with anthracyclines and cyclophosphamide<sup>14,15,20,21</sup>. Current guidelines do not recommend the use of trastuzumab concurrently with an anthracycline due to the risk of cardiotoxicity<sup>22</sup>.

Alkylating agents such as cyclophosphamide are also associated with cardiotoxicity<sup>4,23</sup>. Cyclophosphamide is usually tolerated by the heart at lower doses but it can induce severe cardiac effects at high doses (>60 mg/kg daily)<sup>3</sup>. High-dose cyclophosphamide is used in transplant regimens and is associated with acute cardiotoxicity such as cardiac decompensation, as well as with fatal cardiomyopathy<sup>3</sup>. The pathogenesis of cardiotoxicity with this agent is not fully understood but an increase in free oxygen radicals seems to play a role in oxazaphosphorine-induced cardiotoxicity<sup>1</sup>. The risk of chronic heart failure depends on the dose. For example, with ifosfamide it increases from 8% to 67% at doses ranging from 10 g/m<sup>2</sup> to 18 g/m<sup>2</sup><sup>4,24</sup>.

Taxanes stabilise cellular microtubules<sup>25</sup>. Two members of this drug family, paclitaxel and docetaxel, are widely used for advanced breast, lung, and ovarian carcinomas<sup>26</sup>. When used on

its own, paclitaxel does not seem to cause left ventricular systolic dysfunction, whereas it does seem that paclitaxel increases the effect of doxorubicin-associated cardiac dysfunction<sup>27</sup>. The clearance of doxorubicin (an anthracycline) is therefore believed to be paclitaxel schedule-dependent, occurring most prominently when paclitaxel immediately precedes doxorubicin or follows it by less than one hour<sup>27</sup>. Paclitaxel is formulated in a Kolliphor<sup>®</sup> EL (formerly known as cremophor EL<sup>®</sup>) vehicle to enhance the drug's solubility and it is suggested that the vehicle and not the cytotoxic drug itself is responsible for the cardiac disturbances<sup>24</sup>.

The antimetabolite 5-fluorouracil (5-FU) is associated with cardiotoxicity, usually in the context of continuous infusion rather than bolus injection<sup>28</sup>. The reported incidence of 5-FU-induced cardiotoxicity varies from 1.2% to 18%<sup>29</sup>. The most common presentation is angina pectoris while other manifestations, namely myocardial infarction, left ventricular dysfunction, arrhythmias and sudden death, have been reported<sup>29</sup>. The pathophysiological mechanism of 5-FU-related cardiotoxicity is still unclear and suggested mechanisms cannot be explained by the pharmacological action of 5-FU<sup>1</sup>. Most commonly, coronary artery vasospasm and flouroacetate, a toxic metabolite of 5-FU, are considered responsible for the toxicity<sup>30</sup>. Spasms of the coronary artery due to endothelium, which is a potent vasoconstrictor, are thought to mediate this process<sup>30</sup>.

## b) Radiotherapy

Mediastinal irradiation can improve outcomes for a wide range of neoplasms, including those of the lungs, breast and oesophagus, as well as lymphomas such as Hodgkin lymphoma<sup>31,32</sup>. It was once thought that the heart was relatively resistant to the damaging effects of radiation therapy but it has become apparent more recently that heart damage is actually one of the most critical dose-limiting aspects of radiotherapy<sup>9</sup>. Of most concern is the potential acceleration of coronary artery disease that could lead to myocardial infarction or even sudden death<sup>27,32</sup>.

The risk of radiation-induced cardiac injury can be further increased by the concomitant use of anthracycline-based chemotherapy<sup>8</sup>, especially when larger cumulative doses of doxorubicin (>450 mg/m<sup>2</sup>) are used, when radiation and anti-cancer drugs are given concurrently, and when high-dose volumes of cardiac radiation are administered<sup>31</sup>. In a retrospective study of 1474 survivors of Hodgkin lymphoma, Aleman *et al.*<sup>33</sup> reported that the 25-year combined cumulative incidence of chronic heart failure and cardiomyopathy was 7.9% after mediastinal radiotherapy and anthracycline-containing chemotherapy. The pathophysiology of radiation-induced heart disease is not completely understood. The modern radiation approach that limits the exposure of the heart and reduces the total dose seems to lessen the previously observed cardiovascular risk<sup>27</sup>.

### c) Lifestyle factors

There are many risk factors associated with cardiovascular diseases (CVDs) that have been shown to influence the risk of anti-cancer drug treatment-related cardiotoxicity. These include body mass index, smoking, physical inactivity, alcohol intake, poor dietary habits, hypertension and diabetes<sup>734</sup>. Lower and higher body mass indices are recognised as independent risk factors for heart failure as well as a significant determinant of mortality<sup>8,35</sup>. Previously, only extreme obesity had been independently linked to heart failure.

Cigarette smoking is usually associated with respiratory problems and lung cancer<sup>36,37</sup>. However, research identifies an association between smoking and heart disease<sup>37,38</sup>. Smoking cessation can potentially benefit patients already with heart failure and those at risk of developing heart failure. The literature suggests that current smokers have an increased risk of developing heart failure compared to non-smokers and prior smokers<sup>39</sup>. Moderate alcohol consumption is associated with lower risks of heart failure<sup>39</sup>. The National Heart Foundation<sup>40</sup> advises heart failure patients not to exceed one to two standard alcoholic drinks per day and where cardiomyopathy is diagnosed, they should not consume alcohol at all, to help slow disease progression. In Australia a standard drink is any drink that contains 10 grams of alcohol<sup>41</sup>.

Hypertension and diabetes are major risk factors for developing cardiovascular disease, such as heart failure and coronary artery disease. Hypertension contributes to heart failure by interfering with the cardiac structure and function. Within a normal heart a balance of collagen synthesis and degradation determine the cardiac structure<sup>42</sup>. Hypertension contributes to heart failure by causing left ventricular diastolic dysfunction, resulting in substantial abnormalities, including decreased diastolic distensibility and impaired relaxation<sup>43</sup>. Diabetes, especially when uncontrolled, is an established risk factor for the development of heart failure and is associated with a higher mortality rate<sup>44</sup>. The mechanism underlying the association between diabetes and the development of cardiovascular disease remains poorly understood<sup>45</sup>.

Individuals treated for cancer are more likely than the general population to become obese, develop diabetes, and engage in unhealthy lifestyle behaviours than their non-cancer peers<sup>46</sup>. While an exploration of why these co-morbidities arise is beyond the scope of this paper, it is apparent that cancer patients treated with cardiotoxic agents experience 'double jeopardy' where cardiotoxicity is concerned; that is, cardiotoxic cancer treatment plus a more general cardiac risk related to the fact that they have been treated for cancer.

### d) Non-modifiable risks

Non-modifiable cardiovascular risk factors, particularly age and genetics, increase the likelihood of anti-cancer treatment-associated risk for major cardiovascular problems such as heart failure<sup>47</sup>. Older age at treatment is a significant risk factor for cardiotoxicity. Ageing is associated with decreased functional reserve of multiple organ systems and with changes in the pharmacokinetics and pharmacodynamics of drugs; hence older individuals express enhanced susceptibility to the complications of anti-cancer drug treatments<sup>48</sup>. Genetic predisposition also may be important in determining the risk of cancer treatment-related cardiotoxicity. Apart from an inherited risk for heart disease, genetic polymorphisms could alter membrane permeability, anti-oxidant capacity, or metabolism, favouring the development of cardiac damage during and after anti-cancer drug treatment<sup>49</sup>.

### Detection of anti-cancer treatment-induced cardiotoxicity

The main strategy to minimise cardiotoxicity is early identification of people at high risk and prompt prophylactic treatment<sup>49,50</sup>. The most widely used methods for detecting cardiotoxicity are echocardiogram and cardiac magnetic imaging<sup>51</sup>. Routine use of echocardiogram to assess anti-cancer drug treatment-induced cardiac damage is not very sensitive in identifying early cardiac changes to warrant treatment intervention<sup>52</sup>. The use of new cardiac biomarkers are proving to be a more sensitive and specific tool for the early identification of anti-cancer drug-induced cardiac injury<sup>14,53</sup>. Troponins are the most cardiac-specific biochemical markers among those currently available for the diagnosis of myocardial injury<sup>54</sup>. Troponins are highly sensitive markers of the very small amounts of necrosis, unable to be detected by less sensitive biomarkers, such as creatine kinase muscle and brain isoenzyme<sup>53</sup>.

Brain natriuretic peptide (BNP), also called B-type natriuretic peptide, is a member of a family of structurally related hormones (the natriuretic peptides) that is a useful tool in the diagnosis of acute heart failure<sup>14,55</sup>. A level of more than 400 pg/ml makes the diagnosis of heart failure likely and it is useful in the risk stratification of patients with chronic heart failure<sup>56</sup>. Despite the increasing recognition of these biomarkers, the current standard for monitoring cardiac function detects cardiotoxicity only when a functional impairment has already occurred, thereby excluding opportunities for any early preventive strategies<sup>14,47</sup>.

### Prevention and management of anti-cancer drug treatment-induced cardiotoxicity

The best approach to minimising cardiotoxicity related to anti-cancer drug treatments remains a challenge for clinicians<sup>6</sup>. The dose of cancer drugs given at each session, cumulative



dose, drug combinations and drug sequencing are important strategies in the prevention of anti-cancer drug treatment-induced cardiotoxicities<sup>4</sup>. The cardioprotectant drug dexrazoxane hydrochloride, plus the angiotensin converting enzyme (ACE)-inhibitors and beta-blockers are some of the potential strategies to mitigate cardiotoxicity in cancer patients receiving treatment<sup>57</sup>. The only clinically proven cardioprotective agent for anthracycline-induced cardiotoxicity is dexrazoxane<sup>58</sup>. According to Smith *et al.*<sup>59</sup>, when doxorubicin and epirubicin are given with dexrazoxane the risk of clinical cardiotoxicity is reduced significantly. Dexrazoxane lessens cardiotoxicity by binding to free and bound iron, thus reducing the formation of anthracycline-iron complexes and the generation of free radicals that are believed to be toxic to cardiac tissue<sup>59-61</sup>.

Optimum management of cardiovascular disease before and during anti-cancer drug treatment is essential to reduce morbidity and mortality in cancer patients<sup>7</sup>. The mainstay of cardiac management following anti-cancer treatment is drug therapy, usually initiated after symptoms have developed. ACE-inhibitors have been proposed to both prevent and ameliorate the cardiotoxicity associated with doxorubicin by suppressing the renin-angiotensin system<sup>62</sup>. Beta-blockers have been shown to improve the cardiac outcomes in patients receiving doxorubicin<sup>63</sup>. Carvedilol, a beta blocker, is known to have some antioxidant properties, which may explain its role in preventing cardiotoxicity from doxorubicin chemotherapy but the same effect has not been demonstrated with other beta-blockers<sup>62</sup>. The use of agents such as ACE-inhibitors and beta-blockers to treat cardiotoxicity once it has developed is promising but more data are needed to support their use in this context<sup>49</sup>.

Exercise has proven beneficial in heart failure patients<sup>64,65</sup> and in people with cancer without heart failure<sup>66</sup>, but has not been tested in people with cancer with cancer treatment-induced cardiotoxicity<sup>67</sup>. There are no studies specifically addressing the benefits for people with cancer with cardiotoxicity because people who have survived cancer with heart failure are usually not eligible for these studies due to the study exclusion criteria<sup>67</sup>. A growing body of research nonetheless demonstrates that the benefits of exercise for people with cancer could include increased muscle strength, improved physical functioning, controlled body weight and improved endurance<sup>68-70</sup>. The National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand<sup>71</sup>, recommend that, when medically stable, heart failure patients should be considered for a specifically designed physical exercise program or undertake a modified cardiac rehabilitation program. An understanding of the physiologic effect of exercise is necessary to appreciate the rationale for recommending a long-term, low-exercise intensity training program for people successfully treated for cancer with cancer treatment-induced cardiotoxicity.

## Conclusion

Cardiotoxicity is a recognised complication of anti-cancer drug treatment. Evident from the literature is that there are a number of mechanisms underpinning the risk of cardiotoxicity. Apart from dose or treatment modification, there are few options available to prevent it or manage it once it develops. Consequently, better understanding of the pathophysiology of these factors and what places people with cancer at risk are essential in reducing the incidence and outcomes of this toxicity. In addition, the conventional methods of detecting cardiotoxicity such as the use of echocardiogram are useful in establishing baseline cardiac function and subsequent damage, but cannot actually predict if it might occur. Therefore, the routine use of more accurate methods such as high sensitivity cardiac troponins that can detect cardiac dysfunction much earlier is crucial in identifying loss of cardiac function to then more appropriately shape rehabilitation.

Cancer nurses play a pivotal role in supporting people with cancer during and after cancer treatments, through accurate health assessment and the provision of timely and focused health education. The health care needs of people with cancer at risk of cardiotoxicity can be determined through accurate, ongoing assessment.

The provision of clear and individualised educational strategies for people with cancer to enable them to self-monitor and report changes in health status will develop a culture of symptom management and greater lifestyle choice in people treated with cardiotoxic anti-cancer treatments.

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# Nursing fever management in adult oncology patients: a literature review

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## Abstract

Fever associated with neutropenia, blood transfusion and disease processes is common in adult cancer patients. The literature indicates, however, that the aetiology, rationale and symptoms of fever are often misunderstood, resulting in fever management that is not evidence-based in this cohort. Thus in this review, an overview of fever, with a focus on fever in cancer contexts, is provided. Content includes an explanation of the therapeutic function of fever, an analysis of the physiological consequences of fever and an exploration of the aetiology of fever in cancer patients. Current guidelines for fever management in cancer patients and existing nursing practice are also discussed.

## Background

Fever associated with neutropenia, blood transfusion and disease processes is common in adult cancer patients. The literature indicates, however, that the aetiology, rationale and symptoms of fever are often misunderstood, resulting in fever management that is not evidence-based in this cohort. In an attempt to understand these issues, this paper reviews these issues to establish the current state of the evidence.

Using specific search terms to address five topics ("fever generation", "effects of fever", "aetiology of fever", "nursing fever assessment", "nursing fever management"), the CINAHL, PubMed, JBI and Cochrane databases, were searched. Findings were restricted with language ("English") and year of publication ("between 2005 to 2014").

## Fever generation

Pathogens tend to function most effectively in a defined range of normal body temperature. Fever occurs as a therapeutic response to the presence of pathogens and is considered to be therapeutic fever<sup>1</sup>. It is the body's defensive mechanism, increasing the hypothalamic set-point beyond the level

compatible with pathogenic function<sup>2</sup>. Body temperature regulation is a homeostatic mechanism. When the core body temperature exceeds the limit of the normal range of internal body temperature, called the set-point, heat loss mechanisms are activated. These include vasodilation and sweating. Heat production mechanisms, such as vasoconstriction and shivering, are stimulated when the core body temperature falls below the set-point<sup>3</sup>.

Multiple systems including the immune, nervous, and cardiovascular systems are involved in fever generation, which comprises three distinct phases. In the chill phase, which is the initial phase of fever, the immune system responds to infection and inflammation by releasing pyrogenic cytokines such as interleukin-1 and interleukin-6<sup>4</sup>. These cytokines stimulate the activation of the arachidonic acid cascade. Prostaglandin E2 (PGE2) is then released from the cells of the immune system as part of the arachidonic acid cascade<sup>4</sup>. PGE2 affects thermoregulation in the central nervous system, resulting in a recalibration of the temperature set-point to a higher level than normal<sup>1</sup>. Patients react to an increase in the set-point with chilling and vasoconstriction to decrease heat loss and



increase heat production<sup>3</sup>. The central nervous system sends out signals in response to the elevated set-point via the motor and sympathetic nervous systems, initiating shivering. Shivering, which generates heat, is controlled by the motor system, while constriction of the skin's blood flow to restrict heat loss is mediated by the alpha-1 adrenergic receptors of the sympathetic nervous system<sup>5</sup>.

The next phase of fever is the plateau phase, during which the core temperature reaches the new set-point and shivering stops due to the balance between heat production and heat loss. This second phase is followed by the defervescence phase, when the pathogenic agents are neutralised<sup>6</sup>. In this last phase, the endogenous pyrogen levels fall, resulting in the reduction of the set-point to a lower or normal level. Patients react with sweating and vasodilation to release the excess heat generated in the previous phase<sup>3</sup>.

### Benefits of fever

The balance between fever risks and benefits has been the subject of much controversy in recent years. Fever is a normal body defence in response to a perceived threat to the immune system that marshals innate, adaptive and neuro-endocrine responses. Homeostatically, an elevated temperature enhances immune system function<sup>7</sup>. Elevations in body temperature can improve the efficiency of macrophages in killing invading bacteria, and limit the available iron needed for the replication of many microorganisms<sup>8</sup>. Fever also enhances immunologic functions such as the lymphocyte response to mitogens, the bactericidal activity of neutrophils, the production of interferon, and the secretion of corticotrophin and cortisol<sup>5</sup>. A number of intervention studies support the notion that fever is an important physiological response to infection and that the administration of regular paracetamol to reduce fever is associated with a reduced antibody response, delayed recovery and the prolongation of symptoms<sup>8,9</sup>.

### Side effects

Despite its therapeutic intent, fever also has adverse side effects such as dehydration and an increased metabolic rate. It is reported that a 1°C increase in temperature over 37°C results in a 10%–12% increase in metabolic rate and the loss of 250 ml of fluid from the body in 24 hours<sup>10</sup>. Shivering in fever can increase the metabolic rate from 100% to 200%, leading to increased oxygen consumption and carbon dioxide production<sup>10</sup>. Patients who have respiratory, cardiovascular or metabolic disorders find it difficult to tolerate the increased rate of oxygen consumption caused by fever<sup>3</sup>. Fever in these patients should be reduced to prevent deterioration.

Overall, fever enhances the body's immune system, which strengthens the normal body defence. Nevertheless, the physiological response to fever might be harmful for patients in some cases. For example, in cancer, fever can be a sign of drug allergy to the monoclonal antibodies often used in cancer therapy<sup>11,12</sup>. In addition, febrile neutropenia is one of the major causes of chemotherapy interruptions and dose reductions, which can potentially compromise the efficacy of cancer treatment, add considerably to the length and cost of treatment and adversely affect survival outcomes in curative settings<sup>13,14</sup>. It is, therefore, important to be able to differentiate between the causes and effects of fever to determine the most appropriate response.

## Aetiology of fever in cancer patients

### Infectious origin

Studies indicate that the infectious origins of fever in cancer patients are bacterial, fungal and viral<sup>15-17</sup>. A prospective study (2000–2001) audited the cause of fever among 371 hospitalised neutropenic and non-neutropenic cancer patients. Amongst 477 febrile episodes, infection was reported as the main cause (67%, n=319)<sup>15</sup>. Amongst 206 infectious episodes where the pathogen was identified, bacteria were the most frequent cause (90%, n=256), followed by fungi (6%, n=17) and viruses (4%, n=11). Gram-negative bacilli predominated (48%, n=137) in comparison with Gram-positive cocci (33.5%, n=95) and Gram-positive bacilli (4.6%, n=13). The most frequent site involving infection was the respiratory tract (29%, n=92), followed by secondary bacteraemia (16%, n=50) and the urinary tract (12.9%, n=41). According to Toussaint and colleagues, fever of infectious origin in neutropenic patients (n=239 in 357 episodes) was not significantly more frequent than in non-neutropenic patients (n=80 in 115 episodes, p>0.05)<sup>15</sup>.

These findings are supported by further studies. For example, a retrospective audit (2001–2006) of 95 acute myeloid leukaemia patients during chemotherapy (382 febrile episodes) reported a similar incidence of infectious aetiology (64%, n=244)<sup>16</sup>. Respiratory tract infections were the most common (27%, n=46) in 170 episodes that could determine sites of infection. Bacteria were the most common origin of infection (88%, n=72) of 82 episodes in which microbiological isolates could be obtained, followed by fungi (n=60 episodes). Gram-negative organisms predominated (63%, n=60)<sup>16</sup>. Another retrospective study (2007–2008), which collected data from a computerised registry of 3,197 cancer patients (869 febrile episodes), confirmed similar findings<sup>17</sup>. In Pagano *et al.*'s study, infection was the most common cause of fever (50%, n=435) of which 301 episodes were

initiated by bacterial infection, followed by fungi (13.9%, n=121) and viruses (1.8%, n=16)<sup>17</sup>. Eighty-five per cent (241 cases) occurred in the blood stream (216 cases were primary sepsis), followed by the respiratory tract (10.6%, n=30)<sup>17</sup>.

Chemotherapy is one of the most common indirect instigators of fever in cancer patients, as it causes bone marrow suppression. White blood cells (WBCs) usually reach their lowest levels seven to 14 days after chemotherapy and take one to two weeks to recover spontaneously, leading to the risk of infection<sup>18</sup>. The incidence of febrile neutropenia in patients receiving chemotherapy varies from 6% in patients having breast cancer, to an estimated 10–50% of patients with solid tumours and in more than 80% of patients with haematological malignancies<sup>19</sup>. The frequency of infections ranges from 35% to 78% during induction chemotherapy, and up to 65% during consolidation chemotherapy in acute leukaemia patients<sup>16</sup>. When chemotherapy is used to decrease tumour size prior to surgery, surgery can only be performed when there is adequate bone marrow recovery after chemotherapy. However, post-chemotherapy tumour resections tend to be rather lengthy surgical procedures, increasing the risk of infection that then further raises fever incidence<sup>20</sup>. Oncology patients might be at high risk of postoperative fever due to their low baseline health status, could be malnourished and have chronic immunosuppression from multiple cycles of chemotherapy<sup>20</sup>.

### Non-infectious origin

Cancer is associated with non-infectious fever due to the allergic and inflammatory responses that result from tumour necrosis and the thrombotic events that result from cancer-related conditions such as disseminated intravascular coagulation<sup>21</sup>. All of these processes are associated with the production of pyrogenic cytokines. Tumours can also increase susceptibility to infection through the destruction of normal anatomical barriers<sup>19</sup>. For example, Toussaint cites 112 cases of non-infectious fever in cancer patients, attributed to the tumour itself (27%, n=42), followed by medication (18%, n=28) and post-surgical procedures (17%, n=26)<sup>15</sup>.

Blood transfusion in cancer patients is also associated with the risk of fever<sup>22</sup>. Transfusions of blood products provide vital haemodynamic and other support for oncology patients. They are indispensable in the treatment of patients with cancer, particularly those with leukaemia, lymphoma, and those requiring stem cell transplant. However, blood transfusions carry risks of adverse reactions to blood components and of infection owing to undetected viruses and/or bacteria in the

blood products<sup>22</sup>. This can lead to febrile haemolytic, febrile non-haemolytic and bacterial febrile reactions. In haemolytic reactions, immediate onset of fever can occur during or after the administration of blood due to antigen incompatibility, followed by other severe reactions events such as chest pain, shock and renal failure<sup>21</sup>. Febrile non-haemolytic transfusion reactions, the most commonly reported transfusion reaction, have a complex aetiology<sup>22</sup>. These reactions are primarily due to anti-leukocyte antibodies in the recipient, which react to the antigens of transfused WBCs. Febrile non-haemolytic transfusion reaction is characterised by chills, fever with a rise of temperature of at least 1°C within four hours of transfusion (usually within a few minutes), and defervescence within 48 hours<sup>1</sup>. In addition, febrile reactions can result from bacterial antigens or endotoxins in the carrying solution or the tubing. Bacterial contamination can also be transmitted from a donor or during collection, processing, or storage of blood products. In these instances, fever can occur immediately after the infusion has started<sup>1</sup>.

In addition, fever can be a possible adverse event in patients receiving monoclonal antibodies<sup>21,23</sup>. Monoclonal antibodies are artificial immune system proteins that are able to bind the specific membrane surface proteins of a cancer cell to inhibit their replication<sup>23</sup>. Some cancer cells contain membrane surface proteins that are unique to cancer cells. Monoclonal antibodies recognise those proteins as foreign antigens and attach to them, thereby preventing cell division<sup>24</sup>. However, during this process monoclonal antibodies can cause allergic reactions, including fever<sup>1</sup>, which in some instances can be life-threatening<sup>24</sup>.

### Fever of unknown origin

Fever of unknown is defined as recurrent fever of 38.3°C or higher of at least three weeks, where no certain diagnosis of the fever cause can be identified after one week of investigation in hospital<sup>25</sup>. Febrile episodes associated with tumours have been reported because tumours can cause prolonged fever by intermittent necrosis with subsequent phagocytosis and cytokine production<sup>26</sup>. One large population-based study (n=43,205) showed that fever of unknown origin in cancer patients is associated with haematologic malignancies and some solid tumours<sup>25</sup>.

Despite different methodologies and samples, these studies provide evidence that cancer patients are clearly vulnerable to numerous sources of fever. Whilst fever is beneficial for the body in many ways, there is a need to manage it effectively in oncology patients to avoid unwanted consequences. Current guidelines for fever assessment and management in cancer patients are now reviewed.

## Current guidelines for fever management in cancer patients

### Nursing fever assessment

Non-invasive methods of measuring body temperature in the mouth, tympanic membrane, temporal artery and axillae are often used in practice<sup>27</sup>. However, there is conflicting evidence concerning the accuracy, precision, reliability and practicality of each type of non-invasive temperature measurement method<sup>28-31</sup>. Oral temperature is recommended by the Clinical Practice Guideline of Infectious Disease Society of America (IDSA) to define febrile episodes in neutropenic patients with cancer<sup>32</sup>. According to IDSA, axillary temperature does not provide an accurate core body temperature and rectal temperature should be avoided for hygiene reasons<sup>32</sup>. However, the guideline does not recommend alternatives for patients whose temperature cannot be measured by mouth, such as those with oral cancer. In addition, a study by Ciuraru and colleagues revealed that mucositis, an inflammatory process common in cancer patients, might result in an apparently increased oral temperature when compared with tympanic temperature readings, leading to misdiagnosis of fever<sup>33</sup>. However, this conclusion should be viewed with caution, as the study was limited by a small sample size (n=25 patients having mucositis) and used tympanic temperature as the reference standard, which itself is unreliable<sup>33</sup>. Their use of tympanic temperature was supported by Dzarr's prospective study, which reported that tympanic temperature readings were more consistent with rectal than oral and axillary temperature readings<sup>34</sup>. Although similarly small in sample, 21 haematology patients were recruited through convenience sampling in this study to simultaneously record oral, rectal, axillary and tympanic temperature readings twice a day until neutrophil counts recovered<sup>34</sup>. Amongst 400 separate temperature readings, tympanic thermometry had the highest agreement with rectal thermometry (intraclass correlation coefficient, ICC=0.8), compared to the agreement between oral, axillary and rectal measures (ICC=0.486)<sup>34</sup>. In contrast, several studies used oral temperature as the reference standard to evaluate the accuracy of tympanic temperature and concluded that tympanic temperature should not be used as it tends to yield inaccurate readings<sup>28,35,36</sup>.

### Nursing fever management

Pharmacological and non-pharmacological interventions, alone or in combination, are the mainstay of nursing fever management. Non-pharmacological interventions, mainly based on external cooling methods, are believed to promote heat loss through the skin by conduction, convection or evaporation<sup>37</sup>. While the

set-point hypothalamic temperature remains, these cooling methods actually raise core heat production in response to peripheral cooling. Thus, external cooling methods potentially lead to several adverse effects such as increased metabolic rate, increased oxygen consumption, shivering, vasoconstriction, vasospasm of coronary arteries and rebound hypothermia<sup>37</sup>. Therefore, external cooling should not be used until after antipyretic drugs have started to lower the elevated set-point, and only for comfort reasons<sup>38,39</sup>.

Drugs are used to both treat symptoms and to address the underlying cause of the fever. Antipyretic drugs used for symptom management, such as paracetamol, are believed to inhibit cyclo-oxygenase<sup>40</sup>. This enzyme is responsible for the release of prostaglandins from arachidonic acid, so its inhibition results in a lowering of the set-point temperature in the hypothalamus. Heat loss mechanisms are activated and thus body temperature is reduced<sup>137</sup>. Considerable risks of adverse effects of antipyretics, such as hypotension, liver damage, interactions with other drugs, renal and hepatic toxicity have been confirmed in children treated for cancer and in patients who use paracetamol chronically<sup>137</sup>. Furthermore, although the results of some comparative studies and reviews are inconsistent and inconclusive, none of them found that antipyretics reduced the duration of the illness causing the fever<sup>41</sup>. Indeed, evidence suggests that antipyretics can prolong the illness in patients with fever<sup>41</sup>. The risks and benefits of pharmacological and non-pharmacological methods to reduce fever are many and, as such, their use should be carefully considered in cancer patients and tailored to their therapeutic situation<sup>37,39,41</sup>.

Of more use are antimicrobial drugs, such as antibiotics, anti-virals and anti-fungals, which are used to both prevent and to treat the underlying cause of fever. Infection in neutropenic cancer patients is associated with significant morbidity and mortality, so it is common practice to treat all febrile neutropenic patients with broad spectrum intravenous antimicrobials whether the cause of the fever is known or not<sup>20</sup>. Prophylaxis with granulocyte colony stimulating factor (G-CSF) is also routine in febrile neutropenic patients to enhance their ability to mount a therapeutic defence by hastening WBC production<sup>32</sup>. In recent years, standardised tools and a number of guidelines have been developed for systematic assessment of febrile neutropenic risk in individual patients<sup>42</sup>. These guidelines, which are widely accepted, clarify whether fever in cancer patients should be treated and how it should be treated.

A number of evidence-based guidelines for fever management in adult cancer patients exist, indicating the general awareness of

the vulnerability of cancer patients during febrile episodes and the need to manage fever appropriately in those patients<sup>32,43-45</sup>. However, those guidelines do not embrace some relevant issues. First, cancer-focused guidelines for fever management mainly approach febrile episodes in neutropenic patients while other types of cancer patients, for example those experiencing fever as a result of their disease process or as an adverse event of immunological therapies, are not mentioned<sup>32,44</sup>. Secondly, although guidelines emphasise pharmacological therapy such as antibiotics, antimicrobials or prophylaxis with G-CSF, the appropriate use of antipyretics (such as paracetamol) is not discussed at all, and neither is the key role of nurses in fever management<sup>32,45</sup>. Moreover, although in some policies fever is defined an oral temperature of 38°C and above, few if any guidelines recommend the optimal way to measure it, the alternative site if an oral reading cannot be obtained, nor the optimal measurement methods to ensure accuracy and consistency across measures on the one patient and measures between patients<sup>32</sup>.

This confusion is mirrored in nursing practice. Research consistently suggests that nurses often do not fully understand the aetiology, rationale and symptoms of fever and do not practise evidence-based fever management<sup>46,47</sup>. Recent studies report that between 30% and 50% of nurses invariably regard fever as a harmful event requiring aggressive treatment<sup>46</sup>. Different studies report that nurses tended to treat fever and consider management options based on the temperature value alone rather than consideration of symptoms<sup>48-51</sup>. This is despite the fact that the threshold reported by nurses varied from 37.5°C to 41°C<sup>50</sup>. In addition, they also reported different choices of interventions, even those that are contraindicated such as "alcohol" and "ice packs to the groin"<sup>48,51</sup>. When asked for the rationale underpinning their choice of interventions, some responded that they based their decisions on "what worked" in the past for other nurses or their own experiences<sup>48</sup>.

These studies have many limitations, however, including small sample sizes and lack of validated tools; therefore, it is difficult to draw definitive conclusions from them. There is only one oncology-specific study, undertaken in 2013, which surveyed an online convenience sample of 54 nurses and doctors in cancer care<sup>52</sup>. Its findings are similarly difficult to generalise to oncology nursing due to a number of limitations. For example, the sample size is small, the validity and reliability of the instrument used to measure nurses' knowledge and attitudes is not reported, there is potential for participation bias as the survey was available only with online access, and the aggregate reporting of results

means the responses of the nurses and physicians cannot be determined.

## Conclusion

While fever is a natural and often therapeutic response in cancer patients, an understanding of its nature and potential effect on the patient should guide subsequent nursing management. Unfortunately, research indicates that there are many inconsistencies in the assessment and management of fever in cancer patients, and extant practice guidelines do not provide comprehensive or even evidence-based information as to appropriate nursing responses and the reduction of risk to patients. It is timely then to consider research to generate the high-level evidence required to guide cancer nursing assessment and management.

## Conflict of interest

The authors have no conflicts of interest to disclose.

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\*SSA: Somatostatin analogue



# A nurse-led survivorship intervention for survivors of Hodgkin lymphoma: a pilot study

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## Abstract

Long-term survivors of Hodgkin lymphoma (HL) experience a range of physical and psychosocial late effects of treatment. This study set out to pilot-test the capacity of a nurse-led, survivorship intervention to enhance awareness of health risks and adoption of healthy lifestyle behaviours. Thirty HL survivor participants who were at least five years post potentially curative treatment were recruited. The General Health Index and the Health Promoting Lifestyle Profile II measures were completed at four time points and demographics recorded. The intervention included: exploration of knowledge of health risks; screening for unmet supportive care needs and, delivery of a tailored survivorship care plan. Participants reported a range of issues, including fatigue (57%); "a lot of worry" (47%) and, feeling depressed (23%). Significant post-intervention improvements were reported for: physical activity ( $p=.014$ ); nutrition ( $p=.0005$ ); stress management ( $p=.002$ ) and health promoting lifestyle ( $p=.005$ ). This study suggests that the nurse-led intervention is feasible and has potential to improve awareness of health status and healthy lifestyle behaviours among survivors of HL.

## Introduction

The five-year survival rate for Hodgkin lymphoma (HL) exceeds 90% in many developed countries. The disease has a bimodal distribution occurring most commonly in early adult years (15 to 40) and late adulthood after age 55<sup>1</sup>. As such, survivors of HL have the potential to live for many decades with risk of late effects of treatment that can include second malignancies, cardiac dysfunction, endocrine dysfunction, infertility and psychosocial sequelae<sup>2</sup>. Many of these potential treatment-related late effects are avoidable or may be ameliorated by early detection, risk factor modification and self-management related to adoption of healthy lifestyle behaviours<sup>3</sup>. To date there is limited evidence to support specific recommendations to inform patients of ways to optimise their long-term well-being, but adoption of healthy lifestyle behaviours may offer opportunity to reduce impact or occurrence of treatment-related late effects<sup>3</sup>.

Many long-term cancer survivors successfully adapt to life after cancer and may even experience positive psychological effects from coping with their illness<sup>4</sup>. However, it is now recognised that some cancer survivors develop significant and lasting poor levels

of emotional health<sup>4</sup> and this remains a relatively unexplored area in relation to survivors of haematological malignancies<sup>5</sup>. Evidence from a qualitative study of 1024 cancer survivors of mixed diagnoses indicated that the transition from treatment to long-term survivorship was marked by significant emotional and psychosocial concerns. Eight hundred and ninety respondents (87%) were at least two years from completion of treatment. Almost half of the respondents (501; 49%) reported emotional concerns and over a half (542; 53%) found their emotional needs harder to cope with than their physical needs. Six hundred and fourteen participants (60%) reported relationship problems with a partner or spouse and a third (338; 33%) reported limited emotional resources available to them to cope with emotional needs<sup>6</sup>.

Evidence indicates that many people affected by cancer are largely unaware of their heightened health risks post primary treatment and are ill prepared to manage their future health needs<sup>7</sup>. In a survey of 1040 cancer survivors, of whom 406 (39%) were survivors of haematological malignancies, information needs regarding follow-up care and surveillance (738; 71%);

health promotion (707; 68%); late effects of treatment (655; 63%); psychosocial issues (561; 54%) and, sexual function and fertility (322; 31%) were prevalent<sup>8</sup>.

Unhealthy lifestyle behaviours such as physical inactivity, poor diet resulting in obesity and smoking, are associated with an increased risk of cancer, cardiovascular disease and other chronic conditions<sup>9</sup>. Self-care behaviours (such as diet and exercise) are associated with reduced risk of cancer and other chronic diseases in the general population and increasing evidence indicates they may also contribute to the long-term health and well-being of cancer survivors<sup>10</sup>.

Survivors of HL have been shown to overlook healthy lifestyle behaviours that may help reduce their risk of developing serious late effects<sup>11</sup>. Evidence indicates that interventions that lead to the adoption of health-promoting activities require lengthy consultations that focus on an individual's anxieties, examine past life experiences, aspirations for the future and, determine triggers that can be used to help individuals optimise their long-term health<sup>12</sup>. The delivery of dedicated follow-up care is an essential component of excellent cancer care. Essential components of effective models of survivorship care include comprehensiveness, a coordinated approach and individualised tailored care provision<sup>13,14</sup>. Nurse-led consultations can accommodate tailored, time-intensive consultations in a way that medical follow-up and surveillance clinics are not resourced to do<sup>15,16</sup>. However, to date there are no randomised controlled trials that have been undertaken with long-term survivors of haematological malignancies<sup>17</sup>. The goal of this study was to test whether behaviour change is possible and provides positive health benefits for HL survivors through delivery of a nurse-led intervention.

### Context of the study

This study was conducted in a haematology late effects clinic of a cancer centre in Victoria, Australia.

### Ethics

This study proposal was submitted to the hospital Ethics Committee and approval was granted in May 2010 (Project No 10/09). The study was also registered at The University of Melbourne, Human Research Ethics (HREC) and approval was gained on 21 September 2010 (Ethics ID 1034711).

Pathways for referral were in place for participants found to be in need of emotional support. The pathways were well established as per standard practice in the clinic.

### Methods

A mixed-method, pre/post test, pilot study.

### Aims

To pilot test the potential of a nurse-led health promoting intervention to:

- 1) improve HL survivors' knowledge of health-promoting behaviours
- 2) improve HL survivors' motivation to adopt health-promoting behaviours
- 3) improve HL survivors' perceptions of their health status
- 4) demonstrate a reduction in unmet information needs in relation to late effects and health worry associated with knowledge of the risks of developing late effects
- 5) demonstrate feasibility of implementing the intervention in usual care within existing resources.

### Eligibility criteria

Survivors of HL, at least five years post completion of potentially curative treatment; had received upper torso radiotherapy at any stage in their treatment history; and were a new referral to the haematology late effects clinic.

### Sample

The sample comprised thirty HL survivors.

### Data collection and measures

Demographic data was recorded from consenting participants' medical records including: age, gender, marital status, employment status, previous diagnosis, length of time since diagnosis and treatment completion, type of treatment received in the past, any relapses, performance status, current medications and co-morbidities.

Perceived health status was measured using the General Health Index<sup>18</sup>. This is a validated 22-item tool that measures perception of health and is made up of subscales measuring the concepts of current health, prior health, health outlook, resistance to illness and health worry<sup>18</sup>. Concurrent validity and construct validity using factor analysis have been established<sup>18</sup>.

Health-promoting behaviours were measured using the Health-Promoting Lifestyle Profile II<sup>19</sup>. This is a validated, 52-item tool that assesses frequency of engagement in health-promoting activities. Increased frequency of engagement was used to assess increased motivation to participate in healthy lifestyle behaviours in this study. The items are categorised into six subscales: physical activity; health responsibility; spiritual growth; nutrition; interpersonal relationships; and stress management<sup>19</sup>. Construct validity and reliability have been established<sup>19</sup>.

Emotional distress was measured using a supportive care needs screening tool<sup>20</sup> developed and tested for reliability and validity in the study site and used as a component of usual care. The measure was adapted for the purpose of this study but reliability and validity testing was not undertaken. The adapted late effects supportive care needs screening tool measured unmet need in communication and understanding, physical health, emotional

health, activities of daily living, support and coping, support services and information.

Participants were asked to complete data assessments at four separate intervals across 6.5 months to test the impact of the clinic intervention, with the exception of the late effects supportive care needs screening tool which was completed at baseline (T0) only. This tool was given to participants in the outpatient waiting area and completed prior to entering the clinic room, as per standard practice in the late effects clinic.

All other measures were completed at baseline (T0 – recruitment to the study), at two weeks after the first intervention (T1); at two weeks after the second intervention (T2) and two months after the second clinic intervention (T3). In addition to the study measures, detailed field notes were recorded by the intervention nurse after each face-to-face consultation and telephone interaction, to record participants' experience of the intervention.

### Recruitment and baseline data

Participants who received potentially curative treatment for HL were recruited from referral lists to the haematology late effects clinic between 1 August 2010 and 31 May 2011.

Once eligibility was established, potential participants were contacted by the late effects survivorship nurse who invited participation and permission to mail out a patient information sheet and consent form. If consent was given, the baseline measures were sent via mail to the participants.

### The intervention

The intervention was delivered to participants by the late effects survivorship nurse during two face-to-face consultations, during a visit to the haematology late effects clinic and two telephone consultations (Figure 1).

**Intervention 1** was delivered one month after recruitment to the study at the first clinic consultation. Participants received a face-to-face, tailored education consultation that was based on needs identified from the baseline measures. The consultation included delivery of a tailor-made education package that included information provision and resources that addressed physical activity; healthy eating; smoking status; alcohol consumption; relevant self-examination; sun protection; sexual health and fertility; mental health; and a list of recommended websites and reading.

The aim of intervention 1 was to inform participants about the importance of healthy lifestyle behaviours in a manner that motivated and promoted sustainable, behavioural change. Delivery of the tailored interventions was informed by theories of motivational interviewing<sup>21-23</sup> and evidence from successful randomised controlled trials of motivational interviewing undertaken with survivors of cancer<sup>21,24,25</sup>. Explanation and

rationale for the health-promoting strategies tailored to each participant was a key element of the intervention consultation.

Participants' responses to strategies recommended were elicited and coaching and problem-solving strategies were used to support individuals to incorporate health-promoting behaviours into their daily life. Finally, realistic goals were set with each participant to optimise motivation to self-manage and adhere to recommended behaviours.

Two weeks after the first intervention, each participant received a call from the intervention nurse (telephone intervention 1) to reinforce interventions and to clarify any questions regarding the health-promoting strategies prescribed.

**Intervention 2.** The second face-to-face consultation took place four months after recruitment to the study and was dedicated to reinforcement or modification of strategies introduced during the first intervention session. It provided the nurse and participants with an opportunity to explore ongoing or new concerns and gain support to address any new areas of concern. During this consultation, participants

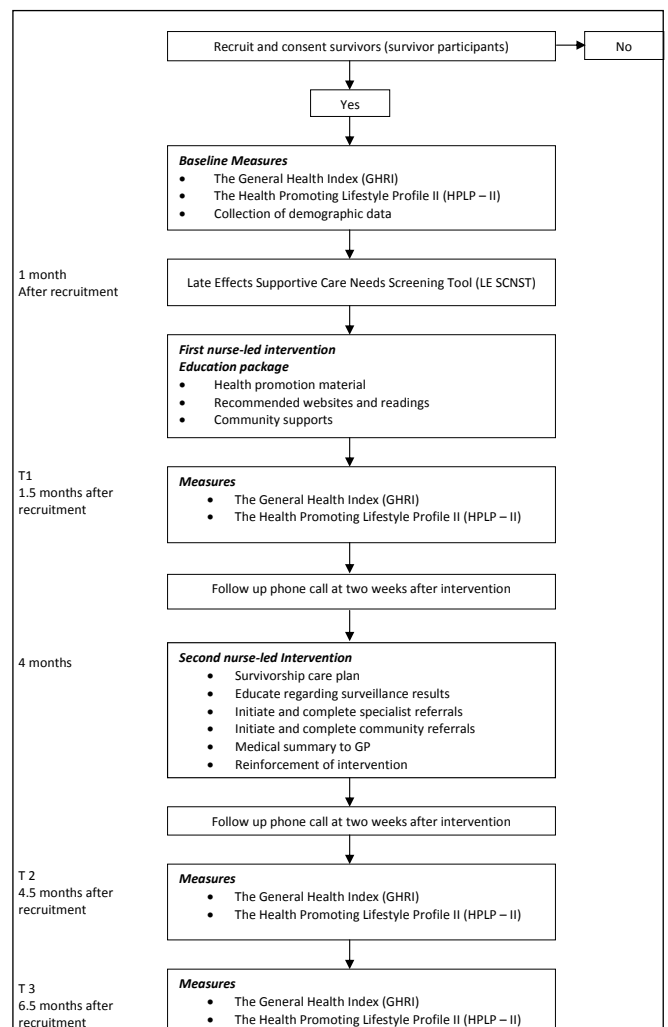


Figure 1: Study schema



received a copy of an individualised Survivorship Care Plan. The Survivorship Care Plan included details of medical history, treatments received, potential for late effects, requirements for follow-up appointments, tests and reasons for them. The care plan focused on the importance of health-promotion activities and provided advice on how to adopt healthy behaviours. It also addressed psychosocial issues, how to identify them and where to get help. The purpose of the Survivorship Care Plan document and the timing of its delivery in this study was to raise awareness of the importance of surveillance, healthy living and a coordinated plan of follow-up care. Their individual risk for potential late effects and the requirements for follow-up appointments, recommended tests and reasons for them were clarified by the intervention nurse. Recommended health behaviours were explained and problem-solving strategies to enable adherence, motivation to adopt the behaviours and self-management were explored, using motivational interviewing techniques.

The Survivorship Care Plan was used to assist participants to move from a structured system of care (treatment phase) to a 'non-system' (survivorship) phase in which there are few guidelines to assist them through to the next stage of life<sup>26</sup>.

A copy of the care plan was mailed to each patient's primary care physician to help ensure they were kept up-to-date with information essential to monitoring their patient's health and to highlight to the patient that they had a source of support and advice close to home.

Telephone intervention 2 took place two weeks after the second clinic intervention. This session was directed at reinforcing strategies introduced during the intervention sessions summarising the main issues discussed, reviewing the recommended health behaviours, and encouraging adoption of these behaviours. Participants were encouraged throughout the session to ask questions to clarify any issues or address any concerns.

The face-to-face intervention consultations aligned with standard late effects clinic follow-up appointments, maximising convenience for participants as they did not have to return to the cancer centre for any additional appointments.

### Data analysis

All data were entered into SPSS Windows Version 20.0<sup>27</sup>. Self-report measures were scored according to their manual or validation papers Health-Promoting Lifestyle Profile II<sup>19</sup> and General Health Index<sup>18</sup>. Scores of multi-item scales were calculated as the mean of the non-missing items, if over half of the items were completed<sup>28</sup>. Descriptive statistics and graphical displays were used to identify missing and out-of-range values and assess the distributional characteristics of test scores prior to formal data analysis<sup>29</sup>. Descriptive statistics (n, percentage of total; mean, standard deviations; or median, interquartile range,

as appropriate) were used to summarise demographic data for participants. In addition, clinical, supportive care needs, physical and emotional health and activities of daily living data were described.

A mixed-model repeated measures analytical framework was applied to all primary outcome analyses for all available data for the General Health Index and the Health-Promoting Lifestyle Profile II. Models were estimated by maximum likelihood, and an unstructured variance-covariance matrix was used to model the covariance structure among repeated measures. A cell mean model was used to compute estimates of the means at each assessment time (baseline and follow-ups one through three). Estimates of change in study outcomes at follow-up assessments from baseline levels were calculated using contrasts within each model<sup>30</sup>. The Bonferroni correction was applied to adjust tests for multiple comparisons; in this case, alpha was set at  $0.05/3 = 0.017$  (two-tailed).

### Results

Thirty-four patients met the study eligibility criteria and were approached to participate. Three patients elected not to participate for the following reasons: not being able to take time off work to attend a clinic appointment; feeling they had nothing to contribute to the study as they had no side effects from treatment; and no reason to attend the late effects clinic. In field notes recorded by the intervention nurse, one patient approached to participate in the study expressed:

*I don't need to come to that clinic — cancer was 10 years ago — I'm over it!*

Of the remaining 31 patients, one was ineligible as they had no previous radiotherapy exposure, leaving 30 patients. One participant withdrew from the study prior to the second nurse-led intervention due to finding the clinic appointments too stressful:

*I am too busy at work to take time off to come to clinic — work [is] very important, normalises my life. Can't take time off for doctors' appointments and tests! Seeing the doctor freaks me out — brings it all back when I want it all to go away. Even though appointments are only twice a year I think about them all the time and they come up so quickly. (ID code 31)*

The demographic and clinical characteristics of participants are presented in Table 1.

*Supportive care needs:* Participants were asked to complete the late effects supportive care needs screening tool to screen for unmet emotional health needs at baseline. Dominant needs during the past 12 months included pain (14; 48.3%); fatigue, tiredness or lack of energy (17; 56.7%); sleep concerns (11; 36.7%) and, lack of sexual interest (10; 33.3%). Nearly half (14; 46.7%) of the participants reported that during the past two weeks they



Table 1: Demographic characteristics at baseline (n=30)

Age at baseline, years	n = 30	%
Median	45.3 (range 27–72)	
Gender	n = 30	%
Male	19	63.3
Female	11	36.7
Marital status	n = 30	%
Married/de-facto	28	93.3
Never married	2	6.7
Employment status	n = 30	%
Full-time	15	50.0
Part-time	7	23.3
Home duties	4	13.3
Retired	1	3.3
Unemployed	2	6.7
Other	1	3.3
ECOG performance status	n = 30	%
0	28	93.3
1	2	6.7
Age at diagnosis, years	n = 30	
Median	27.6 (range 11–50)	
Time since diagnosis, years	n = 30	
Median	17.1 (range 6–47)	
Time since treatment, years	n = 30	
Median	16.1 (range 5–47)	
Cancer treatment modality	n = 30	%
Chemotherapy	24	80.0
Radiotherapy	30	100
Surgery	11	36.7
Autologous transplant	8	27.0
Allograft	1	3.0

had felt a lot of worry or anxiety and nearly a quarter (7; 23.3%) felt sad, flat or depressed most of the time. Three participants (10%) reported that during the past two weeks they had thoughts about hurting themselves or suicide (Table 2).

Participants strongly articulated the ongoing emotional stress in their lives since their cancer diagnosis. Field notes captured the following:

*No one has cared since my treatment finished. Cancer stuffed my life — financially and in every way! Not where I should be. Cancer stopped me from achieving what I should be ... I saw a psychologist during my treatment and they did stuff all — what's the use seeing one again. I still get so angry ... cancer stuffed my life ... my wife hates when I get angry, she couldn't take it anymore! (ID code 30)*

Table 2: Supportive care needs at baseline (n=30)

Number	Question	n=30	%
Your physical health			
	During the past 12 months have you had any of these health concerns for more than a few days:		
	Fatigue, tiredness or lack of energy?	17	56.7
	Sleep problems?	11	36.7
Your emotional health			
	Have you felt sad, flat or depressed most of the time?	7	23.3
	Have you felt a lot of worry or anxiety?	14	46.7
	Have you had thoughts about hurting yourself or suicide?	3	10.0
	Are you currently receiving treatment for psychological/emotion concerns?	5	16.7
Information			
	Would you like some/more information about:		
	Your previous diagnosis or treatment?	18	60.0
	Services to support your emotional well-being?	10	34.5
	Have you any questions that you would like to ask today?	8	26.7

Eighteen (60%) participants reported unmet information needs and required more information regarding their previous diagnosis of HL and its related treatment. A third (10; 33.3%) required information on how to access services to support their physical needs and a third (10; 33.3%), required information on how to access services to support their emotional well-being. Eight participants (26%) reported that they had ongoing information needs and had questions that they wanted to ask at the clinic appointment.

*Perception of risk:* Participants were asked to complete the Health-Promoting Lifestyle Profile II and the General Health Index at four time points over the six and a half months. The participants reported minimal change in perception of health across the seven subsets over the four evaluation time points (Table 3).

Self-reported perceived levels of current health, prior health, health outlook, resistance to illness and overall general health rating index decreased from baseline to follow-up three; however, none of the changes were statistically significant. Health worry/concern and sickness orientation increased from baseline to follow-up three; but again were not statistically significant.

*Health lifestyle behaviours:* Participants reported positive change in all healthy lifestyle behaviours, across the seven subsets over the four evaluation time points (Table 4).

Table 3: Perceived health status. Results of mixed-models analysis, estimates at baseline and follow-up assessments and mean changes from baseline (n=29)

Outcome measure	Baseline		Follow-up 1		M change (95%CI)	P	Follow-up 2		M change (95%CI)	P	Follow-up 3		M change (95%CI)	P
	M	(SE)	M	(SE)			M	(SE)			M	(SE)		
General Health Index														
Current health	31.5	1.38	30.8	1.38	-.70 (-2.23, .83)	.36	31	1.58	-.51 (-2.02, 1.00)	.5	30.8	1.59	-.68 (-2.21, .84)	.37
Prior health	5.6	0.4	5.8	0.47	.17 (-.67, 1.01)	.69	5.9	0.46	.30 (-.52, 1.11)	.46	5.5	0.42	-.14 (-.97, .69)	.73
Health outlook	12.5	0.54	12.7	0.54	.13 (-.48, .75)	.66	12.4	0.59	-1.07 (-.87, .66)	.78	12.4	0.64	-.11 (-.85, .64)	.78
Resistance to illness	11.7	0.74	11.8	0.72	.07 (-.86, .99)	.88	11.2	0.7	-.45 (-1.28, .37)	.27	11.6	0.7	-.14 (-1.13, .84)	.76
Health worry/ concern	13.1	0.7	12.8	0.65	-.30 (-1.04, .44)	.42	12.8	0.72	-.38 (-1.14, .38)	.32	13.3	0.65	.13 (-.70, .96)	.75
Sickness orientation	7.7	0.36	7.6	0.35	-.13 (-.69, .43)	.63	8	0.29	.34 (-.25, .93)	.25	8	0.3	.34 (-.24, .93)	.24
General Health Rating Index	66.9	2.66	66.8	2.55	-.13 (-2.59, 2.32)	.91	66.2	3.08	-.66 (-3.33, 2.01)	.62	65.9	3.06	-1.00 (-4.07, 2.05)	.51

Notes: For the General Health Index, higher scores reflect higher levels of the construct being measured. In this case, a positive M change indicates improvement for all scales; if significant after adjustment for multiple testing (.05/3), p-values in bold for emphasis

Table 4: Lifestyle profile. Results of survivor participants mixed-models analysis, estimates at baseline and follow-up assessments and mean changes from baseline (n=29)

Outcome measure	Baseline		Follow-up 1		M change (95%CI)	P	Follow-up 2		M change (95%CI)	P	Follow-up 3		M change (95%CI)	P
	M	(SE)	M	(SE)			M	(SE)			M	(SE)		
Lifestyle Profile II														
Health responsibility	2.26		2.3	0.11	.05 (-.09, .19)	.5	2.34	0.1	.08 (-.05, .21)	.21	2.38	0.1	.13 (-.01, .26)	.071
Physical activity	2.25		2.39	0.12	.14 (.009, .27)	.037	2.45	0.12	.20 (.04, .36)	<b>.014</b>	2.49	0.13	.24 (.07, .40)	<b>.007</b>
Nutrition	2.46		2.67	0.1	.21 (.11, .31)	<b>&lt;.0005</b>	2.7	0.09	.23 (.14, .33)	<b>&lt;.0005</b>	2.65	0.11	.19 (.06, .32)	<b>.006</b>
Spiritual growth	2.88		2.96	0.1	.08 (-.08, .24)	.32	3.04	0.11	.16 (-.02, .34)	.084	3.04	0.11	.16 (-.008, .33)	.061
Interpersonal relations	2.98		3.03	0.08	.05 (-.14, .23)	.6	3.07	0.1	.10 (-.10, .29)	.32	3.07	0.1	.10 (-.09, .28)	.29
Stress management	2.33		2.44	0.1	.11 (-.01, .24)	.082	2.53	0.1	.20 (.08, .32)	<b>.002</b>	2.5	0.1	.17 (.05, .30)	<b>.006</b>
Health-promoting lifestyle	2.53		2.64	0.08	.10 (.009, .20)	.033	2.69	0.08	.16 (.05, .26)	<b>.005</b>	2.7	0.08	.16 (.05, .27)	<b>.006</b>

Notes: For the Lifestyle Profile II, higher scores indicate a greater number of habits consistent with a health-promoting lifestyle. In this case, a positive M change indicates improvement for all scales; if significant after adjustment for multiple testing (.05/3), p-values in bold for emphasis.

Self-reported health responsibility improved and physical activity improved significantly from baseline to follow-up three (p=.007). Significant change was demonstrated in physical activity after follow-up two at completion of the second nurse-led intervention (p=.014) and was continued.

Nutrition status significantly improved from baseline to follow-up three (p=.006), with significant change demonstrated in nutrition status after follow-up one at completion of the

first nurse-led intervention (p=<.0005). Stress management significantly improved from baseline to follow-up three (p=.006), and this change was demonstrated after follow-up two at completion of the second nurse-led intervention (p=.002). Overall, health-promoting lifestyle significantly improved from baseline to follow-up three (p=.006) and had been demonstrated after follow-up two at completion of the second nurse-led intervention (p=.005).

## Discussion

This pilot study has demonstrated the feasibility of delivery, and potential of the intervention to positively impact healthy lifestyle behavioural change in 30 long-term survivors of HL. Statistically significant behavioural change was demonstrated for: physical activity at follow-up time point two and three, nutrition at follow-up time point one, two and three, stress management at follow-up time point two and three; and health-promoting lifestyle at follow-up point two and three. However, care is needed in interpretation of the data as the numbers are small.

The interventions delivered addressed participants' biological, psychological and social needs and identified patient-centred goals and consultations highlighted recommended health behaviours in response to individualised health risks. During consultation, participants received personalised information regarding their health risks due to their previous treatment such as subsequent malignancies and cardiac dysfunction. They were informed of the need for lifelong surveillance to help detect any complications in a timely manner. For some, this was the first time participants had been told in detail and in a tailored way about their health risks as a consequence of their curative treatment.

This was clearly articulated by one participant:

*Before this clinic I didn't know that I was at risk of all these things. No one has ever told me. (ID code 11)*

Data indicate that the content of the nurse-led consultations, alongside participants' first attendance at the haematology late effects clinic, resulted in participants feeling that their health was not as good as they had perhaps originally thought. Despite the potential anxiety this information might have caused, it is imperative to inform survivors of their health risks as a result of the curative treatments they receive in order to maximise their potential for long-term health and wellbeing. This study indicates that education about vulnerability to health complications arising from curative cancer treatment and preventative measures to take are acceptable and potentially highly beneficial for HL survivors and should be a core component of health-promoting interventions for survivors of HL<sup>31</sup>.

The findings support previously reported evidence of the potential of nurse-led interventions to optimise health outcomes through a patient-centred approach to care, where information is tailored to the specific needs of a cancer survivor early in his or her survivorship trajectory<sup>5,14,32</sup>. The nurse-led consultations in this study were based on expert knowledge of the impact of HL and its associated treatments on individuals in order to determine survivors' future health risks and optimise their wellbeing.

Field notes captured during the study indicate that feeling more informed played a key part in participants' improved health outlook:

*When you explained the clinic over the phone I was so grateful. It was exactly what I needed and what I have been looking for. I broke into tears. (ID code 26)*

In addition, interventions that enable patients to feel more in control of and motivated to self-manage their health needs may reduce reliance on acute health service provision, presentations to community health providers or emergency departments. Further work is needed to test capacity of the intervention to reduce feelings of medical abandonment in the survivorship phase, reported by some patients<sup>14,17,31,33</sup>.

## Limitations

The pilot study recruited 30 patients from one late effects clinic, limiting generalisability and transferability of the findings. There was a lack of random assignment making it difficult to rule out the impact of confounding variables on the findings, but the intent of the study was to test the feasibility of the intervention ahead of undertaking an adequately powered randomised controlled trial as advocated for best practice trial development<sup>34</sup>.

The intervention nurse who recruited participants to the study was employed in the haematology late effects clinic as the survivorship nurse. Therefore, on referral to the clinic, patients were contacted by the nurse as per usual care. This duplication of roles may have resulted in potential participants feeling obliged to participate, although the voluntary nature of participation was repeatedly made clear.

The late effects supportive care needs screening tool was completed only at baseline by participants. It was not possible, therefore, to demonstrate changes in levels of distress throughout the nurse-led intervention. This is an important consideration for any future study.

## Conclusion

This pilot study demonstrated potential for significant healthy lifestyle behavioural changes for health responsibility, physical activity, spiritual growth, stress management and health promoting lifestyle for survivors of HL.

## Recommendation for future study and nursing practice implications

The multiple concerns reported by participants at entry to the study suggest that the intervention may have been delivered later than optimal in the survivorship trajectory. At baseline, participants were reporting significant unmet needs, many of which had been present for at least a 12-month period. Insights

from the study suggest that survivors of HL could benefit from a dedicated, end-of-treatment consultation; providing patients with information about their past diagnosis, associated treatments, their specific risks of developing late effects and, their need for long-term follow-up and the need for primary care integration.

Our findings highlight the importance of psychosocial screening at end of treatment and at defined time points during the first 1–2 years after treatment completion for survivors of HL. Structured screening may enable timely intervention for individuals at risk of emotional distress that may result in considerable negative impact on physical and emotional well-being, capacity to re-engage with aspects of life that bring pleasure and meaning, if left unaddressed.

A randomised controlled trial is now needed to further test the efficacy of the intervention; determine the optimal dose of the intervention; and to establish the best time to deliver the intervention to prevent the considerable levels of physical and emotional needs reported by this study group.

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# The usefulness of the Distress Thermometer in the management of cancer patients: a mixed methods approach

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## Abstract

### Objective

The aim of this study was to investigate the usefulness of the National Comprehensive Cancer Network (NCCN) Distress Thermometer and Problem List in identifying distress levels and psychosocial concerns over the cancer trajectory using a mixed-methods approach.

### Method

Eighty-five cancer patients from the Barwon South West region of Victoria participated in this study by completing the NCCN Distress Thermometer and Problem List over three time periods. Three case studies were also conducted to add a qualitative dimension.

### Results

Emotional concerns decreased as psychological distress levels decreased and a high level of physical concerns were consistent with a high level of psychological distress. Cancer patients' narrative accounts also supported the usefulness of the NCCN Distress Thermometer and Problem List as a screening tool.

### Conclusions

Findings are discussed with reference to implications for psychological/emotional support of cancer patients, the provision of supportive care services and directions for future research.

**Keywords:** Psychological distress, oncology, cancer, supportive care, Distress Thermometer, qualitative.

## Introduction

One in two people in Australia will experience cancer in their lifetime. This high incidence is anticipated to increase the demand on health care services. It will become increasingly important to streamline services according to the needs of the patients to ensure optimal cancer care. Research into the needs of cancer patients identifies psychological support as a priority<sup>1-5</sup>. The implementation of a screening tool to help identify psychosocial issues and concerns of cancer patients has been recommended to ensure that supportive care services are tailored to the specific needs of the patient<sup>5-7</sup>. The utilisation of this screening tool identifies patients with complex psychosocial needs allowing early intervention through referral to services such as social work, psychology or a cancer coordinator.

The diagnosis of cancer is stressful with moderate to high levels of psychological distress manifesting across the cancer trajectory<sup>2,6,8</sup>, that can, over time, develop into depression or anxiety<sup>12,8</sup>. Early intervention in cancer patients can enhance quality of life, increase compliance with treatment and reduce hospital admissions<sup>9</sup>. At certain stages across the cancer trajectory (for example at diagnosis, during treatment, at completion of treatment, during palliation and at recurrence) cancer patients experience higher levels of distress<sup>7</sup>. As such, it is recommended that screening for supportive care needs should be part of standard clinical practice<sup>9,10</sup>. Previous research indicates that health professionals confronted with distressed patients discourage the disclosure of emotional issues as they do not believe they have adequate skills to emotionally

support patients who do express concerns<sup>91</sup>. A screening tool can provide a context where the cancer patient feels at ease in disclosing issues or concerns impacting on their psychosocial wellbeing.

The Distress Thermometer, originally developed by Roth *et al.*, measures psychological distress levels and supportive care needs of cancer patients<sup>12</sup>. The National Comprehensive Cancer Network (NCCN)<sup>13</sup> adopted the Distress Thermometer and added a Problem List that included the practical, emotional, social, spiritual and physical concerns of the patient<sup>6</sup> and rates their overall level of distress using a rating scale from 0 (no distress) to 10 (extreme distress). The Problem List component of this tool helps the patient and the clinician to identify psychosocial issues that may also be impacting on the patient's distress level.

A considerable amount of international research has compared the NCCN Distress Thermometer and Problem List to other tools such as the 14-item Hospital Anxiety & Depression Scale (HADS) and the Brief Symptom Inventory (BSI-18)<sup>8,14,15</sup>. The Distress Thermometer was found to be quick and simple to apply<sup>8,14-16</sup>. Longitudinal studies that have conducted sequential screening with the NCCN Distress Thermometer and Problem List have identified that patients experience different distress levels across the cancer trajectory<sup>17-20</sup>. Research has also demonstrated that if cancer patients are screened sequentially and linked into supportive care services early there is a decrease in psychological distress and levels of depression and anxiety<sup>17</sup>.

Australian studies are limited<sup>21-25</sup>. The evidence indicates that the NCCN Distress Thermometer and Problem List is a reliable tool for identifying psychological distress in an Australian population<sup>22-24</sup>. Lee *et al.* found that the Distress Thermometer can improve the health clinician's ability to refer the cancer patient to the most appropriate supportive care service<sup>23</sup>. While Australian studies provide evidence that the NCCN Distress Thermometer and Problem List is a valid screening tool appropriate for an Australian context, there has been limited investigation of the use of the NCCN Distress Thermometer and Problem List across the cancer trajectory. Two recent literature reviews also supported further investigation of the efficacy of screening with a tool like the NCCN Distress Thermometer and Problem List<sup>5,16</sup>.

As part of its main priorities for Victoria's Cancer Supportive Care Policy, the Department of Health implemented the use of the NCCN Distress Thermometer and Problem List across Victoria in 2009<sup>26</sup>. The extensive use of the NCCN Distress Thermometer and Problem List across Victoria and evidence of the efficiency of the NCCN Distress Thermometer and Problem List over other screening tools supported the use of the tool for this study<sup>8,14,15</sup>.

Based on the recommendations by Snowden *et al.*<sup>16</sup> and Carlson *et al.*<sup>27</sup>, three qualitative case studies were included in the

present mixed-methods study to explore the usefulness of the NCCN Distress Thermometer and Problem List in identifying distress levels and psychosocial concerns across the cancer trajectory. Patients were asked about how being linked into a supportive care service impacted on their distress levels and sense of coping.

The primary aims of this study were to explore whether:

1. Referral to supportive care services early in the cancer trajectory would reduce psychological distress levels and improve emotional concerns and a sense of coping.
2. High numbers of physical concerns would be consistent with high levels of psychological distress.
3. Cancer patients would perceive the NCCN Distress Thermometer and Problem List as useful in identifying psychological distress and psychosocial concerns.

## Method

### Participants

Following appropriate ethics approval (Barwon Health and Deakin University), potential participants were identified via the main database at the participating cancer centre. Equal numbers of males and females within any tumour stream over the age of 18 years were invited to participate. Written informed consent was obtained and patients with cognitive impairment, literacy concerns, language deficit or advanced disease were excluded.

A total of 267 patients completed the initial NCCN Distress Thermometer and Problem List at baseline (T1). Of the 267 patients invited to participate in the study and complete a further two screening tools, 109 consented, 29 declined and 129 did not respond. Completion and return of a second NCCN Distress Thermometer and Problem List was viewed as consent. One hundred and nine participants completed the screening tool at T2, 10–12 weeks post baseline, and 85 at T3, 10–12 weeks post T2. Attrition over the two data time points (T2 and T3) was due to death, progressive disease and/or non-compliance. There were 6 participants that withdrew from the study, 9 died and 9 did not respond.

### Measure

The NCCN Distress Thermometer and Problem List was used to identify levels of psychological distress and psychosocial concerns<sup>6</sup>. The qualitative phase involved interviews with three participants and included questions about: the usefulness of the NCCN Distress Thermometer and Problem List in helping to identify psychological distress and supportive care needs; and the effect of referral to appropriate supportive care services on distress levels and sense of coping.

### Procedure

The study was conducted between 2009 and 2011. Approval was

obtained from the NCCN to reproduce and use the Distress Thermometer and Problem List. All new patients to the cancer centre routinely completed the NCCN Distress Thermometer and Problem List to screen for supportive care needs, as part of the Department of Health's implementation of the screening tool in 2009 (T1 survey). All patients who had completed this initial NCCN Distress Thermometer and Problem List in the clinic were sent an invitation by mail to participate in this project by completing a further two Distress Thermometers at 10–12 week intervals (T2 and T3 surveys), and/or to participate in an interview about the usefulness of the NCCN Distress Thermometer and Problem List. One interviewer conducted the case study interviews, which lasted for 30–45 minutes, which were conducted face to face in an office at the treatment centre. All interviews were audio-recorded and later transcribed verbatim, with pseudonyms used to de-identify participants.

### Statistical analysis

The number of patients with distress levels and psychosocial concerns were presented as frequency and a percentage across time points and compared using the chi-square statistic. The chi-square statistic compared the level of distress over time periods T1 to T3. The median and interquartile range (IQRs) of Distress Thermometer scores were calculated at each time point. The statistical significance of longitudinal change in distress levels across the three time points were analysed using the Friedman test. Subset analysis identified patients with moderate to high levels of distress. Scores for distress levels, emotional concerns, physical concerns and supportive care referrals over the three time periods were analysed using the Friedman test. A Pearson chi-square was performed to determine whether there was any relationship between distress levels and referral to supportive care services.

### Results

Table 1 shows participants by age, gender, cancer diagnosis and time since diagnosis. There were almost equal male (51%) and female (49%) participants and 90% were between the ages of 50 and 79 years. The predominant site of cancer diagnosis was breast (34%) and prostate (18%). Almost all of the participants (75%) were newly diagnosed (0–3 months).

Table 2 reports on the changes in the number of patients with psychological distress levels and psychosocial concerns listed in the NCCN Distress Thermometer and Problem List over the three time periods.

The number of practical, family and spiritual concerns was low for this sample of participants (Table 2). The highest practical concerns were financial (18%), work issues (10%) and transport (9%) at the first time period. The highest score for family issues was dealing with children (9%). There were only two participants (2%) who identified spiritual concerns at the first time period. Insurance/financial, transport and dealing with

Table 1: Distribution of participants according to gender, age group, cancer diagnosis, time since diagnosis

Gender	Number	Percentage
Male	43	51%
Female	42	49%
<b>Age group</b>		
30–39 yrs.	1	1%
40–49 yrs.	8	9%
50–59 yrs.	27	32%
60–69 yrs.	21	25%
>70	28	33%
<b>Cancer diagnosis</b>		
Breast	29	34%
Prostate	15	18%
Bowel	12	14%
Haematology	8	9%
Lung	5	6%
Head and Neck	5	6%
Skin	4	5%
Kidney	2	2%
Endocrine	1	1%
Liver	1	1%
Brain	1	1%
Pancreatic	1	1%
Oesophageal	1	1%
<b>Time since diagnosis at initial Distress Thermometer completion</b>		
< 1 month	10	11%
1–2 months	64	75%
2.1–3 months	6	7%
3.1–4 months	5	6%

children concerns were significantly reduced over the three time periods. All other practical, family or spiritual concerns were not significantly different over the three time periods. Emotional concerns showed the greatest difference over the three time periods.

### Frequency of distress

The NCCN Distress Thermometer and Problem List resulted in a total score for each patient from 0 to 10. The highest levels of reported clinically significant distress occurred at T1 for 32% of participants, of which 20% (17/85) were moderately distressed and 12% (10/85) were highly distressed (Table 3). The frequency of moderate distress remained relatively stable (18%–20%) but the frequency of high distress decreased from 12% to 3% over time. Twelve per cent (10/85) of participants identified no distress at T1 and the frequency of no distress experienced increased over the three time periods. At T3 36% (31/85) of

Table 2: The number of patients with distressing problems over the three time periods (T1, T2, T3)

Problem checklist	Frequency N (%)		
	T1	T2	T3
Practical			
Childcare	1 (1%)	1 (1%)	0 (0%)
Housing	5 (6%)	1 (1%)	2 (2%)
Financial/insurance	15 (18%)	8 (9%)	4 (5%)
Transport*	8 (9%)	2 (2%)	1 (1%)
Work	9 (10%)	6 (7%)	3 (4%)
Family			
Dealing with children	8 (9%)	2 (2%)	2 (2%)
Dealing with partner	6 (7%)	4 (5%)	4 (5%)
Ability to have children*	4 (5%)	0 (0%)	0 (0%)
Emotional			
Depression	11 (13%)	13 (15%)	10 (12%)
Fears*	33 (39%)	24 (28%)	14 (16%)
Nervousness*	37 (43%)	19 (22%)	14 (16%)
Sadness	26 (30%)	22 (26%)	17 (20%)
Worry*	44 (52%)	28 (33%)	25 (29%)
Loss of interest in usual activities	25 (29%)	20 (23%)	21 (24%)
Spiritual	2 (2%)	1 (1%)	1 (1%)
Physical			
Appearance	16 (19%)	14 (16%)	11 (13%)
Bathing	6 (7%)	3 (4%)	4 (5%)
Changes in urination	13 (15%)	8 (9%)	7 (8%)
Constipation	18 (21%)	18 (21%)	10 (12%)
Diarrhoea	9 (10%)	9 (10%)	12 (14%)
Eating	21 (25%)	17 (20%)	9 (10%)
Fatigue	40 (47%)	47 (55%)	44 (52%)
Feeling swollen	16 (19%)	19 (22%)	16 (19%)
Fevers	8 (9%)	9 (10%)	6 (7%)
Getting around	12 (14%)	15 (18%)	8 (9%)
Indigestion	21 (25%)	16 (19%)	14 (16%)
Memory/concentration	27 (32%)	30 (35%)	23 (27%)
Mouth sores	11 (13%)	11 (13%)	11 (13%)
Nausea	9 (10%)	19 (22%)	16 (19%)
Nose dry	10 (12%)	18 (21%)	15 (18%)
Pain	27 (32%)	25 (29%)	24 (28%)
Sexual	7 (8%)	14 (16%)	8 (9%)
Skin dry	22 (26%)	24 (28%)	28 (33%)
Sleep	30 (35%)	30 (35%)	28 (33%)
Feeling tingling	13 (15%)	9 (10%)	20 (23%)

\*Indicate highly significant  $p < 0.01$

Frequency of distress levels over the three time periods (T1, T2, T3)

participants identified no distress. Two-thirds of participants (18/27; 67%) who experienced moderate to high levels of distress were women.

Table 3

	T1	T2	T3
No distress	10 (12%)	26 (30%)	31 (36%)
Low distress (1–4)	48 (56%)	41 (48%)	36 (42%)
Mod distress (5–7)	17 (20%)	15 (18%)	15 (18%)
High distress (8–10)	10 (12%)	3 (3%)	3 (3%)

Using a chi-square statistic levels of distress over time periods 1 to 3 are significantly different at  $p = 0.004$

### Course of distress

There was a significant decrease in distress levels from T1 to T2 (median Distress Thermometer score at T1=1; IQR 0–3 at T2=0; IQR 0–1) and T3 (median Distress Thermometer score at T3=0; IQR 0–2,  $p < 0.01$ ). Of the participants who reported moderate to high levels of distress at T1 (median Distress Thermometer score=6; IQR 5–8) there was a decrease in distress score at T2 (median Distress Thermometer score=3 IQR 1–5) and T3 (median Distress Thermometer score=3 IQR 2–5,  $p < 0.0001$ ).

### Supportive care

Participants were referred to appropriate supportive care services based on their distress level scores and psychosocial concerns identified, using the NCCN guidelines<sup>3</sup>. Participants who obtained a score of 5–7 on the NCCN Distress Thermometer and Problem List were viewed as having a moderate level of distress, while a score of 8–10 was considered a high level of distress. Participants who experienced moderate or high distress levels were referred to supportive care services, although some participants declined the offer of services. Participants were also referred to supportive care services if they identified a number of psychosocial concerns, even if they also reported no or low levels of distress.

The total number of patients referred for supportive care was 67 at T1, 48 at T2 and 12 at T3. Referrals at T2 and T3 included patients who had been referred previously and new referrals. At T1 and T2 the most frequent supportive care referral was to oncology resources or information (56%). The next most frequent referrals were to a cancer support group (29%), a cancer link nurse (26%), social work (20%), dietitian (16%) or a psychologist (14%). At T1 a small number of participants ( $n=11$ ; 13%) were not referred to any supportive care services. This was because they either identified a low distress level or minimal psychosocial concerns.

Overall, there was a decrease in the need for referrals to supportive care services over the three time periods. In addition, most of the participants (25/27; 92%) who identified moderate to high levels of distress at T1 and were linked into supportive care services, then showed a reduction in distress levels at T2 or T3.

There was a decrease in referrals to supportive care services from T1 to T2 (median supportive care referral score at T1=2; IQR 1–3, median supportive care referral score at T2=1; IQR 0–1.5,  $p<0.001$ ). Of the participants who identified moderate to high distress scores, there was also a decrease in supportive care referrals from T1 to T2 (median supportive care referral score at T1=3; IQR 1–3, median supportive care referral score at T2=1; IQR 1–4,  $p<0.001$ ). Of the participants with moderate to high distress scores 81% (22/27) were linked into 2–5 supportive care services at T1 ( $p<0.006$ ).

### Emotional concerns

Of the total sample, 69% (59/85) of participants identified 1–5 emotional concerns at T1. There was a decrease in the number of emotional concerns identified from T1 to T2 (median Distress Thermometer emotional concerns score at T1=2; IQR 0–4, median Distress Thermometer emotional concerns score at T2=1; IQR 0–3,  $p<0.001$ ).

Of the 27 participants who identified moderate to high distress scores, all identified emotional concerns at T1. There was a decrease in the amount of emotional concerns identified from T1 to T2 (median Distress Thermometer emotional concerns score at T1=4; IQR 3–5, median Distress Thermometer emotional concerns score at T2=3; IQR 0–4,  $p=0.005$ ).

At T1, the most frequent emotional concerns identified were worry (44/85; 52%), nervousness (37/85; 43%) and fears (33/85; 39%). Depression was identified by 13% of participants at T1 and is the only emotional concern that increased at T2 (13/85; 15%). At T3, participants identified worry (25/85; 29%) and loss of interest in usual activities (21/85; 24%) as the most frequent emotional concern.

### Physical concerns

Of the total sample, 80% (68/85) of participants identified physical concerns at T1. There was no significant change in the number of physical concerns from T1 to T2 (median Distress Thermometer physical concerns score at T1=3; IQR 1–6, median Distress Thermometer physical concerns score T2=4; IQR 1–7,  $p=0.494$ ). However, of the participants who identified moderate to high distress scores at T1, there was a decrease in the number of physical concerns identified from T1 to T2 (median Distress Thermometer physical concerns score at T1=8; IQR 4–10, median Distress Thermometer physical concerns score at T2=5; IQR 3–9,  $p=0.046$ ).

At T1, 70% (7/10) of participants with high levels of distress (8–10), also identified 10 or more physical concerns and four or more emotional concerns. At T1, fatigue, sleep, pain and memory/concentration were the most commonly reported physical concerns (Table 2).

At T2 and T3 fatigue remained as the greatest physical concern for almost half of the participants.

### Qualitative analysis

A narrative of the three case-study interview participants' cancer experiences was created from the interview data. Cross-case analysis was undertaken using a content analytic strategy. The interview data were coded into two broad categories:

- 1) usefulness of the NCCN Distress Thermometer and Problem List in assisting with concerns; and
- 2) the impact of supportive care services on the cancer patients' sense of coping. Similarities and differences in these categories across the three cases were identified. The content was reviewed by two independent reviewers. Assumed names are used in this report and individual quotes from participants used for illustrative purposes are italicised.

#### David

At the time of interview, David was 70 years old with a newly diagnosed head and neck cancer. He had recently completed surgery, chemotherapy and radiotherapy. David was married and lived with his wife. He had four adult children who he described as being very supportive. He used to work as a plumber and had recently retired.

David agreed that the NCCN Distress Thermometer and Problem List had been useful in alerting him to psychosocial concerns. He admitted that he initially felt confused about which psychosocial concerns he should identify:

*... when I'm filling it out I think to myself; I wonder why I've got to fill that out.*

However, after looking at the items listed in the tool, he realised there were some issues he needed help with:

*Then I say; well, if there was anything wrong with me [they'd] have to know about it.*

David thought that the NCCN Distress Thermometer and Problem List had helped him to confront his concerns, and to communicate these concerns to clinicians.

David had not been referred to any other supportive care services; nevertheless, he described the nursing and reception staff to be very supportive and terrific.

David confirmed that he felt supported because the staff provided a *supportive environment*. David defined a supportive environment as being:

*a good place, a good environment because everything is there.*

He did not indicate, however, what impact this had on his sense of coping.

#### Ann

Ann was a 45-year-old female who had been diagnosed with



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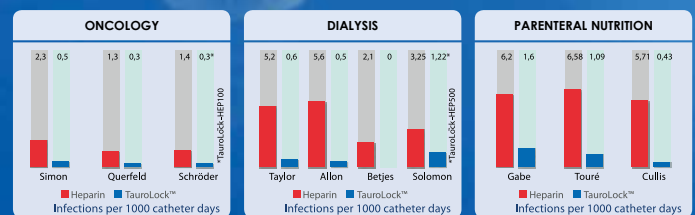
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\* Punt, C.D., Boer, W.E. Cardiac arrest following injection of concentrated trisodium citrate. *Clinical Nephrology*, 2008, 69: 117-118. \*\* Willicombe, M.K., Vernon, K., Davenport, A. Embolic Complications From Central Venous Hemodialysis Catheters: Used With Hypertonic Citrate Locking Solutions. *American Journal of Kidney Diseases*, 2010, 55: pp 348 - 351. \*\*\* Palaschegg, H.-D., Sodemann, K. Risks related to catheter locking solutions containing concentrated citrate. *Nephrol. Dial. Transplant.* 2003, 18: 2688-2690. \*\*\*\* Schlicher, G., Palaschegg H.D., et al. Hypertonic Trisodium Citrate Induces Protein Precipitation in Hemodialysis Catheters. *Selected ASN Meeting Abstracts*, 2011

early breast cancer. Ann had undergone a mastectomy and an axillary node clearance. She had completed chemotherapy and was currently on hormonal treatment. Ann lived with her husband and two children aged eight and 10 years.

Ann reported that utilising the NCCN Distress Thermometer and Problem List had helped to validate and confirm her emotional concerns, especially her depression. In addition, Ann felt that the tool also highlighted and confirmed the areas she did not have concerns about. Ann admitted that, although:

*there were a lot of things [she] didn't have worries about ... [she still had concerns about her] emotional wellbeing and her feelings of depression.*

Ann's opinion was that the NCCN Distress Thermometer and Problem List helped in alerting her to the areas where she needed more support. She felt that the NCCN Distress Thermometer and Problem List directly facilitated her:

*being offered the help of a psychologist and a referral to the lymphoedema clinic.*

She considered that the way in which the emotional concerns were listed (as feelings) made it easier for her to identify where she had concerns. Ann expressed that initially when she had first:

*... seen [Distress Thermometer and Problem List] with all things to tick [it had confronted her but then] curiosity overtook [her] sense of dread.*

She found the NCCN Distress Thermometer and Problem List to be very helpful in identifying her concerns.

Ann described her experience of supportive care services as being very positive and acknowledged that it helped her to cope through her cancer treatment. She felt that the psychologist's support played a large role in her coping with her cancer treatment. Ann considered that the ability:

*... to have someone to talk to that is not a family member who might attack me and to know that they are qualified to hear the things I say.*

This was the most important thing that the psychologist provided. Ann also thought that the fact she had direct access to the psychologist through the hospital was important. In Ann's opinion it meant that the psychologist was:

*familiar with notions surrounding palliative care and other issues [which meant she did not need to explain her story again].*

Ann accessed other supportive care services and considered that they were very helpful also in providing emotional support and information. She considered that the breast care nurse:

*allayed [her] concerns and provided her with a sense of reassurance.*

Ann felt other services like the lymphoedema clinic and education sessions on wigs and makeup provided her with information that:

*...empowered [her] to take care of herself.*

### Paul

Paul was a 60-year-old man diagnosed with advanced prostate cancer. He had been treated with hormonal therapy and radiotherapy. He was completing chemotherapy at the stage of the interview. Paul lived with his wife on a farm in a regional area of Victoria. He had two daughters living in Melbourne. Paul used to be employed as a building contractor and had retired from this position when he bought the farm. Paul expressed that it had become increasingly difficult for him to manage the farm and that he had thought about selling it.

Paul considered that the NCCN Distress Thermometer and Problem List was most useful in identifying and communicating his physical concerns. He felt that the NCCN Distress Thermometer and Problem List helped communicate his:

*degree of sickness [to the doctors].*

Paul's opinion was that the NCCN Distress Thermometer and Problem List alerted the doctors to his psychological distress and physical concerns. He stated he identified certain physical concerns on the Problem List so he could:

*convey to the doctors how he felt ... [which, he hoped] would spur them along to [give him] treatment.*

Paul considered that commencing treatment quickly was very important to him. Paul had felt that his local hospital had not followed up things and had disregarded some of his concerns about his diagnosis. He expressed that he felt the local hospital had just wanted to:

*patch him up and send him back [and noted that they had not offered any other support].*

In relation to supportive care services, Paul felt that he was very well supported throughout his cancer journey. He described the cancer nurse coordinator as:

*helpful and supportive ... [and felt she was] instrumental in contacting the district nurses [back in his own region].*

She organised accommodation for when he attended the cancer centre for treatment. Paul also considered that the most important service that the cancer nurse coordinator provided:

*was someone to talk to.*

He thought this was not only beneficial for himself but for his wife:

*so she's not out there on her own, trying to be the sole carer and social worker.*

Paul also commended the cancer centre for providing access to:  
*supportive information and booklets.*

### Cross-case analysis

#### Usefulness of Distress Thermometer

All three participants were positive about the role the NCCN Distress Thermometer had played in helping to identify their level of psychological distress and their psychosocial concerns. All agreed that the list of psychosocial concerns had helped to further define why they were distressed. For two of the participants, the NCCN Distress Thermometer and Problem List had alerted them to concerns they needed to communicate to their clinicians and improved their ability to communicate these concerns.

There appeared to be some differences between the types of concerns the participants felt the NCCN Distress Thermometer and Problem List had helped them to identify and the way they anticipated these concerns. For example, Ann felt that the Distress Thermometer and the list of emotional concerns helped alert her to identify her psychological/emotional concerns. Paul, on the other hand, felt that the Distress Thermometer and Problem List had helped him to identify and convey his physical concerns. Although he acknowledged high distress levels, Paul related these to physical, rather than emotional concerns. Paul also believed that the NCCN Distress Thermometer and Problem List, through helping to identify his issues, was directly responsible for improving access to treatment.

#### Impact of supportive care services

All participants described similar experiences of supportive care services and agreed that these services were beneficial and helped them cope with their cancer journey. Two of the participants felt that the most important benefit to being offered supportive care services was having someone to listen to their concerns. In addition, both of these participants also described access to information as being important and empowering.

The participants differed in their view of which supportive care service they considered most important in their cancer journey. Ann felt that access to a psychologist played the biggest role in helping her to cope with her cancer treatment. Paul focused more on the practical benefit of being referred to the cancer nurse coordinator for coordination of services and appointments.

#### Discussion

Distress levels were shown to reduce over the cancer trajectory and a referral to supportive care services early in the cancer journey generally led to a reduction in distress levels overall. In addition, a high number of physical concerns were consistent with high distress levels, compared to participants who had

lower distress levels and experienced minimum physical concerns. Emotional concerns decreased as psychological distress decreased, except for depression which remained fairly consistent over the three time periods.

The case study narratives show that the NCCN Distress Thermometer and Problem List was perceived by the participants as being a useful tool in identifying psychological distress levels and psychosocial concerns. The participants' experiences of supportive care services only differed in the type of support required. The participants considered the NCCN Distress Thermometer and Problem List an easy and efficient method of communicating concerns to the health practitioners. Supportive care services such as social work, psychology and the cancer nurse coordinator were found to play a vital role in the emotional support of cancer patients. The main advantage perceived through the case studies was

*someone to talk to.*

#### Implications for the support of cancer patients

Case study narratives demonstrated that cancer patients found the NCCN Distress Thermometer and Problem List useful in alerting them to their specific psychosocial needs. The conclusion that the NCCN Distress Thermometer and Problem List was instrumental in facilitating referrals supports its usefulness as a screening tool. The ability to streamline referrals to the most appropriate supportive care service to support cancer patients is essential for all clinicians. The use of this type of tool in nursing practice provides a quick, simple way to ensure cancer patients are adequately linked into the necessary supportive services.

#### Limitations, conclusions and directions for future research

The longitudinal study design is a strength of this research, but it also meant that the study was susceptible to attrition as participants needed to be well enough to complete the three surveys. The distress scores and concerns identified by participants in this study may be different to those patients who were excluded because they didn't speak English or had low literacy levels. Future research could address this issue. Nevertheless, the findings of this study support the use of the NCCN Distress Thermometer and Problem List as a screening tool for psychological distress and psychosocial concerns. Cancer patients who report high levels of distress and emotional concerns should have access to either a social worker or a psychologist to address their concerns. Finally, further qualitative research could be carried out with a larger sample size to validate these findings and to provide a deeper understanding of the psychological distress of cancer patients and the usefulness of the NCCN Distress Thermometer and Problem List.

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# The role of the cancer nurse coordinator: an observational reflective study

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## Abstract

### Introduction

Cancer is a complex, multifaceted condition requiring multimodal treatments over prolonged periods of time, in a variety of settings, delivered by multiple health professionals. Patients have reported confusion and fragmentation with their care and in many centres, cancer care coordinators (CCCs) have been employed to solve this problem.

### Method

A convenience sample of CCCs were observed over a period of one week to understand and interpret how they apply their role in the clinical setting to meet the needs of their patients and clients.

### Results

Three key prominent themes were observed in the role of the CCC: general assessment; psychological support; and educational support. Coordination of care and of the multidisciplinary team was not observed as a prominent role in the sample observed.

### Conclusion

CCCs assess, educate and support the patient and their family during treatment with an aim of holistic care.

**Keywords:** Cancer, care coordination, multidisciplinary, nurse care coordinator.

## Introduction

The lack of an integrated care system for the cancer patient was highlighted in the *Optimising Cancer Care in Australia* report<sup>1</sup>, which concluded that many patients can become lost in the system. This contributes to patients experiencing unnecessary morbidity, confusion and undue stress. Patients entering the health system require a coordinated response that is focused on improving the patient journey<sup>1</sup>. In Australia, the role of the cancer care coordinator (CCC) was developed, partly as a result of the overwhelming evidence that cancer care is an increasing burden on the health care system, but mostly to improve patient outcomes<sup>12</sup>. Increased satisfaction and decreased anxiety, particularly in the early stages of diagnosis, has been reported as outcomes that impact the patient. When patients are less anxious and better informed they are more likely to discuss and consider treatment options, participating actively in decision-making processes<sup>3</sup>.

To assist cancer patients as they navigate the health care system the term care coordination has emerged<sup>4</sup>. Care coordination is referred to by many different terms, including continuity of care, seamless care, case management, integration of services and discharge planning<sup>2,5-7</sup>. Nutt and Hungerford sought to define nurse care coordinators as an advanced practice nurse who engages directly with a patient; manages the overall care process, including the development and communication of the care plan to all relevant stakeholders; and ensures that all treatment and care is delivered to meet the specific needs of the patient and his/her significant other(s)<sup>7</sup>. The Cancer Nurses Society of Australia (CNSA) position statement on cancer care coordination defines a CCC as "someone who engages directly with a patient, manages the care process, including the development and communication of the care plan, and ensures that all the care needed is arranged and delivered"<sup>8</sup>.

As background preparation for this study, an extensive review of pertinent literature between 2000 and 2013 was undertaken using Pubmed and CINAHL using keywords: "cancer care coordinator", "patient navigator", "clinical care coordinator". Two major themes emerged from the literature: development of cancer care coordination and the role of the CCC.

## Background

### Development of cancer care coordination

Cancer treatments and ongoing care are complex and often confusing, with reports of patients and families feeling lost in the system<sup>29</sup>. The literature suggests that Australian cancer care delivery is fragmented due to the many different services and providers who are responsible for screening, diagnosis, treatment and supporting care<sup>2</sup>. This can result in suboptimal communication between providers and patients, leading to unmet needs during the provision of care<sup>2</sup>.

International research shows that this fragmented care experience is not unique to Australia. In the 1990s the first patient navigation program was established at Harlem Hospital in New York<sup>10</sup>. The program was an attempt to overcome the barriers such as poverty, culture and social injustice, improving health outcomes for cancer patients in a predominately poor community and of African-American and Hispanic heritage. Patient navigation aimed to reduce barriers to care and enable persons with cancer-associated symptoms to receive timely diagnosis and treatment<sup>10-15</sup>. In the United States the commonly recognised barriers to timely care were financial, communication, information, and emotional factors, as well as the medical system itself<sup>5</sup>. The benefit of a patient navigation program in Harlem was illustrated in the five-year survival rates of predominately black women of a low socio-economic background diagnosed with breast cancer. In 1986, 49% of the women diagnosed had stage 3 and 4 disease with a five-year survival rate of only 39%. By 2000, after implementation of the program, 41% of the women diagnosed had early breast cancer and only 21% had stage 3 and 4 disease, and the five-year survival rate had risen to 70%<sup>33,35</sup>.

In the United Kingdom the Calman-Hine Report was published in 1995 by an Expert Advisory Group on Cancer, who then released a plan that outlined radical reforms for Cancer Services<sup>16</sup>. The aim was to improve outcomes and reduce the inequalities in cancer care within the National Health Service (NHS). Subsequently the Improving Outcomes Guidance (IOG) reports and the NHS Cancer Plan 2000 combined to make recommendations that cancer care should be arranged by site specialists, including the specialist cancer nurse working together in multidisciplinary cancer teams<sup>16</sup>.

### A review of the role

McDonald *et al.*<sup>17</sup>, conducted a review of the literature in 2006 in an attempt to develop a working definition of the navigator (coordinator) role in the USA. More than 40 definitions of care coordination were identified, from which they formed their inclusion and exclusion criteria. From 4,730 publications identified, 75 were included identifying 20 different coordination interventions. Care coordination is a dedicated role and the CCC could be a nurse, social worker or other allied health professional or a general practitioner, or, as it is in the United States, even a lay person. Freeman's role description of the patient navigator (coordinator) is to ensure that the patient receives timely diagnosis and treatment, through one-on-one contact and to eliminate the barriers to achieve this<sup>13</sup>. Freeman discusses that the patient navigator is not required to have a particular level of education but should have other qualities, such as being culturally attuned, well connected with the decision makers within the system and knowledgeable about the system to enable them to assist the patient as they navigate a complex health system<sup>13</sup>.

In the United Kingdom, in the report *The Improving Outcomes: A Strategy for Cancer*, it is acknowledged that coordinated care, such as that provided by clinical nurse specialists, can deliver better outcomes for patients<sup>18</sup>. The benefit of one-to-one support was found to achieve a service that outweighed the cost. MacMillan Cancer Support, one of the largest British charities providing specialist health care, information and financial support to people affected by cancer, supported the NHS to create almost 3,000 additional clinical nurse specialist and care coordinator positions, and the UK has recognised that nurses are ideally placed to fulfil these roles<sup>18</sup>.

The Australian government recognises that cancer patients report suboptimal experiences as they traverse the medical system, navigating multimodal and specialist care, describing it as being not dissimilar to "a train trip across Australia"<sup>19</sup>. A range of health professionals provide cancer care across multiple health services and across health sectors, including public, private and community in both metropolitan and rural areas. Thus, patients must move between the services and there are many opportunities for delays and for patients to become lost in the system<sup>20</sup>.

Yates describes care coordination as "enhancing the patient's experience during illness through providing continuity of care across several interconnecting components of cancer care"<sup>14</sup>. It can be said then that cancer care coordination aims to provide a service that occurs logically and in a timely fashion, consistent with the needs of the patient and in context of the medical care

required<sup>47</sup>. The activities of CCCs were explored by Walsh *et al.* in a qualitative research study of 29 Australian clinicians involved in cancer care<sup>21</sup>. Some of the major components identified were: a needs assessment and organisation of care; patient access and navigation of the health system; as well as being the person who ensures effective communication and cooperation between health professionals. In the report from the Clinical Oncological Society of Australia (COSA) 2006 CCCs workshop, Yates identified that key roles of the CCCs are centred on providing continuity of care, enhancing the experience and minimising further distress of the patient diagnosed with cancer<sup>2</sup>.

Using strong consumer input, the *Optimising Cancer Care in Australia* report<sup>1</sup> recommended patient-focused, coordinated, multidisciplinary care, an end to the cancer care "referral lottery", reasonable access to evidence-based quality care, including clinical trials, and support throughout the cancer journey<sup>22</sup>.

The following study explores the role of the CCC in a metropolitan hospital in South Eastern Queensland. The research question was "What are the key activities of the CCC in the Australian hospital environment?"

## Method

This observational study used reflection to understand the role of the CCC. Observation and reflection provided an insight into the role across different tumour streams. A convenience sample of three CCCs responsible for different tumour streams from the same hospital was enlisted into the study to explore the similarities and differences in approach to the same role. Guided by the principles of descriptive ethnography, the researcher collected data by observation and discussion with each CCC<sup>23</sup>. The researcher explored the roles of the CCC by following them closely as they undertook their daily activities. Notes were taken and then analysed for themes around the roles and interactions of the CCC. Reflection was used to gain meaning from the interactions as the researcher continued to observe each CCC in their natural setting.

The study was completed for student learning purposes only and was internally assessed by the local institutional guidelines and designated as negligible risk<sup>24</sup>. Verbal consent was obtained from the CCCs and ethical principles maintained as per ethical guidelines for work which is exempt from full ethical review<sup>25</sup>. The study was reported to the ward as part of development of roles.

## Reflection as a means of exploration and understanding

Reflective practice is a means for empowering the health professional to learn from and build upon clinical experiences and involves purposeful thinking about an experience with

the goal of gaining new insights, ideas and understanding<sup>26</sup>. Reflective practice can also "involve looking at the power relations that exist in the health care environment and asking questions about how and why they exist and whose interests are served by their existence"<sup>27</sup>. To reflect is not enough; the knowledge and new understanding must inform practice. Gibbs<sup>28</sup> model of reflection is frequently used within nursing; it is clear and precise, allowing for description, analysis and evaluation of the experience, assisting the reflective practitioner to make sense of the experience.

## Sample

Two clinical nurse consultants (CNCs) and one clinical nurse (CN) were observed for one week in their role of care coordination within the breast, colorectal and hepatobiliary tumour streams. Observations included the CCC in multidisciplinary team (MDT) meetings, surgical and oncology medical clinical appointments, performing data input and attending telephone consultations.

## Results

The results are presented in three themes: general assessment; psychological support; and educational support.

### General assessment

The CCCs discussed the difficulty of meeting patients personally to assess them at the time of diagnosis. Assessments were conducted in a variety of settings and differing times throughout the patient journey. The first observation was at an initial discussion of the patient at a colorectal MDT meeting. The medical team were concentrating on their individual treatment for the patient. The CNC was able to provide a holistic, detailed presentation of the patient, not just the medical components that each consultant presented to support their preference for particular treatment. This patient was elderly and legally blind and would have had difficulty managing the result of the planned surgery. The patient had already expressed their wishes to the CNC as to what would be acceptable and would not be acceptable when the CNC had met with them to support the decision-making process. This enabled the treatment plan to be inclusive of the patient's needs and preferences, demonstrating patient advocacy.

In a busy surgical review clinic the colorectal CNC had identified that she had several patients that she felt were imperative to assess. The CNC went between clinic rooms quickly, sitting in on discussions with three different consultant surgeons. She made quick observational assessments, listening to the conversation, probing where necessary and involving any other family members for further information. There was a sense of hurriedness without rush as the CNC attempted to see as many patients as possible,

including those that presented with new issues. The advanced skills of the CNC were evident when assessing the physiological processes and symptom management of patients in this setting. The CNC reviewed patients across different diseases, stages and treatment modalities, gathering patient details and specific needs, with an aim to provide holistic care. It was a challenging environment and time management was paramount. The CNC was able to prioritise patients and managed time efficiently, between busy colorectal and hepatobiliary clinics.

### Psychological support

In all tumour streams the CCCs discussed emotional support as being an activity that is most vital yet the most time-consuming of the role. Each new patient completes a psychological screening tool, to assess risk factors that may require referral for further psychological support. Those who are identified *at risk* are prioritised and seen by the CCCs. These patients initially may require significant time and advanced assessment and communication skills. When this occurs it prevents the CCC from seeing all the new patients. This was identified as a major barrier to the CCCs having an initial face-to-face assessment with other newly diagnosed patients. This was evident when observing the breast CN in a busy medical oncology clinic. Observing the CN meet a newly diagnosed patient and her partner who had identified as *at risk* with the psychological screening tool illustrated how advanced communication and assessment skills are integral to the role. The CN experienced some difficulty with the interview and time spent with this couple was significant. A psychologist could have been contacted for support, though the CN did not offer or seek their input. The CN did document and discuss the patient with their CNC and the patient was followed up the following day. In comparison, the breast CNC was observed performing an initial assessment with a newly diagnosed patient. Using the assessment tool, the patient was identified as at high risk of depression and the CNC quickly developed a rapport, agreed on a plan of care, offering referral to the psychologist and providing a point of reference for any future interventions.

The CCCs are acutely aware that this assessment and appropriate referrals are important to achieving optimal outcomes. Reflecting on how the CNC probed gently and sensitively revealed the extent of maturity required for the CCC to provide emotional support in this context. The CNC was not intrusive or counselling, but instead listened and empathetically supported the patient, validating her stressors and offering strategies to support her. In summary, the role of the CCC was to undertake physical, emotional and psychosocial assessments, providing appropriate referrals and strategies to support patients and their

families at initial contact and throughout the entire journey. The use of a screening tool was helpful and provided the CCC with a means to identify at-risk patients efficiently and to prioritise their time effectively.

### Educational support

While providing education to a new patient in the medical oncology breast clinic, the CNS clarified the patient's level of understanding, diagnosis and planned treatment through very focused questions and considered the information required. Reflecting on the CCC's educational role, the CNS structured the session so it felt like information sharing rather than educating. In contrast, the CN when observed appeared to follow a formula or 'script' when providing education to the new patient, which became instructive. The CNS identified those questions the patient wanted to have answered, answering them, looking for understanding and then offered the patient further support with phone calls and clinic appointments.

The ability of the CCC to continue contact throughout the patient journey allows them to build on the information learned and ultimately understanding. Observing how the education is delivered by the CCCs it was evident that the experienced CCC had a patient-centred and flexible approach to the education process and processed superior communication and engagement strategies. Education was appropriately paced, ensuring that the information was checked, retained and relevant to each phase. In summary, the CCC education support role is to provide education, clarify patient understanding, build on that and again review for patient retention.

### Discussion

This observational study has provided insights into the practice of a small sample of CCCs working in one facility. One of the main findings is recognising that cancer care coordination needs to provide the patient with holistic care within the medical model. The *Optimising Cancer Care in Australia* report identifies that there must be an integrated, multidisciplinary, patient-focused health system throughout the cancer journey to ensure best practice<sup>1</sup>.

The specialised cancer nurse has the skills to perform patient assessment and provide appropriate interventions. In this study, the CNCs are advanced clinical nurses with postgraduate qualifications providing them with advanced clinical skills to understand the physical impact of cancer and treatment modality side effects. The advanced clinical nurse is able to provide the patient with knowledge and understanding of their disease, helping to decrease the anxieties that they may experience, empowering the patient and giving them control



to focus on adhering to their treatment and getting well<sup>29</sup>. This study identifies that the CCC requires advanced knowledge of and experience in treating the complexity of patients with cancer. The CCC forms a pivotal role in performing assessments to guide care planning and follow-up, particularly because many caregivers and patients do not communicate their concerns clearly to the clinicians. Literature identifies that many patients and caregivers believe that pain, grief, anger, and suffering are inevitable with cancer and fail to discuss their distress with health professionals<sup>30</sup>.

This study identified that the CNC confidently picked up the cues from the patient and family in regard to requiring emotional support, completed a psychological assessment, and provided support and ongoing referrals. The CCC collaborates with all members of the MDT, facilitating the provision of physical and emotional support to patients and families including therapeutic conversations and supportive strategies<sup>31</sup>. The CCCs in this study demonstrated that they were an essential part of the team, finding time to assess, implement and coordinate care throughout the patient's journey. Although coordination of care was not observed during the study, this was described as arranging referrals to other health professionals, assisting with transportation issues, and guiding patients through the health services of other hospitals.

Willig<sup>32</sup> describes in her phenomenological study exploring the discourse of cancer, highlighting how a patient's needs change as their understanding of cancer changes. The evidence suggests that patients are rarely given 'space' with the medical consultations to ask questions and express any fears, resulting in a lack of emotional issues being investigated in such crucial times<sup>33</sup>. The current study identified that the CCC played an important role in understanding and addressing physical and psychosocial needs of the patient.

Improving education for cancer patients has become recognised as part of the professional role of nurses<sup>34</sup>. Patient education is described as ascertaining existing knowledge, providing information and instructions for self-management, clarifying and reinforcing information, while ensuring individual needs are met<sup>31</sup>. Sensitive communication with patients may challenge nurses in the clinical care setting where time and understanding of how to open the conversation is paramount<sup>33,35</sup>. When oncology nurses do not have strong communication skills, the nurse's communication with patients and families are often at a superficial and non-therapeutic level, failing to meet the patient's needs<sup>34,36</sup>. In this study, the CCCs undertook education at every interaction through questioning and feedback, tailoring and triaging their available resources to each patient. Different

skills were demonstrated by the CCCs depending upon their level of experience; however, they sought to provide education that ensured the patient and family were given many opportunities to ask questions throughout their treatment and beyond.

This observation and reflection allowed a window into the complex roles of the CCC. Cancer care coordination is undertaken differently among the nurses within this service, potentially due to the specific requirements of each tumour stream, although this may also reflect personal preferences and non-preferences also. All of the CCCs in this study acknowledged that the needs of each patient differ greatly in terms of the organisation of their care, and attempting to predict those that require more interventions was important, particularly when clinic times and the balancing of several teams impacted on their ability to screen effectively. Some of the most challenging times for all of the CCCs were the interactions between the other members of the health team, where role overlap, duplication and role conflict were identified<sup>10,29</sup>.

Similarly, Yates acknowledges that the most challenging feature of care coordination is the interface between the functions of an appointed care coordinator and those of other members of the health team<sup>4</sup>. Evaluating the role is integral to demonstrate the need for an experienced oncology nurse as the care coordinator. In her report on the Clinical Oncological Society of Australia Cancer Care Coordinators workshop in 2006, Yates identified "team views of their functioning" and "patient views of their experience" as two strategies that may enable demonstration of outcomes of the role of CCCs<sup>4</sup>. Opportunities for evaluation may include patient satisfaction surveys, quality improvement initiatives, demonstrating cost-effectiveness and decreased hospitalisations due to treatment complications<sup>29</sup>.

The 2010 COSA Care Coordination Conference, *Relationship, Roles, Reality*, highlighted the central role of the CCC within the MDT and that care coordination was the responsibility of the entire team rather than one individual<sup>37</sup>. Similarly a study by Regan *et al.*<sup>31</sup> concluded that the CCC was "everything to everyone"<sup>31</sup>.

In this reflective study, the importance of several key roles of the CCC has been identified, those being needs assessment<sup>21</sup>; enhancing the experience; and minimising further distress of the patient diagnosed with cancer<sup>9</sup>; support throughout the cancer journey<sup>22</sup>; and, in particular, the psychological support services<sup>38,39</sup>.

### Limitations

This study is limited by the small number of participants; however, the observational data does provide an insight into the

CCC role. This is an area of research where larger, more robust studies are needed.

## Conclusion

The role of the CCC can be described as a central point of contact for the patient and their caregivers and integral to the promotion of continuity of care. CCCs assess, provide emotional support, and educate the patient and their family during their cancer treatment journey with an aim of holistic care. Further research understanding the complexities of the role and demonstrating measurable patient outcomes is important in looking to the future of an integrated, multidisciplinary, patient-focused health system. In addition, the development of a framework for continuing professional development, mentoring and clinical practice will provide guidance to and support for nurses aspiring to become CCCs.

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## INTERNATIONAL KEYNOTE SPEAKER

DR MARGARET BARTON-BURKE



**Dr Margaret Barton-Burke is the president of the Oncology Nursing Society (ONS), having been a member for more than 30 years and served as a Director-at-Large and President-Elect before assuming Presidency.**

She is the Mary Ann Lee Endowed Professor of Oncology Nursing at the College of Nursing, University of Missouri, St. Louis and a research scientist at Siteman Cancer Center, St. Louis, Missouri. She earned her Doctor of Philosophy (PhD) from the University of Rhode Island in Kingston.

Dr. Barton-Burke's cancer interest has been in survivorship. Her clinical expertise is in the area of fatigue, sexuality, pain management, and

symptom management. Her research interests are an outgrowth of her clinical interests including long-term cancer survivorship, including the survivorship of black women with breast cancer. She is a co-author of award winning books including *Oncology Nursing Drug Handbook* and *Cancer Chemotherapy: A Nursing Process Approach*. Both books earned the American Journal of Nursing Book of the Year award.

Dr. Barton-Burke is an inaugural faculty and senior faculty member for the African Doctoral Dissertation Research Fellowships (ADDRF) Training Workshop sponsored by African Population and Health Research Center (APHRC) in Nairobi, Kenya. She is a founding member of the Massachusetts Pain Initiative, the Massachusetts Cancer Pain Initiative and several other cancer nursing initiatives. She has received numerous fellowships and most recently was named to the American Association of Colleges of Nursing (AACN) 2014-2015 Leadership for Academic Nursing Program (LANP) Fellowship. Dr. Barton-Burke is the Chairperson of the AACN Research Leadership Network.





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