The Australian Journal of Cancer Nursing

The Official Journal of the Cancer Nurses Society of Australia

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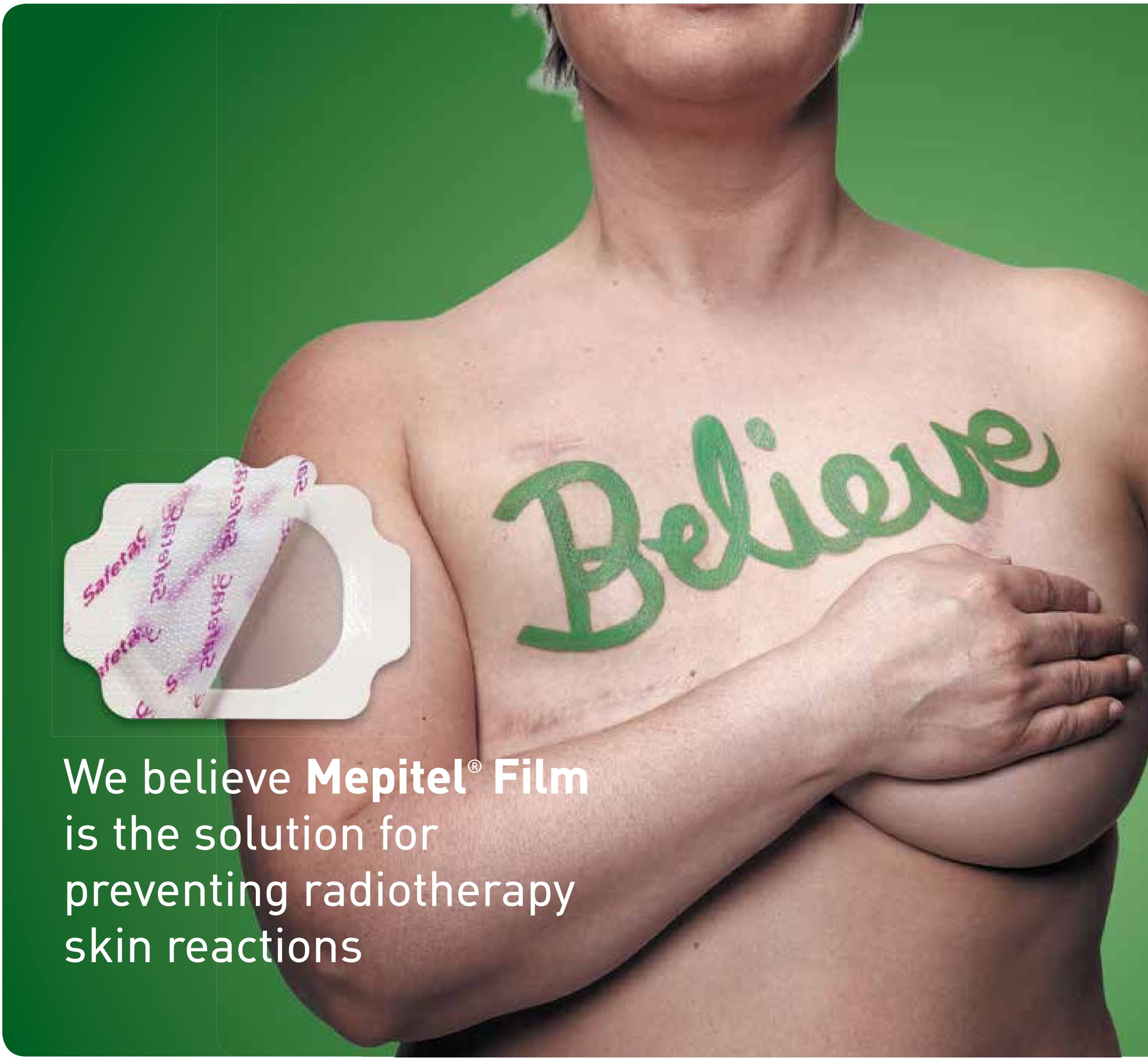
In this issue



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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

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Editorial

Cancer nurses: informed and responsive to change

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Individuals affected by cancer live in a world that is at times dominated by biomedicine, treatment and technology. Most of the time, however, those in our care experience their cancer and treatment in a social world and in one that is very personal. Cancer nurses, therefore, need to be informed about the technology (therapy and developments of) and also about the individual's context, values and beliefs in order to enable them to make informed choices and to be successful in managing treatment.

Oral anti-cancer therapy is a convenient mode of treatment delivery and one which is becoming more common and which perhaps highlights the social and personal nature of cancer treatment as individuals self-medicate and manage their therapy at home. Nurses often function as a conduit, translating and managing the impact that developments and changes in treatment bring to the people they care for.

The first two of our papers in this edition discuss innovation at both an individual level and at a broader organisational level.

Johnson and Adler report on findings from a survey of CNSA members to understand the role of nurses in supporting people being treated with oral anti-cancer therapy. What is clear is that whilst individual nurses are responding to developments in treatment delivery; broader health service-wide practice and organisations are slower to respond. Intradisciplinary and person-centred approaches and systems of care delivery need to be the driving force for organisational change. The authors provide resources and excellent strategies for rethinking care delivery across metropolitan, rural and remote arenas.

Fyfe and Nowack, in their discussion of an innovative nursing role which focuses on the needs of individuals receiving oral anti-cancer therapy, highlight the enormous impact that a dedicated nursing role can have on care delivery. Patient safety was one of the drivers for the development of the role of oral chemotherapy nurse and the development of a suite of resources, practices and quality initiatives clearly highlight the immense value of this specialist role.

Nichols' paper continues the theme of specialist nurse roles and examines how the cancer care coordinator integrates practice and can enhance a more person-centred model of care delivery across the individual's experience — both within and beyond the hospital.

Ireland and O'Shaughnessy's excellent discussion paper brings to light a number of important challenges and controversies with regard to screening that nurses need to be cognisant of. Once again, the authors situate the nurse as pivotal in interpreting and delivering information to enable individuals to make informed choices about their health care.

These four papers clearly demonstrate the breadth of supportive care needs that nurse-led initiatives can address and the depth of understanding that is required to provide informed person-centred care delivery. At the same time, they demonstrate how informed cancer nurses make a difference to people affected by cancer and its treatment.

We hope you enjoy reading this edition and find these studies useful in your own practice.

The Cancer Nurses Society of Australia (CNSA)

Our mission

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

To achieve our mission of promoting excellence in cancer care, the CNSA will act as a resource to cancer nurses around Australia, no matter what their geographical location or area of practice.
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The role of the nurse in patient education and follow-up of people receiving oral anti-cancer treatment: an Australian survey

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Abstract

Introduction

The use of oral anti-cancer treatment (OCT) is increasingly common and it is accepted that for patients OCT provides a sense of control, fewer disruptions to lifestyle, reduced costs for travel and care and eliminates the discomfort of intravenous treatment. OCT use also poses safety challenges with implications for both patients and health care workers. These challenges include new toxicity profiles and adherence issues. Whilst not new, these challenges are especially relevant to nurses who are the primary providers of patient education, side effect management and follow-up.

Objectives

A national cross-sectional survey of Australian nurses working in cancer care was undertaken to assess the nursing role in the education and follow-up of patients receiving OCT.

Methodology

A survey was distributed to members of the Cancer Nurses Society of Australia (CNSA) using snowball sampling; survey data was analysed using descriptive statistics in SPSS. One hundred and eighty-two survey responses were received. The study has received Human Research Ethics Committee approval.

Results

Variation in processes for providing information about OCT to patients was highlighted. The shifting treatment paradigm from intravenous chemotherapy to OCT has reduced the opportunity for contact with patients to monitor toxicities and provide education via traditional avenues. Nurses are also confronted with new side effect and symptom management profiles associated with novel OCT.

Conclusion

Workflow, organisational processes and resources have not kept pace with increasing use of OCT in cancer treatment. This exposes patients to increased risk of harm and poses new challenges for providing optimal nursing care.

Introduction

There have been major advances in the management of cancer and the use of oral anti-cancer agents is increasing as a preferred treatment option. It is estimated that almost half of the new agents in development are oral[1]. The availability of oral anti-cancer treatment (OCT) permits the management of patients in the community setting, reducing the need for patients to attend the hospital for treatment. For the patient, OCT offers a sense of control over treatment and can reduce interference with work, social activities, travel time, costs associated with care and discomfort from intravenous treatment[2]. There are also perceived cost and resource advantages of OCT for the health system, achieved through management of patients in the community setting, minimising the need for patients to travel to or stay in a hospital for prolonged periods.

Historically, the majority of anti-cancer treatment has been administered intravenously in a designated treatment centre with specialist cancer doctors, pharmacists and nurses involved in checking the regimen and ensuring the correct dose and administration of the treatment. The shifting treatment paradigm to OCTs has led to the tightly controlled environment of specialist checks in the hospital environment being circumvented. A recent study of 577 Oncology Nursing Society (ONS) members reported that 56% of participants indicated their workplace had a reliable system to alert nurses when patients receive prescriptions for oral chemotherapy[3]. The perception that OCT is easier, less expensive and has fewer side effects may also have reduced the impetus by health care providers to institute the same rigorous specialist education and monitoring programs provided to patients receiving intravenous anti-cancer treatment[1,4,5].

OCT also presents new challenges in the form of new toxicity profiles and issues related to adherence to prescribed regimens. The literature uses the terms "adherence", "compliance" and "observance" interchangeably[4].

Recognition of problems associated with sub-optimal medication adherence is not new; in 2003 the World Health Organization identified that adherence to long-term therapy for chronic illness is only approximately 50% in developed countries, leading to adverse health outcomes and increased health care costs[6,7]. Adherence rates for patients receiving OCT vary from 20% to 100%[8]. Suboptimal adherence to the prescribed regimen can result in over- or under-medication[9]. Medication adherence may be associated with patient, treatment, clinician or environmental factors[8]. Factors include patient choice, forgetfulness, dietary restrictions, side effects, inadequate understanding of information and/or education provided by the health care team. In addition, financial inability to fund treatment, poor social support and poly-pharmacy in an ageing population might reflect a failure of the health care team to adapt their clinical practice and patient education programs to this shifting treatment paradigm[1,8,9].

A brief review of the literature (2007–2011) was undertaken to explore the role of nurses in the education and follow-up of patients receiving OCT. The search terms included: oral chemotherapy, medication adherence, and patient education. During our review we identified a survey, conducted in Turkey during 2005, reported by Dr Sultan Kav and reproduced internationally by the Multinational Association for Supportive Care in Cancer (MASCC) in 2006[2,10]. The survey explored the role of the nurse in patient education and follow-up of people receiving oral chemotherapy. Based on the findings of the MASCC survey and earlier work undertaken by Dr Kav, the MASCC teaching tool for patients receiving oral agents for cancer was developed[2,11].

Given the increased use of OCT since these initial surveys, we considered that it was timely in 2012 to assess and describe the Australian experience of oncology nurses caring for patients receiving OCT.

Study objectives

The primary objectives of the study were to explore the nursing role in education and follow-up of patients who are taking OCT across Australia and to identify any deficiencies and gaps in patient education about OCT.

Study design

The MASCC survey was adapted to the Australian setting by including an additional four questions to reflect changes in the availability of new OCTs, to capture demographic information and to assess the use of the MASCC Teaching Tool for Patients Receiving Oral Agents for Cancer.

Ethical considerations

Ethics approval was obtained from the Hunter New England Human Research Ethics Committee and permission was granted from the Cancer Nurses Society of Australia (CNSA) Research Committee to access their membership to distribute the survey. Permission to reproduce the MASCC survey was granted[2].

Survey methods and sampling

An invitation to participate in an online, national cross-sectional survey, consisting of 20 multiple-choice and open-ended questions, was distributed to 721 CNSA members via an email alert. The research team did not have direct access to potential participants. A second email alert was sent to members two weeks after the initial invitation. Study participants remained anonymous and snowball sampling was encouraged. Due to the effect of the snowball sampling method, it is impossible to determine a response rate as the number of nurses the survey reached is not known.

Survey data

The survey collected data across three main areas:

- Demographics including institution and geographical location.
- Nursing experience and educational history including nursing qualifications and nursing experience.
- OCT-specific data including drugs, patient and system processes.

Survey results

There were 182 survey responses from nurses in all states and territories except the Northern Territory. The demographics are detailed in Table 1. The demographic characteristics identified that the majority of participants were employed in a metropolitan-based public hospital and had been working as a nurse for more than 16 years. Forty-six per cent had been employed in their current position for six years or more.

Nurse demographics

All respondents indicated they had routine experience with seven or more of the 22 OCTs listed in the survey. They also indicated their practice used a number of newly emerging and experimental treatments. The most commonly used treatments included: Capecitabine, Cyclophosphamide, *Erlotinib**, Etoposide, *Imatinib**, *Lapatanib**, Methotrexate, *Sunitinib**, Temozolomide, *Thalidomide** *and Vinorelbine**. The agents marked with "*" indicate newer treatments that were not in use at the time of the MASCC survey. This reflects the rapid development of experimental and emerging treatments during the seven-year period from the MASCC report to this survey.

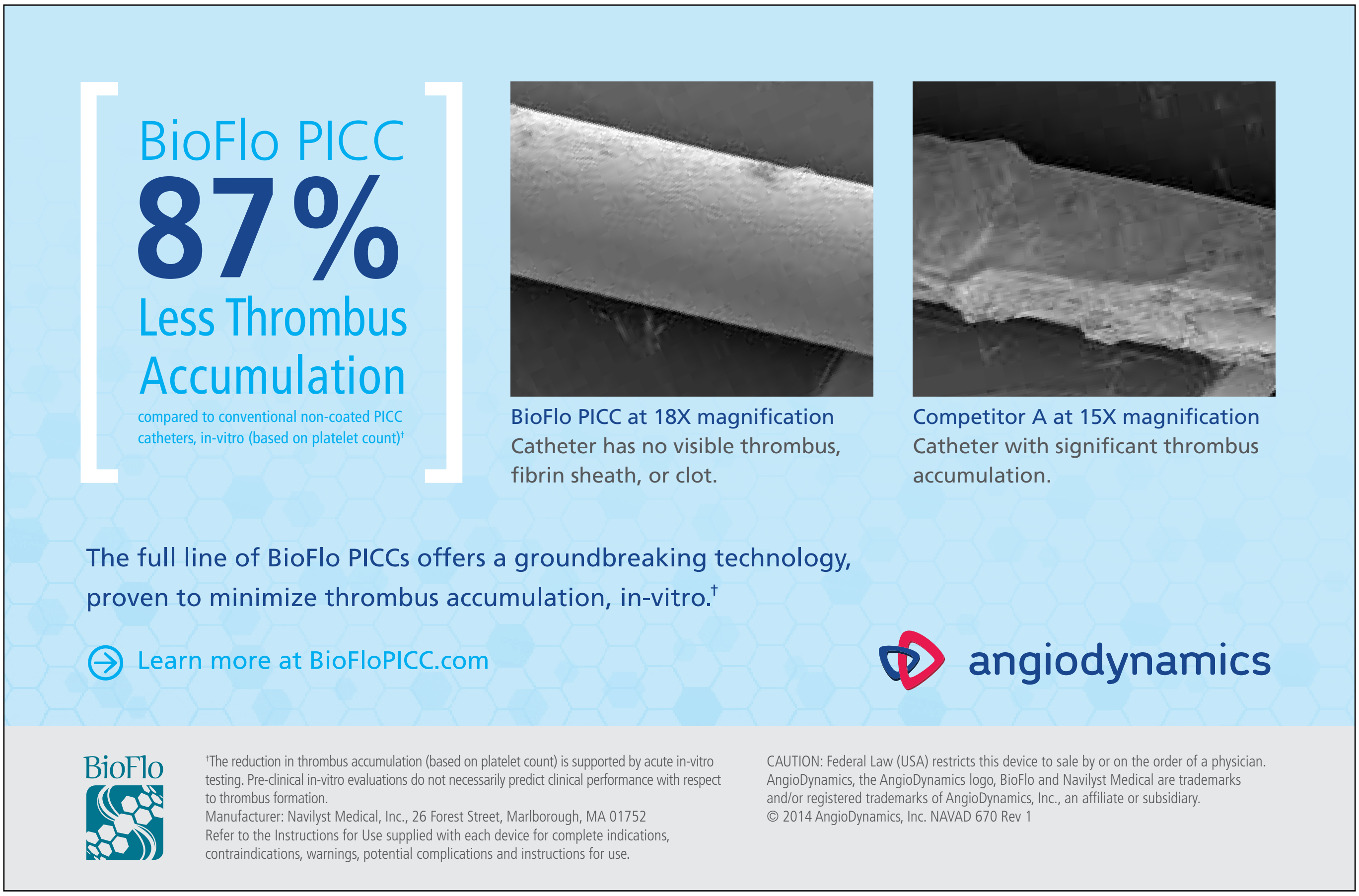
In comparison to the MASCC survey results, our findings (Table 2) indicated fewer nurses working in inpatient settings reported

Table 1: Nurse demographics

Variable	Class	Total (n=182)
Institution		
	Public hospital	116 (64%)
	Private hospital	25 (14%)
	Public teaching hospital	26 (14%)
	Private teaching hospital	2 (1.1%)
	Other, please specify	11 (6.1%)
Geographic location of institution		
	City or metropolitan	124 (69%)
	Regional centre	41 (23%)
	Rural/remote	15 (8.3%)
State or territory		
	New South Wales	53 (29%)
	Queensland	20 (11%)
	Victoria	34 (19%)
	South Australia	22 (12%)
	Tasmania	13 (7.2%)
	Western Australia	33 (18%)
	Australian Capital Territory	5 (2.8%)
Primary employment role		
	Nurse unit manager	27 (15%)
	Registered nurse	40 (23%)
	Clinical nurse specialist	26 (15%)
	Research nurse	10 (5.6%)
	Oncology nurse educator	3 (1.7%)
	Oncology nurse practitioner	5 (2.8%)
	Cancer care coordinator	38 (21%)
	Other, please specify	28 (16%)
Primary place of employment		
	Day treatment unit	66 (37%)
	Inpatient	24 (14%)
	Outpatient clinic	46 (26%)
	Other, please specify	41 (23%)
Number of years working in this position		
	<1 year	25 (14%)
	1–5 years	72 (41%)
	6–10 years	49 (28%)
	11–15 years	13 (7.4%)
	16 and over	17 (9.7%)
Number of years worked in nursing		
	1–5 years	7 (4.0%)
	6–10 years	27 (15%)
	11–15 years	20 (11%)
	16 and over	122 (69%)
Highest level of tertiary education attained		
	Oncology Certificate (or equivalent)	37 (21%)
	Graduate Certificate	23 (13%)
	Diploma	19 (11%)
	Bachelor	49 (28%)
	Masters	34 (19%)
	Doctorate	1 (0.6%)
	Other, please specify	13 (7.4%)

Table 2: Comparison of nurses' involvement in patient education and follow-up and information of OCT with nurses' demographics

		Involved in patient education and follow-up		Received education/ information about oral CT	
Variable	**Class**	**Yes**	**No**	**Yes**	**No**
Primary employment role	Other, please specify	16 (70%)	7 (30%)	18 (72%)	7 (28%)
	Nurse unit manager	16 (62%)	10 (38%)	19 (73%)	7 (27%)
	Registered nurse	24 (65%)	13 (35%)	28 (74%)	10 (26%)
	Clinical nurse specialist	18 (75%)	6 (25%)	18 (69%)	8 (31%)
	Research nurse	8 (80%)	2 (20%)	9 (90%)	1 (10%)
	Oncology nurse educator	3 (100%)		3 (100%)	
	Oncology nurse practitioner	5 (100%)		1 (20%)	4 (80%)
	Cancer care coordinator	30 (83%)	6 (17%)	22 (61%)	14 (39%)
Primary place of employment	Other, please specify	25 (68%)	12 (32%)	24 (63%)	14 (37%)
	Day treatment unit	47 (75%)	16 (25%)	47 (71%)	19 (29%)
	Inpatient	16 (70%)	7 (30%)	21 (91%)	2 (8.7%)
	Outpatient clinic	32 (78%)	9 (22%)	26 (62%)	16 (38%)
Number of years working in this position	<1 year	18 (78%)	5 (22%)	18 (75%)	6 (25%)
	1–5 years	48 (74%)	17 (26%)	48 (71%)	20 (29%)
	6–10 years	33 (72%)	13 (28%)	30 (64%)	17 (36%)
	11–15 years	11 (85%)	2 (15%)	9 (69%)	4 (31%)
	16 and over	10 (59%)	7 (41%)	13 (76%)	4 (24%)



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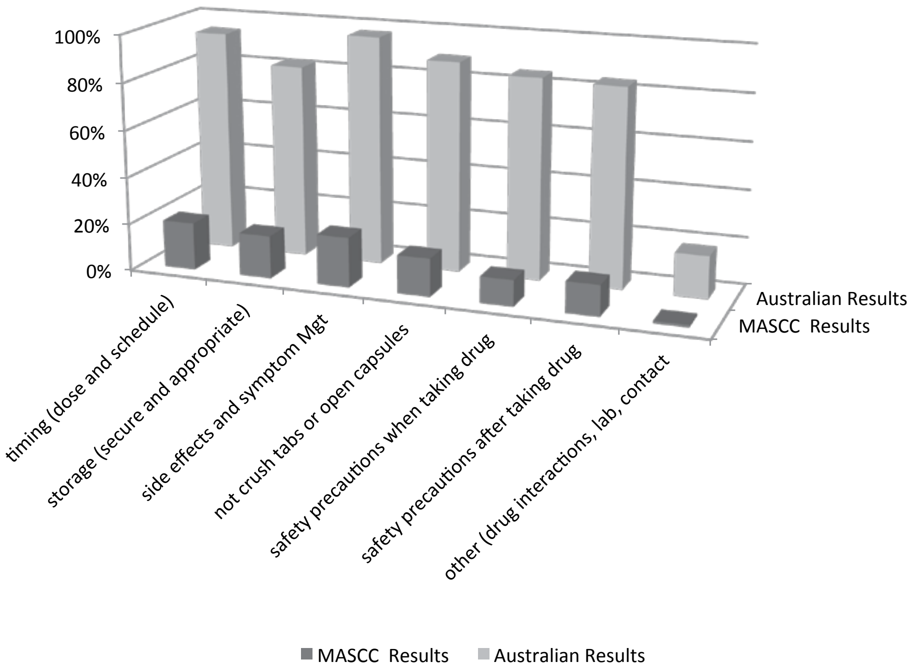

Figure 1: Information given to patients during education and follow-up.

a lack of education/information about OCTs compared with inpatient nurses in the MASCC study (8.7% versus 45.4%). Fewer nurses who had <1 or <5 years' experience reported lack of education/information, (25% and 29% respectively versus 45.4% and 49.9%) compared with the MASCC study. These findings were not statistically significant. The MASCC study reported that nurses who worked on inpatient units and who had less than five years' experience working in their current position reported a lack of education and information about OCTs that was statistically significant. The findings of this study were not consistent with this.

Findings from this study indicate that more nurses who worked in outpatient clinics (78%) and research nurses (80%) reported being involved in patient education and follow-up when compared to nurses with other primary roles and places of employment; however, these findings were not statistically significant.

The information that Australian cancer nurses provide to patients who are prescribed OCT was compared with the results from the MASCC survey (see Figure 1). Although it was not possible to directly compare the results with the Australian cohort results within the MASCC survey, there has been a notable increase over the last seven years since the MASCC report in the number of nurses reporting that they routinely provide the information to patients about their OCT. Interestingly the "other" topics nurses raised with patients during their education and follow-up had not changed significantly but the numbers of nurse respondents reporting they were raising these issues has improved. Other topics that nurses identified included: after-hours contact details (including emergency contact details), blood monitoring, appointments, what to do in the event of contamination with OCT, other support services, sexual health and safety, and reproduction issues.

Figure 2 details the responses for questions about the reasons nurses believe they are not involved in education and follow-up of patients receiving OCT and compares them to the responses reported by the MASCC survey. Responses to "other" included not being a nurse's responsibility, unit workflow precludes nursing input, no policies, lack of resources, misconception that it is not as hazardous as intravenous therapy, rural/remote staff do not receive referrals and an absence of a formalised processes for educating these patients. This is reflected in the responses to the question about difficulties experienced by nurses working with patients receiving OCT (Table 3). Thirty-nine per cent of respondents reported that the physician provides education and follow-up. This figure has almost doubled since the MASCC survey, which may reflect the increasing use of oral agents. It may also reflect a shift to cancer services being predominantly an outpatient service that may or may not be co-located with the treatment centre. It appears that workflow, organisational processes and resources have not kept pace with changes in the treatment paradigm. Side effect management, safety issues and a degree of ambivalence by patients who perceive oral treatment as more favourable than intravenous treatment were issues identified by respondents to "other difficulties" experienced by nurses when working with patients receiving OCT (Table 3).

In this survey, 79% of participants indicated they had access to patient education materials. Figure 3 outlines the responses to the question concerning the type of educational materials used by nurses in the education of patients. We note the high use of eviQ material that has been implemented extensively

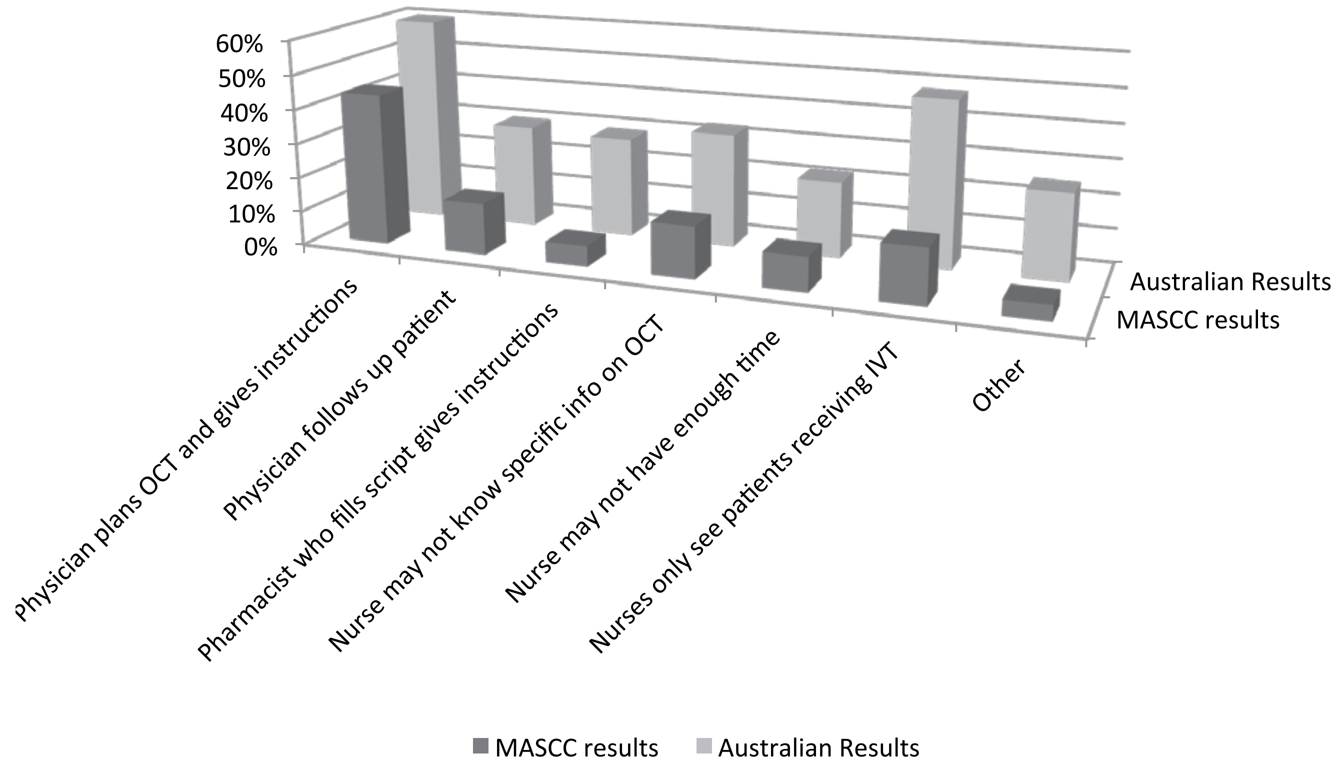

Figure 2: Reasons nurses are not involved in education and follow-up of patients receiving OCT

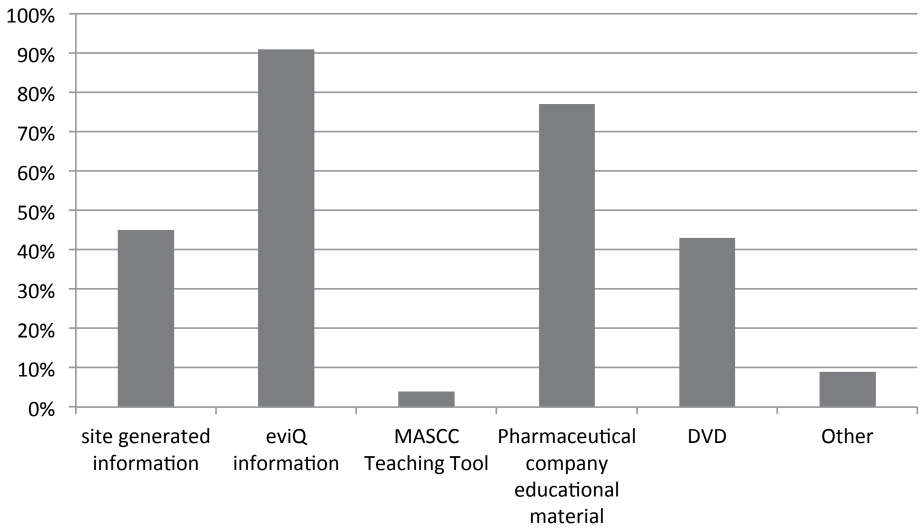

Figure 3: Source of materials used for patient education

since its development in 2004. eviQ provides a diverse range of teaching tools for staff and information in lay language for patients. More than 63% of Australian nurse participants in the MASCC survey indicated they had access to patient education materials; however, in the combined results more than half the participants indicated they had inadequate access to patient education materials.

Table 3: Difficulties experienced by nurses

	Number	%
I did not have any problem	51	32%
Explaining how to take the drugs	19	12%
Side effect and symptom management	46	29%
Explaining the safety issues	33	20%
Usually the patient sees only the physician not the nurse	63	39%
Other, please specify	44	27%

Table 4: Institutions with formal policies/guidelines and patient education materials

N=161	Guidelines/policy for administration of oral anti-cancer treatments	Patient education materials
YES	71%	79%
NO	29%	21%

The number of institutions with formal policies and guidelines to inform the administration and use of OCTs has not changed significantly in the last five years compared to the MASCC survey (71% versus 64.5%) despite increasing prevalence in the use of OCT. This reflects a gap in training and practice when nurses are seeking information in the workplace about OCTs. Seventy-seven per cent of respondents indicated that they continue to use educational materials produced by pharmaceutical companies (Table 4).

Discussion

The survey responses highlighted the gaps and variation in processes and levels of health professional involvement used to provide information about OCT to patients. The shifting treatment paradigm, from intravenous chemotherapy to OCT, has resulted in reduced opportunities for nurses to have contact with patients; that is, they no longer have an appointment specifically to provide education and information about treatment. The loss of these traditional pathways means that health care providers must explore new processes to ensure patients receive information and education that conveys and confirms understanding of the planned treatment, side effects and their management and the importance of adherence to the treatment.

There remains a need for improved access to continuing professional education for nurses as they continue to report difficulties and safety issues (20%) related to new side effect profiles (29%) associated with novel anti-cancer treatments. This may also indicate an evidence gap in the management of novel toxicities experienced by patients receiving OCTs. There is a documented paucity of evidence-based management guidelines for the definitive management of some novel toxicities. For example, pre-emptive strategies to prevent some of the cutaneous toxicities are well established; however, after the onset of these toxicities, management is often pragmatic and efforts to develop effective evidence-based management strategies need to continue[12,13].

Respondents expressed a desire to improve OCT education and supportive care for patients. Suggestions strongly supported the

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use of the same formal education process as is usual practice for patients receiving intravenous chemotherapy. The processes suggested by respondents included:

- A follow-up phone call after commencing OCT.
- The use of an ongoing patient assessment tool throughout the treatment period to evaluate adherence and toxicity management.
- Invest in multidisciplinary care (nurse, pharmacist and physician) to ensure patient access to comprehensive care. In many institutions this would involve organisational change to ensure patients are given education and support by the multidisciplinary team.
- Dispense no more than the exact amount or one cycle of OCT at a time.
- Implement the use of a patient calendar/diary to help limit missed doses and to help avoid the use of medication beyond the prescribed treatment period.
- Changes to methods of patient education such as a group session.

The results of the survey drew attention to the low penetration rate of the MASCC teaching tool to facilitate the planning and implementation of patient education[11]. The MASCC teaching tool is a resource that can be used by a variety of health care providers to assist in planning and providing education to patients, particularly in the absence of sufficient resources to implement a comprehensive education and follow-up service by nursing staff. The tool may be of particular benefit to nurses new to cancer care as it provides a structure and systematic process for providing education to patients about to commence OCT. There is a paucity of similar tools available to nurses and few tools are available to assess and measure adherence to OCT[4].

It is clear from the responses that the integration of OCT into existing cancer services requires organisational change to ensure optimal treatment and safety for the patient receiving OCT. However, due to the increased demand on resources, alternative strategies and resource allocation such as group education sessions, may be considered.

Rural and remote respondents highlighted challenges they experience when OCT is initiated for a rural patient in a metropolitan centre, who then returns to their home in a rural/remote area without appropriate referral. Improved referral patterns back to rural and outreach nursing staff and to local primary health care providers may improve toxicity management, patient safety, and treatment adherence.

Conclusion

Data from this study suggest that nurses continue to play an important role in the education and follow-up of patients receiving OCT. To minimise the risk of harm and to provide optimal nursing care to patients, workflow, organisational processes and resources must continue to adapt. This study reinforces the need for continuing professional education for nurses caring for patients receiving OCT in metropolitan, rural and remote settings. While the eviQ cancer treatment information has been widely adopted, the MASCC teaching tool also provides an additional framework for the provision of consistent and comprehensive education to patients. The use of the MASCC teaching tool can assist nurses who are new to cancer nursing and, where resources preclude nurse involvement, the broader multidisciplinary team. Further research is required to develop robust evidence-based guidelines for the management of novel toxicities, to aid in resolving the difficulties articulated by nurses in explaining safety issues and managing side effects.

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Oral chemotherapy nurse: a trial position at Sir Charles Gairdner Hospital (SCGH), Perth, Western Australia

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Abstract

This article describes the development of an oral chemotherapy nurse role and patient support materials in the Department of Medical Oncology at Sir Charles Gairdner Hospital (SCGH), Perth, Western Australia, and includes a short literature review.

The objectives of the oral chemotherapy nurse role were to: identify areas of patient need, develop processes to support patient safety and quality of care during treatment with oral chemotherapy medications for cancer (oral chemotherapy), and collect resources to support patient safety and quality of care during treatment with oral chemotherapy

The oral chemotherapy nurse undertook two quality improvement projects, developed a system to educate, support and follow up patients with glioblastoma (GBM) treated with combined chemo-radiotherapy and adjuvant chemotherapy, undertook nurse education and was involved as the author of the draft oral chemotherapy policy at SCGH.

Although this position was not made permanent, the process highlighted the needs of patients on oral chemotherapy and opened a dialogue with health professionals committed to improving the safety and quality of care for these patients.

Introduction

In November 2010 the trial position of oral chemotherapy nurse was created using an unrestricted grant from Merck Sharp & Dohme. Oral chemotherapy is the mainstay of treatment for patients with high-grade gliomas, and many of these patients have cognitive and memory impairments. Furthermore, temozolomide treatment, particularly during combined chemo-radiotherapy, can be associated with profound idiosyncratic pancytopenia; therefore, a full blood count is taken weekly, but not necessarily associated with clinical review. The position was created pre-emptively to assist management of the medical workload, as medical staff were unable to dedicate the amount of time required to educate patients and their carers regarding the safe use of oral chemotherapy and to provide education on the range of resources and strategies available to assist patients and carers with medication management. This is particularly relevant in the setting of cognitive and memory impairments associated with a diagnosis of high grade gliomas. The position was envisioned as providing a centralised role for safety monitoring in a setting in which junior medical staff rotated through positions and were unable to provide continuity of monitoring.

Prior to the trial oral chemotherapy nurse role, consultant oncologists and registrars provided education support for patients prescribed oral chemotherapy within the existing service framework that was more tailored to use of intravenous (IV) cytotoxics. Cancer nurse coordinators employed by the Cancer and Palliative Care Network of Western Australia also supported these patients, but more in a care coordination and liaison capacity. The previously undefined oral chemotherapy nurse role was to be developed to specifically address the education and support needs of patients taking oral cytotoxic chemotherapy.

Target group of patients

Patients diagnosed with glioblastoma (GBM), an aggressive brain cancer, were the initial high-need target group to be supported by the oral chemotherapy nurse. In Australia 6.8 people per 100,000 were diagnosed with primary brain cancer for the latest available figures in 2004[1]. The Australian Institute of Health and Welfare (AIHW) ranks primary brain cancer as the 14th most common cancer; however, malignant brain tumours result in the highest potential loss of life and cause the highest economic burden on Australian cancer patients' households than any other type of cancer[1]. Patients with GBM have varied alteration

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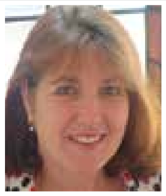

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in cognition and function, dependent on the location of cancer in the brain. GBM has a very poor prognosis with a median survival life expectancy of approximately 15 months in patients having current standard treatment[2]. Patients and patients' family members/carers require a substantial amount of support to complete the complex combined chemo-radiotherapy and adjuvant chemotherapy regimen, and to cope with the difficult diagnosis and sequelae of disease progression[3,4].

Standard therapy for GBM

The standard two-phase treatment for GBM patients, known as the Stupp regimen[2], is depicted in Figure 1. Supportive medications to control nausea, typically a 5HT3 antagonist, are included in this regimen. Potential changes to bone marrow function may result in thrombocytopaenia and neutropaenia. People treated with temozolamide and radiotherapy are also more susceptible to a rare type of pneumonia usually only experienced by those severely immunocompromised, such as sufferers of the acquired immune deficiency syndrome (AIDS). This type of pneumonia (*Pneumocystis jirovecii* pneumonia — PJP) can be difficult to diagnose and treat and is often fatal. However, prophylactic use of antibiotics twice-weekly during the combined chemo/radiotherapy almost completely eliminate this eventuality[5]. Weekly blood tests to monitor bone marrow, liver and kidney function are also part of the initial six weeks of this regimen[6].

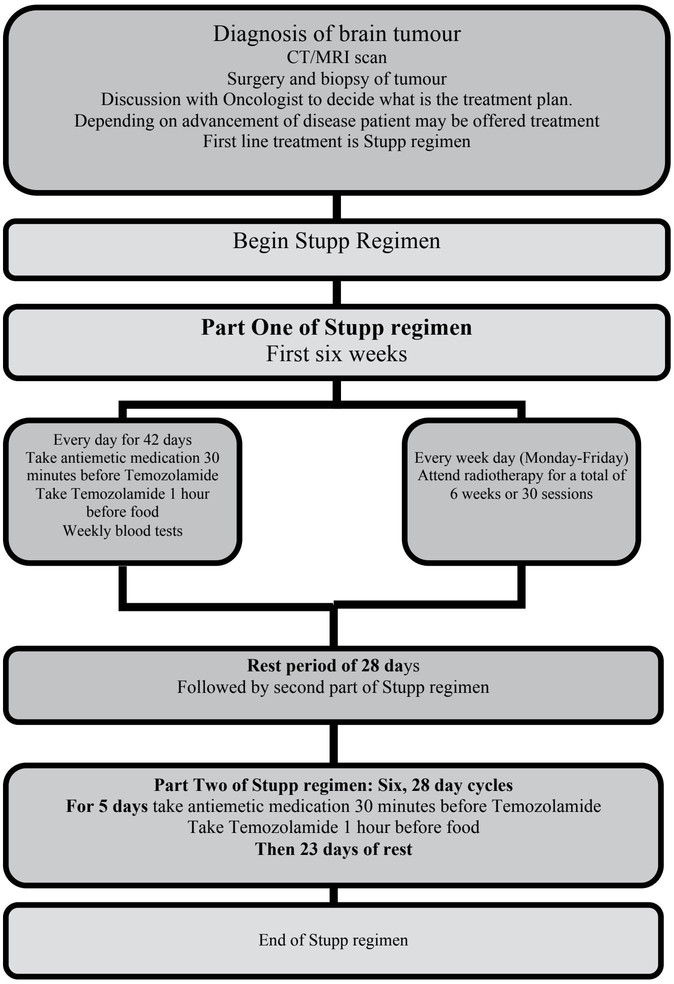

Figure 1: Stupp regimen

Literature search

To assist with definition of the role and identification of potential barriers and enablers to improved safety and quality care, a literature search of academic databases such as ProQuest, Medline, CINAHL Plus (EBSCO), Web of Knowledge and SpringerLink was undertaken. This search included peer-reviewed journal articles describing the role of an oral chemotherapy nurse, oral chemotherapy safety and quality, oral chemotherapy medication errors, and side effect management.

Oral chemotherapy medications are becoming more common, with approximately 25% of all new medications to treat cancer expected to be approved for 2013 being in oral form[7]. Because use of these medications has advanced so quickly, many health care institutions worldwide have lagged behind in policies and procedures to support their use[7]. Nevertheless, some of these medications have the low therapeutic indices and thus potential for devastating toxicities that characterise IV cytotoxic agents. Standard procedures to support safe prescribing, dispensing and administration of IV chemotherapy are widely available.

Cases of serious harm to patients and death, caused by errors in prescription, dispensing and administration of some oral chemotherapy medications have been recorded worldwide, for instance with use of methotrexate and capecitabine[7,8]. A lack of effective policies, processes and procedures to guide those who prescribe, dispense and administer the medications has been a source of error. Doctors, nurses, pharmacists, patients and patient family members are all recorded as having made errors with these medications[9].

Articles discussing the challenges and facilitators of safe and quality oral chemotherapy for cancer treatment were identified, and used to develop the role. Moody and Jackowski (2010) describe the development and implementation of an oral chemotherapy nurse role in their seminal article "Are patients on oral chemotherapy in your practice setting safe?"[10]. Halfdanarson and Jatoi (2010) discuss "Oral Cancer Chemotherapy: The critical interplay between patient education and patient safety" in an article which reviews the issues of patient safety, education and the maintenance of safety infrastructure such as policy and procedure to ensure safe and quality cancer care outcomes[11]. Weingart *et al.* (2007–2011), have produced a number of articles looking at the safety and quality of care for patients taking oral chemotherapy, and indeed Weingart *et al.* (2008) have been responsible for the National Comprehensive Cancer Network (NCCN) *Task Force Report: Oral Chemotherapy* in the USA[7,12-15]. These articles detail the barriers and incentives for patients treated with oral chemotherapy, and those faced by health care institutions struggling to keep up in the development of appropriate systems, policies and procedures to support them. More recently, the problems involved with adherence to oral chemotherapy have been explored and tools developed to assist patients with this ongoing problem[16,17]. Many studies looking at adherence have been undertaken including by Partridge *et al.* (2002) whose widely cited review identified problems that may impact the ability of patients to 'adhere' to their oral chemotherapy.

Grey literature was also sought to support development of the oral chemotherapy role, including guidelines for safe prescription, administration and dispensing of oral chemotherapy by oncology professional bodies in the United Kingdom (UK), United States of America (USA) and Australia. Notably, the Clinical Oncology Society of Australia (COSA) guidelines, American Society of Clinical Oncologists, UK Oncology Nurses Society (UKONS), and the Society of Hospital Pharmacists of Australia (SHPA)[18-21]. These literature searches were ongoing throughout the oral chemotherapy nurse's employment, and a large collection of relevant material was gathered and used to develop the role. The main themes identified in these searches are summarised below.

Issues involved in treatment with oral chemotherapy

Some oral chemotherapies have a narrow therapeutic index, necessitating frequent, pre-treatment monitoring of bone marrow, renal and hepatic function by blood tests[19]. These must be checked by an oncology health professional before beginning each cycle of treatment to determine if therapy should be continued, modified or ceased[18,19]. Alteration in bone marrow, renal and hepatic function can impact immune function and predispose the patient to greater impacts from minor illnesses[22].

Other side effects from oral chemotherapy such as nausea, vomiting, constipation, fatigue, skin rashes and neurological effects require close monitoring and supportive actions and/or medications[19]. It must be noted that not all patients experience any or all of these side effects[14,23,24], but that knowledge of the possibility of them arising and how to manage them is essential to prevent serious patient harm or the cessation of therapy[17,25].

Due to advances in treatment options and increases in length of survival after a diagnosis of cancer, cancer is increasingly being treated as a chronic condition[26]. This means that patients are often on medications for extended periods of time. Long-term use of any oral medication has been linked to a reduced adherence to therapy, including treatments for cancer[27]. Complex regimens involving the use of timed doses, specific relationships to food, supportive medication and rest periods are common[28], and this increasing complexity of drug regimen is associated with a greater difficulty with maintenance of adherence to treatment[26,29].

The cytotoxic and often teratogenic nature of some oral chemotherapies means that special precautions for storage, handling, dispensing and administration of these medications is necessary. Body fluids of people treated with cytotoxic medications may require special consideration, involving use of barrier methods of contraception up to seven days after taking the last dose of chemotherapy and disposal precautions for body fluid spills[30].

Oral chemotherapy is usually taken by the patient at home, meaning that issues usually monitored by health professionals in a health care setting are now the responsibility of the patient or caregiver. This increase in responsibility for management of complex care, can also increase the likelihood of adverse events[7,14,31].

Interventions and processes which support safe treatment and adherence to oral chemotherapy

Using electronic prescribing rather than hand-written prescriptions has been shown to reduce prescription errors by doctors and dispensing errors by pharmacists[9,32]. Patient education has been shown to reduce the number of serious adverse outcomes caused through these errors[11,33,34]. Using a multidisciplinary health care team approach to guide treatment and support patients taking oral chemotherapy for cancer medications has also proven successful in assisting patients to persist with therapy, reduce medication errors and help patients to manage side effects[18,20,35].

Developing and implementing organisational policies, procedures and guidelines for the safe prescription, dispensing and administration of oral chemotherapy has been advocated by professional oncology bodies in Australia, USA and the UK[18,20,35]. These professional bodies have also produced guidelines for the safe prescription, dispensing and administration of chemotherapy in general, with sections devoted to oral chemotherapy[18,20,21]. In Australia, these remain guidelines only, and have not been made standards of care. During development of the oral chemotherapy nurse role, these interventions and processes were consulted and are reflected in the objectives for this role.

Objectives

Objectives of the oral chemotherapy nurse were to:

- identify areas of patient need
- develop processes to support patient safety and quality of care during treatment with oral chemotherapy medications for cancer ('oral chemotherapy')
- collate and develop resources to support patient safety and quality of care during treatment with oral chemotherapy

Method

The role of oral chemotherapy nurse was completely new and, as such, had no job description or scope. Investigations were undertaken to create a framework for the position which would be evidence-based and patient-focused. Evidence which could be used to present a case for sustaining this position also needed to be collected. The role was developed specifically to support patients with brain cancer, but was expanded to include quality improvement exercises which could be applied for all patients taking oral chemotherapy.

Defining the role

Initially, meetings were held with the neuro-oncologists and registrars to discuss the role of the oral chemotherapy nurse. Other meetings and email correspondence was undertaken with the clinical nurse manager (CNM) of the outpatient area, the neurology oncologists, oncology pharmacist and head of department (medical oncology) to discuss and agree on functions of the oral chemotherapy nurse role (Table 1).

Table 1: Agreed role of the oral chemotherapy nurse

Follow up and monitor weekly blood results for brain cancer patients in the first six weeks of the Stupp regimen (parameters were set in regard to acceptable results and process of communication with doctors for advice)
Educate new patients/family carers with GBM on the Stupp regimen
Support more 'vulnerable' patients where necessary. Vulnerable patients were those who had limited carer/family support systems, had additional health challenges including cognitive impairment, or were located in a remote or rural setting.
Liaise with other members of the health care team where necessary to support patients and their families/carers
Preparation and delivery of presentations to communicate the oral chemotherapy nurse role and function
Preparation and delivery of nursing staff education regarding GBM and the Stupp regimen
Quality improvement (QI) exercises to improve safety and quality of care for oral chemotherapy in general
Ongoing liaison with key stakeholders to raise awareness of barriers to safety and quality care and to develop documents, processes, policy and procedure where necessary to improve safe and quality patient care.

Scoping the policies, procedures and processes to support patients taking oral chemotherapy

The oral chemotherapy nurse spent an outpatient clinic session with the neuro-oncologist to ascertain the existing process of diagnosis, treatment planning, patient/carer education and prescription of treatment for patients with GBM. Pharmaceutical company patient education materials usually provided to patients/carers were collected and reviewed. Hospital-based standard regimen plans were accessed on the institution Intranet.

QI exercises

An audit of current oral chemotherapy charts was undertaken (SCGH Quality Improvement (QI) exercise QI 2644). This QI showed that in comparison to IV chemotherapy, there was a paucity of information collected and provided to all members of the health care team regarding any cancer treatment plan for patients on oral chemotherapy. Results showing the type of information recorded in the IV chemotherapy versus oral chemotherapy charts are shown in Table 2.

Table 2: Results of QI 2644 showing the type of information recorded in IV chemotherapy versus oral chemotherapy charts

Information in chart	IV chemotherapy chart	Oral chemotherapy chart
Legal prescription for chemotherapy treatment including supportive therapies	Yes	No
Ongoing nursing assessment with CTCAE* toxicity chart	Yes	No
Integrated progress notes for each treatment	Yes	No
Current blood results	Yes	Sometimes
ECheMa** protocol	Yes	No
ECheMa supportive medication chart	Yes	No
Checklist to show patient received relevant medication and regimen education and allied health referral	Yes	No
Aide-mémoire for treatment	No	Yes

*Common Terminology Criteria for Adverse Events V4.0

**ECheMa is the hospital's own electronic information and prescription source

A second QI, QI 2693 using the Quality Use of Medicine audit for oral chemotherapy for cancer medications[36] was carried out. This audit was prompted by the Victorian Health Department's 'Quality Use of Medicines (QUM) Caution with use of oral chemotherapy for cancer' notice to oncology health professionals[37]. The 'QUM Caution with use of oral chemotherapy for cancer' notice recommended that a key oncology professional undertake the QUM Audit. The audit tool used can be accessed at: http://www.safetyandquality.gov.au/wp-content/uploads/2012/02/MedicatiOral-chemotherapy-QUM-Audit-Tool-Victorian-Department-of-Health.doc Table 3 elaborates key recommendations for the SCGH Department of Medical Oncology, which were outcomes from QI 2693.

Policy development exercise

Acting on recommendations from QI 2693, the clinical nurse manager of medical oncology requested that the oral chemotherapy nurse act as policy author to develop an oral chemotherapy policy. Over six months, using the North Metropolitan Area Health Service Policy and Procedure Framework, this project was undertaken and development of a draft policy for oral chemotherapy for cancer achieved[38].

Table 3: Key recommendations from QI 2693

Area	**Details**
Policy	Development of specific oral chemotherapy policy
Procedure	Development of specific procedure for oral chemotherapy prescription, dispensing and administration
Guideline	Develop guidelines covering safety, prescription, dispensing, administration and nursing role in patient education and follow-up
Staffing HR	Creation of the oral chemotherapy nurse position Pharmacist position in clinic area

A supportive nursing role

A supportive nursing role was developed where patients were delivered pre-treatment regimen information and education, safety and follow-up education and ongoing follow-up telephone contact for side effect and essential monitoring. New patients about to undergo the Stupp regimen were identified at weekly neuro-oncology outpatient clinics by reviewing the clinic list, and accessing patient notes. A coloured 'invitation sheet' was placed in the patient notes for the oncologist to contact the nurse if the patient was beginning the Stupp regimen and was happy to see the oral chemotherapy nurse. When invited, the patient and family/carer were greeted by the nurse after their oncology visit and given written and verbal information about their regimen. Patient and carer/family contact details were obtained and an arrangement made for the nurse to contact the patient after the first week of therapy. Microsoft Outlook calendar was used to make reminders to contact patients and a template for electronic patient note taking was devised. On each patient contact an electronic note was made and saved onto the shared hospital drive for access by relevant health professionals. A separate hard copy was printed to be filed into the permanent patient record. This was a procedure previously not performed at the site.

Vulnerable patients were directly referred by the neuro-oncology consultant, and a similar process followed. These patients may have been at any stage of the Stupp regimen and were contacted more frequently according to needs. Remote and rural patients often attend the SCGH medical oncology outpatient clinic, and patients from areas such as Port Hedland, Busselton and Esperance were seen and supported by the oral chemotherapy nurse. Liaison between the oral chemotherapy nurse and available clinical nurse consultants and cancer nurse coordinators available in these areas were used to increase awareness of patient needs as patients and families/carers often disclosed problems and concerns not previously discussed with other health professionals.

Patient education

An existing education package for patients receiving IV chemotherapy was examined and modified to suit patients who would be receiving oral chemotherapy. Patients and carers were given the opportunity to have additional education with the oral chemotherapy nurse after seeing the oncologist. An education pack was given to each new patient and carer, and this was accompanied by verbal information and 24-hour contact numbers. Verification that the patient's carer understood the regimen and how to manage problems and side effects was undertaken before the patient left the hospital by asking the patient and/or the carer to repeat this information.

Monitoring and follow-up

The oral chemotherapy nurse maintained telephone and face-to-face support to assist patients and carers with weekly or monthly blood test monitoring, and acted as a contact person for patients and carers to discuss and manage side effects of treatment. Liaison between registrars and oral chemotherapy nurse to support and manage patient issues related to regimen was maintained. Liaison between other health professionals and support agencies was effected if social support of the patient and carers was warranted.

QI translated to outcomes

QI exercises informed development of a draft oral chemotherapy policy, collation of education materials into a standard pack to support patients and carers, standardisation of documentation relating to oral chemotherapy to be in line with IV chemotherapy, and locally held patient records for oral chemotherapy mirroring those kept for IV chemotherapy.

Nurse education

Educational presentations were prepared and delivered to nurses in the chemotherapy and radiotherapy outpatient departments regarding management of patients with GBM on the Stupp regimen. The oral chemotherapy nurse became a resource for other health professionals regarding Temozolamide and the Stupp regimen and a starting point for advice about other types of oral chemotherapies. A presentation to inform allied health professionals about the oral chemotherapy nurse role was delivered to nursing staff in the outpatient medical oncology areas. This raised the awareness of staff regarding the presence and role of the oral chemotherapy nurse and resulted in nurses and doctors in this area contacting the oral chemotherapy nurse for advice and to refer management of vulnerable patients.

Documentation of the process

Ongoing documentation of the processes involved in developing the oral chemotherapy nurse role was recorded in a computerised log. This listed in chronological order the identified problems/processes, participants involved and progress of the activities. This 'progress log' was used to develop a business case for an oral chemotherapy nurse position at the end of the trial period. Progress logs were also kept for the QIs, which proved a useful tool when making reports for these exercises.

Discussion

Oral chemotherapy is a rapidly increasing field of cancer treatment for which policies and procedures to support patients and maintain a safe and quality service have lagged worldwide[7]. Researchers and health professionals have tested appropriate processes for supporting oral chemotherapy patients, and identified many challenges that face ongoing patient adherence to therapy and maintenance of safe and quality services[17,26,27,29]. Having an oral chemotherapy nurse to support patients on oral chemotherapy has been trialled by Moody and Jackowski in the USA[10]. Although evaluation of Moody and Jackowski's project was not formally undertaken, documentation of adverse patient side effects has reduced, and over 1710 interventions for patients were recorded. Safety for patients was considered to be improved, because patients were taught about how to manage and report side effects and how to take their medication safely and when to attend appointments[10]. At SCGH all new patients commencing the Stupp regimen with GBM supported by the oral chemotherapy nurse received written and oral patient education, telephone and face-to-face support regarding ongoing symptom management and essential monitoring. In this regard, the safety of the patients at SCGH treated with the Stupp regimen could also be considered improved.

Development of education packs, a draft policy and with enhanced rapport between the multidisciplinary health care team, SCGH has moved closer to improving hospital governance which will support safer treatment of patients on oral chemotherapy. Weingart *et al.* in the NCCN report state this as one of the goals for all health care institutions treating patients on oral chemotherapy[7]. However, the policy is yet to be ratified, due to lack of personnel, chiefly a permanent oral chemotherapy nurse and pharmacist in the outpatient department. Other supports within the policy must also be developed and implemented to move this initiative further. It is a concern that without the presence of an oral chemotherapy nurse, changes may not be further advanced and delivered.

Conclusion

The trial oral chemotherapy nurse position in 2010–2011 highlighted the need for greater patient support and improved safety and quality measures for patients treated with oral chemotherapy within the medical oncology outpatient department. Registered QI reports were delivered to the SCGH quality and safety team and nursing and medical heads of the medical oncology department. A draft policy was created and other supportive documents and systems.

However, without an ongoing oral chemotherapy nurse, these advances are likely to remain dormant, and patients continue to have suboptimal support to successfully and safely complete their oral chemotherapy treatment.

Reflection on the role

As the first oral chemotherapy nurse in Western Australia, I found this role both challenging and rewarding. There was no formal process for development of this role and, therefore, no pre or post evaluations of the service. This information would have been very useful and it is suggested that if such funding were to be available again, a more structured process should be undertaken. However, the QI projects undertaken began a body of evidence which could be used to prepare another business case for this role, or a formal process for another trial oral chemotherapy nurse position.

Patients and carers frequently conveyed their appreciation for the information and follow-up support offered. Nurses working in the high-pressure area of a medical oncology outpatient department with a culture of 'production line' appointments were appreciative of the time I spent educating new patients, following up patient blood results and fielding phone calls relating to oral chemotherapy side effects and patient concerns. However, as a change agent working in an environment of budget cuts, high-volume patient throughput and few standard patient supports, I felt that small changes were at least a step in the right direction. The two-day-a-week role was very intense, filled with educating new patients, following up existing patients, researching and developing new patient support materials, undertaking QI exercises and building a network of health professional associates who continue to raise the profile of issues for patients taking oral chemotherapy.

It would be useful for other medical oncology outpatient units to undertake the QUM audit to ascertain how supported their oral chemotherapy patient recipients were and how institutional policies and procedures catered for oral chemotherapy patients. This audit can be found at: http://www.safetyandquality.gov.au/wp-content/uploads/2012/02/MedicatiOral-chemotherapy-QUM-Audit-Tool-Victorian-Department-of-Health.doc Indeed, a large scoping exercise of Australian hospitals using this audit tool would be interesting.

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ADVERTORIAL

Dissolving the challenges of emesis treatment in cancer patients

Nausea and vomiting are common in cancer patients undergoing chemotherapy.[1] Dysphagia (difficulty swallowing) is also common, especially in patients with head and neck cancers, but also in those undergoing treatment for other malignancies.[2] Dysphagia and patient adherence are particular challenges in the cancer setting that have been helped by the emergence of innovative medication delivery methods, such as orodispersible tablets (ODTs). ODTs combine the advantages of solid tablets (e.g. stability, accurate dosing) with those of liquid formulations (e.g. easy administration, no risk of choking).[3]

Zofran Zydis: key characteristics

Zofran Zydis wafers, a type of ODT, are a freeze-dried, fast-dissolving oral formulation indicated for the prevention and treatment of nausea and vomiting induced by cytotoxic therapy and radiotherapy.[4] Zydis wafers can be given without water and dissolve on the tongue almost instantly (less than 3 seconds)[3,5] reducing the potential for choking or spitting out the dose.[6] Zofran Zydis wafers contain a strawberry sweetener to ensure acceptable taste, which is an important formulary consideration with ODTs.[4,5] Other important characteristics of the Zydis formulation include:

- bioequivalence to conventional tablets[4,6]
- physical and chemical stability with shelf life comparable with conventional tablets.[6]

Zydis: when to use

In general, ODTs are used for patients who either have difficulty swallowing, refuse to swallow or don't have access to water.[5] Therefore, Zofran Zydis wafers may provide an advantage for cancer patients wishing to overcome the challenges of dysphagia and emesis in the management of chemotherapy-induced nausea and vomiting.[4,5]

Ease of use

The ability of Zofran Zydis wafers to dissolve on the tongue within 3 seconds without the need for water offers increased convenience and ease of administration, especially in patients who have difficulty swallowing.[5,6] Therefore, Zofran Zydis wafers may provide an effective solution for the management of chemotherapy-induced nausea and vomiting where dysphagia and poor adherence are identified issues.

Zofran Zydis packs and wafer not shown to scale.

Zofran®
ondansetron

Before prescribing please review the Product Information available on request from Aspen Australia or via www.aspenpharma.com.au

Zofran® Injection, Tablets, Syrup, Suppositories and Zofran Zydis Wafers (ondansetron) – Minimum Product Information. Indications: Prevention and treatment of nausea and vomiting induced by cytotoxic therapy and radiotherapy. Ondansetron (injection) is also indicated for the prevention and treatment of post-operative nausea and vomiting. **Contraindications:**Hypersensitivity to any component of the preparation; concomitant use with apomorphine. See full PI. **Precautions:** Hypersensitivity reactions; dose-dependent QT interval prolongation so caution in those who have or may develop prolongation of QTc; avoid in congenital long QT syndrome; correct hypokalaemia and hypomagnesaemia prior to use; monitor those with subacute intestinal obstruction as ondansetron increases large bowel transit time; caution in patients with phenylketonuria (wafers); paediatric patients; pregnancy (Cat B1); lactation. See full PI. **Interactions:** co-administration with drugs that prolong QT interval and/or cause electrolyte abnormalities; apomorphine; potent inducers of CYP3A4 (i.e. phenytoin, carbamazepine, and rifampicin); tramadol; others (see full PI). **Adverse Effects:** Headache; sensation of warmth or flushing; constipation; xerostomia; local anal/rectal burning sensation following insertion of suppositories; asymptomatic increases in liver function tests with cisplatin; local I.V. injection site reactions; others (see full PI). **Dosage and Administration:** Use lowest effective dose. Place wafers on top of tongue where it dissolves within seconds, and is swallowed. **Emetogenic chemotherapy and radiotherapy: Adults:** 8 mg by slow I.V. injection in not less than 30 seconds, immediately before treatment or two oral doses of 8 mg each at 12 hourly intervals, the first dose given 2 hours before treatment or single 16 mg suppository, 2 hours before treatment. For prevention of delayed emesis after the first 24 hours: 8 mg oral twice daily, or 16 mg suppository rectal once daily, for up to 5 days after a course of treatment. **Children:** experience is limited. 4 years and older: Give I.V. at 5 mg/m² over 15 minutes, immediately before chemotherapy, followed by oral 4 mg twice daily for up to 5 days. Suppositories are not recommended. **Highly emetogenic chemotherapy: Adults:** 8 mg by slow I.V. injection in not less than 30 seconds, immediately before treatment. If required, higher additional I.V. doses may be given up to a maximum of 32 mg in 24 hours. **Post-operative nausea and vomiting (injection only): Adults:** give 4 mg by I.M. or slow I.V. injection. Up to 8 mg if necessary for treatment. **Children:** 2 to 12 years: slow I.V. injection at 0.1 mg/kg up to 4 mg. Hepatic impairment: Maximum total daily dose of 8 mg in moderate or severe dysfunction. See full PI. (PI last amended 15 Oct 2013). **References: 1.** Janelsins MC, et al. Expert Opin Pharmacother 2013. 14(6): 757-66. **2.** Raber-Durlacher JE, et al. Support Care Cancer 2012. 20(3): 433-43. **3.** Fu Y, et al. O. Crit Rev Ther Drug Carrier Syst 2004. 21(6): 433-76. **4.** Zofran (ondansetron). Approved product information. Last amended: 15 OctOber 2013. **5.** Giri TK, Tripathi DL, Majumdar R. Int J Pharm Pharmaceut Sci 2010. 2(3): 38-42. **6.** McLaughlin R, Banbury S, Crowley K. Pharm Tech 2009. Sept (Suppl):1-6.

PBS Information: Zofran Zydis wafer. Authority required: Management of nausea and vomiting associated with radiotherapy used to treat malignancy. Restricted Benefit: management of nausea and vomiting associated with cytotoxic chemotherapy being used to treat malignancy which occurs within 48 hours of chemotherapy administration.

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Coordinating neuro-oncology care from a primary health care perspective: a critical literature review and implications for practice

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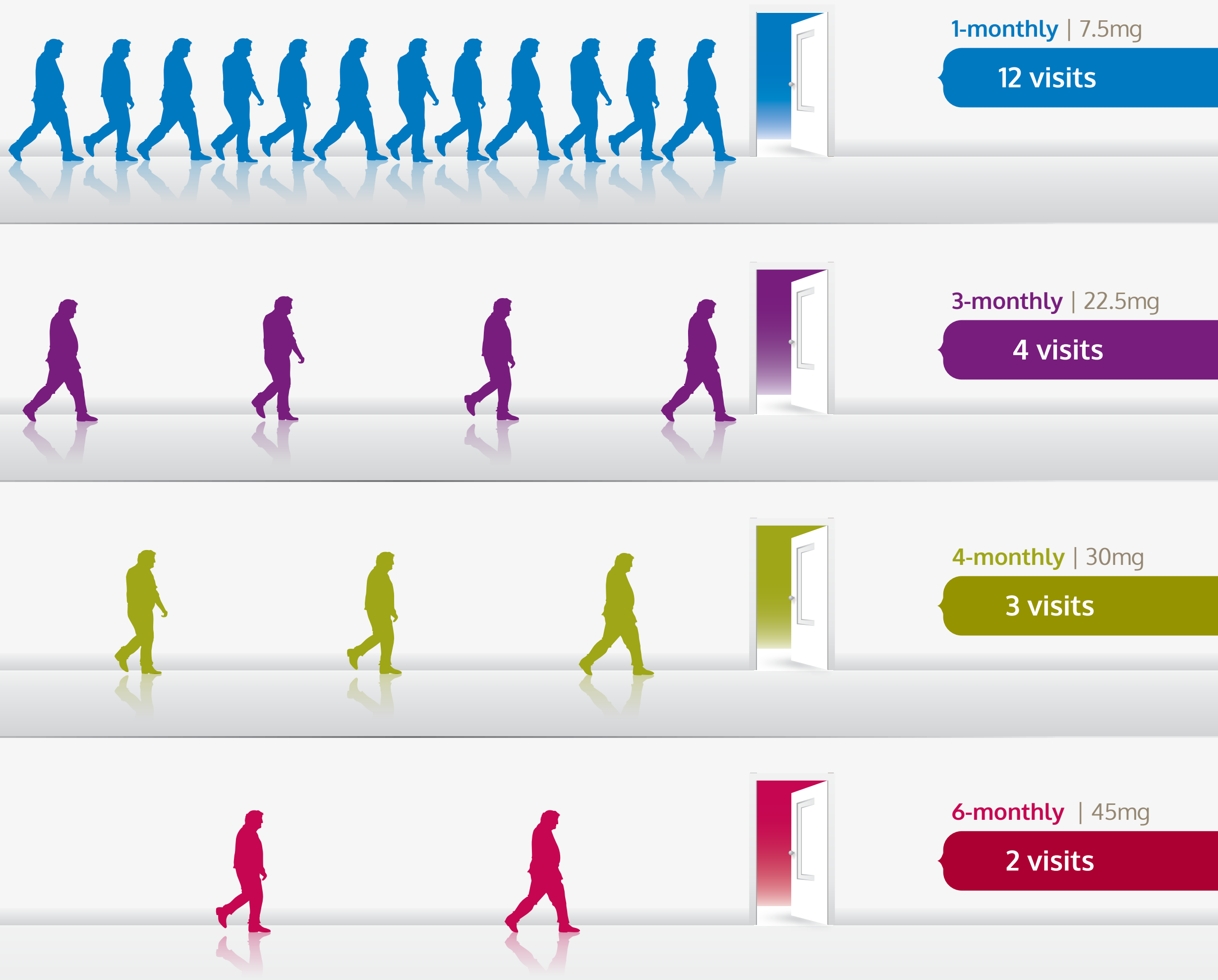
Abstract

Primary brain tumours pose a unique concern for health professionals, generally presenting with a rapid and poor prognosis associated with the development of functional and cognitive deficiencies which creates a profound psychosocial impact. Whilst the diagnosis of a primary brain tumour can be associated with medium- to long-term survival, the majority of patients diagnosed with a high-grade brain tumour will die within 14 months of diagnosis. Given this, patient care needs to be comprehensive, seamless and individually focused. The management of patients by specialist neuro-oncological nurses and cancer care coordinators has resulted in an increased focus on cancer care reform. However, despite the aim of these changes there needs to be an increased emphasis on primary health care as a strategy for achieving coordination of care. Cost-effective primary health care initiatives are urgently needed to achieve not only coordination of care but to also balance the biomedical model. Whilst the biomedical model of care focuses on physical wellbeing in the absence of disease, primary health care encompasses a more comprehensive and holistic notion of wellness. This critical literature review examines primary health care, how it can be applied to the neuro-oncology setting and the implications for practice.

Introduction

Primary brain tumours pose a unique oncological significance. The rapid onset and progression of neurological change brings with it uncertainty and anxiety as the brain is the primary control centre of the body[1,2]. Despite novel and multimodal therapeutic approaches now being available for patients, the majority of primary brain tumours are not curable, thus heightening the need to focus on supportive care[3,4]. The care of patients diagnosed with a primary brain tumour is multifaceted and complex. Without appropriate coordination and support, patients and families often experience fragmented care, avoidable distress and anxiety. Hudson *et al.*[5] support the need for multi-interventional approaches that focus on patient outcomes post-cancer diagnosis and treatment. Barnett *et al.*[6] suggest that primary health care offers coordinated, accessible and efficient care that is patient-centred and considers individual needs. Navigating a complex health system often involves accessing a variety of health professionals that may be located across a number of organisations[7-9]. The coordination of care is essential for coherence of cancer survivorship and quality of life. Primary health care provides a platform to develop health care interventions and activities including intersectoral coordination of care, the provision of accessible care, the use of technology to enhance the provision of care, participation of individuals in health care decision making and the promotion of health and wellness within illness. A primary health care framework offers support and management to remain as healthy as possible and nurses play a major role in shifting health care systems from focusing on illness towards health promotion[10]. Fundamental to this is acknowledging that health is not merely the absence of illness; it is a sense of wellbeing.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Method

An initial literature search was conducted utilising Pubmed, Proquest and MEDLINE. The databases were searched using keywords and the combination of 'primary health care, cancer care coordination, and brain tumours'. Seminal articles were included to provide a historical perspective; however, the research was generally focused from 2000 to 2013. Due to a dearth of literature that specifically pertained to primary health care and the coordination of cancer care, particularly brain tumours, all relevant articles were reviewed as well as the reference lists of articles, which were also searched to identify additional publications.

Context

Primary health care already plays an integral part in our health care system; however, the five principal tenets of primary health care (appropriate technology; collaboration; accessibility; health promotion; and public participation) need to become the focus of health care initiatives. The five principal tenets of primary health care have emerged repeatedly throughout the literature when exploring cancer care coordination. Although not specifically addressed or incorporated as a principal framework of practice for neuro-oncology care, they are addressed and presented in a variety of contexts, and strongly associated with positive outcomes for patients and families. With an anticipated future shortage of health care professionals primary health care is supported as a strategy to ensure optimal delivery of coordinated care for cancer survivors.

Since the 1978 declaration of Alma Ata, the concept, definition and application of primary health care has been varied, manipulated and applied as both a philosophy of care and a framework that has been applied across a number of health strategies[11]. The declaration of Alma Ata formalised primary health care and attempted to define it on a global scale. However, the broad scope of the declaration resulted in varied interpretations, including the implementation of selective primary health care. In contrast to comprehensive models of primary health care, selective primary health care is often viewed as the realistic option; however, maintaining public participation is intrinsically difficult and a significant criticism of most selective primary health care models[12]. Addressing this involves working within an empowerment framework. Individuals and families are encouraged to participate in decision making and planning of care. The key to success is to balance the tenets of comprehensive primary health care with the operational strategies of selective primary health care, this implemented with effective leadership that promotes empowerment, inclusiveness and health promotion[13]. For patients diagnosed with a primary brain tumour, selective primary health care offers a more inclusive approach to care that recognises the social determinants of health.

The five principal tenets of primary health care incorporate both medical and personal care with health-promoting activities and aim to provide a holistic approach to care that encompasses all the determinants of health. The elimination of social, environmental and economic disadvantage is the core principle of accessibility[11]. Collaborative practices need to be extended to incorporate experts from diverse sectors so that the right care can be provided in the right place by the right provider. Technology needs to be utilised in the most appropriate way that will meet the needs of the community[11]. Individuals need to be empowered to have more control over their health through capacity building, and increased health literacy[14,15]. Finally, the central tenant of primary health care is public participation and the recognition of health professionals as partners rather than leaders[11,16]. Prioritising primary health care can improve patient outcomes through the development of sustainable frameworks of care, that place patients at the centre of care rather than the receivers of care.

For individuals diagnosed with a primary brain tumour the traditional emphasis on care has focused on diagnosis and surgical interventions. Jefford *et al.*[17] identify that unlike other health care settings, such as stroke, there has been limited focus on the coordination of long-term care. A primary health care framework offers the opportunity to improve models of care and improve cancer coordination through ensuring that individuals receive comprehensive and accessible care. Primary health care offers empowerment, choice, autonomy and care strategies that are respectful and holistic. More importantly, primary health care can be nurse-led and delivered not only seamlessly but also with empathy and compassion.

Review of the literature

A number of national reports have highlighted the need to improve the coordination of cancer care in Australia. In 2003 the Clinical Oncological Society of Australia, the National Cancer Control Initiative and the Cancer Council Australia released a consultative report *Optimising Cancer Care in Australia*. It was a ground-breaking document that was the blueprint for cancer care reform in Australia. The report highlighted that poorly integrated systems were a major failing of modern health care. The *National Service Improvement Framework for Cancer* (2006) highlighted the optimal cancer service as being seamless, coordinated, continuous and integrated. In response to these reports the role of the Cancer Care Coordinator rapidly emerged as a solution to achieving system reform and improve patient outcomes[18]. However, despite Cancer Care Coordinator roles and broader system changes being implemented across Australia, neither approach has been fully evaluated[19]. Whilst specialist neuro-oncology nurses have identified with and developed the role of cancer care coordination, Lapum *et al.*[20] highlight that there needs to be an increased focus on the identification of nurses as primary health care providers, this being fundamental to legitimising and developing the social structures to support this role.

Cancer care is potentially uncoordinated as patients transit from specialty care including surgery, radiotherapy and chemotherapy and then towards primary care[21]. The need for coordination of care and support beyond the acute care setting has been partially addressed with the development of the cancer care coordinator role. Given the number and variety of health care professionals involved following the diagnosis of a primary brain tumour, the role of a designated coordinator is vital[22]. However, for many regional areas that are not serviced by cancer care coordinators there is a need to re-orient health services to address service gaps. Fundamental to this is focusing on the broader system, including the role that nurses play in the primary care settings. Thinking outside the inflexible, acute hospital environment can have a significant impact on shaping a patient's journey. Embedding primary health care principles into practice at this level moves beyond the individual role of a cancer care coordinator and encompasses a broad spectrum of activities that focus on recovery from illness, guarding against deterioration of health and restorative and rehabilitative care[23]. Most importantly these activities, whilst benefiting from a cancer care coordinator, are not dependant on an individual role.

Cancer care coordinators are identified as being a solution to improving access to services and seamless care. Increased patient outcomes are achieved through the provision of a single point of contact, mapped patient pathways and assistance with access and navigation through services[24-26]. Despite the emergence and partial success of cancer care coordinators, the role has been mired by a lack of clarity and role definition[27]. Whilst Walsh *et al.*[28] highlight the importance of a key contact person, the components of care coordination are also equally important. With the ongoing pressure of limited resources and increased demand on health services, there is an increased focus on innovative and sustainable practices. Yates[29] recognises the importance of improving the clarity, role definition, succession planning and career development of cancer care coordinators. Cancer care coordination roles are varied and multifaceted. However, the tenets of primary health care frequently emerge as strategies for achieving holistic cancer care coordination at the system and organisational level.

The *2006 Clinical Oncological Society of Australia Cancer Care Coordination Workshop Report* identified that care coordination was not a single solution and that optimal seamless and integrated care required a broader system approach[29]. Evans[19] concurred that care coordination should be sustainable, supported and not the sole responsibility of individuals. A primary health care framework is a transformative approach to care at all stages of the cancer trajectory. It goes beyond individuals and broad collections of practitioners to provide a more flexible, integrated and holistic approach to care[30]. Working within a social model of health, a primary health care framework is based on the premise that to improve health outcomes basic needs must be met[31]. Historically Australia has had a relatively non-specific focus on primary health care; however, there is widespread and increasing support for policies and frameworks of practice that invest in primary health care as an approach to achieving improved health outcomes[30,32]. Now is the time for movement as Australia has embarked on major health care reform and now has a primary health care policy that will change the focus and delivery of health care through the development of local primary health care networks. The role of the cancer care coordinators needs to continue to engage a broader spectrum of activities that support health and wellbeing.

Accessibility

The principle of accessibility is focused on social justice and the provision of equity through the elimination of social, environmental and economic disadvantages[11]. The key to improving patient outcomes requires not only improved interventions and treatments but also improved delivery and access to services[33]. Patients are often isolated from the supportive systems of outpatient oncology clinics. This is due in part to the prescription of oral chemotherapy and secondly cognitive barriers to access, and isolation secondary to being restricted from driving[34]. Whereas many cancer care coordinators are hospital-based there is a need for more community-based coordinators to support patients[26]. La Cour and Cutchin[35] discuss the importance of equal inclusion in services for cancer survivors with regard to gender, ethnicity and socio-economic background. Even eliminating transport needs can improve accessibility.

Rural vulnerability and socio-economic status remain significant obstacles to accessibility[36,37]; however, an amplified focus on bridging the gaps between rural, regional and metropolitan services has resulted in insufficient focus on other disadvantaged groups facing abridged accessibility to services. Walsh *et al.*[38] highlight that patients treated in the private system also experience less supportive care, increasing the need to link patients to services between private and public settings. Braum *et al.*[39] consider that by improving accessibility and support, individuals are less likely to delay medical treatment, thus reducing catastrophic events and emergency interventions. Accessibility can be achieved through the mapping of cancer pathways and the development of patient management frameworks and directories of cancer services. Information and resources can be provided for consumers and health care professionals, increasing accessibility and patient involvement as well as improving awareness of care planning and referral pathways. Prompt referrals to medical oncology and the radiation-oncology teams are vital for seamless care. Improved coordination of care must include timely referrals so that care planning can occur whilst patients are able to participate in and voice their desires[40]. Involvement of general practitioners is also vital as they often lose contact with patients only to find themselves as the primary medical provider following treatment[41]. Community-based primary health care coordinators play a fundamental role in supporting patients and families and to assist in accessing care and transitioning between care services as required.

Collaboration

Individuals diagnosed with a primary brain tumour have complex care needs that cannot be adequately provided by a single practitioner or organisation[20]. Building intersectoral collaboration involves the provision of collaborative care, utilising experts from diverse sectors and different alliances can be effectively applied to provide a collaborative approach to care[11]. For many nurses and health care professionals this challenges the propensity to work in organisational silos. Pre-existing referral systems and access to allied health care professionals makes for undemanding collaboration that has a distinct multidisciplinary focus. However, it has long been recognised that within the acute hospital system, there is a tendency to focus on biomedical services and compartmentalisation of care[42]. Collaboration is viewed as fundamental to providing effective use of health care systems with coordinated appointments allowing seamless care and comprehensive assessments[43-45]. Whilst collaboration within the hospital system often runs smoothly, improved discharge planning involves patients being linked with outpatient services, non-government organisations and community health professionals as close to the home as possible.

Building collaboration to an intersectoral level involves the participation of non-government organisations and stakeholders. For example, the Cancer Council Australia works to minimise the impact of cancer through advocacy and the offering of advice and support for carers and those living with cancer. Importantly, information is provided across a number of media as well as financial assistance and transport for treatment services. These services are significant as both direct and indirect health care costs are possibly the most significant barrier to accessible health care[39]. For individuals diagnosed with a primary brain tumour, there is cost associated with not only an inability to work but also others, including family members, who are required to provide full-time support, supervision and care. Collaboration is fundamental. Collins *et al.*[46] describes the needs of carers for patients with a primary brain tumour, recommending improved navigation between health care providers and individualised, staged information as initiatives. Importantly, collaboration involves partnership in health and improved psychosocial care delivery.

Appropriate technology

The principle of appropriate technology focuses on utilising technology in the right setting and by the right provider and in the most appropriate way to meet the needs of the community[10,11]. Poor information transfer is associated with reduced coordination of care, delays in treatments and the duplication of tests and/or investigations[28]. Chew-Graham *et al.*[47] suggest that poorly designed and activity-based funding information systems can be equally detrimental as they can reduce the opportunity for dialogue and self-management. Technology can open access to health care systems; through the use of telehealth, nurses can provide a conduit between patients and health care professionals providing increased assistance and support during the post-discharge period[20,48]. The internet can also provide a valuable source of peer support, where through networking, blogs and chat pages, patients can find and connect with others, and, in turn, build supportive communities. However, Janda *et al.*[49] identify how the significant amount of unfiltered information available on the internet can be distressing for patients and families. From a primary health care perspective, technology needs to be utilised to bridge knowledge gaps, and ensure health equity for this vulnerable population, through enabling choice and assisting with the navigation of information.

Through the use of telecommunications and post-discharge telephone support, nurses can increase assistance and support during the post-discharge period, as patients and families are often overwhelmed during the diagnostic period and have unanswered questions[20,48,50]. For patients diagnosed with a primary brain tumour this is often a lonely period, where little support is provided. Follow-up phone support systems allow for extra information to be imparted, for patients to ask questions and to check that appropriate treatment referrals have been made and acted upon.

Increased emphasis on health promotion

Health promotion involves enabling and empowering individuals to have more control over their health through informed decision making, increased health literacy, capacity building and resilience skills[14,15]. This, in turn, empowers individuals and promotes a healthy illness, as an increased understanding of a diagnosis and treatment options reduces stress and anxiety, enhances navigation of services and results in improved management of side effects and catastrophic events associated with treatment and disease progression[1,11]. Nurses are in the ideal position to lobby for strategies that will ensure improved outcomes and access to health services. Patients and families are often provided with extensive and substantive information without assessing their ability to process and understand this information. Janda *et al.*[49] suggests that patients and family members are often left unprepared for the imminent neurological changes associated with a primary brain tumour. Inadequate discharge planning and a reduced cognitive capacity of patients diagnosed with a primary brain tumour to remember information and appointments often leaves patients not knowing where to access information[37,51].

Assisting patients and family to navigate information should begin as early as possible[52,53] to ensure that patients not only make informed decisions but also to provide support through the early diagnostic stage. Whilst one can impart information rapidly, Abbott *et al.*[54] discuss that this is rarely effective due to the complex nature of health information, and interventions such as comprehensive discharge planning protocols are vital to addressing this. The provision of information needs to be complemented with home follow-up, identifying that social and environmental conditions influence health choices and are vital as patients move through the trajectory of treatment, survivorship and palliative care[21,31,55]. Strategies that have been implemented to address this issue include appointment cards and diary systems. Janda *et al.*[49] conclude that patients' and families' desire for written and verbal information often continues to be unmet due to the urgency of treatment initiation. Whilst patients are often provided with extensive and substantive information, support and/or follow-up must be provided as required to assess their ability to process and understand this information.

Public participation

Public participation is a central tenet of primary health care when medical consultations are focused on the biomedical model and a patient's agendas are often unmet[47]. Resources need to be channelled towards supporting an individual's right and duty to participate in the planning, implementation and evaluation of health care and recognising health professionals as partners rather than leaders in the decision-making process[11,16]. Understanding how participation varies throughout the trajectory of illness is essential to meeting needs[56]. Yates[29] highlights patient-held records, referral pathways and service directories as examples that enable patients to feel valued and in control; both are fundamental to empowering and engaging patients in care[28]. As public participation is fundamental to addressing the social determinants of health, geographical location, access to services and social factors including living and working conditions all need to be assessed when planning care.

Cancer care coordinators engage in educating patients and involving patients in making decisions throughout their care[43]. However, the focus on patient experiences needs to be increased for the effective identification of issues and challenges. Aston *et al.*[57] support that confidence in health choices can be established through connecting vulnerable individuals and populations with broader networks. Community events are essential to building the provider as partner role where the formal, task-orientated and restrained hospital setting is replaced with a sense of normalcy[58]. Connecting individuals from both medical and patient/family background in this setting that is free and accessible allows for respective dialogue and active listening that facilitates a community capacity, as both parties can harness the skills and coping mechanisms shared to empower others[57]. The feedback and evaluation from events such as this provides vital information as to where these services can be improved.

Limitations and recommendations

To the author's knowledge this is the first paper that critically reviews the coordination of cancer care for primary brain tumour patients from a primary health care perspective. Further research is required to develop delivery system designs, clinical information systems and organisational support to integrate the tenets of primary health care into the coordination of care. The successful initiatives provided in this framework build on existing resources and systems of care. Fundamental to success is a program that is not reliant on exorbitant funding or new and daunting practice changes, rather a successful program should build on and change the focus of existing resources and systems of care. Moving and incorporating strategies that address not only health needs but also social needs and determinates of health, where the focus is not only on health but also on the social determinants of health. Reviewing and changing systems at a broader level requires the development of more innovative and sustainable solutions, including the clear definition of roles and the support of sustainable frameworks. Given the anticipated national shortage of health care providers, now is the time for action and a reorientation of services.

Conclusion

Patients diagnosed with a primary brain tumour experience a limited period of time from diagnosis to the terminal phase of their illness. The literature supporting the coordination of cancer care for this vulnerable population is unanimous in support of improved outcomes; however, strategies for achieving this are varied in their application and success. Cancer care coordinators will always play a crucial role in coordinating care; however, nurses working in these roles also continue to face a number of difficulties in establishing and progressing these roles[59]. McMurray[13] contends that working on and within a framework that balances comprehensive and selective primary health care can prioritise care and improve patient outcomes for this vulnerable population. With the application of a primary health care framework, support systems can move away from the biomedical model where the focus is the management of primary brain tumours towards a more holistic framework of care that focuses on the management of health. Importantly in a health care system where there is competition for resources and funding, reducing the demand for acute health care services can be achieved through a primary health care framework.

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Conflicts of interest

No actual or potential financial, personal or academic conflicts of interest exist.

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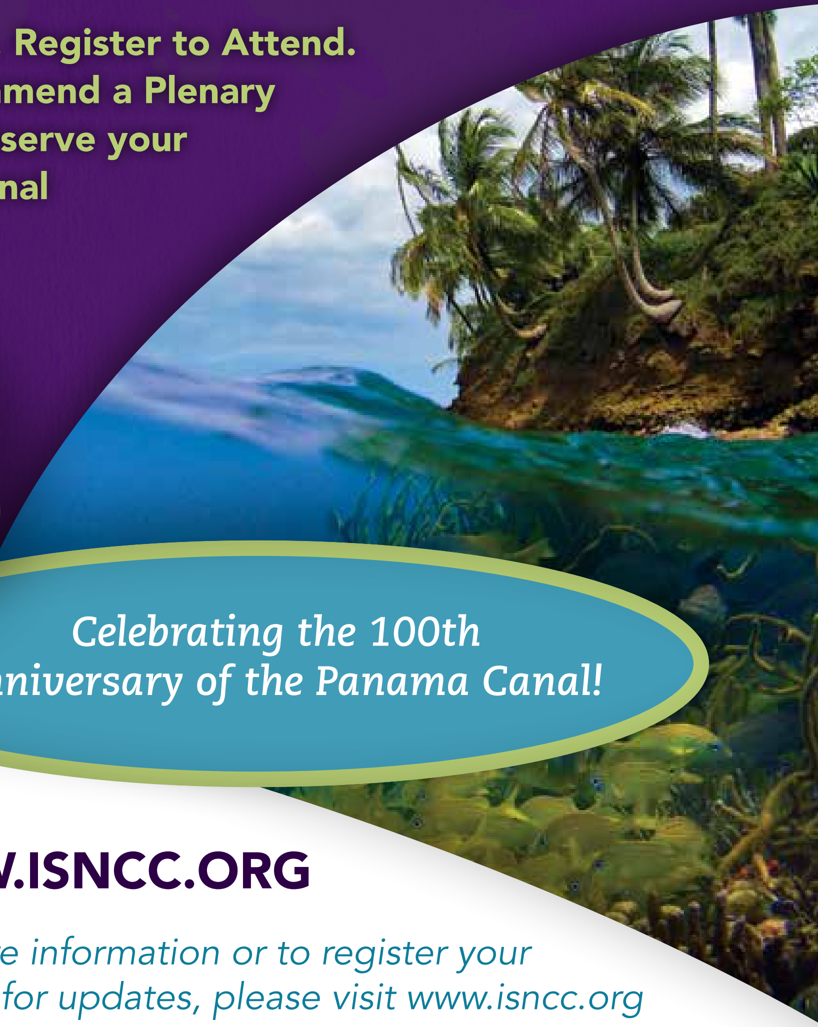

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Screening, testing and treatment of prostate cancer: a call for further research

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Abstract

Controversy exists over the benefits of screening for prostate cancer using the prostate-specific antigen (PSA) and recently the US Preventative Task Force and The Royal Australian College of General Practitioners both recommended against PSA-based screening. The National Health and Medical Research Council currently has an expert panel reviewing the evidence regarding PSA screening. Despite the recommendations of the panel, men will potentially continue to request screening because of the increased profile within the media and men's health initiatives. If diagnosed with prostate cancer, men face a complex decision as to the best treatment option. These decisions cannot be taken lightly.

Men require appropriate delivery of information regarding screening to make an informed decision to screen or not. For men diagnosed with prostate cancer, information about treatment choices needs to be easily understood and appropriate. There are many uncertainties about prostate cancer and education that men find acceptable is a key tool in assisting them to make informed decisions.

Further research needs to be undertaken with men to ensure that the available educational material is unbiased and meets their needs in relation to language, literacy, cultural sensitivity and mode of delivery. This information will then equip nurses to facilitate fruitful discussions with men to assist them during these stressful times.

Background

Prostate cancer was the most commonly reported cancer in Australia during 2008, with over 20,000 cases reported, of which 15,170 were in men aged 45–74[1]. With an increase in the prevalence of prostate cancer and a 10-year survival rate of 77%, more men are living in the community with prostate cancer[2]. Controversies exist around screening and treatment choice for prostate cancer and these controversies may exacerbate the difficult choices that men face. Information is not always easily understood or accessible by men. The internet has increased the access to material; however, choosing credible information is difficult[3].

This paper explores controversies regarding prostate cancer screening and treatment. Complex decisions are required to be made by men regarding prostate cancer; however, the information presented to them can often be interpreted as biased and difficult to understand.

Screening

There has been recent controversy and long-standing debate regarding the value of prostate-specific antigen (PSA) screening. The US Preventative Task Force has now recommended against PSA-based screening for prostate cancer[4]. This recommendation followed a review of the current literature by the US Preventative Task Force. However, it is not universally supported and has been criticised on the grounds that the review underestimated the benefits and overestimated the harms of prostate cancer screening[4].

The National Health Service Prostate Cancer Risk Management Programme in the United Kingdom has not recommended widespread screening since 2000, and in 2001 it suggested that men who are concerned about prostate cancer should decide if they want screening once they have had the benefit of information regarding both the advantages and limitations of PSA testing[5].

Within Australia, the latest recommendation from the Royal Australian College of General Practitioners is that prostate cancer screening should be a low priority and not be discussed with every eligible man because it is unclear if the advantage of screening outweighs the harms[6].

A review of the evidence relating to the effectiveness of using PSA testing for screening of prostate cancer in healthy men, commissioned by The National Health and Medical Research Council, has recently been released[7]. The key findings from the review were that there was inconsistent evidence on the effect of PSA testing with or without digital rectal examination (DRE) on prostate-specific mortality in asymptomatic men. Likewise there was no evidence to suggest an effect on all-cause mortality. The review found that the risk of metastases at diagnosis was reduced. The effect on the quality of life for men diagnosed with advanced prostate cancer through PSA testing was not identified[7].

The review also identified that the benefits and uncertainties for PSA screening needs further consideration, including whether or not routine testing for PSA may have a negative impact on men's quality of life[7]. Despite these findings, there is a likelihood that, with the increased awareness of prostate cancer, through ongoing promotion within the media and men's health initiatives such as the 'Movember' campaign, men may increasingly request screening without necessarily considering the effects.

PSA is routinely elevated in the presence of prostate cancer and in other benign prostate disorders, for example, infection, inflammation and benign prostate hyperplasia (BPH)[8]. It is also elevated following riding a bicycle and physical exercise. PSA testing has relatively high false-positive and false-negative results[5] and a poor specificity to detect prostate cancer over BPH[8]. Since the inception of PSA testing there has been an increase in screening, which has led to a concern that there is an increase in diagnosis of clinically insignificant, benign, prostate cancer[9].

There is an expectation that the advantages and limitations are discussed with men making a decision to test or not. This information, if not presented in an appropriate manner, may potentially cause further confusion for men.

Following a diagnostic procedure, often a biopsy performed through the rectum, men are faced with a difficult decision if diagnosed with prostate cancer. For localised cancer, treatment options include surgery (prostatectomy), external beam radiotherapy, brachytherapy, cryotherapy, and active surveillance without clear consensus regarding treatment value[10]. Prostatectomy, however, remains the preferred curative option[10].

Treatment

Deciding on a treatment is complex and requires considerable contemplation by the man during this stressful time. The information men receive regarding treatment options may not be completely understood by them, or applied appropriately when they make treatment choices. This is due to both the complexity of choices available and the stress men are under when deciding on treatment[11].

The recently published results of the Prostate Cancer Intervention Versus Observation Trial (PIVOT) have demonstrated that in the post-PSA testing era there is no significant difference in overall survival for prostatectomy versus watchful waiting in low-risk, localised prostate cancer over a 12-year period[12]. The PIVOT trial was a randomised control trial, comparing all-cause mortality after radical prostatectomy with watchful waiting[12].

It is of note, that watchful waiting as described in the PIVOT trial is in fact active surveillance by definition. Watchful waiting refers to palliative care for men with prostate cancer, applicable for men with multiple co-morbidities, or those not physically fit for active treatment or those who are elderly and have a life expectancy less than 10 years. Active surveillance continues to have a focus on implementing treatment only when it is required. It is designed to closely monitor the man with prostate cancer, actively treating the disease only when there is evidence of significant growth, which delays or negates potential physical complications of active treatment[11].

Active surveillance has been misinterpreted as 'doing nothing' and therefore not given the acknowledgement it deserves as a viable treatment option. This is potentially because it is often used interchangeably within the literature with the term 'watchful waiting'[1]. Despite this, active surveillance is now the recommended treatment choice for men with low-risk, localised prostate cancer[9]; however, radical prostatectomy is the first choice of men with the disease[10]. The terms 'active surveillance' and 'watchful waiting' need to be clearly separated within the literature and in discussions about treatment options, to reduce confusion amongst men with prostate cancer, clinicians and health professionals.

Adverse outcomes of treatment choices

With each treatment choice there are potential adverse outcomes. The two main adverse events after treatment for prostate cancer are sexual dysfunction and urinary incontinence[13-16]. These two adverse outcomes are common to all active treatment options and can potentially be lifelong, although there is often a reduction of symptoms over time[14,17]. Although not as prevalent, other potential adverse outcomes include urinary retention and faecal incontinence[13,14]. By undertaking an active surveillance regime, these potential adverse outcomes can be delayed or negated.

The physical complications of treatment for prostate cancer can have the potential to lead to psychological issues. Men often bottle up concerns and are not willing to discuss them with others[16], they feel they can solve problems on their own, potentially excluding their significant others within the decision[18]. This, in turn, can lead to marital stress[19] and relationship challenges[16].

While active surveillance may mitigate potential adverse outcomes through active surveillance, there are also potentially adverse outcomes. These include anxiety around living with cancer[20] and the potential of missing the opportunity to treat the cancer prior to it spreading[21]. This should be clearly explained to men when they are considering this option.

A man's personality and his willingness to live with potential adverse events could be the deciding factor in his treatment choice.

Information/education

Men face two key questions when making decisions regarding screening and treatment for prostate cancer. The first is whether they should be tested for prostate cancer. Secondly, if diagnosed with prostate cancer, they need to decide which treatment option to undertake.

The information provided to the man to make these important decisions needs to be presented in a way that is easily understood and readily available during this stressful period. Providing information to wives and partners of men may assist their decision-making process[16]. There are uncertainties that exist with the diagnosis of prostate cancer and these ambiguities need to be individually explored when making decisions[22]. A clear understanding of the potential complications is required when making these decisions, without which the difficulties and complexities will be amplified[16].

Effective education is a key to understanding the uncertainty of prostate cancer[22]. This can only be done by the provision of appropriate information in a manner acceptable to the target audience; in this case, men with or at risk of prostate cancer. These men have varying educational levels, cultural backgrounds and communication skills. Men at risk of prostate cancer and those who have faced a diagnosis, and therefore the need to make a treatment decision, are well placed to contribute to the development of information that is helpful but not overwhelming.

Conclusion

Prostate cancer is a complex area which continues to provide challenges to men and health care professionals. There are many controversies relating to screening, testing and treatment. As the most commonly reported cancer within Australia, emphasis should be placed on providing appropriate, easily understood information to men.

Further research needs to be undertaken to better assist men in making decisions regarding prostate cancer; to understand how men want information presented and the language which would assist them to come to terms with this complex issue. While there is good intent in the educational material that is currently available, is it what men want and in the language that suits their needs? To ensure an unbiased delivery of the information, research into the information needs of men should include the experiences of men who have been diagnosed and treated for prostate cancer, those at risk of developing it and health care professionals caring for these men.

Implications for nursing practice

Utilising research to provide unbiased, easily understood information for men to make informed decisions about prostate cancer should be a major focus for nurses. Nurses have a unique patient–client relationship and are often in a position to counsel men on this sensitive issue. When equipped with this information, nurses can assist men in making decisions regarding this complex, stressful issue.

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“Thank you, Zofran”

Supporting you with the convenience of Zofran Zydis wafer

Dissolves within 3 seconds on the tongue; no water is required.[1]

Zofran Zydis wafer 4 mg, 8 mg

- *Contains a sweetener and strawberry flavour.*[2]

Zofran Zydis packs and wafer not shown to scale.

Zofran® ondansetron

Before prescribing please review full Product Information available via www.aspenpharma.com.au

Zofran® Injection, Tablets, Syrup, Suppositories and Zofran Zydis Wafers (ondansetron) – Minimum Product Information. Indications: Prevention and treatment of nausea and vomiting induced by cytotoxic therapy and radiotherapy. Ondansetron (injection) is also indicated for the prevention and treatment of post-operative nausea and vomiting. **Contraindications:**Hypersensitivity to any component of the preparation; concomitant use with apomorphine. See full PI. PRECAUTIONS: Hypersensitivity reactions; dose-dependent QT interval prolongation so caution in those who have or may develop prolongation of QTc; avoid in congenital long QT syndrome; correct hypokalaemia and hypomagnesaemia prior to use; monitor those with subacute intestinal obstruction as ondansetron increases large bowel transit time; caution in patients with phenylketonuria (wafers); paediatric patients; pregnancy (Cat B1); lactation. See full PI. **Interactions:** co-administration with drugs that prolong QT interval and/or cause electrolyte abnormalities; apomorphine; potent inducers of CYP3A4 (i.e. phenytoin, carbamazepine, and rifampicin); tramadol; others (see full PI). **Adverse Effects:** Headache; sensation of warmth or flushing; constipation; xerostomia; local anal/rectal burning sensation following insertion of suppositories; asymptomatic increases in liver function tests with cisplatin; local I.V. injection site reactions; others (see full PI). **Dosage and Administration:** Use lowest effective dose. Place wafers on top of tongue where it dissolves within seconds, and is swallowed. **Emetogenic chemotherapy and radiotherapy: Adults:** 8 mg by slow I.V. injection in not less than 30 seconds, immediately before treatment or two oral doses of 8 mg each at 12 hourly intervals, the first dose given 2 hours before treatment or single 16 mg suppository, 2 hours before treatment. For prevention of delayed emesis after the first 24 hours: 8 mg oral twice daily, or 16 mg suppository rectal once daily, for up to 5 days after a course of treatment. **Children:** experience is limited. 4 years and older: Give I.V. at 5 mg/m² over 15 minutes, immediately before chemotherapy, followed by oral 4 mg twice daily for up to 5 days. Suppositories are not recommended. **Highly emetogenic chemotherapy: Adults:** 8 mg by slow I.V. injection in not less than 30 seconds, immediately before treatment. If required, higher additional I.V. doses may be given up to a maximum of 32 mg in 24 hours. **Post-operative nausea and vomiting (injection only): Adults:** give 4 mg by I.M. or slow I.V. injection. Up to 8 mg if necessary for treatment. **Children:** 2 to 12 years: slow I.V. injection at 0.1 mg/kg up to 4 mg. Hepatic impairment: Maximum total daily dose of 8 mg in moderate or severe dysfunction. See full PI. (PI last amended 24 Sept 2012). **References: 1.** TK Giri, et al. International Journal of Pharmacy and Pharmaceutical Sciences Vol 2, Suppl 3, 2010. **2.** Zofran Product Information v5 24 Sep 2012.

PBS Information: Zofran Zydis wafer. Authority required: Management of nausea and vomiting associated with radiotherapy used to treat malignancy. Restricted Benefit: management of nausea and vomiting associated with cytotoxic chemotherapy being used to treat malignancy which occurs within 48 hours of chemotherapy administration.

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