The Australian Journal of Cancer Nursing

Cancer Nurses Society of Australia

The Official Journal of the Cancer Nurses Society of Australia

Volume 17 Number 1
June 2016

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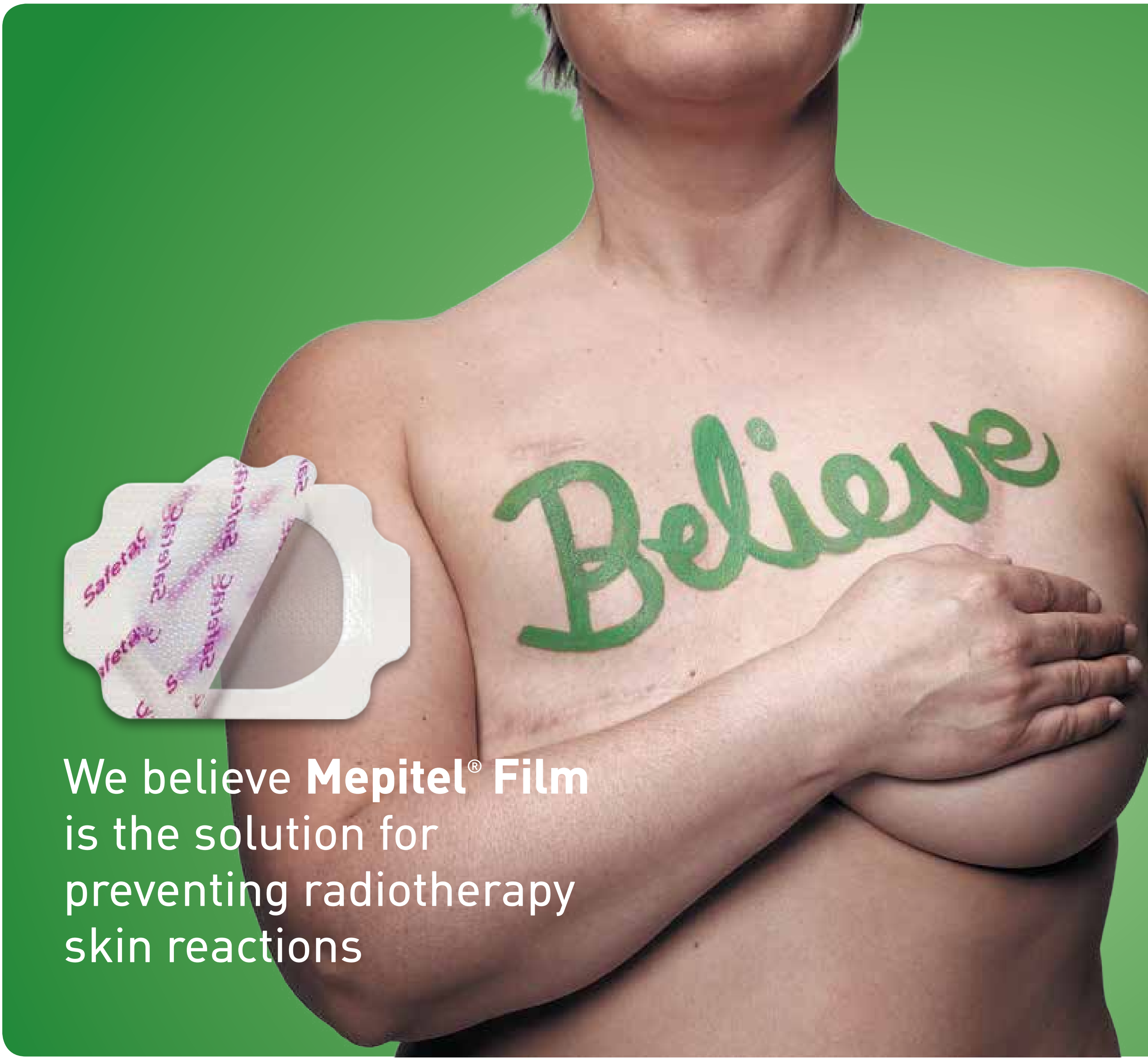
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The Australian Journal of Cancer Nursing

Volume 17 Number 1 — June 2016

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ISSN 1441-2551

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Editorial

Celebrating the science and art of cancer nursing through inspirational leadership

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The Cancer Nurses Society of Australia (CNSA) is in a privileged position to have a vibrant membership comprised of over 1000 nurses committed to providing excellence in cancer care in many and varied ways. Recently, Professor Sanchia Aranda, one of the CNSA's most prominent and long-standing members, has been honoured by the International Society of Nurses in Cancer Care (ISNCC) with the Distinguished Merit Award. The award is made in recognition of an outstanding contribution to the international advancement of the science and art of cancer nursing. Professor Aranda, the Chief Executive Officer (CEO) of Cancer Council Australia, has been making a difference to cancer care and control for over 30 years in many diverse roles.

From her early career as a registered nurse in New Zealand, through to her more recent experiences as Director of Cancer Services and Information and Deputy CEO of the Cancer Institute NSW, she has contributed significantly to improving cancer care. Professor Aranda has reflected diversity, dedication and innovation throughout her career in the many and varied roles she has held, both paid and voluntary. Most notably, Professor Aranda has held directorships with the ISNCC as a Board member (1992–2000), President Elect (2004–2006), President (2006–2010) and Past-President (2010–2012) and most recently as President-Elect of the Union for International Cancer Control (UICC) (2014–2016). Professor Aranda will be the first nurse to serve as the UICC President and this appointment signals her as one of the most influential global cancer leaders. The depth and breadth of her contribution traverses the spectrum of cancer care through prevention, diagnosis, treatment, survivor care and palliation. Professor Aranda has inspired many throughout CNSA and globally to continue to strive to achieve more for patients with cancer.

The five papers presented in this edition of the journal reflect the vibrancy of the CNSA membership and commitment to providing excellence in cancer care. The 22 authors of these papers represent the diversity, dedication and innovation of nurses working in cancer care to improve outcomes for the person with a diagnosis of cancer. While the papers are diverse in content, a common theme is at the heart of each paper: how do we provide cancer care that is accessible and of a high quality, yet meets the needs of the individual patient, the broader population and a changing health care system?

Taylor and Monterosso have undertaken a systematic literature review of validated tools that may be used to identify and measure the informational and practical needs for leukaemia and lymphoma survivors. Comprehensive systematic literature reviews are important as they allow us to synthesise large amounts of information and, where appropriate, translate and implement research findings into clinical practice and policy. However, this review finds there is a paucity of validated tools necessary to evaluate the informational and practical needs of leukaemia and lymphoma survivors and there remains much work to be done to develop and implement valid and reliable tools for this group of survivors.

Ash *et al.* explore the extended scope of practice for the enrolled nurse working in cancer care. This paper provides a considered response to the desire expressed by some health services to press for this extended role and the current gaps in evidence around continued patient safety, clinical outcomes for patients and the role the registered nurse has in the delegation of care to the enrolled nurse and subsequent supervision of that care. This is an important paper in the landscape of the evolving cancer nursing and health care workforce as it will contribute to the national conversation around scope of practice, development of new roles or the extension of existing roles[1].

The paper by Ahern, Gardner and Courtney describes the development and validation of a survey to assess and describe the role of the specialist breast care nurse. It examines the key components of information, education and support to the person with breast cancer and the barriers experienced in performing the role within the diverse geographic practice settings of Australian cancer care.

Febrile neutropenia is a significant complication for the person with cancer and can at times be fatal[2]. Campbell, Cusack and Green report the findings of their qualitative research study designed to explore the experience of the oncology nurse practitioner in regard to their role and responsibilities in the clinical management of febrile neutropenia across the inpatient, outpatient and the home settings in Australia.

The paper by Ngoc, McCarthy and Ramsbotham, "Knowledge, attitudes and practices of oncology nurses regarding fever and fever management in febrile adult cancer patients", complements the paper from Campbell, Cusack and Green. This study identified that evidence-based practice is not always implemented and highlights that education, policy, resources, leadership and ward culture are important components in the translation and implementation of evidence into routine clinical practice to ensure positive change for patient care.

I hope in your reflections on these papers you are challenged to consider your own clinical practice in the context of a rapidly changing cancer care environment and are inspired to strive for excellence in cancer care through your own contribution to the science and art of cancer nursing.

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Systematic review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors

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Abstract

Purpose: To identify validated measurement tools to assess the informational and practical concerns of leukaemia and lymphoma survivors. Cancer nurses have the potential to lead the way in providing quality post-treatment survivorship care.

Method: This systematic review utilised a search of electronic databases for eligible articles published to March 2014. Included articles described a tool to assess informational and/or practical concerns of leukaemia and/or lymphoma survivors.

Results: Seven full text articles were identified that described cancer-specific tools used to assess informational and/or practical needs of this survivor cohort. There was variation in the use of cancer survivor-specific tools and generic cancer tools.

Conclusions: No haematology-specific needs assessment tools were identified. Therefore only tentative conclusions on the best tool for this cohort can be made. Further research is required to develop reliable and validated tools that will support the selection of the most appropriate tool for leukaemia and lymphoma survivors.

Keywords: Leukaemia and lymphoma cancer; survivorship; instruments; measures; tools; supportive care needs; unmet needs; perceived needs.

Introduction

Leukaemia and lymphoma are the most common blood and bone marrow cancers[1]. Effective treatments are largely aggressive and cause a number of long-term and late physical, practical and psychosocial effects, which significantly impact lifestyle in the survivorship phase[2]. Survivorship is defined as the experience of living with, through and beyond a diagnosis of cancer[3]. As with other cancers, the haematology cancer health professional role has extended to include provision of patient care in the survivorship phase. This important step forward has been driven largely by the 2005 Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition*[4], considered the seminal paper for cancer survivorship. The report recommended survivorship care as a priority in the cancer trajectory with a number of specific issues relevant to the survivorship phase. These issues can be categorised according to the seven domains of Fitch's[5] supportive care framework; physical, informational, emotional, psychological, social, spiritual and practical concerns. The framework can be used across the cancer continuum including haematology survivorship care[6]. Whilst survivorship care is developing for other cancers, haematology cancers remain understudied in survivorship literature[7], despite increasing five-year relative survival rates internationally[8-10].

The purpose of this review was to source tools that could be used to assess two domains from the supportive care framework: informational and practical concerns. These were chosen as a result of our findings from a qualitative study undertaken with leukaemia and lymphoma patients that revealed a number of unmet needs, predominately informational and practical[11], thought to relate in part to the extensive nature of the treatment and the uncertainty around long-term remission and potential late effects.

The terms 'informational needs' and 'practical needs' are rarely considered or defined as separate entities in the literature. For clarity and consistency, Fitch's definitions[5] of needs have been used. Informational needs are defined as information to assist in decision-making and acquiring of skills to decrease fear, anxiety and misperception[5]. Fear of recurrence is often reported as an informational need for this cohort[12]. Two recent systematic reviews on this topic reported tools used to measure fear of recurrence; tools to measure other informational needs were not reported[12,13]. Practical needs are defined as direct interventions or help that support the survivor to complete a task or meet a concern[5]. Insurance and employment issues are often cited as unmet needs for leukaemia and lymphoma survivors[14]. Other common informational and practical needs reported in haematology survivorship literature include late effects, fatigue, nutrition, exercise, fertility and sexual concerns, relationship issues, financial issues, personal care and accessing support services[2,8,15–19].

Gates *et al.*[18] argued that haematology cancer nurses have an important role in this changing dynamic, especially in developing sustainable, nurse-led survivorship care. If nurses are to take on a greater role in survivorship care they require accurate, reliable and validated tools to assess patients entering the post-treatment phase[20]. Hawkins *et al.*[19] proposed that tools designed for patients to self-identify perceived needs are required to support survivorship care. These tools could then guide the development of appropriate models of care, resources and tailored support that are patient-centred rather than based on the perceptions of health professionals[5,21]. The timing of patient needs assessments is equally important. Research showing interventions and assessments undertaken in the early survivorship phase (up to two years post-diagnosis) can lead to fewer unmet needs moving into the extended survivorship phase (over five years)[21,22].

There is a dearth of published literature that has critically evaluated tools used to measure the perceived unmet needs of leukaemia and lymphoma survivors[20,23]. Tools specifically developed for these patients in the treatment phase such as the Functional Assessment of Cancer Therapy: Lymphoma or Leukaemia (FACT-LYM, FACT-Leu) have also been used in the survivor population[24,25]. Hence, it is possible that survivor-specific needs may not be captured.

Given that each cancer patient's journey is unique, it is important to measure individual needs and match practical support to meet those needs. Therefore, the leukaemia and lymphoma-specific focus of this paper will add to the limited body of knowledge currently available in this survivor cohort.

The following questions guided this systematic review:

1. What reliable and valid measurement tools are currently available to measure the informational and practical needs of acute leukaemia and lymphoma cancer survivors?
2. What are the implications of the findings from this review for future research and clinical practice?

Method

A systematic review methodology was chosen to guide this review. To guide literature searches and analysis of articles, a study protocol was devised. As the use of needs assessment tools dictates a quantitative study method, qualitative studies and the qualitative component of quantitative studies were excluded. Mixed methods research was included with only the quantitative element evaluated.

Literature search

The primary search utilised the following electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsychInfo, PubMed, EMBASE, PsychArticles, and the Cochrane Library from earliest records to March 2014. Search terms related to leukaemia and lymphoma cancers, assessment, survivorship and needs (see Appendix 1 for the search strategy). A hand search of the reference lists from full text articles was also employed. Searches were restricted to English and adult acute leukaemia or lymphoma survivors. Inclusion and exclusion criteria are shown in Table 1. Studies with only multiple myeloma participants were excluded as these patients have an incurable cancer and could therefore be termed "living with cancer"[26]. Likewise, studies with only allogeneic transplant participants were excluded as they have ongoing conditions such as graft-versus-host-disease.

Quality appraisal and data extraction

One author (KT) reviewed abstract titles to assess eligibility. KT and LM then appraised the instrument/tool(s) used in eligible full text articles to determine whether they measured informational and/or practical needs of the leukaemia or lymphoma survivor. A summary of the selection process using the PRISMA 2009 Flow Diagram[27] is provided in Figure 1.

Table 1: Inclusion and exclusion criteria

Inclusion criteria
Use of a cancer survivor-specific or generic cancer tool or instrument
Validity and reliability of tool tested with leukaemia and/or lymphoma cancer survivors
Informational and/or practical needs reported
Adult leukaemia and lymphoma cancer survivors only
Exclusion criteria
Tools used in the treatment or diagnostic phase
Tools used with relapse or secondary leukaemia or lymphoma cancer survivors only
Studies reporting survivors of a childhood leukaemia or lymphoma cancer
Studies related to caregivers, or comparative studies between caregivers and survivors
Studies with less than 50% leukaemia or lymphoma cancer survivor cohort
Opinion papers, letters, editorials, commentaries, conference proceedings, or case studies

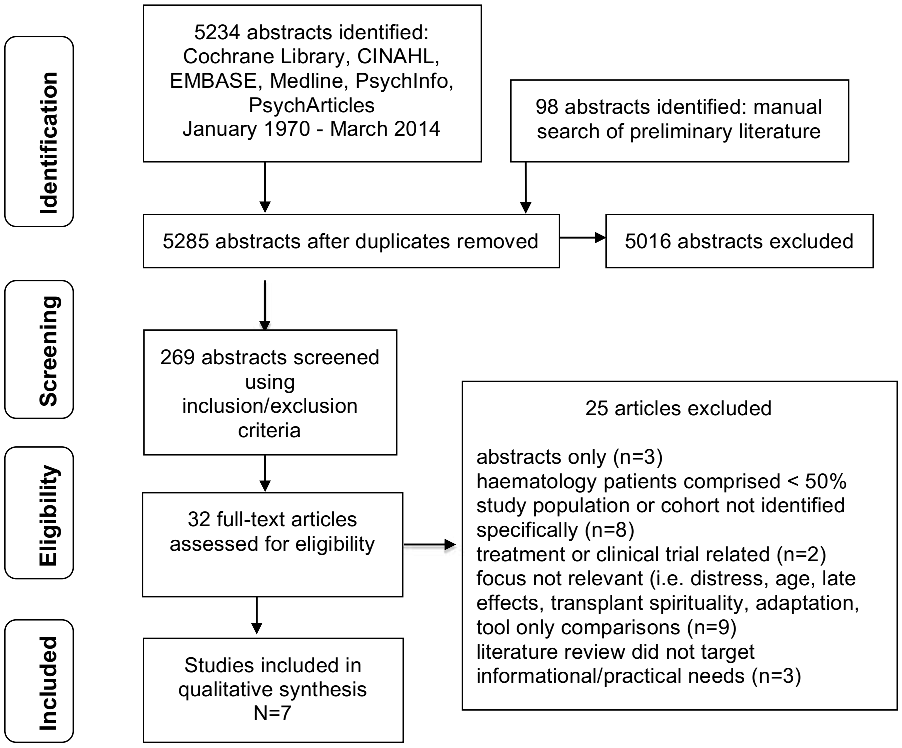

Figure 1: Flow chart of literature search results

The methodological characteristics documented included: authors; publication year; country; study design; comparison group; outcome measures; disease; sample size and response rate; survivorship period; cancer-specific and non-cancer-specific tools; reported unmet informational and practical needs; results and study quality[28], as shown in Table 2. Due to variations in study population, methodologies and tools used, meta-analysis was not possible. Study quality was assessed using Fowkes and Fulton's[28] guidelines and checklist for critically appraising quantitative research. Assessment of the methodological quality of studies utilised a classification system of poor (under 40% of quality items), good (40–70% of quality items) or very good (over 70% of quality items) as reported by Hall *et al.*[8]. In addition, the validity of each tool was assessed according to: how the tool covered the informational and/or practical needs of the participants; correlation with other generic cancer or survivor-specific tools; and whether results confirmed study outcomes. Tool reliability was determined by internal consistency of the items and whether test-retest reliability had been performed. Generalisability of the tool to leukaemia or lymphoma survivors was gauged from the study results, along with the clinical usefulness of the tool for these survivors.

Data analysis

The initial search yielded a large number of abstracts (n=5234). Following removal of duplicate articles and abstract screening using exclusion and inclusion criteria, 32 full text articles were sought and further appraised. Of these, seven articles were reviewed and referred to one or more relevant tools[2,6,29-33]. No tool had been specifically developed for exclusive use with leukaemia or lymphoma survivors. Two studies reported researcher-developed questionnaires[2,29].

The seven included articles reporting haematological cancer survivor cohort studies were from Australia (n=2), Canada (n=1), the United States of America (USA) (n=3), Norway (n=1) and United Kingdom (UK) (n=1). The periods of survivorship ranged from six weeks post-treatment through to 12 years after diagnosis[2,3,7,30-33]. Of the reviewed studies, four utilised comparative groups related to unmet needs among different: treatment types[30]; countries[6]; gender[2]; and survivors and physicians[29]. Outcome measures varied across all studies, although the majority related to unmet needs after treatment completion (Table 2). The assessment of methodological quality[28] revealed most studies (n=5) were "good"; two were classified as "poor". Two studies[32,33] utilised mixed method designs, six studies[2,6,29,31-33] were cross-sectional and one[30] was prospective. Methodological quality varied with sample sizes ranging from 22 to 477 participants and response rates varying from between 29% and 94%.

Table 2: Methodological characteristics of selected articles (n=9)

Authors **Year** **Country**	**Study design** **Comparison group** **Outcomes measured**	**Disease** **Sample size (response rate %)** **Survivorship period**	**Tools** **Cancer survivor-specific** **Non-cancer tools/** **Investigator questions**	**Unmet information/ Practical needs reported**	**Results**	**Study quality**
Arden-Close *et al.*[2] 2011 UK	Cross-sectional Administered questionnaires Gender comparison Health-related quality of life, late effects and perceived vulnerability; satisfaction with care; expectations and satisfaction of clinic visit	Lymphoma n=115 (79.9%) › 5yrs	QoL-CS (Quality of Life Cancer Survivors) Yes SF-12v2 (Medical Outcomes Study Health Survey Short Form 12 version 2) Princess Margaret Hospital Satisfaction with Doctor Questionnaire	Only questions related to discussion of topics, late effects	No gender difference in late effects or perceived vulnerability Men: more late effects, worse health-related quality of life, wanted to discuss more topics (women discussed the topics) Shorter wait time = more topics discussed Health-related quality of life dependent on whether survivors' follow-up expectations are met	Good
Friedman *et al.*[29] 2010 USA	Cross-sectional Mailed questionnaire Comparison of survivors and physicians Informational survivorship care plan needs of survivors and physicians Congruence between survivors/ physicians	Non-Hodgkin lymphoma n=67 (41%) 9 months – 12.6 years Physicians involved in survivorship care n=22 (29%)	Investigator questionnaire	Informational needs to be included in survivorship care plan	Survivorship care plan tailored for particular survivors Survivor: survivorship care plan inclusions: screening for recurrence/late effects; treatment summary; monitor overall health/nutrition/exercise; insurance Survivor/physician concordance higher on medical issues compared to psychosocial issues No differences reported between survivorship length	Poor
Hall *et al.*[6] 2013 Australia Canada	Cross-sectional Cross-cultural Mailed questionnaires Comparison of Australian and Canadian haematology survivors Percentage of survivors reporting unmet needs; domain scores; 10 most prevalent high unmet needs	Leukaemia, lymphoma, multiple myeloma Australia: n=268 (37%) ‹3 years Canada: n=169 (45%) 1–5 years	SUNS (Survivors' Unmet Needs Survey) Yes	Informational needs: cancer recurrence and spread Work and financial needs	Similar levels of unmet needs Fatigue highest concern across both cohorts Multiple areas of need found in: females, younger age, expense due to cancer, vocational education level, seeing doctor about treatment or concerns Work and financial needs higher for Australian survivors	Good
Hjermstad *et al.*[30] 2003 Norway	Prospective cohort at 4 time points Administered questionnaires Comparison of autologous lymphoma with allogeneic leukaemia transplant patients Rehabilitation needs and health-related quality of life; physical function measures of CARES-SF compared to EORTC QLQ-C30	Leukaemia, lymphoma n=123 (94%) ‹1 year post-transplant	CARES-SF (CAncer Rehabilitation Evaluation System Short Form) No EORTC QLQ-C30 (European Organization for Research and Treatment Quality of Life Core questionnaire) No	Financial, insurance, weight gain, transport, fear of recurrence, employment, fatigue	Few patients requested help with any items CARES-SF useful for assessing sexual, marital, medical interaction to address specific issues at follow-up High correlation with physical function between the two scales	Good
Lobb *et al.*[31] 2009 Australia	Cross-sectional Mailed questionnaire No comparison group Assessment of unmet informational and emotional needs after treatment	Leukaemia, lymphoma, multiple myeloma n=66 (50%) 6 weeks – 1 year post-treatment	CaSUN (Cancer Survivors Unmet Needs Survey) Yes	Concerns: fear of recurrence; care coordination; information on services	Care coordination after treatment important, significant for unmarried or working patients Fear of recurrence, emotional and relationship needs greater in younger patients Top endorsed needs: managing health with medical team; communication between doctors; best medical care	Good
Parry *et al.*[32] 2012 USA	Mixed methods Cross sectional Mailed questionnaire No comparison group Health service and psychosocial needs of adult leukaemia and lymphoma survivors	Lymphoma, leukaemia n=477 (45%) ‹4 years	Houts *et al.* Service Need Inventory, refined by Kornlith *et al.* 14 items	Practical needs: child care; financial	Unmet need highest in: sexual issues; handling medical and living expenses; emotional difficulties; employment; health insurance Women more likely to report unmet child care needs Relationships were observed among service needs, overlapping areas of unmet need	Poor
Zebrack[33] 2000 USA	Mixed methods Cross sectional Mailed questionnaires/semi structured interviews No comparison group Experience of quality of life in long term survivors at various life stages	Leukaemia, lymphoma n=53 (50%) 10 years	QoL-CS (Quality of Life Cancer Survivors) Yes 27 In-depth interviews	Fear of recurrence, fatigue, employment, support, financial, family	Fatigue, pain, fear of recurrence – ongoing issues Family distress and finances continue to impact survivors Financial issues worse in older survivors Relapse not related to quality of life Income rated significantly to quality of life Positive associations with ability to cope after cancer	Good

Results

Five tools were identified and could be dichotomised as either those designed for cancer survivors (survivor-specific) or those developed for cancer patients undergoing treatment and used with a cancer survivor cohort (generic cancer tools). Utilising the definitions of informational and practical needs as previously described ensured consistency with the data extracted from the articles. Comparisons of the five main assessment tools identified in this review are shown in Table 3.

The generic cancer tools: CAncer Rehabilitation Evaluation System Short Form (CARES-SF); and European Organization for Research and Treatment Quality of Life Core questionnaire (EORTC QLQ-C30) were not survivor-specific and no data in relation to previous use in any haematology survivor cohorts was described[30]. Reliability scores and validity information was variable in the detail reported. Similarly, the three cancer survivor-specific tools: Cancer Survivors Unmet Needs Survey (CaSUN); Quality of Life Cancer Survivors (QoL-CS); and Survivors' Unmet Needs Survey (SUNS) provided variable reliability and validity data[2,6,31,33].

All studies documented tool domains and scoring scales. Only two tools addressed both informational and practical needs (CaSUN, SUNS)[6,31]. The SUNS is the only tool developed using a mixed cohort that included haematological cancer survivors[6]. All reviewed articles reported the clinical usefulness of the tools to the haematological cohort studied.

The majority of studies (n=5) assessed the informational needs of survivors (Table 2). Of the survivor-specific tools used to assess informational needs, the CaSUN[31] includes an explicit information domain with response items such as: "I need up to date information"; "I need understandable information". It is assumed that follow-up is required for those patients who score highly for such items. The SUNS tool similarly includes an informational domain with questions targeted to "Finding information ..." or "Dealing with fears ... or feelings..."[6]. In general, a high score allows the assessor to identify areas of need. However, neither tool explicitly asks if the survivor would like help with their issue or concern.

Arden-Close *et al.*[2] measured gender-related informational needs using the cancer survivor-specific tool QoL-CS. Although this article made gender-specific recommendations, it did not provide insight into what assessment tools best identify gender differences. Friedman *et al.*[29] developed a questionnaire that focused on information that should be included in survivorship care plans such as: specific information about cancer recurrence; nutrition and exercise; screening plan; and information for family members. This questionnaire both identified needs and

Table 3: Comparison of assessment tools

Tool	Cancer survivor-specific	Content	Scale Scoring	Information needs	Practical needs
CARES-SF (CAncer Rehabilitation Evaluation System Short Form)	No	59 items – degree problem applies 5 summary scales: physical; psychosocial; sexual; marital; medical interaction	5 point Lower scores = fewer problems	No	Yes
CaSUN (Cancer Survivors Unmet Needs Survey)	Yes	35 supportive care needs items, 6 positive outcome items, 1 open-ended item 5 needs domains: existential survivorship; comprehensive cancer care; information; quality of life; relationships	5 point Higher scores = greater needs	Yes	Yes
EORTC QLQ-C30 (European Organization for Research and Treatment Quality of Life Core questionnaire)	No	5 functioning scales: physical; role; emotional; social; cognitive 3 symptom scales: pain; fatigue; nausea and vomiting 6 items: dyspnoea; sleep; appetite; diarrhoea; constipation; financial impact	8 point Function: higher scores = better function Symptom: higher scores = more problems	No	Yes
QoL-CS (Quality of Life Cancer Survivors)	Yes	4 domains: physical well-being (8 items) psychological well-being (18 items) social well-being (8 items) spiritual/existential well-being (7 items)	10 point Higher scores = best QoL	No	Yes
SUNS (Survivors' Unmet Needs Survey)	Yes	5 domains: informational needs (8 items) financial concerns (11 items) access and continuity of care (22 items) relationships (15 items) emotional health (33 items)	5 point Higher scores = greater need	Yes	Yes

enquired whether respondents wanted information. On the other hand, the CARES-SF[30] does enquire if patients would like assistance with their concerns. However, it does not explicitly identify survivor informational needs. In contrast, Parry *et al.*[32] used a non-validated survey that identified informational and practical needs of haematology survivors examining if participants received the help they required.

The definition of "practical need" differed between authors, making identification of suitable tools somewhat difficult. The QoL-CS tool[2,33] examined practical concerns including: employment; sexuality; financial burden and fatigue. Unlike the other cancer survivor-specific tools, a higher score indicated a better quality of life outcome. It was unclear if the tool recommended users to follow up concerns that generated low scores. Similarly, the EORTC QLQ-C30 assessed the practical need of financial concerns, but focused on more treatment-related concerns that are unlikely in the survivorship phase[30]. Needs relating to fatigue management, fertility, sexuality, nutrition, exercise, insurance, finances and employment were explored by the majority of tools or investigator-derived questionnaires to varying degrees. The late effects of treatment were reported as both an informational need and a practical area where a plan for screening should occur[2,29]. Likewise, fear of recurrence issues were similarly reported[6,29-31,33].

Although a variety of tools was used, there was consensus regarding the most prevalent leukaemia and lymphoma survivor informational and practical needs. The commonly reported informational needs were: treatment late effects; cancer recurrence including fear of recurrence; care coordination; and information on available resources[6,29-31,33]. The most consistently identified practical needs were: fatigue management; employment; financial; insurance; family; and sexuality[6,30-33]. Arden-Close *et al.*[2] addressed potential differences in gender and found men wanted more information; however, they were often unable to receive this from the medical consultation. Women, on the other hand, were able to discuss the topics they wanted. Other studies found women had higher unmet needs related to family issues[6,31,32]; similarly younger survivors had higher unmet informational and practical needs[6,31]. Conversely, disease and treatment type did not identify those with greater unmet needs.

Discussion

Providing information across the cancer continuum is one of the most important aspects of care, yet it is a frequently reported unmet need, especially in the survivorship phase[34]. Leukaemia and lymphoma patients differ from other cancer patients in the considerable variability between their cancer types and the range of treatments affecting many aspects of their lives[8]. With improving survival rates, those diagnosed younger (18–45 years) can now expect to live longer, raising additional concerns and unmet needs[2]. Information provision must be individualised and tailored to specific patients' needs[32,34]. As highlighted by Friedman *et al.*[29], survivorship care plans need to account for differing informational and practical needs of survivors, primary care providers and haematologists.

Generic cancer tools include items related to diagnosis and treatment issues, which are not necessarily specific to the survivorship phase. This review has shown that survivor-specific tools can be used to assess unmet needs of leukaemia and lymphoma participants in the survivorship phase. Therefore, tools specific to the survivorship phase would be more appropriate to assess for unmet needs and concerns in this cohort.

Arden-Close *et al.*[2] and Aziz[22] have argued that survivors should be afforded the opportunity to obtain support and access resources earlier in the survivorship continuum. They assert survivors need information about immediate and long-term impacts of the cancer, together with practical needs related to fatigue, exercise, nutrition, fertility, sexuality, insurance, finances, employment and late effects. Leukaemia and lymphoma survivors may also want resources to address healthy lifestyle choices[2,35] or support to deal with the psychosocial aspects such as relationships, anxiety and fear of recurrence, reported in many studies as the highest unmet needs[6,30,31].

We acknowledge a number of limitations. There was variation in tools used across a wide range of survivors from the early survivorship phases (under two years)[6,30-32] through to 12 years post-diagnosis[29,33]. This made comparative generalisations of informational and practical needs difficult and enabled only tentative conclusions. Our findings are limited to comparing those areas surveyed with the assessment tools. As such, the review could not determine a broader range of supportive care needs for all haematological cancer survivors. Further, the relatively low response rate reported for some studies reduces the likelihood of the sample being representative of leukaemia and/or lymphoma survivor populations, and sampling bias could result in distorted conclusions. Extracting the psychometric properties of the tools was hampered by a lack of detailed data to support validity and reliability[6,30,31]. Finally, an inherent bias in interpretation might be considered.

Notwithstanding the limitations, this review identified a consensus on the most prevalent informational and practical needs of leukaemia and lymphoma survivors. This important finding can assist haematology cancer nurses when making decisions regarding the most appropriate tools to use and may assist in the development of haematology cancer survivor-specific tools that measure: perceived informational and practical needs; the extent to which needs are being met; and the survivors' need for support across all supportive care domains. In this way nurses are ideally positioned to provide individualised information and resources to these survivors and further this area of research.

Conclusion

There is a paucity of studies related to leukaemia and lymphoma survivors and specific validated tools that can be used to identify and measure the informational and practical needs of this cohort. While cancer survivor-specific needs assessment tools do exist and have been used with more common cancer groups, further research is required to determine their relevance and applicability to leukaemia and lymphoma survivors to ensure specific concerns are heard and addressed via appropriate support and information. Equally, generating psychometric data will ensure valid and reliable tools are utilised. As the only tool developed that included a haematology cohort, the use of the SUNS tool in further leukaemia and lymphoma survivor populations will allow a greater body of knowledge to be developed.

Appendix: Combinations of search terms used

haematology cancer OR haematology (hematology) malignancy OR hematologic neoplasm OR haematological (hematological) cancer OR blood cancer OR acute leukemia (leukaemia) OR myeloid acute OR lymphocytic acute OR nonlymphocytic acute OR lymphoma OR Hodgkin disease/lymphoma OR Non (non) Hodgkin's OR T-Cell OR B-Cell OR oncology
AND tool/s OR screening tool/s OR instrument/s OR measurement tool/s OR measurement scale/s OR psychological test/s OR questionnaire/s
AND survivor OR survivorship OR cancer survivor/s OR after cancer
AND supportive care need/s OR unmet need/s OR need/s OR needs assessment OR perceived need OR information needs OR practical needs

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The Australian Journal of Cancer Nursing

A scoping exercise by the CNSA Education Standing Committee regarding enrolled nurse (EN) administration of antineoplastic agents

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Abstract

A change to the scope of practice for Australian nurses providing cancer care services is an important national professional issue. This article will outline the contemporary issues that have created opportunities for expanded scope of practice of the enrolled nurse (EN) to include administration of antineoplastic agents. A range of professional issues related to registered nurse (RN) delegation and supervision of EN practice need to be considered. The potential impact on patient outcomes is fundamental to this discussion. The literature review identified limited information; however, a discussion of potential facilitators and challenges associated with expanding the scope of practice of an EN to include antineoplastic agents is presented. There is a need for further clarification of the RN role in delegation, education requirements and competency assessment.

Introduction

Increases in the incidence and treatment of cancer have placed higher demands on oncology service delivery in Australia. Changes to workforce, the place where cancer care is delivered and by whom are key factors that have a potential to impact on the nurse's scope of practice. Nurse administration of antineoplastic agents has traditionally been an exclusive role of the registered nurse (RN); however, enrolled nurses (EN) are now increasingly involved in the delivery of antineoplastic agents. This paper presents a review of literature (grey and published) exploring the key issues for consideration when expanding the role of the EN to include administration of antineoplastic agents, to ascertain current practice, and inform future recommendations for practice.

Background

The increased prevalence of cancer in Australia has had a significant effect on the health workforce. The number of new cancer cases expected to be diagnosed in 2014 is 2.6 times as high as in 1982[1]. Five-year survival from all cancers combined increased from 47% in 1982–1987 to 66% in 2006–2010[1]. Along with these epidemiological changes, the use of antineoplastic agents in cancer control and the associated expenditure has increased exponentially in Australia over the past decade[2].

The influence of Australia's geographic diversity, with approximately 29% of Australians living in rural or remote areas, is another factor which has changed the delivery of cancer care[3]. The provision of oncology care closer to the patient's home is recognised as an optimal level of care for rural and remote patients[4]. Changes in patient acuity, epidemiology, treatment and the spread of patients across Australia have had a significant impact on cancer services, challenging traditional models of cancer care. The administration of antineoplastic agents by ENs has emerged in response to some of these influences. With the changes of practice to the delivery of antineoplastic agents, RNs and ENs require a clear understanding of the professional, legal and quality implications of this expanded scope of practice of ENs. Potential changes in the scope of practice of nurses should be led by nurses. The Cancer Nurses Society of Australia (CNSA) Education Standing Committee identified a lack of clear understanding and offered to undertake a review of the literature to explore considerations related to EN administration of antineoplastic agents, which was supported by the national professional body, the CNSA.

Health workforce changes

In 2013, Health Workforce Australia developed a strategic plan to build sustainable and focused workforce to meet the changing population needs. A number of recommendations, which related to the "optimal use of skills and adoption of workforce innovation and reform", were suggested[5]. These recommendations highlighted the need to focus on building a workforce where evidence-based decisions are taken on the basis of the consumer need rather than on local or traditional referral patterns. A larger workforce than currently exists is required to meet the needs of the person with cancer if their antineoplastic treatment is to be delivered in a safe environment as close as possible to their home[4]. Any changes to a model of cancer care delivery in response to these needs and expansion of the nursing scope of practice requires organisational support and consideration of risk management strategies.

The nursing workforce

In Australia, there are three regulated groups of nurses: ENs, RNs and nurse practitioners (NPs)[6]. The Nursing and Midwifery Board of Australia (NMBA) competency standards define the requirements of all nurses and guides practice. However, the competency standards are not specific to the context in which nursing care is being provided and do not identify specific skills. The EN is defined as an associate to the RN, who demonstrates competence in the provision of patient-centred care as specified by the registering authority's licence to practise, educational preparation and context of care[7]. The EN must work under the direction and supervision of the RN; however, the EN retains responsibility for his/her actions and remains accountable in providing delegated nursing care[7]. It is outside the scope of this paper to review the role of the NP in the delegation and supervision of EN practice.

In the 1990s, the most significant change to the scope of practice of ENs was the addition of medication administration[8]. In recent years, there have been case reports of precedents for ENs to expand their scope of practice to areas which have traditionally been solely within the RN scope of practice. Examples include haemodialysis[9] and care of central venous access devices[10]. The scope of practice of the EN is determined by entry to practice learning, continuing education, and organisational governance and support. For example, an EN may administer intravenous medication on completion of relevant education, development of skills and aptitude and assessment as competent by the employing health service[7]. Employers have a responsibility to ensure processes and guidelines are in place for employees to complete approved educational requirements and are trained for any nursing activity they undertake[11].

Whilst current Australian Nursing and Midwifery Council (ANMC) standards are available to guide nursing practice, operationalising the standards in relation to administration of antineoplastic agents requires further guidelines, recommendations and tools. These will enable RNs and ENs to practise safely and confidently and ensure safe patient outcomes. If a nurse's scope of practice includes administration of antineoplastic agents, they are responsible for ensuring that they are adequately prepared and competent to safely and efficiently deliver the care required. The RN is also accountable for making decisions about who is the most appropriate person to perform an activity that is in the nursing plan of care[7]. When considering expanding the professional scope of practice of a nurse, there is a national decision-making framework for nursing and midwifery practice. Principles of the decision-making framework include the need to make nursing practice decisions in a collaborative context of planning, risk management, evaluation and individual accountability of the nurse for her/his practice[7].

Currently in Australia there are professional guidelines and practice standards for the administration of antineoplastic agents by RNs only[12-14]. However, given current health service and workforce changes, there is a need to explore the advantages and challenges of expanding the scope of practice of other health practitioners such as ENs, to include antineoplastic administration.

Method

A review of the current knowledge around the EN scope of practice and administration of antineoplastic treatments was completed by the CNSA Education Standing Committee. A scoping framework for the literature review was developed to outline key issues and recommendations. Figure 1 outlines the scoping framework developed in July 2012. Context of practice, patient outcomes, RN issues and EN issues (such as scope of practice), and delegation and supervision of EN practice were identified as factors requiring due consideration.

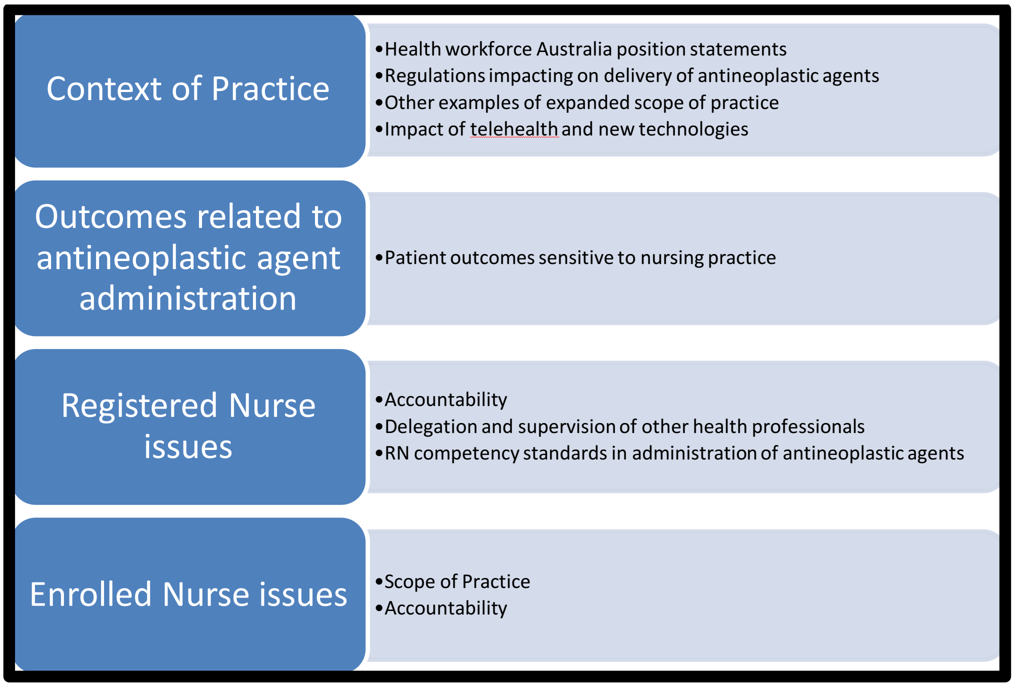
Discussion

Context of practice

Some health services are responding to the need to prepare the health workforce to administer antineoplastic agents in rural, regional and non-cancer specialist settings by considering a tiered service delivery model. The tiered model considers whether some antineoplastic agents or modes of administration are "safer" or "less complex" than others and outline the service delivery responses required[15]. Delineation of service delivery reflects the availability of facilities, infrastructure, clinical and non-clinical support. One model has identified the possibility of "dividing antineoplastic agents into two tiers: Tier I for non-oncology nurses and Tier II for oncology nurses"[16]. The aim of using a tiered approach would be to delineate between antineoplastic agents that are safe for ENs to administer and those required to be administered by an RN. However, there is limited evidence as to the most useful way of delineating the tiers.

There has also been a shift towards the use of oral antineoplastic agents. Some oral antineoplastic agents may be considered "safe"; however, a shift to oral therapy does not correlate with reduced risks associated with treatment. The shift to oral antineoplastic agents has highlighted the need for expertise in the delivery of information and strategies to ensure adherence and safety in the outpatient environment[17].

Expanding the EN scope of practice has implications for organisations and the professional development of the EN into a specialty-based, advanced role. Due consideration would need to be given to the emerging complexities associated with advances in antineoplastic therapy. There is a high potential for harm, with limited margin for error, when antineoplastic agents are used[18]. The risk management strategies currently in place include specialised education and the development and assessment of competence related to administration of these agents by RNs. This would need to be extended to ENs[8]. It has



Context of Practice	•Health workforce Australia position statements •Regulations impacting on delivery of antineoplastic agents •Other examples of expanded scope of practice •Impact of telehealth and new technologies
Outcomes related to antineoplastic agent administration	•Patient outcomes sensitive to nursing practice
Registered Nurse issues	•Accountability •Delegation and supervision of other health professionals •RN competency standards in administration of antineoplastic agents
Enrolled Nurse issues	•Scope of Practice •Accountability

Figure 1: Scoping framework, July 2012

been recognised by the CNSA that the safe and effective delivery of these agents requires highly complex clinical assessment and technical and problem-solving skills[14].

There is a risk that the complex, holistic process of administering antineoplastic agents is reduced to tasks to enable ENs to perform them without clear supervision by the RN. This has been reported in other Australian scope of practice pilot projects[8] questioning the change of roles of the EN in the delivery of patient care. Concerns have been raised that "this could be detrimental to patient care, as complex thinking and analytic skills are seen to be different for the two levels of nurses"[19]. To support safe and effective practice, a nationally consistent approach is required to ensure a minimum level of educational preparation and competence is maintained for ENs involved in the administration of antineoplastic agents.

In light of contemporary issues and potential EN role expansion, future preparation of all nurses administering antineoplastic agents requires review. Preparation should include an emphasis on communication, information provision and promoting self-management. Professional issues need to be included in any education program preparing nurses for antineoplastic administration. Professional issues include areas such as increasing awareness of the scope of practice for RNs and ENs, decision-making principles and the responsibilities and actions associated with delegation and supervision.

Impact on patient outcomes

Patient outcomes are a key element by which to measure service efficacy, patient safety and satisfaction. Changes to a person's functional and disease status contribute to quality of life outcome measures[20]. In the acute care setting it has been demonstrated that outcomes such as 30-day mortality are reduced when there are a higher proportion of baccalaureate-prepared nurses, higher RN to non-RN ratios, lower numbers of casual staff and collaborative nurse–physician relationships[21]. There is limited research regarding factors that influence nurse-sensitive outcomes in cancer control.

The Oncology Nursing Society (ONS) defines nurse-sensitive outcomes as "those outcomes arrived at, or significantly impacted, by nursing interventions"[22,23]. The ONS suggests a framework for the measurement of cancer nurse-sensitive outcomes that involves classifying outcomes such as changes in symptom experience, functional status, safety, psychological distress, and cost/economics[22]. A literature review of nurse-sensitive outcomes in ambulatory services identified a broad range of outcomes potentially sensitive to nursing, but there was little evidence that linked the outcomes with nursing practice[22]. The review indicated that potential areas requiring further research to assess their significance include patient experience, nausea, vomiting, mucositis and safe medication administration[23]. Understanding nurse-sensitive outcomes and the factors that influence them in settings where antineoplastic agents are administered may provide some evidence regarding the impact of a changed service delivery model and/or expanded scope of practice.

RN issues

The ANMC provides a clear process for decision making related to delegation of tasks at http://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements/Frameworks.aspx[26]. Successful delegation relies on the RN's and EN's ability to communicate effectively and resolve conflict, whilst working within health service policy and guidelines[24]. At present there is no determination regarding specific variables which are relevant when deciding if administration of antineoplastic agents should be undertaken by an RN or EN. The RN who delegates an activity to the EN is accountable, not only for the delegation decision, but also for monitoring the standard of performance of the activity, and for evaluating the outcomes of the delegation[24].

Whilst the health workforce has changed to meet the needs of cancer patients, the scope of practice and regulations for the EN have not been reviewed[7]. In particular, the required level of supervision related to administration of antineoplastic agents by ENs has not been defined. Further work is required to determine if supervision is required for EN administration of antineoplastic agents if the activity is deemed to be within an individual's scope of practice and is not a delegated task. How performance is monitored and outcomes evaluated in relation to administration of antineoplastic agents also requires clarification and a nationally consistent approach.

EN issues

Expansion of the scope of practice of ENs to include antineoplastic administration presents some challenges. Given that until recently there has been state-based regulation of nursing registration in Australia, there are likely to be state by state differences in addition to hospital- and ward-based differences in the scope of practice of the EN. It has been reported that rural ENs have greater levels of responsibility compared with their metropolitan counterparts[25]. Role confusion and concerns regarding professional "role erosion" may be further compounded with EN expanded scope of practice[8,9]. It has been suggested that RNs are unsure of the level of EN core education and training. The diversity of EN preparation, ranging historically from Certificate IV to diploma level, has contributed to this confusion. Tensions can arise when role boundaries are not clearly delineated[8,9]. However, the need to consider the expansion of the scope of practice of the EN in cancer care has become an imperative.

Conclusion

As the prevalence and treatment approaches for cancer have changed, health services are considering expanding the scope of practice of the EN to include administration of antineoplastic agents. This literature review has explored the scope of practice and roles of the RN and the EN, highlighting the workforce challenges as RNs struggle to understand and supervise the EN in the changing roles. The safety and needs of cancer patients must underpin any practice change. The organisational requirements must ensure safe and sustainable practice is developed. These requirements should provide decision-making tools to ensure safe practice for both patients and staff and an environment to support the education and preparation of all nurses. This would encompass managing the care of the person receiving antineoplastic agents and RNs delegating and supervising the administration of antineoplastic agents by ENs.

Recommendations

Additional research is required to understand the EN scope of practice across the oncology setting. Investigation of RN supervision and delegation models of care would enable updated scope of practice for both RNs and ENs administering antineoplastic medications underpinned by evidence. The development of new guidelines in view of the changes in the workforce would enable a standardised national approach to antineoplastic education programs.

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The role of the oncology nurse practitioner in the clinical management of febrile neutropenia

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Abstract

Background

The nurse practitioner is a protected title in Australia and is available to an experienced registered nurse educated at Master's level and authorised to function in an advanced and extended clinical role. The role of oncology nurse practitioner (ONP) is to meet the diverse and specialised needs of cancer patients. One important aspect of care for the ONP is the clinical management of febrile neutropenia.

Objectives

The purpose of this paper is to present some of the findings from a qualitative study that explored the ONP role and experience in the clinical management of febrile neutropenia across the inpatient, outpatient and the home settings across Australia.

Method

A descriptive, exploratory research approach was used to describe, explore and generate meaning on the clinical management of febrile neutropenia.

Findings

The research findings indicated that ONPs do significantly impact upon the oncology patient experience in relation to risks and management of febrile neutropenia.

Keywords

Oncology, nurse practitioner, febrile neutropenia.

Introduction

In Australia the title nurse practitioner (NP) is protected under national legislation. Only experienced registered nurses educated at Master's level and authorised to function autonomously and collaboratively in an advanced and extended clinical role can apply to the Nursing and Midwifery Board Australia (NMBA) to use the title nurse practitioner[1]. The NP provides a high level of clinically focused nursing care to patients with varying complexity[2]. The role of the oncology nurse practitioner (ONP) is to meet the diverse and specialised needs of the cancer patient[3-5]. This occurs in partnership with the medical oncologist and wider cancer multidisciplinary team. One important aspect of care for the ONP is the clinical management of febrile neutropenia. This article presents the findings from a qualitative research study designed to explore the experience of the ONP in regard to their role and responsibilities in the clinical management of febrile neutropenia across the inpatient, outpatient and home settings in Australia. Though this role is located in the Australian context, the discussion and outcomes from this study have relevance to nurses working in the area of oncology in many countries around the world.

Background

Febrile neutropenia is a major cause of chemotherapy treatment delays and dose reductions, which can compromise the efficacy of cancer treatment and adversely impact on cancer survival in the curative setting[6]. It is considered a life-threatening oncological emergency; it is defined as a fever of 38.3°C (or at least 38.0°C on two occasions) in the setting of a reduced absolute neutrophil count[7]. Although most cases of febrile neutropenia can be successfully treated, serious complications can develop and mortality can be significant in some patients[8].

To date, in Australia, little attention has been given to exploring the specific role of the ONP in managing febrile neutropenia; however, Nirenberg *et al.*[9] provides strong evidence that oncology nurse interventions can contribute to optimising patient outcomes. With the increasing numbers of ONPs in Australia, it was timely to explore the experiences of these nurses in the clinical management of febrile neutropenia to understand the development of the role in this area and identify the benefits to the patient experience. Despite the inclusion of assessment and management of febrile neutropenia in the majority of available ONP Scope of Practice documents sourced online, the existing peer-reviewed literature fails to inform ONPs about the specific components of their role, in relation to the management of febrile neutropenia.

For these reasons, it was important to investigate the nature of the ONP role, in an attempt to clarify the role and responsibilities of the ONP scope of practice. Identification of the barriers and facilitators for expanding the delivery of safe and effective care to patients with febrile neutropenia could only enhance and support the ONP role.

Method

Design

A descriptive, exploratory research approach was used to describe, explore and generate meaning on the clinical management of febrile neutropenia, in particular the ONP experience of their role and responsibilities. Qualitative research was chosen for its ability to link individuals' perceptions, thoughts and feelings, with the intention of understanding personal experiences, interpretations and constructs[10].

Data collection

ONPs or oncology nurse practitioner candidates (ONPC) from across Australia were invited to participate in this research. Permission was gained to access the Cancer Nurse Practitioners of Australia national database to identify potential participants who were invited, via email, to participate. The researcher sent the emails by a second party and not directly. Participants were provided with a participant information sheet that outlined the research project.

This research used eight in-depth telephone interviews to explore the experience of the ONP in the clinical management of febrile neutropenia. The researcher developed an interview schedule that listed open-ended questions designed to facilitate open dialogue between the researcher and the participant. Interviews were audio recorded and transcribed verbatim.

Data analysis

Thematic analysis was used to examine the data in this research. The framework described by Braun and Clarke[11] was adopted as it was considered an appropriate and auditable approach for the qualitative analysis. Attention was paid to ensuring a systematic method of data analysis, consistent with the six phases described by Braun and Clarke[11]. A thematic map or visual representation of the emerging themes was developed. Ensuring accuracy in terms of content and context of the transcribed interviews was through repeated reading and synthesis of the data, then constant comparison with audio recordings. Becoming immersed in the data was critical to understanding the experience of the participant, as supported by the Braun and Clark[11] framework.

Ethical considerations

Ethical approval was granted by the University of Adelaide Low Risk Human Research Ethics Review Committee. This research was deemed to meet the requirements of the *National Statement on Ethical Conduct in Human Research*[12].

Results

A total of eight ONPs were recruited via invitation to all members of the Cancer Nurse Practitioners of Australia (CNPA) group. Response rate was calculated to be approximately 30% of the invited membership. Written consent to participate was obtained. Six participants were endorsed ONPs, while two were ONPCs working towards endorsement to be an ONP. Four participants were from large metropolitan hospitals, while four were from regional cancer centres. The participants came from five different states across Australia. Qualitative research enables small participant numbers where the interview process elicits insightful and thoughtful information. In this case it was in-depth, hour-long interviews with respect to their experience of the clinical management of febrile neutropenia, with very similar views emerging from the data.

Three themes that represented the role of the ONP in the clinical management of febrile neutropenia emerged. These included:

1. Engaging with and empowering patients to use effective self-care strategies to prevent or manage febrile neutropenia.
2. Holistic and timely nursing assessment and therapeutic intervention.
3. Accessibility and reliability of the experienced nurse practitioner.

1. Engaging with and empowering patients to use effective self-care strategies to prevent or manage febrile neutropenia

The participants identified a range of strategies that enabled their patients and carers to be empowered to respond to a change in their condition. The experienced ONP could demonstrate the importance of developing rapport, arming patients and their family with information and instilling confidence in their patients to respond early to a change in their condition and prevent a medical emergency:

> *… What I give my patients, in this nursing model, is all about empowerment. You're empowering your patients via information.* [Int 7, p. 15]

Patient education was readily mentioned by the participants, particularly in relation to the significance of febrile neutropenia; understanding the signs of infection; and how and when to access emergency care. Advanced communication skills were demonstrated through the ONP skills to assess their patients' learning ability. This enabled an appropriate level of patient education that saw the patient and/or carer respond to a change in condition through self-care strategies or contacting the ONP:

> *… education on side effects, signs of infection to look for, temperature and monitoring.* [Int 4, p. 3]

2. Holistic and timely nursing assessment and therapeutic intervention

In the event of the patient experiencing an episode of febrile neutropenia, conducting an advanced clinical assessment and implementing early intervention was the priority of the ONP. This theme emerged with an emphasis on a timely holistic assessment; including ordering of diagnostic tests, and planning and initiating early intervention. Participants recognised the need for a thorough advanced clinical assessment that incorporated a full clinical history and performing a physical examination:

> *I would assess them, do a full set of obs (observations), we would take bloods, including blood cultures. I would do a full physical assessment, listen to their chest and just identify whether there were any obvious sources of infection.* [Int 5, p. 3]

In addition to understanding the need for a thorough assessment, the ONP took this one step further and demonstrated the importance of timely therapeutic interventions. Emphasis was on "prompt" and "early" intervention:

> *… the priority is prompt treatment for early intervention, getting it all initiated. It takes away the burden of increasing the risk of them being septic and having to go to ICU.* [Int 6, p. 4]

> *I do the septic workup here in the oncology unit.* [Int 2, p. 2]

> *If they're clinically stable, I would request a full blood count, commence antibiotics and get them admitted.* [Int 5, p. 7]

For those ONPs working in the outpatient setting, forming a plan that the inpatient treating team could follow, once the patient was admitted to hospital was seen as an important part of the ONP role in enhancing the patient experience through continuity of care. The hospital team respected the ONP role and followed the plan without question:

> *You're putting plans in place. Some of them you can plan and execute, and others you plan and then someone else has to execute them. [Int 7, p. 8]*

Participants described how they as well as their patients valued the nursing role in holistic assessment with an emphasis on the psychosocial needs of the patients:

> *… the medical team have different perspectives in which to give them information that we can offer with nursing. I think as nurses we have more time to spend with patients, making sure that they understand and what the problems are, the management, what the options are and also making sure that they're coping with their disease and linking them in with other services.* [Int 8, p. 10]

3. Accessibility and reliability of the experienced nurse practitioner

There were a number of participants who considered their accessibility and reliability as critical to their patients' outcomes of care. The participants believed that the ONP was considered reliable in terms of their level of experience and knowledge; their accessibility; and their ability to collaborate and liaise with multidisciplinary team members effectively. Multiple participants identified with being readily available and their role provided a central point of contact for the oncology patient:

> *... being that contact person, patients may ring me during the day time, you know with a temperature of 38.* [Int 1, p. 2]

The ONP demonstrated specialist experience and knowledge and collaborated with the treating team as demonstrated in the following extract:

> *I would say to the RMO [resident medical officer], these are the things I've done, I've asked for a bed, they've just taken bloods, I've asked for a urine and a sputum, and there was nothing to swab, and I took a history, and this is what I think it is. So there's a much more in-depth conversation about the clinical encounter.* [Int 7, p. 11]

The ONP frequently interacted with the immediate treating oncologist. The ONP worked collaboratively, demonstrating effective liaison with the wider multidisciplinary team, especially during the process of admitting a patient from the community to hospital:

> *I would come out of the clinic rooms and then get, what we call the ball rolling, so I would ask the outpatient nurses to phone the bed manager, try and get a bed and then ask them to do the tests that I've requested, urine and set of observations if I haven't already done a set of obs [observations], and, so it's a case of getting the system working and prior to the RMO [resident medical officer] coming to do the admission.* [Int 7, p. 2]

Discussion

The purpose of this paper is to present some of the findings from a qualitative study that explored the ONP role and experience in the clinical management of febrile neutropenia in the inpatient, outpatient and home settings across Australia. These findings demonstrate that ONPs do positively improve upon the oncology patient experience in relation to the timely management of febrile neutropenia. The ability of the endorsed NP to work autonomously, critically analyse and take immediate action in requesting diagnostics and prescribing antibiotics positively impacted on patient care. Urgency of treatment of the febrile neutropenic patient is critical to a positive patient experience. These distinguishing features of the NP are what allows endorsed NPs to prescribe from the Pharmaceutical Benefits Scheme governed by the authorising body and are different from other advanced oncology nurse roles[2].

There were a number of elements of the ONP role that were thought to underpin competent performance and impact on the effective management of febrile neutropenia. These elements included the ONPs ability to empower patients to engage in self-care strategies through family and patient education; timely therapeutic intervention that was enhanced by greater accessibility to treatment options and holistic nursing assessment; and the NP's extended knowledge of febrile neutropenia, along with understanding how to appropriately navigate the health care system all impacted on positive patient outcomes. These findings were supported by the literature that places emphasis on facilitating processes for timely emergency care of the oncology patient[3,4,6]. The ONP is well placed to facilitate these processes[3-6].

ONPs identified applying evidence-based knowledge and appropriate patient-centred teaching strategies as critical attributes that enabled them to engage patients and carers to be responsible for self-care strategies. The experienced NP demonstrated the importance of developing rapport and arming patients and their families with information that allowed them to make sound judgements and respond appropriately to signs of febrile neutropenia or a change in their condition[13]. Development of the nurse–patient therapeutic relationship enabled trust, resulting in timely presentation and treatment of the patient. Like Nirenberg *et al.*[13], who emphasised the importance of patient education in recognising the early signs of likely chemotherapy-induced complications, Australian ONPs perceived this as an important element of the role. The knowledge imparted by the ONPs allowed patients to understand the risks associated with febrile neutropenia and the importance of seeking appropriate treatment in the event it was suspected. It was proposed by the ONPs that this knowledge enabled the patients to feel comfortable and take control of their care, by seeking help early and not to be concerned about accessing advice. This view by the participants was supported in the literature, where patient education was identified as critical in improving patient outcomes[3,6,9]. ONPs acknowledged that patients did in fact demonstrate a positive impact of education through prompt presentation in the event of signs of deterioration in their condition. This nursing practice also reflects the NP Standards of Practice[2] that states that NPs used their advanced skills to educate and support others to enable their active participation in care.

It was the views of the ONPs that they were more accessible to a patient and their families than the medical oncologist. They were more easily accessible either for telephone, outpatient or emergency department consultation in the event of suspicion of febrile neutropenia. The ease with which a patient could contact the ONP was thought to improve the patient's likelihood of reporting a change in condition. Leonard[6] agrees that NPs are well placed to identify those patients at greatest risk of febrile neutropenia, and advise these patients how to reduce the risk of infection, how to be vigilant for signs of infection and when to seek medical attention. The ONP participants clearly saw their accessibility as enhancing their role in facilitating rapid management of the febrile neutropenic patient, whether they worked in the inpatient, outpatient or community sector.

The ONP was also well placed to conduct a timely nursing assessment and utilise their extensive knowledge of febrile neutropenia management to have a positive impact on the patient experience, through expeditious treatment planning. Like Cox *et al.*[14], who provided evidence of the NP role in minimising patient waiting times, hospital admissions and emergency department presentations, the ONPs in this study identified with facilitating immediate assessment and therapeutic intervention, supporting these previous findings and adding strength to confirming the positive impact of the ONP role. The ONPs' specific cancer knowledge and ability to critically analyse clinical situations enables them to apply timely, evidence-based practice. The NP role is highly clinically focused and regulated by the National Board; in contrast, advanced practice nursing has a much wider domain of practice and is not regulated[1].

The ONP frequently collaborated with the medical oncologist and demonstrated effective liaison with the wider multidisciplinary team, especially during the process of admitting a patient from the community or outpatient setting to hospital. The nature of these collaborative relationships were dependent on individual ONP skills and were different for endorsed versus candidate NPs. This difference may be partly due to the accepted status of an ONP by their colleagues. The ONPs' knowledge of the health care system assisted in the facilitation of timely management of the oncology patient. In most instances the clinical management of the patient once admitted to hospital remained the responsibility of the medical staff; however, the ONP still continued to contribute to the care in the area of psychosocial assessment and referral advice. The exception to this was for ONPs working in a regional setting, where there were medical staff with limited experience in the management of cancer patients. There seemed to be a general consensus in large tertiary hospitals that the ONP Scope of Practice was not required to extend to the inpatient management of febrile neutropenia due to the number of oncology medical staff; however, in a regional setting, the ONP contributed to a much greater extent. Communication between the ONP and medical staff was thought to be critical to the effective clinical management of patients. There were similarities between the findings of this study and Leonard[6], who identified the importance of timely and patient-centred communication between the health care providers being critical to the patient monitoring for and adhering to the treatment of febrile neutropenia.

Limitations

This study was limited to the Australian context of which the role of the ONP is in its infancy. This is also a reflection of the small sample size; however, the process of qualitative research does account for this. The richness and consistency of the findings that emerged, however, means that it may be relevant to ONPs in other countries around the world.

Conclusion

The findings of this research have led to a clearer understanding of the specific contributions that ONPs make to the clinical management of patients experiencing febrile neutropenia. The Australian Nurse Practitioner Standards for Practice[2] that provided the framework for interpretation of the emerging themes has assisted in the clarification of key elements of the role that contribute to improving the patient experience. The core elements of the ONP role that are thought to positively contribute to these improvements were multifaceted and included timely therapeutic intervention that was enhanced by the accessibility of the ONP, along with their ability to utilise advanced assessment skills and facilitate expeditious treatment through collaboration with the wider multidisciplinary team and access to critical health service resources. It is hoped that these findings will further inform the development of the ONP Scope of Practice into the future.

Acknowledgements

We wish to acknowledge the nurses who gave their time to contribute to this study.

Conflicts of interest statement

The authors declare that there are no conflicts of interest.

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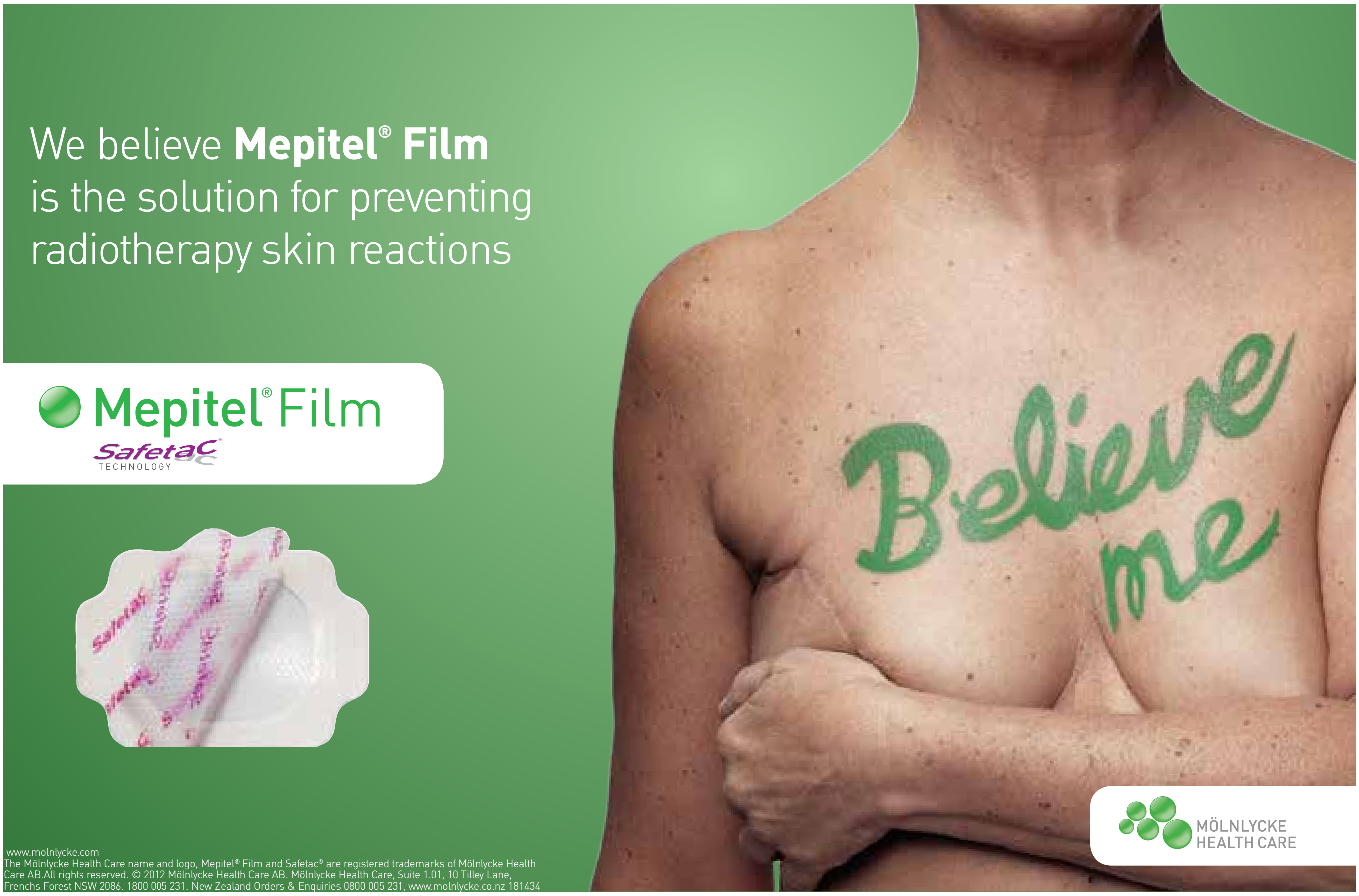

Development, face validity and reliability testing of a survey instrument to explore the role of the Australian breast care nurse

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Abstract

This paper reports the development of a survey instrument to explore the role of the breast care nurse (BCN) in the provision of information and support to Australian women with breast cancer, as well as the differences experienced by BCNs working in urban, rural and remote areas.

A comprehensive literature review and a panel of experts were used to inform the survey questions. The instrument was developed in an online format and pilot tested by a group of BCNs before being issued to participants.

The final version of the Breast Care Nurse Survey consists of 59 items organised into three sections. The survey was completed by 50 BCNs. Cronbach's alpha for Section Three of the survey was 0.935, indicating strong internal reliability; however, further validation of this instrument is recommended.

This is the first national survey to collect data about the role of the BCN in Australia, specifically related to the provision of education, information and support and the perceived barriers to undertaking the role.

Introduction

Breast cancer is the most common cancer among Australian women, with 12,567 cases diagnosed in 2007[1]. By 2015, the number of new breast cancer cases among women is projected to be 22% higher than in 2006, with the numbers of women diagnosed with breast cancer estimated to be around 15,409[1]. There is evidence many women do not have adequate information about their disease and treatment, nor receive enough practical and emotional support from health professionals[2-6]. Addressing these needs for rural women can prove even more difficult with rural health service provision challenged by issues of equity, coverage and supply[7].

Specialist breast care nurses (BCNs) were formally introduced to the Australian health care system in the 1990s to facilitate better continuity of care and psychosocial support for people diagnosed with breast cancer[8]. Evidence shows that BCNs are valued highly by their patients[8-10]; however, there has been little contemporary research conducted to investigate and report on the role of the Australian BCN[8,11]. This paper describes the development of a survey instrument to explore the role of the Australian BCN in the provision of information and support to women with breast cancer, with a particular focus on the differences between BCNs working in urban versus rural and remote Australia.

Background

In Australia, patients are treated in both public and private sectors and in urban, regional, rural and remote areas. Cancer care is delivered in a variety of settings, with a wide range of services provided. In 2004, the Australian Government established a National Service Improvement Framework for Cancer, which recommended a more coordinated approach to cancer care was required in which services be provided within a patient-centred and multidisciplinary framework[12]. The care of Australian women with breast cancer involves health professionals working collaboratively in multidisciplinary teams aiming to meet the multiple health needs of patients[12,13]. As a member of the multidisciplinary team, the specialist BCN was introduced in Australia in the mid-1990s to assist women with breast cancer through all aspects of the cancer care continuum[14]. A description of the evolution of the role of the Australian BCN follows.

The evolution of the Australian BCN

Since the introduction of the BCN to the Australian health system, the number of BCNs in Australia has grown; however, the exact number of BCNs currently employed in Australia is not known as no national database is maintained[15]. In recent years, organisations such as the McGrath Foundation have helped to raise the profile of BCNs in Australia. Jane McGrath personally recognised the importance of having a BCN during her treatment of breast cancer and, as a result, the McGrath Foundation was established to fund more BCN roles to support Australian families experiencing breast cancer, particularly those in rural and remote areas[16]. The McGrath Foundation sourced additional funding from the Australian Government Department of Health and Ageing in 2008 for funding of BCN support in 44 communities nationwide over four years. As at April 2013, the McGrath Foundation had placed 83 BCNs in Australian communities[16]. Further to this, the McGrath Foundation received additional Government funding of $19.5 million to increase the number of BCNs working for the McGrath Foundation[17].

Although the BCN position has been operating in Australia for almost 20 years, there is some doubt about whether all women with breast cancer have adequate access to a BCN. Campbell, Khan, Rankin, Williams and Redman[18] undertook a quantitative study (n=544) to explore access to BCNs by Australian women with breast cancer, with a focus on access to systematic BCN care. Systematic care was defined as having contact with a BCN at least three times; preoperatively, postoperatively and at follow-up. In this study, over half of the women surveyed had no BCN contact and only 11% received systematic BCN care[18]. Further, research conducted by Eley and Rogers-Clark[19] found adoption of the BCN model to be slow, with only 16 BCN positions for a population of four million in Queensland, Australia. Historically, there has been debate about the smaller caseload of BCNs in rural and remote areas, suggesting the role of the BCN in rural and remote settings is unsustainable[14].

BCNs in Australia are employed in a variety of health care settings and delivery of this health care service varies widely. Research suggests there is disparity of clinical roles, use of structured clinical pathway and inconsistent provision of continuity of care between BCN practice in Australia[20,21]. Currently, the McGrath Foundation is developing a National Breast Care Nurse Directory. Improved networking and collaboration between BCNs, and improved referral pathways between BCNs and from other health care professionals are two of the intended benefits of the Directory[22]. In Australia, the development of competency standards and educational requirements was regarded as an important step in addressing issues of role variation amongst BCNs[23].

Competency Standards

In 2003, the National Breast Cancer Centre commissioned a project to define a set of Specialist Breast Nurse Competency Standards in an attempt to standardise the role of the BCN in terms of outcome measures, training and education[23]. This project also noted the importance of the need to reflect the broad dimensions of specialist breast nurse practice[23]. As a result, the Specialist Breast Nurse Competency Standards were developed in Australia in 2005 to inform policy and procedure development, assist the community's understanding of the purpose of these nurses, provide a framework for curriculum development and evaluation and provide guidance for health workforce planning[13]. The Specialist Breast Nurse Competency Standards include five domains, each with associated competency standards, competency elements and performance criteria. These competency standards should be used in conjunction with other relevant competency standards for registered nurses and advanced practice nurses providing a framework that BCNs must meet to ensure that women with breast cancer are cared for by nurses who are well equipped to provide safe and effective nursing care[13,24,25].

There is a lack of rigorous research evaluating BCN service delivery in Australia, as reported in a recently published literature review[15]. This review revealed the provision of information and support to all Australian women with breast cancer through the BCN service is an area requiring more research. It was recommended that studies be conducted on a large scale, using participants from diverse geographical areas to gain an insight into the level of access experienced by Australian women from both urban and rural and remote areas. Additionally, a gap in evidence on the differing roles of BCNs working in varying geographical and practice contexts was identified[15].

Therefore, a study to address this gap was designed and a new survey instrument developed. This paper describes the process followed to develop and test face validity and reliability of a survey instrument to explore the role of the BCN in the provision of information and support to Australian women with breast cancer in both urban areas and rural and remote areas.

Method

A literature review of published material (2006–2012) was completed to identify current research and surveys developed in the area of BCN[15]. The authors from three Australian studies and one United Kingdom study were contacted to source pre-existing BCN survey instruments who then provided copies of their surveys[19,26,27]. The surveys sourced were useful for item generation; however, none could be used in their entirety to address the research questions for this study. Therefore, a new survey instrument was developed.

Item generation phase

Based on a review of published literature, the authors generated a pool of items relevant to exploring the role of the BCN in different contexts and geographical locations. As well, items were added to examine the breadth of the BCN role in the provision of education, information and support and perceived barriers to undertaking their role. Two items collecting demographic detail (see Table 1, sections 1 and 2) were replicated from a pre-existing survey completed in the United Kingdom[26]. Questions collecting specific geographical information were consistent with a previous survey conducted by the authors[28] and were based on the latest available information from the Australian Bureau of Statistics[29]. This required allocation of an Australian Bureau of Statistics Remoteness Area code to each participant, enabling comparisons between respondents working in urban areas with those working in rural and remote areas. Collection of geographical data in this way is useful for enabling direct comparison of results with other studies exploring geographical differences.

The performance criteria for Specialist Breast Nurse Competency Standards 1.1, 1.2, 1.3, 4.1 and 4.2 were used as a framework for generating items to explore the breadth of the BCN role in the provision of education, information and support and the regularity with which they undertake these activities, that is, their perceived ability to undertake these activities[30]. Given the lack of consistency about the role in Australia in the published literature, the researchers considered that national competency standards were an appropriate source for description of the type of care that might be expected of BCNs. Frequency was explored as a way of providing baseline data about the potential for these competencies to be realised.

Item selection phase

Content and face validity

A panel of five experts was chosen to evaluate the draft survey for comprehensiveness, clarity and completeness. These experts included two research academics with extensive experience developing and testing survey instruments, one currently practising BCN, one representative from the McGrath Foundation and one representative from the Breast Cancer Network Australia. This panel of experts was provided with a draft copy of the survey and an evaluation form, which guided the panel to comment on the content and structure of the survey.

Completed evaluation forms from the expert panel were collated and feedback was discussed within the research team, resulting in substantial modification of the draft survey to reflect this feedback. A number of suggestions were made to refine terminology or vocabulary and these were followed. A question was added to determine how many of the participants were McGrath BCNs. Questions related to time frames were carefully considered and altered to demonstrate clarity of provision of care, for example, per week/month. The relevance of two items were questioned and subsequently deleted. The questions exploring competency standards were restructured to eliminate ambiguity. Subsequently, the survey was transformed into an online format using Qualtrics software[31]. Five 'test runs' were completed to check flow and design resulting in minor alterations to improve text and structure.

Pilot testing

Ethical approval was granted (2013 196N). Snowball sampling was used to generate a database of expressions of interest in this research from Australian BCNs[32], resulting in a total of 70 expressions of interest. Three BCNs were randomly chosen from this database of 70 Australian BCNs to test the face validity of the online version. They were asked to complete the online survey as well as the evaluation form used by the panel of experts. The data collected in this evaluation was used solely for assessment and improvement of the survey design.

Internal reliability

After item selection and pilot testing was finalised, the final version of the survey was distributed in August 2013 to all 70 BCNs to assess internal reliability. All data were analysed using SPSS Version 20.0[33]. Cronbach's alpha, the most frequently used indicator of internal reliability, was used to test and report on internal reliability[34].

Results

Survey composition and reliability

The final version of the survey consisted of three sections, which comprised a total of 59 structured items, with 26 of these questions allowing for additional open-ended responses. Section One (13 structured items) collects data about the education, experience and qualifications of each participant. Questions requesting the physical workplace address of the participant were required to accurately apply an Australian Bureau of Statistics (ABS) Remoteness Area code to each participant[29]. These codes were allocated using an address coding tool on the ABS website[17]. Once these codes were allocated, detailed address information was deleted from the database to protect the identity of participants.

Section Two (20 structured items) collects data about the work context and caseload of the BCN. Questions were asked to determine the average caseload of BCNs, the average consult times, methods of consult used, whether travel is involved as well as questions about clinical characteristics of patients.

Since there were no pre-existing instruments available to explore the kinds of care BCNs are expected to deliver, the Specialist Breast Nurse Competency Standards[30], specifically those relating to the provision of education, information and support, were used as a framework for Section Three. Section Three comprised 26 structured items, with each item also allowing for an open-ended response. In this section, performance criteria for Competency 1.1, 1.2, 1.3, 4.1 and 4.2 were listed and respondents were asked about the regularity that each of these are undertaken during their work as a BCN using a four-point Likert scale (always, sometimes, rarely, never). Respondents were also asked to explain any perceived barriers to undertaking each of the competency performance criteria. A sample of survey questions is provided in Table 1, Section 3.

Of the 60 participants who began the survey, 50 completed the survey, resulting in a completion rate of 83%. Accurate population data are not available because there are no national

Table 1: Sample of survey questions in each section of the survey

Section 1: Your education, experience and qualifications

1. How many years have you been working as a breast care nurse?

☐ Less than 1 year ☐ 1–2 years ☐ 3–5 years ☐ 6–10 years ☐ 11+ years

2. Are you employed?: ☐ full-time ☐ part-time

3. What is your highest qualification?

☐ Hospital-trained Registered Nurse
☐ Bachelor of Nursing
☐ Graduate Certificate
☐ Graduate Diploma
☐ Master of Nursing
☐ PhD

4. Do you have a qualification in Breast Care Nursing?

☐ Yes ☐ No

Section 2: Your work context

1. What is your **CURRENT** patient case-load?

☐ 0–10 patients ☐ 11–20 patients ☐ 21–30 patients ☐ 31–40 patients
☐ 41–50 patients ☐ 50–100 patients ☐ 100+ patients

2. Approximately how many **NEW** breast cancer patients do you see each month?

☐ None ☐ 1–5 ☐ 6–10 ☐ 11–20 ☐ 21–30 ☐ 31–40 ☐ 40+

3. How soon after a patient is diagnosed with breast cancer do you consult with the patient?

☐ At diagnosis ☐ Within one or two days ☐ Within one week
☐ More than a week

4. How regularly do you consult with patients within the first **MONTH** of diagnosis of breast cancer?

☐ Never ☐ Daily ☐ 2–3 times per week ☐ Once a week
☐Once a fortnight ☐ Once per month ☐ As-needed basis

Table 1 *(Continued)*

Section 3: Provision of education, information and support

When thinking about the education, information and support that you provide in your role as a BCN:

1. How regularly do you undertake any of the following activities? Please select one response from column 2*.

2. Do you perceive there to be any barriers to you being able to fulfil each of these activities? Please explain your answer in column 3** and simply write an 'X' if you perceive there to be no barriers.

Reference: National Breast Cancer Centre (NBCC) (2005). Specialist Breast Nurse Competency Standards and Associated Educational Requirements.

	*Regularity undertaken				**Barriers perceived
	Always	**Some-times**	**Rarely**	**Never**	**Explain barriers perceived or write 'X' to indicate not applicable.**
1.1a Demonstrate comprehensive and advanced knowledge and appreciation of the experience and impact of breast cancer and its treatment on the physical, psychological, social, sexual and spiritual well-being of clients and their family/significant others					
1.1b Use contemporary standards and guidelines to inform comprehensive and timely assessment of current and potential support needs across the continuum of breast cancer care.					
1.1c Routinely assess all clients for psychosocial risk factors and distress at the time of diagnosis and on a regular basis using a systematic, evidence-based approach.					

Table 2: Demographic and professional profile of breast care nurse respondents

Characteristic **n**		**Total n=50**		**Major cities n=20**		**Inner regional n=21**		**Outer regional, remote or very remote n=9**	
		n	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Years working as BCN	0–5 years	32	64	13	65	12	57	7	78
	6–10 years	11	22	2	10	7	33	2	22
	More than 10 years	7	14	5	25	2	10	0	0
Employment basis	Full-time	20	40	8	40	9	43	3	33
	Part-time	30	60	12	60	12	57	6	67
Highest qualification	Hospital-trained or Bachelor of Nursing	5	10	2	10	0	0	3	33
	Graduate Certificate or above	45	90	18	90	21	100	6	67
Hold BCN qualification*	Yes	42	84	17	85	18	86	7	78
	No	8	16	3	15	3	14	2	22

**Not all of these qualifications are tertiary level*

data specifying the number of BCNs working in Australia; however, it is estimated that there could be up to 400[35]. The demographic and professional characteristics of respondents are summarised in Table 2. Cronbach's alpha was calculated for Section Three only. The statistic was 0.935, indicating strong internal reliability.

Discussion

The BCN Survey has been used successfully to explore the role of the Australian BCN in the provision of information and support to women with breast cancer[36]. This has enabled researchers to report on the differences based on geographic location, a clear gap found in the literature. To our knowledge, this was the first survey to collect data about BCN perceived capacity to undertake the facets of the role related to provision of information, education and support and the barriers to undertaking their role.

The internal reliability of the BCN Survey as measured using Cronbach's alpha was found to be strong (0.935). This high value may suggest that there is some item redundancy and the survey would benefit from further testing using factor analysis, for example. However, the items were closely aligned with competency statements[13], suggesting that there may be redundancy in the standards.

The tool could be extended to investigate other aspects of the role of BCNs described in the remaining competency standards and could be useful to identify educational support to assist BCNs to meet the competency standards associated with their role.

In the development of this survey content validity was achieved using sources such as a literature review and consultation with experts. However, further content validity testing using the calculation of a content validity index would allow quantitative validation of the tool in terms of whether the items accurately measure all aspects of the construct.

Conclusion

There is limited evidence on the role of Australian BCNs in different contexts and geographical areas[15]. Therefore, a new survey instrument on the role of the BCN was developed and tested for content validity and internal reliability. This instrument was used in a national study to explore the ways in which rural and remote BCN roles differ to urban BCN roles. It has enabled an investigation of the range of roles performed by a BCN in the provision of information and support and to what extent reported BCN roles are consistent with the Australian Specialist Breast Nurse Competency Standards. The structure of this instrument could be used to investigate further the kinds of care BCNs are expected to deliver. Using the instrument further would provide more information about the support required by BCNs and the effectiveness of current BCN educational programs. This instrument has been found to have strong content validity and high internal reliability; however, further use and testing of this instrument in different contexts is recommended.

Acknowledgement

Tracey Ahern was supported by an APA Scholarship.

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Knowledge, attitudes and practices of oncology nurses regarding fever and fever management in febrile adult cancer patients

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Abstract

The literature indicates that nursing fever practice is often not evidence-based. This study aimed to investigate the fever knowledge, attitudes and practices of oncology nurses and to determine the participants' intentions to administer paracetamol to febrile cancer patients. The cross-sectional study (n=65), using an adapted survey underpinned by the Theory of Planned Behaviour (TPB), was conducted in one Australian cancer setting. Participants' scores revealed that their fever knowledge was generally consistent with the evidence; however, nursing cultural norms likely precluded the translation of this knowledge to practice. The TPB-based model explained 26% of the variance in respondents' intentions to administer paracetamol (p=0.001), to which "subjective norms" (p=0.037) and "indirect perceived control" (p=0.016) were significant contributors. The practices of oncology nurses did not reflect their theoretical knowledge, highlighting the need for further education and to target the cultural norms that appeared to preclude evidence-based fever practice in this setting.

Introduction

Fever should be managed effectively in cancer patients to avoid unwanted consequences. Research indicates that fever management in other conditions is not evidence-based, although few oncology-specific studies have been undertaken in this field. Thus, the aim of this cross-sectional study, using the adapted Paediatric Fever Management Survey underpinned by the Theory of Planned Behaviour (TPB), was to investigate the fever knowledge, attitudes and practices of oncology nurses in one Australian specialised cancer setting. In this paper, the methodology and findings of the study are provided.

Aim of the study

The aims of this study, in one specialised cancer setting, were to: (1) investigate the fever knowledge and attitudes of oncology nurses and their intentions to administer paracetamol to febrile cancer patients; (2) examine relationships between participants' demographics, knowledge, attitudes, practices and intentions to administer paracetamol to febrile cancer patients; and (3) understand the predictors and beliefs underlying participants' intentions to administer paracetamol.

Theoretical framework

The TPB, which provides a framework to understand and predict behaviour, guided data collection and analysis in this study. The theory proposes that: a) the more positive the individual's attitude toward the behaviour; b) the more supportive of the behaviour the environment in which they are situated is; and c) the greater their sense of capability in successfully undertaking the behaviour (perceived behavioural control), the more likely they are to perform the behaviour[1]. In some circumstances, where factors beyond the person's control exist, if the person's intention is likely to be prevented, they are unlikely to carry out the behaviour. Therefore, the actual behaviour of the individual might be affected from perceived behavioural control, either indirectly or directly[1,2].

With respect to fever management, in 2005, Walsh *et al.* used the TPB to predict Australian paediatric nurses' intentions to administer paracetamol and explored factors influencing this intention[9]. Regression analysis revealed that 25% of the variation in nurses' intentions to administer paracetamol was significantly predicted by three key elements of the TPB. The findings of this study guided the subsequent development of a program of peer education and peer support that was tested in a large cohort of paediatric nurses in the same facility[9]. This peer educational intervention consisted of four one-hour sessions targeting evidence-based knowledge, misconceptions, normative, attitudinal and control influences over fever management. A quasi-experimental method using validated survey and chart audits was subsequently used to evaluate the effectiveness of this TPB-based intervention on nurses' intentions to reduce fever by antipyretic administration[9]. The authors reported that the nurses' intentions to administer paracetamol were reduced after the intervention. The chart audit confirmed this result by finding a higher temperature threshold reached in the experimental group before they intervened to reduce fever with paracetamol (mean temperature difference of 0.68°C, p=0.01). These results indicate that TPB was effective in predicting factors that influence nurses' intentions to administer antipyretics and provided a useful framework for a successful intervention to increase the uptake of evidence-based fever management. A TPB-adapted diagram related to this present study is provided in Figure 1.

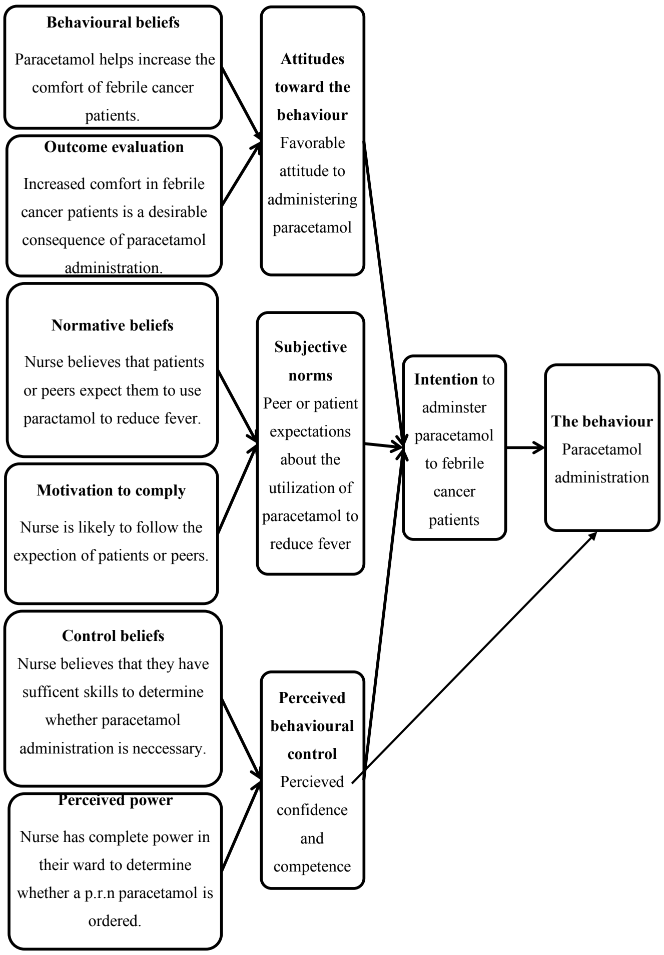

Figure 1: TPB-adapted diagram

Methods

A cross-sectional survey, using an instrument underpinned by the TPB, was conducted in 65 oncology nurses in one Australian cancer setting. Eligibility criteria comprised nurses who were officially employed in the cancer unit as a registered nurse and involved directly in the care of adult cancer patients. The study received ethical approval from the relevant hospital.

The Fever Management Survey was originally developed to explore Australian paediatric nurses' knowledge, attitudes and determinants of fever management and was validated in this setting[3]. Adaptation of this instrument to the cancer context was undertaken with a panel of five local cancer nursing experts within the study hospital and with one of the original instrument developers to ensure face validity relevant to oncology during a series of three Delphi rounds. The adapted instrument was then evaluated by 10 different expert oncology nurses in three external hospitals to assess content validity and to ensure its format was acceptable to users. The instrument was returned by all 10 experts with recommendations for minimal changes, most of which were concerned with item format.

The adapted survey consists of four sections.

Section 1: Demographic information

This section comprises eight items that identified participants' age, academic qualifications, oncology nursing qualifications, employment status, level of seniority, years of experience practising in the oncology setting and current position. Item responses indicating the length of time provided continuous data. The remaining questions elicited several categorical options for participants to choose.

Section 2: Knowledge

This section comprises twenty-three items. Twenty-one items assessed participants' knowledge of the physiology of fever (6 items), signs and symptoms of fever (3 items) and fever management (12 items). These 21 questions consisted of 17 multiple-choice items and three items asking participants to circle more than one answer. The two remaining questions in this section investigated participants' choices with respect to non-pharmacological and pharmacological methods for fever management. A list of physical interventions and criteria for antipyretic administration were provided for participants to choose from.

Section 3: Attitudes

This section comprises twenty-eight items. Twenty items assessed participants' attitudes about fever management with respect to antipyretics (9 items), nursing activity (8 items) and miscellaneous practices (3 items). The eight remaining items of the section evaluated participants' attitudes about fever effects. Participants responded using a 5-point Likert rating, ranging from "strongly disagree" (1) to "strongly agree" (5). Questions in the original scale were modified to reflect the adult context of cancer care. The scale in the original study in the paediatric context reported good reliability of 0.76[4].

Section 4: Intentions

Forty-seven items underpinned by the TPB explored the factors that potentially influenced participants' intentions to administer paracetamol (the usual drug prescribed for adults) in the adult setting. Twenty items evaluated participants' behavioural attitudes, 12 items surveyed subjective norms, 14 items elicited perceived control and one item assessed the intentions of the participants to administer paracetamol. Participants responded using a 7-point Likert scale, ranging either from "extremely likely" (1) to "extremely unlikely" (7) or "extremely desirable"(1) to "not at all desirable" (7).

Data collection

Participants were informed about the purpose of the study and its ethical implications during formal information sessions. They were subsequently provided with access to the survey and were allocated time during shifts to complete it anonymously. They returned completed surveys to a sealed box in each practice area. Return of surveys implied consent. Reminders were sent to non-responders by email after a fortnight.

Data analysis

Data were entered into the Statistical Package for Social Science version 21 (SPSS 21), with 10% of cases randomly checked for data entry accuracy. Variables were checked for invalid response codes and missing data. No case with more than 10% data missing was found and excluded.

Descriptive statistics were determined for all study variables. The Kolmogorov-Smirnov statistic was used to examine whether the data were normally or not normally distributed. A *p* value <0.05 was considered statistically significant for inferential analyses. For bivariate analyses, since the normality assumption was violated, non-parametric tests (namely Mann-Whitney, Kruskal-Wallis and Spearman tests) were employed where the identified variables were dichotomous, multiple categorical or continuous variables respectively.

To assess the influence of the three TPB-based components on the likelihood that participants intended to administer paracetamol to febrile cancer patients, a forward conditional logistic regression analysis was performed with a dichotomous dependent variable ("intention" and "no intention"), after assumptions were checked and assessed as met. Distribution and formulae to calculate TPB-based components are presented in Table 1.

According to the TPB, the cross products of the strength of a belief and the corresponding outcome evaluation/motivation to comply/perceived power are indirectly associated with behavioural intentions[5]. Since the data were not normally distributed, Spearman's *rho* determined correlations between the underlying beliefs of the participants and their intentions to administer paracetamol. Cohen's principle was applied to define the strength of correlation[6]. In this study, r=0.1 to 0.29 was defined as a small/low correlation, r=0.3 to 0.49 implied a medium/moderate correlation and r=0.5 to 1 indicated a large/high correlation.

Results

Demographics (*n*=65)

Sixty-five participants (response rate=58.56%) participated in the study. Details are provided in Table 2.

Table 1: Distribution and formulae to calculate four TPB-based components

TPB-based components	Underlying beliefs	No of items	Formulate to calculate	Possible range
Belief-based attitude (behavioural attitude)	Behavioural beliefs (b_i)	i=10	$A = \sum_{i=1}^{n} b_i e_i$ = 3.3+3.3+…+3.3= 3.3.10=90	-90 to 90
	Evaluation of the outcome (e_i)	i=10		
Subjective norms	Normative beliefs (b_j)	j=6	$SN = \sum_{j=1}^{n} b_j m_j$ = 3.3+3.3+…+3.3= 3.3.6=54	-54 to 54
	Motivation to comply (m_j)	j=6		
Indirect control	Control beliefs (c_l)	l=5	$PBC = \sum_{l=1}^{n} c_l p_l$ = 3.3+3.3+…+3.3= 3.3.5=45	-45 to 45
	Perceived power (p_l)	l=5		
Direct control	Control beliefs (c_l)	l=2	$PBC = \sum_{l=1}^{n} c_l p_l$ = 3.3+3.3 = 3.3.2 = 18	-18 to 18
	Perceived power (p_l)	l=2		

Abbreviations: A, behavioural attitude; SN, subjective norms; PBC, perceived behavioural control.

Table 2: Demographic characteristics of participants

Characteristics		N	%
Academic qualifications			
	General hospital certificate	13	20
	Post-registration certificate	5	7.7
	Diploma/Degree	43	66.2
	Postgraduate certificate	12	18.5
	Postgraduate diploma	4	6.2
	Masters	5	7.7
	Others	4	6.1
Oncology/Haematology certificates			
	Yes	19	29.2
	No	45	69.3
	N/A	1	1.5
Current employment status	Full-time	41	63.1
	Part-time	24	36.9
Level of employment			
	Grade 5 (RN)	33	50.8
	Grade 6 (CN)	19	29.2
	Grade 7 (NUM/CNC)	10	15.4
	N/A	3	4.6
Length of RN experience (years)			
	<1	2	3.1
	1–4	15	23.1
	5–10	17	26.2
	>10	31	47.7
Length of oncology experience (years)			
	<1	4	6.2
	1–4	19	29.2
	5–10	21	32.3
	>10	21	32.3
Length of time in current settings (years)			
	<1	11	16.9
	1–4	35	53.8
	5–10	18	27.7
	>10	1	1.5

Table 3: Participants' knowledge, attitudes and intentions to use paracetamol to reduce fever

Participants' knowledge, attitudes and intentions			Number of items	Median ffl IQR	Range	Possible score
Knowledge domain	1	Physiology of fever (Items 1,2,3,5,6,21)	6	5 ffl 1	1–6	0–6
	2	Signs and symptoms of fever (Items 4,8,20)	3	1 ffl 1	0–3	0–3
	3	Fever management (Items 7,14,10,11,12,13,15,19,9, 16,17,18)	12	6 ffl 2	2–9	0–12
	Overall knowledge score (n=65)		21	11 ffl 3	7–16	0–21
Attitude domain	1	Fever effects (items 3,4,5,6,7,8,26)	7	3.57 ffl0.57	2.71–4.71	1–5
	2	Fever management (items 10,12,14,15,16,23, 24,25,11,17,19,20,21,27, 28,13,18,22)	18	3.89 ffl0.58	3–4.5	1–5
	Overall attitude score (n=65)		**25**	**3.88ffl 0.42**	**3.04–4.32**	**1–5**
Intention	Intention score (n=62)		1	2 ffl 3	1–7	1–7

Participants' knowledge

Overall scores of participants' knowledge, attitudes and intentions to administer paracetamol are provided in Table 3. Participants' overall median knowledge score on the 21 knowledge items was 11 (IQR=3, range 7–16, possible score 0–21). The last two knowledge items (items 22, 23) revealed variations in criteria for antipyretic administration amongst respondents and the physical interventions they used to manage fever in cancer patients. Most nurses decided to treat fever at temperatures from 38.0°C to 38.4°C (n=44, 67.7%). Slightly smaller percentages were reported in other temperature thresholds ranging from 38.5°C to 38.9°C (n=40, 61.5%), 39°C to 39.4°C (n=41, 63.1%), 39.5°C to 40°C (n=42, 64.6%) and above 40°C (n=40, 61.5%). Forty-six respondents (70.8%) indicated they would administer paracetamol to a patient who had concurrent fever and pain. In terms of the interventions they would provide, most chose encouraging fluids (n=59, 90.8%), removing unnecessary clothing

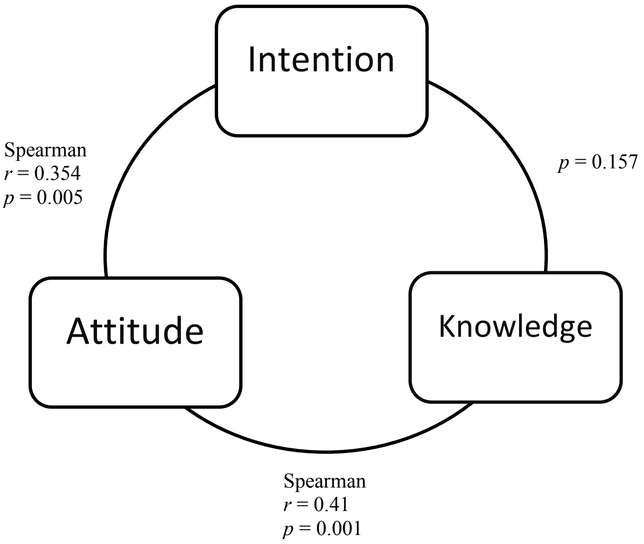

Figure 2: Associations amongst participants' knowledge, attitudes and intention to administer paracetamol

Table 4: Participants' demographics, knowledge, attitudes and intention to administer paracetamol

	Age	Academic qualification	Employment levels	Oncology certificates	Nursing experience	Oncology experience
Knowledge	*r*=0.34 *p*=0.008	x	x	x	x	x
Attitude	*r*=0.29 *p*=0.023	Kruskal Wallis *p*=0.023	Kruskal Wallis *p*=0.015	Mann-Whitney U *p*=0.013	*r*=0.324, *p*=0.008	*r*=0.309, *p*=0.012
Intention	x	x	x	x	x	x

x: no significant difference was found with p>0.2 (n=59, 90.8%) and tepid sponging (n=60, 92.3%). A number of participants (n=53, 81.5%) chose to use fans to reduce fever.

Participants' attitudes

As individual items were regarded as either true or false based on evidence, the 5-point Likert scale that measured this component could range from 1 (strongly non-evidence-based) to 5 (strong evidence-based). A score of 3 was therefore regarded as "neutral" and 4 was "evidence-based". Thus, overall, participants demonstrated evidence-based attitudes in that their median attitude was 3.88 (25 items, ffl0.42, range 3.04–4.32) on a 5-point Likert scale (from 1 "strongly non-evidence-based" to 5 "strongly evidence-based"). A score of 3.88 was also the most frequent score (n=7, 10.8%).

Participants' intentions

Responses of sixty-two (95.4%) nurses had a median of 2.0 (ffl 3.0), ranging from 1 (extremely likely) to 7 (extremely unlikely). The most frequent response was 1 (n=22, 33.8%), followed by 2 (n=18, 27.7%).

Associations

Positive correlations were found between participants' age and their knowledge score (Spearman's *rho*=0.34, *p*=0.008) as well as their attitude score (Spearman's *rho*=0.29, *p*=0.023), indicating that the older the participants were, the better their fever knowledge and attitude. No association was found between the median intention score and participants' age (*p*=0.33).

A moderate positive correlation was observed between participants' knowledge scores and their attitude scores (Spearman's *rho*=0.41, *p*=0.001). Intention scores were not associated with knowledge scores (*p*= 0.157) but were moderately positively associated with attitude scores (Spearman, *r*=0.354, *p*=0.005). Details are presented in Table 4 and Figure 2.

Role of TPB-based components in predicting intentions

The overall model was statistically significant (c2=13.106, p=0.001). The model as a whole explained 26% of the variance in intention (Nagelkerke R Square). Two independent variables, namely subjective norms *(OR* = 0.964, *p* = 0.037) and indirect perceived control (*OR*=0.949, *p*=0.016) made a unique, statistically significant contribution to the model. Details are provided in Table 5.

Moderately significant correlations were found between the participants' intentions to administer paracetamol and six underlying behavioural beliefs, namely "reduced body temperature" (*r*=0.429, *p* <0.001); "reduced patient anxiety" (*r*=0.351, *p*=0.004); "reduced temperature set-point" (*r*=0.335, *p*=0.006); "increased activity" (*r*=0.333, *p*=0.007); "reduced carer anxiety" (*r*=0.319, *p*=0.01); and "increased comfort" (*r*=0.3, *p*=0.015). Highly significant correlations were found between the participants' intentions to administer paracetamol and three underlying normative beliefs, namely senior medical staff (*r*=0.673, *p* <0.001), senior nursing colleague (*r=0.646, p* <0.001) and nursing peers (*r=0.505, p* <0.001).

Highly significant correlations were found between the participants' intentions to administer paracetamol and their beliefs about controlling factors, particularly "actual body temperature" (*r*=0.539, *p* <0.001). Moderate significant correlations were found between the participants' intentions to administer paracetamol and their beliefs about two other factors; namely the "reason for patients' admission" (*r*=0.314, *p*=0.011) and "ward expectations" (*r*=0.309, *p*=0.012). Moderate significant correlations were found between the participants' intentions to administer paracetamol and their beliefs that it is "completely under their control" to determine whether to administer it or not (*r*=0.4, *p*=0.001).

Discussion

Knowledge and attitudes: the role of education

A key finding in this study is that this cohort was one age-category younger than the average age of Australian nurses (39.25 compared to 44.5 years), but not a particularly academically specialised cohort[7]. There is time for them to gain further postgraduate education to enhance their evidence-based fever knowledge and attitudes during their career.

As the results clearly indicate, however, specialised oncology knowledge and study does not necessarily translate to evidence-based fever management practice. So it is germane to question educational relevance rather than the level or type of education obtained. The problem might be one of content, and whether the concept of fever management is addressed in undergraduate and postgraduate cancer curricula or in hospital-based education programs at all. It could also be a matter of content delivery, and whether the pedagogy underpinning a fever curriculum and the teaching strategies that enact that curriculum convey the necessary messages in ways that are accessible and relevant to students. Until recently, nursing education in both the university and clinical environments was driven by a teacher-centred model where teachers are assumed to know best and assume

Table 5: Regression analysis for the model of intention based on the TPB

	N	B	S.E.	Wald	Odd ratio	95% CI for Odd ratio		*p value*
Subjective norms	65	-0.036	0.017	4.33	0.964	0.932	0.998	0.037
Indirect control	65	-0.052	0.022	5.855	0.949	0.909	0.990	0.016
Overall model	**Nagelkerke R Square = 0. 26**							

great control over the teaching and learning process[8]. Sanna *et al.* emphasise rather that adult learners have many characteristics that, if utilised, can greatly enhance their learning outcomes in an economical way[9]. These andragogical principles recognise that adult learners are internally motivated, self-directed, goal-oriented and relevancy-oriented, such that a teacher-centred model might not be suitable in clinical learning environments[9]. Recent literature emphasises two main principles that enhance outcomes whilst maximising resources in clinical and university education situations: a learner-centred approach and active engagement between learners and teachers[10]. These principles are relevant to the results of the present study with respect to the design of a fever education program that is currently under way.

First, the content of the program should ideally aim to harness the strengths and overcome the weaknesses identified in the pre-test survey. Knowledge deficits were not an issue as much as attitudes and intentions irrespective of knowledge, and the apparent influence of ward culture on these variables. Addressing these variables is not simply a matter of supplying content, it is a matter of engaging learners and raising their self-awareness[11]. Authorities in this field argue that educational strategies based on real-life scenarios that encourage group discussion and reflection and which enable the safe airing of issues arising in practical experience are useful[9,11]. Active group discussions can facilitate participants' self-identification of the existing problems and, furthermore, determine suitable strategies to solve those problems. Through simultaneous strategies of peer education and support, participants would share their experiences and discuss their perspectives with their colleagues. In this approach, the education team would be guides and facilitators rather than "experts in charge". The added advantage of this approach in a clinical setting is that the power differential between learners and educators is more balanced, creating a safer and more supportive place in which teaching and learning can occur[12].

Second, attitudes and intentions in the study context appear likely to be influenced by ward culture. Thus, it is useful here to consider the adult learning strategies that would help to target the culture shift necessary to ensure translation of the nurses' knowledge base into actual practice. For example, a number of peer education strategies, such as harnessing local opinion leaders and airing issues at educational meetings, has been found effective within similar Australian settings[13]. Irrespective of methodology, the principle underpinning all peer education is that clinical experts or formal leaders in the facility enable the knowledge and skill development of less experienced nursing staff[14]. Adult learners are a valuable educational resource as they bring the richness and diversity of their lives with them to learning issues[9]. Adult learners also tend to determine their own educational needs and goals, and usually have expectations about how an education program will accommodate these. Therefore, in peer educational activities, adult learners not only identify their own learning goals and motivations but also bring their experience to share and help others identify the most appropriate solutions to learning problems.

Intentions to administer paracetamol: the role of cultural norms

In this study, a key feature of the results was that participants who received social approval for their fever interventions and who perceived they could control influencing factors were more likely to provide paracetamol to febrile patients. Nevertheless, the present study reported many instances of fever practices that were clearly counterproductive. These included the consistent use of tepid sponging and fans and the aggressive use of paracetamol to reduce fever, despite respondents' demonstration of a reasonable theoretical understanding that these interventions are contraindicated in oncology contexts. This finding suggests that the reasons nurses choose to ignore the evidence is often a matter of tension between their own knowledge, the evidence mandated in clinical policies, procedures and guidelines, and a collective ward culture that values conformity to prevailing norms. Ward cultures are guided by commonly held beliefs, rules, language, policies and expected behaviours that create the workplace environment, guide care delivery and influence both the emotional and physical health of workers[15-18]. The study findings revealed that participants were likely to conform to colleagues' expectations, regardless of their own knowledge. This suggests a task-oriented ward culture that valorises tradition, ritual, experiential knowledge and what group leaders think over research-created knowledge[19]. Since culture is characterised by norms, values and beliefs, one suggestion to overcome this problem is the development of a culture in which evidence-based practices are highly valued and eventually become the norm[19]. Thus, emerging research supports the crucial role of nursing leadership in this process[19-21].

Leadership can be understood as both an approach that focuses on people and interpersonal relationships and a process wherein an individual influences a group to achieve a common goal[21,22]. Leadership is not necessarily a matter of seniority, because all nurses within a ward group can be agents for, or leaders of, cultural change. Strong leadership facilitates support, feedback, interest and engagement between the leader and the group and is known to greatly enhance the uptake of evidence into practice[21]. Sandstroma and colleagues further argued that leaders who acknowledged the importance of evidence and who actively facilitated and role modelled the implementation of evidence into the ward culture were the change agents who most guaranteed the uptake of evidence into practice[23]. It is, therefore, vital that nursing leaders and significant change agents at the service level, including nursing directors, nursing managers, clinical nurse consultants, and ward-level 'coal face' registered nurses understand how to acquire evidence and facilitate its uptake into practice through good leadership[24].

It is equally important that leaders recognise how prevailing ward cultures can impede research implementation. Organisational issues such as clinical nurses' lack of time to implement research-based change, limited access to research literature, and lack of support for innovation can constitute significant barriers and are routinely cited in the literature[20,24]. Thus, recent research has highlighted that at a structural level factors such as policy revisions, the allocation of resources, opportunities for education as well as human and material support are important characteristics of an organisational structure conducive to evidence-based practice[23]. This is further facilitated by organisational leadership that strongly promotes research values and demonstrates institutional acceptance of the polices[19]. However, the literature does not provide firm conclusions on precisely which of these strategies is most effective. Knowledge translation strategies are necessarily as varied as the workplace cultures for which they are developed[19].

Study limitations

The study has a number of limitations. The relatively small sample size (n=65) precludes generalisation to non-oncology, non-fever samples, as does the fact that the characteristics of non-respondents were not known. In addition, the process of adapting a validated paediatric instrument to the adult cancer setting was not without problems as the meaning of some items was ambiguous and unsuitable for adult cancer patients.

Conclusion

This cross-sectional study applying the TPB aimed to investigate the fever knowledge, attitudes and practices of oncology nurses in a large cancer service. Results revealed that participants' fever knowledge was generally consistent with evidence; however, nursing cultural norms likely precluded the translation of this evidence to practice. The findings indicate that the practice of oncology nurses in this setting did not reflect their theoretical knowledge, highlighting the need for further education and a need to target the cultural norms that appeared to preclude evidence-based fever practice in this setting.

Conflicts of interest

The authors declare that there are no conflicts of interest.

Acknowledgements

The study described in this paper was funded by a Queensland Health Nursing and Midwifery Research Grant. This support, and the participation of survey respondents, is gratefully acknowledged.

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