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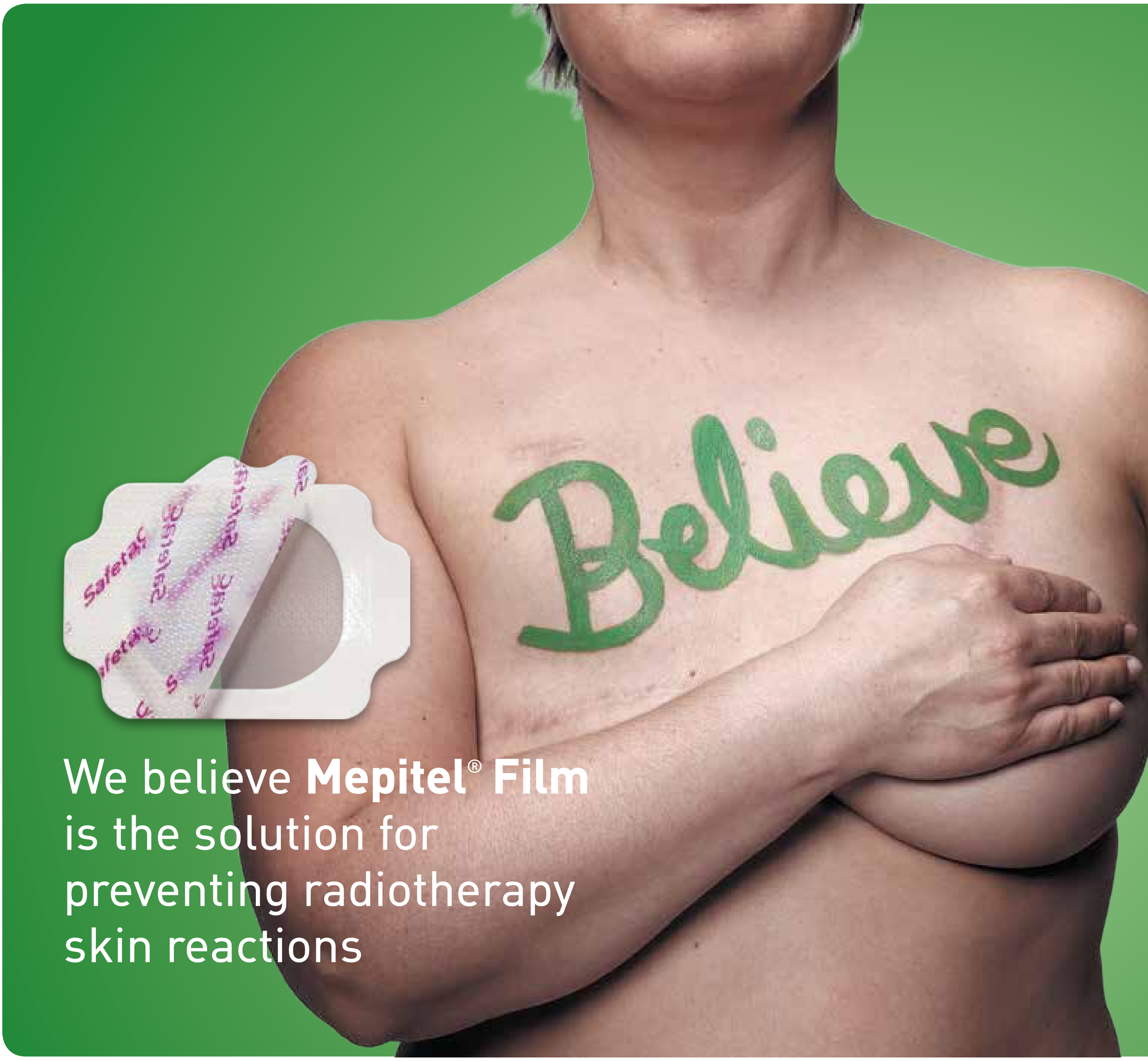
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Editorial

Professional leadership in the context of cancer nursing organisations

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Introduction

Every nurse is a leader. Rather than being situated only within a traditional leadership role or title, nursing leadership is about *critical thinking, action and advocacy* across all roles, practice settings and domains of nursing practice. When high-quality nursing leadership is enacted, positive patient, provider and system outcomes are demonstrated[1-3]. Leadership begins in undergraduate education and continues throughout one's career. Nursing leadership in this context is about looking beyond nursing as a series of scientific acts of caring that can change individual lives, to include lifelong commitment to political action for system change. It requires nurses to lift their gaze from focusing only on individuals to populations and from the local to global context[2,4,5].

More than ever, the need for nursing leadership in the cancer care environment is paramount. Across Australia and Canada, we share similar challenges. Against a backdrop of an increasing number and complexity of cancer patient and family needs, cancer nursing is facing critical challenges to optimally address these needs. Some of the most pervasive challenges include: (i) the impact of efficiency discourses on limiting nursing roles and opportunities to practise to full scope; (ii) limited specialty education and certification opportunities; and (iii) fewer resources to demonstrate the impact of nursing on patient and system outcomes through research. There are fewer formal nursing leadership positions and more reports of moral distress and burnout among all cancer nursing roles[2,6].

Professional cancer nursing organisations such as the Cancer Nurses Society of Australia (CNSA) and the Canadian Association of Nurses in Oncology (CANO/ACIO) have an important role to play in addressing these challenges. As the national voice for cancer nurses within each of our countries, CNSA and CANO/ACIO must advocate for high-quality cancer care, including articulating cancer nurses' unique role and demonstrating impact for cancer patients and within the cancer care system. As member-based organisations, it is imperative that CNSA and CANO/ACIO foster leadership capacity among its members. A high functioning elected Board of Directors (BoD), known as the National Executive Committee (NEC) within the CNSA, and various other committees who provide effective leadership to the organisation and its members is also essential.

Both CNSA and CANO/ACIO have had a long history of excellent nursing leadership within their respective BoDs and committees. Historically, senior nursing leaders have willingly and actively stepped up to be nominated and have moved these professional organisations forward. However, the changing landscape requires that we proactively build capacity in the next generation of leaders, to be active advocates for high-quality nursing services within complex and changing environments, as well as to provide leadership in formal roles within our professional organisations. In this editorial, we offer some reflections and strategies for leadership-building within our respective professional cancer nursing organisations, so that the current workforce and next generation of cancer nurses are prepared to lead change to improve the health of people at risk for/living with cancer.

A society that builds generations of professional leaders

It is extremely encouraging to learn that CANO/ACIO has embarked on a number of strategies to build capacity for nursing leadership among its members and BoD within the current strategic plan. As a foundation, CANO/ACIO articulated a Nursing Leadership position statement, believing that: a) all cancer nurses are leaders; b) leadership promotes equitably high-quality, safe and accessible care; and c) cancer care organisations, academic institutions, provincial and national professional nursing associations and individual practitioners/leaders play a fundamental role in supporting cancer nurses to develop leadership capacities[7]. This position statement sets the bar for individuals, educational, professional and health care organisations regarding leadership development of cancer nurses in Canada. The recent formalised collaboration between the CNSA and CANO/ACIO through a memorandum of understanding will enable us to explore resource sharing and joint projects in leadership capacity building.

To support cancer nurses in their leadership development, both organisations are working to identify and increase access to educational resources and workshops pertaining to leadership. Formal succession planning processes are also under consideration for BoD/NEC, local chapter/regional group, and specialist practice network (SPN)/special interest group (SIG) leaders. Our members have the opportunity to join the leadership of SPNs/SIGs to network with others in formal and informal leadership roles, or, within the CNSA, participate in a newly formed group of key opinion leaders whom the NEC relies on to inform policy influence and other advocacy strategies. Cancer nurses interested in developing their research-related leadership skills may join the research committee. A significant gap in both organisations' current strategic plans persists in relation to engaging undergraduate student or early career members, providing mentorship to the next generation of cancer nurses and in identifying "rising stars" who hold the potential to take on formal leadership roles. A focus on engagement of undergraduate students and early career nurses should be considered for future strategic plans of both organisations.

A challenge still remains as to how to encourage cancer nurses to believe they have the capacity to take on formal leadership roles within CNSA and CANO/ACIO BoDs. Often, it is through informal mentorship and encouragement to put one's name forward for nomination. Below outlines the experiences we had as we were considering whether to be nominated for the President role within our respective organisations.

> **RC:** During the CNSA Winter Congress 2013, Professor Mei Krishnasamy (CNSA Past President) and Sandy McKiernan (Incumbent President) encouraged me to be nominated for the President role as they saw the leadership within me that I had not realised. I was flattered and shocked at the same time. Although I had the experience of serving on several CNSA committees, I was feeling very inadequate in comparison with numerous past CNSA leaders with extensive experience as a director. I subsequently checked with my mentor Professor Patsy Yates (CNSA Inaugural Chair), who knew me well, whether I really had what it takes to lead a national organisation. Prof Yates's encouragement further assured me that I would have the support I required in this role. All these three leaders instilled such courage in me. If it were not for the encouragement of these three nurse leaders, I would not have considered running for presidency and now have the privilege to serve cancer nursing in this national leadership role. I am determined to pay it forward and to be a leader that instils courage and confidence to future cancer nurse leaders.
>
> **TT:** I was encouraged by a past CANO/ACIO president and long-time mentor (Esther Green) and my current mentor/supervisor (Professor Sally Thorne) to put my name forward for nomination for President. At first I had every reason NOT to do it — *I don't have the skills, the BoD needs a different kind of leader, isn't there someone else more qualified than me?, I'm too busy, I should finish my PhD first,* and so on ... But my mentors were persistent and gave me every reason why I SHOULD put my name forward — *because it was my turn to step up and contribute in this way, that it's a privilege to participate in such an important national organisation, you have an opportunity to have a voice in impacting high-quality cancer care, and that leadership skills are rapidly honed by leading within a group of supportive, collaborative leaders!* I quickly realised that the reciprocal benefit for me being involved in the CANO/ACIO BoD was by far going to outstrip everything that I put into it. I have gained additional amazing mentors, nationally and internationally, and my own leadership skills continue to develop. Most importantly, I have the satisfaction of contributing to improving cancer care through investing in the future of cancer nursing.

We must include strategies that not only build leadership skills, but also offer mentorship to continue to build confidence and capacity in the next generation of cancer nurses to step forward into formal leadership roles within our organisations.

The role for strong governance

It is critical that BoDs of nursing professional organisations continue to focus on good governance, which forms the foundation for effective strategies for the organisations to fulfil their missions. A view once commonly held was that governance of not-for-profit (NFP) organisations was generally poor compared with the for-profit sector, but there is now evidence that this is not the case. The recent Australian Institute of Company Directors' NFP Governance and Performance Study reported that 80% of NFP directors surveyed (n=1,195) believed that the quality of governance had improved compared with three years previously[8]. The calibre and experience of non-executive directors of NFP organisations has also increased; over 75% with more than four years of experience as a director, and over 40% (n=1,259) with over 10 years of experience[8].

For our organisations to further enhance our impact, we must prepare future leaders with an understanding of high-quality governance. For the reason of succession planning, training opportunities on governance should not be limited to board members, but also those who are serving on or leading various committees. Governance structures of both organisations should also be regularly reviewed to ensure that they optimally align with their mission, vision and goals.

The role of nursing scholarship

Mentors and leaders in nursing academia are often under-utilised in moving the leadership agenda forward within professional organisations. In Australia and Canada, we are fortunate to have many outstanding cancer nurse academics who are contributing to the science of cancer nursing as well as educating the next generation of cancer nurses. While there are many examples of practice–research/education collaborations within our two countries, there is much room and opportunity for growth.

We have been working for almost two decades to narrow the practice–research gap. However, some wonder if we have "overshot" and unknowingly widened this gap by creating distance between clinicians and researchers. Walley and colleagues suggest we may need to revisit putting *practice* back into *evidence* — generating evidence that is embedded in practice[9]. Cancer nursing professional organisations can play an important role in purposefully bringing together academics, researchers, clinicians and educators to work more closely together to advance cancer nursing practice, promote nurses' opportunities to practise to their full scope, create systems of care that optimally align cancer nurses with patient needs and demonstrating impacts on patient/family, care provider and system outcomes. Evidence generated in practice can then be used to influence policy affecting patients and families affected by cancer.

Closer collaborations between academics and researchers may further build bridges to opportunities for developing a future cancer nursing workforce and influencing high-quality nursing care. Although most undergraduate nursing programs produce generalist nurses, there may be strategies to begin to influence academic programs to integrate cancer curricula, given the high prevalence of cancer in both countries. Graduate programs could be influenced to develop specialty training for advanced practice roles and/or cancer nurse researchers. Mentorship programs between researchers and/or clinicians and students could offer a solid strategy to build capacity and passion for cancer nursing practice and research.

The role of influencing policy

Engagement with policy makers (for example, ministers of health, research funding bodies, national cancer control organisations, health services boards) is also a critical nursing leadership strategy to influence the health of people at risk for/living with cancer. Professional cancer nursing organisations must aim to influence policy through advocacy strategies and positioning key cancer nursing leaders on boards, decision-making groups and key leadership positions. It is also important to look beyond cancer and health silos, to include influence across social, economic, and environmental domains. The cancer care system can only be transformed to achieve high-quality care for *all*, when we influence policy to consider the social determinants of health at the individual and population levels.

Summary

In this editorial, we have depicted the importance of strong governance, nursing scholarship and influencing policy in the context of our professional organisations. Both the CNSA and CANO/ACIO are committed to ensuring that we will continue to build future generations of cancer nurse leaders. Every nurse is a leader. We invite you to ponder your role in contributing to professional leadership through your professional organisations.

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Understanding and managing symptom effects of cerebral oedema in high-grade glioma patients: a review of the literature

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Abstract

High-grade glioma (HGG) is a primary brain tumour which is associated with a high mortality rate. An HGG diagnosis is an overwhelming experience for patients and their families, with patients suffering from a range of symptoms associated with disease progression and treatment resulting in poor outcomes and quality of life. For the neuro-oncology nurse, it is difficult to deliver comprehensive health care to this patient group. A search of the literature was conducted for the years 2004 through September 2015. Based on predefined criteria, 16 records were retrieved for review with a major focus on symptoms and treatment of cerebral oedema. The findings were grouped based on emerging categories relating to treatment and management of cerebral oedema, quality of life, functionality and psychological health and nursing assessment and interventions. This article aims to provide health care professionals with a better understanding of the symptom management and effects of cerebral oedema in HGG patients.

Introduction

A malignant brain tumour diagnosis can be devastating and difficult to comprehend for both patients and their families. The most commonly diagnosed brain tumours in adults are gliomas, which make up around 40% of all primary brain tumours[1]. Gliomas are aggressive in nature and can occur in any area of the central nervous system, but primarily arise from the glial cells that surround and support the neurons of the brain[2]. The glial cells are thought to give the neurons the support required to perform functions such as thought processes, sensation, muscle control and coordination[2,3]. Gliomas are classified as being typically malignant and are graded I–IV, as defined by the World Health Organization's (WHO) system based on cellular characteristics[3,4]. Gliomas are categorised into three histologic types: astrocytoma (grade I–IV); oligodendrocytoma (grades II–III); and oligodendrogliomas, a mix of these two cell types (grades II–III)[5]. Grade III and IV astrocytomas are commonly recognised within the literature as being high-grade gliomas (HGG) and affect approximately 75% of all patients diagnosed with glioma brain tumours. HGG patients are predominately male (M 1.6 v F 1.0)[6] and aged between 40 and 60 years of age at diagnosis[2,7]. HGG are referred to as anaplastic astrocytoma (grade III) or glioblastoma multiforme (GBM) (grade IV), with GBM being the most aggressive form of all brain tumours[2,4]. HGG cells have a predisposition for rapid and constant infiltration of surrounding healthy brain tissue and, when biopsied, numerous blood vessels and necrotic cells are seen towards the centre of the tumour[1,8,9]. HGG are generally located in the cerebral hemispheres of the brain but can be found anywhere within the central nervous system[1,2]. When the tumour growth crosses the midline of the brain, is greater than 5 cm in diameter and neurological deficits are present, the patient's overall prognosis is poor[10].

Brain tumours are the key cause of neurological symptoms and complaints in all cancer patients[2]. Consequently, they can result in major morbidity, a loss in the patient's overall functioning and a decreased quality of life (QoL) and life expectancy[11]. Prior to 2005, the only treatment available for HGG was maximal surgical resection with radiotherapy[12]. Currently, HGG patients are given Temozolomide chemotherapy concurrently with radiotherapy following maximal surgical resection. A further six months' chemotherapy treatment then follows, adding to the patient's survival rate[12]. Presently the median survival from diagnosis for patients with HGG is only 15 months[13,14]. For many patients diagnosed with HGG, their long-term survival remains elusive and focus is given to symptom management and QoL, over the prolongation of life[15].

As the number of patients diagnosed with HGG grows, the management and complications of cerebral oedema as a side effect are often under-reported in the literature. These side effects represent an important source of morbidity for patients with a diagnosis of HGG and it is important to understand how to manage these effects within this patient population. By doing this, health care professionals can improve medical care and outcomes for this vulnerable group and ultimately improve their QoL. This review of the literature aims to identify the effects and management of cerebral oedema in patients diagnosed with HGG as well as identify any gaps in current understandings.

Method

A primary search of the literature was conducted in Pubmed, Cochrane databases, Proquest and CINAHL for the years 2004 through to September 2015 using the keywords and combinations 'high-grade glioma, glioblastoma multiforme, GBM, anaplastic astrocytoma, symptom management, treatment, cerebral oedema, corticosteroids, cancer rehabilitation and nursing assessment' to yield the search results. This search initially generated 1964 citations. A further search strategy was applied and papers were included if they met the following criteria: Australian and international articles expanding from the United Kingdom, New Zealand, America and Europe; adults (aged >18 years); and patients who were located across all health care settings. A total of 54 records were retrieved with major focus pertaining to the symptoms and treatment of cerebral oedema in glioma patients. Following a review of these articles and their abstracts, paediatric studies and duplicate papers were excluded. Consequently, 16 articles were selected for review. These included randomised controlled trials, retrospective chart reviews, systematic reviews, meta-data analysis, correlational descriptive studies, exploratory studies and cross-sectional surveys. The findings from these papers were grouped into three categories:

- Symptoms and management of cerebral oedema
- Functionality, psychological health and QoL
- Nursing assessment and interventions

The discussion of the literature is presented under these categories.

Symptoms and management of cerebral oedema

Patients diagnosed with HGG will experience and suffer from a variety of symptoms resulting from surgical resection, radiotherapy and chemotherapy. However, cerebral oedema remains one of the biggest challenges in treating the neuro-oncology patient[16]. Side effects experienced by many patients with brain tumours are identified within the literature as being related to an increase in intracranial pressure. This includes symptoms such as headache, seizures and cognitive and focal deficits[17]. Any rise of pressure within the cranial vault can result in the clinical presentation of headache. However, brain tumour headache has been studied in work produced by Eadie[18], who draws on germinal studies from Kunkle *et al.*[19] to explain brain tumour headache. She describes their theory of headache as being related to localised traction on pain-sensitive intracranial structures, such as the large venous arteries and veins, sinuses and cranial nerves. Headache is a very common symptom associated with the diagnosis of brain tumours, with up to 53% of patients diagnosed with brain tumours likely to experience headache[20]. Approximately 77% of these headaches are described as tension headaches. Lovely[20] relates the tumour location to the headache type but states that tumour-related headache is rarely persistent after patients are diagnosed and treatment begins. She highlights the need for palliative measures to be taken if headache becomes a persistent symptom. It is evident that patients diagnosed with HGG are commonly prescribed steroids to aid in the reduction of cerebral oedema[21]. Once steroids are prescribed, patients experiencing headaches are generally managed and relieved due to a reduction in pressure on the brain[22].

Corticosteroids

Dexamethasone is the most common of corticosteroids prescribed to aid in the relief of cerebral oedema and the reduction of neurological deficits associated with brain tumours. Dexamethasone remains the drug of choice for prescribers due to its ability to improve symptoms within a short period and its noted mineralocorticoid activity and long half-life[22]. However, it is argued that while steroids are a medication prescribed to aid in the reduction of symptoms related to cerebral oedema, they can often affect the patient due to associated side effects. A retrospective chart review conducted by Sturdza *et al.*[23] shows that of 88 patients with brain tumours receiving radiotherapy, 52% experienced side effects such as an increased appetite, increased blood sugar levels, proximal muscles weakness and insomnia when receiving a corticosteroid protocol of up to 16 mg per day. Furthermore, qualitative research by Sturdza *et al.*[23] shows that those patients who were prescribed doses up to 16 mg per day experienced and described side effects to the prescriber at follow-up appointments. These adverse effects were described as an increased appetite and weight gain, insomnia and gastrointestinal symptoms such as nausea and vomiting. Studies by Hempen *et al.*[24] and Ryan *et al.*[25] similarly discuss the use of dexamethasone in aiding in the reduction of cerebral oedema. However, they emphasise that while corticosteroids initially led to impressive clinical improvements, following treatment, patients were left with a reduction in symptom relief and a rise in toxicity, which could ultimately result in steroid myopathy.

Evidence presented by Kellog *et al.*[26] supports this by stating that patients who have received a high-dose regime of corticosteroids to treat symptoms of cerebral oedema are likely to experience side effects related to corticosteroid use. They describe the cessation of corticosteroid therapy as being the central goal of care for HGG patients so that further complications can be eliminated. Kellog *et al.*[26] continue to state that while attention should be given by health professionals into the tapering of corticosteroids, the side effects should also be highly considered as they are common, can cause morbidity if left untreated and are often masked by the symptoms of cerebral oedema[25,27]. Though corticosteroids and their use in relieving cerebral oedema and headaches are explored within the literature, drugs such as opioids, gabapentin and topiramate have been used alternatively with similar effects to corticosteroids[21,28]. However, upon investigation, there is little quantifiable evidence to demonstrate this. Along with headache, seizure is a major complaint and cause of morbidity, with up to 30% of HGG patients suffering from seizure-related activity during their illness[29].

Seizures

Cerebral oedema adds to the overall mass of the tumour, resulting in an increase in intracranial pressure and reduction in local blood flow, leading to a disruption in the tissue homeostasis of the brain[30]. It is this mass that acts as an irritant to the tissues of the brain, resulting in the occurrence of abnormal electrical discharges and it is these discharges that produce seizures[20]. While there are many different forms of seizures, the most commonly occurring are simple focal seizures, complete partial seizures and tonic-clonic seizures[31,32]. Seizures are one of the main presenting features in 30–90% of brain tumour patients, in particular HGG patients. This is due to the glioma cells' growth and rapid infiltration of the brain tissue causing an irritant response[33]. For patients experiencing seizures, and their families/caregivers witnessing, these seizures can be very distressing for all.

On diagnosis, first-time seizure HGG patients are generally prescribed long-term antiepileptic drugs to reduce the risk of recurrence[29]. Seizure management is well covered in the literature showing there are a large range of antiepileptic drugs that have various mechanisms of action to suit the HGG patient. Drugs such as sodium valproate and phenytoin act at the sodium receptor sites within the brain while other drugs such as gabapentin, benzodiazepines and phenobarbital activate with gabapentin synthesis[29].

However, one significant problem that is noted with the use of antiepileptics is the large numbers of medication interactions that can occur[29]. Along with medication interactions, compliance is an important aspect to seizure control in HGG patients and often symptoms of medications associated with seizure control can cause the side effect of fatigue, which can result in patients forgetting their medications[20,34]. Lovely[20] argues that the side effects related to antiepileptics can lead to patients refusing the drugs altogether, which as a result can lead to poor patient outcomes and QoL due to minimal or no seizure control. Although much has been written on the prescribing of antiepileptic medications, there is little guidance written for nurses caring for brain tumour patients and the associated emotional and mental effects seizure symptoms can carry.

Functionality, psychological health and QoL

Patients with HGG often experience ongoing deficits, which affect their overall functioning, psychological health and QoL. These deficits arise from the changes caused by the brain tumour and its treatment[35]. Focal deficits are impairments that change the patient's ability to function and perform everyday tasks to one's normal ability. Supratentorial deficits (lobes of the cerebrum) are the most commonly reported deficits with changes in cognition, in particular memory and the ability to learn new tasks, occurring. Further supratentorial deficits may include motor weaknesses, visual-spatial disorders, sensory deficits, speech, hearing, smell and vision deficits. Infratentorial deficits (the brainstem and cerebellum) include difficulties with balance, swallowing, coordination, hearing and speech[36]. Fox *et al.*[37] present data from a correlational study of a survey of 73 adult patients diagnosed with HGG. This study aimed to identify symptom clusters in HGG patients by conducting a once-off survey using seven brief measures and scales for patients to be assessed against. The evidence presented showed that patients diagnosed with HGG report symptoms of depression, fatigue, pain, sleep disturbances and cognitive deficits. Fox *et al.*[37] highlight that participants significantly correlated the above symptoms with their QoL; however, headache was identified as the main source of pain and correlated with the patients' overall functionality but did not relate to QoL.

Psychological health

Studies by Mainio *et al.*[38] and Pelletier *et al.*[39] present similar findings and advise that depression is the main predictor of QoL of HGG patients, suggesting that patients who are diagnosed with depression during their HGG journey are more likely to have a decline in health status, resulting in a decreased life expectancy. While Fox *et al.*[37], Mainio *et al.*[38] and Pelletier *et al.*[39] all discuss the effects of HGG on patient functioning, they do not identify the importance that the diagnosis places on the patient's family and caregivers. There is strong evidence by Bell *et al.*[35] and Levin *et al.*[36] suggesting that patients who have focal deficits related to their diagnosis affecting their functionality were more likely to suffer psychologically and have a decreased QoL. While medication is the primary management for symptom clusters in brain tumour patients, other therapies such as rehabilitation are used to aid in symptom relief and management.

Functionality and QoL

Cancer rehabilitation is used to help maximise a patient's ability to function with independence and adapt to their illness with the focus of care being on improving QoL, no matter how long or short the time period[34,40]. Recommendations from mixed-level range of evidence rehabilitation studies suggest that all patients diagnosed with and undergoing cancer therapies should have access to rehabilitation services to improve QoL[41]. Marciniak *et al.*[42] suggest that cancer rehabilitation outcomes for patients with brain tumours have been shown to be effective in generating substantial functional improvements, reducing hospital admissions and improving QoL. This is highlighted by McCartney *et al.*[34] and Cramp and Daniel[43], who discuss the effectiveness of nutritional support, treatment of pain, fatigue and sleep programs, psychological input and exercise programs to help build strength and the ability to perform everyday activities, assisting the patient to retain some functionality throughout their illness. While cancer rehabilitation is an effective tool in improving the QoL of brain tumour patients, it is argued that the accessibility to services limits the effectiveness of this therapy. McCartney *et al.*[34] write that patients in rural and remote areas suffer barriers related to access in services and patients who have access are often 'missed' due to the high demand for one service, such as physiotherapy, who care for a large range of patient needs.

The needs of the HGG patient and their family are unique and change throughout the entire course of their illness experience. Davis and Stoiber[44] discuss the need for effective communication to be given to the patient and their family to aid in coping with symptoms which can be extremely difficult to deal with, such as personality changes, memory loss, hallucinations and even violent behaviour. While medications can be given to help combat these symptoms, many people witnessing these behaviours find it difficult to cope, especially if they have not been informed about the possibility of these behaviours occurring. Davis and Stobier[44] draw on literature to argue that families who are poorly informed regarding symptoms and treatments are more likely to struggle during and following disease progression. They highlight the significance of nurses assisting in the patient continuing 'normal' life by working with the family in managing medications, social work and psychiatry needs by making the appropriate referrals to members of the multidisciplinary team. It is vital that each patient's symptoms and illness are treated as individual as specific areas of the brain cause unique deficits for each patient, resulting in very specific needs being met.

Nursing assessment and interventions

Throughout the literature, the nurse's role in caring for the HGG patient is made evident by many of the papers reviewed. Nurses are regarded as an influential part of the multidisciplinary team, forming one of the strongest supporters for patients on their HGG journey[44]. As part of the supportive role, nurses face many challenges when caring for the HGG patient and this has been highlighted throughout all articles reviewed. However, there is minimal evidence and research conducted in relation to strategies that nurses can undertake to relieve the pressures and challenges that the HGG patient may face during their diagnosis, treatment stages, disease progression and eventual death.

It is difficult for nurses, even those trained within the oncology field, to distinguish between the symptoms of disease progression, treatment side effects and those of steroid toxicity, as the symptoms are closely described[45]. A retrospective study by Ryan *et al.*[25] specified that of 59 participants, 51% described one or more steroid-related symptom. Of these 51%, 19% required hospitalisation for "steroid-related complications". Ryan *et al.*[25] discuss the incidence of steroid toxicity occurring in patients with brain metastases receiving up to 16 mg of dexamethasone per day while undergoing radiotherapy. Of 88 patients, 91% complained of at least one associated side effect of steroid toxicity. While these studies show a high incidence of steroid toxicities in neuro-oncology patients receiving corticosteroids, they do not factor in low-dose corticosteroid regimes or the nurse's role in caring for these patients. From this review of the literature it is clear that nurses need to educate their patients, but also themselves about the symptoms associated with treatments such as corticosteroids. This includes how to best manage, understand and treat them.

Health care accessibility

Ensuring that patient care is individualised is an essential part of caring for the HGG patient. Nichols[46] describes the importance of individualised care to be given to HGG patients, stating that due to the majority of patients diagnosed given less than 14 months to live, patient care and requirements need to be comprehensive, seamless and individual, involving all members of the multidisciplinary team collaborating as one to ensure the best outcomes for patients. Nichols[46] also discusses the importance of making health care accessible for all patients and by involving all members of the family in the care giving of the patient. Schulmeister and Gobel[47] discuss symptom management issues within oncology nursing by highlighting that nurses' assessment skills tend to focus on managing one symptom at a time rather than by using a holistic approach, reducing the comprehensiveness of the nursing process. They discuss the use of multidimensional tools in improving nursing awareness for the needs of the individual patient.

Symptoms experienced by patients require a holistic approach to care and Schulmeister and Gobel[47] state nurses who show an understanding of symptom management improve clinical outcomes for their patients. This is further highlighted by Lovely[20], who states that the nurse plays the critical role within the multidisciplinary team by performing baseline assessment of the brain tumour patient and by also setting up a plan for patient care to involve input from the patient and their family. She also writes that constant revaluation and plan revision is required throughout the entire length of illness to focus on changing patient function and needs, while emphasising that patients with HGG reach a vital point in their cancer journey where further treatment through surgical resection, chemotherapy and radiotherapy become futile and the focus of care turns to symptom management and end-of-life care[20]. Lovely[20] highlights the importance of holistic and focused, individualised care within neuro-oncology, making it a substantial piece of work in relation to the nursing management and understanding of the HGG patient.

Table 1: Summary of literature included in the review

Study	Aims	Study design/ methods	Sample/setting	Key findings
Kunkle *et al.* (1940)	To define the quality and intensity of brain tumour headache. To ascertain in how many cases the occurrence and location of the headache could be explained and to outline the common mechanisms of brain tumour headache. To define when headache might be expected to have value in diagnosis and localisation of brain tumour.	Correlational design.	Analysis of 72 patients with location and size of tumour established at time of operation or autopsy.	Patients diagnosed with glioma presented with headache as a first symptom in one-half of participants due to the speed of growth and the likelihood of occlusion occurring in the lateral, third, and fourth ventricles.
Lovely (2004)	To observe the symptoms frequently observed in brain tumour patients, focusing on the descriptions, causes, treatments and nursing implications.	Literature review.	Research and review articles and textbooks pertaining to symptoms frequently observed in brain tumour patients.	Patients with brain tumours commonly have symptoms caused by the tumour or treatment. Treatment approaches for these symptoms will help the patient cope with those impairments caused by the symptoms.
Sizoo *et al.* (2010)	To explore specific problems and needs experienced in the end-of-life phase of patients with HGG.	Retrospective chart review.	Fifty-five patients who received treatment in an outpatient clinic and died between January 2005 and August 2008 were selected.	HGG patients, unlike the general cancer population, have specific symptoms in the end-of-life phase.
Sturdaz *et al.* (2008)	To document the use of steroids and frequency of their side effects in patients with brain tumours.	Survey/retrospective chart review.	A survey of oncologists was conducted to document steroid prescribing practice. A retrospective chart review of 88 patients treated with whole brain radiotherapy was conducted for a 6-month period to document doses prescribed, tapering schedules, and side effects.	There are considerable variations in the prescribing practices within a single institution, with many patients receiving high doses of steroids for considerable periods of time and developing related side effects.
Hempen *et al.* (2002)	To analyse dosage and duration of dexamethasone intake and to compare the advantages and disadvantages of this medication during the course of radiation therapy.	Retrospective study.	Data from 138 consecutive patients was analysed.	Dexamethasone was found to effectively minimise neurological symptoms and radiotherapy-related side effects in patients with primary and secondary brain tumours; however, the side effects of dexamethasone were found to increase over time.
Kellog *et al.* (2013)	To determine the survival and complications associated with treatment of cerebral tumours with surgical resection followed by stereotactic radiosurgery.	Retrospective study	Fifty-nine consecutive patient charts were reviewed to ascertain overall survival, local control, surgical complications, Stereotactic radiosurgery complications, and corticosteroid complications.	Complications associated with this patient population are low.
McCartney, Butler & Acreman (2011)	To investigate the experiences of rehabilitation for brain tumour patients.	Exploratory study.	Semi-structured interviews of three focus groups consisting of health care professionals.	The barriers to accessing rehabilitation for this group of patients are complex, but some of the solutions could be reached through education and coordination of services.
Bell *et al.* (1998)	To assist physiatrists and other rehabilitation personnel serving this population by reviewing the pathophysiology and treatment effects of patients living with brain tumours.	Literature review.	Critical review of literature pertaining to functional impairments and rehabilitation interventions of brain tumour patients.	Cancer patients can benefit significantly from rehabilitation intervention in regards to symptom management from treatments.
Fox *et al.* (2007)	To describe co-occurring symptoms such as depression, fatigue, pain, sleep disturbance, and cognitive impairment, QoL and functional status in patients with high-grade glioma.	Correlational, descriptive study.	Seventy-three patients diagnosed with high-grade glioma in the United States.	The differences in the models of QoL and functional status indicates that symptom clusters may have unique characteristics in patients with high-grade gliomas.
Mainio *et al.* (2005)	To determine the association of depression with survival of patients with a primary brain tumour.	Qualitative/descriptive study.	Seventy-five patients with a solitary brain tumour who underwent surgical resection.	Preoperative depression seemed to be a significant prognostic factor for worse survival in glioma patients.

Study	Aims	Study design/ methods	Sample/setting	Key findings
Pelletier *et al.* (2002)	To document the prevalence of depression, fatigue, emotional distress, and existential issues in brain tumour patients. To examine the interconnectedness of these problems, and to explore their relationship with disease-related variables and QoL.	Cross-sectional, question-based survey.	Seventy-three patients with primary brain tumours who presented to a neurological clinic at a tertiary cancer centre for ongoing care.	The presence of depressive symptoms was the single most important independent predictor of QoL in this cohort of brain tumour patients.
Marciniak *et al.* (2001)	To assess the extent of functional gains measured before and after inpatient rehabilitation in patients who have primary or metastatic brain tumours, and to identify whether the tumour type, recurrent tumour, or ongoing radiation influences outcomes.	Retrospective, descriptive study.	A referred sample of 132 persons, all with functional impairments from a brain tumour and discharged from inpatient rehabilitation during a three-year time period.	Metastatic or primary brain tumour type does not affect the efficiency of functional improvements during inpatient rehabilitation. Patients receiving concurrent radiation therapy make greater functional improvement per day than those not receiving radiation.
Cramp & Daniel (2008)	To evaluate the effect of exercise on cancer-related fatigue both during and after cancer treatment.	Systematic review and meta-analysis.	Where data was available, meta-analyses were performed for fatigue using a random-effects model.	Exercise can be regarded as beneficial for individuals with cancer-related fatigue during and post cancer therapy.
Pilkey & Daeninck (2008)	To qualify and quantify corticosteroid use within palliative care.	Retrospective chart analysis.	Sixty-five patient charts were reviewed, looking at the effects of corticosteroid prescription in palliative neuro-oncology patients.	The use of corticosteroids to assist in side effects were appropriately prescribed by physicians in relation to published guidelines with respect to dosing, tapering and prophylaxis.
Ryan *et al.* (2011)	To explore corticosteroid-related toxicity in patients with primary and secondary brain tumour.	Retrospective, descriptive study.	Eighty-eight patients with brain tumours were surveyed.	A high incidence of steroid toxicity occurs in neuro-oncology patients receiving high-dose corticosteroid regimes; however, more work is required in relation to low-dose corticosteroid regimes and their effects on patients with brain tumours.
Nichols (2014)	To examine how primary health care can be applied to the neuro-oncology setting and the implications for practice.	Critical literature review.	Search of databases 2000–2013, selecting articles pertaining to primary health care and the coordination of cancer care, particularly brain tumours.	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.

Family impact

The definition ‘patient care’ is not just limited to the patient itself; it also involves the care of family and friends of the HGG patient[48]. Serious illnesses are exceptional events that affect the life of not just the person who is suffering the illness, but the entire family unit[49]. A number of articles reviewed emphasise the importance of family involvement in patient care but very few discuss the burden family members face with a HGG diagnosis. Van Horn and Kautz[50] write that in many cases, members within the family are burdened more with the patient's illness, which, over time, results in feelings of shock, anxiety, guilt and often fear. They describe the illness experience of one family member affecting the whole family unit because every individual health experience is closely interwoven. While Van Horn and Kautz[50] discuss the negative impacts that affect the family unit, they do not describe the role of the nurse in supporting the family. Mattila *et al.*[49] describe the use of supportive methods used by nursing staff in their interactions with cancer patients and their family members by using a qualitative questionnaire approach. This study focused not only on emotional support but informational support, which backs the application of further nursing assessment and education to neuro-oncology nurses to ensure consistent care is given to HGG patients.

Recommendations for future research

This review emphasises the importance of the ongoing education for neuro-oncology nurses to better understand the symptom management of cerebral oedema in HGG patients. It also indicates that further evidence is required surrounding the treatment of HGG patients with corticosteroids in relation to the benefit versus the side effects of corticosteroid use. Prospective studies reviewed reported higher incidences of steroid toxicity-related side effects than those which were retrospective in nature, but this is difficult to determine due to the insufficient number of retrospective studies reviewed surrounding steroid toxicity. Barriers to the accessibility of cancer rehabilitation services were highlighted; however, these were generalisations which require further investigations to provide further insight for health professionals caring for the neuro-oncology patient. Due to the progressive nature of HGG, and with patients given a median survival of 15 months following treatment[13,14], many of the answers given by patients in retrospective reviews may have been influenced by cognitive deficits which are often displayed in the HGG patient. For these reasons above and the median survival rate, further research is required to help understand the symptoms and management of cerebral oedema in HGG patients.

Conclusion

HGG such as anaplastic astrocytoma (grade III) and glioblastoma multiforme (grade IV) are aggressive and malignant brain tumours which affect all areas of patients' lives from the day of diagnosis, until the day of death. The care of these patients requires a holistic and individualised approach and the priority is an empathetic and compassionate approach given by the neuro-oncology nurse. As nurses, it is important that patients with HGG do not feel the stigma that can be associated with brain tumours. When patients present with neurological deficits and symptoms of tumour such as seizures and headaches, they can often feel a prejudice against them due to the abnormal effects that tumour growth can have on their body[34]. It is important for nurses in our role to provide support to these patients to improve their functionality, psychological health and overall QoL by using a variety of therapies. By better understanding the pathophysiology, symptoms and treatments of cerebral oedema in HGG patients, nurses can improve the symptom management and assist in improving the functionality and QoL for this vulnerable group of patients and their families.

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Using distress screening assessments to improve quality care

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Abstract

Introduction

Alleviating distress experienced by patients with a diagnosis of cancer is important. Distress screening and targeting interventions aimed at the cause of distress improves quality of life for cancer patients. Distress screening was introduced to the ambulatory treatment centre in 2015 at initial education and when a change of treatment was implemented.

Objectives

To improve understanding of nurse-led interventions that may assist patients following distress screening as a quality project.

Methodology

A literature review was conducted examining resources published between 2010 and 2015.

Results

The review revealed a range of successful, nurse-led interventions and revealed some potential barriers to effective screening.

Conclusion

Developing and implementing a clinical management pathway to assist nurses in responding effectively to distress screening is needed. Continuing education to inform nurse-led interventions can also support effective integration of distress screening into clinical practice. Additionally, improving the consistency of use of the distress screening tool allows evaluation of the effectiveness of nurse-led interventions.

Introduction

The importance of easing distress experienced by patients and their families as they confront a diagnosis of cancer has emerged as a significant theme in cancer care. Distress is defined as "A multifactorial, unpleasant, emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common, normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation and existential and spiritual crisis" by the National Comprehensive Cancer Network (NCCN), as quoted by Schilli[1]. Brown[2] identifies that distress can occur anywhere along the cancer trajectory from diagnosis to treatment and beyond into post-treatment survivorship, making it a critical consideration in caring for cancer patients and their families.

In recent years, distress screening has been internationally identified as a critical "6th vital sign" in caring for cancer patients as cited by Bultz[3], Fitch[4] and Howell[5]. Recent research described by Fitch[4], Carlson[6], Estes[7] and Smith[8] indicates treating distress significantly improves individual quality of life, treatment compliance and survival rates, while also reducing unplanned hospitalisations. Estes[7] describes screening as an evidence-based approach to assessing for psychological distress in patients in addition to the need for intervention. The authors further emphasise that screening underpins the values of cancer care and indicate that in the United States it is now a requirement for agencies requiring accreditation from the American College of Surgeons.

As evidence mounts indicating that recognising and treating distress was critical in caring for cancer patients, the Day Treatment Centre (DTC) at Calvary Mater Newcastle introduced distress screening in 2015. Screening was included for all education appointments for new chemotherapy patients and to appointments where patients received a change of treatment protocol. Nursing staff were introduced to the screening tool at a staff meeting, asked to have patients complete the document and, on completion, to file the tool in the patient notes.

Aim

The primary aim of this literature review is to improve understanding of nurse-led interventions that may assist patients following distress screening as a quality project for the DTC. At the crux of this is the knowledge that completing a screening tool is only useful if it is acted upon rather than there being no actioning of the document by health care providers, as identified by Fitch[4] and Howell[5].

Secondarily, aiming to identify patient, resource and nursing skill or knowledge-based barriers to the successful implementation of effective distress screening was recognised as a helpful goal in this review.

Methods

A review of existing knowledge surrounding distress and how to effectively conduct screening was undertaken. This was completed by means of a literature review using articles dated from 2010 to 2015 and sourced from the PubMed, Ovid, ProQuest and CINAHL search engines. Keywords entered into the search engine were "distress screening", "nursing interventions" and "barriers". This resulted in 24 articles being reviewed, with 17 identified as suitable for the purposes of this study.

Results

Nursing interventions

Nurses' close and, at times, lengthy interactions with patients and their families result in them being in an excellent position to conduct a thorough screening process. Key to providing effective distress screening is the use of a valid tool and appropriate follow-up actions using an evidence-based approach, as recommended by Blais[9]. Implementing the appropriate follow-up action is critical in this process as if the correct treatment for distress is not offered then the screening process becomes ineffective.

A number of nursing interventions were found in the literature and were grouped into eight categories, as follows:

- Conducting a thorough assessment of root causes of distress
- Appropriate referrals based on the source of distress
- Implementing effective symptom management
- Education regarding treatment, side effects and self-care at home
- Management of psychological symptoms
- Developing a therapeutic relationship using strong communication skills
- Advocacy for the patient's care and wishes
- Acknowledging distress is normal!

Conducting a thorough assessment of root causes of distress

Pivotal to effective screening for distress and its subsequent management is the thorough assessment of identified root causes. Tavernier[10] discusses that referring patients to services or implementing care must be based on the specific cause of distress rather than on only the distress itself, so that interventions target the cause rather than just providing a "band aid approach". Howell[5] supports this, identifying that purely acknowledging and addressing the severity of distress alone does not explain the reason for it and, importantly, screening does not lead to a specific course of action to address distress. Consequently, once distress is reported in the screening process, the nurse must conduct a more detailed and thoughtful assessment of issues raised in the physical, psychological, spiritual, socio-economic or social areas before implementing strategies to address concerns.

Appropriate referrals based on the source of distress

Once the cause of distress is identified, consideration needs to be given as to what level of intervention is required. If immediate nursing interventions are not appropriate, referral on to other services may be needed. Tavernier[10] discusses referring patients to psychology services for anxiety when nurse-led interventions such as relaxation and mindfulness are ineffective or deemed inappropriate. Both Estes[7] and Blais[9] support referrals for counselling as well when patients are reporting distress as a result of trying to come to terms with their diagnosis. Of course there are many other services available to refer to for a variety of reasons such as a dietitian for weight loss concerns or occupational therapy for helping identify aids needed in the home, which is why being able to identify the cause of distress is essential. To help with navigation for appropriate referrals, the development of clinical management pathways is critical so that nurses can easily make evidence-based recommendations to patients and their families as documented by Howell[5], Fitch[4], Bultz[3] and Schilli[1].

Implementing effective symptom management

Evidence-based symptom management is critical to alleviating distress. If disease symptoms or treatment side effects are the root cause of distress for an individual or their carer(s), then knowing how to control them is essential to success. Blais[9] recognises that, as front-line staff, nurses are best placed to assess and provide supportive symptom management. Essential to this is that the advice and care provided be evidence-based using guidelines such as those from the Joanna Briggs Institute or the Cochrane Review Database, as discussed by Tavernier[10]. In the United States this is already in place, with the NCCN-developed *Distress Management Guidelines*, cited by Tavernier[10], Estes[7], and Schilli[1], while in Canada there are similar guidelines as described by Fitch[4], Howell[5], Bultz[3] and Blais[9]. Once again, the importance of developing local clinical management pathways to guide the clinician is needed to support evidence-based care.

Education regarding treatment, side effects and self-care at home

The process of educating patients about proposed treatment, side effect profile, how to care for themselves when not admitted to hospital and even when their appointments are, was recognised by Fitch[4] and Hammmelef[11] as essential to reducing or addressing distress identified in the screening process. As this time point within the DTC is the trigger time for screening, this particular nursing intervention is already addressed in this environment. However, screening is undertaken in a variety of settings across the cancer trajectory from diagnosis to survivorship or death and, as such, it remains a critical intervention to alleviate patient and carer distress.

Management of psychological symptoms

Estes[7] identifies that nurses are well positioned to educate patients and their families on coping mechanisms such as mindfulness and deep breathing to decrease or manage their stress. Additionally, she advocates the benefits of meditation and exercise to the psychological wellbeing of patients and their families. This is further supported by Fitch[4], who also advocates for the use of relaxation techniques to help patients at various stages throughout their journey in addition to referring on to multidisciplinary team members such as psycho-oncology services. Howell[5] details the Canadian "care map-depression in adults with cancer", which also recommends the introduction of support groups, relaxation techniques and education as ways for nurses to respond to distress, with referrals and pharmacological intervention the appropriate next step.

Developing a therapeutic relationship using strong communication skills

The development of a therapeutic relationship with the patient and their family/carer is supported by Estes[7], Blais[9] and Vaartio-Rajalin[12] as important nurse interventions to help treat distress. Creating an environment where the patient and family can feel comfortable disclosing any worries or issues enhances the ability to address these concerns and to reassess the progress in mitigating them. Vaartio-Rajalin[12] also highlights that communication is enhanced with the addition of a care coordinator who follows the individual for the complete journey, allowing for continuity of assessment and care.

Advocacy for the patient's care and wishes

Surprisingly, Vaartio-Rajalin[12] was the only author who recognised that advocating for the patient's wishes in the medical setting and acting as a "patient translator" was an important nurse-led intervention to address distress. Most hospitals treat and support patients with a variety of levels of health literacy, often requiring nurses to explain what the doctor means or to have discussions with the medical team about the patient's concerns. Advocacy is an essential component of nursing care and should be used when needed to help mitigate distress.

Acknowledging distress is normal!

In the literature a lesser reported intervention was to acknowledge that distress is a normal reaction to a cancer diagnosis and subsequent treatment. In doing this, patients and their families can be reassured that what they are experiencing is not uncommon and can be treated, as discussed by Smith[8]. Logically, Blais[9] goes a step further and identifies that purely discussing the distress and its cause is an intervention in itself, potentially needing no further action.

Barriers to effective DS

In the literature a number of barriers to effective distress screening were found and convened into six categories, as follows:

- Inadequate time for staff to complete further assessments and implement appropriate interventions
- Limited training on how to manage root causes of distress
- Patient compliance in acknowledging distress and agreeing to recommended care
- Inadequate awareness by nurses of how to integrate distress screening into care
- Lack of confidence in communicating with patients and their families about sensitive topics
- Lack of resources available to meet patient needs

Inadequate time for staff to complete further assessments and implement appropriate interventions

Time was found to be the main barrier for effective DS. Chen[13] found that a lack of time was a significant obstacle to providing appropriate psychosocial care to patients by nurses. Fitch[4] states that nurses find the limitation of time prevents a more holistic appraisal from being attended, and this point of view is also supported by Estes[7]. Additionally, Martensson[14] suggests that constrictive time frames also reduce the ability of nurses to accurately recognise specific psychosocial issues their patients are experiencing.

McGovern-Phalen[15] and Chiang[16] found that nurses are concerned with adding another job (DS) into their workflow and workers were concerned with who would instigate the interventions from the screening tools with already limited resources in terms of time. Consequently, available nursing hours are seen to be impacted by the addition of distress screening and ensuring available resources and pathways are in place is essential to maximising the success of screening process.

Limited training on how to manage root causes of distress

Research has shown that people with cancer frequently have distress that requires correct interventions for effective management. As previously discussed, these interventions need to be targeted at the root causes of distress. From an observational study when nurses were educated on the distress screening tool, referral rates to the appropriate services increased and were more accurate[10]. In their study, Estes[7] identified that inexperience in dealing with sources of distress can cause psychological signs to be overlooked or missed. Additionally, Fitch[4] noted that nurses often feel unprepared to respond to patients' emotional responses from screening. This inexperience and unpreparedness is reported by nurses themselves in their lack of skills and knowledge with recognising distress and knowing the correct referral pathway, as discussed by Carlson[6]. Critically, nurses need to be armed with evidence-based knowledge surrounding the management of the many and varied causes of distress. This can be supported by the development of localised guidelines such as clinical management pathways and staff education programs based on these processes.

Patient compliance in acknowledging distress and agreeing to recommended care

Research has shown that patients, their families and carers can be hesitant to converse about psychological issues with nurses. Furthermore, hesitancy may be due to worrying about being stigmatised for having mental health issues or troubling the provider[4,7,9,13]. Patients, family and carers have fears about being labelled weak and inept in providing self-care and believe providers are occupied with other patients' treatments, leaving little time to be concerned with their issues, as reported by Fitch[4]. Surprisingly, Estes[7] reveals that patients even believe doctors may not have the necessary skills to address their issues.

A fear of reporting distress for patients is detailed by Fitch[4], who explained that care providers are sometimes thought to be distracted from concentrating on treating the patient's cancer, instead focusing on resolving the causes of distress. Alarming to some is that if the distress is secondary to treatment side effects the treatment itself can be stopped. Fitch[4] also refers to studies that have shown that patients experiencing problems described as unmet needs refused assistance at assessment time and that in some studies as many as half the participants are affected this way.

Both Fitch[4] and Blais[9] reveal that in refusing support for distress patients have described feeling like they expected the side effects as a result of treatment and par for the course, they felt they had enough to deal with, they were not comfortable talking about their issues or that they had enough support from family and friends. Martensson[14] also notes that patients sometimes do not wish to talk to nurses about their distress. Patients can feel ashamed that they are having difficulties coping or have no confidence to communicate this concern to the providers[5].

Inadequate awareness by nurses of how to integrate distress screening into care

Nurses' knowledge deficit of how to screen for distress is perceived as a barrier to effective screening. Tavernier[10] describes some nurses' attitude towards screening as a barrier in itself as they perceive the process to not be beneficial. Schilli[1] saw this barrier often conveyed in the opinion of nurses, who stated that screening is futile or is surpassing what can be addressed or treated correctly in the cancer care environment. Efforts to heighten awareness around why screening is useful, how to successfully screen patients and what interventions can be implemented could potentially be useful in addressing this barrier.

Lack of confidence in communicating with patients and their families about sensitive topics

Concern and uncertainty about having "difficult" conversations can be a significant barrier to effective screening. Martensson[14] and Chen[13] report that nurses are not totally confident in appraising patients' emotional needs and in offering appropriate nursing interventions or support. Studies have shown that a high number of nurses have failed to recognise and address anxiety and depression in patients, as described by Martensson[14]. Chen[13] identifies that nurses acknowledge that a lack of confidence in communicating with patients and their families about sensitive topics is a barrier to providing correct psychosocial care. Kennedy Sheldon[17] highlights the need for nurses to receive education on how to react to emotional distress so they can feel confident in responding to psychological symptoms.

While some clinicians are comfortable discussing distressing subject matter with patients and their families, many are still developing these skills and, as such, this creates a barrier to effective responses to the findings of the screening process.

Lack of resources available to meet patient needs

Resource availability in the health system is frequently under stress and with the introduction of distress screening it is, at times, further pressured. Tavernier[10] and Fitch[4] found that a barrier to successful utilisation of distress screening was the limited resources available, such as referral pathways needed to respond to an individual patient's needs. Another example of limited resources creating a barrier was given by Chiang[16] where they described a cause and effect analysis that found insufficient social work resources were a barrier to optimal screening.

Anecdotally, Fitch[4] describes that nurses have shown they are disinclined to screen patients if there are no resources to help them in decision making for further interventions and assessment. If resources are limited or unavailable, then screening is severely compromised as the appropriate interventions are unable to be implemented.

Limitations

Due to a lack of data or literature from Australia, the local experience of patient distress is not widely available with documents describing "global experiences" instead. The majority of literature available is sourced from North America, which doesn't allow for cultural, service-based and procedural differences.

Implications for the future

Consideration should be given to developing and implementing a series of clinical management pathways to respond to issues of distress raised in screening. This would support nurses in responding to distress by providing localised guidelines for evidence-based, nurse-led interventions and referrals, where appropriate.

Continuing education regarding the management of root causes of distress such as disease symptoms, anxiety and socio-economic factors needs to occur for successful integration of distress screening into clinical practice. Additionally, education regarding communication and having difficult conversations is required to ensure distress can be discussed comfortably with patients, families and carers.

Finally, ongoing consultation with key stakeholders, especially patients, is needed to ensure distress screening continues to be an effective tool in caring for and supporting cancer patients and their families.

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Optimal cancer care pathways: developing best practice guides to improve patient outcomes and identify variations in care

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Abstract

Introduction

The pathway for people undergoing diagnosis and treatment for cancer is complex and often poorly understood by patients, clinicians and administrators. In Australia, national Optimal Cancer Care Pathways (OCPs) have been developed to map this journey for specific tumour types.

Aim

The primary objectives of establishing the OCPs are to describe the standard of care and targets for evaluating cancer care programs, and improve understanding of the components of the pathway for both clinicians and consumers.

Method

Multidisciplinary expert groups for each tumour stream reviewed and agreed upon the content for each pathway. This was followed by public consultation with peak national bodies and key stakeholders.

Results

OCPs for 15 tumour streams, with consumer versions and quick reference guides for general practitioners, have been published online. The full suite of OCPs provides nurses and other health care professionals with improved resources for addressing their patients' needs and questions.

Practice implications

State-based health departments in Australia are responsible for implementing the OCPs in their jurisdiction. Structural support for implementation is provided by the federal government. Performance expectations, clinician engagement and system accountability will be integrated in the implementation process.

Introduction

The pathway for people undergoing diagnosis and treatment for cancer is complex and often poorly understood by patients, clinicians and administrators. It can involve hospital and ambulatory care, multiple health care providers, and a series of diagnostic imaging and pathology services. The need for clearly defined pathways to facilitate the delivery of quality care has been recognised by the American Society of Clinical Oncology (ASCO)[1].

In Australia, national Optimal Cancer Care Pathways (OCPs) have been developed and agreed upon by clinicians to map the journey for specific tumour types. The OCPs provide a template for evaluating cancer care programs as well as fostering a shared understanding of the whole pathway and its distinct components to promote quality cancer care and patient experiences. The detailed overview of the cancer care pathway provided by the OCPs is particularly useful for health care professionals that may only be involved at one discrete step, as can be the case for many nurses.

The National Cancer Expert Reference Group (NCERG) is a panel of clinical experts and jurisdictional and consumer representatives established by the Council of Australian Governments in 2010. In developing a national work plan for improving cancer care in Australia, the NCERG identified the value of a national approach to delivering consistent and optimal cancer care. In Victoria, the Department of Health and Human Services (DHHS) provided funding and oversight and commissioned a not-for-profit organisation, Cancer Council Victoria (CCV), to deliver the program. This unique collaboration ensured access to a wide and diverse range of clinical and policy networks and facilitation of a consensus process between clinicians, peak national bodies, consumers, funders, policy makers and endorsers.

Conceptual framework

The OCPs are a framework for delivering consistent, safe, high-quality and evidence-based care for people with cancer. They are not guidelines but standards of care that promote consistency in the delivery of health care and the clinical management of the patient[2]. The concepts of integrated care pathways and multidisciplinary management are supported by a growing body of literature[3-6]. The well-documented benefits of care pathways include increased collaboration, more effective clinical care, better resource utilisation and cost management, and improved clinician–patient communication and patient satisfaction[7-9]. Walling *et al*. note that a number of clinical practices for which there is a solid evidence base are not the norm in practice and that these practices “should be incorporated into care pathways to facilitate them becoming the expectation rather than the exception”[5].

Much of the literature discusses care pathways in the context of individual health services or focuses on the diagnostic and treatment phase of the patient pathway. De Bleser *et al*. report that historically pathways have been limited, focusing on specific tasks and the acute hospitalisation period, and under-reporting the roles of patients and their carers[3]. Clinical pathways that address long-term chronic or terminal conditions are less common and are often lengthy documents laden with medical jargon or may only be available to health professionals through a paid subscription service[10]. Consequently, these pathways may only be relevant and accessible to a narrow range of health care professionals and do little to promote a patient-centred approach to care.

Numerous benefits have been associated with patient-centredness, including better health outcomes, improved compliance with treatment, greater adoption of health-related lifestyle changes, and more effective patient–healthcare professional relationships[11]. Recent literature and evolving patient needs demonstrate that patient-centredness, which respects individual patient preferences, values and needs, is a key requirement for health care integration[4,12,13]. There are many elements involved when using a patient-centred approach and, in the context of cancer care, some of the most important aspects include providing accurate and relevant information and empowering patients to be involved in their own care to the level with which they are most comfortable.

The 2011 Institute of Medicine’s National Cancer Policy Forum highlighted the importance of patient-centred care and identified a "lack of tools to facilitate treatment planning" and potential issues around patient health literacy as key obstacles[14]. In response, care pathways are increasingly being extended to incorporate not only the concept of coordination, but also to provide the necessary framework and information to facilitate patient-centred care[12].

ASCO has recently published recommendations on pathway development including that pathways should address the full spectrum of cancer care from diagnosis to survivorship, and that a collaborative national approach is necessary[1]. To date, there are very few examples of documented pathways with the scale (which apply across health services and jurisdictions), breadth (which span from prevention through to survivorship and end-of-life care), and depth (which include optimal communication, supportive care, time frames and early integration of palliative care) that the OCPs provide. Furthermore, OCPs are unique in that they document a consensus view on what care *should* look like, beyond minimum requirements.

Methods

A project steering committee was established by CCV and the DHHS, with expert clinical, consumer and policy maker representation, and a project manager appointed. Multidisciplinary expert groups were established for each tumour type to review and agree upon the content for each pathway. The pathway template was based on a previous iteration of similar work published as the Patient Management Frameworks. Expert group nominations were sought for interstate clinicians, rural representatives, consumers, and a range of allied health professionals. From the nominations, expert groups were selected to ensure adequate multidisciplinary and multi-organisational representation, with a National Chair selected from an expert in the field.

For each tumour type, a preliminary literature review was undertaken to inform the pathway content. This draft was reviewed by the expert group and the content refined. The criterion for content inclusion was that the information was optimal and not modified by practicality, such as access in a rural setting.

Once the expert group agreed upon the content of the pathway, a period of public consultation followed. This included invitations to peak national bodies, medical colleges, cancer councils, specialty groups, consumer advocacy groups and clinical networks. Consultation for each OCP spanned a 4- to 6-week period and feedback was considered by the chair of the expert group and the steering committee. Where changes were proposed and agreed, these were ratified by the expert reference group. Formal endorsement was then sought by the NCERG, Cancer Australia, Cancer Council Australia, and the Australian Health Ministers Advisory Committee.

Serial public consultations of the generic pathway content (content that applies across multiple tumour types) combined with serial review by each expert group had multiple advantages:

1. The OCP content was iteratively refined over the project lifespan based on accumulated feedback.
2. A rich understanding of multidisciplinary expert opinion on all aspects of the care pathway informed the OCPs.
3. The nuances and differences in clinical practice, and the appropriateness of this variation by tumour type became apparent; in some cases "accepted" optimal practice in one discipline and care pathway was applied to others.

A multi-level communication strategy was developed to enhance engagement of all stakeholders across the health care sector.

Results

OCPs for 15 tumour streams, across 10 tumour groups, have been published online.

Three different resources have been developed for each tumour stream:

1. Clinical Optimal Care Pathways: Developed by multidisciplinary expert groups for health care professionals and administrators.
2. Quick reference guides for general practitioners: Based on the clinical OCP to familiarise general practitioners with the entire care pathway.
3. Quick reference guides for consumers: To help patients and carers navigate the care pathway at point of diagnosis.

The OCPs reflect the current evidence base and clinical practice as well as incorporate emerging areas of practice such as optimal supportive care, clinician to consumer communication, specialist to primary practitioner communication, and time frames to care.

A consumer web portal has also been developed to support the dissemination of the consumer OCPs. The OCP resources are listed in Table 1.

The overarching purpose of the resources is to improve patient experience and outcomes through consistent system-wide cancer care based on a standardised pathway of optimal care. They provide health care professionals and administrators with an agreed nationwide approach to care across each of the tumour types. The pathways are applicable to care, whether it is provided in a public or private service. The consumer versions assist patients and carers as they navigate the care pathway and empower them to ask the right questions at the point of diagnosis.

Table 1: OCP resources

Tumour stream	OCP (clinical, consumer, general practice)
Lung	1. Lung
Colorectal	2. Colorectal
Upper gastro-intestinal	3. Hepatocellular carcinoma
	4. Pancreatic
	5. Oesophagogastric
Skin	6. Melanoma
	7. Basal cell carcinomas and squamous cell carcinomas
Haematological	8. Acute myeloid leukaemia
	9. Hodgkin and diffuse large B-cell lymphomas
Head and neck	10. Head and neck
Breast	11. Breast
Urology	12. Prostate
Brain	13. High grade glioma
Gynaecological	14. Endometrial 15. Ovarian

A key benefit of the OCPs is that they provide a detailed overview of the entire pathway to health care professionals that may only be involved at one stage. This can be highly beneficial to cancer nurses, who are often key coordinators of a patient's care. Nurses also field a wide range of questions from patients that may be overwhelmed, have low health literacy, or are trying to manage their anxiety during periods of uncertainty between steps of the pathway. The OCPs equip nurses to guide patients on key issues such as what to expect and the reasonable time frames for referrals and treatment. Furthermore, nurses can direct patients to the consumer versions of the OCPs, which are well suited to address broad questions and provide a useful guide to cancer care that can be referred back to at each step in the pathway. The full suite of OCPs thus provides nursing staff with improved resources for addressing their patients' needs and questions.

In contrast to clinical practice guidelines that guide appropriate practice and decision making, the OCPs provide a guide to the patient journey to ensure patients with cancer and their families receive optimal care and support. Whilst the OCPs are not intended to be clinical guidelines, they are consistent with and draw on relevant guidelines. Like clinical guidelines, they are ultimately aimed at establishing effective, high-quality and safe health care practices and policies.

Practice implications

All Australian states and territories have committed to improve cancer care by working towards the adoption of OCPs. In Victoria, a project steering group has been established to oversee the early phase of adoption of the pathways. This group will not only engage with health care professionals to facilitate awareness and understanding of the OCPs but also establish plans for using data to measure the effectiveness of, and variation from, the pathways.

The following statewide implementation activities have commenced:

- Mapping patient flows across tumour types to inform what and how to monitor compliance and identify quality improvement opportunities.
- Using cancer networks to facilitate uptake and statewide, multidisciplinary tumour stream meetings to identify priority areas.
- Establishing a Community of Practice model to support those involved in implementation activities.
- Promoting inclusion of OCP implementation within health service's statement of priorities so that health service executives are accountable for reporting on compliance to the OCPs.
- Advocacy to incorporate OCPs into the National Standards.
- Engagement with the Victorian Primary Health Network alliance to implement key steps of the OCPs, particularly in the pre- and post-treatment phases of the pathways.

The potential for measurement of patient movement along the pathway is considerable using currently available data collections. Measuring the total pathway allows cost and activity (both appropriate and inappropriate) to be evaluated and related to outcomes. A range of indicators could be selected to measure compliance through the analysis of health care data such as timeliness to care, outcome data mapped against optimal infrastructure and staffing requirements, multidisciplinary team activity, and evidence of communication with the patient's clinician and specialist.

While data collection and analysis related to the pathways will facilitate long-term improvements to cancer care in Australia, the OCPs also provide many immediate benefits for both clinicians and patients. The OCPs stipulate the expectations for care that health care professionals should work to and ensure that all nurses, primary care practitioners, specialists and other medical service providers deliver accurate and consistent information to patients. The OCPs eliminate the uncertainty regarding processes and time frames, allowing health care professionals to work to an agreed set of standards. Having the OCPs accessible to the general public in a variety of formats better equips patients and their carers to measure their own experience against these defined expectations and act as advocates. The pathways can also be used by clinicians to promote discussion and collaboration between health professionals and people affected by cancer.

Like clinical guidelines, the OCPs share the challenge of obsolescence. ASCO recommend that oncology pathways be updated continuously to reflect the rapid development of new scientific knowledge[1]. A survey of expert group members established that a major review every five years with minor review at three years is a sound approach to ensure the OCPs remain relevant. However, it is recognised that government and project funding cycles provide ongoing challenges to updating the OCPs. The provision of structural support from the government and a commitment to the implementation of the OCPs will go some way in securing future funding for their continuous revision and use.

Conclusion

The OCPs are intended to guide the delivery of consistent, safe, high-quality and evidence-based care for people with cancer. The pathway aligns with key service improvement priorities, including providing access to coordinated, multidisciplinary and supportive care and reducing unwanted variation in practice. The OCPs can be used by health services and professionals as a tool to identify gaps in current cancer services and inform quality improvement initiatives across all aspects of the care pathway. The pathway can be a particularly useful resource for nurses and other health care professionals that may not be familiar with all steps involved in the OCP, or that need to provide further information to patients. The OCPs can also be used by clinicians as an information resource and tool to promote discussion and collaboration between health professionals and people affected by cancer.

For the OCPs to be successful, performance expectations must be embedded and clinician engagement and accountability must be integrated at every step of the implementation process.

The Optimal Cancer Care Pathways are available at www.cancer.org.au/OCP. The interactive consumer web portal is available at www.cancerpathways.org.au

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A systematic approach to breast care nursing in the rural setting: development of a database and support tool to ensure continuity of care

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Abstract

Breast care nurses (BCNs) are known to improve the cancer experience for those diagnosed with breast cancer. This paper examines the specialist breast nurse competencies and the development of a database and support tool to assist BCNs in the provision of continuity of care in a rural hospital in New South Wales (NSW). The database and tool, guided by the competencies, supports the provision of optimal care through a more structured approach to management.

Introduction

Breast cancer remains the most commonly diagnosed cancer in Australian women, with one in eight women diagnosed by the age of 85 and a five-year survival rate exceeding 90%[1,2]. Breast care nurses (BCNs) are employed in varying roles, depending on their place of work, to support women with breast cancer in many public and private cancer centres throughout Australia[3]. BCN practice is currently guided by the 2006 *Specialist Breast Nurse Competency Standards*; however, these do not provide information about the timing of an intervention with the patient or what should be included within that intervention. To date, these remain the only standards available in Australia[3]. Some metropolitan hospitals employ more than one BCN, but in the rural setting there is likely to be only one BCN working within the multidisciplinary team, regardless of their experience or length of time in the role. As a consequence, the rural or sole BCN, particularly if new to the role or relieving, may have insufficient support or information on the requirements of the role. It is known that BCN practice currently varies[3,4] and without guidelines the documentation that the BCN keeps on the patient regarding past and planned interventions will also vary. This paper examines a support tool and database developed and used in a rural hospital in New South Wales (NSW) to establish a framework to ensure optimal continuity of care for patients as well as aiding new and relieving BCNs.

The Specialist Breast Nurse Project and Competencies refer to people affected by breast cancer as women and the project refers to the specialist breast nurse as female[5,6]. For convenience, we have continued this convention; however, we acknowledge that men are also diagnosed with breast cancer and that the need for support is essential, regardless of gender[1]. The tool and database are equally applicable to the needs of men with breast cancer. The terms breast care nurse (BCN) and specialist breast nurse refer to the same role and in this paper the term BCN has been used.

Background

The inclusion of a BCN as part of the care team for women with breast cancer is widely acknowledged as improving the cancer experience by reducing informational and psychosocial needs[7-11]. The National Breast Cancer Centre (NBCC) conducted a demonstration project in 1998 examining the impact and cost of BCNs as a model of care in Australia. At that time there were few nurses working in these positions[5]. The NBCC reported on the viability and acceptability of using BCNs within the multidisciplinary cancer team and developed evidence-based interventions. These were to be used at diagnosis, peri-operatively and up to 10 weeks after surgery, based on the needs of women with breast cancer. The report provided specific details of discussion points and referrals to be included at each intervention. The majority of women found these interventions beneficial. The recommendation was made that utilising BCNs was an effective method of providing both supportive and evidence-based care[12].

Some years later, Yates *et al.* found that there were significant variations between BCN roles within Victoria and consequently developed the *Specialist Breast Nurse Competency Standards*[4]. They built upon existing competency standards for registered nurses[12]. These competencies fell into five domains: supportive care; coordinated care; collaborative care; clinical leadership; and the provision of education and information. They acknowledged that the competencies had to encompass the multidisciplinary context within which the BCN works and had to be broad enough to reflect the complexity and varying needs of their patients. A 2015 literature review by Ahern and Gardner examining the role of Australian BCNs found that there was still no consistent structure and there remained great variation within the BCN scope of practice[3]. They could not determine adherence to the competency standards as there had been no further research into this area since their publication, despite the growth of the BCN role within Australia. It is widely accepted that BCNs improve the experience for women with breast cancer by providing continuity of care through the cancer journey, giving information and support as well as making timely referrals to meet their needs[8-11,13]. The question remains as to how to best support BCNs to provide consistent care for women when there is variation within roles and nurses working in isolation.

The specialist breast nurse competencies

The specialist breast nurse competencies are available on the Cancer Australia website[6]. Yates *et al.* define the level of skill and knowledge required and the behaviour and attitudes required for the BCN role under five domains[4]. They are:

Supportive care: Identify the physical, psychological, social, sexual and spiritual needs of the patient using up-to-date, evidence-based information to provide supportive interventions across the continuum of care and develop a therapeutic relationship with the patient and family.

Collaborative care: Work with the patient and family and the multidisciplinary team to facilitate, implement and evaluate a plan of care that meets the individual needs of the patient.

Coordinated care: Ensure that relevant, comprehensive care and support is provided to the patient across the continuum of care that is appropriate for the needs of the patient.

Information provision and education: Provide individualised, comprehensive information to the patient to support them to make informed decisions about their own health care across the continuum. This should include information on pathophysiology, treatments and self-management. It must be evidence-based and take into account individual needs and preferences.

Clinical leadership: Contribute to breast cancer nursing through clinical leadership and professional activities incorporating contemporary, evidence-based care.

The competencies contain performance criteria that demonstrate what action needs to be taken to achieve the competency. Care provided will overlap across the domains. For example, within the domains of information provision and education, coordinated care, collaborative care and supportive care, the BCN must assess the patient's understanding of their situation. The BCN will provide information about sensitive issues using advanced communication skills. She will demonstrate advanced-level knowledge that is evidence-based and comprehensive about treatments and outcomes and provide informational resources suited to the patient's needs. She will develop and implement a care plan for the patient across the continuum, providing timely information that is tailored to meet the patient's needs and preferences. The BCN will collaborate with the team to ensure a consistent and coordinated approach to the patient's needs.

Whilst these competencies outline what is expected of the BCN, they provide little guidance in the day-to-day functioning of the role; for example, what should be included in the intervention and when it should take place. The NBCC Specialist Breast Nurse Project conversely provided details of what should be included in the early interventions[5]. Put together, they provide a more useful and comprehensive framework for the daily work of the BCN which, in turn, should result in improved, more consistent care for the woman with breast cancer.

Development of a tool and database

The tool and database were developed in 2012 for use at the rural hospital by the existing BCN and nurses covering the role, for their own use. The adaptations of the documents are outlined in Tables 1 and 2. Table 1 focuses on the period from diagnosis to 10 weeks after surgery. Many BCNs target this time period for interventions, whilst other BCNs focus on coordinating care on a continuum. Table 2 outlines contact points deemed necessary after the surgical episode through to the completion of all treatment and beyond.

Tables 1 and 2 serve as tools to prompt points of contact needed and the information that should be included within each intervention. These must be individualised to the patient. There are points that are repeated throughout the tables to ensure that they are covered. This allows the new or relieving BCN to easily identify what has or has not been covered previously as well as serving as an aide-mémoire for the BCN.

Referrals are included under most contact points on the tool to ensure that as needs arise the appropriate referrals are considered. In Table 3 a list of possible referral sources is provided. All referrals are not necessarily applicable to all patients but the list serves as a prompt to ensure needs are addressed.

Table 1: Support tool

Contact points of BCN to provide information and support	
Diagnosis	• Introduction of self and role, provision of contact details • Discuss: diagnosis/prognosis, treatment goals/options, practical issues • Breast reconstruction (especially immediate) • Cultural/spiritual issues • Check psychological risk factors (distress thermometer) • Discuss response to diagnosis • Check social support networks • Offer family discussion • Offer referral to psychologist • Give written information — BCNA/CC booklets: EBC, partners, children, emotions, sexuality, after surgery • Give support group information • Order My Journey kit and My Care kit
Pre-op	• Discuss surgical procedures and interventions • Discuss possible complications/side effects • Prosthesis/rebate • Order My Journey kit/My Care kit if not ordered prior • Check received written literature • Discuss post-op exercise
Post-op	• Discuss results/prognosis • Discuss possible treatment options • Breast reconstruction/prosthesis • Wound care/drain • Discharge plan • Discuss what happens next. • Check received My Journey/ My Care kits • Introduce treatment team. • Discuss feelings, problems, solutions • Offer family discussion • Check practical support • Discuss family issues/needs • Discuss lymphoedema precautions • Post-op exercises • Seroma management
1–6 weeks follow-up	• Discuss results/prognosis • Discuss treatment plan • Adjuvant therapy • Possible side effects • Fertility • Clinical trials • Breast reconstruction. • What happens next? • Discuss feelings, problems solutions, effects on intimacy/relationships • Offer family discussion • Check psychological problems (distress screening) • Support networks • Offer counselling • Check arm range of movement/wound healing
6–10 weeks follow-up	• Discuss treatment plan • Discuss adjuvant treatment • Side effects • Clinical trials • Breast reconstruction • What happens next? • Discuss feelings, problems, solutions • Inform of support group • Check for psychological problems • Check arm range of movement
Between all these points of contact, the patient may initiate their own BCN consultation as needed. Encourage patient to contact for support/information.	

Table 2: Support tool

Coordination and contacts post-surgery	
Medical oncology appointment	• Support patient in clinic if needed • Clarify any points that need further discussion after clinic • Provide further written information • Explain plan/appointments • Discuss psychological risk factors (distress tool) • Check arm mobility • Referrals as needed
Education/pre-treatment	• Ensure treatment booked and patient aware of schedule • Ensure clinic booked prior to next cycle • Provide verbal and written information (eviQ)
Follow-up at end of treatment	• Discuss feelings, problems, solutions • Intimacy/relationships • Review breast cancer journey
After radiation oncology appointment	• Discuss appointment and any queries • Ensure patient aware of IPTAAS and has forms • Discuss accommodation • Travel assistance as required. Provide further information as needed • Encourage patient to contact post-radiotherapy if having concerns
Post-radiation	• Discuss healing • Refer to CHN if needed for dressings • Provide support/information as needed • Ensure follow-up medical oncology appointment booked
After commencing endocrine therapy	• Verbal and written information on specific drug • Advise on management of side effects • Support compliance literature, BCNA support • Rebook for clinic if struggling to comply
3–6 month follow-up post all treatment	• Discuss feelings, problems, solutions • Intimacy/relationships • Check prosthesis fitting done • Ensure contact details supplied and patient aware can contact any time in future if needs/wants to
Between all these points of contact, the patient may initiate their own BCN consultation as needed. Encourage patient to contact for support/information.	

Table 3: Referrals

Referrals are an individualised need and can occur at any point throughout these contacts (and at any other time, as needed). The following list of referrals is included to assist BCNs in awareness of possible referrals, as necessary. The BCN may not be able to directly refer to these but can facilitate it happening.	
Surgeon — reconstruction	Social worker
Medical oncology	Psychologist
Radiation oncology	Genetic counsellor
Physiotherapist	Fertility specialist
Lymphoedema specialist	Exercise physiologist
Dietitian	Support group
Financial supports (CanAssist, Cancer Council)	Sex therapist

The spreadsheet database (Table 4) used to track patients is very useful in ensuring that all points are covered for each patient. It is simple in its design, allowing each point of contact to be easily recorded. This database is not a substitute for professional documentation, but rather a checklist that allows BCNs to easily identify where patients are in their continuum of care and which needs are still to be addressed in order to ensure optimal care. This serves as an easy reference point for a new or relieving nurse or an aide-mémoire for a sole BCN.

Discussion

Use of this tool ensures continuity of care for the woman with breast cancer. It prompts contact at designated times and recommends the essentials of each intervention, whilst always responding to the woman's needs. It has been suggested that there is a lack of standardisation, many different practices and even variation between individuals in the BCN role[3,4,14,15]. This tool has the capacity to ensure that all nurses working as BCNs, either as their substantive role or covering leave, are working in a standardised way, and it may be used to address national variation. The database and tool provide a structure and time frame as to the specific aspects of care that should be addressed. In line with the *Specialist Breast Nurse Competency Standards*, this should always be individualised to the needs of the patient rather than prescriptive[14]. It allows interventions and discussions with the woman to be tracked.

It is well recognised that cancer patients can have high levels of anxiety[16,17]. Therefore it is essential, at diagnosis or at initial contact, to identify the patient's level of anxiety and the possible underlying causes. The use of a tool such as the Distress Thermometer[20] can assist in gauging levels of anxiety and areas of concern[18]. This should also be used periodically throughout

Table 4: Database

Name	Seen pre-op	Surgery	Hospital visit(s)	F/u call 1–2 days if home with drain in situ:	F/u call 1–6 weeks post-surgery between these dates:	F/u call 6 to 10 weeks post-surgery between these dates:	Medical oncology appointment	F/u call if did not see after medical oncology appointment	Chemo dates	Herceptin finish date	F/u one month after starting endocrine therapy:	F/u when adjuvant treatment ends:	Final call 3 months after finishing treatment if agreed at previous call	Radiation oncology appointment	Radiation dates	F/u call 1–2 weeks after finishing radiation therapy
Jane Doe	Y	Y	Y	Y	Y	Y	Y	-	Y	Y	n/a	Y	Y	n/a	n/a	n/a
John Doe	Y	Y	Y	n/a	Y	Y	Y	-	n/a	n/a	Y			Y	Y	Y

the continuum of care. Use of the Distress Thermometer is prompted throughout the BCN tool, ensuring that distress is highlighted early and that appropriate interventions can be offered.

In an Australian study, Ussher *et al.* identified that women had unmet informational needs about sexuality[19]. This tool ensures that the BCN is prompted to have a conversation with the woman about sexuality, rather than deferring to another time and risking omission.

Women can have ongoing needs for advice and support after treatment is completed[20]. This tool facilitates the seeking of permission at the end of treatment for the BCN to make future follow-up phone calls to address and finalise needs before discharging the patient from the service. At this point, the BCN also advises that the patient may initiate future contact, if required.

While acknowledging the usefulness of the tool, a criticism by the BCNs has been the time necessary to complete the database, given workload constraints. With repeated use, the process has become more efficient and is beneficial to care provided.

Implications for practice

This tool and database system provides a standardised framework for structured assessment and interventions for women newly diagnosed with breast cancer.

It has been acknowledged that the care pathway for the management of patients with metastatic breast cancer can be poorly defined and inadequate[21]. Therefore, the development of a similar tool for these patients may also better support their care.

Conclusion

There is a need for further development and standardisation of competencies across Australia, for patients with both early and metastatic breast cancer, to optimise and standardise care, whilst ensuring it remains individualised to the woman's needs. The current *Specialist Breast Nurse Competency Standards* do not provide specific details or on the interactions that should occur for a woman with breast cancer, nor when they should occur in the diagnostic and treatment trajectory. Combining the principles of the competencies with the details of the original Specialist Breast Nurse Project allowed the BCNs in the rural hospital in NSW to develop the database and tool, which has improved the quality and continuity of care provided to their patients.

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