The Australian Journal of Cancer Nursing

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Cancer Nurses Society of Australia

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

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The Cancer Nurses Society of Australia (CNSA)

Our mission

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

To achieve our mission of promoting excellence in cancer care, the CNSA will act as a resource to cancer nurses around Australia, no matter what their geographical location or area of practice.
The CNSA will be the link between cancer nurses in Australia, the consumers of cancer nursing services and other health professionals involved in cancer care.

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The Australian Journal of Cancer Nursing

Editorial

Nurse-led cancer care

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In this issue of *The Australian Journal of Cancer Nursing* we focus on nurse-led cancer care. We have chosen three research studies in different settings, all of which demonstrate the impact of excellent cancer nursing and multidisciplinary care: an intervention enhancing survivorship for long-term survivors of Hodgkin lymphoma; a focus on the position of cancer coordinator-led care in a regional hospital and a project enabling nurse-led screening and interventions using a supportive care resource kit.

Nurse-led care in cancer management has been shown to be cost-effective or cost-neutral, to reduce readmissions and to provide high levels of satisfaction for patients[1,2]. In addition to these outcomes, cancer nurses are in an excellent position to develop opportunities for health promotion and supportive care within a person-centred approach. Cancer care through a 'health promotion lens' builds on the care and activities focused on cancer and its treatment alone and situates supportive care in the context of the individual. Cancer nurses are in an ideal position to develop initiatives, such as those described in this issue, that provide a person-centred, holistic supportive care package in both the long and short term.

Fitzhugh Mullen likened surviving cancer to being saved from drowning but then abandoned on the beach[1]. In an innovative and person-centred approach[3] to survivorship care, Priscilla Gates *et al.*'s study takes us through the development of a nurse-led intervention for people treated for Hodgkin lymphoma that clearly demonstrates both short- and long-term benefits for patients. The success of early diagnosis and modern treatment for this haematological malignancy means that many people now survive. The paradox, however, is that having been cured from their original malignancy, Hodgkin lymphoma survivors are at a higher risk of other cancers and chronic conditions. Gates' intervention sets out to address these issues.

Melanie Regan and colleagues used action research methods to examine the clinical practice of cancer care coordinators in a regional hospital in Australia. The categorisation of the broad array of clinical activities undertaken by cancer Care coordinators provides clarity to this often nebulous role. The scope of the activities of care coordination clearly goes beyond the position description. Of particular importance are functions as part of a multidisciplinary team and as an individual health care provider. Concepts important in long-term management and chronic conditions, such as self-management and health promotion, are also essential components of this role.

In the final paper, Sibilah Breen *et al.* describe the evaluation of a supportive care resource kit. The kit, comprised of seven components: clinician training package; screening tools; referral protocols; supportive care service directory; clinician referral and action checklist; patient note sheets; and information leaflets, was developed to train and enable cancer clinicians to provide supportive care more effectively. The ten clinicians – eight nurses and two radiation therapists – participating in the study used the kit and their training to undertake screening and referral for supportive care needs in the clinical setting. Training and skill development of clinicians is essential to enable cancer clinicians to build and be confident in their repertoire of support care skills, as increasing numbers of patients are surviving both with and after cancer.

These three studies clearly demonstrate the breadth of supportive care needs that nurse-led initiatives can address. At the same time, they demonstrate how skilled cancer nurses make a difference to people living, often for many years, with the ongoing effects of cancer and its treatment.

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

Reference

1. Beaver K *et al.* Economic evaluation of a randomized clinical trial of hospital versus telephone follow-up after treatment for breast cancer. Br J Surg 2009; 96(12):1406-15.
2. Lewis *et al.* Nurse-led vs. conventional physician-led follow-up for patients with cancer: systematic review Journal of Advanced Nursing 2009; 65(4), 706–23.
3. Cancer Nurses Society of Australia. Workforce Position Statement. Sydney. Cancer Nurses Society of Australia, 2002.

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The Australian Journal of Cancer Nursing

Insights into the development of a nurse-led survivorship care intervention for long-term survivors of Hodgkin lymphoma

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Abstract

Hodgkin lymphoma is a highly curable cancer with increasing numbers of survivors at risk of medical and psychosocial morbidity which can impact on their quality of life and long-term survival. An innovative model of nurse-led survivorship care has been developed to enhance 1) awareness of individual health risks, 2) benefits of adopting healthy lifestyle behaviours and 3) reduction in psychosocial distress. A phase 1, quasi-experimental study is being undertaken to test the capacity of the intervention to deliver against the aims outlined. Thirty survivors of Hodgkin lymphoma and 30 healthy participants have been recruited to the study. The nurse-led consultations include an education package tailored to these individuals' health needs, screening for emotional distress and delivery of an individualised survivorship care plan. Study measures include the General Health Index, the Health Promoting Lifestyle Profile II and the late effects Supportive Care Needs Screening Tool. This paper outlines the rationale and key design issues behind the development of the nurse-led intervention and some preliminary indication of the benefit of the intervention from participants' perspective.

Background literature

With advances in multimodality therapy, five-year survival rates from Hodgkin lymphoma (HL) now exceed 90%[1]. Long-term survivors of HL are an important and expanding patient group with a unique and wide range of survivorship issues. In Australia in 2007, 538 patients were diagnosed with HL and the median age at diagnosis was 31 years[2]. This results in a large cohort of survivors who were diagnosed at a young age, who received intensive, highly curable treatment and who are now at risk of developing long-term late effects including secondary malignancies, cardiac dysfunction, endocrine dysfunction, infertility and psychosocial sequelae[3]. Many late effects are avoidable or able to be ameliorated by early detection and/or risk modification. As the numbers of HL survivors grow, it is increasingly important that they normalise their lives and incorporate healthy behaviours into their lifestyles in order to achieve optimal health outcomes.

Haematology LE

Secondary malignancies and non-malignant comorbidities

While the survival rates for patients with HL are impressive, unfortunately many are not cured. Among those who do not survive, approximately half will die from HL, 20% from new cancers and 14% from cardiovascular complications[4]. Ng reports that the risk of death from causes other than HL in this group is four times more than the general population beyond 20 years from diagnosis[5]. Reports from large cohorts have shown a seven to 18 times higher risk of second malignancies compared with the general population The most prevalent secondary malignancies in patients treated for HL are leukaemia, breast, lung, gastrointestinal and thyroid cancers, melanoma and non-Hodgkin lymphoma[6].

Cardiovascular disease is the most common non-malignant cause of death in survivors of HL and radiation therapy to the mediastinum is one of the key treatment-related key risk factors for cardiac deaths[7]. Cardiac complications after mediastinal radiotherapy are thought to be due to radiation-induced inflammation and fibrosis of the individual cardiac structures, with signs and symptoms manifesting 10–15 years after completion of treatment although non-symptomatic abnormalities may develop much earlier[7]. The long delay before expression of serious damage may explain why radiation damage to the heart has been grossly underestimated[7].

Radiation-induced heart disease includes a wide spectrum of cardiac pathologies such as coronary artery disease, valvular heart disease, myocardial dysfunction, pericardial disease and electrical conduction abnormalities[3].

General risk factors for cardiovascular disease such as hypertension, diabetes, hypercholesterolaemia, obesity-reduced physical activity and smoking may also contribute to the risk for cardiovascular diseases in survivors of HL[7]. In addition to the physical effects there may also be educational, emotional and behavioural sequelae. For these reasons, HL survivors need to be knowledgeable about the possible consequences of the illness and vigilant about their health behaviours[8].

Psychosocial impact

Survivors of HL, similar to other cancer survivors, experience a multitude of psychosocial effects post-treatment[7]. Because many survivors of HL are in adolescence or young to middle adulthood, unique age-related problems relating to parenthood, sexuality, fertility, body image, employment and career development are salient[9]. Studies of the psychosocial status of long-term survivors of HL indicate that they experience anxiety, fear of recurrence, concern about lack of energy, sexual and fertility concerns, work issues, financial concerns, concerns about education or career, altered body image, concerns that their children will develop cancer and an overprotective family[9].

A study of 1024 cancer survivors in the USA indicates that transition from treatment to long-term survivorship is often marked with emotional and psychosocial concerns[10]. Five hundred and forty-two (53%) patients found their emotional needs harder to cope with compared to their physical needs. Five hundred and two (49%) patients in Wolff's study reported that they felt depressed, 614 (60%) reported relationship problems with partner/spouse, and 338 (33%) reported limited emotional resources available to them to cope with emotional concerns[10].

Information needs

Evidence indicates a critical transition as cancer survivors complete primary treatment and enter into a new trajectory of self-care and reduced medical surveillance. The majority are largely unaware of their heightened health risks and are ill prepared to manage their future health needs[11]. Beckjord *et al.* surveyed 1040 cancer survivors between two to five years post-diagnosis. Results indicated that information needs were prevalent for this group, including information needs related to; follow-up care and surveillance (738/71%), health promotion (707/68%), late effects of treatment (655/63%), psychosocial issues (562/54%), and sexual function and fertility (322/31%)[11]. Hudson *et al.* reported knowledge deficits amongst 266 cancer survivors regarding their cancer treatment and their increased vulnerability to health problems such as secondary cancers and cardiovascular disease[12]. Subsequently, some survivors demonstrate limited awareness of their health risks and ability to choose to adopt self-protective and healthy behaviours[12].

Healthy behaviours

For survivors of HL, adopting self-care behaviours such as healthy nutrition and regular aerobic exercise may reduce the risk of subsequent cancers and cardiovascular events, as established in the general population[13]. However, evidence indicates that some survivors of HL do not adopt healthy lifestyle behaviours known to reduce their risk of developing serious late effects[13]. Hollen and Hobbie hypothesised that survivors may have poorer decision-making skills than their peers who have not had cancer and subsequently engage in more risk-taking behaviours, such as smoking[14]. It is likely that some cancer survivors engage in risky behaviours due to social pressure and/or an increased need to identify with their healthy peers as a result of feeling different because of their cancer experience[14]. Likewise, engaging in unhealthy behaviours may provide them with an opportunity to exert control after experiencing the uncertainty and lack of control associated with cancer despite the potential adverse health consequences[15]. Hudson *et al.* proposed that interventions designed to enhance survivors' knowledge about their risks of late effects and to motivate them to practise healthy protective behaviours may reduce morbidity and mortality[12]. These interventions warrant further research and evaluation in practice, and theory is needed to drive intervention research[16].

Theoretical framework of intervention

However, there is limited evidence to inform the content of interventions to best prepare survivors to hear about their risks of developing late effects and to motivate them to engage in health promoting behaviours. This study draws on Pender's Revised Health Promotion Model[17] to inform the content and focus of a novel, nurse-led intervention aimed at enhancing knowledge, perception of health status and motivation. Pender's model is concerned with the way in which humans interact with their environment to pursue health, based on their interpretation of threats and benefits[17].

Interventions that lead to the adoption of health promoting activities are resource-intensive. They require lengthy consultations that focus on an individual's anxieties, examine past life experiences and aspirations for the future, and determine triggers that can be used to help individuals optimise their long-term health. Evidence indicates that nurse-led services, delivered by advanced practice nurses (APNs), can accommodate tailored, resource-intensive interactions in a way that medical follow-up and surveillance clinics are not resourced to do[18].

The context of the study

The late effects clinic at Peter MacCallum Cancer Centre (Peter Mac) was established in 2000 and is one of only three known late effects units for adult cancer survivors in Australia. The clinic has an Australia-wide referral base including hospitals, advocacy groups, primary care physicians or survivors may self-refer. Patients are required to be five years post-completion of curative treatment. There are currently 592 patients on the late effects unit data base, of these almost half (269; 45%) are survivors of haematological malignancies and more than half of these (140; 54%) are survivors of HL, of these 135 received upper torso radiotherapy.

The haematology late effects team includes a haematologist, transplant physician, radiation oncologists, fellow and registrar, cardiologist, endocrinologist, primary care liaison officer, psychologist and a specialised late effects social worker. In

recognition of the considerable health deficits experienced by survivors of haematological malignancies in 2008, a Late Effects advanced practice nurse was appointed to the team to work specifically with survivors of haematological malignancies.

The study

In 2010, based on the need outlined above, a nurse-led intervention, informed by best available evidence was developed.

Aims

Primary aim: To establish whether receiving a health promoting intervention from a specialist cancer nurse demonstrates capacity to improve HL survivors' knowledge of and motivation to adopt health promoting behaviours.

Secondary aims: To establish whether receiving a health promoting intervention from a specialist cancer nurse demonstrates capacity to:

- improve HL survivors' perceptions of their health status
- reduce patient-reported unmet information needs in relation to LE
- reduce health worry associated with the knowledge of the risk of developing LE.

Methodology

A phase 1, quasi-experimental pilot study was developed to assess the study aims. The study is defined as a phase 1 project as described in the Medical Research Council Complex Health Intervention Framework[19]. A phase 1 study is described as the identification of components of an intervention and the background mechanisms by which they will influence outcomes to provide evidence that can predict how they relate to and interact with each other[19]. The purpose of this paper is to outline the development of the intervention based on the needs of HL survivors as articulated in the literature presented above.

Population and setting

Thirty people who had received curative treatment for HL were recruited from referral lists to the haematology late effects clinic at Peter Mac.

Thirty healthy controls matched for age and gender were recruited to provide data at baseline only, to help contextualise HL survivor data at entry to the study.

Inclusion/exclusion criteria

To be eligible for the study group, survivor participants:

- had a diagnosis of HL
- received upper torso radiotherapy at any stage during their treatment history, regardless of other therapies.
- had to be at least five years post-completion of their curative treatment for HL
- had to be a new referral to the haematology late effects clinic at Peter Mac
- had to be aged over 18 years
- had to be able to complete study requirements in English
- had a sibling, partner or significant other unaffected by a diagnosis of cancer who met eligibility criteria outlined below, and were willing to take part as a control participant.

To be eligible, healthy participants:

- had to be a sibling, partner or significant other of a study group HL survivor
- had never have been diagnosed with cancer (excluding non-melanoma skin cancers)
- were of comparable age (+/– five years) and gender to the study group HL survivor
- had to be aged over 18 years
- had to be able to complete the study requirements in English
- had no co-occurring serious and/or uncontrolled illness that impacted on their functional status, including heart disease, stroke, respiratory disease, diabetes, dementia and Alzheimer's disease.

Recruitment

Survivor group: All new, eligible patients referred to the haematology Late Effects Clinic were contacted by the haematology Late Effects APN and invited to participate. The haematology Late Effects APN introduced the study and asked for permission to mail out a patient information letter and consent form. A letter was sent to the potential participant explaining the study and asking permission to send out study measures. If the patient agreed and returned the signed consent form, baseline measures were sent out. Completed questionnaires were returned in a reply-paid envelope to the Late Effects APN (Figure 1).

Healthy participants: the haematology late effects APN asked eligible survivors to identify and give permission to approach a healthy participant selected from a list of study preferred control participants. This list included: 1) a partner or sibling of comparable age and same gender; 2) a friend of comparable age and same gender; 3) a sibling or partner of other age; 4) a friend of other age; 5) a partner or sibling of other gender; or 6) a friend of other gender. If consent was given, the haematology Late Effects APN phoned the healthy participant introduced to the study and asked for permission to mail out an information letter and consent form. If the signed consent form was returned, baseline measures were sent out and completed questionnaires were returned in a reply-paid envelope. Healthy participants were required to complete measures at baseline only.

Ethics

This pilot study was approved by the Peter MacCallum Cancer Centre Ethics Committee in May 2010 and The University of Melbourne Ethics Committee in September 2010. All aspects of the study design were approved by the ethics committee.

This study is being conducted as part of a Master of Philosophy (MPhil) Nursing Research at the University of Melbourne.

The intervention

The study intervention was manual-based and protocolised, based on best available evidence, ensuring that the intervention was consistently delivered to all study participants. It was delivered to patients during two face-to-face, nurse-led consultations within the context of the haematology late effects clinic. The totality of the intervention was delivered over two clinic appointments and two telephone calls that spanned six months.

Intervention 1: At the first clinic appointment, the survivor participant received a tailored education package based on needs identified from the baseline data, as well as a list of recommended

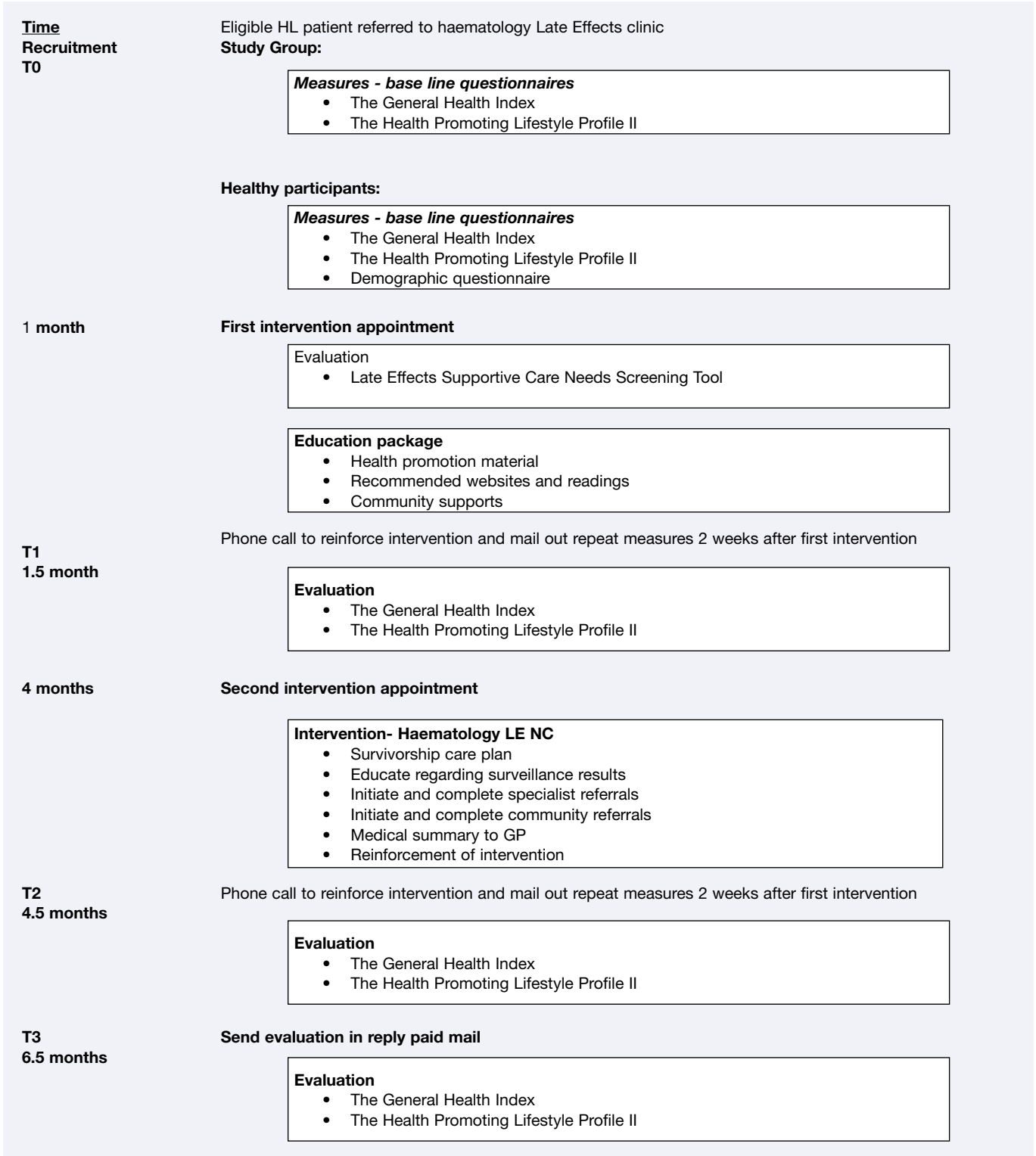

Figure 1. Study schema.

websites and reading. The nurse-led consultation focused on the delivery of evidence-based interventions appropriate to the health-related needs of survivors of HL, including physical activity; healthy eating; smoking status; alcohol consumption; self-examination; sun protection, sexual health, fertility and mental health.

Intervention 2: At the second clinic appointment (four months after recruitment to the study), the survivor participant attending for nurse-led consultation received an individualised survivorship care plan survivorship care plan, as advocated by the Institute of Medicine's (IOM) landmark report *From Cancer Patient to Cancer Survivor: Lost in Transition*[20]

The purpose of the survivorship care plan in this study was to raise awareness of the importance of surveillance and healthy living and to provide a coordinated plan of follow-up care. It included details of medical history, treatments received, potential for LE, requirements for follow-up appointments, tests and reasons for them. The care plan focuses on health promotion and highlights the need for and how to adopt healthy behaviours. It also addresses psychosocial issues, how to identify them and where to get help. A copy of the care plan was sent to each patient's primary care physician to ensure they are kept up to date with information essential to monitoring their health and to provide the patient with a knowledgeable source of support and advice close to home.

Two further nurse-led consultations were conducted via telephone to reinforce the intervention and to identify and respond to any new concerns. The first call took place two weeks after first clinic appointment. The second call took place two weeks after the second clinic appointment.

Data collection and measures

Baseline data were completed after consent had been obtained and before the first nurse-led intervention session (T0). The following information was obtained from consenting participants' medical records: current age; gender; marital status and employment status; previous diagnosis; length of time since diagnosis and treatment completion; type of treatment received in the past; any relapses; ECOG performance status; current medications and comorbidities.

For healthy controls age, gender, relationship to survivor, marital status, employment status, ECOG performance status, current medications and comorbidities were recorded via a demographic questionnaire.

Screening for emotional distress was undertaken at baseline using the Late Effects Supportive Care Needs Screening Tool. The Late Effects Supportive Care Needs Screening Tool has been adapted from the Supportive Care Needs Screening Tool[21] and has not yet been validated.

The Late Effects Supportive Care Needs Screening Tool was given to participants in the outpatient waiting room and completed prior to entering the clinic room. This tool was used to measure the participant's communication and understanding, physical health, emotional health, activities of daily living, support and coping, support services and information needs.

Health behaviours, perceived health status and knowledge of risks of late effects were measured using:

The General Health Index. This is a validated, 22-item tool that uses a five-point Likert scale with summed scores to measure perception of health. Subscales measuring the concepts of current health, prior health, health outlook, resistance to illness and health worry are contained in this tool[22]. Concurrent validity and construct validity have been established[23]

The Health Promoting Lifestyle Profile II is used to measure health promoting behaviours. This validated, 52-item tool uses a four-point scale to assess frequency of engagement in health promoting activities. The items are categorised into six subscales: physical activity; health responsibility; spiritual growth; nutrition; interpersonal relationships; and stress management[24]. Construct validity has been established in previous studies[23].

Participants in the study group were asked to complete data assessments at four separate intervals over a 6.5 month period to test the impact of the clinic intervention. Patients were asked to complete measures at baseline (T0), at two weeks after the first intervention (T1); at two weeks after the second intervention (T2) and two months after the second clinic intervention (T3) (Figure 1).

Data analysis

Baseline characteristics of the two groups will be analysed using descriptive statistics and compared using the chi-squared test for categorical variables and a t-test, or nonparametric equivalent for continuous variables. Mean scores on all outcome measures will be compared pre- and post-intervention for the General Health Index and HPLP-11. Mean differences between groups pre- and post-intervention will be calculated initially for each, follow-up time, then controlling for baseline scores.

Results

The nurse-led survivorship care intervention commenced in September 2010 and recruitment was completed to the intervention in February 2012. Data analysis is underway. Thirty survivors of HL have been recruited to the study (Table 1).

Table 1. Survivors of HL recruited to study.

	n	%
Survivors of HL	30	100
Gender		
Male	19/30	63
Female	11/30	37
Age		
Median current age	44 (27–72)	
Median age at diagnosis	27 (11–50)	
Median years since diagnosis	14 (6–47)	
Median years since completion of treatment	12 (5–47)	

Patients recruited to the study had received one of three treatment plans (Table 2).

Table 2. Curative treatment.

	n	%
Received upper torso radiotherapy	30	100
Received combined chemo/radiotherapy	24	80
Received radiotherapy alone	6	20

To date 16/30 patient/survivor participants have completed all study requirements. Of the remaining 14 participants, six participants received the first nurse-led intervention only eight had received both nurse-led interventions.

Thirty healthy participants have been recruited to the study (Table 3). Twenty-seven of the 30 recruited have completed all study requirements.

Table 3. Healthy participants recruited to study.

	n	%
Healthy participants	30	100
Gender		
Male	17/30	57
Female	13/30	43
Median age	42 (24–71)	

Only three patient/survivor participants approached to take part declined to participate. Reasons for not participating include: not having a suitable person to nominate as the healthy participant and being unable to take time off work to attend the clinic. One of the participants declined signing the patient information consent form as they felt that their HL diagnosis and associated treatment was in the past and they had no need to attend a haematology late effects clinic. No healthy participants approached to take part in the study declined. No participants from either cohort withdrew from the study indicating acceptability of this intervention.

All patients received upper torso radiotherapy and 24/30 received combined chemotherapy and radiotherapy.

Thirty healthy participants were recruited after having been nominated by the patient/survivor with a similar median age of 42 (24–71). Unsolicited feedback from healthy participants indicates that they may have greatly valued being involved in the study. Some commented on the positive impact of having an opportunity to reflect on their own health and wellbeing.

Although no formal analysis has taken place as yet, reflections from detailed field notes demonstrate the impact of the intervention. One patient/survivor stated that after receiving his tailor-made health promotion education package, "I didn't want to let the nurse down or the work that she is trying to do! I feel too embarrassed that I drink and smoke so much! My wife is also giving up smoking so that I can give up!" (Quotes presented reflect comments recorded by the APN after consultations with participants. Patients were aware that the APN would record any feedback on the interventions as part of the study data collection processes and this had been approved by the ethics committee.) This participant was able to cease smoking through the ongoing support of the Smoking Cessation APN at Peter Mac and linkage with a new general practitioner (GP) in his community. He proudly voiced "I am seeing the new GP 'who is great!' Everything looking up – because of you and coming to that clinic"

Similarly, participants appreciated receiving a copy of their own survivorship care plan and felt empowered that it was mailed to their GP so they were up to date with current and accurate information. "This is exactly what I need – a piece of paper that tells my story! This clinic is what I have been waiting for – thank you!"

Field notes also indicate that patients/survivors valued the opportunity to complete the late effects Supportive Care Needs Screening Tool. Some expressed that for the first time for many years, someone had taken the time to ask how they were feeling, "since the end of my treatment I have been in a black hole – no one has really cared". This participant expressed that, "at my previous clinic appointments it was all about the lymphoma and if it was coming back – there was no time to tell them I was really struggling!" Alarmingly, two young males aged 36 and 39 documented that during the past two weeks they had thoughts about hurting themselves or suicide. One of these males documented, "I am very grateful for the screening tool as it allowed me to write down how I really feel. I didn't know things were really so bad and now I have some help". The APN initiated a referral to a psychologist and made contact with the patient's GP so that ongoing assessment and support would occur.

Recruitment to the study has been completed in a timely manner. Recruiting 30 participants to the patient/survivor group took eight months, which equates to about two new patients from every haematology late effects clinic, which reflects the support of the medical team to refer patients to this initiative. This study demonstrates the feasibility of this nurse-led intervention within the context of a multidisciplinary team. It took nine months to recruit the healthy participant group.

Participants have been very keen to support the study. As long-term survivors of HL, they were keen to "give something back" and also to "help other patients". Interestingly, since participating in the study, two young males in the patient/survivor group have enquired about volunteer work at Peter Mac. Participants were also keen to be involved in a supportive care research project as previously many had been involved in scientific research clinical trials during their treatment, but this was their first experience of a nurse-led supportive care study.

Nearly half (14/30) of the patient/survivors participants are still to complete the two nurse-led interventions and all of the evaluations which span four time points over six months. Twenty-

seven healthy participants have returned their evaluations. Many patients have required follow-up phone calls as reminders to complete measures after the second and final nurse-led intervention. It appears the participants no longer having face-to-face contact with the APN require more encouragement to adhere to study requirements. In future studies, the time points between the first and second nurse-led intervention may be shortened to increase adherence to questionnaire follow-up. However, a methodological strength of this study is the longer follow-up at six months post-referral to the clinic, allowing a longer term evaluation of the intervention and demonstrating sustainability of behavioural change over this period.

Discussion

Over the course of the study, there were numerous comments from participants regarding the perceived benefits of the nurse-led intervention and these were recorded as researcher field notes. However, collecting qualitative data was outside the scope of this study and, as such, these were not routinely collected or recorded. We recommend that future research considers collecting qualitative feedback on the interventions developed, as these comments will help more thoroughly evaluate the intervention, in particular allowing evaluation of what specific aspects of the intervention were of greatest value.

The components of the intervention have been tested through this phase 1 study. The study has provided an opportunity to test the feasibility and acceptability of the nurse-led initiative and the relevance of the measures used to assess the intervention. As soon as all of the data has been collected, detailed analysis will be undertaken to examine the capacity of the intervention to improve HL survivors' knowledge of and motivation to adopt health promoting behaviours, to reduce patient-reported unmet information needs and health worry associated with the knowledge of risk of developing late effects. This full study data will be published at the end of 2012.

Conclusion

Formal evaluation of this innovative, nurse-led intervention to enhance the general health status of survivors of HL, attending a multidisciplinary, haematology late effects clinic is in progress. The nurse-led survivorship interventions are informed by patient-reported concerns, are delivered by a haematology Late Effects APN, have been based on best-available evidence and endorsed by a multidisciplinary team of experts in the field. The APN role, situated within a multidisciplinary, late effects haematology team offers a new model of cancer survivorship care that may prove to be applicable to other patient groups with chronic illness in the future.

References

1. Chow LM *et al.* Survival and late effects in children with Hodgkin's lymphoma treated with MOPP/ABV and low-dose, extended-field irradiation. J Clin Oncol 2006; 24(36):5735–41.
2. English D *et al.* Cancer Survival Victoria 2007. Estimates of Survival in 2004 (and comparisons with earlier periods). Melbourne, VIC: Victorian Cancer Registry, Cancer Epidemiology Centre, Cancer Council Victoria, 2007.
3. Aleman BMP & van Leeuwen FE. Are we improving the long-term burden of Hodgkin's lymphoma patients with modern treatment? Hematol Oncol Clin North Am 2007; 21(5):961–975.
4. Donaldson SS, Hancock SL & Hoppe RT. The Janeway lecture. Hodgkin's disease--finding the balance between cure and late effects. Cancer J Sci Am 1999; 5(6):325–333.
5. Ng AK *et al.* Long-term survival and competing causes of death in patients with early-stage Hodgkin's disease treated at age 50 or younger. J Clin Oncol 2002; 20(8):2101–8.
6. Friedman DL & Constine LS. Late effects of treatment for Hodgkin lymphoma. J Natl Compr Canc Netw 2006; 4(3):249–57.
7. Ng AK. Review of the cardiac long-term effects of therapy for Hodgkin lymphoma. Br J Haematol 2011; 154(1):23–31.
8. Absolom K *et al.* Health promotion for survivors of childhood cancer: a minimal intervention. Patient Educ Couns 2004; 55(3):379–84.
9. Fernsler J & Fanuele JS. Lymphomas: long-term sequelae and survivorship issues. Sem Oncol Nurs 1998; 14(4):321–328.
10. Wolff N. The burden of cancer survivorship; a pandemic of treatment success. In Handbook of cancer survivorship, M Feuerstein, ed. New York: Springer, 2006.
11. Beckjord EB *et al.* Health-related information needs in a large and diverse sample of adult cancer survivors: implications for cancer care. J Cancer Surviv 2008; 2(3):179–89.
12. Hudson MM *et al.* Feasibility of implementing health promotion interventions to improve health-related quality of life. Int J Cancer Suppl 1999; 12:138–42.
13. Haupt R *et al.* Smoking habits in survivors of childhood and adolescent cancer. Med Pediatr Oncol 1992; 20(4):301–6.
14. Hollen PJ, Hobbie WL & Finley SM Cognitive late effect factors related to decision making and risk behaviors of cancer-surviving adolescents. Cancer Nurs 1997; 20(5):305–14.
15. Tyc VL, Hudson MM & Hinds P. Health promotion interventions for adolescent cancer survivors. Cogn Behav Pract 1999; 6(2):128–136.
16. Bhattacharyya O *et al.* Designing theoretically-informed implementation interventions: fine in theory, but evidence of effectiveness in practice is needed. Implement Sci 2006; 1:5.
17. Pender NJ. Health promotion in nursing practice. 3rd edn. Stanford: Appleton & Lange, 1996.
18. Beaver K *et al.* Comparing hospital and telephone follow-up after treatment for breast cancer: randomised equivalence trial. BMJ 2009; 338:a3147.
19. Campbell M *et al.* Framework for design and evaluation of complex interventions to improve health. BMJ 2000; 321(7262):694–6.
20. Hewitt P & Ganz PA. From Cancer Patient to Cancer Survivor: Lost in Transition. Institute of Medicine and National Council of the National Academies. Washington DC: The National Academies Press, 2006.
21. Pigott C *et al.* Unmet needs in cancer patients: development of a supportive needs screening tool (SNST). Support Care Cancer 2009; 17(1):33–45.
22. Davies AR & Ware JE Jr. Measuring Health Perceptions in the Health Insurance Experiment (R-2711-HHS). Santa Monica, CA: Rand, 1981.
23. Smith AB & Bashore L. The effect of clinic-based health promotion education on perceived health status and health promotion behaviors of adolescent and young adult cancer survivors. J Pediatr Oncol Nurs 2006; 23(6):326–34.
24. Walker SN, Sechrist KR & Pender NJ. The Health-Promoting Lifestyle Profile: development and psychometric characteristics. Nurs Res 1987; 36(2):76–81.

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Cancer care coordinators' relationships with the multidisciplinary team and patients: Everything to everyone

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Abstract

This study aimed to examine the role of cancer care coordinators (CCCs) by investigating what is practically involved in care coordination and what CCCs' perceptions of their role are. Using a qualitative approach with an action research design, two CCCs from a large regional hospital in Australia undertook a patient record audit, analysed using content analysis, and reflected upon within a reflective group process. In practice, cancer care coordination involves a variety of activities which support the multidisciplinary team, cancer patients and carers. The participants' perspective – that they were everything to everyone – was an acceptable way of defining the parameters of their role. Areas requiring consideration are multidisciplinary team function in regard to liaison and shared responsibility, strategies to reduce the potential deskilling of team members, increasing awareness of the importance of promoting patient self-management, critically reflecting on relationships with team members and patients, and endeavouring to gain organisational and multidisciplinary team support for what appears to be a role on which there is great reliance.

Introduction

In Australia, a range of peak bodies concerned with cancer care have recommended the establishment of cancer care coordinator (CCC) positions to help mitigate the complexities of living with cancer and cancer treatments[1-3]. As a result, all Australian states and territories have implemented, or are implementing, CCC roles to improve patients' experience of navigating the health care system[4]. However, there is great variation in the role and scope of practice of CCCs. Furthermore there has been little robust evidence of their impact on patient outcomes[4].

Care coordination is an approach to the provision of health care that aims for continuity of care as an end result[5]. A commonly accepted conceptual definition of continuity of care is a pattern of care experienced by a patient where health care professionals know what has already happened with the patient, various health care professionals agree on a management plan, and a health care professional is designated to continue to care for them in the future[5]. Care coordination activities include provision of information and emotional support, navigation through health service systems, and liaison with the multidisciplinary team[6-10]. Therefore, employing health care professionals in the role of care coordinator is one component of a strategy to achieve continuity of care.

Internationally, the role of a nurse navigator as a vehicle to support care coordination is gaining recognition with several studies examining aspects of their care[11,12]. In Australia, a variety of existing cancer nursing roles have been established aimed to help improve continuity of care for patients. An early care coordination role was that of the breast care nurse (BCN)[13]. Clinical trials coordinators have sometimes fulfilled the role of care coordinator[3] and specialist cancer nurses, such as chemotherapy and stomal therapy nurses have been described as important in ensuring continuity of care by having oversight of a patient's pathway[14]. The role of site specific cancer nurses, such as neurological cancer nurse coordinator[6], have been developed, but in areas where the number of patients with a specific diagnosis are low, generalist care coordinator roles have been introduced.[14] Therefore, while the scope of practice is varied[15] and evidence for the role of the CCC is limited, research is required to establish an evidence base to inform the development of such roles.

The aims of this study were to examine the role of the CCC in care coordination for cancer patients in a large regional health setting, and to use the knowledge gained from the collaborative

research experience to enhance the participants' practice and inform others about the role. CCCs' perceptions of their role and the activities were examined.

Design

As this study examined CCCs' clinical practice within a new model of service delivery and care, action research was used as the methodological framework. Using action research and reflective group processes with participants promotes a sense of ownership of the findings and can provide an impetus for change[16].

Setting

This research was conducted in a large regional hospital in Australia that provides comprehensive cancer care including surgery, chemotherapy, radiotherapy and palliative care for patients diagnosed with a wide range of cancers.

Participants

In 2006, the hospital employed two CCs in response to local stakeholder needs. The position description was developed using the limited evidence available within the literature and was predominately based on the model of the specialist BCN, as at that time it was the only evidence-based role described in the Australian literature[13]. The CCC position was developed to help patients navigate their cancer experience with the aim of achieving continuity of care. There are no other CCCs in the region. The CCCs who participated in this study provide care for patients in the inpatient surgical and medical wards, the ambulatory chemotherapy and radiotherapy units, as well as patients at home in the community. A letter of invitation for voluntary consent to participate in the study was sent to the CCCs. Approval was sought from the participants' manager for work time to be allocated to the study. Ethical approval for the study was obtained from the regional hospital as well as the university ethics committee.

Procedure

In this study, the action research design included two cycles of planning, action and review and reflection. Data collection and analysis occurred in both cycles.

Action research cycle 1

In the first cycle (Figure 1), the researcher and participants used the participants' position description, along with the research literature on the CCC role, to determine and define categories of care coordination activities that represented the clinical practice of participants. These categories were recorded to create a category definition table. A category of 'other' was included to allow for activities that were not initially apparent to the research team. Each category was given a definition that was agreed upon by the researcher and participants, and together, the group reflected on the meaning of each category by discussing the activities in relation to specific care episodes. The researcher wrote notes regarding the discussion, including comments by the participants, which were used to help clarify emerging concepts and guide further reflection.

Action research cycle 2

In the second cycle (Figure 2), the category definition table developed during cycle 1 was used as a tool to audit 20 de-identified patient medical records. Purposive, intensity sampling[17] was used, with records chosen by the participants from patient care that had involved a minimum of two interactions with either CCC, thus providing information-rich data. The

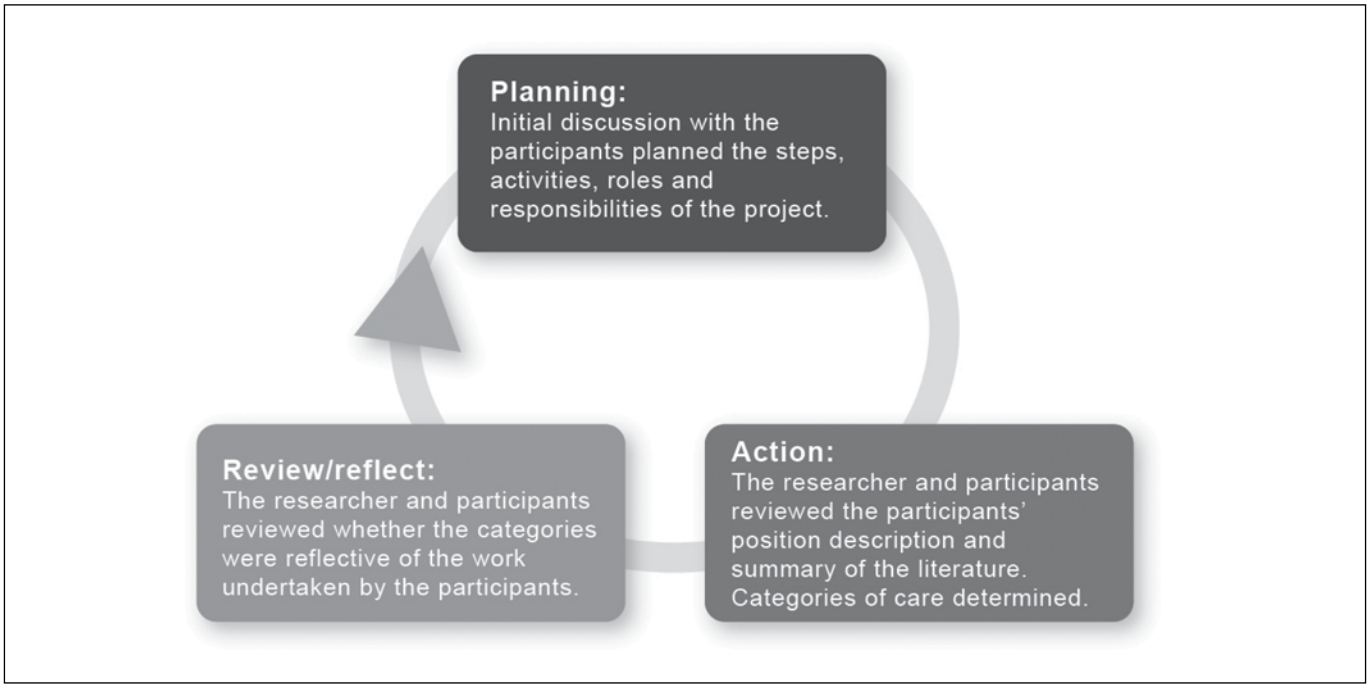

Figure 1. Action research cycle 1.

records were of patients who had been discharged from the care of the CCCs, with the care provided over a time that could be up to six months, the usual time frame designated by the organisation for the participants' provision of service to patients. Undertaking the audit utilised a content analysis method[18]. This method involved looking for evidence of each category in the medical records and counting the number of times a category was identified. The participants read aloud the sections of each record that involved their interactions with the patients, while the researcher placed a mark under each category, with the participants' confirmation, when a category was identified. Categories were tallied and percentages calculated on the resulting data. The total number of activities within each category enabled the group to review and reflect upon the activities undertaken in their role of CCC. Using a process of group reflection, current care coordination activities were discussed, with a view to producing recommendations for improved practice. Again, the researcher wrote notes on the discussion.

To increase the trustworthiness of the findings of this study, each medical record audit was undertaken by the researcher and the participants as a team[18]. This allowed discussion, and consensual agreement was achieved in 100% of cases, thus providing consistency in the identification of activities within categories as well as the counting of frequency. Validity was further enhanced by referring back to the literature on care coordination throughout the process to determine whether the activities in the audit were reflective of contemporary practice[18].

Findings

Two CCCs employed by the regional hospital consented to participate in the study. Both participants were nurses, each with greater than 20 years of clinical experience. Six meetings were held with the researcher and participants across the two action research cycles. Each meeting ran for approximately two hours and were held in the shared office of the participants.

Action research cycle 1

Categories of care were defined in this cycle (Table 1). The categories of assessment, liaison, emotional support, information provision, and education, were activities participants undertook that were also identified in the research literature. The categories of promotion of care appropriateness, support for carers, and documentation were undertaken by the participants but not reported in previous studies. All categories of care defined by the group were used to undertake an audit of patient medical records as described in the second action research cycle.

Action research cycle 2

From the 20 records audited, a total of 310 care activities (as defined in Table 1) were counted. The results of the audit are presented in Figure 3, which compares the frequency of activities within a category. Assessment (23%, n=70) and liaison (23%, n=71) were the most frequently occurring activities, making up nearly half of all care activities provided by the participants. Emotional support (15%, n=46), information provision (9%, n=27), education (10%, n=31), promotion of care appropriateness (11%, n=33) and support for carers (10%,

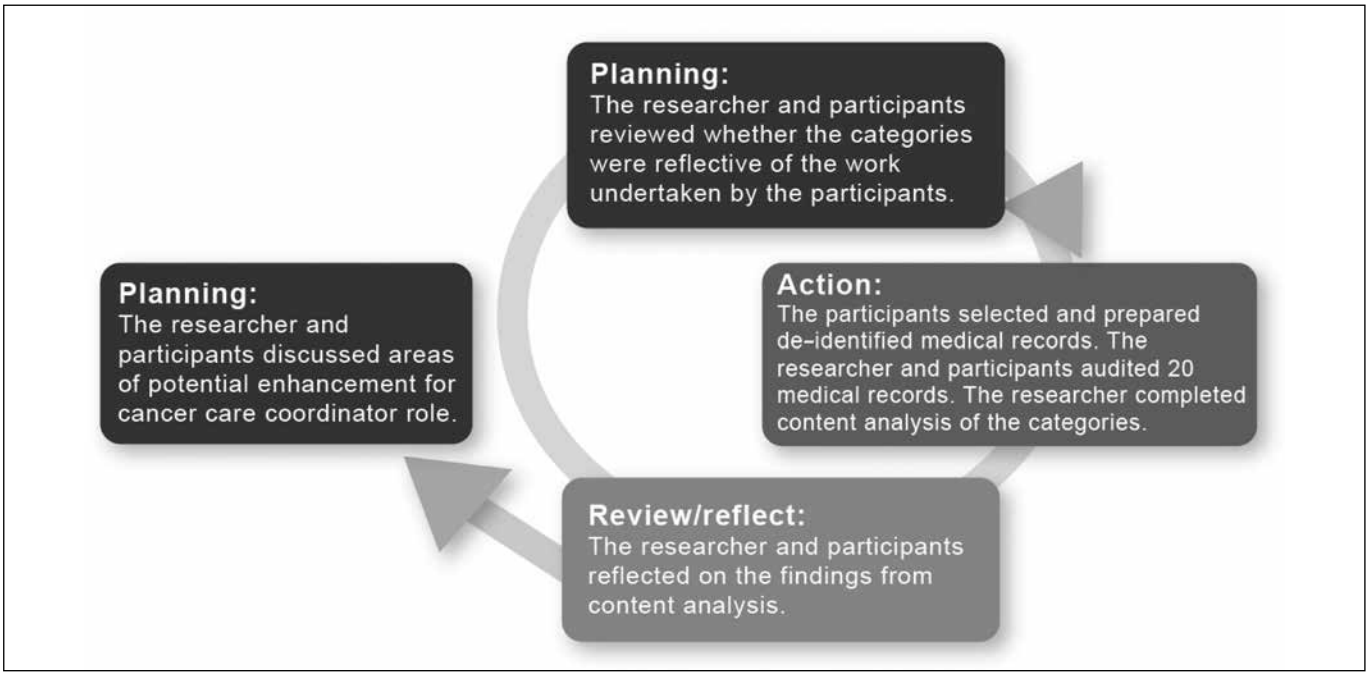

Figure 2. Action research cycle 2.

n=32) were all recorded at similar levels, with documentation and other not rating.

Also noted was the number of interactions (face-to-face visits or phone calls) between the participants and each patient and/or carer, which were reported in the records. A total of 248 interactions were counted with an average of 12 interactions per patient.

Whilst working towards producing recommendations for improved practice, the group reflection evolved from a discussion about care coordination activities and centred on five areas regarding participants' relationships with the multidisciplinary team and patients.

The five areas discussed were:

1. Liaison with the multidisciplinary team.

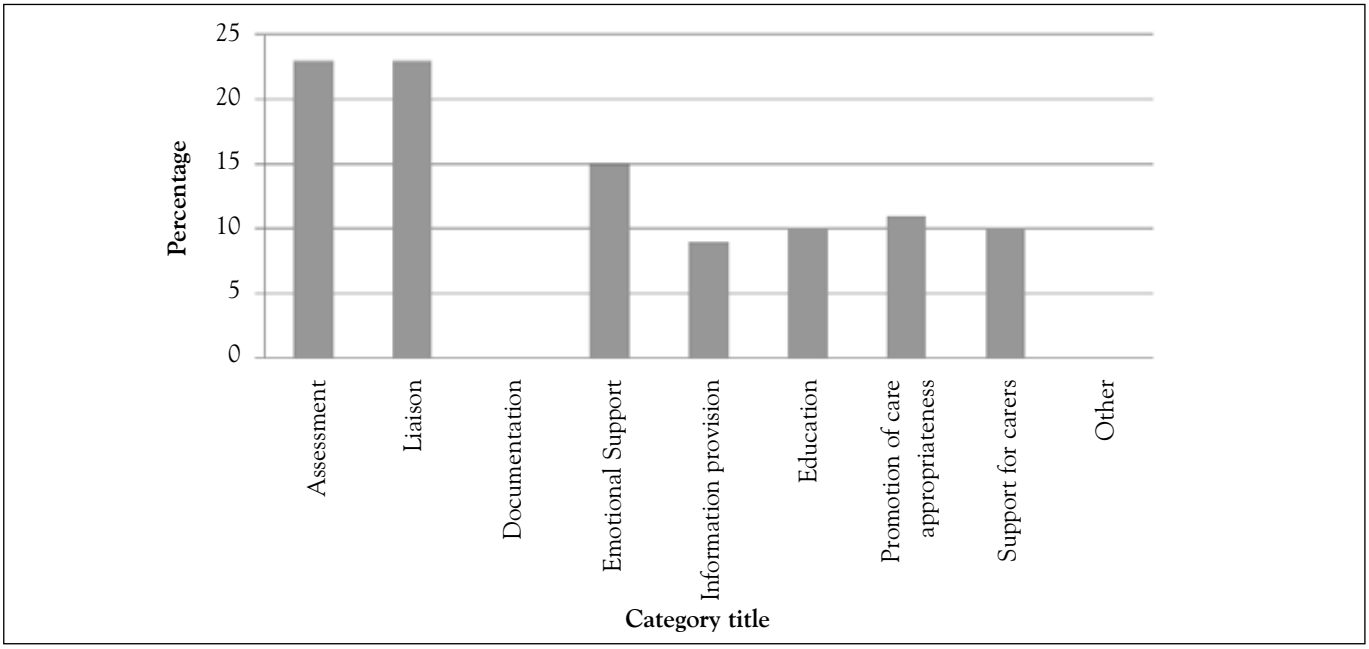

Figure 3. Frequency of care activities.

Table 1. Category definitions.

Category number	Category title	Category definition
One	**Assessment**	Assessments may be physical or psychosocial and include all activities that are assessing some aspect of patients' experience. May be at beginning and/or throughout care.
Two	**Liaison**	All activities that encompass discharge planning, discussing care or assessment with any other health professional including referral to other health professionals or services.
Three	**Documentation**	Writing in medical record, and own notes, which form part of the medical record at the closure of care episode. Filling in forms, writing referrals.
Four	**Emotional support**	Reassurance, listening, encouragement, suggesting strategies for coping to patients.
Five	**Information provision**	Giving patients written material, verbal explanation.
Six	**Education**	Patient activity that involves ascertaining existing knowledge, educating on topic, checking for understanding and reinforcing at another time. Education is tailored to individual need. Instructions for self-management.
Seven	**Promotion of care appropriateness**	Giving care direction within the multidisciplinary team, promoting evidence-based practice, advocacy, promoting a holistic approach, promotion of consideration beyond the acute episode, encouraging team members to think about the patient in 'real life' as opposed to 'hospital life'.
Eight	**Support for carers**	Assessment, emotional support, information provision and education, specifically for carers.
Nine	**Other**	Activities that do not fit into any other category listed.

2. Being the lynchpin within the team.
3. Potential deskilling of team members.
4. Promoting self-management with patients.
5. Being everything to everyone.

Liaison with the multidisciplinary team

Reflecting on their liaison with the multidisciplinary team led the participants to express they "would like the team to liaise better with us". Their role within the team seemed to include undertaking activities for other health professionals that they could have undertaken themselves. Overall, the participants felt the multidisciplinary team seemed to "take advantage of our willingness to do a lot of the activities of patient care and in doing so absolve their responsibilities".

Being the lynchpin within the team

Their liaison role within the multidisciplinary team led the participants to consider themselves the "lynchpin of the team". Participants considered that they were involved in "keeping the whole team system going", acting as a "safety net for patients". Both participants agreed that their "role was created to fill the holes that were in the system" and perceived that they needed to provide a "communication conduit" for the team in order for it to function safely and effectively "if communication breaks down we deal with it anyway". A belief was expressed that, although ideally the team would provide appropriate care all the time, they "don't know what we know, we have the overall picture as well as details that are vital. We know the patient over time as opposed to a one-off intervention".

Potential deskilling of team members

A potential deskilling of team members was discussed, due to the reliance on CCCs by the rest of the multidisciplinary team. By relying on the CCCs to "provide the majority of supportive care services" to cancer patients, the rest of the team would potentially lose, or not learn, the skills required to undertake this care themselves. Participants recognised this, therefore they "teach them to do tasks themselves whenever possible", educating the team members about their potential role in care coordination. The participants stated they "do try to do this but it [was] problematic due to the transient nature of the team membership, [meaning] that this would be a constant activity".

Promoting self-management with patients

Promoting self-management with patients was agreed to be an activity that was necessary and desirable, but underrated in the medical record audit, which showed many activities were done by CCCs for the patients. In fact, the audit showed a large number of patient interactions overall. The participants believed that this activity was under-represented in the audit compared to what they thought happened in actual practice.

Being everything to everyone

That the participants considered themselves everything to everyone was exemplified by the discussion about their responsibility for the liaison within the multidisciplinary team, being the lynchpin within the team holding the team system together, undertaking activities, at times, that other members of the team could have done, and providing care for patients and carers that, at times, could have been self-managed. Whilst acknowledging that they "do everything for patients and the team", participants were essentially happy to do so "it's our job", believing their current role to be indispensable for both safe patient care and an effective multidisciplinary team.

> *It would be nice to pop in to see a patient and provide support, education and information without checking if everything is working well. But part of understanding the patient in context means you have to check the system; whether we like it or not the system is flawed and the patient is within that system.*

Discussion

The two action research cycles conducted in this study produced an overview of the activities undertaken by the participants in care coordination, and five areas regarding participants' relationships with the multidisciplinary team and patients.

Activities of care coordination

Assessment, liaison, emotional support, providing information, and education were all activities listed in their position description, which the participants readily identified with as regular day-to-day activities. This is supported in the literature as these activities appeared in numerous papers related to CCCs in both Australia and internationally[4,6-9,13,19]. Promotion of care appropriateness arose as a category from a role responsibility listed in the participants' position description as advocacy – an activity also accounted for in the literature[6-7,20]. This category was expanded during reflective group discussion to include promoting appropriate use of each of the multidisciplinary team members' professional skills and resources, which has been identified as a common activity undertaken by BCNs[13].

The categories of support for carers and documentation originated solely from the participants' perceptions and were not identified in the literature as part of CCCs' role, although there is discussion of issues that families face as they navigate the health care system, such as confusion and anxiety[4]. In this study, participants felt that providing support for carers was an important activity in itself, because they viewed both patients and their carers as being in their care. As well, participants discussed how, on occasion, they provide support to carers independent of

the care they provide to patients. The audit showed that support for carers comprised 10% of the care coordination activities, thus supporting the participants' original decision to include it as a category. Documentation was not an activity mentioned in the literature but was an important category for the participants as they both stated they spent a lot of their time writing in various records and forms about their patients. Not surprisingly, it did not rate in the content analysis, as the participants did not document about documentation, but including it as an activity was meaningful for the participants.

Relationships with the multidisciplinary team and patients: Improving liaison with the multidisciplinary team

The CCCs spent a great deal of their time liaising with multidisciplinary team members, discussing aspects of patient care, even to the extent of assuming the responsibility for all team communication. Both participants expressed the wish that other multidisciplinary team members would liaise better with them. The literature on liaison and communication within cancer multidisciplinary teams describes similar problems to the participants' experience. Members of the multidisciplinary team encounter communication difficulties when assuming other members have communicated relevant information[21-24], and in teams where roles are poorly defined and understood, problems with communication arise[25]. These statements support the perspective of the participants, in their doubts about whether team communication would be as effective without their input.

The ideal communication system within the multidisciplinary team has been described as all members of the multidisciplinary team being responsible for liaising and collaborating with one another as well as with the patient[26]. A benefit to health professionals working within an effective multidisciplinary team is better communication between team members[21,23,27-28].

The lynchpin within the team: To be or not to be

Coordinating the internal dynamics of the multidisciplinary team is an experience not unique to the participants. CCCs are essential members of the multidisciplinary team; they are effective in coordinating the complex care pathway[29] and their role should include disseminating information to other health professionals[21-22]. A study into the role of the BCN in the United Kingdom found that these nurses had an informal leadership role in ensuring the effective coordination within the multidisciplinary team[30], quite similar to the way participants in this study acted as a conduit to keep the team system going.

Another study recommends that members of the multidisciplinary team share decision making and accountability[31]. The Department of Human Services, Victoria[5] policy on cancer care coordination recommends that the coordination of patient care is the function and responsibility of the whole multidisciplinary team, not an individual care coordinator. This strategy is aimed at reducing reliance on individuals[5] such as the CCCs in this study.

Upskilling versus deskilling other team members

A shifting of responsibility from some members of the multidisciplinary team to CCCs was identified in this study. Participants described activities they undertook that they believed other team members could have done themselves, creating a risk of deskilling team members. The literature on deskilling team members discusses specialist nurse roles deskilling general nurses[32-38]. Criticisms of specialist roles include that removing or reducing elements of general nurses' roles will reduce their confidence, motivation and job satisfaction and render care fragmented[36] Due to the existence of specialist nurses, general nurses relinquish many of the more challenging skills and are disinclined to learn them[36]. This concept of relinquishing echoes the participants' comments about the multidisciplinary team, waiting for CCCs to carry out a specific task rather than team members learning to do it themselves[32,36].

The participants' practice of teaching the multidisciplinary team to undertake their care activities whenever possible is supported in the literature. Mytton and Adams[36] describe the importance of empowerment in nursing including the provision of supervision, information and opportunities with specialist nurses having the potential to pass on skills and knowledge to general nurses. Marshall and Luffington[37] recommend specialist nurses teach generalist nurses how to expand their role without taking over the care themselves. Each of the roles of specialist and generalist nurse should be collaborative, with specialist nurses encouraging generalist nurses to extend the boundaries of their practice[37]. Such findings could be expanded to encompass practice with the broader multidisciplinary team.

Promoting patient self-management: Where is the evidence?

Promoting patient self-management was an activity rarely documented in the medical record audit, although participants believed that they undertook this activity more than was represented in the findings. Increasing awareness of the importance of this activity was a topic of discussion for the group in cycle 2. Patient self-management in chronic illness leads to less frequent accessing of services, better interaction between doctors and patients, improved quality of life, and reduction in health care costs[39]. For CCCs, the key component to promoting self-management with patients is educating them about its benefits and tasks[39], and requires the patient and health care professional to share complementary knowledge and authority over the health care processes[40].

Everything to everyone: The team and the patients

Participants described how they believed the rest of the team could have done more but that because the problems would land at their feet, they would rather stop them before they began. Participants knew, at times, they were doing a great deal for patients but viewed them as scared and vulnerable and identified their care as something they could do for them.

In Oudshoorn's[41] study on power and empowerment in the nurse–patient relationship, he commented on nurses' attitudes and beliefs regarding their hold on expert knowledge, arguing that nurses need to find the balance between knowing what is best for patients and empowering patients to be involved in their care. In this study, the participants acknowledged that they do everything for the patients, as they believed the patients wouldn't do everything for themselves. The participants were conflicted between knowing what is best for their patients and empowering them towards self-management. Greater patient empowerment can challenge the traditional role of nurses providing the caring to the patients, creating tension between the nurse as carer and the nurse as empowerer[42]. Critical reflection can help overcome the concern that greater patient autonomy in self-management is akin to leaving the patient to fend for themselves[41].

Limitations

This study has a small sample size, but builds on emerging evidence and may mean that others wanting to develop similar roles can learn from the findings. Another limitation of the study was the audit and content analysis of the care coordination activities counted how often the activities happened, but not how long they took. Some activities that occurred less often may have taken longer to carry out and some activities that were done more often may have been the quickest to do. Examining the activities from a time perspective may have altered how the activities were ranked.

Implications for nursing

The reflective group process produced several recommendations for the role of the CCC. These included: exploring aspects of the multidisciplinary team function in regard to liaison and shared responsibility; extending strategies to reduce the potential of deskilling other team members; increasing awareness of the importance of promoting patient self-management; critically reflecting on relationships with team members and patients; and endeavouring to gain organisational and multidisciplinary team support for what appears to be a role on which there is great reliance. More research is needed in all aspects of this role so everyone involved can learn from what others are doing to overcome some of these issues.

Conclusion

In practice, the cancer care coordinator role involves a variety of activities which enable the multidisciplinary team to support patients and carers. Documentation is an essential part of the role. In this study, the CCCs' perceptions of their role were that they were essentially happy with their busy liaison role within the multidisciplinary team and that they were the lynchpin of this team. Levels of patient self-management promoted were considered by participants to be adequate. Believing their role to have been created to fill gaps in the system for patients resulted in the perception of being everything to everyone.

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References

1. Cancer Nurses Society of Australia. Workforce Position Statement. Sydney: Cancer Nurses Society of Australia, 2002.
2. National Breast Cancer Centre. National profile study of multidisciplinary care and observational study of multidisciplinary care. Camperdown, NSW: National Breast Cancer Centre, 2004.
3. National Cancer Control Initiative, Clinical Oncological Society of Australia & The Cancer Council of Australia. Optimising cancer care in Australia. Melbourne: National Cancer Control Initiative, 2003.
4. Cancer Nurses Society of Australia. Position statement for cancer care coordinators. The Australian Journal of Cancer Nursing 2008; 9(1),2–4.
5. Department of Human Services Victoria. Linking Cancer Care: A guide for implementing coordinated cancer care. Melbourne: Department of Human Services Victoria, 2007.
6. Jackson K. The role of the cancer nurse coordinator in neurology. Aust Nurs J 2008; 15(8):29–31.
7. Platt V, Plaster M, Jenkin R *et al.* Development of the Western Australian cancer nurse coordination service. The Australian Journal of Cancer Nursing 2008; 9(1):17–21.
8. Roberts S, Schofield P, Freeman J, Hill D, Akkerman D & Rodger A. Bridging the information and support gap: evaluation of a hospital-based cancer support nurse service. Patient Educ Couns 2002; 47:47–55.
9. Stowers M & Williams M. Improving the cancer patient journey: The impact of a regional cancer coordination model. The Australian Journal of Cancer Nursing 2008; 9(1):5–11.
10. Walsh J, Harrison J, Young J, Butow P, Solomon M & Masya L. What are the current barriers to effective care coordination? A qualitative study. BMC Health Services Research 2010; 10:132.
11. Swanson J & Koch L. The role of the oncology nurse navigator in distress management of adult inpatients with cancer: a retrospective study. Oncol Nurs Forum 2010; 37(1):69–76.
12. Marchand P. The clinical nurse specialist as nurse navigator: ordinary role presents extraordinary experience. Can Oncol Nurs J 2010; 20(2):80–3.
13. Specialist Breast Nurse Project Team. Specialist breast nurses: an evidence based model for Australian practice. Kings Cross: National Breast Cancer Centre, 2000.
14. National Breast Cancer Centre & National Cancer Control Initiative. Clinical practice guidelines for the psychosocial care of adults with cancer. Camperdown, NSW: National Breast Cancer Centre, 2003.
15. Evans A. Report on the 2010 cancer coordination conference: Relationships, roles, reality. Cancer Forum 2010; 34(3).
16. Taylor B. Qualitative critical methodologies. In Taylor B, Kermode S & Roberts K, eds. Research in nursing and health care: Evidence for practice. 3rd edn. South Melbourne: Thompson, 2007, pp. 318–362.

17. Patton MQ. Qualitative research and evaluation methods. 3rd edn. Thousand Oaks, CA: Sage, 2002.
18. Lupton D. Content Analysis. In Minichiello V, Sullivan G, Greenwood K & Axford R, eds. Handbook for research methods in health sciences. Sydney: Addison Wesley, 1999; pp. 449–461.
19. The London and South East Lung Cancer Forum for Nurses. Guidelines on the role of the specialist nurse in supporting patients with lung cancer. Eur J Cancer Care 2004; 13:344–348.
20. Yates P. Cancer Care Coordinators: Realising the potential for improving the patient journey. Cancer Forum 2004; 28(3):128–132.
21. Seek AJ & Hogle WP. Modeling a better way: Navigating the healthcare system with patients with lung cancer. Clin J Oncol Nurs 2007; 11:81–85.
22. Strusowski P. A multidisciplinary model for cancer care management. Oncol Nurs Forum 2006; 33:697–700.
23. Tripathy D. Multidisciplinary care for breast cancer: Barriers and solutions. Breast J 2003; 9:60–63.
24. Penson RT, Kyriakou H, Zuckerman D, Chabner BA & Lynch TJ Jr. Teams: Communication in multidisciplinary care. Oncologist 2006; 11:520–526.
25. Firth-Cozens J. Multidisciplinary teamwork: The good, the bad, and everything in between. Qual Health Care 2001; 10:65–66.
26. Zorbas H, Barraclough B, Rainbird K, Luxford K & Redman S. Multidisciplinary care for women with early breast cancer in the Australian context: What does it mean? Med J Aust 2003; 179:528–531.
27. Rushtaller T, Roe H, Thurlimann B & Nicoll JJ. The multidisciplinary meeting: An indispensable aid to communication between different specialties. Eur J Cancer 2006; 42:2456–2462.
28. Flessig A, Jenkins V, Catt S & Fallowfield L. Multidisciplinary teams in cancer care: Are they effective in the UK? Lancet Oncology 2006; 7:935–943.
29. Viklund P, Wengstrom Y & Lagergren J. Supportive care for patients with oesophageal and other upper gastrointestinal cancers: The role of a specialist nurse in the team. Eur J Oncol Nurs 2006; 10:353–363.
30. Amir Z, Scully J & Borrill C. The professional role of breast cancer nurses in multidisciplinary breast cancer care teams. Eur J Oncol Nurs 2004; 8:306–314.
31. Ponte PR, Gross AH, Winer E, Connaughton MJ & Hassinger,J. Implementing an interdisciplinary governance model in a comprehensive cancer centre. Oncol Nurs Forum 2007; 34:611–616.
32. Castledine G. Are specialist nurses deskilling general nurses? Br J Nurs 2000; 9(11):738.
33. Kendall-Raynor P. Evaluation of specialist nurses show they are cost effective. Nurs Stand 2007; 21(35):5.
34. Brookes K, Daly J, Davidson P & Hancock K. Community health nursing in Australia: A critical literature review and implications for professional development. Contemp Nurse 2004; 16(3):195–207.
35. Duffin C. Specialist nurses deskill profession. Nurs Stand 2001; 15(18):5.
36. Mytton E J & Adams A. Do clinical nurse specialists in palliative care deskill or empower general ward nurses? Int J Palliat Nurs 2003; 9(2):64–72.
37. Marshall Z & Luffingham N. Specialist nursing. Does the specialist nurse enhance or deskill the general nurse? Br J Nurs 1998; 7(11):658–662.
38. Vere-Jones E. Specialist vs generalist. Nurs Times 2006; 102(21):16–17.
39. Coleman M T & Newton,K. Supporting self-management in patients with chronic illness. American Family Physician 2005; 72(8):1503–1510.
40. Holman H & Lorig K. Patient self-management: A key to effectiveness and efficiency in care of chronic disease. Public Health Reports 2004; 119(3):239–243.
41. Oudshoorn A. Power and empowerment: Critical concepts in the nurse-client relationship. Contemp Nurse 2005; 20(1):57–66.
42. Elliott M A & Turrell AR. Dilemma for the empowering nurse. J Nurs Manage 1996; 4:273–279.
43. Coffey S. The nurse-patient relationship in cancer care as a shared covenant, A concept analysis. Adv Nurs Sci 2006; 29(4):308–323.

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Enabling supportive care screening and evidence-based referrals for patients with cancer: patient acceptability and clinician implementation of the Supportive Care Resource Kit (SCRK)

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Abstract

The Resource Kit was developed to enable supportive care screening of cancer patients accompanied by evidence-based referrals. Patient acceptability of the screening/referral process was assessed alongside clinician ability to undertake screening/referral in line with training received and the resource kit protocols. Forty patients and seven clinicians participated. Patients completed a brief screening tool to identify unmet needs and participated in a discussion with a trained clinician who identified strategies to meet these needs. Patients subsequently completed an acceptability questionnaire whilst clinician actions to identified needs were assessed. Patient acceptability of the screening/referral process was high and future use endorsed (97%) with the process helping to fully identify patient needs (91%) and promote realisation that help/support was available when needed (100%). Clinicians successfully applied skills learned from training to appropriately refer 88% of patient domain needs in line with the resource kit protocols. Future use of the resource kit may assist the incorporation of supportive care screening/referral into clinical practice to improve patient care.

Introduction

Cancer patients experience a range of supportive care needs (psychological; physical; practical; informational) as a result of their diagnosis and treatment with the number and type of needs differing between individuals and disease stage. Psychosocial guidelines recommend early identification and referral of cancer patients with unmet supportive care needs, to improve patient outcomes[1-3] such as emotional/physical functioning, pain and quality of life[4-13]. Supportive care screening is perceived as useful by oncology clinicians resulting in an increase in: awareness of patient concerns; discussion of supportive care needs and doctor-patient communication[7,14-19]. Supportive care is, therefore, improved by routinely and systematically screening cancer patients for unmet needs accompanied by provision of evidence-based referrals and information and support. The need for supportive care screening of cancer patients is underpinned by research highlighting that: i) clinician identification of individual patient physical/psychosocial needs is sub-optimal[15,20-22] and ii) patient reluctance to raise supportive care concerns or to discuss them only at the initiative of the clinician[23,24]. Conversely, clinicians generally defer to patient wishes in relation to raising supportive care issues[23] or lack confidence to address supportive care issues[25].

There is no 'definitive' screening instrument for the detection of supportive care needs in cancer patients[26,27]. However, recent studies suggest screening needs to be achieved with a minimum number of items to maximise patient/clinician acceptability[28]. One such instrument is the Distress Thermometer and Problem List[1]; a single-item, self-report measure of psychological distress accompanied by a problem list of supportive care needs. Whilst increasing numbers of studies have been published utilising the Distress Thermometer[29-35], only a subset of these report implementing *both* the Distress Thermometer and Problem Checklist as intended by its authors[1]. In addition, how institutions have developed referral protocols, staff training and assessment programs to implement screening, are rarely described[33-35].

In Victoria, the state government has set targets for the implementation of routine supportive care screening for cancer patients[36]. However, how these screening targets are to be achieved within routine clinical practice has not been clearly addressed. The need for clinician training in supportive care has also been targeted; however, little guidance on how to train clinicians is available other than the provision of clinical supervision/communication skills training, which are linked with improved patient outcomes[37-38]. Considerable planning to implement screening is required if health care services are to incorporate a systematic screening process into routine clinical practice and to overcome potential workplace barriers[39].

The Supportive Care Resource Kit

We have developed the resource kit to train and enable cancer clinicians to undertake supportive care screening accompanied by evidence-based referrals. The kit is comprised of seven components[40,41].

1. Clinician training package. This covers a range of topics including common supportive care needs, how to improve supportive care and patient disease/demographic risk factors for adverse psychological adjustment. An overview of supportive care screening methods is presented alongside when/how to use the kit's referral protocols to refer patients following screening. Use of additional decision-making tools (Figure 1) and documentation is discussed with a multipart case study provided to apply the knowledge gained to clinical contexts.

2. Patient screening tools. The Distress Thermometer/Problem Checklist was chosen as the screening tool due to ease of completion, validation and assessment of a range of domains of patient need[1]. A second screening tool, the Kessler Psychological Distress Scale[42], was provided when patients indicated a distress score of ≥4[1] to assist decision making around referrals for psychological/emotional issues. This two-stage system is currently recommended to increase the specificity of screening for distress[32] such that unnecessary referrals are minimised.

3. Evidence-based referral protocols (Figure 2). All items assessed by the Distress Thermometer/ Problem Checklist were accompanied by a specially developed referral protocols adapted from current psychosocial guidelines[3]. Where necessary, protocols were modified in line with feedback from a multidisciplinary network of local supportive care practitioners assembled into a project advisory group. Individual issues from the Distress Thermometer/Problem Checklist are addressed with step-by-step suggestions and were written to accommodate a range of patient preferences for problem resolution and to cover a range of available services. If a particular service was not available within a specific regional area, alternative suggestions for care were provided. These protocols were therefore designed such that they could be potentially suitable for use at any cancer treatment facility.

4. Supportive care service directory (Figure 3). This contains a list of supportive care practitioners relevant to the referral protocol and were listed by practitioner type and location[43].

5. Clinician referral and action checklist (Figure 4A). This is a means for clinicians to record patient needs identified/discussed and any actions taken, following completion of the screening tool.

6. Patient note sheet (Figure 4B). This enabled clinicians to provide a hard copy of any verbal information provided to meet identified patient needs.

7. Information leaflets. These were a selection of leaflets included to complement information provision to patients.

Our previous reporting on clinician acceptability of the resource kit found that it improved identification of patient needs, improved communication and was supported for implementation into routine care (although time and the perception of the nursing role were identified as potential barriers)[40]. However, patient acceptability of the screening/referral process utilising the resource kit resources was not investigated and no measure of how clinicians implemented or operationalised the resource kit resources/protocols (following training) was made. The aims of this pilot study were therefore to: i) assess patient acceptability/screening/referral with the resource kit resources; and ii) assess the appropriateness of use of the resource kit resources by clinicians to identify and meet the supportive care needs of patients in line with training/the resource kit protocols provided.

Methods

Design

This was a prospective pilot study conducted within the chemotherapy and radiotherapy departments at a large regional hospital in Victoria, Australia. Approval for this project was granted by the Human Research Ethics Committees at Monash University and the regional recruitment hospital.

Participants

A convenience sample of patients attending the chemotherapy and radiotherapy departments of the recruitment hospital were identified. Eligibility criteria included: confirmed diagnosis of malignant disease; aged 18+ years; ability to read, write and speak in English; and no significant cognitive deficits as judged by a treating clinician. Following confirmation of study eligibility, a member of the study team approached patients to gain written consent. Patients were then provided with a copy of the screening tool to complete. A convenience sample of oncology clinicians were also nominated for study participation by unit managers of the chemotherapy and radiotherapy departments. Following nomination by unit managers, oncology clinicians provided written consent for study participation and completed a half-day training course in the use of the SCRK.

Procedure

Following patient completion of the screening tool, a trained study clinician undertook a discussion with the patient regarding identified needs (that is, a *screening discussion*). Discussions were held either on the same day of the visit (chemotherapy patients) or on the following day's scheduled visit (radiotherapy patients). During the screening discussion, clinicians discussed patient problems identified in the screening tool and provided information and referrals as guided by the referral protocols in the resource kit. Where possible, the screening discussion was held in a private clinic room. Clinicians recorded all issues discussed/information provided/referrals made on the clinician referral and action checklist. One week following the screening discussion patients completed a telephone acceptability questionnaire about their experience of the screening/referral process.

Outcome measures

Distress Thermometer *and PL*[1]. The Distress Thermometer is a single-item, self-report measure of psychological distress consisting of an 11-point scale ranging from "No distress" (0) to "Extreme distress" (10). Guidelines recommend a cut-off score of four to distinguish between patients with mild distress and those with moderate/severe distress[1]. The Problem Checklist contains 35 needs commonly experienced by cancer patients grouped into five domains: practical, family, emotional, spiritual/religious and physical.

Demographic questionnaire: was self-completed by patients to collect age, marital and employment status information.

Disease data. Primary cancer site and extent of disease information was obtained from the patient medical record.

Clinician referral and action checklist. A one-page form completed by clinicians following individual screening discussions with patients to document issues identified from the screening tool and document actions taken (Figure 4).

Patient acceptability questionnaire. A 25-item survey developed to assess patient acceptability of the screening and referral process (using the resource kit). It contained three sections: patient experience of completing the screening tool, patient experience of the screening discussion and the outcomes from the screening discussion (for example, information provision, referrals). The majority of questions asked patients to rank their agreement with statements on a five-point Likert scale ranging from 1 "Strongly agree" to 5 "Strongly disagree" alongside two numeric questions (time to complete screening tool; number of referrals given).

Analysis

Simple descriptive statistics were completed on patient demographic, disease, and Distress Thermometer variables as well as patient acceptability data. Clinician adherence to the resource kit protocols was analysed via content analysis[44,45]. Completed patient screening tools were assessed to obtain a list of identified domain needs. These needs were used as the basis for comparison with the Clinician Action and Referral Checklists. Categories for the content analysis were agreed upon by the three researchers and included: a) Was the identified need discussed with the patient? b) Did the discussion alone address the need? c) Was information provided? d) Was a referral offered? and e) Was the referral appropriate? (that is, did it match those provided in the referral protocols?)

One researcher read aloud the documentation and the other two researchers notated under each category a mark to answer each of the above questions for each clinician/patient interaction. Totals were tallied across each domain of the PL. Patient refusal of referrals were noted. Each researcher's results were compared and any differences resolved with additional discussion to gain consensus.

Results

Recruitment and sample characteristics

Forty-three patients were approached for study participation (22 chemotherapy; 21 radiotherapy) with 20 patients from each department consenting to participate. All consenting patients completed the Distress Thermometer and screening discussion, whilst 38 (95%) commenced and 35 (88%) completed the acceptability questionnaire. Ten clinicians were approached and consented to participate in the study from the chemotherapy (five nurses) and radiotherapy (two radiation therapists and three nurses) departments.

The majority of patients were female (52%), with a mean age of 66 years (±13 years); most were married (78%) and retired or pensioners (58%). Most prevalent primary cancer sites were those of the gastrointestinal tract (38%) and breast (28%), with the majority of tumours classified as localised/locally advanced (65%) (Table 1).

The mean Distress Thermometer score was 3.1(±2.5) with 38% of patients recording an elevated distress score of ≥4. The mean number of unmet needs identified per patient was 6.6(±4.8) with a range of 0–19 with the most prevalent needs including: fatigue (63%); sleep (48%); worry and memory loss/concentration (40%) (Table 2).

Of the 10 clinicians trained to use the resource kit, seven completed screening discussions with patients (five nurses; two radiation therapists) and all were female. The average number of screening discussions completed per clinician was 6.3(± 5.8) with a range of 2–18. Six clinicians completed the acceptability questionnaire (one radiation therapist and five nurses).

Patient acceptability/perceived usefulness

Patients spent an average of nine minutes completing the screening tool (±3.4 minutes) with a range of 5–15 minutes. Screening tool content and format was acceptable to the majority of patients, with 73% of patients requiring no help with completion (Table 3). The majority of patients indicated that they would be happy to complete a screening tool as part of

future treatment (89%) and 84% indicating that completing the tool assisted them to communicate their needs with their nurse/radiation therapist.

On average patients reported spending 19 minutes (±15 minutes) talking to a nurse/radiation therapist in the screening discussion (range of 5–90 minutes). All patients reported that a nurse/radiation therapist encouraged them to talk through their problems and to ask questions in the screening discussion (100%) and listened to what they wanted/needed (100%; Table 3). Patients agreed that the screening discussion helped them: to fully identify their needs (91%); realise that their experience/feelings were normal (97%); realise that help was available when needed (100%). All patients appreciated the opportunity to talk through their issues and questions and the majority indicated that they would be happy to complete similar discussions as part of future treatment (97%). Nine per cent of patients would have preferred to complete the discussion in a more private location.

The patient note sheet was seen as helpful in assisting patients to recall information/referrals by 60% of patients, whilst 79% reported receiving referrals that were useful. Eighty-one per cent of patients appreciated the opportunity to get more information and referrals from a similar discussion in the future whilst 73% indicated that they would be comfortable to *initiate* a similar discussion by the self-completion of a screening tool if made available in a public area.

Clinician adherence to SCRK protocols

Eighty-eight per cent (n=35) of clinician referral and action checklists were completed and returned to the study following the completion of the patient screening discussion. Although the PLs identified individual patient needs, clinicians documented

Table 1. Summary of patient disease and demographic characteristics.

Characteristic	No. of patients	%
Gender		
Male	19	48
Female	21	52
Age		
Mean (± SD)	66 (± 13)	
Range	39-89	
Marital status		
Married/de-facto	31	78
Widowed	5	13
Divorced/separated	2	5
Not stated	2	5
Employment status		
Employed (working)	3	8
Employed (sick leave)	4	10
Employed (unpaid leave)	5	13
Retired/pensioner	23	58
Other	4	10
Not stated	1	3
Recruitment location		
Radiotherapy department	20	50
Chemotherapy department	20	50
Primary cancer site		
GIT	15	38
Breast	11	28
Prostate	5	13
NHL	3	8
Bladder	3	8
Lung	2	5
Skin	1	3
Extent of disease		
Localised/locally advanced	26	65
Metastatic	13	33
unknown	1	3

Abbreviations: SD; standard deviation.
GIT = Gastrointestinal
NHL = Non-Hodgkin Lymphoma

these according to domain. Physical (86%) and emotional (71%) domains were the most commonly recorded (Table 4). The majority (88%) of identified needs were addressed, with 100% of needs in the practical and family domains being addressed and 87% of physical and 84% of emotional domain needs addressed (Table 4).

Of those patients who had their needs discussed, the discussion alone addressed the need in only 11% of cases, whilst a combination of discussion *and* information was required in 46% of cases. The remaining 43% of patients were provided with referrals for supportive care services when either discussion alone, or discussion plus information provision was not sufficient. Referrals were most common for practical problems (100%) and emotional problems (52%). Thirty-eight per cent of referrals were rejected by patients, with rejections in the main for emotional needs.

Overall, when domain needs were addressed by clinicians (via discussion, information provision or referral), all actions (100%) were judged to be consistent with those recommended in the resource kit referral protocols. However, clinician adherence to use of the Kessler Pyscological Distress Scale for patients scoring ≥4 on the Distress Thermometer as an additional decision aid only occurred in nine of 14 cases (64%).

Discussion

We developed the resource kit to train and enable oncology clinicians to undertake supportive care screening/referral as part of routine clinical practice in line with current supportive care guidelines. This study built on previously reported clinician acceptability data forthe resource kit[40] by assessing both patient acceptability of the screening/referral process (using the resource kit resources) and assessing how successfully clinicians operationalised the resource kit protocols in clinical practice following training.

Patient acceptability of the screening tool content and layout was high, with 89% supporting future use whilst an even higher number (97%) supported future "screening discussions" and all appreciating the opportunity to discuss their needs. Such high value of future screening discussions may have been partially attributable to the enhanced communication and rapport

Table 2. Summary of patient distress thermometer scores and problem checklist needs identified.

Characteristic	No. of patients	%
Distress thermometer		
Mean (± 2.5)	3.1 (± 2.5)	
Range	0-8	
Scores ≥4	16	40
Missing data	1	3
Problem checklist issues		
Mean issues identified (± SD)	6.6 (± 4.8)	
Range	0-19	
Ten most prevalent checklist Issues		
Fatigue	25	63
Sleep	19	48
Worry	16	40
Memory loss/concentration	16	40
Pain	13	33
Skin	13	33
Getting around	12	30
Nervousness	11	28
Difficulty eating	11	28
Nausea	11	28
Changes in urination	10	25
Breathing	9	23
Constipation	9	23
Indigestion	9	23
Depression	8	20
Fears	7	18
Sadness	7	18
Loss of interest	7	18
Diarrhoea	7	18
Mouth sores	7	18
Tingling hands and feet	7	18
Missing data	1	3

Abbreviations: SD; standard deviation.

Table 3. Patient acceptability data for use of the resource kit.

Acceptability item	No. (%) Strongly agree	No. (%) agree	No. (%) Unsure	No. (%) disagree	No. (%) Strongly disagree
Completing the distress thermometer					
The questionnaire did not take too long to complete	10 (26)	26 (68)	-	2 (5)	-
The layout of the questionnaire was easy to read	11 (29)	27 (71)	-	-	-
The language in the questionnaire was easy to understand	10 (26)	27 (71)	1 (3)	-	-
I needed help to complete the questionnaire	-	4 (11)	-	27 (73)	-
The questionnaire covered issues relevant to me	5 (13)	32 (84)	-	1 (3)	
I would have liked to complete the questionnaire in a more private location	1 (3)	2 (5)	-	32 (84)	3 (8)
I would be happy to complete the questionnaire again as part of my future cancer care	5 (13)	29 (76)	2 (5)	2 (5)	-
Completing the questionnaire helped me to communicate with my nurse/radiotherapist	4 (11)	28 (73)	3 (8)	3 (8)	-
The screening discussion#					
The length of the discussion was appropriate	7 (20)	28 (80)	-	-	-
I would have liked to discuss the questionnaire in a more private location	-	3 (9)	-	30 (86)	2 (6)
The nurse/radiotherapist encouraged me to talk about my problems and to ask questions	6 (17)	29 (83)	-	-	-
The nurse/radiotherapist was easy to talk to	14 (40)	21 (60)	-	-	-
The time I spent with the nurse/radiotherapist helped to fully identify my needs	4 (12)	27 (79)	2 (6)	1 (3)	-
I appreciated the opportunity to talk through any issues or questions I had with the nurse/ radiotherapist	10 (29)	24 (69)	-	-	-
The nurse/radiotherapist listened to what I wanted/ needed	12 (34)	23 (66)	-	-	-
My discussions with the nurse made me realise that there is help available if I need it	14 (41)	20 (59)	-	-	-
My discussions with the nurse/radiotherapist made me realise that the feelings that I have are normal for someone with a diagnosis of cancer	10 (29)	24 (69)	1 (3)	-	-
I would be happy to complete another similar discussion with a member of the nursing/ radiotherapy staff again as part of my future cancer treatment	8 (23)	26 (74)	1 (3)	-	-
Outcomes of screening and discussion					
The nurse/radiotherapist gave me referrals that were useful*	3 (21)	8 (57)	3 (21)	-	-
The notes sheet I took away from the discussion helped me to remember the information/referrals that I was given**	3 (14)	18 (82)	1 (5)	-	
The nurse/radiotherapist completed the notes sheet for me**	2 (9)	18 (82)	2 (9)	-	
I would appreciate the opportunity to get more information and referrals in a similar discussion with nursing/radiotherapy staff in the future	2 (6)	24 (75)	3 (9)	3 (9)	-
I would be comfortable to initiate a similar discussion with my nurse in future by picking up a questionnaire in the waiting room and completing it	3 (9)	21 (62)	1 (3)	8 (24)	1 (3)

** = data available from 14 patients who reported that they recalled receiving a referral as a result of the screening discussion*

** = data available from 22 patients who reported that they recalled receiving a patient note sheet during the screening discussion*

developed between patients and clinicians. Patients reported they were encouraged to talk about issues, ask questions, were listened to, had their feelings/experiences normalised and reassured that additional help was available (if needed). This is strong support for the acceptability of screening/referral from the patient perspective alongside positive endorsement of both nursing and radiation therapist skills in this role.

Patients also considered that the length of the screening discussions was appropriate. However, this contrasts with our previous findings that clinicians perceived the discussions as too lengthy[40]. With other studies also citing time as an important barrier for implementing supportive care by clincians[31,35], institutions may, therefore, need to balance patient needs with clinician time by allocating additional resources and scheduling specific times for screening. Whilst increasing numbers of studies indicate patient benefits of supportive care screening[4-13], no large-scale studies of cost-effectiveness have been completed and are likely needed to advise equitable resource allocation.

Whilst this pilot study illustrated overall patient acceptability of screening/referral with the resource kit, it did not collect data about specific treatment time points at which it should occur. One possibility is for patients to decide themselves when they require assistance and to self-complete screening tools which are readily available to initiate a discussion when required. This could potentially save time for oncology clinicians who may screen patients with few or no apparent issues. However, almost one-third of our sample stipulated that they would not feel confident to *initiate* the screening/referral process by themselves. This may suggest that those who may most need assistance with unmet supportive care needs may be those least willing to initiate a discussion – a finding which is supported by previous research where patients often consider supportive care discussions to be held only at the initiative of the clinician[23,24]. A recent study also found that asking patients if they required help with emotional issues (as part of a screening process) was not a reliable indication of those who actually most required assistance[46]. Together these findings indicate that dedicated times for screening/referral/documentation need to be scheduled for *all* patients at appropriate junctures in their care,

Overall, clinicians operationalised the training they received to undertake screening/referral with the resource kit successfully into the clinical setting. Of all patient domains of need identified with the screening tools, 88% of these needs were recorded as being addressed by clinicians within the screening discussion. In these cases all clinician actions taken to address patient needs were consistent with both the resource kit referral protocols and the training clinicians had received to use the kit. The reasons for 12% of issues remaining unaddressed, however, remains unclear. This lack of discussion occurred only in the physical and emotional domains, which were the two domains of highest need overall. Whilst this may reflect a need for further training, or a lack of time to address all patient identified needs, it may also be a result of omissions in clinician documentation

Of note in this pilot study was that all actions taken in response to patient domains of need addressed by clinicians were *consistent* with training received and the resource kit protocols. However, it should be noted that researchers were unable to locate the Kessler Pyscological Distress Scale documentation for around one-third of patients scoring ≥4 on the Distress Thermometer. This limited our findings and the reasons for this lack of documentation were not clear Additional training and support may, therefore, be needed in the use of the K10 in conjunction with the Distress Thermometer to highlight the importance of this binary mechanism to ensure that patients receive appropriate referrals, and that scarce psycho-social resources are not overburdened inappropriately.

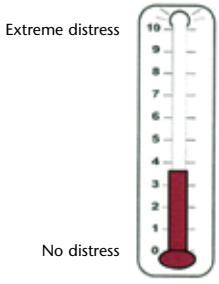
Our study indicates that 57% of patient needs were addressed by either discussion alone or a combination of discussion and information provision. The remaining 43% of patients were offered referrals in addition to discussion and information provision. These findings are in line with Fitch's[47] model of

Table 4. Summary of actions taken by clinicians in the screening discussion in relation to identified patient domains of need on the screening tool.

Domains of need	No. (%) patients with need identified within a specific domain		No. (%) patients who had need(s) discussed		No. (%) patients for whom discussion alone addressed need(s)		No. (%) patients for whom discussion and information addressed need(s)		No. (%) patients for whom appropriate referrals made to address need(s)		No. (%) of referrals rejected by patients	
Practical problems	5	(14)	5	(100)	-	-	-		5	(100)	1	(20)
Family problems	3	(9)	3	(100)	-	-	2	(67)	1	(33)	-	-
Emotional problems	25	(71)	21	(84)	2	(10)	8	(38)	11	(52)	7	(64)
Physical problems	31	(86)	27	(87)	4	(15)	16	(59)	7	(26)	1	(14)
Spiritual problems	0	(0)	0	(0)	0	(0)	0(	(0)	0	(0)	0	(0)
Total			56	(88)	6	(11)	26	(46)	24	(43)	9	(38)
					56 (100)							

Distress thermometer scoring

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.



Example 1:

Distress Thermometer<4

If a patient has indicated that their level of distress is **less than 4** on the thermometer then they are *not* considered to be showing elevated levels of distress and no actions or referrals are needed.

However, IF a patient has indicated any emotional problems from the accompanying problem checklist (eg worry), these issues should be discussed with the patient.

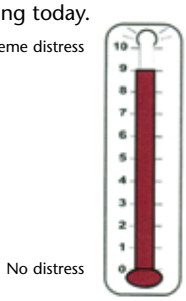
Example 2:

Distress Thermometer ≥4

If a patient indicates that their level of distress is **greater than or equal to 4** then their level of **distress is considered to be elevated.** Some supportive actions and referrals are needed with this patient.

For all pastients with a score of ≥4 the Kessler Psychological Distress Scale (K10) should also be administered. When considering supportive care actions for these patients both the K10 score and the Emotional problems checklist should be considered.

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.



If patient expresses thoughts of suicidal ideation or self harm an URGENT referral to Psychiatric Services is required.

Figure 1. Example page illustrating a decision making rule from the resource kit.

supportive care which indicates that the majority of patient needs are addressed by the timely provision of information and discussion of issues. For patients to whom referrals were recommended, over one-third (38%) of these were rejected, the majority for emotional needs. The rate of referral rejection is lower than other studies[30,48] and may reflect differences in the culture, populations recruited or in clinician training/experience. However, it is also possible that some patients never carried through with their referrals following this study, thereby decreasing overall referral rates. Within the confines of the ethics approvals given for this study it was not possible to track future referral uptake by patients – a limitation that must be acknowledged in this pilot study.

Lack of uptake of referrals for psychological/emotional issues in this study may occur as a result of clinician need for additional support and training. For example, training in communication skills[49], how to make a referral, or clinical supervision, may increase oncology clinician confidence when dealing with patient emotional concerns. This result also ties in with other data around some clinicians not feeling confident with emotional issues being part of their scope of practice[40,49,50]. In our previous study, some trained clinicians admitted to feeling more comfortable offering and encouraging patient uptake of referrals which were *not* related to psychological or emotional issues. However, patient reticence to accept referrals for psychological/emotional issues may also reflect community stigma around referrals or a belief that 'nothing can be done' in relation to these concerns[38,40].

Dealing with Partner-interpersonal problems

If a patient is experiencing interpersonal problems with their partner during their cancer treatment or recovery:

Initial assessment

- Clarify the exact nature of the issue with the patient AND;
- Assess family and social support structure AND;
- Assess family roles.

Suggested referrals to supportive care paractitioners

- Cancer Care Nurse/Breast Care OR'
- Social Worker.

If problem continues and/or is causing significant patient distress family or couples counselling may be needed:

- Psychologist OR;
- Counsellor OR;
- Psychiatrist.

Suggested referrals to supportive care services

- Relationships Australia (ph. 1300 364 277 or www.relationships.com.au)

Information

- Provide appropriate information and/or literature (if available) AND/OR;
- Refer to cancer Helpline (13 11 20) for further verbal/sritten information.

Figure 2. Example page from one of the evidence-based referral protocol pages included in the resource kit.

Bush Nursing Centres, Community Health & Hospitals

Bass Coast

Bass Coast Community Health Service	1 Back Beach Rd	San Remo	3925	5678 5388	Service Availability Mon-Fri 8.30-4.30

Nursing
- *Breast Care*
- *Community*
- *District#*

Allied Health
- *Dietitian**
- *Occupational Therapist**
- *Physiothersapist**
- *Psychologist*

General Practice

** Home visits during centre hours*
 # 24 hour palliative care by arrangement

Bass Coast Regional Health Wonthaggi Hospital & Family Resource Centre	Graham St	Wonthaggi	3995	5671 3333 5671 3378	Service Availability Mon-Fri 9.00-5.00

Nursing
- *Breast Care*
- *District*#*

Allied Health
- *Dentist*
- *Dietician*
- *Occupational Therapist**
- *Physiotherapist*
- *Social Worker*
- *Speech Thertapist*

General Practitioner on-call service for after hours emergencies

** Home visits during centre hours*
 # 24 hour palliative care by arrangement

Figure 3. Example page from the supportive care service directory.

A

SUPPORTIVE CARE REFERRAL AND ACTION CHECKLIST

Date: _____ Patient Name: _____
MR No: _____ D.O.B. _____
Address: _____ Telephone No: _____
Completed by: _____ Department: _____

Issue identified:	Discussed	Referred
_____	☐	☐
_____	☐	☐

Comments/actions:
_____
_____
_____
_____
_____

Issue identified:	Discussed	Referred
_____	☐	☐
_____	☐	☐

Comments/actions:
_____
_____
_____
_____
_____

B

MY NOTES AND REFERRALS

Date: _____ Patient Name: _____
MR No: _____ Completed by _____

Issue that I need help with:	Things that I can do to help:
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Issue that I need help with:	Things that I can do to help:
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Figure 4. Excerpts from (A) clinician referral and action checklist and (B) patient note sheet.

Limitations and methodological considerations

We acknowledge the methodological limitations of this pilot study The sample size for this study was small and from only one hospital. While there were different cancer diagnoses, ages and needs identified, it must be acknowledged that our limited sample is not necessarily representative of other regional or metropolitan cancer populations. In addition, only six clinicians from two departments (and two clinical backgrounds) undertook patient screening discussions. Further work is currently under way to gather additional acceptability and usage data across a wider range of hospitals, with a wider variety of clinician backgrounds (for example, social workers) and across a wider variety of settings (for example, surgical wards, community health).

Our assessment of whether the clinicians addressed all identified patient needs in the screening discussion was limited by clinician documentation. The quality of written documentation varied widely, and in some cases, limited researcher judgement. Future work should include increased training in documentation for clinicians and provision of a system that is more user-friendly and able to be incorporated more easily into routine care. Screening discussions could also be audio-recorded for content analysis. However, consideration of the potential effect of recording around the non-disclosure of sensitive issues by patients within the screening discussion would need to be considered.

Conclusions and clinical implications

The results of this pilot study, combined with the previously reported clinician acceptability data, suggest that the resource kit is an acceptable mechanism for enabling clinician training and implementation of supportive care screening for cancer patients within routine clinical practice. The referral protocols contained within the resource kit are uniquely wide-ranging, allowing for use across different institutions where not all services may be available. They incorporate a variety of support services which are accessible Australia-wide making the kit potentially transferable across different locations, with only the service directory needing to be adapted/developed to the local region.

Most importantly, the resource kit incorporates several vital mechanisms to implementing best practice evidence-based psychosocial care including: i) the introduction of a data collection system Distress Thermometer/PL) to monitor patient psychosocial needs accompanied by evidence-based management (the resource kit referral protocols); ii) the empowerment of patients to talk about psychosocial issues (by allowing dedicated time for discussion of unmet needs); and iii) training in the provision of best practice supportive care for clinicians. Future revisions of the kit and the associated training could also include additional information on the process and skills required to make successful referrals for emotional/psychological issues and how to reduce the associated stigma of these referrals. Different models of clinician training may also be considered such as online/internet resources[51]. For example, in Australia supportive care screening and referral resources and competencies could be developed and located on websites such as EdCan (http://www.edcan.org/).

However, a number of barriers to routine supportive care screening and evidence-based referral still remain and need to be addressed at a governmental and institutional infrastructure level for all oncology clinicians. These include a lack of undergraduate training in psychosocial care, training in behavioural skills to address and manage distress (for example, communication skills training), funding of staffing, and potentially clinic space, to provide the needed care, and the provision of formal systems of support for clinicians who provide supportive care (for example, clinical supervision or peer support).

A combination of additional refinement and testing of systems (such as the resource kit) to enable supportive care screening/referral in Australia *in combination* with an increased recognition of the importance of supportive care by state and federal government is a step in the right direction for best practice and the improvement of psychosocial outcomes for patients with cancer. The high acceptability of the resource kit supports the role of oncology nurses and other clinicians to complete both screening and referral and should, therefore, be considered alongside other quality assurance measures of patient care.

Acknowledgements

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References

1. National Comprehensive Cancer Network (NCCN). NCCN clinical practice guidelines in oncology. Distress management, version 1, 2008. http://www.nccn.org/professionals/physician_gls/PDF/distress.pdf Retrieved 12 May 2008.
2. National Institute for Clinical Excellence (NICE). Improving supportive and palliative care for adults with cancer: The manual. London, UK: National Institute for Clinical Excellence, 2004.
3. National Breast Cancer Centre (NBCC) and National Cancer Control Initiative. Clinical practice guidelines for the psychosocial care of adults with cancer. Camperdown, NSW: National Breast Cancer Centre, 2003.
4. Macvean ML, White VM, Pratt S, Grogan S & Sanson-Fisher R. Reducing the unmet needs of patients with colorectal cancer: A feasibility study of The Pathfinder Volunteer Program. Support Care Cancer 2007; 15(3):293–299.
5. Carlson L, Groff S, Maciejewski O & Bultz B. Screening for Distress in Lung and Breast Cancer Outpatients: A Randomized Controlled Trial. Journal of Clinical Oncology 2010; 28(33):4884–4891.
6. McLachlan SA, Allenby A, Matthews J *et al.* Randomised trial of coordinated psychosocial interventions based on patient self-assessments versus standard care to improve the psychosocial functioning of patients with cancer. J Clin Oncol 2001; 19(21):4117–4125.

7. Velikova G, Booth L, Smith A *et al.* Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomised controlled trial. J Clin Oncol 2004; 22(4):714–724.
8. Siegel K, Mesagno FM, Karus DG & Christ G. Reducing the prevalence of unmet needs for concrete services of patients with cancer: Evaluation of a computerized telephone outreach system. Cancer 1992; 69(7):1873–1883.
9. Kearney N, Miller M, Maguire R *et al.* WISECARE+: Results of a European study of a nursing intervention for the management of chemotherapy-related symptoms. Eur J Oncol Nurs 2008; 12(5):443–448.
10. Kearney N, McCann L, Norrie J *et al.* Evaluation of a mobile phone-based, advanced symptom management system (ASyMS©) in the management of chemotherapy-related toxicity. Support Care Cancer 2009; 17(4):437–444.
11. Boyes A, Newell S, Girgis A, McElduff P & Sanson-Fisher R. Does routine assessment and real-time feedback improve cancer patients' psychosocial well-being? Eur J Cancer Care 2006; 15(2):163–171.
12. Girgis A, Breen S, Stacey F & Lecathelinais C. Impact of two supportive care interventions on anxiety, depression, quality of life, and unmet needs in patients with nonlocalized breast and colorectal cancers. J Clin Oncol 2009; 27(36):6180–90.
13. Bramson I, van der Linden M, Eskins F *et al.* Evaluation of a face-to-face psychosocial screening intervention for cancer patients: acceptance and effects on quality of life. Patient Educ Couns 2008; 70(1):61–68.
14. Pruyn JFA, Heule-Dieleman HAG, Knegt PP *et al.* On the enhancement of efficiency in care for cancer patients in outpatient clinics: an instrument to accelerate psychosocial screening and referral. Patient Educ Couns 2004; 53(2):135–40.
15. Kruijver IPM, Garssen B, Visser AP & Kuiper AJ. Signalising psychosocial problems in cancer care: The structural use of a short psychosocial checklist during medical or nursing visits. Patient Educ Couns 2006; 62(2):163–77.
16. Velikova G, Brown JM, Smith AB & Selby PJ. Computer-based quality of life questionnaires may contribute to doctor-patient interactions in oncology. Br J Cancer 2002; 86(1):51–59.
17. Espallargues M, Valderas JM & Alonso J. Provision of feedback on perceived health status to health care professionals: A systematic review of its impact. Medical Care 2000; 38(2):175–186.
18. Greenhalgh J & Meadows K. The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: a literature review. J Eval Clin Pract 1999; 5(4):401–416.
19. Detmar S & Aaronson N. Quality of life assessment in daily clinical oncology practice: a feasibility study. Eur J Cancer 1998; 34(8):1181–1186.
20. Hedstrom M, Kreuger A, Ljungman G, Nygren P & von Essen L. Accuracy of assessment of distress, anxiety and depression by physicians and nurses in adolescents recently diagnosed with cancer. Pediatr Blood Cancer 2006; 46(7):773–779.
21. Keller M, Sommerfeldt S, Fischer C *et al.* Recognition of distress and psychiatric morbidity in cancer patients: a multi-method approach. Annals Oncol 2004; 15(8):1243–9.
22. Fallowfield L, Ratcliffe D, Jenkins V & Saul J. Psychiatric morbidity and its recognition by doctors in patients with cancer. Br J Cancer 2001; 84(8):1011–1015.
23. Detmar SB, Aaronson NK, Wever LD, Muller M & Schornagel JH. How are you feeling? Who wants to know? Patients' and oncologists' preferences of discussing health-related quality-of-life issues. J Clin Oncol 2000; 18(18):3295–3301.
24. Maguire P. Improving communication with cancer patients. Eur J Cancer 1999; 35(14):2058–2065.
25. Snyder C, Dy S, Hendricks D *et al.* Asking the right questions: Investigating needs assessments and health-related quality-of-life questionnaires for use in oncology clinical practice. Support Care Cancer 2007; 15(9):1075–1085.
26. Kirkova J, Davis MP, Walsh D *et al.* Cancer symptom assessment instruments: a systematic review. J Clin Oncol 2006; 24(9):1459–1473.
27. Carlson L & Bultz B: Cancer distress screening – Needs, models, and methods. J Psychosom Res 2003; 55(5):403–409.
28. Mitchell A. Pooled results from 38 analyses of the accuracy of distress thermometer and other ultra-short methods of detecting cancer-related mood disorders. J Clin Oncol 2007; 25(29):4670–4681.
29. Mitchell A. Short screening tools for cancer-related distress: a review and diagnostic validity meta-analysis. J Natl Compr Canc Netw 2010; 8(4):487–494.
30. Mitchell A, Baker-Glenn E, Granger l & Symonds P. Can the Distress Thermometer be improved by additional mood domains? Part I. Initial validation of the Emotion Thermometers tool. Psycho-oncology 2010; 19(2):125–133.
31. Shimizu K, Ishibashi Y, Izumi H *et al.* Feasibility and usefulness of the 'Distress screening program in ambulatory care' in clinical oncology practice. Psycho-Oncology 2010; 19(7):718–725
32. Clover K, Carter GL, MacKinnon A & Adams C. Is my patient suffering clinically significant emotional distress? Demonstration of a probabilities approach to evaluating algorithms for screening for distress. Support Care Cancer 2009; 17(12):1455–1462
33. Thewes B, Butow P & Stuart-Harris R. Does routine psychological screening of newly diagnosed rural cancer patients lead to better patient outcomes? Results of a pilot study. Aust J Rural Health 2009; 17(6):298–304.
34. Vitek L, Rosenwieg M & Stollings S, Distress in patients with cancer: definition, assessment and suggested interventions. Clin J Oncol Nurs 2007; 11(3):413–418
35. Fulcher C & Gosselin-Acomb T. Distress Assessment: practice change through guideline implementation Clin J Oncol Nurs 2007; 11(6):817–821
36. Victorian Government Department of Human Services. Victoria's Cancer Action Plan 2008–2011. http://www.health.vic.gov.au/cancer/vcap.htm Retrieved 18 January 2010.
37. Girgis A, Cockburn J, Butow P *et al.* Improving patient emotional functioning and psychological morbidity: Evaluation of a consultation skills training program for oncologists. Patient Educ Couns 2009; 77(3):456–462.
38. Bambling M, King R, Raue P, Schweitzer R & Lambert W. Clinical supervision: Its influence on client-rated working alliance and client symptom reduction in the brief treatment of major depression. Psychother Res 2006; 16(3):317–331.
39. Jacobsen PB, Donovan KA, Trask PC *et al.* Screening for psychologic distress in ambulatory cancer patients: a multi-centre trial of the Distress Thermometer. Cancer 2005; 103(7):1494–1502.
40. Ristevski E, Breen S & Regan M. Incorporating supportive care into routine cancer care: The benefits and challenges to clinicians' practice. Oncol Nurs Forum 2011; 38(3):E204–E211.
41. Ristevski E & Breen S. The Supportive Care Resource Kit: A tool to enable supportive care screening and referral for cancer patients in rural Victoria. Asia Pac J Clin Oncol 2007; 3(Suppl. 2):A108.
42. Andrews G & Slade T. Interpreting scores on the Kessler Psychological distress scale (K10). Aust N Z J Public Health 2001; 26(6):494–497.
43. Breen S & Ristevski E. Access to supportive care services for rural cancer patients. Asia Pac J Clin Oncol 2007; 3(Suppl. 2):A109.
44. Grbich C. Qualitative Research in Health: An Introduction. St Leonards, NSW: Allen & Unwin, 1999.
45. Lupton D. Content analysis. In Minichiello V, Sullivan G, Greenwood K & Axford R, eds. Handbook for Research Methods in Health Sciences. Sydney: Pearson Education Australia, 1999, pp. 450–461.
46. Baker-Glenn E, Park B, Granger L, Symonds P & Mitchell A. Desire for psychological support in cancer patients with depression or distress: validation of a simple help question. Psycho-Oncology 2008; 20(5):525–531
47. Fitch M. Supportive care framework. Can Oncol Nurs J 2008; 18(1):6–14.
48. Curry C, Cossich T, Matthews JP, Beresford J & McLachlan SA. Uptake of psychosocial referrals in an outpatient cancer setting: improving service accessibility via the referral process. Support Care Cancer 2002; 10(7):549–555.
49. Schofield P, Carey M, Boneviski B *et al.* Barriers to the provision of evidence-based psychosocial care in oncology. Psycho-Oncology 2006; 15(10):863–872.
50. Botti M, Endacott R, Watts R, Cairns J, Lewis J & Kenny A. Barriers in providing psychosocial support for patients with cancer. Cancer Nurs 2006; 29(4):309–316.
51. Pasacreta J, Kenefick A & McCorkle R. Managing distress in oncology patients. Description of an innovative nurse online educational program. Cancer Nurs 2008; 31(6):485–490.

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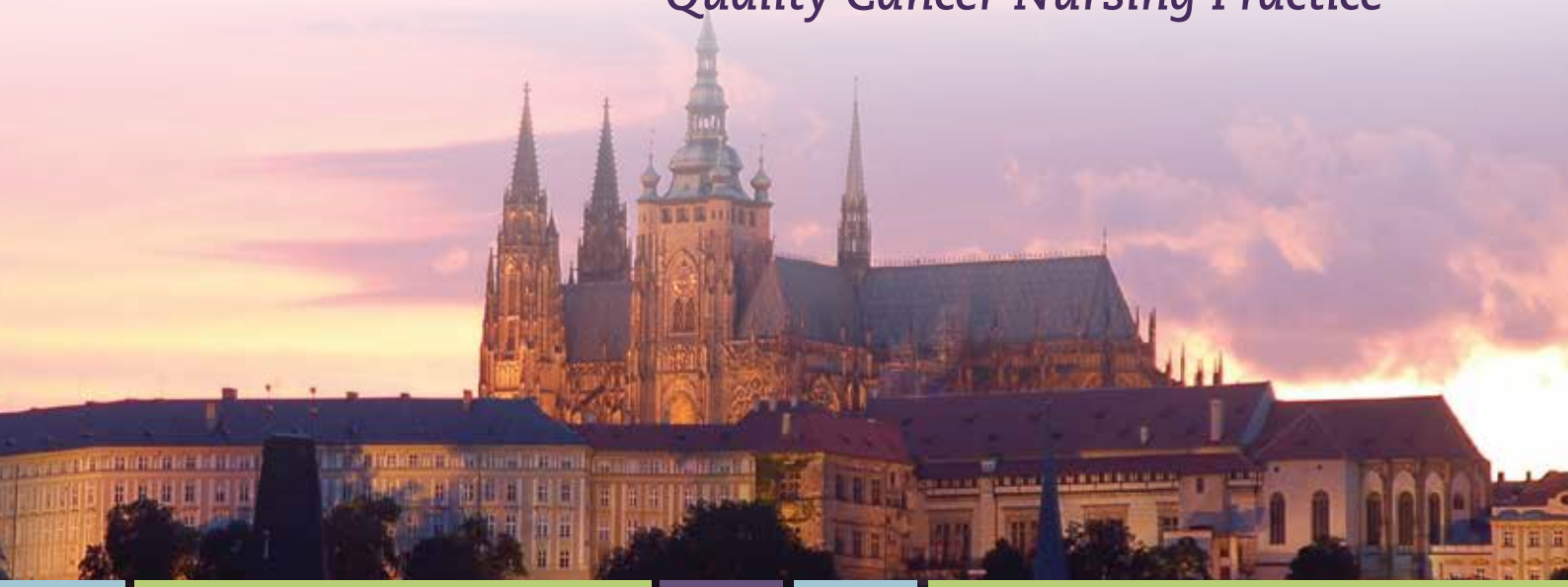

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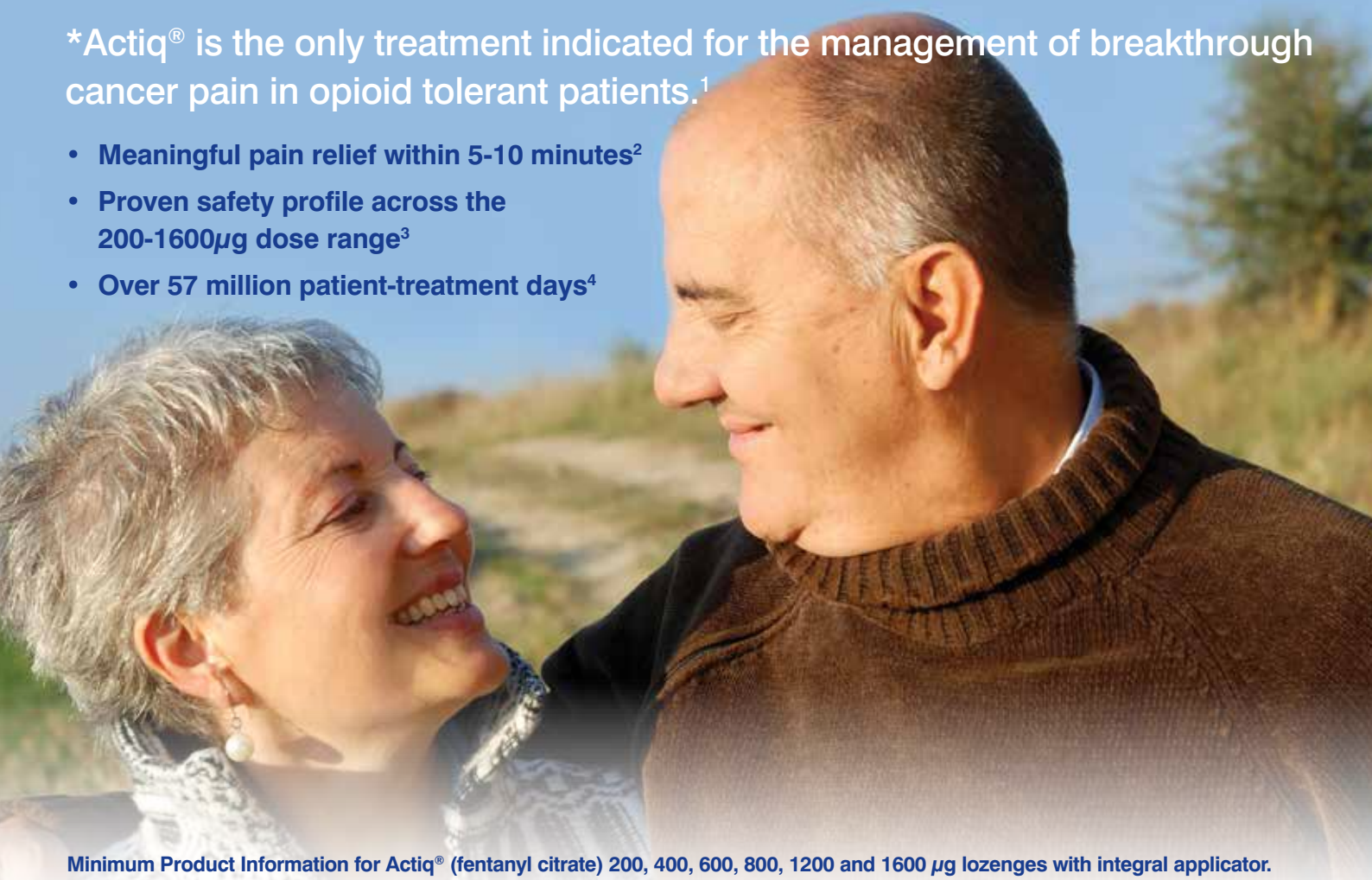

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