The Australian Journal of Cancer Nursing

The Official Journal of the Cancer Nurses Society of Australia

Volume 20 Number 2
November 2019

In this issue

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References:
1. Martin W et al. Poster presented at 16th Annual ENETS Conference 6-8th March 2019, Barcelona, Spain, Poster H14.
2. Somatuline® Autogel® Approved Product Information March 2019.

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

Notes for contributors

All correspondence relating to the journal should be directed to the editors. Guidelines for contributors to the journal can also be obtained from the editors. The *AJCN* is published twice a year.

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Editorial

Introduction from the new editors

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It is our great honour to introduce ourselves to you as the new co-editors of *The Australian Journal of Cancer Nursing.* The role of editor is one of considerable responsibility, with which comes many new challenges, and we are both very excited to have been selected for this important task. As both cancer nursing experts and academics, we are very aware of the need to disseminate high quality research and education to nurses working within the cancer field. With this goal, we will be continuing to share with you articles of high quality research and scholarship commensurate with the current issues relevant to cancer nursing.

We are very excited about the future of the journal and to building on the very positive work of the outgoing editors. With commitment and enthusiasm, Moira Stephens and Tish Lancaster have led the development of the journal, Tish since 2009 with Moira joining in 2012. While Moira and Tish move to a new chapter in their lives, we are both looking forward to solidifying the journal's many existing strengths but also to leveraging new opportunities to take the journal in a new direction.

We are aware of the excellent editorial board and reviewers who have made a significant contribution to the journal over the years, and we will continue to welcome their input, while also seeking to expand members with expertise in cancer nursing. We also encourage new authors to submit their work and we will be pleased to work with them to develop their manuscripts in preparation for publication in the journal.

We are deeply honoured to take on the role as co-editors and look forward to working with you all to disseminate the rich body of research and scholarly works of the cancer nursing community.

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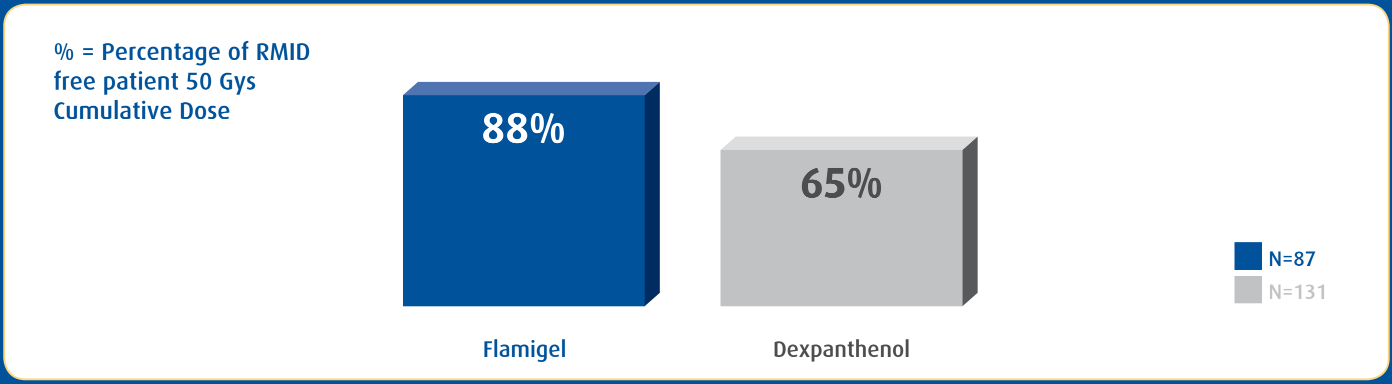

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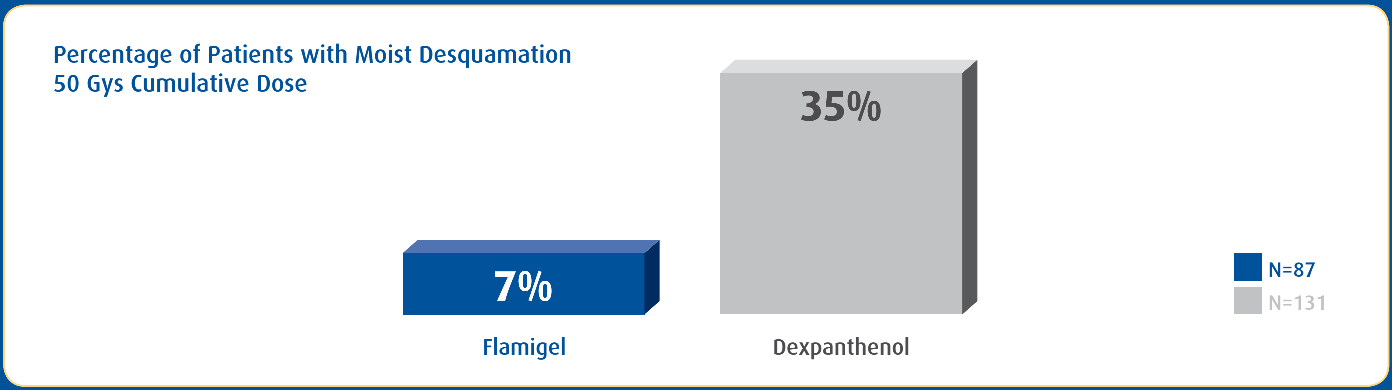

KEY RESULTS:

After 25 fractions of radiotherapy (50 Gy), patients in the Preventive Hydrogel group (N = 202) developed RIMD significantly less frequently and later than patients in the Dexpanthenol group (N = 131; incidence = 7% vs 35% respectively, odds ratios = 7.27; probability of RIMD-free survival after 50 Gy = 0.88 vs 0.62).

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References: 1. Censabella et al., Hydroactive colloid gel vs historical controls for the prevention of radiotherapy-induced moist desquamation in breast cancer patients: Preliminary results Annals of Oncology (2016) 27 (6): 497-521. 10.1093/annonc/mdw390. **2.** Censabella et al., Management of radiotherapy-induced skin reactions: Retrospective comparison of a hydroactive colloid gel and a dexpanthenol cream on the development of moist desquamation in breast cancer patients. Eur J O N 18 (2014) 499–504. **3.** The aftercare for fractionated resurfacing consists of applying a cooling, wound-healing gel supplement with cooling thermal water. Crevitis B., Tempo Medical April 2012.

The Australian Journal of Cancer Nursing

Optimal care pathways for lung cancer in South West Victoria

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Keywords lung cancer, optimal care, regional/rural, health equity, health services

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Abstract

Aim This study reports on any barriers to optimal treatment for lung cancer in South West Victoria.

Methods Treatment pathways on all patients newly diagnosed with lung cancer was collated (2015, n=200).

Results A total of 88% of the lung cancer patients had a history of smoking. Many of the patients presented at Stage III or IV at diagnosis (59%), 25% were diagnosed after an emergency department visit, 85% had chest x-rays, 92% had CT scans, and 86% saw their specialist within 2 weeks. Patients residing in Geelong were more likely to have their treatment plan discussed at a multidisciplinary meeting compared to patients in the South West (75% versus 42%). At 12 months post-diagnosis there was a higher survival rate for patients residing in Geelong compared to those living in the South West region (51% versus 31%) and for females (57% versus 36%).

Conclusion The majority of patients had a history of smoking and many presented with late-stage disease.

Introduction

Lung cancer is divided into non-small cell lung cancer (NSCLC) and small cell lung cancer (SCLC), with differences in tumour behaviour and therefore treatment. Tumour stage at diagnosis and how long a newly diagnosed person waits until first treatment can affect outcomes[1,2]. In the Barwon South West region of Victoria there are many smaller regional/rural towns, with up to 100 km to travel to the nearest major health service (Figure 1). Concerns about distance to travel while unwell, time away from work, a reluctance for regular medical checkups, and fear of the unknown all have the potential to delay presentation.

We have previously reported that approximately 20% of those diagnosed with cancer in the emergency department (ED) have lung cancer, and 38% of persons newly diagnosed with lung cancer had visited the ED for many reasons, not necessarily resulting in cancer diagnosis, 6 months prior to diagnosis[3]. Patients presenting to the ED often have a worse outcome and a later stage at diagnosis. Ideally, presenting at an earlier stage will result in a better outcome.

The Barwon South West region consists of coastal resort areas with small townships, a large rural farming region and smaller farmlets. As at 2016 there were 418,103 people residing in the

32,767 km^2 region[4] with 25% (n=104,908) aged older than 60 years. In 2016, there was a high percentage (29.2%) of the population whose household was in the lowest socioeconomic quartile. Therefore the Barwon South West region has a substantial section of the population that are of an older age or in a lower socioeconomic sector, both associated with increased risk of lung cancer[5,6]. In 2015, it was reported that 22% of males and 12% of females in the Barwon South West were currently smoking[7], 46% of the population having ever smoked.

Cancer Council Victoria have developed a set of optimal care pathways to promote and acknowledge a standard of care[8]. For example, the Barwon South Western Regional Integrated Cancer Services (BSWRICS) supports all health services in the region to improve quality, coordination and planning of cancer services. BSWRICS fulfils its role by consulting and collaborating with regional health partners and consumers and works toward providing equitable services for the rural and regional areas of South West Victoria. Prior studies have acknowledged the challenges of distance and remoteness in providing appropriate health services[9]. Supporting this service is a large database, the Evaluation of Cancer Outcomes Barwon South West (ECOBSW) Registry, a listing of all residents newly diagnosed with cancer in the region and a recording of their treatment pathways[10]; any identified deviation from the standard of care is investigated. This study reports on any barriers to optimal treatment for lung cancer in our regional/rural area.

Methods

The ECOBSW Registry has electronically and manually collected data on all newly diagnosed lung cancer tumours in the Barwon South West Region from all major health service medical records[10]. Demographics, treatment pathways and outcome data were recorded for all newly diagnosed patients in the region from 2009 to 2015. This data, linked to the recommendations of the optimal care pathways[8], are reported in this study for the most recent complete year of 2015. For the purpose of comparing regional and rural regions, the Greater Geelong area was defined as towns within 30 km of central Geelong, with the remainder of the region labelled as South West. The term 'ever smoked' described persons who had smoked more than 100 cigarettes or cigars anytime during the course of their life.

Results

In 2015 there were 200 persons newly diagnosed with lung cancer in the Barwon South West region (Figure 2). A total of 85% were aged older than 60 years; the average age was 72.2 years (SD 10.7 years), with the youngest 41 years and the oldest 98 years. Of the 200, 56% were men; their average weight at diagnosis was 76.6 kg (SD 14.7 kg) and for women it was 65.7 kg (SD 17.0 kg). Just under one third (32%, n=63) had private health insurance.

Prevention is always better than cure; however, 176 (88%) had a history of ever smoking, with 69 (35%) currently smokers at diagnosis. Those younger than 60 years were more likely to be currently smoking (65% versus 28%, $p<0.01$). In addition, 22 had recorded in their medical record that they had prior asbestos exposure.

The initial recommended investigation is chest x-ray, with any suspected cancers immediately referred. It was recorded in the medical records that 85% had a chest x-ray. Contrast spiral computed tomography (CT) of the chest and upper abdomen is recommended if the chest x-ray is inconclusive. Our study found 92% had a supportive investigation of a CT scan. Tumours

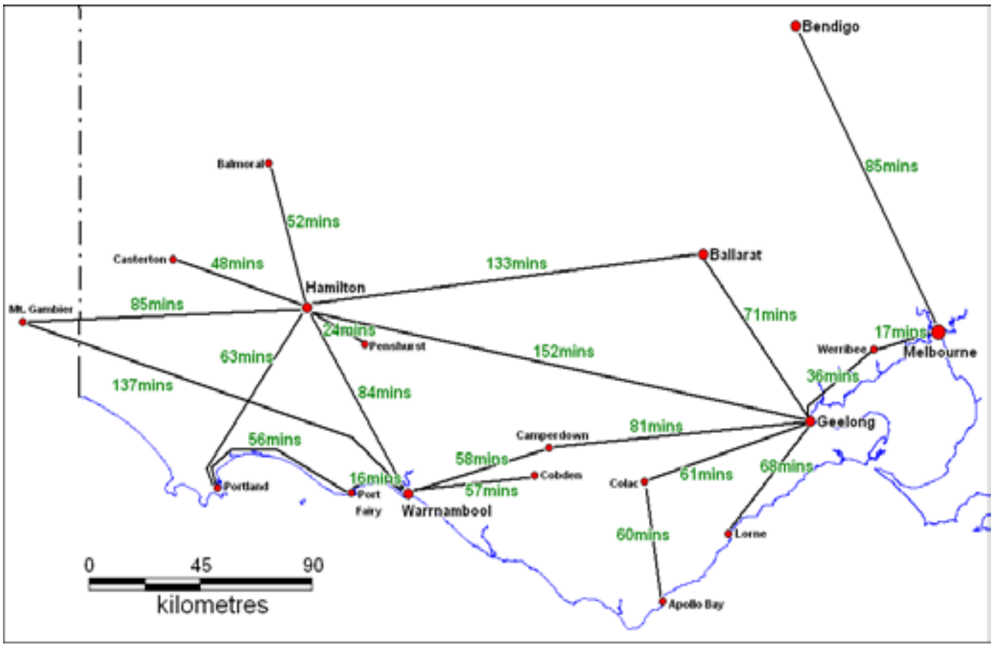

Figure 1. Relative travel times between health services in the Barwon South West region.

by primary site are displayed in Table 1, with the highest percentage in the upper lobe, bronchus or lung. The morphology showed that there were 132 NSCLC, 25 SCLC and 43 other. It is recommended that patients see a specialist within 2 weeks of referral. Dates allowing this calculation were recorded in the medical record for 83 patients, with 71 (86%) seen within this period. Referral pathways were also recorded – 50 (25%) were diagnosed after an ED attendance or an emergency admission.

The majority (n=138, 69%) of patients were diagnosed at a health service in the main regional city, Geelong. Endobronchial ultrasound (EBUS) was included for 14 consumers and positron emission tomography (PET) scans for 111. A total of 85 (43%) were diagnosed at Stage IV, 32 (16%) at Stage III, 14 (7%) at Stage II, 27 (14%) at Stage I and 42 (21%) were not recorded in the medical record.

Some 65% (n=129) of patients were discussed at a multidisciplinary meeting. A higher proportion of patients who were residents of Greater Geelong were presented to a multidisciplinary meeting than residents from the South West region (75% versus 42%, p<0.01). A higher proportion of Stage I–III were presented to a multidisciplinary meeting compared to Stage IV and stage not recorded in the medical record (88% versus 51%, p<0.01). There was no significant difference in proportions presented to the multidisciplinary meeting for public or private patients (p=0.49) or for those aged younger or older than 60 years (p=0.68).

Table 1. Number of new diagnosis by primary site.

Primary site	Total (%)
Main bronchus (C34.0)	11 (6%)
Upper lobe, bronchus or lung (C34.1)	85 (43%)
Middle lobe, bronchus or lung (C34.2)	8 (4%)
Lower lobe, bronchus or lung (C34.3)	53 (27%)
Overlapping lesion of bronchus and lung (C34.8)	6 (3%)
Bronchus or lung unspecified (C34.9)	19 (10%)
Anterior mediastinum (C38.1)	1 (0.5%)
Mesothelioma of pleura (C45.0)	15 (8%)
Mesothelioma of peritoneum (C45.1)	1 (0.5%)
Mesothelioma of other sites (C45.7)	1 (0.5%)
TOTAL	**200**

Surgery occurred for 28 (14%) patients. Surgery benefits those with early stage NSCLC. Our study found 13 (54%) of 24 patients with Stage I NSCLC at diagnosis had surgery. Those that did not have surgery included a higher proportion of men (n=8, 73%, p<0.01). Radiotherapy was received by 93 (47%). Radiotherapy may be beneficial to those with advanced local NSCLC for whom surgery is not suitable. This study found 15 (79%) out of 19 within this criteria had radiotherapy. For all patients, radiotherapy may be beneficial for palliative intent. Of those referred to the palliative care unit (n=129), there were 72 (56%) who had radiotherapy. Chemotherapy was received by 74 (37%). Chemotherapy is often recommended for advanced disease and good performance status; 42 patients diagnosed with Stage IIIb or IV cancer had an ECOG of 0 or 1 and 28 (67%) had chemotherapy. NSCLC with localised inoperable disease may benefit from combined chemotherapy and radiotherapy; of the 19 that met this criteria, nine (47%) had chemoradiation.

A total of 129 (65%) were referred to the palliative care unit, and a total of 35 had an advanced care plan reported in the medical record. More than half (n=110, 55%) died 12 months post-diagnosis, with a higher proportion of South West residents having died (69% versus 49%, p<0.01) and more men (64% versus 43%, p<0.01). There was no significant difference in the proportion of those

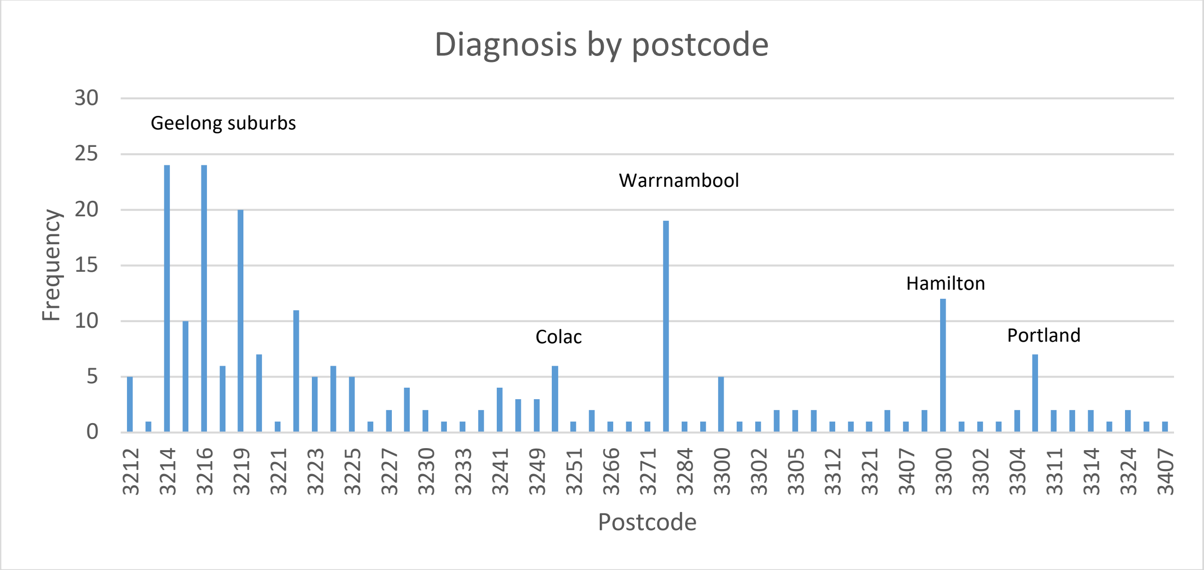

Figure 2. Location of persons diagnosed with lung cancer in the Barwon South West region.

who died and public or private patients (p=0.67), nor for those aged younger or older than 60 years (p=0.23).

Discussion

We found 88% of our lung cancer patients had a history of smoking. Within the Barwon South West general population, 46% had ever smoked. The Victorian Government banned smoking in enclosed public places in 2007, in cars carrying children in 2010, at train stations and tram stops in 2014, at school entrances in 2015, and all outdoor dining areas in 2017[11]. We can do our best to optimise healthcare but is the damage already done before the patient arrives at the health service? Additionally, 43% of those diagnosed were Stage IV at diagnosis and this is a conservative estimate, with 21% of stages not recorded in the hospital medical record.

One-quarter were diagnosed after an ED visit; this figure is consistent or conservative compared to prior national and international studies[12,13]. Symptoms of lung cancer are often respiratory symptoms, pain, neurological events or fever. Lung cancer patients present at a late stage and often from financially deprived populations. Potential financial constraints might be a reason for presenting to the ED where all costs are met.

Multidisciplinary meetings, whereby treatment plans are discussed and deliberated on by clinicians of many disciplines, commenced in the Barwon South West region in 2006 and have grown in size by increasing the number of tumour streams and health services administering the meetings over the years. In 2015, 16% of all cases discussed were lung cancer. However, the proportion of those presented who are residents from the South West in this study is not ideal, and further work to increase the number of these meetings in the more remote health services is required.

Unexpectedly, age was not related to those who had died within the first 12 months. More men and residents of the South West region had not survived. However, we do acknowledge the potential for a Type II error in our report, with small numbers involved in some of the comparisons.

If we are to move forward in reducing the number of lung cancer patients, then as a society we have the responsibility to say smoking is not okay. We can work as a health service to improve treatment in the rural/remote regions, but it is important to note that preventative health strategies must work simultaneously to address the damage done prior to people presenting for diagnosis and treatment. Even so, we can do better, by increasing the number of patients presented to multidisciplinary meetings, and this is high on our agenda.

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The Australian Journal of Cancer Nursing

Optimising consent and adherence in high-risk medical settings: nurses' role as information providers in allogeneic bone marrow transplant

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Keywords consent, qualitative methods, professional aspects, ethics

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Abstract

Complex medical procedures such as allogeneic bone marrow transplant (allo-BMT) require extensive medical and psychosocial information to be communicated to patients. Whereas, previously, patients only received information from their doctor and only during consultations, increasingly they access information in various modalities, from numerous sources and from a range of different health professionals, and at different times throughout the course of their illness and treatment. We present qualitative data from interviews with patients and nurses reflecting on information provision during allo-BMT. Patients' vulnerability and the unpredictability of transplant outcomes highlights the necessity for, and importance of, ongoing information support. In this paper we highlight the role of nurses in supporting patients' and families' informational needs throughout the transplant trajectory. Nurses have a critical role in ensuring that patients receive relevant, rigorous and salient information during the course of allo-BMT so that their autonomy is respected and their adherence and capacity to cope is optimised.

Consent, complexity and the bone marrow transplant process

The complexity of bone marrow transplant (BMT) for both patients and practitioners is well established[1]. Before treatment can take place, patients are required to provide consent to the intervention. A patient's consent is contingent on them having been provided with information that is 'material' to them, that is to say, is of relevance to their decision-making. Consent can only be considered to be valid after the patient has not only been provided with material information but has also understood it to the degree they desire in order to be able to make an 'informed' decision about whether or not to proceed with the intervention under consideration. Information provision forms part of the element of 'disclosure' that, along with 'competence' and 'voluntariness', enables a valid consent to be obtained where it is felt that "[t]he opportunity for voluntary decision-making is only present where there has been adequate disclosure by the health professional"[2(p331)]. The information provided by health professionals to patients must therefore include comprehensive information about the benefits and risks of the proposed treatment, and any alternatives[2-4]. This information includes effects of treatments on both patients' physical health and the social implications of decisions to proceed with such procedures.

It is important that, as part of the consent process, health professionals employ a range of information transfer skills – assessing patients' capacity, knowledge, information preferences, values and health literacy – so that they can provide information in a form that the patient wishes and can comprehend. This is an important skill because patients' understanding of information varies according to their preferences, values and literacy competencies[5,6]. Increasingly, patients now source information themselves about their conditions and treatments through the internet[7-9]. However, many patients often have difficulty relating this information to their own situation or assessing the trustworthiness of the information they find. Health professionals therefore play a key role in helping patients interpret information they find online[10].

The complexity of information provision is further heightened in the case of high-risk procedures with uncertain outcomes such as BMT. While information disclosure about complex therapies is frequently imagined as occurring at a single time point – and often in a calm and controlled environment prior to the commencement of a procedure or treatment – this is overly simplistic as information about complex therapies and/or chronic conditions is, of necessity, generally provided at multiple times and in different contexts over the course of a patient's illness[11]. This was certainly the case we present here which investigated how consent was negotiated with patients undergoing allogeneic bone marrow transplant (allo-BMT).

Allo-BMT is a highly complex procedure composed of many individual procedures that may include, but are not limited to, the insertion of central line, administration of sub lethal chemotherapeutic agents, irradiation, blood tests, biopsies, insertion of nasogastric tube, pain medication and infusion of donor cells. Each of these procedures carries a degree of risk and/or discomfort, and requires the provision and reiteration of information and confirmation of ongoing consent from the patient[12].

As such, BMT has an enormous physical, psychosocial and emotional impact on patients and their families[13]. Patients require prolonged hospital admission and periods of isolation during the transplantation. They often undergo numerous invasive medical procedures and experience a range of acute and chronic adverse effects, many of which are life-threatening and/or substantially impact on their quality of life[14]. In addition, the patient experiences uncertainty regarding their survival and the outcomes of therapy, profound changes in body image, and an almost complete loss of independence during the immediate post-transplant phase[15,16]. The psychological impact of these effects is heightened because, for many patients, transplant represents their best and/or last hope of cure whilst simultaneously exposing them to their greatest risk of death.

The complexity and time-consuming nature of the BMT process therefore means that multiple health professionals need to be involved to adequately support patients across the whole timeline of the BMT[17]. The protracted nature of the transplantation and the range and severity of the complications that recipients may experience as part of the transplant process make it necessary for nurses to provide ongoing information and support to the patient throughout the transplant procedure[18]. Nurses' expertise in patient advocacy, patient education and patient support are particularly central to the ongoing consent process in this setting[19].

It is noteworthy that it is impossible and impractical – and also legally and ethically unnecessary – for health professionals to provide all information about BMT in an attempt to obtain 'fully' informed consent. Legally, medical practitioners have a duty to exercise reasonable care and skill, both in the provision of professional advice, as well as in their diagnoses and treatment of patients. In the decision in *Rogers v. Whitaker* [1992] HCA 58, the High Court held that a responsible medical practitioner is to provide the patient with relevant information about material risks. A risk is considered material if a reasonable person in similar circumstances would attach significance to the risk, or if the doctor is, or should be, cognisant that the particular patient would express concern about the risk. This principle is also consistent with the guidelines from the National Health & Medical Research Council (NHMRC)[20].

What is instead required is for health professionals to satisfy themselves that patients have "demonstrably engaged" with the education process and that the consent they provide is valid[21]. Additionally, much of the available evidence regarding the success and effects of the procedure has been analysed at a population level, and this creates one of the greatest challenges faced by clinicians in the BMT process – how to translate this information from a population level for an individual patient and their circumstances. Nurses' skills lie in overcoming this dissonance to effectively translate this evidence for individuals and adequately support patients emotionally as they learn to interpret and apply this information to their individual situations[22].

Elsewhere we have presented a detailed analysis of how patients and their families in our study understood consent to BMT as a complex, relational decision-making process "embedded in social relations of obligation and reciprocity"[23(p1269)]. Here we detail patients' and nurses' perceptions of the complexity of information delivery and support across the transplant trajectory. We draw attention to the centrality of nurses' roles and their expertise in supporting patients' information needs throughout the transplant process.

Method

This research formed part of a larger project aimed at investigating the process of decision-making in high risk medical procedures – in this case allo-BMT – through in-depth interviews with patients, their significant others and health professionals[24]. Health professionals and patients were purposively sampled from BMT units of tertiary teaching hospitals in Sydney, Australia.

This project was funded by an Australian NHMRC project grant (no. 457439). Approval to conduct the research was received from the relevant University and Area Health Service Human Research Ethics Committees.

Our study included four groups of participants – transplant haematologists, nurses and other health professionals in the transplant team, patient-nominated significant others, and patients. In total, the data set comprised 53 interviews. Nine nursing and allied health professionals were interviewed, including six nurses with varying roles such as transplant coordinator, clinical nurse consultant and ward nurse.

A total of 16 patients undergoing allo-BMT were included in the study; 8 were interviewed twice and one was interviewed three times, resulting in a total of 26 patient interviews. Repeat interviews were conducted in order to provide patient perspectives both before and after the transplant.

We decided at the study design stage to restrict participation to only those patients who had already consented to undergo allogeneic BMT since few, if any, patients who are offered a BMT subsequently refuse. It is usually only those patients for whom it is thought that BMT could be a therapeutic option, are considered 'fit' enough to survive the rigours of the transplant, and have already indicated a willingness to undergo the procedure, who are referred to a specialist BMT unit for consideration of transplantation. Only patients deemed to be fluent in English were included in the study because the research team did not have expertise in using translated interview data and had concerns about the accuracy and nuance of patients' responses being lost through translation. We acknowledge this as a limitation of our research.

During the semi-structured in-depth interviews, patients were asked questions about how they had made the decision to undergo transplant in relation to their personal circumstances and interactions with health professionals and members of their social network. Interviews were thematically analysed by the first two authors with a focus on information-giving, interpersonal relationships and the lived experience of transplant. Following immersion in the data via re-reading of transcripts and discussion with the broader research team, the first two authors developed a broad coding framework and used constant comparison to define, strengthen, collapse and expand different themes. The data presented in this paper focuses on a subset of these themes regarding how patients assimilated the information they needed to initially consent to proceed with the transplant and how nurses supported their ongoing consent and compliance over the lengthy transplant journey. All participant names and quoted names are pseudonyms.

Findings

Patients and health professionals alike described information about the transplant – including procedures, side effects, rigours of transplant – as complex. This complexity was due to not only the large volume of information that patients were given access to – both by health professionals and information they found themselves via the internet – but also the unpredictability and variability of possible effects. These aspects meant that information provision was an ongoing activity achieved through multiple interactions with various health professionals over the course of the transplant. In this way, BMT provides a clear example of how consent needs to be viewed as an ongoing process rather than a static event at one point in time. For example, in their interviews, the nurses reflected on the informational complexity in terms of how challenging it was for patients to understand:

> *I think the whole area of transplantation is just so complex that even all of us have difficulty understanding everything that's going on, so it would be so difficult for a patient who just hasn't go the medical background or a certain level of education to understand everything that happens, or everything that could possibly happen – Kathleen, nurse.*

Over the course of the transplant, patients and their families accessed information about the procedure during consultations and interactions with a variety of health professionals and from printed resources, including the internet and a book called *Allogeneic bone marrow transplant: a patients' guide* written by transplant doctors, nursing and allied health professionals and published by the Bone Marrow Transplant Network New South Wales[25]. The BMT Network book provided an easy reference for patients and their families to address certain issues and questions that arose between their hospital visits. It contained detailed information about transplant preparation, donor searching, stem cell donation, transplant procedures, complications, nutrition, life after BMT, emotional impacts of BMT, social relationships, and practical issues including finances, accommodation and transport. Accessed internet resources included websites recommended by the relevant bodies such as the Leukaemia Foundation, the Cancer Council NSW and government departments. These websites provided further information about transplant procedures, emotional aspects of transplant and family relationships, accommodation, and financial services. Patients also accessed blogs written by transplant survivors.

Nurses recognised patients' different information preferences and needs, as well as how challenging the nature and volume of information about BMT was:

> *Some patients will say quite specifically "Don't tell me about it – I don't wanna know, I just wanna get through each day and then get out'a here" – Eva, nurse.*

> *Patients don't want a lot of information, I mean what they want is to be cured... occasionally patients have said "... can't you just put me to sleep and wake me when it's all over?" – Kathleen, nurse.*

This was confirmed by patients who articulated how the volume and complexity of the available information and their fluctuating vulnerable state meant that they were often overwhelmed by the information:

> *I was just so sick and I just blocked things out. I just couldn't, I couldn't take it all in, they just sort of [provide the information] holus bolus and it was just too much, too much information on top of everything – Elizabeth, patient.*
>
> *Uh, well, actually, I felt quite involved [in decision-making] and I think that was to do with the staff because they [nurses] were always explaining everything, and if there was something that wasn't explained… then you know I would ask and… it would be explained to me – Claire, patient.*

Patients often relied upon nurses to translate information into lay terms and to evaluate the relevance of this information for their specific transplant journey. Although it was often the case that patients had only one consultation with the transplant haematologist before proceeding to transplant, many of them also attended a hospital-hosted information day. At the information day, presentations were given by various health professionals from the BMT team – including a transplant haematologist, transplant coordinator, clinical nurse consultants, ward nurses, psychologist, dental specialist and social worker – and often a BMT survivor who described their own transplant experience. The professionals presented information about transplant procedures, complications, infection control and self-care. Emotional and practical implications of the transplant for patients and their family members were also discussed.

Patients emphasised how attending such a day helped them to understand information about the transplant they had received from the BMT book and their consultations, and the way the presentations provided content knowledge and reassurance:

> *The education session was good. I think the book and the education session worked well together. [The information day taught me] to be not so scared by the book. No because the book – if you read – the book's very good… I think it's really well written and it's really good on having a lot of, um, psycho-social aspects and talking about emotional support as well as the medical side of it. But if you just looked and read, the scariest chapter is the complications of bone marrow transplant. And that's quite scary for anyone to read and I think that when you go to the education session what the doctors then do, is um, clarify that. They clarify it and they sort of start saying "oh, some people will get this, a few people get this, this is pretty rare, this is pretty common". Rather than just having the complications, and the book doesn't quite have that finesse to it that a doctor can do in the education session. So you actually come away with a feeling of "oh, that isn't that bad, we found out there's these three bad things to worry about and the rest we don't have to worry about so much" –William, patient.*

Nurses fulfilled roles as both transplant coordinators and ward nurses in the BMT setting. This led to them having more sustained interactions with patients over the course of their treatment where they provided information to patients more frequently than the doctors. This ongoing information support over the prolonged course of the BMT played a significant role in keeping the patient informed about what was happening and why:

> *I ask a few questions along the way… they fill me in on what was needed to be known… and I'm learning bits and pieces as I travel through. Sometimes I understand, sometimes I don't – Quincy, patient.*
>
> *I would rather they come in and say "this is what's going to happen next" – that way I can sorta understand – Mia, patient.*

This ongoing provision of information not only ensured that the patients' consent remained valid throughout the transplantation period, but it also provided them with reassurance that what they were experiencing was to be expected:

> *The only things that I ever needed to know was if something – if I didn't feel well, why didn't I feel well? – Edward, patient.*

Nurses' role was also seen as ongoing and not restricted to specific consultation times as they had greater opportunities for more informal and accessible information provision with patients. The more frequent contact with patients led to more ad-hoc questioning from patients over the course of the BMT procedure. This information provision often occurred during interactions with nurses delivering clinical care rather than being a separate designated task.

Discussion

Information about BMT is enormously complex, and health professionals need to consider patients' informational needs and preferences when communicating with them about the procedure[26]. Additional complexity is present as patients' informational needs may often change throughout the course of their treatment[27] as their physical, cognitive and emotional vulnerability fluctuates.

Acknowledging and accounting for this complexity within information provision activities was found to be a challenging task in our study. Whilst becoming informed about transplant procedures and side effects through printed and internet-based resources was viewed as important by patients, these resources only became useful when presented by or discussed with health professionals. These interactions helped patients to understand the importance of different aspects of the BMT and manage the volume of available information by having it interpreted for them and their questions responded to over time.

The need for discussion, interpretation and repeated presentation of information over the long course of BMT identifiably positions this task within the remit of nurses given their unique role in supporting patients' physical and emotional needs while concurrently providing clinical care over an extended period of time. In identifying the role of nurses in this process, we emphasise how these professionals complement other members of the transplant team by using their unique positions and skills to ensure adequate information is both provided and understood by the patient – to the best of their ability – over the course of the transplant. We also emphasise that the importance of the process and practice of information provision is equally as important to consider as the content of that information in achieving ongoing consent.

BMT is a complex and complicated procedure that cannot, and should not, be viewed solely in terms of the biomedical stages in the process. Almost all patients who undergo BMT experience a wide range of psychological and psychosocial disruption to their lives, beginning during their in-patient admission. It is during this time that the patients invariably rely on the nurses to remind them of relevant information about the next phase in the transplant trajectory.

The literature has identified nurses' role in informed consent processes to include that of communicators, information givers and advocates[28,29]. Our findings support these claims and highlight the need for further research on these roles in different clinical contexts.

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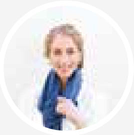

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Improvement in early survival of cancer in South West Victoria

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Abstract

Background The Victorian Cancer Plan aims to increase survival. As such, our study investigated the improvement in 12-month survival for newly diagnosed cancer patients in South West Victoria.

Methods Patients diagnosed in 2009–10 and 2014–15 and their treatment pathways are recorded in the Evaluation of Cancer Outcomes Barwon South West (ECOBSW) Registry. 12-month survival was compared and any association with demographics, diagnostic measures and treatment analysed.

Results 12-month survival was 77% for 2009–10 and 79% for 2014–15. Improvement in survival was found for those aged older than 70 years (increased by 5%), females (4%), those residing in higher socioeconomic regions (4%), head and neck cancers (4%), those who had surgery (3%), and surgery and a systemic agent (6%). There was no improvement in survival for any other combination of treatments.

Conclusion Although the overall 12-month survival did not significantly change, the improvement in some subsets of patients, particularly surgery, is promising.

Introduction

The Victorian Cancer Plan focuses on improvement in cancer outcomes[1]. Positive changes in 5-year survival have been reported[2,3], with significant increases for prostate cancer, kidney cancer, non-Hodgkin lymphoma and breast cancer[2]. However, the first outcome measure is 12-month survival. Early survival is likely to be related to tumour progression at presentation and timeliness of treatment. In Victoria, 12-month survival from 2006 to 2009 improved by 2%[1]. The goal is now to double that improvement to 4%. Whilst such an increase for all cancer patients as a group might be considered challenging, there are likely to be subsets of patients where this goal is achievable.

Early detection improves survival. As such, timely diagnostic procedures, treatment and care is the responsibility of the health service. Regional and rural areas are supported by both public and private health services with links in communication across the stream of services. How well they respond to a patient's need may influence outcomes. One such region is in South West Victoria where the health services have worked towards better communication, treatment and care supported by the Barwon South Western Regional Integrated Cancer Services (BSWRICS). The vision is to improve the patient experience and outcomes by connecting care and driving best practice.

BSWRICS is supported by the Evaluation of Cancer Outcomes Barwon South West (ECOBSW) Registry that records treatment pathways for all newly diagnosed cancer patients in the region[4,5] – this dataset allows analysis of patterns of short-term survival. The goal of this study was to identify subsets of patients where short-term survival rates have not have increased over the years and where further attention by the health services might be needed.

Methods

The ECOBSW Registry collects clinical information on all newly diagnosed cancer patients in South West Victoria (population 418,103)[4,5]. The Registry records the entire patient journey, including diagnosis, treatment and outcomes. This study reports on 12-month survival for patients diagnosed in 2009 and 2010 and compares this to patients diagnosed 5 years later in 2014 and 2015, accessed from Births, Deaths and Marriages. We hypothesise that survival will have improved for some subcategories of cancer patients and may be related to demographics, tumour stream, or type of treatment received.

The Barwon South Western Region spans from the city of Geelong to the South Australian border. The region encompasses the smaller towns of Colac, Warrnambool, Camperdown, Hamilton and Portland. The connecting landscape is mostly farming with some industrial regions, smaller farmlets and timber industry. The region is surrounded to the south by coastal towns with many tourist attractions and coastal resorts. There is a large influx in population during the summer season; however, this report details the cancer journey of permanent residents.

Socioeconomic scales used in this paper were established from the Australian Bureau of Statistics SEIFA codes linked to town or postcode. The lowest tertile of the scales are the most disadvantaged regions.

Statistical analysis

The goal of the study was to assess the change in survival over two time periods and with independent groups of patients. We acknowledge that some subsets may have poor survival in 2009–10 and improved, stayed the same or decreased in 2014–15, while other subsets may have had a good survival rate in 2009–10 and improved, stayed the same or decreased. Our interest was in any change in survival. By analysing the 12-month survival for newly diagnosed cancer patients in 2009–10 and using a Chi-square statistic to compare 12-month survival for those diagnosed in 2014–15, we were able to assess changes in early survival rates within subcategories. To avoid significance due to multiple comparisons, while acknowledging that a Bonferoni correction can produce false negatives, we reduced the level of significance by half to $p=0.025$.

Results

Newly diagnosed cancer patients numbered 3,858 for the years of 2009–10 and 3,965 for 2014–15. Twelve months after diagnosis, 2,988 (77%) and 3,125 (79%) of patients survived ($p=0.13$), respectively.

There was an improvement in early survival for those aged older than 70 years (65% to 70%) and females (78% to 82%)($p<0.01$) and no difference for those younger than 70 years (88% to 87%) and males (77% to 76%)($p>0.05$) (Figure 1). Survival for those with the marital status of single improved over the time periods (70% to 74%, $p=0.02$). There was no difference in survival rates across time periods for history of smoking and country of birth. Patients residing in the highest socioeconomic regions had increased survival rates for Index of Relative Socio-Economic Disadvantage (81% to 84%) and Index of Relative Socio-Economic Advantage and Disadvantage (81% to 85%) (Figure 2).

Survival rates increased for two health services in the region that were the diagnosing organisation labelled C (79% to 89%, $p<0.01$) and G (82% to 94%, $p=0.02$) (Figure 3), and for patients with head and neck cancer (76% to 90%, $p<0.01$) (Figure 4). There was no significant change in early survival for public or private patients or for different stages of tumour at diagnosis.

There was no significant difference in survival rates for patients whose cases were presented to a multidisciplinary meeting (Figure 5). Survival for patients that had surgery increased over the time periods from 92% to 95% ($p=0.02$) and those who had surgery and received a systemic agent from 91% to 97% ($p=0.01$). There was no significant change in the rate of survival for all other combinations of treatments.

Discussion

This study reports on changes in early survival across a 5-year time period in a regional/rural setting of South West Victoria. Some of the subsets analysed have lower than average early survival in the first analysed time period and improvement might have been inevitable. Cancer is more common in older age and is often associated with more comorbidities complicating treatment decisions. Indeed, advanced age is one of the risk factors for high mortality in the first 12 months from diagnosis[6,7]. However, optimistically, this current study has found a 5% increase in short-term survival for the older age group of patients.

Health services with high volumes of surgery have reported better outcomes than low volumes[8]. This study reports on higher than average early survival rates for patients in a regional/rural setting who have had surgery and, in addition, an improvement over the 5-year time period. The increasing use and refinement of minimally invasive and robotic techniques in cancer surgery may have contributed to improvement in early survival. Recent

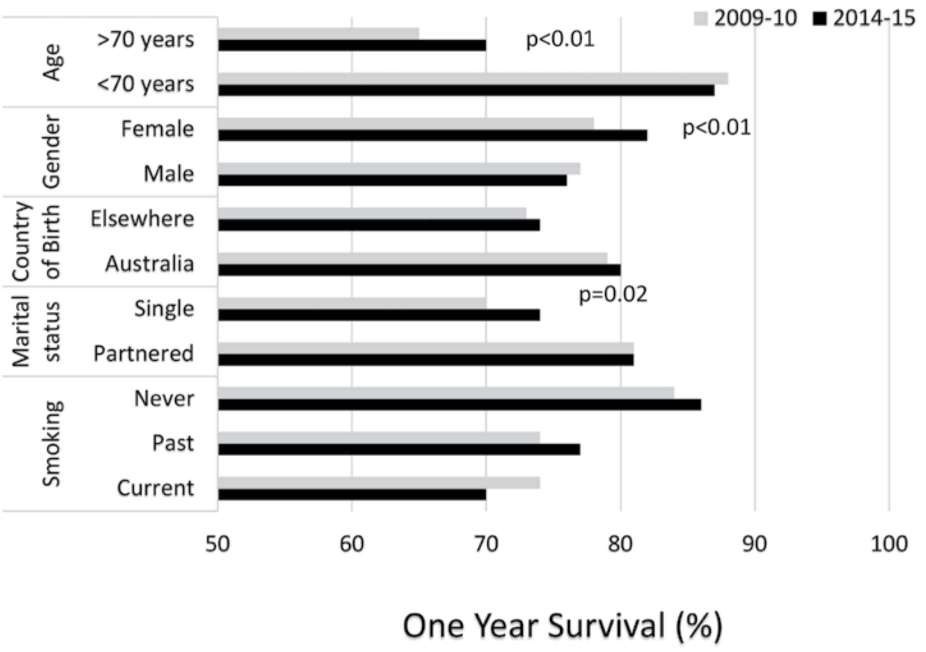

Figure 1. 12-month survival for patients diagnosed in 2009–10 and 2014–15 by demographics. p value is shown for significant change in survival.

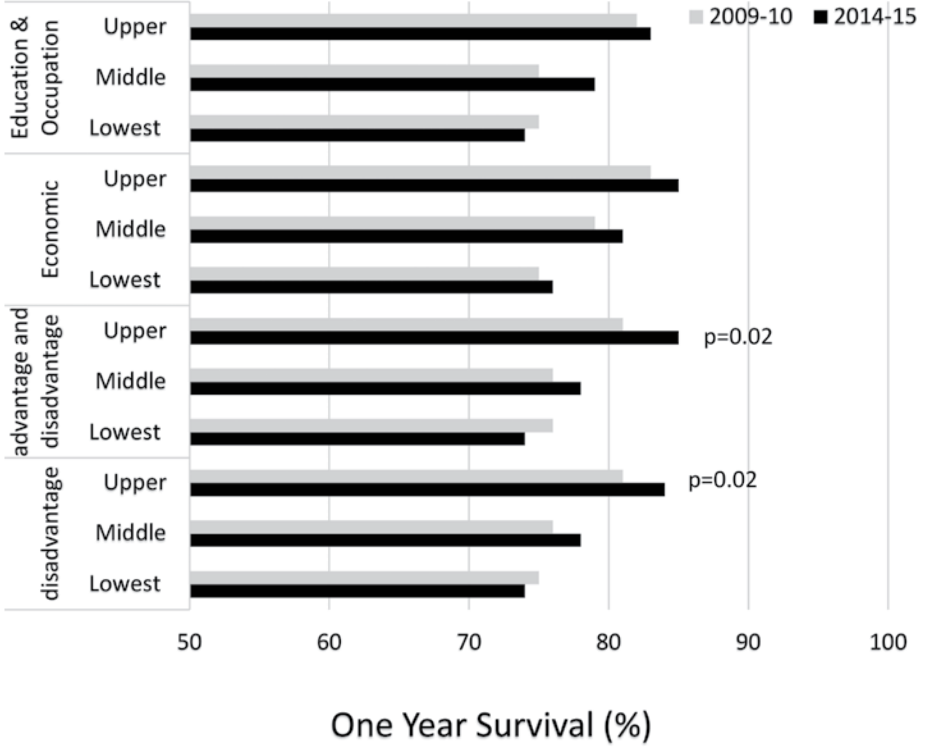

Figure 2. 12-month survival for patients diagnosed in 2009–10 and 2014–15 by socioeconomic code associated with residential address. Socioeconomic levels are the upper, middle or lowest tertile with the lowest the most disadvantaged. p value is shown for significant change in survival.

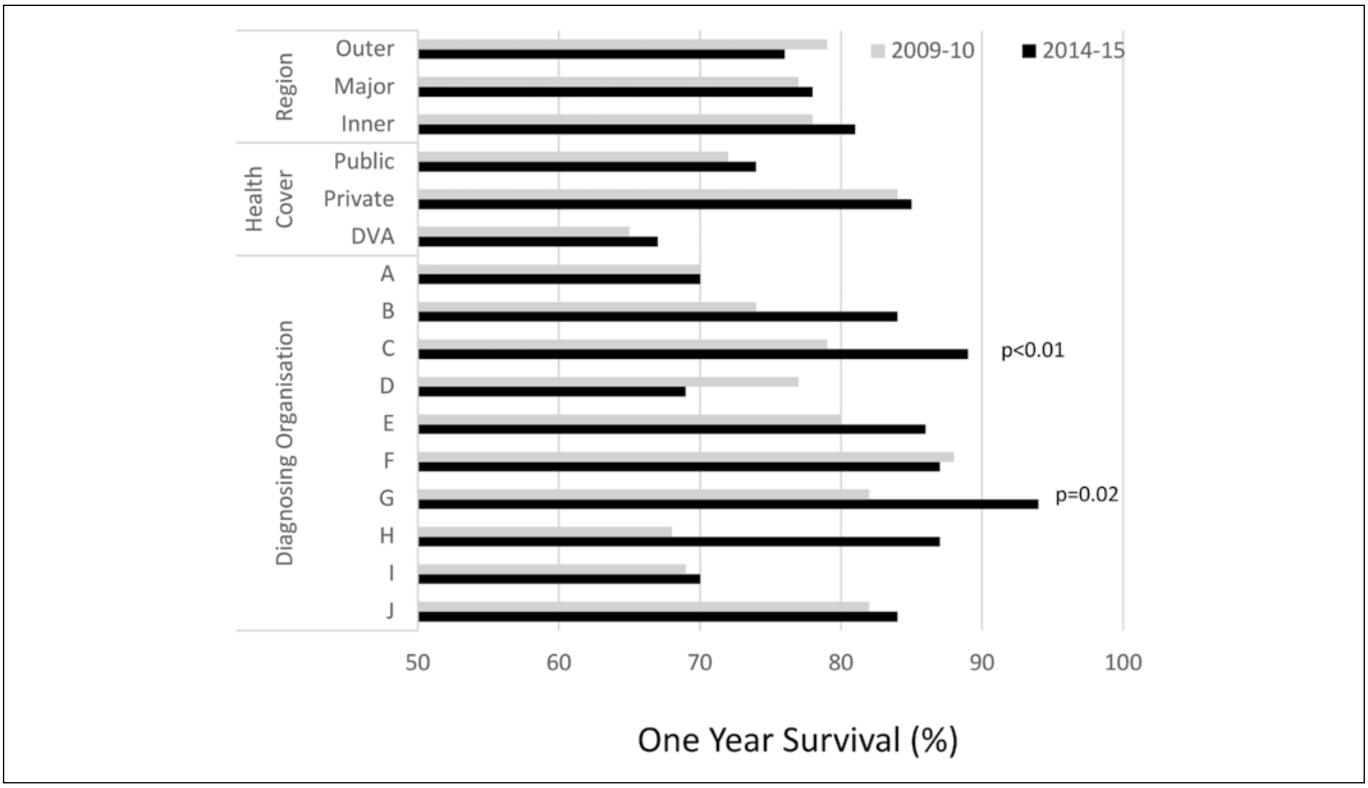

Figure 3. 12-month survival for patients diagnosed in 2009–10 and 2014–15 by region of residence, health cover and diagnosing organisation. The Outer region includes the far South West from Hamilton to the South Australian border, the Inner is from Hamilton to outer Geelong, and the Major is the Greater Geelong region. p value is shown for significant change in survival.

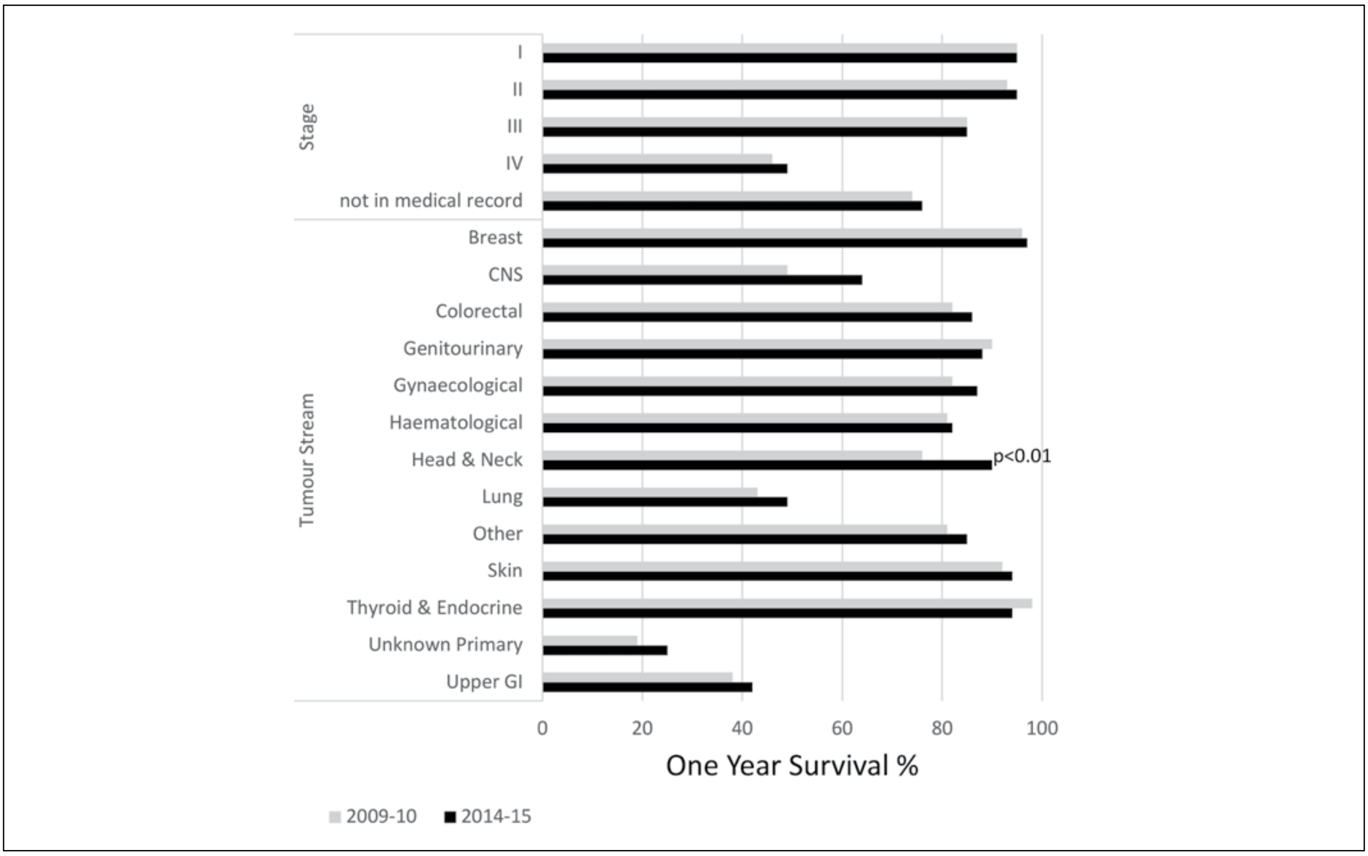

Figure 4. 12-month survival for patients diagnosed in 2009–10 and 2014–15 by tumour stage and tumour stream. p value is shown for significant change in survival.

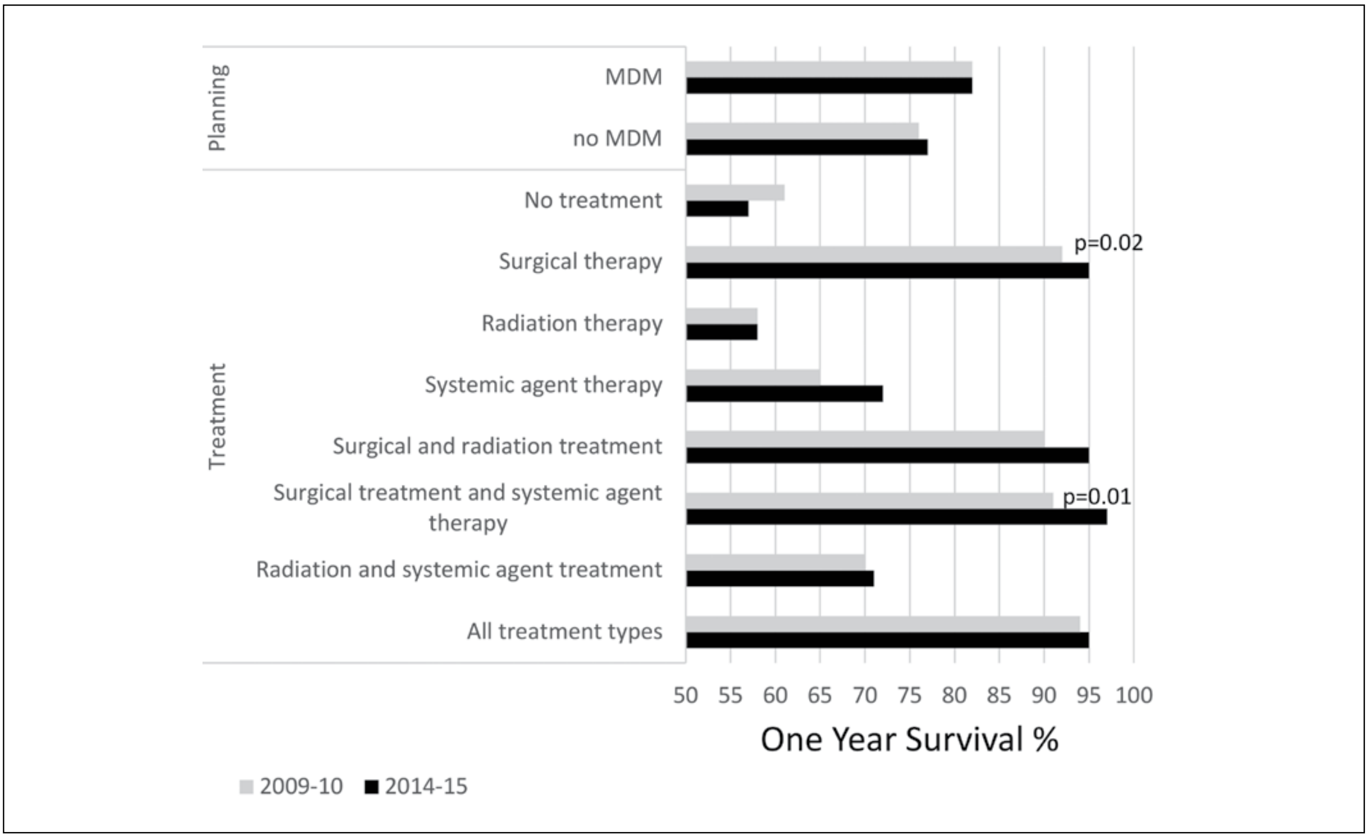

Figure 5. 12-month survival for patients diagnosed in 2009–10 and 2014–15 by treatment planning and treatment. p value is shown for significant change in survival.

studies suggest that minimally invasive surgery is associated with reduced perioperative morbidity and mortality in select cancers[9]. Improved early outcomes in lower stage cancer treated with surgery are thus expected to improve 1-year survival rates.

The improvement in survival for patients treated with surgery may also be the result of better patient selection. With increasing evidence for curative intent radiotherapy in some cancers, patients with surgical risk factors such as poor functional status or significant comorbidities may be referred on for radiotherapy in place of surgical resection. Patient selection has been enhanced by joint decision-making at multidisciplinary team meetings and clinics which are becoming the standard of practice.

In addition, trends in the use of neoadjuvant or adjuvant therapy may explain the improvement seen in the group treated with a combination of surgery and systemic therapy[10-13]. Neoadjuvant chemotherapy is increasingly used to downstage cancer prior to surgical resection. Adjuvant chemotherapy is becoming more prevalent in the setting of resected early stage cancer with lymph node involvement. The improvement in early survival of head and neck cancers might be reflective of this improvement in surgery.

We cannot suggest an explanation for the improvement in early survival for females, as breast cancer survival remained fairly constant; however, gynaecological cancers appeared to show a non-significant improvement and may have contributed to this association. Of interest, there were no significant decreases in early survival for any subcategories.

Prior studies have reported many factors related to short-term survival which are often tumour stream dependent. Short-term survival for oesophageal squamous cell carcinoma was related to gender, stage, type of surgery and infection post-surgery[14]. Comorbidities and frailty[15] are often complicating factors in both treatment and optimal outcomes; however, we recognise for our current study that comorbidity data was not available. We acknowledge that we have not performed in-depth analysis within tumour streams where patterns might alter considerably; however, it is promising to see improvement in early survival for some subsets of cancer patients. Whether the improvement continues on to 2019–20 remains to be seen but the early changes are promising.

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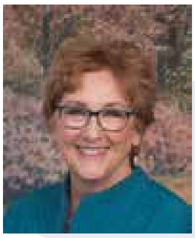

International Keynote Speaker

Deborah K. Mayer, PhD, RN, AOCN, FAAN is an advanced practice oncology nurse (ANP-BC) who has consulted with organizations on issues to improve cancer care and has over 40 years of cancer nursing practice, education, research, and management experience. Dr. Mayer earned a PhD from the University of Utah, her MSN from Yale University, her BSN from Excelsior College, her Nurse Practitioner Certificate from the University of Maryland, and her diploma from Pennsylvania Hospital School of Nursing.

Dr. Mayer is past president of the Oncology Nursing Society (ONS), was a member of the National Cancer Institute's National Cancer Advisory Board (a Presidential appointment) and Board of Scientific Advisors. Dr. Mayer was elected as a fellow of the American Academy of Nursing. She is active in ONS and the American Society of Clinical Oncology (ASCO). She served as the Editor for the ONS' *Clinical Journal of Oncology Nursing* (CJON) from 2007-2015 and has published over 150 articles, book chapters and editorials on cancer related issues. She was awarded the ONS Lifetime Achievement Award in 2015 and, in 2016, was appointed as the only nurse to Vice President Biden's Cancer Moonshot Blue Ribbon Panel. In 2018, she began her role as Interim Director of the Office of Cancer Survivorship with the National Cancer Institute's Division of Cancer Control and Population Sciences.

Dr. Mayer is on faculty at the School of Nursing at UNC and is the UNC Lineberger Director of Cancer Survivorship. Her program of research focuses on the issues facing cancer survivors and improving cancer care. She has a clinical practice working with breast cancer survivors. As a nurse who works "frontline" with cancer survivors, and as a cancer survivor herself, she brings a unique perspective to her clinical, research and health policy collaborations with cancer survivors and advocates, primary care providers, cancer specialists and researchers.

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