The Australian Journal of Cancer Nursing

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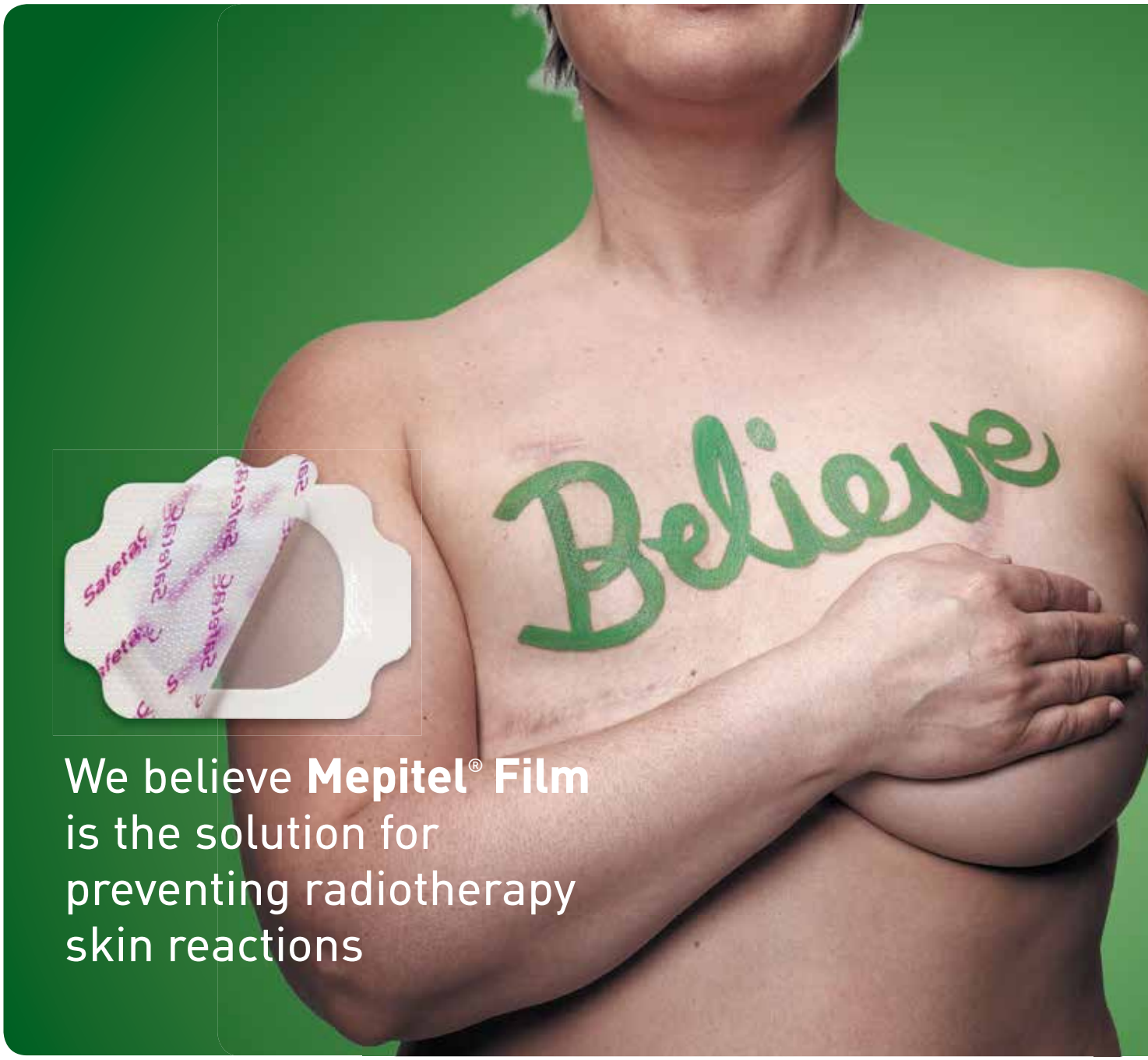
In this issue



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

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

Notes for contributors
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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The Australian Journal of Cancer Nursing

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Cancer Nurses Society of Australia

CAMBRIDGE PUBLISHING

Editorial

Role diversity: opportunities for all cancer nurses

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I have a question for you. What do articles on cancer epidemiology, prostate cancer specialist nurses, reducing cytotoxic exposure risk, an education program for patients receiving oral chemotherapy and caring for young people with cancer have in common? I will provide my thoughts at the end of this editorial, but while you are reading think about these words from a Palestinian writer, Randa Abel-Fattah:

> *In a multicultural, diverse society there are countless ways in which people negotiate the everyday lived experience and reality of diversity*[1].

In this issue, Cameron and Roder provide an easy-to-digest and very useful overview of cancer epidemiology. They talk about epidemiological information as a "communication currency" that can be used to debate and address health issues. The authors provide numerous examples of clinical practices that have been changed as a result of epidemiological evidence; for example, the shift from radical mastectomy to lumpectomy followed by adjuvant treatments. Looking at cancer care through a preventative lens, epidemiological data has directed us to think beyond treatment and focus on how to stop a cancer developing in the first place. As a result, adolescents are receiving a human papilloma virus vaccination and health professionals are advising patients about healthy lifestyle choices such as avoiding excessive sun exposure, not smoking, maintaining a healthy weight and doing regular exercise. This paper emphasises how nurses can use cancer data in their daily practice when advocating for patients and the general community. It is a "must read".

Patricia Campbell has contributed an excellent example of an action research project resulting in practice change. The paper clearly outlines the steps taken to address the exposure risk to health care workers handling intravenous (IV) cytotoxics. The highlight for me was the author's ability to successfully engage, and work with such an extensive range of key stakeholders: oncology pharmacists, senior clinical nurses, department managers and educators, Workplace Health and Safety, infection prevention and control and key personnel from the external, third-party pharmaceutical company who provided the drugs. Despite the diverse roles and vested interests of these people, a mutually acceptable solution was reached. The solution, a closed system for IV cytotoxic medication administration, met the needs of the organisation, provided an overall net cost benefit and significantly reduced the cytotoxic exposure risk to nurses without compromising patient care. An impressive example of a nurse-led initiative with a positive outcome that will benefit many.

Sykes and colleagues discuss the impact of 12 prostate cancer specialist nurses working in rural and metropolitan settings around Australia. These roles were supported by the Prostate Cancer Foundation of Australia in an attempt to address some of the disparities in care and challenges faced by men with prostate cancer and their families. As is the case with any new role, some of the nurses had to be persistent and resilient as they attempted to establish referral pathways and manage relationships with a diverse range of existing staff. The nurses were innovative in how they conveyed their existence and explained their role. A national media launch announced the roles followed by local media campaigns that emphasised specific benefits to the local community. This paper illustrates how "a one size fits all" approach is not appropriate and showed how the nurses utilised their local knowledge, skills and education to ensure their role met the patients' needs.

The paper by Griffiths and Pascoe also illustrates how nurses can adapt their role to meet the needs of patients, but this time, it's required within the context of a changing treatment landscape. Oral cancer treatments are becoming commonplace. While convenient for patients, and possibly cost-saving for health care institutions, oral treatments have provided another opportunity for nurses to diversify and expand their role. This paper talks about oral treatments shifting control from the health professional to the patient, particularly in reporting side effects. I believe patients have always had the responsibility for reporting side effects, but oral therapies have certainly shifted the responsibility for adherence to treatment regimens to the patient. This study evaluated the role of a nurse-delivered education program that facilitates adherence, toxicity monitoring and safety for patients self-administering oral chemotherapy in the home. The authors utilised the "MASCC Teaching Tool for Patients Receiving Oral Agents for Cancer©" developed by the Multinational association of Supportive Care in Cancer (MASCC). Their findings indicate a structured and individualised approach to education was beneficial to patients in relation to knowledge, confidence and overall wellbeing. This paper reminds us of the

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Visit **www.cosa2014.org** and select "VOYCE (YERVOY Clinical Network): supporting medical oncologists and nurses in managing patients on YERVOY treatment" in the 'add-ons' section of the registration portal. This breakfast session is free for conference delegates but it's important to register as places are limited.

VOYCE Breakfast Meeting Agenda, 3rd December, 2014

Time	Details
7:15am	Registration and breakfast served
7:25am	Welcome and introduction (A/Prof. Alex Guminski)
7:35am	Introduction to VOYCE for medical oncologists (A/Prof. Alex Guminski)
7:40am	Introduction to Nurse VOYCE (Dr Donna Milne)
7:45am	Interactive case studies (A/Prof. Alex Guminski & Dr Donna Milne)
8:15am	Q&A and summary (A/Prof. Alex Guminski & Dr Donna Milne)
8:30am	Close

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Other serious immune-related adverse reactions such as Guillain-Barré syndrome, myasthenia gravis-like symptoms, severe sensory and motor neuropathies and severe endocrinopathies have also been reported in clinical trials with YERVOY. Please refer to full Product Information for descriptions of these events. Other adverse effects include colitis, GI haemorrhage, hypotension and abnormal hepatic function. Please refer to full Product Information for a full list of adverse events. **DOSAGE AND ADMINISTRATION: Liver function tests and thyroid function tests should be evaluated at baseline and before each dose of YERVOY. Additionally, any signs or symptoms of immune-related adverse reactions, including diarrhoea and colitis, should be assessed during treatment with YERVOY. YERVOY must not be administered as an IV push or bolus injection. Patients should be monitored for the signs and symptoms of immune-related adverse reactions during and after cessation of therapy. The recommended induction regimen of YERVOY is 3 mg/kg administered intravenously (IV) over a 90-minute period every 3 weeks for a total of four doses. Patients should receive the entire induction regimen (four doses) as tolerated, regardless of the appearance of new lesions or growth of existing lesions. Assessments of tumour response to YERVOY should be conducted only after completion of induction therapy. Additional treatment with YERVOY (re-induction with four doses) may be considered for patients who develop progressive disease after deriving clinical benefit.** The recommended re-induction regimen of YERVOY is 3 mg/kg administered IV over a 90-minute period every 3 weeks for a total of four doses as tolerated, regardless of the appearance of new lesions or growth of existing lesions. Management of immune-related adverse reactions may require omission of a dose or permanent discontinuation of YERVOY therapy and institution of corticosteroid or other immunosuppressive therapy. Please refer to full Product Information for a full description of guidelines. Please refer to full Product Information for preparation and administration instructions. Each vial of YERVOY is for single use in one patient only. Store in a refrigerator (2°C to 8°C), do not freeze, protect from light. **PRESENTATION:** YERVOY concentrate solution for infusion (5 mg/mL) is available in packs containing one vial of 50 mg of ipilimumab in 10 mL or one vial of 200 mg of ipilimumab in 40 mL. Prepared from the Approved Product Information dated 31 July 2013. BMS Medical Information: 1800 067 567. Bristol-Myers Squibb Australia Pty Ltd, ABN 33 004 333 322, 4 Nexus Court, Mulgrave, VIC 3170. BVC0062 10/14. YER/0117/09-14. Date of preparation: October 2014.

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range and diversity of well-established resources, developed by internationally recognised organisations that are available for all to use.

In the final paper, Peter Lewis and colleagues discuss the range of issues faced by adolescents and young adults (AYA) as they live through and beyond their cancer diagnosis and treatment. Each year, approximately 1700 AYAs are diagnosed with cancer in Australia[2] and will have to deal with at least some of the issues outlined in this paper. This qualitative study highlights the role of the multidisciplinary team (MDT) in supporting young people's independence, friendships and new relationships. An MDT with a range of skills has the potential to ease the distress caused by a life-changing cancer diagnosis. This is particularly important when we know care is often fragmented and may be provided by health professionals without adequate training to meet the needs of this group.

So what do all these papers have in common? For me, they all illustrate the diversity of roles filled by cancer nurses and the diverse needs of patients. I believe such diversity could be used to attract new nurses to our specialty and to remind existing cancer nurses of the opportunities available to them. In many health care systems there is much talk about having to work within budgetary and resource constraints, and doing more with less — it can all sound hopeless and overwhelming. So next time you hear such talk, reflect back on what you have read in this issue of *The Australian Journal of Cancer Nursing* and think about what you have already achieved and the opportunities ahead.

I will finish with some words from Steve Jobs, slightly modified by me, that illustrate what happens when people don't experience diversity in the workplace:

> *A lot of people in our industry haven't had very diverse experiences. So they don't have enough dots to connect, and they end up with very linear solutions without a broad perspective on the problem. The broader one's understanding of the human experience, the better [outcomes] we will have*[3].

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Cancer — using epidemiological data to understand cancer patterns

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Abstract

Epidemiology is used to describe cancer trends in the population, investigate means by which cancer can be tackled, and evaluate interventions. It is an important tool used by policy makers and planners to identify and address public health issues. Developing an understanding of cancer data, how it is sourced, reported and used is useful for nurses working in all areas of cancer control to better understand the current cancer care context and how it is informed. Epidemiological data are used by consumer groups, non-government organisations, governments and the media when discussing health service needs and outcomes. In this report, the current state of cancer epidemiology in Australia is reviewed, and in particular, how epidemiological data are gathered, reported and used to advance cancer control is described.

Introduction

Cancer epidemiology is the quantitative study of determinants of cancer-related states and events in populations and the changes in population health that occur in response to cancer control initiatives. Cancer is a term used to describe diseases where processes of cell division, by which tissues normally grow and renew themselves, become uncontrolled and lead to a proliferation of malignant cells.

Epidemiological methods are used in the cancer field to show patterns of cancer and indicate directions health bodies can take to prevent and manage cancer at a population level. Information derived from epidemiological studies is used to develop cancer control policy and guide the implementation of environmental health initiatives, health promotion programs, and screening, treatment and support services.

Importance of epidemiology

Epidemiology is often regarded as having begun in modern times with the investigation of a cholera outbreak in London in the 1800s that related to use of the Broad Street pump. However, prior to that investigation, the study of population health had occurred in various forms throughout the ages, often using death records kept by religious and social organisations. Death records have been used to identify many risks of cancer, including scrotal cancer in chimney sweeps, breast cancer in nuns, and nasal cancers in snuff takers. The data were often reported as maps of deaths, through newspaper articles and medical journals. The epidemiology of earlier times used relatively simple methods, generally restricted to identifying one cause for one outcome in relatively small population samples. With the increased use of computer technology and advanced statistical techniques, however, it is now possible to examine low risks in large population groups over long periods of time and in a multivariate risk factor context (that is, analysis of more than one risk factor).

Resulting data are used in many different contexts, including, for example, to support:

- implementation of anti-smoking legislation and campaigns, based on evidence of increased lung cancer and other diseases in smokers
- implementation of the breast and cervical cancer screening programs, based on evidence of mortality reductions from early detection and treatment
- the promotion of increased fruit and vegetable consumption and increased physical exercise to reduce excesses in body weight and decrease the risk of colorectal cancer.

There are many examples where clinical practice has been changed by clinical epidemiological evidence. These include the shift in practice from radical mastectomy to lumpectomy supported by adjuvant therapies for the treatment of breast cancer and the increased emphasis now placed on psycho-social support for people with cancer.

Epidemiology provides the data for identifying, analysing and framing responses to population health problems. In many ways epidemiological information is used as a type of communication currency by stakeholders and the community to address health issues.

Key terms and concepts in cancer epidemiology

There is a range of methods, tools and rules used in data collection and the analysis and interpretation of data in relation to cancer patterns. Terms used in cancer epidemiology include:

- **Cancer risk**: The probability of an individual developing cancer over a specified period, conditional on the individual not dying in that period[1].
- **New cancer case or incidence case**: This is person who has a new cancer diagnosed for the first time. One person may have more than one cancer and therefore may be counted more than once in incidence statistics if it is decided that different cancers apply.
- **Cancer death**: A death for which the underlying cause is regarded to be cancer. Persons with cancer who die of other causes are not counted in cancer death statistics.
- **Cancer prevalence**: The number of cancer cases existing in a population in a given period of time, usually a year. This would generally include all existing and new cases occurring in that period.
- **Crude cancer incidence or mortality rate**: This is a rate expressed as number of events per specified population size (for example, new cases or deaths per 100,000 people). It may be summarised as the number of cancer cases or deaths that occur in a specified number of people in the "at-risk population". It may be calculated for the entire population or for specific age, sex or other specified components of the population.
- **Age-standardised cancer incidence or mortality rate**: This is an age-adjusted rate calculated to summarise the risk of cancer or cancer death in a population. By adjusting for age, it allows comparison of rates between populations that have different age distributions. Age-standardised rates are commonly used to assess changes in rates over time (for example, changes in rates between 1900 and 2005) or differences in rates between population sub-groups (for example, Indigenous and non-Indigenous components of the population). Generally this is done by adjusting rates to those that would have applied, had a "standard" age distribution applied. In Australia, the Australian 2001 mid-year population is commonly used as the standard or the World Standard Population. Both give different results due to differences in age weighting and care should be taken to be explicit about the "standard" age distribution being used when presenting age-standardised rates.
- **Relative risk**: This can be defined as the ratio of the proportions of people experiencing cancer or cancer death in two populations or two population components. For example, if lung cancer in a population of smokers is six times more prevalent than in a non-smoking population, the relative risk is six.
- **Relative odds (odds ratio)**: This is the ratio of odds of people experiencing cancer or cancer death in two populations or two population components. For example, if the odds of having as opposed to not having a cancer in a population are 10 times higher than the corresponding odds in a comparison population, the relative odds (or odds ratio) would be 10.

Cancer registries in Australia

Data on cancer, its risk factors, diagnosis, treatment and outcomes may be obtained from multiple sources, including:

- Population surveys.
- Cancer registries — population-based and clinical registries, both generic for different tumour types and tumour-specific.
- Hospital patient databases.
- Mortality databases.
- Clinical trials data.
- Environmental data.
- Databases held by clinician and other professional bodies.
- Medical and Pharmaceutical Benefits insurance databases.
- Other databases held by cancer screening or treatment services.

Australian cancer statistics are produced by a number of bodies. All newly diagnosed cases of cancer (excluding non-melanoma skin cancer) and cancer deaths are reported as required by state and territory legislation[2]. Data on cancer-related and non-cancer deaths of persons with cancer are also available from state and territory registries of births, deaths and marriages. Australia is fortunate in being one of few countries in the world that has close to complete coverage of the population with cancer registration.

Data items collected by the population state and territory cancer registries in Australia include names, sex, date of birth, home address, primary site of cancer, morphology type (that is, cell type), date of diagnosis, date and cause of death, and in some instances, stage (or extent of cancer) at diagnosis, tumour grade (level of aggressiveness) and depth of cancer penetration (for example skin cancers). State and territory registries supply a minimum data set to the Australian Cancer Database (compiled by the National Cancer Statistics Clearing

House) at the Australian Institute of Health and Welfare (AIHW) for statistical analysis[3]. This database is maintained by the Australasian Association of Cancer Registries and AIHW. Data on treatment patterns and relevant prognostic biomarkers are generally not collected. Clinical registries, including hospital-based registries, generally collect the same minimum data set plus additional data. These may include items proposed by state or federal health authorities to monitor best practice or to support clinical research.

The minimum data set used by state and territory cancer registries is employed primarily to produce cancer incidence, mortality and survival statistics. It may also be used in conjunction with population health survey data to investigate cancer risk factors. For example, risk factor survey data may be superimposed over a cancer incidence map for a given cancer, often in a given region or for a particular time period, to indicate the risk factors responsible for the cancer patterns of interest. While such data may only be indicative of causal relationships, given the multi-factorial nature of cancer, the data can provide a useful guide to appropriate remedial programs. For example, lung cancer rates may be influenced by ambient pollution and occupational exposures, as well as smoking, and remedial programs may need to tackle more than one cause. Reports on cancer in Australia are provided by state and territory cancer registries and the AIHW, as for example through the biennial Cancer in Australia report[4].

The Australian situation

More than 120,700 new cases of cancer were diagnosed in Australia in 2012, according to statistics projected from the Australian Cancer Database (2009 data)[4]. Between 1991 and 2009, numbers of new cases diagnosed annually nearly doubled, from 66,393 to 114,137, mostly due to increases for prostate, breast, bowel and female lung cancers, as well as population growth and ageing. Changing risk factors such as increasing rates of obesity and other lifestyle factors underlay the increase in incidence and are discussed in following sections.

The latest estimates of five-year survival from all cancer types combined are 65% for men and 67% for women in 2006–2010[4]. This represents an improvement from the corresponding 1982–1987 survival figures of 41% and 53% respectively and means there are increasing numbers of cancer survivors. In 2007 there were around 774,700 Australians living with cancer, who had been diagnosed in the previous 26 years[5]. Despite survival gains, cancer remains a leading killer, with approximately 43,000 people annually dying from their cancers[4].

There are variations in cancer patterns between the sexes and across age groups. The strongest demographic pattern reflects the biology of the disease, that is, the increase in risk with age. In 2012, 75% of cancers in males and 65% of those in females occurred at age 60 years and over[2]. With advances in screening and treatment leading to increases in cancer survival, the likelihood of being diagnosed with more than one primary cancer in a lifetime is increasing.

Excluding non-melanoma skin cancers that are not recorded in Australian state and territory cancer registries, the most common cancers are cancers of the prostate, breast, bowel, melanoma of skin and lung (Figures 1 and 2).

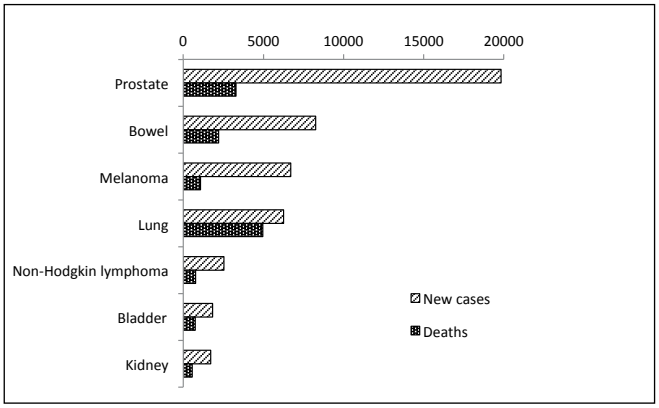

Figure 1: Numbers of common cancers in males, Australia, new cases (2010), mortality (2011).

Source: AIHW Australian Cancer Incidence and Mortality (ACIM) books, 2014

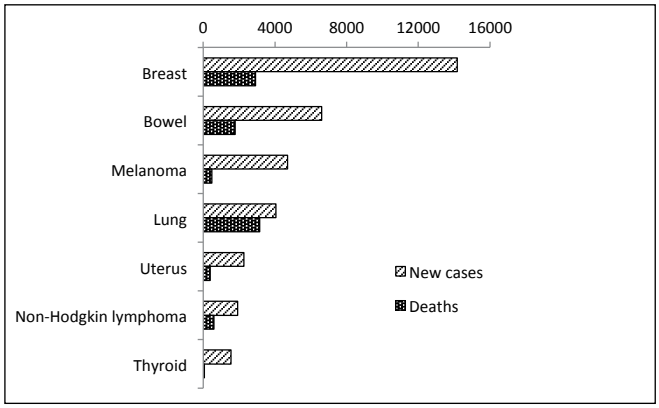

Figure 2: Numbers of common cancers in females, Australia, new cases (2010), deaths (2011)

Source: AIHW Australian Cancer Incidence and Mortality (ACIM) books, 2014

While it is important to know cancer numbers for service planning, it is also important to identify trends in cancer risk, including effects of increases in size and ageing of the population. Comparing trends across different cancers can assist assessments of effects of public health and clinical interventions.

Incidence data collected since the early 1980s show a number of pronounced changes. Male incidence rates increased rapidly through the 1990s, largely due to increases in prostate cancer detection (reflecting the introduction of prostate-specific antigen — PSA — testing in the late 1980s), but then fell rapidly in the late 1990s before fluctuating, probably at least in part to

changes in diagnostic procedures[4]. Meanwhile a comparatively steady increase in female cancer incidence from the early 1980s would largely reflect the increase in breast cancer (Figure 3). The increased incidence of 1.8% between 1990 and 1999 is thought to have been influenced by increased detection resulting from the national breast cancer screening program, plus the increased use of non-program mammography and ultrasound. Between 1994 and 2010 breast cancer mortality rates reduced by approximately 30%, from 31 to 22 per 100,000, which is attributed to screening and treatment advances[4].

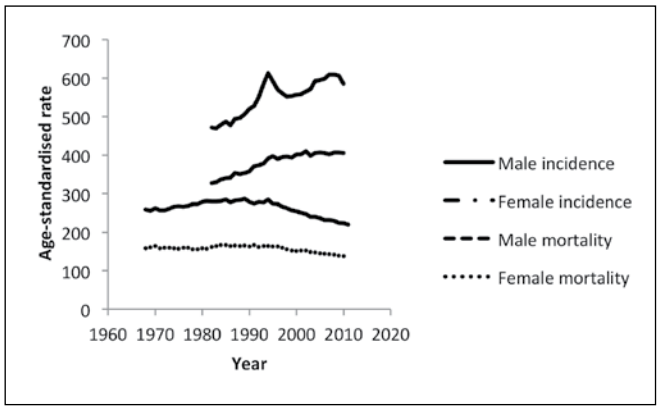

Figure 3: Trends in age-standardised cancer incidence and mortality rates by year, Australia

Source: AIHW Australian Cancer Incidence and Mortality (ACIM) books, 2014

Over the long-term, Australia's cancer mortality rate (all cancers combined) has fluctuated. In males it was at its lowest at the beginning of the 20th century before increasing over time due to smoking. This has now declined to about the same rate as it was in the 1960s. Meanwhile, in females, the cancer mortality rate was relatively stable before declining in the last two decades. The changes in cancer mortality seen over the past century can be attributed to: changing risk factors for cancer such as lifestyle factors; the earlier detection of cancer due to screening and improved diagnostic technology; and changes in clinical practice that have increased survival prospects.

Lung cancer mortality rates have been changing rapidly in opposite directions according to sex (Figures 4 and 5). Between 1991 and 2009, male lung cancer mortality rates fell by 26% from 75 to 56 per 100,000 but rose by 37% in females, from 24 to 33 per 100,000, reflecting the later peak in smoking rates in women[4].

A notable success has been the continuing fall in cervical cancer incidence and mortality rates (Figure 5). Both rates have fallen consistently over the last four decades, reflecting the use of Pap smear and related follow-up treatment of pre-invasive abnormalities. This success was strengthened with the introduction of the National Cervical Screening Program in the 1990s that organised not only a "safety" reminder system

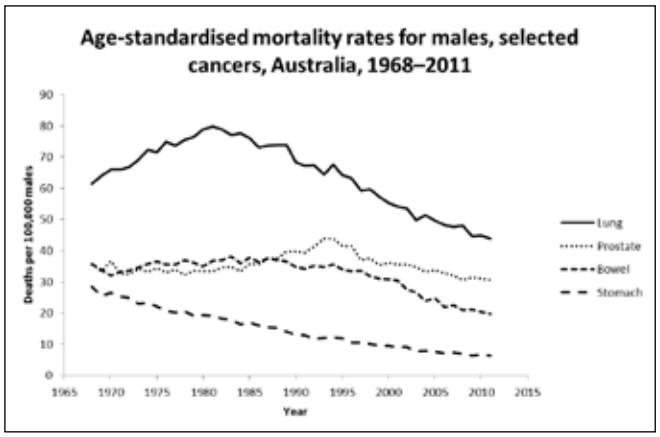

Figure 4: Trends in cancer mortality rates per 100,000 Australian males, 1968–2011

Source: AIHW Australian Cancer Incidence and Mortality (ACIM) books, 2014

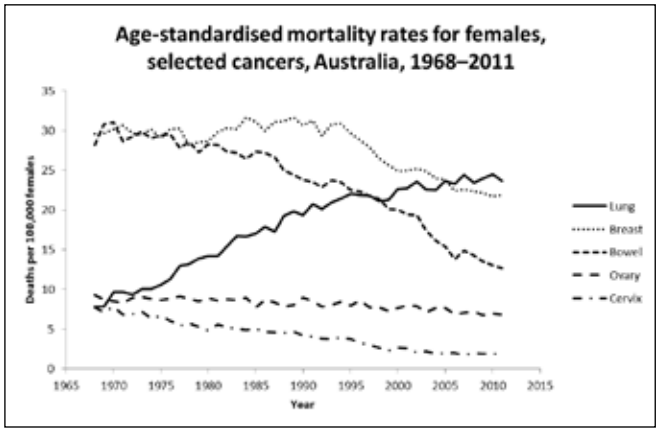

Figure 5: Trends in cancer mortality rates per 100,000 Australian females, 1968–2011.

Source: AIHW Australian Cancer Incidence and Mortality (ACIM) books, 2014

for women but also provided guidelines for the treatment of screen-detected abnormalities. However, the reductions in cervical cancer rates have not eradicated inequalities in risk across the population. Further public health action is needed in this regard as incidence rates of cervical cancer are almost three times higher in the Indigenous population and mortality rates are more than four times higher in this sector of the population[4].

Indigenous Australians have a higher incidence of cancer diagnosis and of cancer-associated mortality than non-Indigenous Australians. Their cancer rates are elevated for cancers of the lip/mouth/pharynx, lung, oesophagus, pancreas, cervix, uterus and liver, but lower for cancers of the prostate, female breast, testis, colorectal, brain, melanoma of skin, lymphoma and leukaemia. In general, cancer survival is lower for Indigenous Australians due to later diagnosis, higher rates of co-morbidity (for example, diabetes), and less complete care[6].

While cancer trends are important for the population as a whole, comparisons of rates by geographic area can also lead to vital

insights. Figure 6 shows the all-cancer mortality rate variations between states and territories, which generally indicates that there are similar rates across jurisdictions, although with a lower incidence in the Australian Capital Territory and higher mortality rate in the Northern Territory. When these rates are further examined by cancer type, variation is seen for melanoma of skin rates, which tend to be higher for Queensland, Western Australia and New South Wales and higher in males (Figures 7 and 8). These data should be interpreted with caution as the individual state and territory rates are from different publication years, but they provide a sense of how differences can be identified when data are examined in more detail.

It should also be noted that even when there appear to be few differences in cancer rates between states and territories, there can be large geographical variations within these jurisdictions and occasionally overt cancer clusters. Asbestos-related mesotheliomas have been seen to cluster in geographic areas where historic manufacturing of asbestos products or asbestos mining took place, such as in Wittenoom in Western Australia,

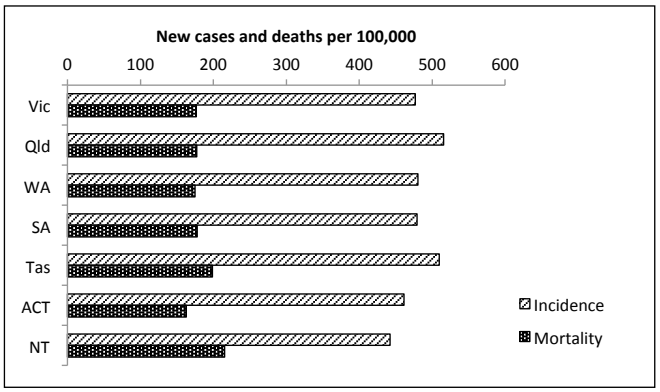

Figure 6: Age-standardised incidence (2004–2008) and mortality (2006–2010) rates for all cancers, persons by state and territory

Source: Australian Institute of Health and Welfare & Australasian Association of Cancer Registries (AIHW & AACR) 2012. Cancer in Australia: an overview, 2012

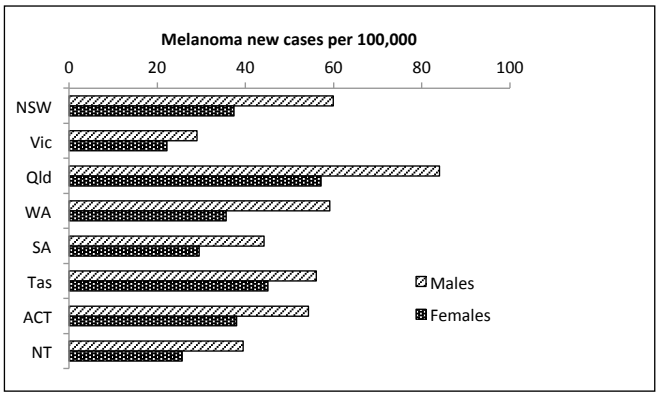

Figure 7: Age-standardised incidence for melanoma of skin, by state and territory for 2008–2012 (year varying by individual state/territory publication)

Source: State and Territory Cancer Registry reports 13–20

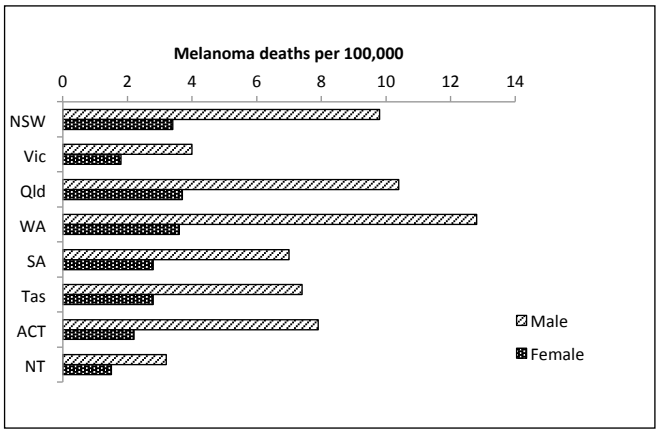

Figure 8: Age-standardised mortality for melanoma of skin, by state and territory for 2008–2012 (year varying by state/territory publication)

Source: State and Territory Cancer Registry reports 13–20

the consequences of which are still being realised[7]. Female breast cancers have also appeared as clusters in some hospital settings and other work places; however, investigation usually shows the number of cancer cases is not significantly higher than the number that could have occurred by chance.

Practical application of information: cancer risks

What does the evidence indicate regarding reducing the risk of developing cancer? An important change has been the growing understanding in Australia and internationally that while some cancers are not related to lifestyle choices (for example, inherited genetic risk) many cancers and cancer deaths are preventable through lifestyle change and screening. Indeed approximately a third of cancers are considered to be preventable by following appropriate food and nutrition guidelines[8]. Other important risk factors that need to be addressed in Australia include tobacco smoking, excess exposure to ultraviolet solar radiation, excessive body weight, lack of physical activity, excess alcohol consumption and exposures to workplace carcinogens[9]. Human papilloma virus vaccination has recently been introduced for school age males and females to prevent cervical cancers. With an increased appreciation of preventive opportunities, there has been a corresponding shift in emphasis from a traditionally treatment orientated approach to an increase in prevention and early detection. Education around healthier lifestyle choices and the introduction of population-based screening signify a greater emphasis on prevention and early detection to reduce the impact of cancer. While there is a high level of awareness of the link between tobacco smoking and cancer (more than 90% aware) there is a much lower awareness of the cancer risk associated with alcohol intake (37% aware)[10].

Cancer Council Australia advocates a nationally coordinated approach to the prevention of cancer in its National Cancer Prevention Policy[9]. This policy outlines strategies for management

of lifestyle risk factors which can be modified to reduce risk of developing cancer, including strategies related to cessation of tobacco use, avoiding excess sun exposure, improvements in diet, increasing physical activity and limiting or ceasing alcohol intake. However, identifying the importance of lifestyle is a first step only in modifying habits in the general population. Considerable effort and funds are being put into cancer prevention strategies, including public education campaigns and targeted political lobbying. For example, the Australian State and Territory Cancer Councils have conducted cancer prevention campaigns, including the Quit (smoking cessation) program, which is run in collaboration with the National Heart Foundation to reduce tobacco use. Another example is the SunSmart Schools Program, which is directed at reducing the incidence of skin cancer. Latency periods in cancer development mean that lag times of a decade or more may occur between the introduction of preventive initiatives and manifestation of their effects on cancer incidence.

Cancer screening

The control of cancer in Australia is a National Health Priority. Eight cancer types have been targeted for attention, namely, lung cancer, melanoma of skin, non-melanoma skin cancers, colorectal cancer, non-Hodgkin's lymphoma, prostate cancer, cancer of the cervix and female breast cancer. These cancers have been chosen because evidence indicates that improvements from prevention, early detection or treatment are likely to bring the greatest benefit to the highest number of people[11]. This brings us to an important strategy used to lessen the impact of cancer in Australia: population-based screening programs.

Screening occurs when asymptomatic populations are tested with the purpose of detecting disease precursors or early disease. This is done to prevent or treat conditions at a curable stage and thereby decrease incidence or increase survival, and decrease morbidity and mortality[12]. Population-based screening is an important strategy to reduce the incidence and burden of cancer through the early detection of cancers, and as in the case of cervical, breast and bowel cancer, the detection of pre-cancerous conditions. The screening programs currently in use in Australia are female breast, cervical and bowel screening.

When determining whether a screening program may be used, epidemiological data are used to identify what population groups may be appropriate for screening, the ones that are at highest risk, and whether resulting screen detection rates and sensitivity are sufficient to achieve the desired health outcomes. Overall, there needs to be a greater level of benefit than harm at a population level for the screening program to be implemented.

Cancer data and nurses

Nurses have roles in all areas of cancer control and as such have an interest in the ways in which cancer data are used to inform and shape cancer policy. As advocates for patients and as community role models, developing and furthering our understanding of cancer data use better enables us to inform others (including those affected by cancer and the general community) about cancer prevention risks and how they can be mitigated on an individual and a population level.

Conclusion

Epidemiology is an important tool for assessing cancer patterns and risk factors and for informing stakeholders, such as cancer health care professionals, policy makers and planners, the media and consumers. Epidemiology has been widely used to inform clinical care, frame population health policies, and plan cancer control services. Epidemiology is a key area of science and is used along with health economics to guide policies on cancer screening, clinical investigations and care.

Useful cancer epidemiology websites and other resources

International Agency for Research on Cancer
www.iarc.fr

The Cancer Council Australia
www.cancer.org.au

Australian Institute of Health and Welfare
www.aihw.gov.au

National Cancer Institute (USA)
www.cancer.gov

Australasian Association of Cancer Registries
www.aihw.gov.au/cancer/aacr/

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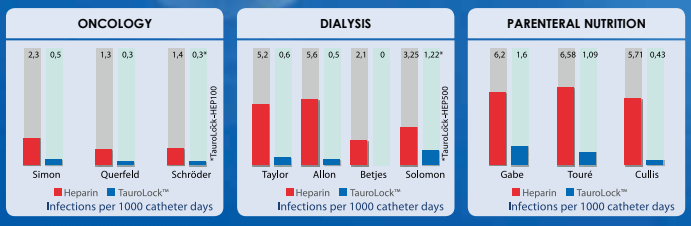

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* Punt, C.D., Boer, W.E. Cardiac arrest following injection of concentrated trisodium citrate, Clinical Nephrology, 2008, 69: 117-118. ** Willicombe, M.K., Vernon, K., Davenport, A. Embolic Complications From Central Venous Hemodialysis Catheters;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

Untangling the lines — reducing cytotoxic exposure risk via the implementation of a closed intravenous cytotoxic administration system: an action research project

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Abstract

Background: Administration of cytotoxic medication can present an occupational health risk to nurses, especially when it involves inserting an intravenous (IV) spike at the bedside. Despite best efforts, cytotoxic exposure can still occur.

Method: An action research project was undertaken with the aim to successfully implement a closed system for IV cytotoxic medication administration that is prepared off-site and transported by a third-party pharmaceutical company.

Results: Evaluation was based on safety, ease of use, including any potential barriers to user acceptance; and product cost. Project outcomes indicated a significant reduction in cytotoxic exposure risk to nurses with no associated micro-bacterial risk for patients. Users reported the system as being easy to manage, resulting in the facilitation of consistent practice when administering IV cytotoxic drugs within the hospital. A rise in direct costs was noted; however, when compared to the expense of managing staff exposure, an overall net cost benefit was found.

Conclusion: This project has had positive results for oncology nurses and health care workers who are seeking to reduce cytotoxic exposure risk and establish the safest possible practice at the bedside.

Introduction

It has been well documented that antineoplastic and cytotoxic agents have carcinogenic, teratogenic and mutagenic properties leading to changes in cell DNA, and for this reason are classed as hazardous drugs[1]. Occupational exposure can also lead to acute symptoms such as eye and skin irritation and nausea. Strong links have also been made to miscarriages amongst pregnant health care workers (HCWs) and congenital birth defects in their children, as well as the development of cancer itself[2-6]. For this reason, every action should be taken to minimise, and where possible eliminate, the occupational exposure risk to HCWs during the preparation of and delivery of chemotherapy[4].

In 2004, the United States Centers for Disease Control and Prevention published a workplace safety and health alert via the National Institute for Occupational Safety and Health (NIOSH) regarding the prevention of "Occupational Exposures to Antineoplastic and Other Hazardous Drugs in Health Care Settings"[7]. This alert described the risks of exposure and defined the term *hazardous drugs* to include "...drugs that are known or suspected to cause adverse health effects from exposures in the workplace"[7]. One of the alerts key recommended actions was the use of a closed system and closed system transfer device during both preparation and administration of hazardous drugs, based on their potential to limit the level of aerosol leakage of the drug and exposure to sharps[7]. A closed system is defined by NIOSH as "a device that does not exchange unfiltered air or contaminants with the adjacent environment" while the closed system drug-transfer device is defined as "a device that mechanically prohibits the transfer of environmental contaminants into the system and escape of hazardous drug or vapour concentrations outside the system"[7]. Within Australia, hazardous drug guidelines are legislated by states and territories[8]. In 2008, the WorkCover Authority of NSW updated its guidelines to include the use of closed administration devices during cytotoxic drug administration based on international recommendations[9].

Literature review

Historically, the oncology nurse administering the chemotherapy used a standard IV giving set (administration system) and attached it directly to the chemotherapy flask at the patient's chair/bed side[10]. This often involved spiking the flask of chemotherapy[11]. While this system was economically attractive and readily available, the prevention of occupational exposure relied solely on the nurse's personal compliance in wearing

adequate personal protective equipment (that is, impervious gown and nitrile gloves tested for use with cytotoxic agents, goggles and well-fitted particulate filter face mask[12]). Since 1981, steps have been undertaken to reduce occupational exposure during drug reconstitution[13]. Closed system transfer devices were first used during the drug compounding process in 1998[10]. However, it was not until 2004, when NIOSH[7] and subsequently in 2006 the American Society of Health-System Pharmacists[14] and in 2007 the International Society of Oncology Pharmacy Practice (ISOPP)[1] issued guidelines calling for the use of closed system drug-transfer devices; that oncology pharmacists, nurses and doctors began to realise that they did not have to accept a compromise on safety. Since this time, the use of closed system drug-transfer devices and closed system guidelines began to be seen as best practice when compounding or administering chemotherapy[6,8,10,14].

The effectiveness of closed system drug-transfer devices in the reduction of occupational exposure risk in a pharmacy setting was documented by Wick *et al.*[15], who performed surface wipe tests for cyclophosphamide and ifosfamide before and after the use of closed system drug-transfer devices and found no trace of the drugs after closed system drug-transfer device use. Siderov *et al.*[16] repeated the study in Australia using cyclophosphamide and found a considerable reduction in surface contamination. This was also found by Nyman *et al.*[17] who, in addition to surface wiping done in the previous studies, also collected urine specimens from HCWs to test for the presence of cyclophosphamide. Although his study found lower levels of contamination six months after the implementation of closed system drug-transfer devices, he noted that the device did not eradicate all traces of the drug. A similar result was found by Hon *et al.*[18] in a multi-centre study of all HCWs potentially exposed to chemotherapy. This verified that while the use of a closed system drug-transfer device may lower cytotoxic exposure, the HCW cannot rely solely on the device and it is still necessary to wear appropriate personal protective apparel[19-22].

Reducing our cytotoxic exposure risk

The Sydney Adventist Hospital is a 360-bed private hospital, providing over 8500 cytotoxic infusions per year within the day infusion centre and inpatient oncology ward. An external pharmaceutical company is responsible for the preparation and delivery of the cytotoxic medication. The prepared products are delivered to the infusion centre and oncology ward and stored appropriately until administration. Prior to commencement of the project, the IV delivery system required nurses to spike the prepared infusion bag at the patient's bedside at the time of administration. Despite adopting the safest possible practice at the bedside, cytotoxic exposure occurred; resulting in nine reported incidents over a nine-month period, with an equal number of near-miss incidents. An investigation revealed that the main cause of the exposure was related to either IV spike displacement occurring after nurses had spiked the infusion bag or faulty administration sets with leaking airways and needle-free valves (Table 1).

Table 1.

Reason for cytotoxic exposure	Number of incidents
Displacement of IV spike	3
Leakage from needle-free valves on IV lines	3
Split in IV line	1
Leakage from airway	2

While it could be argued that these specific incidents of cytotoxic exposure risk made up a very small percentage of the total drugs administered per year and that the risk was as low as reasonably achievable[7], the preventable nature of the incidents along with Australian and international recommendations to use a closed administration system[7-9] meant that this was an unacceptable risk.

The decision to implement a closed system for the delivery of IV cytotoxic medication was taken and the search for a suitable product began. The challenge was to safely implement and evaluate a product's performance in the workplace without compromising patient or HCW safety. For this reason, action research was identified as the being the most suitable model to manage the process.

Methodology

Action research is defined as "research in and on action"[22]. The cyclical nature of this model[23,24] (Figure 1) provided a framework to effectively improve practice without compromising safety. Action research is flexible in nature and "responsive to participants' changing needs as findings are repeatedly fed back to them, reflected on and, perhaps, acted on"[24]. The first step in the action research cycle is critical as it defines the purpose of the project[25]. Reflection on and gathering data regarding current practice along with researching best practice are required to identify the benefits and pitfalls of the proposed change. Another important element in action research is the development of strong collaborative relationships with key stakeholders, so that all have ownership of the project[23].

The goal of this project was to reduce the exposure risk to HCWs via the implementation of a pre-spiked closed system for IV cytotoxic administration. That is, the cytotoxic flask would arrive with an IV bag access device in situ and be connected to a closed system administration set.

The first step was to establish a working group consisting of oncology pharmacists, senior clinical nurses, department managers and educators from the day infusion centre and oncology ward. In April 2012, a formal risk assessment was undertaken, indicating that the current practice presented a

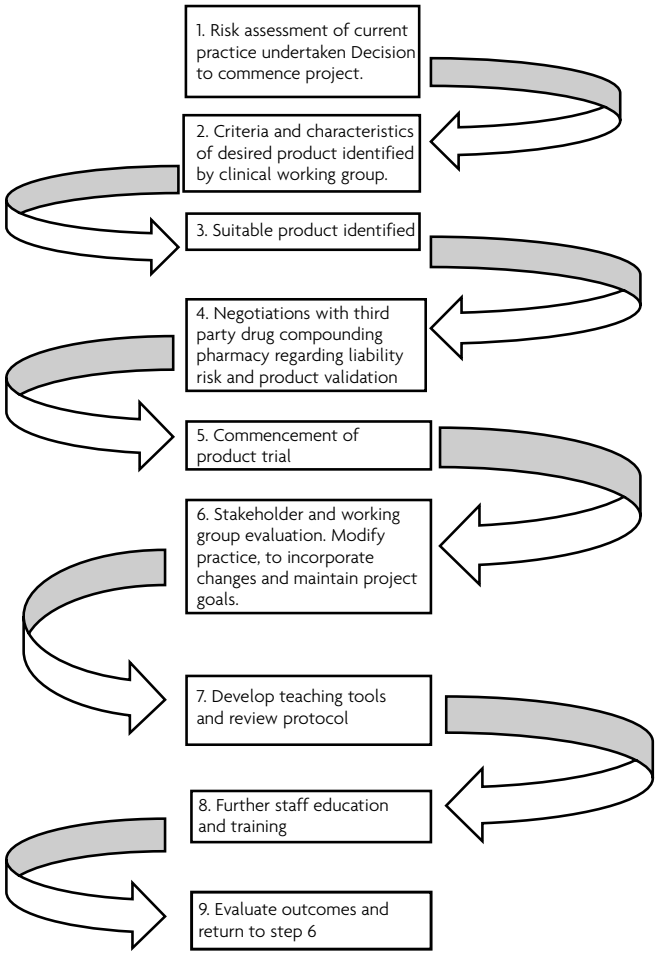


Figure 1: Action research methodology

high risk of experiencing occasional cytotoxic drug leakage. A literature review highlighted that in order to reduce the risk of occupational exposure; a closed IV system of cytotoxic delivery must be established[1,7,10,12,26]. Consultation with the workplace health and safety manager, staff health and wellbeing advisor, infection prevention and control and risk departments occurred and the recommendation to commence a product trial as part of the action research project was approved.

The next step was to identify a list of essential criteria (Figure 2) to help identify specific features of a closed system to meet our facility's requirements. The working group's preference was to use an IV bag access device and administration set that were specifically designed to work together to form a closed system and ideally made by the same company. Previous experience with linking systems together from different manufacturers had been problematic. It was often very difficult to get to the root cause of the problem when an issue occurred, for instance, using an IV bag access device from company A and connecting it to an administration line set manufactured by company B was potentially problematic as connections may not be secure as neither product was specifically designed to work together.

Device validation

Before any further decisions about product preference could be made, pharmaceutical requirements needed to be considered, particularly when a third-party company prepares the medication. The practice of using a specialised pharmaceutical company to prepare cytotoxic medication is recommended by WorkCover NSW[9] and the New South Wales Nurses and Midwives Association[21] as a control measure to avoid cytotoxic exposure and regulate drug preparation in order to protect HCWs working with hazardous drugs. However, this practice was not evident in the information provided by the manufacturers of the various closed systems we reviewed. As a result, there are limited data to support the safe performance of products during transportation between an external compounding site and the facility administering the medication. Our pharmaceutical supplier had to undertake their own independent dye ingress and pressure testing in order to ascertain the integrity of the product and determine if any cytotoxic leakage would occur when the product was put under external physical pressure.

As more closed system drug-transfer devices have been introduced to the Australian market, a small number of studies have begun to emerge regarding various products which have been tested against airborne and droplet leakage[20] as well as micro-bacterial and mechanical assessment[21,26,27]; however, there is scant information available about the design and effectiveness of this new technology. At the time of the project there were little independent or local data available to assist with the product assessment.

Although some manufacturers provided drug stability and micro-bacterial data regarding the closed system for up to seven days, this did not provide adequate information for our requirements. Our medication is pre-ordered, and if a treatment is cancelled, the prepared cytotoxic is stored appropriately and is available for use prior to the expiry date. In some instances we sought information about how the IV access device and administration add-on set would perform up to 120 days in situ. Once again, additional independent testing, including drug stability, micro-bacterial and product degradation and had to be performed by our pharmaceutical provider to ascertain its performance.

A review of available closed systems and devices indicated that there was one product that could potentially meet the set criteria — CLAVE™ distributed by Hospira. At the time, the CLAVE™ Oncology system offered needle-free line sets for one CLAVE™ Connector IV bag access device with one IV spike for flush bag (Bifuse add-on set with Spiros™) and two CLAVE™ Connector IV bag access devices with one IV spike (Trifuse add-on set with Spiros™). Even though the CLAVE™ device and administration system worked well together, these two products did not fulfil the criteria to fully meet the department's requirements as outlined in Figure 2. Working closely with the product distributor, an add-on administration set was designed

that could accommodate up to four cytotoxic drugs with a flush line to safely manage the multi-drug regimes that our centre regularly administered. Hospira undertook to deliver a new product that would meet our requirements (Figure 3) pending Australian Therapeutic Goods Administration[29] (TGA) approval.

The CSTD and associated system:

1. Does not require the nurses to spike the chemotherapy
2. Fits securely into the IV bag — preferably with a lock
3. Is free of airways on the chemotherapy lines
4. Is needle-free and also has no additional needle-free ports (other than on the main infusion line)
5. Can be attached to a generic IV pump set
6. Has sufficient IV attachment ports to avoid the need to piggyback additional line sets to manage multiple chemotherapy drug regimes
7. Has minimal line length above the air chamber. Manually back-flushing the line with saline to remove air was not considered best practice
8. Is DEHP (Di-(2-Ethylhexyl) phthalate)[28] free
9. Can be readily obtained and supply of product is reliable

Figure 2: Criteria for a CSTD and associated system

Figure 3: Quinfuse add-on set with SpirosTM (photo courtesy of Hospira Pty Ltd, used with permission)

The external pharmaceutical company responsible for preparing the cytotoxic drugs expressed concern about whether the IV bag access device would remain safely in situ during transportation. Unless the device could be secured, they were unwilling to accept liability for any spillage occurring during transport throughout the trial period. The working group met, all potential scenarios were discussed and contingencies were put in place to manage potential risk, a new protocol was devised and a period for trial agreed upon.

Allowing for safety and logistical considerations, the trial period commenced with a planned overnight change from the old system to the new. Staff support was supplied by Hospira personnel and ward educators to prepare for the new product and during the product implementation, with the initial goal of familiarising nursing staff with the new product and promoting safe practice. Despite detailed planning, the swift change highlighted a number of practice variations in the way IV cytotoxic medication was administrated. Senior clinical nursing staff met together and brainstormed the safest method to configure and administer the medication. Diagrams were developed for various scenarios, providing decision support and assisting in standardising nursing practice. The diagrams were provided as reference tools in the oncology ward and day infusion centre to assist the nurses in the choice of product and manner of practice they would follow in order to achieve a safe and cost-effective outcome.

Results

The project was evaluated at four months and again at nine months post-implementation using the following criteria:

1. Safety, including incidents of staff exposure, patient infection and any issues relating to transport.
2. Ease of product use including staff satisfaction with product.
3. Cost analysis.

During the first four months post-product implementation, two out of the three administration sets were available to trial, that is, Bifuse add-on-set with Spiros™ and Trifuse add-on set with Spiros™; while awaiting TGA approval for the use of the Quinfuse add-on set with Spiros™. A further five-month trial was undertaken to allow all three closed system sets to be included in the data.

1. Safety

Quantitative data relating to HCW cytotoxic exposure was collected prior to, during and after the project completion and reviewed. There were no incidents of leakage during transport. It was noted that only one incident of cytotoxic leakage occurred, shortly after the project began. This was due to usage of the IV access bag device and administration set outside intended guidelines; where it was attempted to piggyback two cytotoxic administration sets together. The arrival of the Quinfuse add-on set with Spiros™ mitigated this risk by providing capacity to hang more cytotoxic medication on the same add-on set and there have been no further exposures relating to IV administration. No incidents of patient infections related to product use or delays in patient treatments have been identified.

2. Ease of Use

At four months post-implementation, staff satisfaction with the initial product was positive, but a level of frustration was expressed about the difficult logistical challenge of managing multiple cytotoxic drug protocols with the available product. Nine months after trial implementation the staff responses indicated a much higher satisfaction with the product and the management of multiple cytotoxic drugs due to the availability of the Quinfuse add-on set with Spiros™. Nursing staff were no longer required to connect multiple systems to each other in order to administer more than two cytotoxic drugs, the connection system was easy to manage and there were no further episodes of cytotoxic exposure due to leakage from lines.

3. Cost analysis

Quantifying the cost of change over the project period has been difficult as there are a number of variables that make it difficult

to compare costs before and after the product trial. These variables include treatment type, the number of IV cytotoxic drugs per treatment, whether pre-medication is administered using the same system, and any increase in the number of treatments. In order to obtain a comparison of costs prior to the project and since product implementation, the cost analysis was based on the average monthly expenditure and treatment activity averaged over the six months prior to the project, with each month equalling 28 days. This was then compared to the average monthly expenditure and activity during the trial period. It was assumed that the ratio of cytotoxic to non-cytotoxic treatment would remain the same prior to and during the project. Treatment activity levels were based on total inpatient admissions in the day infusion centre regardless of reason for admission; cytotoxic or non-cytotoxic administration, type of administration (IV or other) or number of cytotoxic drugs per admission.

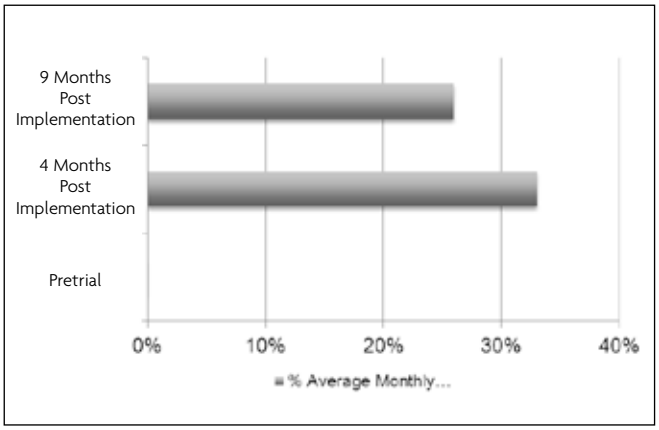
During the first four months after implementation there was a cost increase of 33% compared to pre-trial levels; however, the introduction of the Quinfuse add-on set with Spiros™ decreased this by 7% (Graph 1). This was due to the fact that while awaiting its arrival, a combination of the other two administration sets had to be substituted when administering cytotoxic protocols with a greater number of drugs, which added cost each time this occurred. This factor, along with a slight decrease (2.4%) in treatment activity over the same period, combined to increase the average cost of each treatment. However, once the Quinfuse add-on set with Spiros™ became available, the average monthly cost per treatment decreased along with a 3.75% rise in activity from pre-trial levels. We anticipate that this average monthly expense will reduce further as refined contract pricing becomes available.

In addition to the cost of the administration system, there has been a small percentage increase on drug preparation fees, which includes the cost of purchasing and inserting the CLAVE™ Connector IV bag access device into the cytotoxic bags. Conversely, there has been a saving in pharmaceutical fees associated with having to reorder medication at short notice following a leakage incident, as no further incidents have occurred. These factors have not been included in the cost analysis.

Although much has been written regarding the harmful effects of cytotoxic exposure there is little information available regarding the cost in real terms.

One comparison study of cost of closed system drug-transfer devices across five products indicated that Clave™ was the most cost-effective system[30]. While recognising that implementation of a closed system would bring higher direct costs to the department, the project aimed to compare any cost benefits associated with the product's implementation and HCW safety.

The WorkCover Authority of New South Wales requires that a doctor with experience in health monitoring, manage HCWs who experience hazardous drug exposure[9]. The cost of following up on staff exposure, along with potential lost work time and any long-term effects on health cannot be easily quantified and will vary within institutions. However, both international and local standards indicate that following cytotoxic exposure, staff members should be assessed by a specialist medical officer with experience in occupational health[9,31]. This assessment may include a physical examination, counselling and laboratory studies[31]. Ongoing biological monitoring may also be required. Based on this information, our conservative best estimate indicates that the average monthly increase in implementing this closed system is approximately 25% of the cost of the *initial* consultation for one HCW following cytotoxic exposure at our facility. This indicates that the cost of treatment and follow-up for HCW cytotoxic exposure far outweighs the increased costs associated with implementing a closed system.



Graph 1: Percentage average monthly cost per cytotoxic treatment at four and nine months after implementation compared with pre-trial

Positive impacts for the industry

The Quinfuse add-on set with Spiros™ was developed to assist with hanging multiple cytotoxic drug protocols and has now become available across Australia. In addition, the pharmaceutical company now offers formal validation for facilities wishing to use the CLAVE™ Oncology system.

Discussion

The ethical implications of undertaking this project were considered by the working party with safety for patients and HCWs given priority. Through the action research process, staff members were kept informed and were able to provide input both formally and informally at each stage of the project, allowing us to easily integrate an ethical decision-making model[32] as part of the process. Patients were informed that a product was being trialled and due diligence was undertaken to prevent any negative impact on their care.

This action research project has clearly indicated that with appropriate risk assessment and stakeholder consultation, safety improvements can be initiated and implemented by nurses at the bedside. A number of barriers to change were

encountered during the project, including a lack of sufficient product validation data, which made safe implementation more challenging. Another barrier was the increased costs associated with using the new product, including the additional pharmacy fees for the addition of the IV bag access device.

Nursing and pharmacy staff also had an initial reluctance to change as many believed they were already carrying out best practice and were not aware of the new technology available to them. Another reason for the resistance to change expressed by nurses was the inconsistency in practice between ward and day oncology areas. This was seen as a significant problem at the start of the project and the action research model provided an excellent framework to manage the inconsistency via the process of consultation, staff education and evaluation of outcomes. This gave the nursing staff opportunity to see the direct impact of the changes being made and adjust their practice accordingly[24]. As a result, this practice improvement has informed local policy and staff education across the hospital.

Nine months after the implementation of the product trial and a further 12 months after the completion of the project all stakeholders agree that the benefits have outweighed any of the initial inconvenience and cost brought on by the change. In addition, product and practice continue to be actively reviewed and the outcomes indicate significant benefits not only in HCW safety, but also in staff education and training. As the action research cycle suggests[22,23], consultation with all stakeholders, along with strategic evaluation at each step is integral to the successful implementation and evaluation of the project and leads to evidence-based and sustainable practice change[33].

Conclusion

As more information about the harmful effects of cytotoxic drugs on HCWs emerges, the pressure to undertake best practice both on the pharmaceutical side and at the bedside is mounting. The need for more independent studies and research on safe systems of cytotoxic delivery is important, providing the evidence and confidence for oncology facilities to improve safe practice at a local level.

Undertaking a trial of a closed system and associated devices presents a challenge for any oncology unit wanting to change practice. The fact that the project involves hazardous drugs means that no product trial can be undertaken without extensive risk assessment and consultation with stakeholders. Action research provides an excellent framework to undertake this type of study, allowing appropriate decisions to be based on the evidence and outcomes that unfold throughout the project. The ability to promptly respond and modify practice ensures safe and successful change management has been achieved.

Limitations

It should be noted that while the principles of action research can be applied universally, the information and criteria used for product identification in this action research project were specific to the needs of the day infusion centre and oncology department in which it was implemented and may not be applicable in every circumstance in other facilities.

A further project limitation is that only one product was scrutinised. Initially it was planned that another closed system would be trialled and evaluated. However, following extensive risk assessment and consultation with all stakeholders, it was decided not to trial the second product. This was due to the fact that drug stability, product degradation and micro-bacterial growth in the administration set was unable to be validated for the length of time required.

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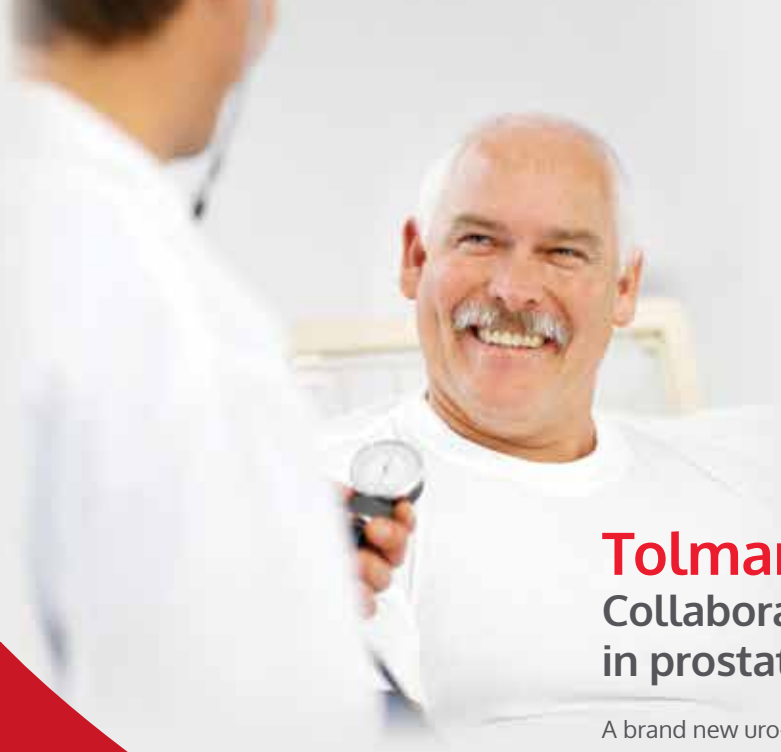

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Prostate cancer specialist nurses in Australia — changing the face of supportive care through a national approach

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Abstract

The Prostate Cancer Specialist Nursing Service is a three-year pilot program launched by the Prostate Cancer Foundation of Australia (PCFA) in May 2012. This national program is the first of its kind in Australia, and has placed 12 prostate cancer specialist nurses (PCSNs) in selected hospitals across Australia as part of a structured program. The nurses are supported through a professional development framework which is delivered through PCFA. The program has been formally evaluated and the findings will be published later this year. The research examines the effectiveness of the service as a best practice model for providing specialist nursing care through a structured program. This paper reports on the structure of the service and its implementation at a local level, in both the clinical and strategic contexts since its launch. It also explores some of the challenges identified in the implementation process during the first 12 months.

Background information

The delivery of health care in Australia to those affected by cancer is recognised as having a number of challenges. Australia is a large country with a landmass of about 7.692 million square kilometres[1] with a dispersed and growing population. In December 2012 the population of Australia was 22,906,400[2], with an annual growth rate of 1.8%. The majority of the Australian population is concentrated in New South Wales, Victoria and Queensland, but shifts in economic prospects in other states and territories are influencing migration into these areas. Provision of cancer services in Australia has traditionally focused on a city-centric model, which has historically posed challenges for those patients in regional and rural Australia. Regional and rural cancer patients are 35% more likely to die within five years of a cancer diagnosis than patients in metropolitan areas[3].

A number of initiatives have been introduced at a national and state level through both government and non-government agencies to try and address some of these challenges. These initiatives include the development of regional cancer centres, visiting medical officers to regional centres, and training local service providers to undertake specialist roles in accordance to locally defined needs, such as nurse practitioners.

Another challenge for delivering cancer services in Australia is the structure of service provision. Cancer services are delivered through both public and private providers, with many patients moving between the two systems to access the services they require. This further adds to the complexity at a local level, which creates additional opportunities for the patient to become lost in the system and warrants the need for a more coordinated approach at a service delivery level.

Improving survival rates for those affected by prostate cancer, along with the constant emergence of new treatments, such as advances in the medical management of prostate cancer, now result in men with this disease being managed within a chronic illness model[4].

In 2008, approximately 20,750 men were living with prostate cancer in Australia and this figure is estimated to increase to 25,300 by 2020[5]. This predicted increase adds to the burden on the health system to respond to the increase in demand for both treatment and supportive care services. There is also growing recognition of the need for effective models for providing survivorship care within Australia.

In recognising a need for effective supportive care within the Australian community and health contexts, PCFA has taken the lead to introduce a national Prostate Cancer Specialist Nursing Service as part of a structured program. This pilot program places nurses in all states and territories to work from a defined practice framework to exclusively benefit those affected by prostate cancer, across the continuum of care[6].

The sites were selected following a competitive tender process and provide services to patients across the continuum of care in a multidisciplinary context. Their locations are shown in Figure 1.

The primary objective for the prostate cancer specialist nurse (PCSN) role is to provide direct patient care and subsequently improve the patient's experience. The strategic aims of the Prostate Cancer Specialist Nursing Service are to:

- develop affiliations and links between cancer services
- ensure quality patient care and equity of access
- support and develop multidisciplinary care
- maintain ongoing professional development
- contribute to the education and training of health care professionals, patients and carers
- promote the use of evidence-based practice.

The PCSN is an expert point of contact for the patient, providing both psychosocial and clinical support to men with prostate cancer using a structured approach. The PCSN assists patients to make optimal use of the resources available in their immediate community, and streamline service delivery when referral to another centre is required. In larger, metropolitan-based centres, the role of the PCSN focuses on providing information, supportive care and care coordination to men with prostate cancer, in the context of the multidisciplinary team. The PCSN assesses patients and makes onward referrals to the relevant nursing and allied health specialties based on the assessment process. Ongoing care is determined on an individual needs basis. However, in developing the model, it was identified that specialist medical and nursing resource is at its most limited in regional and rural communities. Thus the PCSN adopts a framework for providing primarily supportive care and intervention, with scope for expansion of the role, where there is locally identified need, to incorporate a more clinical function, providing there are structured links to the patient's treating team. One such example is the provision of advice to patients on continence or erectile dysfunction issues arising as a result of treatment.

Service structure

PCFA also provides professional development support through a structured framework. This includes an induction program where the nurses attended a training event to familiarise themselves with all aspects of prostate cancer and the psychosocial care requirements. The professional development support also includes monthly team teleconferencing, mentorship, provision of educational resources and ongoing professional development funding to ensure the nurses are able to access accurate, up to date information on prostate cancer management. A further team training event is currently being planned to up-skill the nurses in practices such as advanced psychosocial assessment,

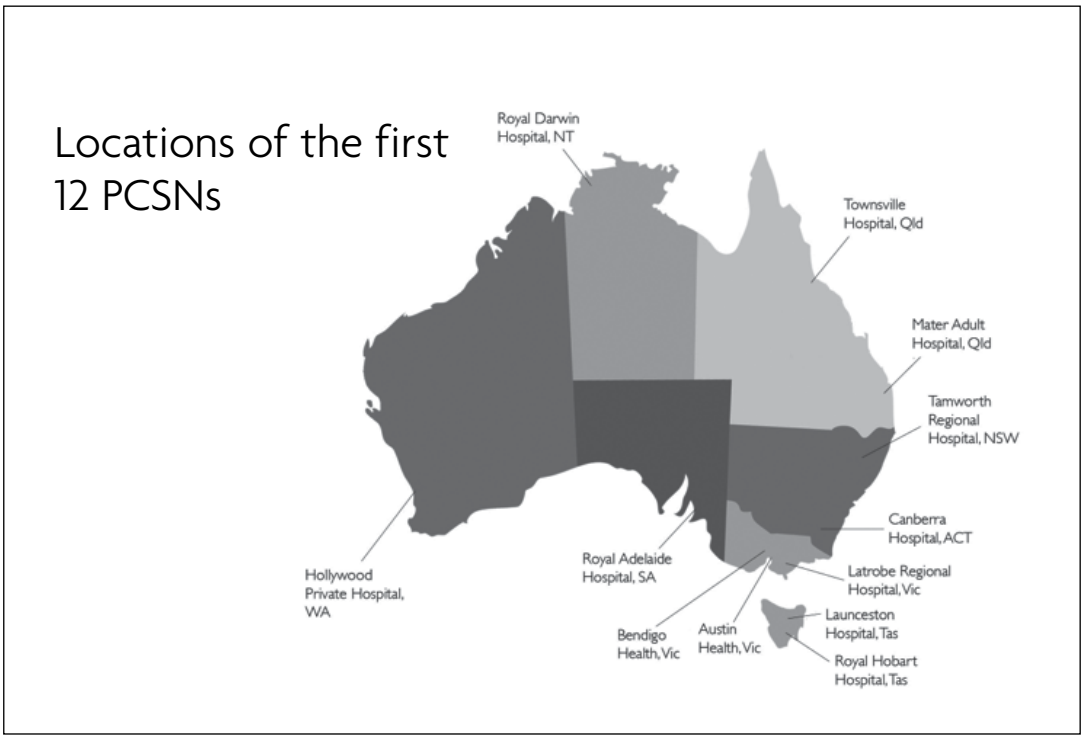

Figure 1: Locations of the PCSNs

research techniques and presentation skills. These were subjects identified as requiring additional training on a needs analysis completed by the PCSNs.

Formal evaluation of the program has now been completed. It measured whether this innovative service has a positive impact on reducing the psychosocial burden on those affected by the disease, and improved the delivery of cancer services at a strategic level, both locally and as part of a national model for service delivery. This is a partnership project with Queensland University of Technology Institute of Health and Biomedical Innovation, and will be reported later this year.

Practice in a clinical context

The PCSN is recognised as an integral component of the cancer multidisciplinary team and works from a structured framework to provide care to men and families affected by all stages of prostate cancer. The Practice Framework and Competency Standards developed for PCSNs are based upon the competency standards set out in both the National Cancer Nursing Education Project[7] and Competency Standards for Registered Nurses[8]. These competencies are recognised as best practice frameworks for nursing standards in the Australian context.

Patient activity

The service was formally launched in May 2012 with a training event. Following this, the nurses returned to their respective hospitals to continue their work. Table 1 shows the number of patients referred to the service and the number of episodes of care delivered by the nurses in the first operational year.

Table 1: Number of patients referred to the service

Patient referrals	
Number of patients referred to the service	2095
Total episodes of care delivered by the service	7121

The service has provided 4217 metropolitan patient and 2904 regional patient contacts. Patients may present to the PCSN at any point in their cancer journey. Table 2 provides data on the patients' status at time of referral to the service.

Table 2: Stage in pathway at time of referral to service (new patients)

Stage in pathway	Frequency	Percentage
At diagnosis	849	40.5%
During treatment	318	15.2%
Immediately prior to treatment	388	18.5%
Longer than two weeks of treatment	469	22.4%
Within two weeks of treatment	71	3.4%
Total	2095	100.0%

To aid consistency in care delivery, the PCSN plays a key role within the multidisciplinary team (MDT) through both formal and informal communications. The main purpose in this context is to advocate for the patient and coordinate care, aiming to ensure a streamlined approach to care resulting in higher patient satisfaction and a reduction in anxiety[9]. To ensure efficient use of available services on the patient's behalf, the PCSN engages and networks with both internal and external stakeholders.

Referrals to the Prostate Cancer Specialist Nursing Service can come from other health care professionals, the patients themselves or their family at any stage in their cancer journey.

Table 3 provides details of the primary treatment which patients received or were scheduled to receive at the time of referral to the service and this is indicative of the multidisciplinary nature of the position.

Table 3: Details of primary treatments for new patients to the service

Primary treatment	Frequency	Percentage
Active surveillance	110	5.3%
External beam radiotherapy	224	10.7%
High dose rate brachytherapy	9	0.4%
Hormone treatment	294	14.0%
Low dose rate brachytherapy	36	1.7%
None *includes awaiting treatment decision	927	44.2%
Other primary treatment, e.g. Orchidectomy	11	0.5%
Other surgical procedure, e.g. transurethral resection of prostate	10	0.5%
Radical prostatectomy	474	22.7%
Total	2094	100.0%

Table 4 provides details of the purpose for the patient contact. This information is useful in understanding how the role operates in the context of referral pathways and patient flow and understanding the caseload of the PCSN. This also demonstrates that some patients will have higher needs than others, requiring greater input by the PCSN; for example, patients having multimodality treatment or those with complex psychosocial needs.

Table 4: Purpose of the contact

Purpose of contact	Frequency	Percentage
Contact with family	191	2.7%
Contact with treating team	695	9.8%
Formal MDT discussion	137	1.9%
New patient assessment	1788	25.1%
Other, e.g. nurse-led clinics	541	7.6%
Patient initiated contact	1572	22.1%
Planned review assessment	2197	30.8%
Total	7121	100.0%

Following diagnosis, the decision-making process can be a time of high anxiety for patients and their families. The role of the PCSN is to support the patient and their families through this process. Patients are often faced with a choice of treatment options, which can create confusion and uncertainty[10]. A significant role of the PCSN is to ensure that patients are provided with information on all aspects of treatment options to allow them to make an informed choice. The service enables patients to have a constant point of contact in order to lessen the potential for psychosocial distress or to 'get lost in the system' when attending multiple health care providers. The role requires the PCSN whenever possible to be present when the diagnosis is delivered. Where this is not possible, the aim is to establish contact with patients within five days of a referral being made to the service. Patients are offered a face-to-face consultation where available; however, this can occur over the telephone, if necessary, which is particularly beneficial to those patients living a significant distance from the treating centre.

The PCSN also provides men with ongoing support during and following treatment. The PCSN is a constant throughout the continuum of care and has the knowledge to guide patients and answer questions relating to survivorship issues such as side effect management. The supportive needs of the patient and their carers, where appropriate, are assessed throughout this process and the PCSN addresses these needs as required.

Needs assessment includes:

- Physical — assessment of health-related issues and their impact on the person.
- Psychological — assessment of emotional concerns and coping mechanisms.
- Social — assessment of social wellbeing, including formal and informal support systems, financial resources and coping styles.
- Information — assessment of need and the provision of tailored educational material.
- Spiritual — enquiring about patient preferences and linking patients into services as required.

The level of specialist care in relation to the effects of treatment, such as incontinence and erectile dysfunction, directly provided by the PCSN is determined by the current service provided in each geographical area. Where possible, duplication of care is avoided and patients are referred to other specialist nurses or allied health professionals, as appropriate. However, PCSNs provide direct specialist care in regional areas where resources are limited and the nurse has been trained to undertake this function. Table 5 provides details of the activities of the PCSN in the clinical context.

Influencing care at a strategic level

Along with the clinical component of the role, the PCSNs are involved in a range of strategic activities at a local, state and national level. These activities include informing policy development, participation in quality improvement and research activities, the delivery of education sessions and participation in PCFA health programs.

At inception of the service, the PCSNs undertook a service mapping project to identify both local services providers and determine the typical patient pathway for their respective cohort of patients. This early systematic review of services available for patients in the wider community provided an opportunity to establish professional relationships with other health care providers and insight into gaps in services, to influence future projects and resources for men with prostate cancer. It also identified local gaps in care where their services could influence change. A number of common issues were identified by the prostate cancer specialist nursing team, resulting in the development of the following projects:

- Advocating for the specific clinical service provision at a local level.
- Consistent standardised patient information.
- Standardised distress screening model for men with prostate cancer.
- A nursing model of care specific to men affected by prostate cancer to enable them to better understand their cancer journey.
- Improved ways of delivering prostate cancer education messages to regional and remote Australia.

PCSNs are now working in partnership with each other and with other key, external stakeholders to progress these initiatives.

Table 5: Total activities performed per reporting period

Activity type	Frequency undertaken	Percentage
Psychosocial assessment and support (patient)	5192	19.1%
Psychosocial assessment and support (carer)	2262	8.3%
Provision of information (written or verbal)	4599	17.0%
Care coordination	4025	14.8%
Discussion of treatment options	1591	5.9%
Onward referral to other health care provider	869	3.2%
Continence assessment/advice	1979	7.3%
Sexual function assessment/advice	1085	4.0%
Other clinical intervention	226	0.8%
Symptom assessment/management	1201	4.4%
Communication with treating team	3853	14.3%
Other intervention not listed	108	0.4%
Referral to non-government body	138	0.5%
Total patient activity	27128	100.0%

PCSNs have been involved in informing policy and service development initiatives at both a local and state level to improve service delivery for men with prostate cancer. The PCNs team, as a collective, is also involved in a number of quality improvement and research projects to improve the delivery of patient care, including the delivery of standardised psychological distress screening using a validated prostate cancer-specific tool[11].

PCSNs deliver education sessions and presentations to nursing and medical colleagues within their organisations as well as at state and national conferences. The education covers a variety of topics relevant to the PCSN role, providing an explanation of the role, treatment options for prostate cancer, case presentations and clinical input. PCSNs also engage with their local communities, presenting at men's health forums and PCFA-affiliated prostate cancer support groups.

The nurses have also taken an active role in the development and delivery of PCFA Health Programs. The Rural Education Roadshow is an Australian Government-funded initiative to take prostate cancer specialists to regional and remote areas in all states and territories across Australia to deliver education sessions to local health professionals and consumers affected by prostate cancer[12]. This program aims, through structured education, to improve the knowledge and skills of primary care providers from all disciplines who may come into contact with prostate cancer patients in the primary or secondary care context. The consumer stream aims to aid men and their families in gaining a better understanding of the disease, enabling informed decision-making in both managing their treatment and their prostate cancer journey. The PCSNs have been active in developing and delivering this program in their respective states and territories. The PCSNs have also provided an expert advisory role in the development of PCFA consumer resources and booklets.

Taking things forward at a professional level

Australian nursing standards typically do not require a registered nurse to have role-specific qualifications when practising within a particular specialty. However, ongoing training and education is encouraged at all levels and is part of the nursing registration process. PCSNs are committed to their ongoing professional development and maintaining expertise as a specialist nurse. Educational opportunities have been sought by all nurses within the program, both formally and informally. Many have gained further qualifications in sexual health and counselling and hold postgraduate qualifications in prostate cancer nursing.

The PCSNs are active members of professional organisations relevant to their role, including the Australian and New Zealand Urological Nurses Society, Cancer Nurses Society of Australia and Australian and New Zealand Urogenital and Prostate Clinical Trials Group. Many of the nurses have been involved in these groups as executive members and have been invited as speakers to both state and national meetings. The PCSNs are also supported through a structured professional development framework delivered through PCFA. This includes financial support for professional development activity, monthly teleconferences, journal club, annual training events and access to mentoring.

Involvement in professional development activities not only contributes to their career progression, but also adds to development of their teams and colleagues. These activities are integral to the PCSN role and demonstrate their value as nurse leaders at both an organisational and national level as part of a team. This participation and strategic influence ultimately leads to a high standard of patient care delivery.

Triumphs and challenges in establishing the roles

Similarities in terms of challenges in establishing the services at a local level, be it in a metropolitan centre or regional or rural centre, have included issues such as instituting a referral pathway, raising awareness of the position within the hospital and the wider community, and managing reactions of existing staff. Initially, there was a belief among some hospital departments that the new position would replace the work of existing services, rather than complement it. This resistance has taken some time to resolve in some areas. Some staff saw the role as either not needed or as a diminution of their own role. This has been overcome with time and effective teamwork with the demonstration of the valuable input of the PCSN.

The process of becoming incorporated into the regular practice of the hospital has happened at different time intervals throughout the service. A major challenge in establishing the Prostate Cancer Specialist Nursing service at a local level was to ensure both men diagnosed with prostate cancer and the health care providers were aware that the service existed, what the service offered and how to access it. A national media launch announcing the service was followed up by host hospitals undertaking local media campaigns promoting the Prostate Cancer Specialist Nursing Service in community newspapers, local hospital publications and through television and radio. Attendance at primary care education seminars, urology and oncology professional development opportunities and networking with other health care professionals has also added to the service profile. The PCSN is now regarded as a vital link in service delivery at a metropolitan, regional and rural level.

A metropolitan perspective

In the metropolitan public health care system, patients newly diagnosed with prostate cancer are typically referred to the PCSN from outpatient clinics. Where possible, the PCSN will be in attendance at diagnosis to provide information and support. Referrals can also come from MDT meetings, ward referrals, cancer coordinator referrals or patient self-referral. These patients are mostly treated on site and referred to specialist departments within the hospital in accordance to their treatment plan. The patient and his family will have access to the PCSN throughout their journey to access the support and information they require. Regular correspondence with general practitioners (GPs) in primary health care facilities also provides

continuity of care. Patients attending these centres often have access to a large number of service providers with the PCSN acting as the central conduit.

The private health care setting differs in that most referrals are from the specialists' private rooms. The success of the Prostate Cancer Specialist Nursing service relies on the accessibility and referral to the service from external providers. Initial correspondence to the specialists, explaining the benefits of the service was followed by personal visits with referral forms and brochures. The resultant early uptake by urologists and oncologists quickly extended to include ward referrals, GPs, other specialist nurses and patient self-referrals. Another noted challenge for the metropolitan-based nurses is dealing with high volumes of patients. For this reason, the model is one which encourages intervention based on individual need rather than case management, which is noted to create capacity issues in other models[13].

The role has also developed to include innovative ways of delivering patient education in group contexts and nurse-led survivorship clinics to better manage high volumes of patients without compromising patient care.

The PCSN coordinates each patient's cancer journey and is a point of contact for the patient and his family as they progress through the treatment pathway specific to the individual's need. Continuity of care is optimised through informing the GP or primary health care facility of the ongoing care plan.

A regional and rural perspective

Establishing a new service in the regional and rural contexts has also created challenges. The variations in hospital service provision over a wide geographical area have resulted in a diversity of experiences for the PCSNs.

The initial task for many regional and rural-based nurses was the establishment of the referral process. This has taken some time to refine and continues to create challenges. It has been difficult to notify a diverse range of practitioners of the availability of the service within their different individual health services and allow time for them to incorporate this step into the care of their patients. In some areas, limited urology services have been an obstacle to referrals at time of diagnosis, which is often when men are faced with challenges around making informed treatment decisions. Where there is no radical prostatectomy surgery offered locally in some regional and rural areas, patients may have to travel to metropolitan hospitals for surgical intervention. These patients are also not always referred to the PCSN for follow-up care on return to their usual place of residence.

Other early challenges turning to triumphs involved establishing information technology infrastructure, internal admission and bookings alerts, documentation pathways and reporting processes for medical records. Establishing a professional relationship with the other specialist nurse roles has been helpful in ensuring ongoing care for regional and rural patients once they returned home following the completion of their primary treatment.

Patients often have to travel long distances to have treatment or consultations with their treating team, which can also be an issue in the regional and rural context and if urgent appointments are necessary. Careful coordination of appointments for a patient travelling over 150 kilometres for a follow-up appointment with the medical and nursing specialist staff can be difficult. In this instance, phone consultations and videoconferencing is used when available. The coordination of this care by the PCSN is demonstrating the value of the role in these contexts.

Another challenge has been the impact of knowing a patient through a previous connection, whether that is through a previous nursing position or a personal connection outside of work. It has been noted that this has the capacity to cause anxiety for some patients, particularly when discussing personal issues related to side effects of treatment. Patients are informed that the consultations are confidential, but this can still be confronting and may initially impair openness and a feeling of anonymity.

The acknowledgement by work colleagues of the PCSN role as a legitimate and welcome part of the MDT has been displayed through the wide variety of health care workers who now refer to the service. This has occurred over different times in the varying services. Fostering good relationships with clinicians, community nursing services and continence services have also been achievements.

The effective use of local and national media has resulted in an increase in community support. Many patients have self-referred to the service as a result of these campaigns. Public speaking events with various hospital, community and support groups have also been welcomed with positive feedback and an uptake in referrals to the service from the health professional sector.

Implications for practice

Implications for practice following the implementation and evaluation of this role include a greater understanding of the value of the specialist nurse role at both a clinical and strategic level, and greater recognition of the complexities of providing prostate cancer care in the Australian context. The Prostate Cancer Specialist Nursing Service is based on a structured model, which lends itself to other applications including other tumour streams and similar roles on an international level. The structured model provides clarity of role function to both the nurse and the cancer MDT and this aids in reducing the potential for role delineation.

A potential challenge for the role is placement of nurses in high-volume treatment centres. This is mitigated by following a model of intervention based on individual need rather than case management as this was anticipated to be non-sustainable at the commencement of the service.

Summary

The Australian health care system can be a complex environment for many patients to navigate as they face the challenges of treatment choice and access to care. Despite early challenges in some areas in establishing connections with existing services, the PCSN is now regarded as vital in ensuring quality care through coordination and collaboration with the MDT to enable effective care delivery.

While the PCSN role has a clinical and patient care focus, since inception the specialist nurses have recognised the importance of maintaining their own professional development, raising awareness of prostate cancer and their roles and participating in activities to influence care at a strategic level.

The Prostate Cancer Specialist Nursing Service has been enthusiastically supported by health care professionals and warmly received by the patients and families faced with making treatment decisions at a difficult time.

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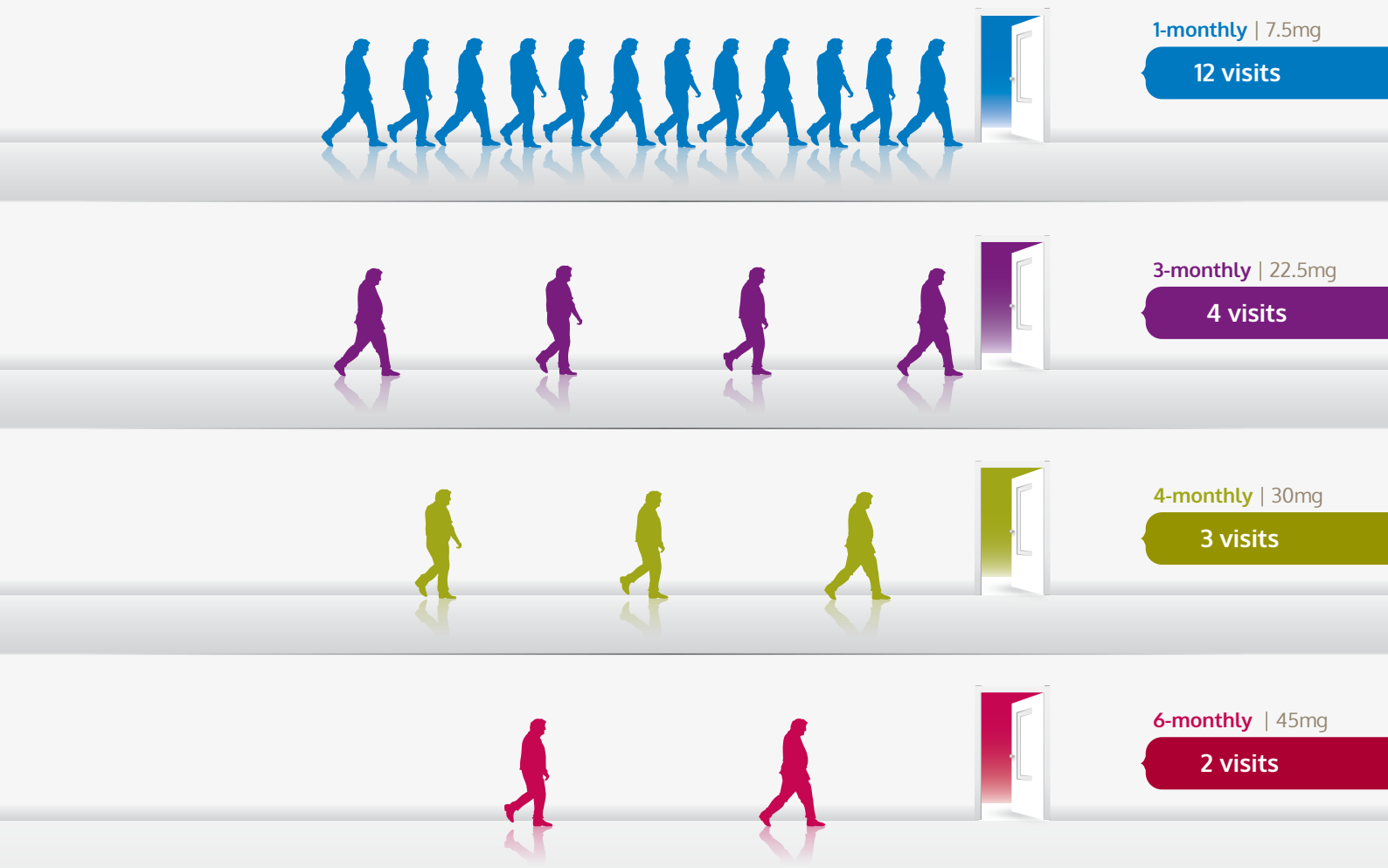

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Evaluation of an education program to facilitate patient adherence, toxicity monitoring and promote safety and wellbeing in the self-administration of oral chemotherapy in the home setting: an Australian study

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Abstract

Introduction:

The use of oral chemotherapy as a cancer treatment is increasing, posing significant challenges for health care professionals with respect to patient adherence, toxicity monitoring and safety in the home.

Aim:

To evaluate an education program promoting patient knowledge to facilitate patient adherence, toxicity monitoring and promote safety and wellbeing in the self-administration of oral chemotherapy in the home setting

Methodology:

Cancer patients (*n*=15) prescribed oral chemotherapy received education using a teaching tool developed by The Multinational Association of Supportive Care in Cancer (MASCC)™. Supportive care needs were screened using the Distress Thermometer. Patients' knowledge, understanding and supportive care needs were assessed pre- and post-education. A follow-up phone call addressed issues relating to the education program and patient wellbeing.

Results:

Data were analysed using descriptive statistics. Individualised education facilitated knowledge and understanding around key issues pertaining to oral chemotherapy. Participants reported feeling less fearful, nervous and worried.

Conclusion:

Nurse-led education may facilitate medication adherence, toxicity management, and enhance patients' wellbeing.

Keywords: Oral chemotherapy, patient education, cancer nursing.

Introduction

Cancer is a common disease with the incidence in Australia reported as one in two males and one in three females who will experience a diagnosis before age 85[1]. The mainstay of cancer treatment commonly includes systemic therapy. Traditionally, this has been delivered via the parenteral route requiring hospital admission, often in the ambulatory setting where specially trained cancer nurses provide the necessary education, support and monitoring of patients' clinical and psychosocial needs[2-4]. However, with the advent of increasing use of oral chemotherapy[5], change in how patients are cared for and managed along the continuum of their cancer treatment is now evolving[6]. This change is paving the way for a new treatment paradigm that shifts the delivery of chemotherapy from a safe, controlled process, which is monitored on a regular basis by doctors and nurses in hospitals or outpatients clinics, to the patient's home[7,8]. The implication of this change is that patients and their carers now are required to be more involved in their cancer care, taking responsibility for the safe administration and monitoring of potential toxicities while at home.

Oral chemotherapy (antineoplastic therapies including cytotoxic agents, biological and/or targeted therapies[6]) offers many advantages to the patient and family, including convenience associated with fewer hospital and clinic visits, no requirement for intravenous access and an improved sense of control for the patient[6,9]. However, this mode of delivery potentially poses significant challenges for health care professionals, many of which revolve around adherence, toxicity monitoring and safety issues for the patient and their carer in the home

setting[10-12]. Importantly, the literature suggests that the role of the cancer nurse in providing education, monitoring for toxicities and follow-up care is pivotal to successful cancer treatment and optimal clinical outcomes for patients receiving oral chemotherapy[3,12]. Further, providing education and helping patients and their carers to better understand the issues around cancer and its treatment assists them to be more informed, enhances effective coping strategies to optimise clinical outcomes[13,14] and an improved sense of wellbeing[13].

Study aim

The study aimed to evaluate an education program delivered in a nurse-led clinic to facilitate patient adherence, toxicity monitoring and promote safety and wellbeing of cancer patients self-administering oral chemotherapy in the home setting.

Review of the literature

Adherence issues

Adherence is not just about the common belief by clinicians that the patient "forgot to take their tablet"[10, p. 24]. Patients may not take their prescribed medication regularly or may stop it all together because of lack of knowledge, fears of potential toxicities, or not understanding how to manage toxicities at home[10].

The literature provides an understanding of the barriers and challenging factors associated with patient adherence to oral chemotherapy. These include issues around the different toxicity profile compared to traditional chemotherapy; socio-economic factors; health care system factors; physical and psychological factors and treatment factors.

The toxicity profile of the newer targeted oral agents is frequently different to patient expectations. The toxicities commonly include skin reactions, hand and foot syndrome, diarrhoea, hypertension and other cardiac problems[15]. These issues, therefore, need to be addressed by health care professionals to enhance patients' and carers' understanding and to enable them to cope with the responsibility of taking their tablets and monitoring and reporting any problems or concerns in a timely manner[12].

Socio-economic factors encompass the consequences of low language literacy; lack of family and/or social supports; poor living conditions; work and/or lifestyle that is too busy; limited access to a health care facility and/or pharmacy; lack of health insurance; and the cost of medications[12].

In addition, there are a number of health system factors that are known to contribute to non adherence. They include poor relationship and subsequent communication between the health care provider and the patient; poor health care provider communication skills; inadequate provision of patient education; education that is not tailored to the needs or level of understanding for patient, and the lack of continuity or coordination of care[16].

Physiological and psychological factors known to impact on ability and/or willingness to adhere to oral chemotherapy are multiple. Physical factors that are commonly associated with the older patient such as tremor, poor eyesight and/or dry mouth are reported as impacting on adherence; they may impact on ability to manipulate or swallow oral dosages of tablets[17]. Furthermore, older patients are more likely to have co-morbidities such as diabetes and/or cardiac problems, resulting in the use of polypharmacy, requiring different administration instructions which may lead to confusion and poor adherence[18]. Psychosocial stress, anxiety, fear or depression commonly associated with a cancer diagnosis; pre-existing behavioural/cognitive impairment; knowledge and understanding of disease and perceived benefit of treatment; motivation; fear of potential toxicities; alcohol or substance abuse[18] are all reported to impact on adherence to oral chemotherapy.

Treatment factors are also reported to have an adverse impact on adherence and include oral chemotherapy regimens with complex dosing and/or administration requirements[11].

Safety issues

There are a number of key safety issues associated with self-administration of oral chemotherapy in the home setting including medication errors[6], inadequate communication by clinician, lack of patient education regarding potential toxicities[4,6,19], inability of clinicians to monitor adherence and toxicity in real time[6,9,20] and issues pertaining to biohazards of oral chemotherapy, that is, storage and handling in the home setting[6].

The provision of cancer treatment in the traditional hospital setting lends itself to close monitoring of the patient and opportunities for nurses to discuss concerns, clarify patient understanding of treatment and provide verbal and written information and support[21]. However, because the use of oral chemotherapy has increased in recent years[10,17,22,23], administration and toxicity monitoring has moved to the home setting where the responsibility for drug administration and management of subsequent toxicities has shifted to patients and their carers[7,24,25].

Responding to these adherence and safety issues, the American Society of Clinical Oncology (ASCO), the US Oncology Nursing Society (ONS)[26] and the Clinical Oncological Society of Australia (COSA)[27] guidelines address the high potential for harm from chemotherapy. They can be used to guide clinical practice with the aim to assist medical, nursing and pharmacy staff in the prevention of medication errors, improve safety and facilitate adherence with respect to cancer treatment[27,28].

Education and support

In response to the need to provide a consistent and comprehensive approach to patient education and support, the Multinational Association of Supportive Care in Cancer (MASCC) Education Study Group has led the development

of an evidence-based teaching tool for patients receiving oral chemotherapy[29]. The MASCC™ Teaching Tool for Patients Receiving Oral Agents for Cancer (MOATT)© provides health care providers with a structured format to ensure that all key areas of patient assessment and teaching are addressed. The education tool can be accessed from the website www.mascc.org.

The role of the cancer nurse in providing patient education and support, to facilitate adherence and promote safety within the home, is identified as a "cornerstone"[3, p. 21] to successful cancer treatment using oral chemotherapy[3,4,12,21]. Nursing interventions that incorporate patient and carer education around early identification of toxicities and reminder prompts such as calendars and diaries are known to improve adherence[30] and therefore clinical outcomes[31]. However, there is evidence of a worldwide gap in terms of patient education about oral chemotherapy[32]. Nurses cite factors such as a lack of organisational protocols or guidelines for oral chemotherapy in their workplace; a lack of appropriate educational materials and insufficient knowledge about oral chemotherapy as reasons for not initiating education programs on oral chemotherapy[30,32].

Methodology

Overview

This study used a two-stage, mixed-method approach to evaluate an education program promoting patient and/or carer level of knowledge and understanding of oral chemotherapy and wellbeing. Quantitative data was collected at Time 1 (T1) pre and post the education program and at Time 2 (T2) one week post the education program during the follow-up phone call. Qualitative data was collected at T2 and addressed wellbeing and education program content.

Sample

All patients (n=15) who were referred to the nurse-led clinic during the project time (December 2012 to March 2013) consented to participate. Patient demographics are detailed in Table 2.

Inclusion criterion

All patients who were 18 years of age and over, had been referred by their treating medical oncologist to the clinical nurse coordinator (CNC) for routine cancer care and supportive care and who had been prescribed oral chemotherapy were invited to participate in the study. There were no formal exclusion criteria for the study. Patients with limited English were accompanied either by an English-proficient speaking family member or a previously booked interpreter.

Ethics

This study was approved by the Austin Health Human Research Ethics Committee (HREC) protocol number H2012/04873.

Table 2: Characteristics of participants

Gender	*n*=15
Male	8
Female	7
Mean age	
Men	55.75 years
Women	58.28 years
Tumour type	
Breast	2
Colorectal	4
Renal	3
Brain	3
UGI/GIST	2
Lung	1

Interventions: Design

Time 1 (at the education session)

Before and immediately following the education program in the nurse-led clinic, the patient and/or carer were invited to complete the adapted MASCC™ evaluation questionnaire (pre- and post-questionnaire) comprising 13 questions (Table 1). The responses were used to assess the patient and/or carer level of knowledge and understanding of their oral chemotherapy. The CNC used the MOATT© to structure the education program. The teaching tool's content included key assessment questions about oral chemotherapy, generic education discussion points, drug-specific education and evaluation questions to help ensure that the patient and/or carer was confident about the self-administration of oral chemotherapy. In addition, the patient and/or carer were asked to complete the National Comprehensive Cancer Network® (NCCN®) Distress Thermometer Screening Tool to assist the CNC in assessing the patient's level of emotional distress and supportive care needs.

Individualised, written, take-home drug information (Appendix 1) detailing specifics about the patient's oral chemotherapy, potential toxicities (side effects), special precautions, drug and food interactions, and when and who to call with questions, was provided. Patients were also encouraged to keep a diary to assist with adherence and monitoring of toxicities.

Time 2 (one week post-education program)

One week after the education program the CNC made phone contact with the patient and/or carer. They were asked questions related to the education program and the drug-specific, written, take-home information. Specifically, questions were asked about the content of the education program and how it helped the patient and/or carer to adhere, monitor toxicity and safely administer their oral chemotherapy at home. The NCCN® Distress Thermometer Screening Tool was completed for a second time, with further supportive communication provided by the CNC as required.

Table 1: Pre- and post-education evaluation questionnaire (conducted at T1 in nurse-led clinic) results from participants (n=15)

No.	Evaluation question	Number of participants (%): Pre-education	Number of participants (%): Post-education
1	Do you know the name(s) of your tablet(s)? Yes No	 7 (46.7%) 8 (53%)	 15 (100%) 0 (0%)
2	If yes, what are the name(s) of your cancer tablet(s)? Participants who reported correct name(s) of the tablet(s)	 7 out of 7 (100%)	 15 (100%)
3	Do you know when to take your cancer tablet(s)? Yes No	 10 (66.7%) 5 (33.3%)	 15 (100%) 0 (0%)
4	If yes, when will you take your cancer tablet(s)?	9 out of 10 (90%) responded correctly	15 (100%)
5	Do you know how many tablet(s) to take? Yes No	 9 (60%) 6 (40%)	 15 (100%) 0 (0%)
6	If yes, how many will you take? Number of participants who responded correctly Participants who responded incorrectly	 8 out of 9 (88.9%) 1 (11.1%)	 15 (100%) 0 (0%)
7	For how long do you need to take your tablet(s)? Participants who responded correctly	 8 out of 9 (88.9%)	 15 (100%)
8	Do you need a blood test before starting your next cycle of oral chemotherapy? Yes No/don't know	 8 (53%) 7 (46%)	 14 (93%) 1 (6.7%)
9	Does it matter if you take your tablet(s) with food? Yes No	 8 (53%) 7 (46.7%)	 14 (93%) 1 (6.7%)
10	Where do you plan to keep your tablet(s)? Participants who responded adequate knowledge Participants who responded inadequate knowledge	 0 (0%) 15 (100%)	 12 (80%) 3 (20%)
11	What are the main side effects you can expect to experience? Participants who responded adequate knowledge Participants who responded inadequate knowledge	 3 (20%) 12 (80%)	 15 (100%) 0 (0%)
12	What can you do to help reduce/manage the side effects? a) Take anti-nausea medication as prescribed: Correctly responded Yes/No Not sure b) Take anti-diarrhoea medication as prescribed: Correctly responded Yes/No Not sure c) Use moisturising cream on my skin/hands/feet: Correctly responded Yes/No Not sure d) Avoid sun exposure: Correctly responded Yes/No Not sure e) Avoid certain foods/drink such as grapefruit that may interfere with my chemotherapy tablet(s): Correctly responded Yes/No Not sure e) Avoid other medications such as herbal over the counter type tablets that may interfere with my chemotherapy tablet(s): Correctly responded Yes/No Not sure f) Report uncontrolled side effects to my doctor/nurse: Correctly responded Yes/No Not sure	 6 (40%) 9 (60%) 4 (27%) 11 (73%) 2 (13.3%) 13 (86.7%) 8 (53.3%) 7 (46.7%) 8 (53.3%) 7 (46.7%) 6 (40%) 9 (60%) 8 (53.3%) 7 (46.7%)	 15 (100%) 0 (0%) 13 (86.7%) 2 (13.3%) 8 (53.3%) 7 (46.7%) 13 (86.7%) 2 (13.3%) 14 (93.3%) 1 (6.7%) 13 (86.7%) 2 (13.3%) 15 (100%) 0 (0%)
13	When should you call the doctor or nurse? If I feel unwell If I have a fever If I have uncontrolled side effects Other — please describe	 9 (60%) 11 (73%) 11 (73%) 10 (75%)	 12 (80%) 15 (100%) 15 (100%) 9 (60%)

Appendix 1: Oral Chemotherapy Patient Information

DRUG-SPECIFIC INFORMATION	
DRUG NAME (generic & trade)	
What the drug looks like	

Dose and schedule	
How many tablets? Dosage of each tablet	
How many times a day?	
For how long?	
What to do if you miss a dose	

Where the drug should be stored	
Away from the heat	
Away from humidity	
Away from the sun	

Potential side effects (including tests for monitoring)	
1. Skin rash ☐	How to manage and when to report to nurse/doctor:
2. Nausea and vomiting ☐	How to manage and when to report to nurse/doctor:
3. Diarrhoea ☐	How to manage and when to report to nurse/doctor:
4. Fatigue ☐	How to manage and when to report to nurse/doctor:
5. High blood pressure ☐	How to manage and when to report to nurse/doctor:
6. Hand & foot syndrome ☐	How to manage and when to report to nurse/doctor:
7. Other ☐	How to manage and when to report to nurse/doctor:

Some precautions	
Swallow tablet whole without chewing ☐	
With or without food? ☐	
Manual handling ☐	

Drug and food interactions	
Other medications:	
Foods:	

When and whom to call with questions	
Tina Griffiths (nurse)	(03) 9496 4607 Mon to Fri business hours
Austin Hospital	(03) 9496 5000 After hours and ask for oncology doctor on call

For the treatment of symptoms of carcinoid syndrome[1]

Somatuline® autogel®
lanreotide

- READY TO INJECT IN A PRE-FILLED SYRINGE[1]
- AUTOMATIC SAFETY SYSTEM (RETRACTABLE NEEDLE)[1]

A convenient way to treat patients with symptoms of carcinoid syndrome[1]

Reference

1. Somatuline Autogel Product Information. Date of first inclusion in ARTG: 11 September 2003. Date of most recent amendment: 23 July 2013.

PBS Information: Authority required (STREAMLINED for Public Hospitals only). This product is a Highly Specialised Drug listed on the PBS as a Section 100 item. Refer to PBS schedule for full authority information.

Before prescribing please refer to full Product Information, which is available from Ipsen Medical Information, Ph: (03) 8544 8100 or from http://secure.healthlinks.net.au/content/ipsen/pi.cfm?product=ispsatgi

Somatuline® Autogel®: Lanreotide as acetate in a pre-filled syringe (60, 90 and 120 mg) fitted with an automatic safety system. **Indications**: Treatment of acromegaly when circulating growth hormone and IGF-1 levels remain abnormal after surgery and/or radiotherapy or in patients who have failed dopamine agonist therapy; the treatment of symptoms of carcinoid syndrome associated with carcinoid tumours. **Contraindications**: Lactation; hypersensitivity to lanreotide or related peptides or other excipients. **Precautions**: May experience hypoglycaemia or hyperglycaemia (monitor blood glucose levels); slight decrease in thyroid function; may reduce gall bladder motility (recommend gall bladder echography); exclude presence of obstructive intestinal tumour; monitor kidney and liver function; may reduce heart rate in patients without an underlying cardiac problem (monitor heart rate; caution with treatment initiation in patients with bradycardia). Not recommended for use in children. See full PI for further information. **Interactions with Other Medicines**: Reduced absorption of cyclosporin A, decreased bioavailability of cyclosporine, increased availability of bromocriptine, additive bradycardia effects with beta-blockers, decreased clearance of quinidine, terfenadine. **Effect on driving/ using machinery**: If affected by dizziness do not drive or use machinery. **Adverse Events**: Common to very common: diarrhoea or loose stools, abdominal pain, cholelithiasis, fatigue, dizziness, headache, sinus bradycardia, alopecia, hypotrichosis, hypoglycaemia, nausea, vomiting, dyspepsia, flatulence, abdominal distention, abdominal discomfort, constipation, biliary dilatation, injection site reaction (pain, mass, induration, nodule, pruritis), laboratory investigation changes. See full PI for further information. **Dose**: Acromegaly: For first time treatment the starting dose is 60 mg every 28 days; for patients previously treated with Somatuline LA every 14, 10 or 7 days, the starting dose is 60 mg, 90 mg or 120 mg respectively every 28 days. Dosage should be adjusted according to GH and/or IGF-1 response. Patients well controlled on lanreotide can be treated with 120 mg every 42–56 days. Carcinoid Syndrome: 60 to 120 mg every 28 days, adjusted according to symptomatic relief. **Administration**: Deep subcutaneous injection in the superior external quadrant of the buttock (healthcare professional or carer); or the upper, outer thigh (self-administration). *Decision for injection by patient or carer to be made by a healthcare professional. Patients must be controlled on Somatuline Autogel and patients/carers must be motivated, competent and trained to inject*. **Storage**: 2°C–8°C. **Date of first inclusion in ARTG: 11 September 2003 Date of most recent amendment: 23 July 2013**

For further information about Somatuline Autogel, contact Ipsen Pty Ltd:
T (03) 8544 8100 **F** (03) 9562 5152 **E** info@ipsen.com.au
Level 2, Building 4, Brandon Office Park, 540 Springvale Road, Glen Waverley, VIC 3150 Australia

Ipsen Pty Ltd, ABN 47 095 036 909 Somatuline® Autogel® is a registered trade mark
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Innovation for patient care

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lanreotide

Data analysis

Quantitative data was analysed using descriptive statistics and is reported as frequency and percentage distribution. Categorical yes/no responses were used for questions that directly related to the issues of adherence, safety and toxicity monitoring (T1 — pre–post questionnaire) and wellbeing (T1 and T2). Qualitative data using open-ended questions was reported as the most frequently cited responses at T2.

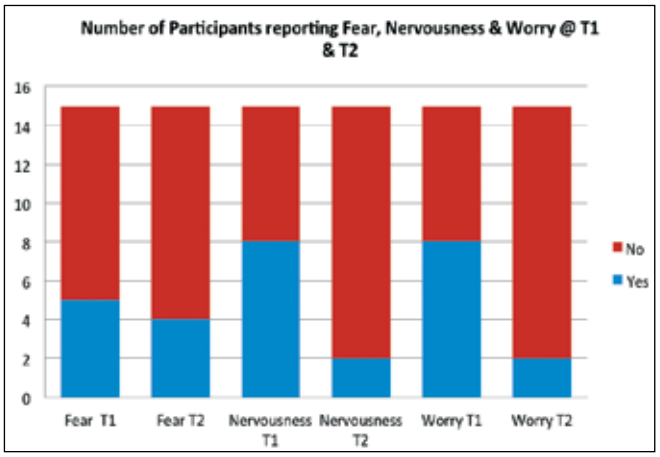
Findings

Quantitative data

The participants' level of knowledge about their oral chemotherapy improved after the education program, with 100% reporting a better understanding about when, how many tablets and for how long to take tablets (that is, continuous or cycling). Participants' knowledge improved with regard to the need or not to have a blood test before starting their next cycle of oral chemotherapy, the impact of food interaction, knowing how to store and handle their tablets, and their understanding of what to expect in terms of toxicities and related management strategies. The findings are presented in Table 1.

With respect to wellbeing, the overall Distress Thermometer scores for all participants diminished from T1 to time T2. The average Distress Thermometer score at T1 was 3.8 out of a possible score of 10 with 8 (53.3%) participants identifying a score of 4 or more. At T2, the average Distress Thermometer score was 2.3, with 13 participants (86.7%) reporting less emotional distress (lower Distress Thermometer score) at T2 compared to T1. Emotional problems of fear, nervousness and worry decreased from T1 compared to T2 (Table 3).

Table 3: Findings related to wellbeing at T1 and T2



Qualitative data

Qualitative data was collected during the follow-up phone call at T2. While all participants reported that they found the education program helpful, it was the individualised, written, take-home information that reinforced their knowledge and understanding of their oral chemotherapy regimen.

> *(the take-home information) is like my 'bible' — tells me everything, I need to know … the diet/food interaction … it helps me to manage my side effects and to expect to know what was going to happen.* (Participant #11, female, 60 years old, with metastatic breast cancer.)

> *the information sheet allowed me to go over the instructions and directions (about how and when to take my tablets)* (Participant #5, male, 58 years with metastatic renal cell carcinoma.)

In relation to wellbeing, the participants reported feeling more confident in managing their oral chemotherapy:

> *Yes* [the education session] *helped me a lot to better understand what it is all about … I feel more confident about it all.* (Participant #8, female, 55 years old, with brain cancer.)

Discussion of the findings

This study evaluated the impact of an education program delivered by the CNC in an oral chemotherapy, nurse-led clinic based in a tertiary public hospital in Melbourne. Specifically, it aimed to demonstrate improvement in patients' and/or carer(s') level of knowledge and understanding about self-administration of oral chemotherapy, and how this impacted on adherence, safety in terms of storage and handling, and capacity to monitor toxicities to mitigate clinical risks associated with side effects. The potential effect of the education program and support on the patients' sense of wellbeing was also explored.

Impact on adherence

Adherence has been reported in the literature as a significant obstacle to successful cancer treatment with oral chemotherapy in terms of clinical outcomes[12,33]. Multiple factors such as fear of toxicities, not knowing how to manage toxicities and complex regimens that are cyclical with changing doses are known to impact on adherence[10]. Therefore, clear strategies to assist patients to adhere to their treatment regimen may maximise the benefits and reduce the treatment-associated risks[6].

Ream[14] highlights the importance of nurses providing a tailored approach to education that facilitates confidence for patients with regard to understanding treatment details and how to manage potential toxicities[13]. Additionally, Winkeljohn[4] reports that patient education and support addresses the underlying barriers to adherence and may lead to optimal clinical outcomes[12]. Furthermore, research has shown that providing careful assessment of individual needs and emotional support to people living with cancer is an important aspect of education in the clinical setting[34] that promotes patient adherence.

The study findings highlight that a structured and individualised approach to the education program provided by the CNC improved participants' knowledge and confidence about when and how to take their tablet(s). In addition, participants also

improved their level of knowledge and understanding about the continuous or cyclical nature of their respective chemotherapy regimens with all 15 (100%) participants correctly reporting their chemotherapy regimen after the education session.

Impact on safety issues

Oral chemotherapy agents have a high potential for harm, particularly if precautions around handling, storage and self-management strategies of potential toxicities are not understood by the patient and/or not undertaken in the home setting[6].

The findings of this study reflect the literature, with the results of the questionnaire pertaining to knowledge about safe storage of tablet(s) and how to manage toxicities demonstrating an improved knowledge and understanding after the education and support program. For example, all participants (n=15) in the study reported that they did not know how to safely store and handle their tablet(s) at home prior to the education session. Following the education and support program, 12 participants (80%) reported adequate knowledge about safe storage. All participants demonstrated an improved level of knowledge around managing toxicities such as nausea, food and drug–drug interaction, and knowing when to report uncontrolled toxicities.

Previous studies contend that patient education is paramount to support the safe use of oral chemotherapy in the home setting[27] and that patients should be given verbal and written information that includes dose instructions (when to take their tablet(s) and if it is to be taken with or without food), potential toxicities and safe storage instructions[27,35]. Safety issues are also linked to the potential for food interactions which are known to impact on the absorption of the tablet(s) and/or interaction of enzymes in the gastrointestinal tract or liver[17].

In this study the participants reported that the provision of the individualised, written, take-home information enhanced their knowledge about safety issues associated with administration, storage, handling and monitoring of toxicities.

Impact on wellbeing

Appropriate and effective education in the clinical setting is recognised as having a positive impact on patients feeling better prepared and more confident to participate in their health care and to use effective coping strategies[13]. Patients also experience less anxiety and distress about treatment when they know what to expect and are aware of self-care strategies[13]. Furthermore, the facilitation of self-care strategies and learning to live positively with cancer enhances a patient's sense of wellbeing by reducing feelings of helplessness associated with uncertainty and lack of knowledge[3,10].

The findings of this study support the notion that patient wellbeing is associated with knowledge and support about their cancer and its treatments. Cancer patients who participated in the study reported that they were less emotionally distressed (as demonstrated by a decrease in Distress Thermometer scores) one week after receiving the education program and support delivered by the CNC, with a decrease in the number of participants who reported feeling fear, nervousness and/or worry at this time.

Limitations

The limitations of this study relate to the small sample size (n=15) and hence the results cannot be generalised to a larger population of cancer patients receiving oral chemotherapy.

Additionally, the limited time frame in which the researcher had to recruit participants and the short period of data collection between T1 and T2 does not provide insight into how patients were managing their oral chemotherapy over an extended time period. However, it is anticipated that the study findings will contribute to the existing literature highlighting the impact of patient education programs on patients receiving oral chemotherapy.

Recommendations for clinical practice

For cancer patients receiving oral chemotherapy, issues around adherence, safety and the need for a patient-centred approach to education and support have been well reported in the nursing literature[10,12,34,36]. These issues give rise to implications for clinical practice for nurses in the cancer setting.

Being able to engage with patients and families to effectively assess their educational and support needs is pivotal to patient-centred nursing care[13,34,37]. Therefore, nurses should have adequate access to professional communication skills training and support to:

- improve their skills around assessing patient learning needs
- elicit patient supportive care and informational needs
- undertake patient- and family-centred education[13,36].

These skills are also considered important to be able to address the emotional aspects of cancer care that are considered to be a profound determinant of the quality of life and wellbeing[13,38].

The provision of individualised, written, take-home information is pivotal in reinforcing patient and/or carer knowledge, understanding and/or confidence around oral chemotherapy[31].

Nurse-led education that helps patients to learn about their oral chemotherapy may assist them to better understand the complexities associated with their medication[10,39] and may increase their confidence to self-administer and cope with their cancer treatment, which in turn may lead to an improved sense of wellbeing[13,38].

Conclusion

With the increasing use of oral chemotherapy to treat a wide variety of cancers, health professionals are faced with unique

challenges in caring for patients. Many of these revolve around adherence, toxicity management and safety issues in the home setting. This study reported that the provision of individualised patient and/or carer education about safe administration and handling, early identification and management of toxicities, together with individualised, written, take-home resources improved patient and carer knowledge around oral chemotherapy. The patients additionally reported an enhanced sense of wellbeing from feeling less distressed, fearful, nervous or worried about their oral medication.

Cancer nurses are well placed to provide appropriate and effective education programs on oral chemotherapy to ensure that patients and their carers are able to confidently and safely self-administer their medication in the home setting.

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Cancer Nurses Society of Australia

Caring for young people with cancer: practical implications of qualitative engagement with cancer survivors and members of the multidisciplinary team

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Abstract

Many adolescent and young adult (AYA) cancer survivors live with ongoing adverse consequences of their cancer experience. While an increasing number of these young Australians have direct access to care in the specialised Youth Cancer Service, many continue to receive care in diverse, non-specialised settings. It is important that health professionals in specialised and non-specialised settings are aware of the continuing diverse consequences of cancer, including the challenges created for negotiating family, peer and intimate relationships. This paper draws together insights derived from qualitative studies into the experiences of AYAs who have survived cancer, with a focus on our recent Australian study of young people diagnosed during adolescence and young adulthood. We describe how members of multidisciplinary teams (MDT) can help young cancer survivors maintain their social relationships.

Introduction

Approximately 1700 young Australians aged between 15 and 29 years are diagnosed with cancer every year[1]. Due to recent advances in treatment, a greater proportion survive their illness and treatment than ever before. Indeed, members of this patient population have a 95% chance of surviving for one year after diagnosis while 88% will be alive at five years across all diagnoses[1].

Survival, however, is not always easy. Young people who survive cancer often live with a range of issues, including the adverse social effects of illness and treatment: disrupted life plans[2], loss of independence[3,4], stigma[3], and exclusion from the experiences of daily life commonly enjoyed by people of their age[5,6]. These difficulties are further complicated by a number of barriers which include health professional training and development needs in survivorship, lack of role clarity in the follow-up of cancer survivors, and a lack of research to inform practice, education and policy[7,8]. Health professionals also need skills, expertise, and resources to help young survivors manage the social effects of cancer in their daily lives and relationships.

The Growing Up with Cancer study

To gain insight into the longer term experiences of people diagnosed with cancer in adolescence or young adulthood, we conducted an innovative, qualitative study of young people, the Growing Up With Cancer project[9,10]. This study included 48 in-depth interviews with 27 young people aged between 16 and 29 years who had been diagnosed with cancer in adolescence or young adulthood (the youngest was diagnosed at age 11 and the oldest at age 22).

Young people who participated in this study provided many insights into how health professionals could assist survivors of cancer. Some participants described how the guidance they received from health professionals during treatment helped them negotiate their diagnosis and treatment, and helped them develop expectations for their life following treatment. Others described how they benefited from the diverse skills provided by a multidisciplinary team (MDT) to help them return to school and other activities, while others spoke of how cancer support groups, social workers, and/or psychologists smoothed their transition from cancer patient to cancer survivor.

All the young people in our study spoke about the ongoing effects their cancer experience had on their relationships with parents and peers, and on their capacity and willingness to establish new intimate or sexual relationships. In this way, the Growing Up With Cancer study provides important insights into how nurses — and other health care professionals — can support young cancer survivors to maintain relationships with their parents and peers and to form new relationships.

Supporting young people's independence

Adolescents and young adults (AYAs) enjoy a degree of independence usually unavailable to younger children, and this can be significantly compromised by cancer and its treatment[3,10]. For example, some of our participants lived in their own accommodation before diagnosis but returned to the family home for parental care during treatment and recovery[10]. This is a common experience (as it is for many young people facing serious illnesses) and requires them to negotiate the loss of independence and then re-establish their independence as they recover[11]. While many young people and their parents successfully manage this process, not all families will have the emotional resources or the communicative skills to do so and compromised independence can last for years after treatment has finished[12].

Families with compromised resources or skills might benefit from the guidance of health professionals experienced in facilitating strong family relationships[13]. Members of the MDT can provide guidance for families during the period of illness and treatment that helps to prepare the family to renegotiate a young person's independence when they are well enough to care for themselves. This would include helping young people and parents to understand and empathise with the other's perspective; the experience and frustration of lost independence[10]; and the desire to (over)protect vulnerable offspring. One practical strategy is to engage in activities designed to "scaffold" the young person as they develop — or redevelop — their independence during recovery[10]. At the same time, members of the MDT need to support parents in a process of stepping back.

Supporting friendships

Young people are typically separated from their peers during illness and treatment[5,6]. This is problematic as peers form a critical support network for AYAs, whether sick or well, hospitalised or at home. In the Growing Up With Cancer study, young people diagnosed when they were school students spoke at length about the process of returning to school and of renegotiating their place within the peer group[10]. While there were few accounts of explicit bullying, many spoke of feeling misunderstood by friends, or of friends being unsure of how to talk about cancer.

A number of strategies can support young people re-entering their social worlds. In general terms, when re-entering their peer group after treatment, it is important that young cancer survivors are honest when discussing their health, and patient with friends who might not understand the extent of the ongoing effects of cancer treatment[10,12]. For most young people in our study, talking about their cancer experience at the 'right' time and in the 'right' place was beneficial for them and their friendships. What constitutes the right time or place will, of course, vary from person to person and situation to situation. Health professionals can encourage young survivors to think in advance about how they might approach disclosure. For example, how much do they want to talk about their experiences, and with whom? How can they let friends know who they in turn can tell so young survivors retain a sense of control over their experiences?

Young cancer survivors were generally receptive to questions about the experience of illness or treatment and to hearing about the experience of those events from the perspectives of their friends[10]. Again, AYAs with cancer can be encouraged to think about how to let friends know that talking about cancer, and how they felt about their friend having cancer, are both okay.

Friends who are uncertain about a young cancer survivor's physical capabilities after treatment can be encouraged to choose social activities that are mutually enjoyable[10]. One young woman in the Growing Up With Cancer study described how she enjoyed dancing with her friends but was sometimes restricted in her physical activity by ongoing fatigue. At these times, she said, her friends were happy to stay home and watch movies with her[10].

Several electronic and printed resources have been developed in Australia to help guide young people's renegotiation of relationships with their peers. CanTeen's freely available resources[14] offer valuable guidance to help friends and partners during this often challenging time. Resources such as *A guide to supporting your friend when they have cancer*[15] are a simple and effective way for young people to address issues that arise when they return to their usual social worlds. Programs such as *Recapture Life — AYA*[16] are also useful for members of the MDT to be aware of and direct young people to where appropriate. Furthermore, CanTeen's e-mental health platform[17,18] provides a primary site where young people living with cancer can find information, connect with others going through a similar experience, express their feelings, utilise tools for support and access professional psychosocial support services that will meet their individual needs*. Health professionals may find these resources useful for their own practice and understanding.

Health professionals can do an enormous amount to facilitate the maintenance of social relationships during treatment periods, thus supporting young cancer survivors' social reintegration into their peer group. Strategies including facilitating attendance at important social events from which they would normally be absent because of their illness, or facilitating involvement in the event some other way[10]. For example, one parent told us that her daughter's friends held a fashion parade in the hospital ward to show off their end-of-school formal dresses as a way of including her in the event.

Health professionals can also provide information or educational materials to the young person's school or even attend their school in order to educate school students and teachers about the range of issues faced by young cancer survivors[19]. For example, Ronald McDonald House Charities has a freely available printed resource known as *EdMed* that provides teachers with information and educational strategies they can apply to children with a diverse range of illnesses[20]. Ronald McDonald House Charities can also provide teachers with a one-hour *EdMed* professional development session[20]. Also, if a young cancer survivor agrees, health professionals can invite peers into the clinic in order to demystify the medical aspects of cancer and provide a shared familiarity of the clinical setting for young people and their peers. Each of these suggestions must, of course, be undertaken in collaboration with young cancer survivors themselves, be 'offered' rather than 'prescribed' and be done with the support of the institution.

Supporting new relationships

As well as affecting existing relationships, the ongoing effects of cancer often intrude on the formation and conduct of new relationships. Ongoing medical surveillance can be time-consuming and anxiety-provoking[10]. The physical effects of treatment can leave young people feeling unattractive and unworthy, even when their physical appearance has been "restored"[5]. Lingering scars, the need for medication, and constraints on activity can be difficult to talk about with new friends, and particularly with new sexual partners. For many young cancer survivors, a cancer history can be experienced as stigmatising[10].

Members of the MDT can talk to young cancer survivors about how the ongoing physical and psychological effects of cancer might shape their experience of everyday life. They can provide young cancer survivors with specific techniques for communicating with others about their cancer history and its effects — introducing the mundane daily scenarios that may create challenges for young people, and exploring possible responses to them. This would give young people the chance to consider how they might disclose their cancer experience to new acquaintances in the future, minimising the anxiety or distress that may result when they find themselves, as one of our participants, said "in an awkward situation"[10]. One practical approach here is for 'experienced' cancer survivors to share their experiences and strategies with 'inexperienced' survivors; cancer support groups play a vital role here.

When young people begin intimate relationships, health professionals could also encourage them to contemplate how their cancer history and its effects might be accommodated into life with their partner. This can range from relatively straightforward processes such as regular medical appointments to more complex and difficult activities such as a couple deciding to have children using *in-vitro* fertilisation. In this latter scenario, CanTeen's free resource *Maybe Later Baby* provides clear and accurate information to help young people understand their fertility options before and after treatment[21]. It also contains information for health professionals working with these young people.

Health professionals could support the young person and their partner by including them in medical consultations with the young cancer survivor's consent. This would allow them to address issues of communication, intimacy and sexuality. Empowering young people as actors in their own relationships is an important part of scaffolding independence for older AYAs. Such strategies may present challenges in medical settings where romantic partners are not usually present, especially in paediatric clinics, or for parents who are used to being the primary support in the young person's medical engagements. However, we see no reason why these challenges could not be addressed with sensitivity and perseverance.

Conclusion

Young people who have had cancer correctly perceive that others have difficulty understanding their cancer experience and what the implications are for their future. While educating parents, friends and partners is undoubtedly beneficial, it cannot negate the challenges that young people often face as they try to accommodate the ongoing impact of cancer on their relationships. Even the best-resourced young people are likely to undergo challenging periods when they need extra support from experienced and well-informed health professionals.

There are many ways health professionals working as members of an MDT can work with young people, their parents and peers to support the development and maintenance of rich and mutually satisfying relationships. Empirical research on the experiences of young cancer survivors, such as the Growing Up with Cancer project, provides valuable insights into how current practice can be improved to better meet their needs. Any improvement requires recognition that cancer is experienced not just in health care contexts, but in social contexts; that cancer challenges many of the tasks of adolescence, and that cancer disrupts relationships that are of great importance to young people.

* **Recapture Life — AYA** is an online, group-based cognitive-behavioural therapy program for adolescents and young adults who have completed cancer treatment. It is currently available to Australian residents, with plans for international implementation in progress.

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