



Government of Western Australia
Department of Health
WA Cancer and Palliative Care Network

Evaluation of the Western Australian Cancer Nurse Coordinator Role Final Report

August 2011





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Western Australian Cancer Nurse Coordination

Evaluation of the Western Australian Cancer Nurse Coordinator Role

Final Report

August 2011

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Acknowledgements

This study was generously funded by the Western Australian Cancer and Palliative Care Network.

The contributions of a number of colleagues made this study possible. Firstly, we acknowledge the valuable input of Violet Platt, the Director of Nursing of the Western Australian Cancer and Palliative Care Network, and the Cancer Nurse Coordinator Team who are committed to the provision of high quality evidence-based care to people with cancer and their families. These individuals provided the passion and were the driving force behind the study. A special acknowledgement and thank-you are also extended to the following members of the Western Australian Cancer and Palliative Care Network whose patient commitment to this project and insightful input throughout the study were essential: Rhonda Coleman, Ian Hammond, Barbara Buchanan and Sylvia Gardner.

The study was supported by Melissa Berg, who was the project manager and worked professionally and tirelessly on the project. The contributions of Leanne Lester and Kathy Rainbird for undertaking the data analysis for the study are also acknowledged.

Finally, warmest gratitude is extended to all participants in this study. These people included patients, carers, cancer nurse coordinators and multidisciplinary healthcare professionals. Their willingness to be involved in the study, share their experiences and offer their knowledge has resulted in a report that captures the challenges, complexity and magnitude of this important area of care.

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Glossary of terms

Episode of care

An episode of care was defined by the Cancer Nurse Coordinator (CNC) team as the sum of all episodes of contact with an individual patient, direct and indirect, within a 24-hour period.

Clinical care management

The higher level patient care tasks undertaken by CNCs, including management of patient care and treatment decisions/application of cancer treatment knowledge.

Formal multidisciplinary team (MDT) meetings

Broadly defined for this study as meetings with healthcare professionals where patient treatment plans were discussed.

Informal multidisciplinary team meetings

Any informal meeting where patient care management plans were developed or reviewed.

Levels of intervention

Level	Duration	Purpose
1	5-10 minutes	Provision of information
2	10-30 minutes	Sign posting/referral to other services
3	30-60 minutes	New patient assessment of psychosocial and physical needs
4	1-2 hours	Patient and family
5	≥2 hours	Complex ongoing intervention (according to individual needs)

Physicians

This broad term was used to represent oncologists, haematologists and radiologists.

PREFACE

The cancer journey for many people is complex and challenging. Cancer care is delivered by many healthcare professionals in multiple settings including public, private and community health environments. The possibility of getting lost in the health care system for cancer patients is high. Cancer coordination has been identified as a strategy to assist those affected with cancer to navigate the health care system.

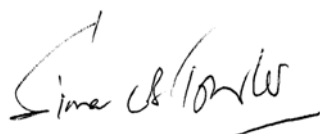
In Western Australia, the 2005 Cancer Services Framework advocated for the development of a state-wide Cancer Nurse Coordinator (CCNC) Service. Under the leadership and direction of the WA Cancer and Palliative Care Network ('the Network') in partnership with all health care providers and services, public and private, the WA Cancer Nurse Coordinator Service commenced.

Since 2006, thousands of people affected by cancer have received support from Cancer Nurse Coordinators (CNCs). Coordination activities range from sign-posting, education and navigation through to complex care coordination in partnership with multiple providers.

The CNC team members are dynamic clinical experts who work in partnership with all health care providers to ensure the delivery of coordinated quality cancer care across the state. As cancer nurse leaders, the team members are responsible for many strategic change developments on a national and state level to maintain the continuous improvement of cancer service delivery.

This research explores the integration of this new model of service delivery into Western Australia by consulting with patients, their families, health care providers and the coordination team. I would like to commend Professor Leanne Monterosso and her team for this excellent piece of research which provides ground-breaking evidence in relation to the complexities of care coordination as a method of health care delivery.

This research confirms the significant impact that cancer nurse coordination has made to the delivery of cancer care in WA.



Dr Simon Towler
Chief Medical Officer
Western Australia

EXECUTIVE SUMMARY

Background

In October 2006 the CNC Service was implemented as a key element of the WA Cancer and Palliative Care Network to ensure an integrated approach to cancer care and delivery in Western Australia (WA). The CNC's involvement in the patient process was proposed to: ensure a one-on-one relationship between patient and CNC; facilitate navigation of the cancer care system; provide a central point for information and support; provide a direct link into the Cancer and Palliative Care Network's Tumour Collaboratives; and all of the benefits that can be achieved through a multidisciplinary care model. To date there has been modest empirical evaluation of the cancer coordinator role in Australia or internationally and a lack of published evidence on which to guide evaluation. Since inception of the CNC role in WA, feedback from patients, carers and healthcare professionals has endorsed the utility and importance of the CNC role.

Objectives

The specific objectives of the evaluation were to:

1. determine the impact of the CNC role on consumers and changes to care coordination
2. determine the impact of the CNC role on care providers and changes to practice
3. determine the changes to systems and processes required to facilitate improvements to cancer coordination.

Scope

Phase 1

Aimed at determining CNC's perceptions regarding role development and implementation, how the role contributed to patient care outcomes and the extent to which CNCs undertook a range of activities relevant to their role. Phase 1 involved:

- administration of a survey to 17 CNCs between March 2008 and June 2008
- conduct of in-depth interviews with 22 CNCs between June 2008 and July 2008.

Phase 2

Aimed at determining patients', carers' and multidisciplinary healthcare professionals' understanding and experience of: cancer nurse coordination; awareness and perceived input of the CNC role to cancer care. Phase 2 involved:

- administration of surveys to 148 healthcare professionals, 90 patients and 46 carers between July 2008 and March 2010.

Key findings

CNC data

1. CNCs are experienced nurses with significant cancer nursing experience and tertiary education qualifications.
2. Utilisation of CNCs in metro and rural regions has resulted in a high workload which is inequitable.
3. CNCs spent 70 per cent of time on clinical consultation and 30 per cent on administrative and strategic tasks.
4. Most referrals arose from within the CNC team, physicians and medical staff, or Multi Disciplinary Team (MDT) meetings.
5. At referral at least 50 per cent of patients had complex psychosocial needs and a moderate level of function status.
6. CNCs performed a large number and a broad range of tasks.
7. Tasks related to direct nursing care and patient education were performed most frequently on a daily basis.
8. Tasks related to care management planning; patient advocacy; multidisciplinary clinical care; and MDT meetings were conducted weekly.
9. Strategic, team communication and professional development activities were performed less frequently.
10. Implementation of the cancer nurse role has resulted in a reduction of CNC clinical workload and increased time for strategic activities.
11. CNCs have a clinically significant impact on patient care, particularly related to advocacy and meeting patients' informational and psychosocial needs.
12. CNCs are experts in cancer care, and the pivotal/central contact throughout the continuum of the cancer patient journey.
13. CNCs have developed the role to strategically complement existing services.
14. Large clinical and administrative workloads impact on CNCs' ability to undertake more strategic initiatives.
15. CNCs are fulfilling the core components of the specialist cancer nurse: clinical expert, resource consultant, educator, change agent, researcher and advocate.

MDT data

16. Healthcare professionals agreed that all patients benefit from the CNC Service.
17. Healthcare professionals agreed that patients who had seen a CNC experience a more coordinated cancer journey.
18. Healthcare professionals view the key functions of the CNC role as: being a focal point of contact throughout the patient care trajectory; coordinating all aspects of patient care; providing patient education and information; and accountability.
19. There is variation in healthcare professionals' understanding about the scope of the CNC role.
20. Healthcare professionals who have regular contact with CNCs have a greater awareness of the CNC role.
21. The majority of healthcare professionals had at least weekly contact with a CNC.
22. Case load, funding and resources were considered the main barriers to impact on the CNC role by healthcare professionals.
23. Healthcare professionals recommended increasing the availability of CNCs.

Patient data

24. A moderate proportion of patients would have preferred contact with the CNC earlier in the cancer journey.
25. Patients reported high satisfaction with CNC services related to communication and information.
26. Carers, family and friends required access to emotional support.
27. Patients required assistance to access counselling services.
28. Patients reported their journey went smoothly and the CNC was an important part of the treatment team.
29. Patients reported they were satisfied with the overall level of support provided.
30. Aspects of care most valued by patients were provision of information, emotional and practical support.
31. Patients recommended more face-to-face contact and increased availability of CNCs.
32. There was variation in patients' understanding about the scope of the CNC role.
33. Patients required ongoing care following treatment completion.

Carer data

34. A large proportion of carers would have preferred contact with the CNC earlier in the patients' cancer journey.
35. Carers required assistance to develop communication skills to facilitate open communication with doctors.
36. Carers required contact from CNCs when patient care issues arose.
37. Carers' family and friends required access to emotional support and counselling services.
38. Carers required assistance to avoid carer "burnout".
39. Carers required more practical support for issues related to patient treatment and follow-up care.
40. Carers agreed that CNCs were an important part of the patient's treatment team.
41. Carers agreed that CNCs made the cancer journey easier.
42. A moderate proportion of carers did not believe the patient's journey went smoothly.
43. Carers reported they were satisfied with the overall level of support provided.
44. Aspects of care most valued by carers were information provision, emotional and practical support.

Recommendations

Organisational framework: Western Australian Cancer and Palliative Care Network

1. The Western Australian Cancer Nurse Coordination Service should continue and be provided with appropriate resources to grow and continue to meet the cancer population needs.
2. The WA Cancer and Palliative Care Network ('the Network') should maintain the role of Cancer Nurse to support the CNC Service and explore opportunities to increase availability as required.
3. The Network should develop appropriate survivorship care models.



Resources and systems: Western Australian Cancer and Palliative Care Network

4. The Network should secure more resources to increase access to care coordination and psychosocial care for future patients and carers by increasing numbers of CNCs to meet the demand.
5. The Network should explore opportunities to delegate non-coordination activities to administrative staff.
6. The Network should develop strategies to facilitate open communication between carers and Healthcare professionals.
7. The Network should develop mechanisms to improve the level of practical support provided to carers when dealing with patients' treatment and follow-up care.

Cancer Nurse Coordination Service

8. The CNC Service should develop strategies to enable earlier referral and contact with patients.
9. The CNC Service should develop strategies to improve access to psychosocial support and counselling services for patients, carers, family and friends.
10. The CNC Service should develop mechanisms to facilitate timely communication with carers.

BACKGROUND

The CNC role was developed in response to recommendations made by the Western Australian Cancer Services Taskforce ('the Taskforce') as reported in the Western Australian Cancer Services Framework¹. The following initiatives of the Taskforce recognised the need for an integrated approach to cancer care and delivery in Western Australia that should include a state-wide team of cancer nurse coordinators.

Initiative 11: The Director of the WA Cancer and Palliative Care Network will audit current services and develop a plan ensuring patients have access to a range of supports such as allied health, psychosocial, and complementary supportive care. CNCs have a referral role to clinical psychology and other psychosocial support services, liaising closely with the Cancer Helpline and other non-government sources of psychosocial support.

Initiative 18: The Network and CNCs work with the Aboriginal Medical Service to improve knowledge of cancer and support available by Aboriginal Medical Service health workers.

Initiative 27: Cancer units are developed in some regional centres with formalised links to a cancer centre, CNCs, audit and tumour collaboratives. A lead clinician at each local site will be identified to run the unit, supported from identified funds.

Initiative 30: Other regions, in conjunction with the Rural Medical Service, develop cancer outreach programs, each with a lead clinician and providers having formal links with a specified cancer centre and the relevant CNCs.

Initiative 31: Rural CNCs are set up immediately, reporting to Area Health Services and the State Cancer Network Secretariat.

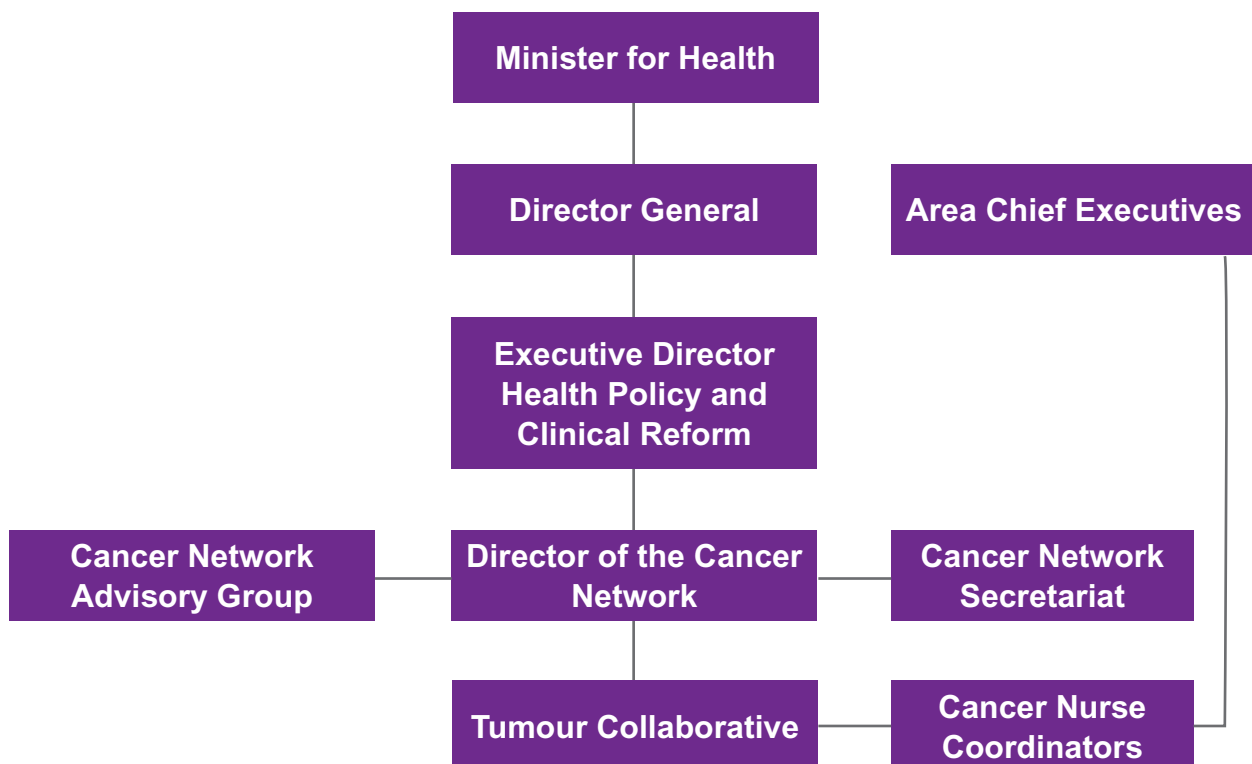
WA Cancer Network structure (Figure 1)

In October 2006 the CNC Service was implemented as a key element of the WA Cancer and Palliative Care Network to ensure an integrated approach to cancer care and delivery in Western Australia. The CNC Service's involvement in the patient process was proposed to:

- ensure a one-on-one relationship between patient and CNC
- facilitate navigation of the cancer care system
- provide a central point for information and support
- provide a direct link into the tumour collaboratives and all of the benefits that can be achieved through a multidisciplinary care model.

It was anticipated the model of cancer care coordination would be adapted to suit the needs of the patient group depending on the tumour collaboratives and location (i.e. metro/rural). After considerable discussion with Directors of Nursing and Area Chief Executives it was decided that metropolitan CNCs would be managed by the Network Director of Nursing, and rural CNCs would be managed by their local regional Director of Nursing with support from the Network Director of Nursing for professional and role development.

Figure 1: Structure of the Western Australian Cancer Network



Cancer coordination in Australia

In Australia the coordination of cancer care has been a key focus following publication of the Optimising Cancer Care in Australia report in 2002². This report highlighted the complexity of the management of individuals with cancer. Cancer care involves multiple care providers across different care settings and over a considerable time frame. Importantly, the report emphasised the need to provide integrated multidisciplinary care and proposed that optimal cancer treatment for all individuals would lead to improved survival, quality of life and smooth transition through the cancer journey.

The key elements of integrated cancer care include provision of ongoing support for patients and families throughout the cancer care trajectory; access to appropriate and timely care; and effective communication among care providers, patients and families². Evidence indicates that cancer care coordinators improve patient experiences of the care process through improving and streamlining care pathways and referrals, improved information transfer among healthcare professionals and patients and developing relationships based on understanding and trust^{3,4}.

Cancer care in Western Australia

There is widespread disparity in access to cancer services in WA, a vast state of over 2,500,000 sq km which accounts for over 30 per cent of Australia's total land mass. From a total population of 2.2 million (10 per cent of Australia's total population)⁵, 38 per cent (n=800,000) of the population is located in remote and rural areas. The recent mining and economic boom has contributed to a 38 per cent increase in population over the last nine years, with large growth in metropolitan, outer metropolitan and regional areas. People living in the latter areas are disadvantaged in terms of transport and financial support to access healthcare services⁶. Further, the majority of cancer services are located in the capital city of Perth.

Cancer nurse coordination in Western Australia

Cancer coordination models exist in all Australian states and the ACT; however there is considerable variation in the scope of practice, level and function of roles according to health systems and clinical service characteristics. The WA model is unique because it is state-wide and centred in nursing. The CNC is the only health professional with a whole system view of state-wide cancer care and service delivery.


The WA cancer coordinator role was based on the Cancer Relief MacMillan Nursing Model of Specialist Cancer Nursing (Miller, 1995) requiring the domains of clinical expert, resource consultant, educator, change agent, researcher and advocate to facilitate seamless coordination of care for patients across WA. CNCs are funded by the WA Cancer and Palliative Care Network because they coordinate care across health services.

Metro CNC role

Each tumour collaborative has an allocated CNC and/or cancer nurse. In addition, one CNC has been allocated to provide relief cover, and one metro/rural CNC is located within the WA Country Health Service metropolitan office who is responsible for coordinating and transitioning care for rural patients when receiving treatment in the metropolitan area. Metro CNC roles are generally tumour-specific, interacting with the metropolitan health care system and are employed by the WA Cancer and Palliative Care Network at SRN Level 4. Cancer nurses have recently been employed to support the head and neck, urology, skin, upper gastrointestinal and colorectal CNC roles due to increasing numbers of patient referrals since role implementation.

Rural CNC role

Rural CNCs are allocated to each of the seven country health service regions and work across the 10 tumour collaboratives as the primary link in each region for the coordination of all cancer services.



Rural CNC roles are region-specific and therefore provide care to patients with all cancer types, interact with the rural and the metropolitan health care system and are exclusively used by rural patients. These rural positions are funded by the WA Cancer and Palliative Care Network with CNCs employed by and operationally responsible to the WA Country Health Service at SRN Level 3. Rural CNCs are professionally responsible to the Director of Nursing of the WA Cancer and Palliative Care Network for professional and role development.

Developments since implementation of the CNC service

Since the introduction of the WA CNC Service, a number of position statements and policy documents applicable to cancer care coordination have been published^{2, 3, 7}. There are a number of irregularities in these publications regarding the definition of cancer care coordination, with the terms care continuum, case management, continuity of care, integration and seamless care often used interchangeably. However, there is agreement that care should be delivered in a coherent, logical and timely manner. Further, coordination is viewed as the key to ensuring continuity of cancer care and is reliant upon collaboration with functional systems, organisations, teams and healthcare professionals.

In 2008 the peak cancer nursing body in Australia, the Cancer Nurses Society of Australia (CNSA), published a position statement for cancer care coordinators in response to the growing numbers of care coordinator roles being established in Australia with little consistency in role definition and evaluation parameters⁷. CNSA defines a cancer care coordinator as “someone who engages directly with a patient, manages the care process, including the development and communication of the care plan and ensures that all the care needed is arranged and delivered” (p:2).

A review of Australian coordination roles showed that variations exist in the disciplinary background of persons appointed to coordination roles, some being integrated into health care teams, some being institution-based while others work in geographically defined regions, some focusing on specific populations while others have responsibility for diverse groups of people with cancer⁸.

The scope of practice of cancer care coordinators throughout Australia is diverse; however, most activities are conducted in collaboration with a multidisciplinary team and include:

- screening and assessment for clinical and supportive care needs
- facilitating evidence-based practice
- timely referral to relevant health care providers
- timely communication; development of clear pathways; and liaison among patients, family members and the healthcare team, resulting in patient-reported continuity of care
- education and information provision to patients and family members

- promoting patient/family/caregiver participation in care and its coordination
- promoting a whole-of-team approach to the delivery of physical and emotional support to the patient and family
- assisting patients and family members to navigate the health care system by coordinating appointments, streamlining investigations, explaining procedures and advocating for them where appropriate^{7, 9}.

CNSA recommends that cancer care coordinators should have a relevant postgraduate qualification in cancer nursing or at least five years' cancer nursing experience⁷. This position is based on the nursing profession's focus on "comprehensive, person and family-centred models of care" (p:3). Further, advance practice cancer nurses have the essential knowledge regarding diagnostic workup, the wide range of cancer treatments and their side effects, best practice interventions and are familiar with promoting self care^{8, 10}.

Study purpose


1. to provide a preliminary evaluation of how the CNC role contributes to meeting the objectives of the Western Australian Cancer Services Framework
2. to provide benchmarks for future role evaluation
3. to develop an evidence-base framework for rigorous ongoing evaluation.

To date there has been modest evaluation of the cancer coordinator role in Australia or internationally and a lack of published evidence on which to guide evaluation. Since inception of the CNC role in WA, anecdotal feedback from patients, carers and healthcare professionals has endorsed the utility and importance of the CNC role.

As with other advanced practice nursing roles, use of systematic approaches for the implementation, development and evaluation of the CNC role is critical to providing benchmarks for future evaluation of cancer care coordination and producing a sound basis for a rigorous ongoing evaluation framework.

Specific aims

1. to describe patients' and families' understanding and experience of cancer nurse coordination
 - a. How was care coordinated?
 - b. How could care have been better coordinated?
2. to determine patients' and families' awareness of the CNC's role and input to cancer care
 - a. What were the levels of awareness of the CNC role?
 - b. What specific functions did the CNC perform?
 - c. How did patients perceive this care was delivered?

- 
3. to describe the current CNC role by engaging with CNCs and key stakeholders
 - a. How is the CNC role understood and perceived by CNCs and stakeholders?
 - b. How does the CNC role contribute to patient care outcomes?
 - c. How has the role evolved since inception?
 - d. What are the current gaps in evidence around the CNC role and what specific data development would facilitate a clear understanding of the impact of the role?
 - e. What are the enablers and barriers to role success?
 - f. What are the common components of the CNC roles across collaboratives, rural and remote regions?
 - g. What components are specific to individual CNC roles?
 - h. Are CNCs members of multidisciplinary teams and how do they contribute to care planning?
 4. to identify patient-centred and service-oriented outcomes that can be used as a basis for a future health economic evaluation
 5. to identify criteria and variables required for comprehensive patient data collection and development of a robust database
 6. to describe role innovations developed by CNCs since inception and assess evaluation data from each of these
 7. to explore the training and development needs of CNCs.

An important feature of this study was the level of inquiry undertaken in collaboration with patients, carers, CNCs, multidisciplinary healthcare professionals, cancer nursing clinicians and cancer nursing academic researchers. The broad scope of the study was demonstrated by representative and comprehensive sampling of participants from metropolitan, regional and rural regions. No previous studies of this scale have been undertaken in Australia to evaluate the role of the cancer care coordinator.

Ethical considerations

Ethical approval to conduct the study was obtained from Curtin University, Sir Charles Gairdner Hospital, Royal Perth Hospital, Fremantle Hospital, King Edward Memorial Hospital for Women and the WA Country Health Service. This process was considerably time-consuming and lasted from January 2008 until April 2009. Amendments were made to the recruitment process of patients and carers in response to the larger than expected numbers of potential participants. These factors significantly delayed project completion.

Design

A prospective, two-phase descriptive study using a combination of quantitative and qualitative methodologies was used. The study was undertaken between October 2008 and March 2010.

Data analysis

Data were analysed by independent statisticians to ensure independence of researcher data.

Quantitative: Descriptive statistics were applied to the majority of the data. Non-parametric tests (Mann-Whitney) were used to determine any significant differences according to location of CNC (i.e. metro or rural). A random sample of 10 per cent of data cases was checked for accuracy and no systematic errors were noted.

While there were differences according to location, small numbers of responses meant that in many cases significance was not reached.

Qualitative: Interviews were transcribed verbatim and examined using content analysis. Credibility and consistency of the data analysis was confirmed by comparing the identified issues with those independently recorded by the project manager who performed the interviews. Transcribed records of interviews were examined using content analysis that was undertaken by an independent health researcher with over 12 years' experience in the evaluation of cancer care in Australia. Content analysis involved reading each transcript in its entirety, initially using a process of familiarisation in order to list key ideas and recurrent themes and then applying a thematic framework approach. All key issues, concepts and themes raised by the respondents relating to each of the questions in the interview guide were identified and included in a comprehensive list. The resulting list of identified issues was then further examined to reveal over-arching key elements that highlighted important aspects of the CNC role.

PHASE 1

Target population and procedure

Phase 1 sought to provide the evidence for Specific Aims 3-7 (see pages 15-16) and to guide Phase 2. Phase 1 focused on Cancer Nurse Coordinators and comprised the following two components:

- **Survey of CNCs (March 2008 – June 2008)** Metro and rural CNCs who had been in their role for at least six months were asked to complete the Self-Report Activity Questionnaire. Potential participants were emailed a letter of introduction and information sheet specific to this component of Phase 1. The return of completed surveys was recognised as implied consent.
- **Semi Structured Interviews with CNCs (June 2008 – July 2008)** Following the analysis of the Self-Report Activity Questionnaire data, all metro and rural CNCs were invited to participate in either a face-to-face or telephone semi-structured interview depending on location. CNCs who provided written consent participated in the interviews which sought to further explore the perceptions of CNCs regarding their experiences of role implementation, perceived enablers and barriers, and professional achievements.

Instruments

The Self-Report Activity Questionnaire

The Self-Report Activity Questionnaire was based on the EverCare Nurse Practitioner Role and Activity Scale¹¹. This scale was modified by Krishnasamy et al.⁹ for use in the Australian context with cancer coordinators at the Peter McCallum Cancer Institute. We modified this version to suit the Western Australian cancer nurse coordination context using a process of consultation and testing by CNCs for clarity, apparent internal consistency and content validity. The questionnaire was renamed the Self-Report Activity Questionnaire and comprised 165 items with 11 subscales. The questionnaire demonstrated a high degree of internal consistency with an overall Cronbach's alpha coefficient of 0.976, and individual subscale Cronbach alpha coefficients ranging from 0.421 to 0.957.

Semi-Structured Interview Guide for Cancer Nurse Coordinators

The interview guide comprised 30 open-ended questions to further explore the perceptions of CNCs regarding role development and implementation. Key findings from analysis of the questionnaire data were used to inform the interview questions which were developed in consultation with the study's reference group. All CNCs were sent an email to introduce this component of Phase 1, an information sheet and consent form. CNCs who consented to study participation were contacted to arrange a time for a face-to-face or telephone interview.

Results Cancer Nurse Coordinator survey

Sample

All 17 Self-Report Activity Questionnaires distributed were returned (100 per cent response rate). This number constituted the total number of CNCs with at least six months' experience in the role at the time this phase was conducted.

Demographic characteristics

On average CNCs had spent 1.9 years in the role, had been nursing for 18.6 years and had worked with cancer patients for 9.5 years. Ten CNCs held a Bachelor Degree. There was a range of graduate qualifications including: Graduate Certificates (n=10); Graduate Diplomas (n=10) of which one was a Graduate Diploma (Nurse Practitioner); one Master of Nursing (Coursework); and one Master of Nursing (Nurse Practitioner).

Finding: CNCs are experienced nurses with significant cancer nursing experience and tertiary education qualifications.

Clinical characteristics

Average workload over a six-month period (Table 1)

Each CNC received an average of 15 new patient referrals and performed 78 patient interventions per month. The largest number of patient interventions occurred at level 2¹.

Table 1: New patient referrals and interventions per month (n,%)

	Metro CNC	Rural CNCs
New patient referrals	15 (100)	14 (100)
Total number of interventions	65 (100)	88 (100)
Level 1	18 (28)	23 (26)
Level 2	26 (40)	36 (41)
Level 3	15 (23)	19 (20)
Level 4	5 (7)	10 (11)
Level 5	1 (2)	2 (2)

¹ At the time data included in this survey was collected, intervention levels were defined as follows over a 24-hour period: Level 1, 5-10 minutes, providing information; Level 2, 10-30 minutes, sign posting/referral to other services; Level 3, 30 minutes – 1 hour, new patient assessment of psycho-social and physical needs; Level 4, 1-2 hours, patient and family support; Level 5, 2 hours or more, complex ongoing intervention (as per individual needs)

Time spent on clinical consultation and strategic/non clinical tasks (Table 2)

The average number of rostered hours spent per week on clinical consultation was 26 hours, and 11 hours per week were spent on administrative/strategic tasks (e.g. service delivery improvements). Metro CNCs worked an average of five hours overtime and rural CNCs worked an average of 11 hours overtime.

Table 2: Hours per week spent on clinical consultation and strategic/non-clinical activities (n,%)

Activities	CNCs
Clinical consultation	26 (70)
Administrative/strategic tasks	11 (30)

Finding: Utilisation of CNCs in metro and rural regions has resulted in a high workload which is inequitable.

Finding: CNCs spent 70 per cent of time on clinical consultation and 30 per cent on administrative and strategic tasks.

Sources of referral (Table 3)

The main sources of referrals were physicians (18 per cent), other CNCs (17 per cent), MDT meetings (14 per cent), CNCs (13 per cent) and other hospital medical staff (12 per cent). A higher proportion (7 per cent) of rural CNC referrals came from GP/primary care physicians in a community setting compared with metro CNC referrals who received no GP/primary care referrals.

Table 3: Sources of referral to CNCs

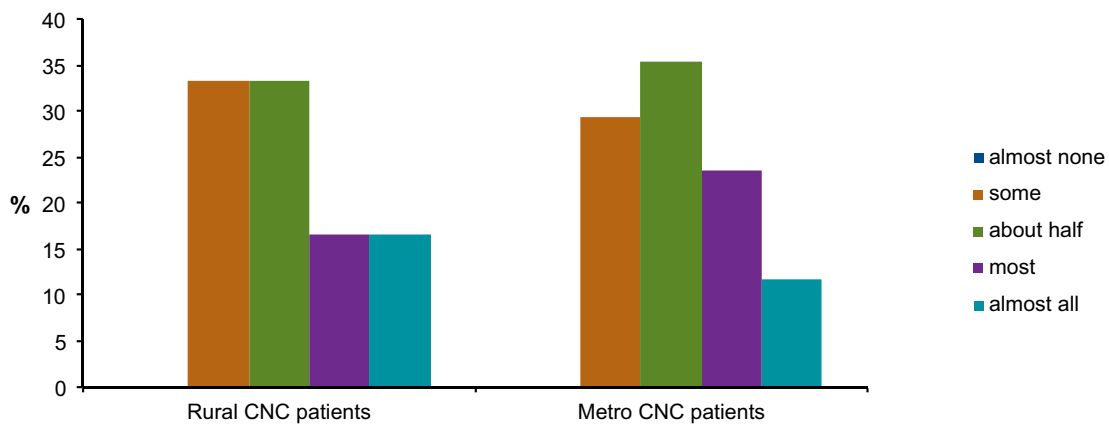
Source of referral	%
Physicians	18
CNCs	17
MDT meetings	14
Patient sourced by CNC	13
Other medical staff (hospital)	12
Other nurses (hospital)	8
Allied health	3
Patient self referral	4
Carer referral	3
NGO or community service	3
GP/primary care physician	3
Other medical staff (community)	1
Other	1

Finding: Most referrals arose from within the CNC team, physicians and other medical staff, or MDT meetings.

Patient caseload (Figures 1 - 3)

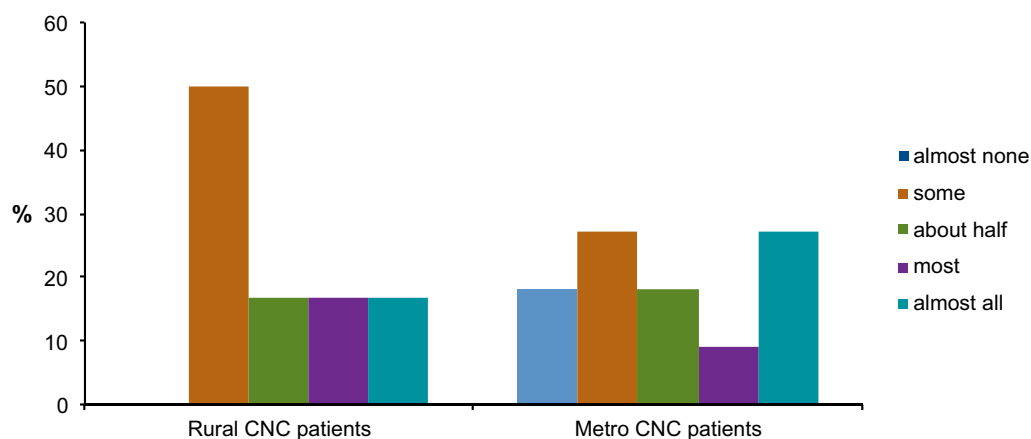
The majority of CNCs (n=12, 71 per cent) perceived at least half of their patients had complex psychosocial care needs at referral.

Figure 2: Percentage of patients with complex needs at referral.



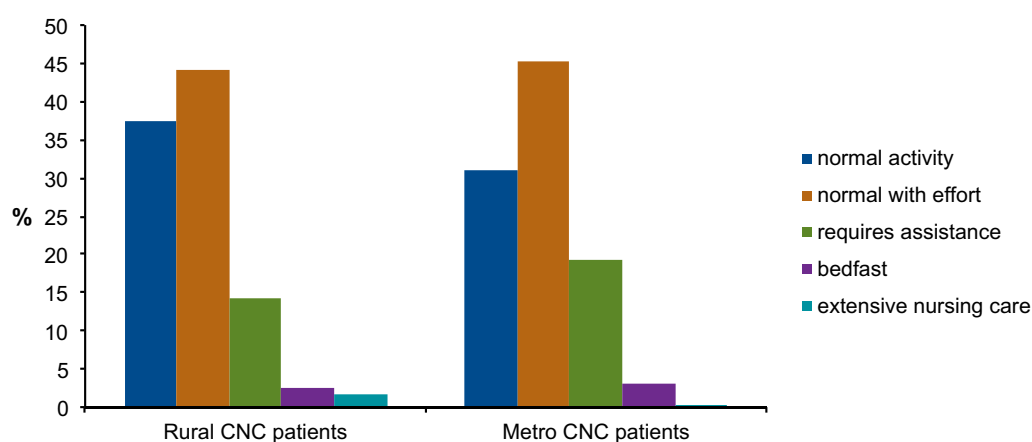
Fifty three percent of CNCs reported at least half to almost all patients were referred at diagnosis.

Figure 3: Percentage of patients referred at diagnosis



Using the modified Karknofsky Performance Status (AKPS) Scale¹² to assess patients' functional status at referral, half the patients had a moderate level of function and could carry out normal activity with effort indicating the presence of disease symptoms (Figure 4).

Finding: At referral at least 50 per cent of patients have complex psychosocial needs and a moderate level of function status.

Figure 4: Functional status of patients at referral

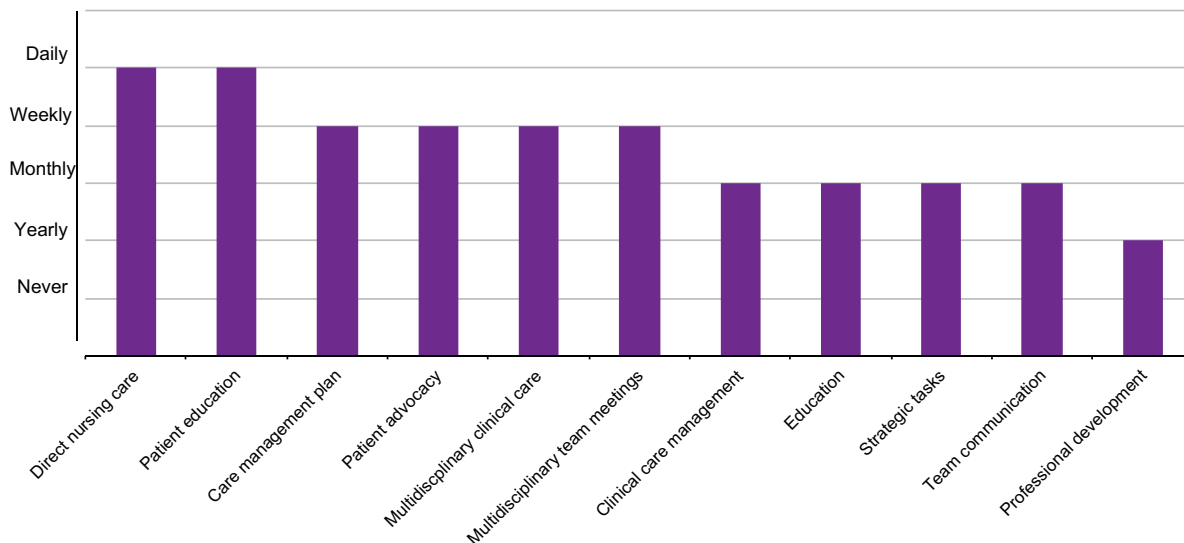
Role-related CNC activity

CNCs were asked to indicate the frequency with which they undertook a range of activities (n=130) relevant to their role over a 12-month period. Activities were categorised into 11 key areas: direct nursing care; clinical care management; patient education; care management plan; patient advocacy; multidisciplinary clinical care; multidisciplinary team meetings; education services; strategic tasks; professional development; and team communications. Response categories ranged from: one/more times daily; one/more times weekly; one/more times monthly; one or more times yearly; never and not applicable. The mode (md) was calculated for each task and overall for each key area.

Key areas of CNC activity (Figure 5)

Tasks related to direct nursing care and patient education were conducted **at least once a day**; tasks related to care management planning, patient advocacy, multidisciplinary clinical care and multidisciplinary team meetings were conducted **weekly**; tasks related to clinical care management, education services, strategic tasks and team communications were conducted less frequently on a **monthly** basis. Tasks within the key area of professional development were conducted infrequently on a **yearly** basis.

Figure 5: Average frequency (mode) of CNC activities



Finding: CNCs performed a large number and a broad range of tasks.

Most frequently performed activities

Tables 4-8 include the top 10 activities performed by CNCs: most frequently (one or more times per day), frequently (one or more times per week), infrequently (one or more times per month), and rarely (one or more times per year).

Table 4 outlines the 10 activities most frequently performed by CNCs one or more times per day. The activities fell in the areas of direct nursing care and patient education and included corresponding with patients or families; conducting patient assessments; educating patients and families about disease and/or progression; and educating patients about the healthcare professionals to contact when needed.

Table 4: The 10 tasks most frequently performed by CNCs on a daily basis (N=17)

Activity Items	n	%
Return email or phone correspondence to patients or families	14	82.4
Document and manage clinical caseload activity data relevant to my role	13	76.5
Provide patients and/or families with my contact details	12	70.6
Conduct a psychosocial (emotional and social support) assessment of patients*	10	58.8
Complete a symptom management assessment of patients*	10	58.8
Complete a needs assessment of patients*	10	58.8
Educate patients and/or families about the appropriate health care professional to contact if issues/concerns arise	10	58.8
Discuss queries or health status changes with patient and provide support	10	58.8
Educate patient about disease state and/or progression	10	58.8
Educate family about patient disease state and/or progression	9	52.9

* In person/by phone/via video conference or email.

Finding: Tasks related to direct nursing care and patient education were performed most frequently on a daily basis.

Table 5 details the 10 activities most frequently performed by CNCs one or more times a week. These primarily included: patient assessment, educating patients and families about care options and diagnostic workup and redirecting or referring acute illness enquiries from patients and families.

Table 5: The 10 tasks most frequently performed by CNCs on a weekly basis

Activity Items	n	%
Act as the person responsible for continuity of care for patients	12	70.6
Collaborate with patient to ensure the care management plan is patient-focused	11	64.7
Provide patients and families with strategies to ask questions or raise issues during a consultation with a health care professional (e.g. difficulties managing treatment, psychological, sexual, or relationship issues)	11	64.7
Review or assess a patient at the request of a member of the health care team	11	64.7
Advise or suggest other treatments or care for patients (e.g. complementary therapy, psychological counselling/support, dietary/nutritional therapy)	11	64.7
Read and consider results from diagnostic tests performed on patients	10	58.8
Monitor and follow up patients with ongoing complex needs	10	58.8
Coordinate/summarise/develop a care management plan for new patients	10	58.8
Consult with appropriate discipline specialist/s about patient's condition changes	10	58.8
Communicate with a social worker/s regarding a patient's treatment or care	10	58.8

Activities undertaken infrequently by CNCs fell in the areas of: communicating with multidisciplinary healthcare professionals, interacting with other nurses to discuss current nursing practices and strategic work to promote the CNC role (Table 6).

Table 6: The 10 tasks most frequently performed by CNCs on a monthly basis

Activity Items	n	%
Communicate with palliative care services regarding transfer of patients	11	64.7
Communicate with a pharmacist/s regarding a patient's treatment or care	11	64.7
Encourage nursing or other staff to seek teaching opportunities with the CNCs	11	64.7
Educate nursing staff to enhance their ability to recognise changes in patients' conditions (formal/informal education)	11	64.7
Meet with individuals or key health providers/organisations to build and/or promote the CNC role or the professional network surrounding the role	11	64.7
Write reports (e.g. monthly activity report, annual report, HDWA reports)	11	64.7
Attend CNC team meeting (in person/teleconference/videoconference)	11	64.7
Communicate with palliative care services to discuss care management plans	10	58.8
Communicate with an occupational therapist regarding a patient's treatment	10	58.8
Educate nursing staff about nursing practice activities for example, neutropenic precautions, central venous access device care including PICC and port management, chemotherapy (formal/informal education)	10	58.8

Activities reported by CNCs as being undertaken less frequently on an annual basis included educational activities, professional development and advanced practice activities.

Finding: Tasks related to care management planning, patient advocacy, multidisciplinary clinical care and multidisciplinary team meetings were conducted weekly.

Table 7: The 10 tasks performed by CNCs on a yearly basis

Activity Items	n	%
Attend a professional development course for training (e.g. management)	17	100.0
Attend regional meeting, state, national or international conferences/ symposia	15	88.2
Present at regional meeting, state, national or international conference/symposia	15	88.2
Communicate/arrange with relevant staff regarding handover cover	15	88.2
Deliver a community education talk	14	82.4
Present data related to my area of expertise at meetings or conferences	14	82.4
Attend a health related professional development course relevant to my role	14	82.4
Convene formal/informal working group or workshop to improve service provision	13	76.5
Participate in recruitment and selection processes for new staff	12	70.6
Collaborate / provide intellectual input for ongoing research projects	11	64.7

Finding: Strategic, team communication and professional development activities were performed less frequently.

Tasks rarely undertaken by CNCs are shown in Table 8.

Table 8: The 10 tasks rarely performed by CNCs

Activity Items	n	%
Communicate with other therapist/s (e.g. music, art, play) regarding patients' treatment	13	76.5
Participate at regional meetings, state, national or international conferences/symposia	11	64.7
Lead/chair MDT meetings	10	58.8
Apply for research or infrastructure funding (e.g. prepare grant applications)	10	58.8
Prepare papers for publication in peer reviewed journals	10	58.8
Prepare material for submission to publications other than peer reviewed journals.	10	58.8
Meet with patients in their home	9	52.9
Conduct patient rounds on wards with doctors	9	52.9
Communicate with a psychiatrist/s regarding a patient's treatment or care	8	47.1
Organise MDT meetings and coordinate meeting outcomes	8	47.1

Key findings

1. CNCs are experienced nurses with significant cancer nursing experience and tertiary education qualifications.
2. Utilisation of CNCs in metro and rural regions has resulted in a high workload which is inequitable.
3. CNCs spent 70 per cent of time on clinical consultation and 30 per cent on administrative and strategic tasks.
4. Most referrals arose from within the CNC team, physicians and other medical staff, or MDT meetings.
5. At referral at least 50 per cent of patients have complex psychosocial needs and a moderate level of function status.
6. CNCs performed a large number and a broad range of tasks.
7. Tasks related to direct nursing care and patient education were performed most frequently on a daily basis.
8. Tasks related to care management planning; patient advocacy; multidisciplinary clinical care; and multidisciplinary team meetings were conducted weekly.
9. Strategic, team communication and professional development activities were performed less frequently.

Cancer Nurse Coordinator interviews (June 2008 – July 2008)

Sample

22 CNCs with at least six months' experience in the role participated in a semi-structured interview (response rate = 100 per cent). Face-to-face interviews were conducted with metro CNCs and rural CNCs who were in Perth during the interview period (n= 16) and telephone interviews were conducted with the remaining rural CNCs (n = 6) located in regional and remote areas. The average time taken for the interviews was two hours and 14 minutes (min = one hour 15 minutes, max = three hours 36 minutes). Five key themes were identified.

Key themes

1. issues relating to the establishment of the CNC role
2. impact of CNCs on patient care and outcomes
3. impact of CNCs on the broader cancer care system
4. integration of CNC role into the health care system, including other healthcare professionals' views of the role as well as CNC involvement in the MDT
5. ongoing issues that impacted upon the ability to fulfil CNC role expectations.

Issues relating to the establishment of the CNC role

Facilitating factors

1. settings where CNCs were valued as a MDT member
2. CNCs' pre-existing knowledge of cancer services and networks, and established professional relationships
3. employment of cancer nurses to assume some of the clinical load enabled CNCs to undertake more strategic tasks
4. working within an environment with well established cancer services, timely referral of patients, access to relevant databases and practical items such as mobile phones, laptops and work car
5. peer support.

Challenges

1. initial non-acceptance of the CNC role at role inception by healthcare professionals
2. poor communication, delayed referrals, lack of access to hospital databases and private patient data.

3. rural-specific issues:

- being the sole CNC to cover a huge area and the need to travel to multiple sites within regions
- limited cancer services
- up-skilling inexperienced nursing staff to provide cancer-specific follow-up care
- providing coordination for patients in remote communities (including Aboriginal patients).

Finding: Implementation of the cancer nurse role has resulted in a reduction of CNC clinical workload and increased time for strategic activities.

Impact of CNC role on patient care and outcomes

Impact of CNC role on care

1. educating patients and carers about cancer diagnosis and treatment
2. coordinating and streamlining care to prevent fragmentation and ensure care closer to home
3. empowering patients in decision-making
4. providing psychosocial support throughout the cancer journey
5. referral to relevant psychosocial services when appropriate through psychosocial assessments and ongoing monitoring
6. improving communication among healthcare professionals and treatment facilities.

Finding: CNCs have a clinically significant impact on patient care, particularly related to advocacy and meeting patients' informational and psychosocial needs.

Impact of CNC role on cancer care system

Unique service aspects of the role

1. experts in cancer care
2. patient focus and being the constant single point of contact for patients
3. increasing referrals to allied health services
4. eliminating duplication of services when patients are treated across multiple sites
5. reducing unnecessary travel for rural patients (e.g. use of video conferencing for follow-up/review)
6. improving communication among healthcare professionals including GPs, local hospitals and NGO cancer services; two-way flow between metro and rural CNCs; and working across public and private sectors
7. focus of metro versus rural roles: metro CNCs provide care to patients with specific tumour types; rural CNCs provide care to all cancer patients, act as a resource and change agent, and build capacity in regional nurses to provide cancer care and assume care coordination where necessary.

Finding: CNCs are experts in cancer care, and the pivotal/central contact throughout the continuum of the cancer patient journey.

Examples of CNC initiatives, innovations and strategic achievements

1. **implementation of new services and clinics:** videoconference clinics; intravesical chemotherapy; chemotherapy units in regional towns; urology nurse-led follow-up clinic; sentinel lymph node biopsy procedure for regional breast cancer patients; Haematology Outreach Clinic; AYA Youth Development Officer service; and survivorship group.
2. **MDTs:** introduction of regional MDTs; audits of existing MDTs; introduced documentation for MDTs; involved in development of educational DVDs for patients and GPs about MDTs.
3. **system improvements:** Cancer Service Planning and Cancer Link meetings; improved referral pathways; standardised referral forms; ensuring all new patients with needs are seen by a CNC; introduction of psychosocial screening; introduction of a system to track neoadjuvant patients to facilitate treatment planning; introduction regional meeting/networking for all regional cancer services; established Cancer Portfolio Holder concept across rural region to facilitate transfer of information to hospital wards as required.
4. **patient resources and access:** development of new information packs and strategies for patient access both in metro and rural regions; development of a patient treatment summary booklet; standardising cancer information in each clinical area; development of a patient information website; provision of information packs to regional hospitals; standardised process for provision of information to patients who have lymph node dissections; developed cancer care record sheets.
5. **improved communication with service providers:** establishing correspondence pathways and email updates to GPs, rural CNCs and social workers; provision of diagnosis details, treatment pathway and CNC details to GPs after diagnosis.
6. **education resources and access for other healthcare professionals:** regular education programs for healthcare professionals; nursing resource library; raised awareness of relevant patient databases (e.g. Mediweb); developed CNC Information Manual; provision of psycho-oncology information for healthcare professionals.
7. **improving inequity of cancer services:** established links to site-specific physiotherapy services for metro patients; researched the inequity of access to oral health services by head and neck cancer patients.
8. **links/networks with cancer-specific and allied health services:** established Haematology Interest Group; established Brain Tumour Association; aligned and involved with national tumour-specific special interest groups; established links and spoke with elders of the Aboriginal Council; involvement in projects with healthcare professionals (e.g. with those in head and neck and upper GI cancer areas).
9. **nurse practitioner role:** business case for implementation of a nurse practitioner role.

Finding: CNCs have developed the role to strategically complement existing services.

Integration of the CNC role into the health system

Aspects of the CNC role valued by healthcare professionals

1. reliability and responsiveness
2. capacity to alleviate clinical load of some healthcare professionals by providing patient education about diagnosis and treatment
3. providing cancer expertise and leadership
4. knowledge of individual patient's cancer journey status
5. capacity to provide consistent and reliable communication
6. motivator and "champion" for MDT and other meetings.

Concerns about some healthcare professionals' perception of the role

1. lack of understanding about the scope of CNC role and inappropriate use of CNC time
2. lack of referrals by medical and nursing staff
3. lack of understanding regarding governance and accountability of the role.

Issues that may impact on CNCs' ability to fulfil role expectations

CNC workload

1. large clinical load: reduced time available for strategic tasks and impact on work/life balance
2. increased support from cancer nurses to alleviate the clinical load and increase the level of patient care initiatives and strategic work undertaken.

Management and team work

1. issues with management and/or WA Cancer and Palliative Care Network: some CNCs felt undervalued and/or unappreciated; lack of financial support for conference attendance; not all CNCs expected to work at the same level; lack of support from hospital management for CNC role; lack of assistance to navigate aspects that are beyond CNC level of influence
2. isolation of role and CNC team: not belonging to a hospital team; independent nature of work; limited time to meet as a team
3. dealing with healthcare professionals: having "to prove yourself"; lack of two-way communication with some teams.

Practical issues

1. lack of standardised documentation
2. duplication of patient data collected across different Health Department software systems
3. data collection for the Network is time-consuming; lack of dedicated database and patient record system
4. lack of suitable office space: impacts upon privacy and confidentiality during telephone calls; working across three or more sites.

Finding: Large clinical and administrative workloads impact on CNCs' ability to undertake more strategic initiatives.

Finding: CNCs are fulfilling the core components of the specialist cancer nurse: clinical expert, resource consultant, educator, change agent, researcher and advocate.

Key findings

1. Implementation of the cancer nurse role has resulted in a reduction of CNC clinical workload and increased time for strategic activities.
2. CNCs have a clinically significant impact on patient care, particularly related to advocacy and meeting patients' informational and psychosocial needs.
3. CNCs are experts in cancer care, and the pivotal/central contact throughout the continuum of the cancer patient journey.
4. CNCs have developed the role to strategically complement existing services.
5. Large clinical and administrative workloads impact on CNCs' ability to undertake more strategic initiatives.
6. CNCs are fulfilling the core components of the specialist cancer nurse: clinical expert, resource consultant, educator, change agent, researcher and advocate.

Recommendations

1. The Network should secure more resources to increase access to care coordination and psychosocial care for future patients and carers by increasing numbers of CNCs to meet the demand.
2. The Network should explore opportunities to delegate non-coordination activities to administrative staff.

PHASE 2

Target population and procedures

During this phase questionnaires were administered to multidisciplinary healthcare professionals, patients and carers. Anonymity of all participants was ensured as no name-related data was requested. This phase sought to provide the evidence for Specific Aims 1-3 (see pages 13-14). Questionnaires were based on instruments previously developed and used for an evaluation of the cancer coordinator role at the Peter MacCallum Cancer Institute⁹. We adapted these instruments to suit the Western Australian context after considering findings from Phase 1. Individual components included:

- **survey of multidisciplinary healthcare professionals:** Multidisciplinary healthcare professionals with whom CNCs had professional contact during the previous 12 months either during formal or informal MDT meetings, were invited to participate in an online survey using the online SurveyMonkey tool. The sample also included healthcare professionals known to have a common interest in the CNC role who were nominated by WA Cancer and Palliative Network executive staff. In order to maintain the privacy of the contact information of Health Department employees, the contact details of potential MDT participants were provided to a WA Health Department employee who was independent from the project team. Potential participants were invited by the Clinical Lead of the Cancer and Palliative Care Network to participate in the online MDT survey. Return of the completed survey was used to indicate implied consent.
- **survey of patients:** Patients who had received at least three direct episodes of care in the period between 30 November 2008 and 31 May 2009, at least one of which was a level 3 intervention or higher, were invited to participate in this survey. 553 patients were identified. Patient names were cross-checked against the death register of the Registry of Births, Deaths and Marriages and CNCs to ensure no deceased patients were included in the target population. Up to 40 eligible patients were randomly selected per CNC (rural, AYA and tumour stream service). Patients were mailed: a letter signed by his/her CNC that also included a photograph of the CNC to aid accurate recall; an information sheet; a patient questionnaire and a reply paid envelope. Return of a completed survey was used to indicate implied consent. Patients were also given the option to nominate their primary carer for inclusion in the study.
- **survey of carers:** Primary carers who were nominated by a patient were mailed a covering letter signed by the nominating patient's CNC that included a photograph of the CNC to aid accurate recall; an information sheet; a carer questionnaire and a reply paid envelope. Return of a completed survey was used to indicate implied consent.

Instruments

1. Cancer Nurse Coordination Project Multidisciplinary Team Member Questionnaire

The questionnaire comprised 18 questions. Testing for clarity, apparent internal consistency and content validity was undertaken between 14 October and 3 December 2009 with one medical oncologist, one radiation oncologist, two allied healthcare professionals, one cancer nurse and one psychologist (n=6). A high degree of internal consistency was demonstrated by an overall Cronbach's alpha coefficient of 0.949 and individual Cronbach's alpha coefficients of 0.881 to 0.971 across the two survey subscales.

2. Cancer Nurse Coordination Project Patient Questionnaire

The questionnaire contained 23 questions. Testing for clarity, apparent internal consistency and content validity was undertaken between 27 October and 30 November 2009 with three metropolitan and three rural patients (n=6). The internal consistency reliability of the instrument was demonstrated by an overall Cronbach's alpha coefficient of 0.948. Cronbach's alpha coefficients for subscales were: communication CNC role (0.882); information provision (0.811); treatment and care provision (0.906); practical support (0.844); and overall satisfaction with CNC (0.853). Internal consistency overall and across subscales indicated a high degree of internal consistency.

3. Cancer Nurse Coordination Project Carer Questionnaire

The amended questionnaire contained 23 questions. Testing for clarity, apparent internal consistency and content validity was undertaken between 10 November 2009 and 3 February 2010 with four metropolitan and two rural carers (n=6). The internal consistency reliability of the instrument was demonstrated by an overall Cronbach's alpha coefficient of 0.951. Cronbach's alpha coefficients for the key areas of the questionnaire were: communication CNC role (0.917); information provision (0.919); treatment and care provision (0.919); practical support (0.841); and overall satisfaction with CNC (0.873). Internal consistency overall and across subscales indicated a high degree of internal consistency.

Multidisciplinary team survey (July 2008 – March 2010)

Inclusion criteria

1. multidisciplinary healthcare professionals with whom CNCs had professional contact during the previous 12 months through formal or informal MDT meetings
2. other healthcare professionals with whom CNCs had significant interaction and who were involved in the care of cancer patients
3. other healthcare professionals known to have a common interest in the CNC role and nominated by WA Cancer and Palliative Network executive staff.

Recruitment process

To maintain the privacy of the contact information of Health Department employees, contact details of potential healthcare professionals were provided to a Health Department employee who was independent from the project team. A total of 449 potential participants were invited by the Clinical Lead of the Cancer and Palliative Care Network to participate in an online MDT survey using the SurveyMonkey tool.

Results

148 (33 per cent) MDT surveys were submitted and evaluable.

Demographic characteristics

(see Appendices 1-2 for detailed results)

Attendance at MDT meetings

75 per cent (n=111) of healthcare professionals frequently attended a formal MDT meeting. The majority of healthcare professionals (n=80, 54 per cent) attended formal MDT meetings in the metropolitan area only, 19 per cent attended rural MDT meetings only (n=28), three healthcare professionals attended both metropolitan and rural MDT meetings and 25 per cent (n=37, 25 per cent) did not attend any MDT meetings.

Professional discipline of participants

34 per cent (n=51) of healthcare professionals were nurses, 20 per cent (n=29) were allied healthcare professionals, 15 per cent (n=22) were surgeons and 13 per cent (n=20) were physicians (broad definition that included haematologists, medical oncologists and radiation oncologists). A further 18 per cent (n=26) of healthcare professionals were from 'other' professions.

Area of healthcare

The majority of healthcare professionals (n=80, 54 per cent) worked in secondary or tertiary care and 37 per cent (n=55) worked in primary care. Nine percent (n=13) of healthcare professionals worked in primary, secondary and tertiary care. A smaller proportion of healthcare professionals who worked in primary, secondary and tertiary care attended MDT meetings in metropolitan regions (39 per cent) than in rural regions (46 per cent).

MDT attendance

The majority of surgeons (n=21, 96 per cent), physicians (n=17, 85 per cent) and other professionals (n=13, 50) attended MDT meetings in the metropolitan area. A large proportion of nurses (n=21, 41 per cent) did not attend meetings as their contact was usually at ward level. Forty-eight per cent (n=14) of allied healthcare professionals attended metropolitan meetings and 35 per cent (n=10) attended rural meetings.

Experience with cancer patients

The majority of healthcare professionals (n=133, 90 per cent) had worked in cancer care with 60 per cent (n=89) having six years' or more experience and 30 per cent (n=43) having fewer than six years' experience. Healthcare professionals who had more than six years' experience were more likely ($\chi^2=9.683$, $p=0.008$) to be aware of organisational barriers that impacted on the CNC role than those with five years or less experience with cancer patients.

Frequency of patient contact with CNCs

The majority of healthcare professionals (n=101, 68 per cent) had at least weekly contact with a CNC regarding patient care, with 12 per cent (n=18) having contact several times a day and 34 per cent (n=50) having contact several times a week. Healthcare professionals who attended meetings in the metropolitan area had more frequent contact with a CNC regarding patient care than healthcare professionals who attended rural meetings. Healthcare professionals who were in contact with CNCs at least several times per week had a higher awareness of tasks performed by CNCs as a team member within their clinical area ($F=3.943$, $p=0.03$) than healthcare professionals who had contact with a CNC on a monthly basis.

MDT meetings frequently attended

A large proportion of healthcare professionals attended the MDT meetings at Sir Charles Gairdner Hospital as follows: head and neck (n=9, 43 per cent), lung (n=10, 40 per cent), upper GI (n=9, 33 per cent), urology (n=3, 33 per cent) and neuro-oncology (n=6, 75 per cent).

CNC attendance at MDT meetings

CNCs were in attendance at 88 per cent (n=98) of MDT meetings attended by healthcare professionals.

Survey results

Perceived patient experience of CNC care by healthcare professionals (Table 9)

Eighty per cent (n=118) of healthcare professionals agreed that all patients benefit from CNC care and experience a more coordinated cancer journey. Of note, 55 per cent (n=11) of physicians agreed that only patients with complex care needs benefit from CNC care.

Finding: Healthcare professionals agreed that all patients benefit from the CNC Service.

Finding: Healthcare professionals agreed that patients who had seen a CNC experience a more coordinated cancer journey.

Table 9: Background of healthcare professionals by profession

	Surgeons (n=22)	Physicians (n=20)	Nurses (n=51)	Allied Health (n=29)	Other (n=26)	Total (n=148)
Agree that patients who see a CNC experience a more coordinated cancer journey n(%)						
Yes	21(95.5)	13(65.0)	38(74.5)	24(82.8)	22(84.6)	118(79.7)
No	0(0.0)	5(25.0)	6(11.8)	1(3.4)	1(3.8)	13(8.8)
Unsure	1(4.5)	2(10.0)	7(13.7)	4(13.8)	3(11.5)	17(11.5)
Opinion on complex needs and CNC Service n(%)						
All patients benefit	20(90.9)	9(45.0)	42(82.4)	25(86.2)	23(88.5)	119(80.4)
Only patients with complex needs benefit	2(9.1)	11(55.0)	9(17.6)	4(13.8)	3(11.5)	29(19.6)
Awareness of CNC tasks (m,sd)*	11.9 (3.8)	11.5(3.7)	12.1 (4.5)	13(3.6)	12.5 (3.3)	12.3 (3.9)

*Total possible score=16.

Awareness of activities performed by CNCs

Sixteen key activities performed by CNCs were listed in the MDT survey. On average, healthcare professionals were aware of the majority of the activities performed by CNCs (m=12.3, sd=3.9). Healthcare professionals viewed the key functions of the CNC role as: focal point of contact throughout the patient care trajectory; coordinate all aspects of patient care; provide patient education and information; and accountability. Healthcare professionals were less aware that CNCs arranged transport or accommodation options for patients (n=79, 53 per cent), conducted patient assessments (n=86, 58 per cent) and helped patients manage symptoms and side effects (n=86, 58 per cent). Only 41 per cent (n=9) of surgeons were aware that CNCs were involved in the provision of education for other healthcare professionals; and 50 per cent (n=10) of physicians were aware of CNCs' involvement in the implementation of cancer service improvements (site-specific or broader health system).

There was considerable similarity between the top 10 most frequently identified CNC activities by the MDT members and those reported by the CNCs (Table 10). See Appendix 3 for detailed responses according to discipline.

Finding: Healthcare professionals viewed the key functions of the CNC role as: focal point of contact throughout the patient care trajectory; coordinate all aspects of patient care; provide patient education and information; and accountability.

Finding: There was variation in healthcare professionals' understanding about the scope of the CNC role.

Table 10: Top 10 CNC tasks identified by both healthcare professionals and CNCs

Activity items	MDT (n=148) n(%)	CNC (n=17) n(%)
Communicates with doctors and other healthcare professionals re care management	139(93.9)	7(41.2)
Provides patients with education about diagnosis and symptoms	128(86.5)	9(52.9)
Refers to relevant services	127(85.8)	9(52.9)
Refers patients to relevant services	127(85.8)	9(52.9)
Educates patients about appropriate healthcare professional to contact if issues arise	126(85.1)	9(52.9)
Receives contact from patients when issues or concerns arise	126(85.1)	9(52.9)
Receives contact from families/carers when issues or concerns arise	126(85.1)	8(47.1)
Supports the patient's family/carers	123(83.1)	8(47.1)
Provides patients with education about treatment and side effects	116(78.4)	6(35.3)
Arranges patients' appointments and timing of treatments	108(73.0)	9(52.9)

Healthcare professionals who were in contact with CNCs at least several times a week had a higher awareness of tasks performed by the CNC in their role as a team member within their clinical area ($F=3.943$, $p=0.03$). Healthcare professionals who agreed that patients who have seen a CNC experience a more coordinated cancer journey than those who have not seen a CNC, had a higher awareness of tasks performed by CNC in their role as a team member within their clinical area ($F=21.528$, $p<0.001$).

Finding: Healthcare professionals who had regular contact with CNCs have a greater awareness of the CNC role.

Contact with CNCs by MDT members and patients

Overall 76 per cent ($n=84$) of healthcare professionals had face-to-face contact with CNCs at MDT meetings, 69 per cent ($n=76$) had face-to-face contact through one-to-one meetings with CNCs and 58 per cent ($n=64$) had telephone or email contact only with CNCs. Fifty-one percent ($n=56$) of healthcare professionals' cancer patients had contact with a CNC when there was a need, 43 per cent ($n=48$) at diagnosis, 32 per cent ($n=36$) before treatment, 27 per cent ($n=30$) at the patient's first appointment and 24 per cent ($n=27$) after treatment commencement (Table 11).

Finding: The majority of healthcare professionals had at least weekly contact with a CNC.

Table 11: Instances when patients have contact with CNCs as perceived by healthcare professionals

Instance	n(%)
When there was a need	56(50.5)
At diagnosis	48(43.2)
Before treatment	36(32.4)
At first meeting with physician/surgeon	30(27.0)
After treatment	27(24.3)
Unsure	12(10.8)
Other	9(8.1)
Never referred a patient	2(1.8)

* Multiple responses allowed
Missing data, (n=111)

Awareness of organisational barriers to CNC role (Appendix 4)

Healthcare professionals were asked to indicate if they were aware of any organisational barriers impacting on the CNC role. 37 per cent (n=55) of healthcare professionals were aware of organisational barriers to the CNC role. There was no significant difference between awareness and profession ($\chi^2=5.292$, $p=0.726$). The top three organisational barriers perceived to impact upon the ability of the CNC role to contribute to patient care/outcomes task were: case load (n=37, 51 per cent), funding (n=26, 51 per cent) and resources (n=25, 9 per cent).

Finding: Case load, funding and resources were considered the main barriers to impact on the CNC role by healthcare professionals.

Table 12: Awareness of organisational barriers to CNC role (n,%)

	Surgeons (n=22)	Physicians (n=20)	Nurses (n=51)	Allied Health (n=29)	Other (n=26)	Total (n=148)
Yes	9(40.9)	9(45.0)	19(37.3)	12(41.4)	5(19.2)	54(36.5)
No	8(36.4)	7(35.0)	23(45.1)	11(37.9)	13(50.0)	62(41.9)
Unsure	5(22.7)	4(20.0)	9(17.6)	6(20.7)	8(30.8)	32(21.6)

Suggestions for addressing barriers were as follows:

Surgeons

- Increase funding to employ more CNCs.
- Federal leadership to promote the value and need of cancer nurse coordination.

Medical and radiation oncologists

- Increase funding to employ more CNCs.
- Budget and financial responsibility for CNCs should rest with hospitals.
- Consultation should take place within individual cancer units to determine the best use of CNCs.
- The CNC role should be integrated into the health system.
- The CNC role should be devolved to area health services.

Nurses

- Increase number of CNCs in metro and rural areas.
- Employ 1.0 FTE CNC per tumour stream/per tertiary site in metro area.
- Employ 1.0 FTE CNC per rural district of WA Country Health Service rather than per rural region.
- Improve understanding of CNC role.

Allied Health Professionals

- Increase funding to employ more CNCs.
- Provide additional support for CNCs either through nursing or allied health hours.

Other professionals

- Increase funding to employ more CNCs.
- Provide 1.0 FTE CNC per rural district of WA Country Health Service rather than per rural region.
- Incorporate role into standards of care so the role is non-negotiable.

Summary of perceived role of CNC in patient care

- Provide a local point of contact.
- Has the ability to co-ordinate all aspects of cancer care.
- Provide education.
- Provide accountability.
- Provide other practical information.
- Assist with patient arrangements.

Finding: Healthcare professionals viewed the key functions of the CNC role as: focal point of contact throughout the patient care trajectory; coordinate all aspects of patient care; provide patient education and information; and accountability.

Finding: Healthcare professionals recommended increasing the availability of CNCs.

Finding: There was variation in healthcare professionals' understanding about the scope of the CNC role.

Summary of role improvement strategies

The CNC role could be improved or developed through:

- increased availability
- attendance at more clinics
- allocation of an administrative person to assist CNCs
- increased visibility
- improved communication.

Key findings

1. Healthcare professionals agreed that all patients benefit from the CNC Service.
2. Healthcare professionals agreed that patients who had seen a CNC experience a more coordinated cancer journey.
3. Healthcare professionals viewed the key functions of the CNC role as: being a focal point of contact throughout the patient care trajectory; coordinating all aspects of patient care; providing patient education and information; and accountability.
4. There was variation in healthcare professionals' understanding about the scope of the CNC role.
5. Healthcare professionals who had regular contact with CNCs have a greater awareness of the CNC role.
6. The majority of healthcare professionals had at least weekly contact with a CNC.
7. Case load, funding and resources were considered the main barriers to impact on the CNC role by healthcare professionals.
8. Healthcare professionals recommended increasing the availability of CNCs.

Recommendations

1. The Network should secure more resources to increase access to care coordination and psychosocial care for future patients and carers by increasing numbers of CNCs to meet the demand.

Patient survey

Of the 326 patients invited to participate, 90 completed surveys were returned, indicating a 28 per cent response rate. 85 patients (94 per cent) recalled the CNC named on the letter accompanying the questionnaire. Data from five patients (metropolitan=2, rural=3) who did not recall his/her CNC were excluded from analysis. The final sample comprised 85 patients.

Demographic variables

(see Appendices 5-6 for detailed results)

- The average age of patients was 58 years.
- There were 43 males and 39 females.
- 79 patients spoke English at home.
- 43 patients had finished high school.
- 28 patients were retired.
- 49 patients resided in the metro area, and 36 resided in rural regions.
- 60 patients had chemotherapy, 57 had surgery, 40 patients had radiotherapy and 26 patients had other treatments/care/therapy including; palliative care, physiotherapy, dietetics, dental, physiotherapy, speech or psychosocial care. Of these treatments, the majority were conducted at Sir Charles Gairdner Hospital: surgery (n=18, 32 per cent), radiotherapy (n=22, 55 per cent) and chemotherapy (n=18, 41 per cent) (Appendix 6).

Initial contact with CNC

Initial contact with a CNC occurred more often before patients' first treatment (39 per cent, n=31), at diagnosis (31 per cent, n=25) or after the patient's first treatment (n=20, 25 per cent). For patients with a metro CNC, initial contact with a CNC before the first treatment (46 per cent, n=21) while a greater proportion of patients with a rural CNC had initial contact after first treatment (35 per cent, n=12).

Frequency of contact

Fifty percent of patients (n=40) had contact with a CNC a few times, 13 per cent (n=11) had weekly contact, 12 per cent (n=10) had monthly contact, 8 per cent (n=7) had fortnightly contact and 6 per cent (n=5) had less than monthly or once only contact. The most common form of contact was face-to-face (92 per cent, n=78) or telephone (82 per cent, n=70). Twelve percent (n=10) of patients had email contact with CNCs. There was a significant difference between the age of patients and frequency of contact with CNCs ($F=3.696$, 0.029) with patients who had at least weekly contact being younger (mean=48, $sd=20.4$) than patients whose contact was fortnightly/monthly (mean=56, $sd=11.7$). There was no significant difference between the frequency of contact and the number of hospital sites visited ($X^2=4.793$, $p=0.091$), number of cancer treatments received ($X^2=1.159$, $p=0.560$) or gender ($X^2=3.174$, $p=0.205$).

Preference of contact type

Twenty-four per cent (n=20) of patients preferred telephone contact, 34 per cent (n=29) preferred face-to-face contact and 45 per cent (n=38) preferred a combination of telephone and face-to-face contact.

Patient preference for contact frequency

Although the majority of patients (71 per cent, n=57) were content with the timing of initial contact in their cancer journey, 26 per cent (n=12) of patients with a metro CNC and 32 per cent (n=11) of patients with a rural CNC would have preferred earlier contact.

Finding: A moderate proportion of patients would have preferred contact with the CNC earlier in the cancer journey.

Number of treatments and hospital sites visited by region

A significantly higher ($X^2=6.532$, $p=0.011$) proportion of rural patients (n=21, 58 per cent) attended more than two hospital sites compared with metro patients (n=15, 31 per cent). Approximately half (n=42, 49 per cent) of all patients had fewer than two treatments while 51 per cent (n=43) of patients had two or more treatments.

Survey results

Patients were invited to respond to a series of statements related to key patient care activities: communication (10 statements); provision of information (four statements); treatment and care (10 statements); and practical support (seven statements).

Communication with CNCs (Table 13)

There was a high level of agreement from patients (78 per cent to 96 per cent) regarding statements related to communication. The majority of patients agreed with the statements regarding the communication experience of the care provided by CNCs. A large proportion of patients agreed they were given helpful answers to questions about his/her cancer and treatment (96 per cent, n=77), they were helped to understand information given to them by their doctor (96 per cent, n=71) and they could contact the CNC when they needed to (95 per cent, n=79).

Table 13: Agreement with communication experience of the care provided by CNC by region (n,%)

Statement	Agree	Neither agree or disagree	Disagree
I was given helpful answers to questions about cancer and its treatment	77(96.3)	1(1.3)	2(2.5)
I was helped to understand information given to me by my doctor	71(95.9)	2(2.7)	1(1.4)
I could contact the CNC when I needed to	79(95.2)	1(1.2)	3(3.6)
My questions about any changes that occurred in my health were answered	63(87.5)	7(9.7)	2(2.8)
I was helped to understand my cancer diagnosis	63(87.5)	7(9.7)	2(2.8)
I could ask questions I was not able to ask my doctor	55(84.6)	8(12.3)	2(3.1)
The CNC contacted me when any cancer care or treatment issues came up	57(81.4)	8(11.4)	5(7.2)
The CNC helped me realise there were other questions I should ask my doctor that I had not thought of before	53(79.1)	8(11.9)	6(9.0)
The CNC communicated with my GP and other doctors	60(78.9)	15(19.7)	1(1.3)
I was helped with ways to raise issues with my doctor that I needed answers for	47(78.3)	8(13.3)	5(8.3)

* Missing data, n=60-83

Provision of information (Table 14)

Patients also demonstrated a high level of agreement (74 per cent to 95 per cent) with statements related to provision of information. A large proportion of patients agreed they were provided with information about their treatment and its side-effects (95 per cent, n=74), were told about all the care options available to them (90 per cent, n=70) and were provided with information about the diagnosis, symptoms and tests (85 per cent, n=63).

Table 14: Agreement with information experience of the care provided by CNCs (n,%)

Statement	Agree	Neither agree or disagree	Disagree
I was provided with information about my treatment and side effects	74(94.9)	2(2.6)	2(2.6)
I was told about all the care options available to me	70(89.7)	5(6.4)	3(3.8)
I was provided with information about my diagnosis, symptoms or tests	63(85.1)	6(8.1)	5(6.8)
The information provided helped to reassure me	74(73.7)	2(2.5)	2(3.8)

* Missing data, (n=74-79)

Finding: Patients reported high satisfaction with CNC services related to communication and information.

Provision of treatment and care provided by CNCs (Table 15)

Patient agreement for statements related to treatment and care provision by CNCs ranged from 70 per cent to 94 per cent. A large proportion of patients agreed: their concerns were listened to and taken care of (94 per cent, n=68); and they were provided with information about health services or healthcare professionals and how they could help them (90 per cent, n=68). There was less agreement for the provision of emotional support to family or friends (73 per cent, n=43) and being provided with access to counselling groups (70 per cent, n=38).

Table 15: Agreement with treatment and care provided by CNC (n,%)

Statement	Agree	Neither agree or disagree	Disagree
My concerns were listened to and taken care of	68(94.4)	4(5.6)	0(0.0)
I was provided with information about health services or healthcare professionals and how they could help me	68(89.5)	5(6.6)	3(3.9)
I was helped to make important treatment decisions	55(85.9)	4(6.3)	5(7.8)
I was helped to access other health services I needed	58(84.1)	8(11.5)	3(4.3)
I was given emotional support	57(83.8)	8(11.8)	3(4.4)
I was regularly asked about physical and emotional problems	61(81.3)	10(13.3)	4(5.3)
My wishes were included in my care plan	52(78.8)	12(18.2)	2(3.0)
I was provided with ways to manage my symptoms and side effects	52(77.6)	12(17.9)	3(4.5)
My carer, family/friends were given emotional support	43(72.9)	13(22.0)	3(5.1)
Access to counselling services or support groups was arranged for me	38(70.4)	13(24.1)	3(5.6)

* Missing data, (n=54-76)

Finding: Carers, family and friends required access to emotional support.

Finding: Patients required assistance to access to counselling services.

Provision of practical support by CNCs (Table 16)

While the majority of patients agreed with the 10 items related to practical support provided by CNC, proportions were smaller in this area of CNC care than in other areas (62 per cent to 76 per cent) with between 11-18 per cent disagreeing with the statements. Given the large number of missing data it is not possible to draw any specific conclusions.

Table 16: Agreement with practical support provided by CNC (n,%)

Statement	Agree	Neither agree or disagree	Disagree
I was provided with assistance or information for the Patient Assistance Transport Scheme (PATS)	42(76.4)	7(12.7)	6(10.9)
My appointments for tests, procedures, treatment and/or follow-up were arranged by the CNC	40(74.1)	8(14.8)	6(11.1)
I was given help to find where I had to go or who I had to see at each hospital	34(69.4)	8(16.3)	7(14.3)
I was given support for non-health related problems that impacted on my cancer or treatment	39(68.4)	10(17.5)	8(14.0)
Transport or accommodation was arranged for me so that I could attend treatment	30(66.7)	7(15.6)	8(17.8)
I was given support for practical problems	25(65.8)	6(15.8)	7(18.4)
The CNC helped coordinate doctors and services when I went to another hospital	23(62.2)	9(24.3)	5(13.5)

* Missing data, (n=38-57)

Provision of general support by CNCs (Table 27)

The majority of patients agreed their cancer treatment went smoothly at each stage (n=66, 86 per cent); the CNC was an important part of their treatment team (n=63, 84 per cent) and felt the help provided by the CNC made their cancer journey easier (n=64, 88 per cent).

Table 17: Agreement with general support provided by CNC (n,%)

Statement	Agree	Neither	Disagree
My cancer treatment went smoothly at each stage	66(85.7)	4(5.2)	7(9.1)
Overall, the help provided made my cancer journey easier	64(87.7)	7(9.6)	2(2.7)
The CNC was an important part of my treatment team	63(84.0)	8(10.7)	4(5.3)

* Missing data, (n=73-77)

Finding: Patients reported their journey went smoothly and the CNC was an important part of the treatment team.

Satisfaction with level of support and needs being addressed by region (Table 18)
95 per cent (n=77) of patients were satisfied with the level of support provided by the CNC. Few patients (n=3, 4 per cent) had needs that were not addressed.

Table 18: Satisfaction with level of support and needs being addressed by region

Statement	Metro	Rural	Total
Satisfied with level of support provided (n=81)	45(95.7)	32(94.1)	77(95.1)
Have needs that were not addressed by CNC (n=77)	2(4.4)	1(3.1)	3(3.9)

*missing data (n=80)

Finding: Patients reported they were satisfied with the overall level of support provided.

Most valuable aspects of care or support provided by CNC by region (Table 19)
The provision of emotional support (69 per cent, n=50), information (67 per cent, n=47) and practical support (59 per cent, n=43) were considered the most valuable aspects of care or support provided by CNCs. A greater proportion of metro patients valued the provision of information more highly (74 per cent, n=31) compared with rural patients (58 per cent, n=18) while a greater proportion of rural patients (77 per cent, n=24) valued emotional support more highly compared with metro patients (62 per cent, n=26).

Table 19: Most valued aspects of care or support provided by CNC by region (n,%)*

Aspect of care statements	Metro (n=42)	Rural (n=31)	Total (n=73)
Providing information	31(73.8)	18(58.1)	49(67.1)
Emotional support, care, reassurance, understanding, listening	26(61.9)	24(77.4)	50(68.5)
Practical support	26(61.9)	17(54.8)	43(58.9)
Contactable/available	10(23.8)	11(35.5)	21(28.8)
Personal contact	2(4.8)	4(12.9)	6(8.2)
Approachable	1(2.4)	3(9.7)	4(5.5)
Home visits	0(0.0)	2(6.5)	2(2.7)

* Multiple responses allowed

* Missing data

Finding: Aspects of care most valued by patients were provision of information, emotional and practical support.

Aspects of CNC least valued

Patients were asked to describe an aspect of the CNC service they valued least. Of the 43 patients who responded, 38 (88 per cent) commented all aspects were valued.

Patient suggestions for role improvement

- make the role the CNC will play clearer
- improve availability and numbers of CNCs
- more face-to-face contact with CNC
- contact rural patients earlier so they have more time to arrange accommodation and transport
- contact patients after treatment completion.

Finding: Patients recommended more face-to-face contact and increased availability of CNCs.

Finding: There was variation in patients' understanding about the scope of the CNC role.

Finding: Patients required ongoing care following treatment completion.

Key findings

1. A moderate proportion of patients would have preferred contact with the CNC earlier in the cancer journey.
2. Patients reported high satisfaction with CNC services related to communication and information.
3. Carers, family and friends required access to emotional support.
4. Patients required assistance to access counselling services.
5. Patients reported their journey went smoothly and the CNC was an important part of the treatment team.
6. Patients reported they were satisfied with the overall level of support provided.
7. Aspects of care most valued by patients were provision of information, emotional and practical support.
8. Patients recommended more face-to-face contact and increased availability of CNCs.
9. There was variation in patients' understanding about the scope of the CNC role.
10. Patients require ongoing care following treatment completion.

Recommendations

1. The CNC service should develop strategies to enable earlier referral and contact with patients.
2. The CNC service should develop strategies to improve access to psychosocial support and counselling services for carers, family and friends.
3. The Network should secure more resources to increase access to care coordination and psychosocial care for future patients and carers by increasing numbers of CNCs to meet the demand.
4. The Network should develop appropriate survivorship care models.

Carer survey

135 primary carers were invited to participate, of which 46 returned completed surveys (response rate=34 per cent). Data from one carer who did not recall the named CNC was excluded from the analysis. The final sample comprised 45 carers.

Results

Demographic variables

(see Appendices 7-8 for detailed results)

- The average age of carers was 57 years.
- 31 carers were female and 14 were male.
- All 45 carers spoke English at home.
- 18 carers had finished high school.
- 27 carers were retired.
- 10 carers were also caring for a dependent child.

Timing of initial contact with CNC

For a large proportion of carers initial contact with his/her CNC occurred before the patient's first treatment (30 per cent, n=12) or at diagnosis (35 per cent, n=14). A greater proportion of carers with a metro CNC made contact before the first treatment (35 per cent, n=10) than carers with a rural CNC (18 per cent, n=2) while a greater proportion of carers with a rural CNC made contact at diagnosis (55 per cent, n=6) than carers with a metro CNC (28 per cent, n=8).

Contact wanted earlier in cancer journey

Forty nine percent (n=18) of carers would have preferred contact earlier in his/her family member or friend's cancer journey.

Finding: A large proportion of carers would have preferred contact with the CNC earlier in the cancer journey.

Frequency of contact

Almost half the carers (47 per cent, n=17) had contact with a CNC a few times overall with 11 per cent (n=4) having weekly or fortnightly contact. The most common form of contact with a CNC was face-to-face (98 per cent, n=39), followed by telephone (83 per cent, n=33) and email (15 per cent, n=6).

Preference of contact type

Fifty-three per cent (n=21) of carers preferred combination of telephone, email and face-to-face contact, whereas 25 per cent (n=10) of carers preferred face-to-face contact and 25 per cent (n=10) of carers did not have a preference.

Survey results

Items in the carer survey replicated those of the patient survey. Carers were invited to respond to a series of statements related to key patient care activities: communication (10 statements); provision of information (four statements); treatment and care (10 statements); and practical support (seven statements).

Communication with CNCs (Table 20)

Carers demonstrated a moderate to high level of agreement (62 per cent to 88 per cent) with statements related to communication. The majority of carers agreed they were: helped to understand the patient's cancer diagnosis (n=35, 85 per cent); given helpful answers to questions about cancer and its treatment (n=35, 88 per cent); could contact the patient's CNC when necessary (n=36, 86 per cent; and was helped to understand information given by the doctor (n=35, 85 per cent).

Table 20: Agreement of carers with communication experience of the care provided by CNC (n, %)

Statement	Agree	Neither agree nor disagree	Disagree
I was helped to understand the cancer diagnosis	35(85.4)	4(9.8)	2(4.9)
I was given helpful answers to questions about cancer and its treatment	35(87.5)	2(5.0)	3(7.5)
I could contact the CNC when I needed to	36(85.7)	3(7.1)	3(7.1)
I was helped to understand information given by the doctor	35(85.4)	4(9.8)	2(4.9)
I could ask questions I was not able to ask the doctor	29(78.4)	2(5.4)	6(16.2)
My questions were answered about any changes that occurred in my health	33(76.7)	6(14.0)	4(9.3)
The CNC communicated with the GP and other doctors	31(75.6)	6(14.6)	4(9.8)
The CNC helped me realise there were other questions I should ask the doctor that I had not thought of before	27(75.0)	3(8.3)	6(16.7)
The CNC helped with ways to raise issues with the doctor	23(67.6)	4(11.8)	7(20.6)
The CNC contacted me when any cancer care or treatment issues came up	23(62.2)	9(24.3)	5(13.5)

* Missing data (n=34-43)

Finding: Carers required assistance to develop communication skills to facilitate open communication with doctors.

Finding: Carers required contact from CNCs when patient care issues arose.

Provision of information by CNCs (Table 21)

The majority of carers agreed they were: provided with information about diagnosis, symptoms or tests (n=36, 90 per cent); provided with information about treatment and its side-effects (n=34, 90 per cent); and were told about all the care options available (n=28, 80 per cent). Six carers (15 per cent) disagreed the information provided helped to reassure them.

Table 21: Agreement of carers with provision of information by CNC (n, %)

Statement	Agree	Neither agree nor disagree	Disagree
I was provided with information about diagnosis, symptoms or tests	36(90.0)	1(2.5)	3(7.5)
I was provided with information about treatment and its side effects	34(89.5)	2(5.3)	2(5.3)
I was told about all the care options available	28(80.0)	5(14.3)	2(5.7)
The information provided helped to reassure me	29(74.4)	4(10.3)	6(15.4)

Treatment and care experience of carers (Table 22)

Agreement for these items ranged from 50 per cent to 91 per cent. The majority of carers agreed: I was provided with information about health services/professionals and how they could help (n=39, 91 per cent); I was helped to access other health services we needed (n=35, 85 per cent); my concerns were listened to and taken care of (n=34, 83 per cent); the patient was helped to make important treatment decisions (n=34, 83 per cent); and patient's wishes were included in their care plan (n=33, 83 per cent). In contrast to patient findings, a large proportion of carers neither agreed nor disagreed, or, disagreed with the following statements regarding the treatment and care experience provided by CNC:

- I was regularly asked about the patient's physical and emotional problems (28 per cent, n=11)
- I was provided with ways to manage the patient's symptoms and side effects (27 per cent, n=11)
- I was given emotional support (22 per cent, n=9)
- Other family or friends were given emotional support (41 per cent, n=13)

- Access to counselling services or support groups was arranged for me (49 per cent, n=14)
- With the help provided, I avoided carer “burnout” (50 per cent, n=18)
- I was helped to make sure that my own self-care needs were met (34 per cent, n=14)

Table 22: Agreement of carers with treatment and care provided by CNC (n,%)

Statement	Agree	Neither agree nor disagree	Disagree
I was provided with information about health services/professionals and how they could help	39(90.7)	3(7.0)	1(2.3)
I was helped to access other health services we needed	35(85.4)	4(9.8)	2(4.9)
My concerns were listened to and taken care of	34(82.9)	2(4.9)	5(12.2)
My patient was helped to make important treatment decisions	34(82.9)	4(9.8)	3(7.3)
Patients wishes were included in their care plan	33(82.5)	5(12.5)	2(5.0)
I was given emotional support	33(78.6)	1(2.4)	8(19.0)
I was provided with ways to manage symptoms and side effects	30(73.2)	3(7.3)	8(19.5)
I was regularly asked about patient's physical and emotional problems	28(71.8)	4(10.3)	7(17.9)
I was helped to make sure that my own “self-care” needs were met	24(66.7)	7(19.4)	5(13.9)
Other family or friends were given emotional support	19(59.4)	3(9.4)	10(31.3)
Access to counselling services or support groups was arranged for me	15(51.7)	9(31.0)	5(17.2)
With the help provided, I avoided carer “burnout”	18(50.0)	8(22.2)	10(27.8)

* Missing data, (n=29-43)

Finding: Carers’ family and friends required access to emotional support and counselling services.

Finding: Carers required assistance to avoid carer “burnout”.

Provision of practical support (Table 23)

The level of agreement for these items was lower and ranged from 36 per cent to 69 per cent. Compared with the categories, 18-32 per cent of carers disagreed with the following statements:

- I was given support for non-health related problems that impacted on the cancer or treatment (n=9, 24 per cent)
- We were provided with assistance or information for the Patient Assistance Transport Scheme (PATS) (n=7, 21 per cent)
- Transport or accommodation was arranged so that the patient could attend treatment (n=9, 32 per cent)
- We were given support for practical problems (n=9, 32 per cent)
- Tests, procedures, treatment and/or follow-up were arranged by the CNC (n=7, 19 per cent)
- We were given help to find where we had to go or who we had to see at each hospital (n=6, 18 per cent)

Table 23: Agreement with practical support provided by CNC (n,%)

Statement	Agree	Neither agree nor disagree	Disagree
Tests, procedures, treatment and/or follow-up were arranged by the CNC	25(69.4)	4(11.1)	7(19.4)
The CNC helped coordinate doctors and services when we went to another hospital	18(64.3)	6(21.4)	4(14.3)
We were provided with assistance or information for the Patient Assistance Transport Scheme (PATS)	21(63.6)	5(15.2)	7(21.2)
I was given support for non-health related problems that impacted on the cancer or treatment	23(60.5)	6(15.8)	9(23.7)
Transport or accommodation was arranged so that the patient could attend treatment	13(46.4)	6(21.4)	9(32.1)
We were given support for practical problems	11(39.3)	8(28.6)	9(32.1)
We were given help to find where we had to go or who we had to see at each hospital	25(75.8)	2(6.1)	6(18.2)

* Missing data, (n=28-38; n, %)

Finding: Carers required more practical support for issues related to patient treatment and follow-up care.

Provision of general support by CNCs (Table 24)

A large proportion of carers agreed the CNC was an important part of their treatment team (n=33, 80 per cent) and felt the help provided by the CNC made their cancer journey easier (n=33, 78 per cent). A moderate proportion of carers disagreed the patient's cancer treatment went smoothly at each stage (n=11, 26 per cent).

Table 24: Agreement with general support provided by CNC (n, %)

Statement	Agree	Neither agree nor disagree	Disagree
The cancer treatment went smoothly at each stage	29(67.4)	3(7.0)	11(25.6)
The CNC was an important part of the treatment team	33(80.5)	2(4.9)	6(14.6)
Overall, the help provided made the cancer journey easier	33(78.6)	4(9.5)	5(11.9)

* Missing data, (n=40-43)

Finding: Carers agreed that CNCs were an important part of the patient's treatment team.

Finding: Carers agreed that CNCs made the cancer journey easier.

Finding: A moderate proportion of carers did not believe the patient's journey went smoothly.

Level of support and needs met by CNCs (Table 25)

The majority of carers were satisfied with the level of support provided by the CNC (n=34, 85 per cent). 19 per cent of carers (n=7) had needs that were not addressed by CNCs. Carers who were not satisfied with the level of support provided by the CNC stated (n=4 metro, n=2 rural): when CNC was unavailable there was no other advisor to contact; they were unable to reach the patient's CNC; both the patient and carer need a lot more emotional and physical support right from the start. Those carers whose needs were not addressed (n=5 metro, n=2 rural) felt it took too long to become aware of the CNC, few alternatives for advice were given, they were not aware of all the services provided by the CNC and they were not provided with enough information.

Table 25: Satisfaction of carers with level of support and needs met by patients by region (n, %)

Statement	Metro n=25	Rural n=13	Total n=38
Satisfied with level of support provided (n=40)	23(85.2)	11(84.6)	34(85.0)
Have needs that were not addressed by CNC (n=36)	5(20.0)	2(18.2)	7(19.4)

Missing data, (n=38)

Finding: Carers reported they were satisfied with the overall level of support provided.

Most valuable aspects of care or support provided by CNCs (Table 26)

The provision of practical support (91 per cent, n=31), emotional support (62 per cent, n=21) and being contactable or available (24 per cent, n=8) were considered the most valuable aspects of care or support provided by CNCs. A greater proportion of metro carers valued the CNC being approachable, contactable and available compared to rural carers while a greater proportion of rural carers valued the provision of information, emotional support and practical support than metro carers.

Table 26: Most valued aspects of care or support provided by CNC by region (n, %)*

Statement	Metro (n=24)	Rural (n=10)	Total (n=34)
Practical support	21(87.5)	10(100.0)	31(91.2)
Providing information	15(62.5)	8(80.0)	23(67.6)
Emotional support, care, reassurance, understanding, listening	14(58.3)	7(70.0)	21(61.8)
Contactable/available	8(33.3)	0(0.0)	8(23.5)
Personal contact	4(16.7)	1(10.0)	5(14.7)
Approachable	3(12.5)	0(0.0)	3(8.8)

* Multiple responses allowed
Missing data, (n=34)

Finding: Aspects of care most valued by carers were information provision, emotional and practical support.

Carers were also asked to comment on aspects of the care or support provided by the CNC they did not consider valuable. Of the 23 carers who answered this question, 13 (57 per cent) commented all aspects were valued.

Carer suggestions for role improvement:

- improving availability of CNCs
- increased doctor liaison
- more contact initiated by CNC.

Key findings

1. A large proportion of carers would have preferred contact with the CNC earlier in the patient's cancer journey.
2. Carers required assistance to develop communication skills to facilitate open communication with doctors.
3. Carers required contact from CNCs when patient care issues arose.
4. Carers' family and friends required access to emotional support and counselling services.
5. Carers required assistance to avoid carer "burnout".
6. Carers required more practical support for issues related to patient treatment and follow-up care.
7. Carers agreed that CNCs were an important part of the patient's treatment team.
8. Carers agreed that CNCs made the cancer journey easier.
9. A moderate proportion of carers did not believe the patient's journey went smoothly.
10. Carers reported they were satisfied with the overall level of support provided.
11. Aspects of care most valued by carers were information provision, emotional and practical support.

Recommendations

1. The Network should develop strategies to facilitate open communication between carers and healthcare professionals.
2. The CNC Service should develop mechanisms to facilitate timely communication with carers.
3. The CNC Service should develop strategies to improve access to psychosocial support and counselling services for patients, carers, family and friends.
4. The CNC Service should develop mechanisms to improve the level of practical support provided to carers when dealing with patients' treatment and follow-up care.
5. The Network service should develop mechanisms to improve the level of practical support provided to carers when dealing with patients' treatment and follow-up care.

CONCLUSION

Findings from this study confirm the value and need for the continuation and growth of the Western Australian Cancer Nurse Coordination Service. Importantly, the Cancer Nurse Coordinator role has been shown to fulfil the core elements of the specialist cancer role: clinical expert, resource consultant, educator, change agent, researcher and advocate. Importantly, the CNC role is valued by patients, carers and healthcare professionals as the pivotal and central contact throughout the continuum of the patient's cancer journey.

The CNC Service was implemented in 2006 as a key element of the WA Cancer and Palliative Care Network to ensure an integrated approach to cancer care and delivery in WA. At the time of implementation of the CNC Service, there was scant anecdotal evidence from other countries that suggested cancer care coordinators can improve patient experiences of the care process. This evidence was based on the premise that care coordination improved and streamlined care pathways and referrals, improved information transfer between healthcare professionals and patients, and developed relationships based on understanding and trust. The notable lack of evidence to support the efficacy and justification of the CNC service in WA, the first nurse-led service of its kind in Australia, provided the justification for this study. Of note, while cancer coordination models exist in other Australian states, the WA model is the only state-wide and nurse-led service.

Use of surveys to collect quantitative and qualitative data was a strength of this study because it ensured accurate data collection, minimising the risk of incomplete data. At the time of evaluation, the CNC service had been in progress for several months. While this limited the level of enquiry to a descriptive study, we were able to evaluate the CNC role from the perspective of patients, carers, healthcare professionals and CNCs themselves.

Our study provides the first empirical evidence to demonstrate that patients who received care from a CNC experienced a more coordinated patient journey. Healthcare professionals in this study viewed the CNC role as being a focal point of contact throughout the patient care trajectory; coordinating all aspects of patient care; providing patient education and information; and being reliable and accountable. Findings from patients and carers confirmed these attributes and reported high levels of satisfaction with the provision of information, emotional and practical support. Further, these aspects of care were most valued. Importantly, findings showed the CNC role has evolved considerably since its introduction and has resulted in a number of significant innovations in care and strategic systemic improvements.

We have also identified key areas for role and system development that will potentially lead to further streamlining of WA cancer services and improved outcomes for patients, carers and families. This includes the need for appropriate survivorship models of care. Further research is recommended to explore the outcomes of patients who have not had access to CNC care, and the development of patient-sensitive health outcomes that can be used to further measure the impact of the CNC and cancer nursing roles.



Recommendations

1. The Western Australian Cancer Nurse Coordination team should continue and be provided with appropriate resources to grow and continue to meet the cancer population needs.
2. The WA Cancer and Palliative Care Network should maintain the role of cancer nurse to support the CNC service and explore opportunities to increase availability as required.

KEY STUDY FINDINGS

CNC data

1. CNCs are experienced nurses with significant cancer nursing experience and tertiary education qualifications.
2. Utilisation of CNCs in metro and rural regions has resulted in a high workload which is inequitable.
3. CNCs spent 70 per cent of time on clinical consultation and 30 per cent on administrative and strategic tasks.
4. Most referrals arose from within the CNC team, physicians and other medical staff, or MDT meetings.
5. At referral at least 50 per cent of patients have complex psychosocial needs and a moderate level of function status.
6. CNCs performed a large number and a broad range of tasks.
7. Tasks related to direct nursing care and patient education were performed most frequently on a daily basis.
8. Tasks related to care management planning; patient advocacy; multidisciplinary clinical care; and multidisciplinary team meetings were conducted weekly.
9. Strategic, team communication and professional development activities were performed less frequently.
10. Implementation of the cancer nurse role has resulted in a reduction of CNC clinical workload and increased time for strategic activities.
11. CNCs have a clinically significant impact on patient care, particularly related to advocacy and meeting patients' informational and psychosocial needs.
12. CNCs are experts in cancer care, and the pivotal/central contact throughout the continuum of the cancer patient journey.
13. CNCs have developed the role to strategically complement existing services.
14. Large clinical and administrative workloads impact on CNCs' ability to undertake more strategic initiatives.
15. CNCs are fulfilling the core components of the specialist cancer nurse: clinical expert, resource consultant, educator, change agent, researcher and advocate.

MDT data

16. Healthcare professionals agreed that all patients benefit from the CNC Service.
17. Healthcare professionals agreed that patients who had seen a CNC experience a more coordinated cancer journey.
18. Healthcare professionals viewed the key functions of the CNC role as: being a focal point of contact throughout the patient care trajectory; coordinating all aspects of patient care; providing patient education and information; and accountability.
19. There was variation in healthcare professionals' understanding about the scope of the CNC role.
20. Healthcare professionals who had regular contact with CNCs have a greater awareness of the CNC role.
21. The majority of healthcare professionals had at least weekly contact with a CNC.
22. Case load, funding and resources were considered the main barriers to impact on the CNC role by healthcare professionals.
23. Healthcare professionals recommended increasing the availability of CNCs.

Patient data

24. A moderate proportion of patients would have preferred contact with the CNC earlier in the cancer journey.
25. Patients reported high satisfaction with CNC services related to communication and information.
26. Carers, family and friends required access to emotional support.
27. Patients required assistance to access counselling services.
28. Patients reported their journey went smoothly and the CNC was an important part of the treatment team.
29. Patients reported they were satisfied with the overall level of support provided.
30. Aspects of care most valued by patients were provision of information, emotional and practical support.
31. Patients recommended more face-to-face contact and increased availability of CNCs.
32. There was variation in patients' understanding about the scope of the CNC role.
33. Patients required ongoing care following treatment completion.

Carer data

34. A large proportion of carers would have preferred contact with the CNC earlier in the cancer journey.
35. Carers required assistance to develop communication skills to facilitate open communication with doctors.
36. Carers required contact from CNCs when patient care issues arise.
37. Carers' family and friends required access to emotional support and counselling services.
38. Carers required assistance to avoid carer "burnout".
39. Carers required more practical support for issues related to patient treatment and follow-up care.
40. Carers agreed that CNCs were an important part of the patient's treatment team.
41. Carers agreed that CNCs made the cancer journey easier.
42. A large proportion of carers did not believe the patient's journey went smoothly.
43. Carers reported they were satisfied with the overall level of support provided.
44. Aspects of care most valued by carers were information provision, emotional and practical support.

RECOMMENDATIONS

A. Organisational framework: Western Australian Cancer and Palliative Care Network

1. The Western Australian Cancer Nurse Coordination team should continue and be provided with appropriate resources to grow and continue to meet the cancer population needs.
2. The Network should maintain the role of cancer nurse to support the CNC Service and explore opportunities to increase availability as required.
3. The Network should develop appropriate survivorship care models.

B. Resources and systems: Western Australian Cancer and Palliative Care Network

1. The Network should secure more resources to increase access to care coordination and psychosocial care for future patients and carers by increasing numbers of CNCs to meet the demand.
2. The Network should explore opportunities to delegate non-coordination activities to administrative staff.
3. The Network should develop strategies to facilitate open communication between carers and healthcare professionals.
4. The Network should develop mechanisms to improve the level of practical support provided to carers when dealing with patients' treatment and follow-up care.

C. Cancer Nurse Coordination Service

1. The CNC Service should develop strategies to enable earlier referral and contact with patients.
2. The CNC Service should develop strategies to improve access to psychosocial support and counselling services for patients, carers, family and friends.
3. The CNC Service should develop mechanisms to facilitate timely communication with carers.

REFERENCES

1. WA Health Clinical Services Framework 2005 – 2015. Perth: Department of Health Western Australia.
2. Clinical Oncological Society of Australia, The Cancer Council Australia and the National Cancer Control Initiative 2002: Optimising Cancer Care in Australia. National Cancer Control Initiative, Melbourne, 1–122.
3. Goodwin JS, Satish S, Anderson ET, et al. Effect of nurse case management on the treatment of older women with breast cancer. *Journal of the American Geriatric Society*. 2003; 51(9):1252-9.
4. Australian Bureau of Statistics. 3101.0 - Australian Demographic Statistics, Sept 2010. Available from <http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0>. Accessed 16 May 2011.
5. Economic Roundup Spring 2007. Canberra: Labour eHerald; 2008 [updated 2008; cited 2008 06/03/2008]; Available from: http://www.treasury.gov.au/documents/1329/HTML/docshell.asp?URL=09_Key_themes_from_the_TreasuryBusiness_Liaison_Programme_-_October_2007.asp. Accessed 16 May 2011.
6. Cancer Nurses Society of Australia. Position Statement for Cancer Care Coordinators. March 2008.
7. Yates P. Achieving coordinated cancer care: report on the Clinical Oncological Society of Australia Care Coordination Workshop. *Cancer Forum*. 2007; 31(3): 169-72.
8. Krishnasamy M, Dolence A, McMillan R. Evaluation of the Nurse Coordinator Role at Peter MacCallum Cancer Centre. Melbourne: Peter MacCallum Cancer Centre; 2009 Contract No.: Document Number].
9. Seek A, Hogle W. Modelling a better way: Navigating the healthcare system for patients with lung cancer. *Clinical Journal of Oncology Nursing*. 2007; 11(1):81-5.
10. Abdallah L, Fawcett J, Kane RL, Dick K, Chen J. Development and psychometric testing of the EverCare Nurse Practitioner Role and Activity Scale (ENPRAS) *Journal of the American Academy of Nurse Practitioners*. 2005; 17(1):21-6.
11. Abernethy AP, Shelby-James T, Fazekas BS, Woods D, Currow DC. The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice. *BMC Palliative Care*. 2005; 4:7.

APPENDICES

Appendix 1: Background of healthcare professionals by region and attendance at MDT meetings

Discipline	Attended metro MDT meetings only (n=80)	Attended rural MDT meetings only (n=28)	Attended Metro and rural MDT meetings (n=3)	Did not attend MDT meetings (n=37)	Total (N=148)
Physicians					
Haematologist	1(50.0)	0(0.0)	1(50.0)	0(0.0)	2(1.4)
Medical Oncologists	11(91.7)	0(0.0)	1(8.3)	0(0.0)	12(8.1)
Radiation Oncologists	5(83.3)	0(0.0)	1(16.7)	0(0.0)	6(4.0)
Surgeons	21(95.5)	1(4.5)	0(0.0)	0(0.0)	22(14.9)
Nurses	15(29.4)	15(29.4)	0(0.0)	21(41.2)	51(34.5)
Allied Health	14(48.3)	10(34.5)	0(0.0)	5(17.2)	29(19.6)
Other	13(50.0)	2(7.7)	0(0.0)	11(42.3)	26(17.6)
Length of time working in cancer care					
less than 1 year	4(57.1)	3(42.9)	0(0.0)	0(0.0)	7(4.7)
1-5 years	23(62.2)	8(21.6)	0(0.0)	6(16.2)	37(25.0)
6-10 years	10(40.0)	9(36.0)	0(0.0)	6(24.0)	25(16.9)
more than 10 years	40(62.5)	6(9.4)	3(4.7)	15(23.4)	64(43.2)
I don't usually work with cancer patients	3(20.0)	2(13.3)	0(0.0)	10(66.7)	15(10.1)
Frequency of contact with CNC					
Several times a day	7(41.2)	6(35.3)	0(0.0)	4(23.5)	17(11.5)
Several times a week	31(62.0)	11(22.0)	2(4.0)	6(12.0)	50(33.8)
Weekly	25(75.8)	3(9.1)	1(3.0)	4(12.1)	33(22.3)
Fortnightly	6(75.0)	1(12.5)	0(0.0)	1(12.5)	8(5.4)
Monthly	5(33.3)	3(20.0)	0(0.0)	7(46.7)	15(10.1)
Less frequently	6(24.0)	4(16.0)	3(0.0)	15(60.0)	25(16.9)
Patients who have seen a CNC experience a more coordinated cancer journey					
Agree	63(78.8)	23(82.1)	1(33.3)	31(83.8)	118(79.7)
Disagree	8(10.0)	1(3.6)	2(66.6)	2(5.4)	13(8.8)
Unsure	9(11.2)	4(14.3)	0(0.0)	4(10.8)	17(11.5)

Appendix 2: MDT meetings frequently attended by healthcare professionals (N=148)

Meetings attended*	Fremantle	King Edward	Royal Perth	Sir Charles Gairdner	Other Metro Area	Rural Area
Breast (n=27)	0(0.0)	0(0.0)	4(14.8)	7(25.9)	5(18.5)	11(40.7)
Colorectal (n=34)	9(26.5)	0(0.0)	11(32.4)	7(20.6)	5(14.7)	2(5.9)
Gynaecology (n=12)	0(0.0)	9(75.0)	0(0.0)	0(0.0)	0(0.0)	3(25.0)
Head & Neck (n=21)	4(19.0)	0(0.0)	4(19.0)	9(42.9)	0(0.0)	4(19.0)
Lung (n=25)	4(16.0)	0(0.0)	6(24.0)	10(40.0)	2(8.0)	3(12.0)
Lymphoma (n=12)	3(25.0)	0(0.0)	5(41.7)	2(16.7)	1 (8.3)	1(8.3)
Upper GI (n=19)	4(22.2)	0(0.0)	4(22.2)	9(33.3)	0(0.0)	2(11.1)
Urology (n=9)	2(22.2)	0(0.0)	1(11.1)	3(33.1)	1(11.1)	2(22.2)
Melanoma (n=6)	0(0.0)	0(0.0)	0(0.0)	2(33.3)	2(33.3)	2(33.3)
Neuro-oncology (n=8)	0(0.0)	0(0.0)	0(0.0)	6(75.0)	0(0.0)	2(25.0)
Paediatric (n=1)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	1(100.0)
Sarcoma (n=1)	0(0.0)	0(0.0)	0(0.0)	1(100.0)	0(0.0)	0(0.0)
Rural MDT (n=9)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	9(100.0)
Local Cancer Link Meeting (n=15)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	15(100.0)
Regional Cancer Link Meeting (n=12)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	0(0.0)	12(100.0)
Other (n=12)	3(25.0)	0(0.0)	2(16.7)	6(50.0)	0(0.0)	1(8.3)

* multiple responses allowed

Appendix 3: Awareness of CNC tasks of healthcare professionals by discipline (n=148)

Task	Surgeons (n=22)	Medical (n=20)	Nurses (n=51)	Allied Health (n=29)	Other (n=26)	Total (N=148)
Collaborates with doctors	21(95.5)	19(95.0)	47(92.2)	27(93.1)	25(96.2)	139(93.9)
Collaborates with other healthcare professionals	20(90.9)	18(90.0)	46(90.2)	29(100.0)	25(96.2)	138(93.2)
Receives contact from carers when issues/ concerns arise	20(90.9)	16(80.0)	43(84.3)	25(86.2)	22(84.6)	126(85.1)
Receives contact from patients when issues/ concerns arise	20(90.9)	16(80.0)	43(84.3)	27(93.1)	21(80.8)	127(85.8)
Collaborates with doctor re changes in patient's condition	19(86.4)	17(85.0)	40(78.4)	22(75.9)	23(88.5)	121(81.8)
Conducts patient assessments	11(50.0)	10(50.0)	29(56.9)	22(75.9)	14(53.8)	86(58.1)
Educates patients about appropriate HCP to contact if issues arise	19(86.4)	15(75.0)	42(82.4)	27(93.1)	23(88.5)	126(85.1)
Provides patients with education about diagnosis and symptoms	20(90.9)	18(90.0)	40(78.4)	27(93.1)	23(88.5)	128(86.5)
Provides patients with education about treatment and side effects	16(72.7)	14(70.0)	36(70.6)	27(93.1)	23(88.5)	116(78.4)
Helps patients manage symptoms and side effects	10(45.5)	8(40.0)	32(62.7)	23(79.3)	13(50.0)	86(58.1)
Supports the patient's family/carers	19(86.4)	15(75.0)	42(82.4)	24(82.8)	23(88.5)	123(83.1)
Refers patients to relevant services	18(81.8)	14(70.0)	46(90.2)	25(86.2)	24(92.3)	127(85.8)
Arranges patients' appointments and timing of treatments	16(72.7)	15(75.0)	37(72.5)	20(69.0)	20(76.9)	108(73.0)
Arranges transport or accommodation options for patients	9(40.9)	13(65.0)	29(56.9)	13(44.8)	15(57.7)	79(53.4)
Involved in the provision of education for other healthcare professionals	9(40.9)	11(55.0)	34(66.7)	19(65.5)	17(65.4)	90(60.8)
Involved in the implementation of service improvements for the cancer patient population	16(72.7)	10(50.0)	32(62.7)	20(69.0)	15(57.7)	93(62.8)

* multiple responses allowed

Appendix 4: Organisational barriers perceived to impact upon the CNC role by healthcare professionals

Barrier	Several times a day (n=8)	Several times a week (n=16)	Weekly (n=10)	Fortnightly (n=3)	Monthly (n=6)	Total (N=51)
Case load	6(75.0)	14(87.5)	5(50.0)	3(100.0)	4(66.7)	32(74.4)
Funding	3(37.5)	10(62.5)	6(60.0)	2(66.7)	1(16.7)	22(51.2)
Resources	5(62.5)	9(56.3)	3(30.0)	2(66.7)	3(50.0)	22(51.2)
Public vs private interface	5(62.5)	7(43.8)	1(10.0)	2(66.7)	1(16.7)	16(37.2)
Geography	3(37.5)	7(43.8)	2(20.0)	0(.0)	2(33.3)	14(32.6)
Organisation behaviour	3(37.5)	6(37.5)	2(20.0)	1(33.3)	2(33.3)	14(32.6)
Organisation environment	6(75.0)	3(18.8)	2(20.0)	1(33.3)	1(16.7)	13(30.2)
Resistance to change	1(12.5)	7(43.8)	1(10.0)	2(66.7)	2(33.3)	13(30.2)
Role definition	2(25.0)	5(31.3)	3(30.0)	1(33.3)	2(33.3)	13(30.2)
Communication	2(25.0)	4(25.0)	4(40.0)	1(33.3)	1(16.7)	12(27.9)
Culture	1(12.5)	2(12.5)	5(50.0)	2(66.7)	0(.0)	10(23.3)
Demographics	2(25.0)	3(18.8)	1(10.0)	1(33.3)	0(.0)	7(16.3)
Duplication of services	1(12.5)	2(12.5)	2(20.0)	0(.0)	2(33.3)	7(16.3)
Medico-legal issues	1(12.5)	0(.0)	0(.0)	1(33.3)	0(.0)	2(4.7)

* Multiple responses allowed

Appendix 5: Patient demographic characteristics according to metro or rural region

Demographic variable	Metro (n=49)	Rural (n=36)	Total (N=85)
Age mean(sd) (n=85)	56.7 (20.6)	60.3 (10.8)	58.3 (17.1)
Gender (n=82)			
Male	28(59.6)	15(42.9)	43(52.4)
Female	19(40.4)	20(57.1)	39(47.6)
Speak English at home (n=81)	45(95.7)	34(100.0)	79(97.5)
Highest level of education (n=82)			
No formal schooling	0(0.0)	0(0.0)	0(0.0)
Primary schooling	2(4.3)	2(5.7)	4(4.9)
Secondary schooling	25(53.2)	18(51.4)	43(52.4)
Trade apprenticeship	6(12.8)	2(5.7)	8(9.8)
TAFE college	9(19.1)	6(17.1)	15(18.3)
University undergraduate	2(4.3)	3(8.6)	5(6.1)
University graduate	3(6.4)	2(5.7)	5(6.1)
Other	0(0.0)	2(5.7)	2(2.4)
Employment (n=81)			
Working full-time	6(13.0)	8(22.9)	14(17.3)
Working part-time	5(10.9)	3(8.6)	8(9.9)
Home duties	3(6.5)	5(14.3)	8(9.9)
Studying	1(2.2)	0(0.0)	1(1.2)
Sick or other leave	3(6.5)	2(5.7)	5(6.2)
Retired	18(39.1)	10(28.6)	28(34.6)
Not employed	6(13.0)	1(2.9)	7(8.6)
Other	4(8.7)	6(17.1)	10(12.3)
Carer (n=77)	12(27.7)	8(25.0)	20(26.0)

Appendix 6: Patient cancer treatments according to location of service

Treatment type	Fremantle	King Edward	Royal Perth	Sir Charles Gairdner	Rural Site	Other Site
Surgery (n=57)	9(15.8)	3(5.3)	12(21.1)	18(31.6)	6(10.5)	9(15.8)
Metro (n=38)	9(23.7)	3(7.9)	7(18.4)	13(34.2)	0(0.0)	6(15.8)
Rural (n=19)	0(0.0)	0(0.0)	5(26.3)	5(26.3)	6(31.6)	3(15.8)
Radiotherapy (n=40)	1(2.5)	0(0.0)	12(30.0)	22(55.0)	0(0.0)	5(12.5)
Metro (n=22)	1(4.5)	0(0.0)	5(22.7)	13(59.1)	0(0.0)	3(13.6)
Rural (n=18)	0(0.0)	0(0.0)	7(38.9)	9(50.0)	0(0.0)	2(11.1)
Chemotherapy (n=60)	10(16.7)	1(1.7)	9(15.0)	21(35.0)	13(21.7)	6(10.0)
Metro (n=33)	8(24.2)	1(3.0)	5(15.2)	14(44.4)	2(6.1)	3(9.1)
Rural (n=27)	2(7.4)	0(0.0)	4(14.8)	7(25.9)	11(40.7)	3(11.1)
Other(n=26)	6(13.6)	1(2.3)	2(4.5)	18(40.9)	11(25.0)	6(13.7)
Metro (n=15)	5(33.3)	1(6.7)	2(13.3)	12(80.0)	3(20.0)	1(6.7)
Rural (n=11)	1(9.1)	0(0.0)	0(0.0)	6(54.5)	8(72.7)	5(45.5)

* Multiple responses allowed

Appendix 7: Carer demographic characteristics by metro or rural regions

Demographic variable	Metro (n=31)	Rural (n=14)	Total (n=45)
Age mean(sd)	54.9 (12.6)	59.9 (8.2)	56.5 (11.6)
Gender			
Male	8(25.8)	6(42.9)	14(31.1)
Female	23(74.2)	8(57.1)	31(68.9)
Speak English at home	31(100.0)	14(100.0)	45(100.0)
Highest level of education			
No formal schooling	0(0.0)	0(0.0)	0(0.0)
Primary schooling	0(0.0)	1(7.1)	1(2.2)
Secondary schooling	12(38.7)	6(42.9)	18(40.0)
Trade apprenticeship	3(9.7)	1(7.1)	4(8.9)
TAFE college	5(16.1)	0(0.0)	5(11.1)
University undergraduate	4(12.9)	2(14.3)	6(13.3)
University postgraduate	6(19.4)	3(21.4)	9(20.0)
Other	1(3.2)	1(7.1)	2(4.4)
Employment			
Working full-time	6(19.4)	3(21.4)	9(20.0)
Working part-time	5(16.1)	2(14.3)	7(15.6)
Carer full-time	3(9.7)	1(7.1)	4(8.9)
Carer part-time	3(9.7)	0(0.0)	3(6.7)
Home duties	3(9.7)	1(7.1)	4(8.9)
Sick or other leave	0(0.0)	2(14.3)	2(4.4)
Retired	8(25.8)	4(28.6)	12(26.7)
Not employed	3(9.7)	0(0.0)	3(6.7)
Other	0(0.0)	1(7.1)	1(2.2)
Carer			
Dependent child	8(25.8)	2(14.3)	10(22.2)
Aged friend/relative	2(6.5)	0(0.0)	2(4.4)
Child/adult with physical/intellectual disability	1(3.2)	0(0.0)	1 (2.2)
Other	2(6.5)	1(7.1)	3(6.7)

Appendix 8: Carer contact with CNC by metro or rural regions (n=45)

Contact variable	Metro (n=31)	Rural (n=14)	Total (n=45)
Timing of initial contact with CNC (n=37)*			
When family member attended first outpatient clinic appointment	18(60.0)	4(57.1)	22(59.5)
During first hospital admission	2(6.7)	1(14.3)	3(8.1)
During subsequent hospital admission	6(20.0)	0(0.0)	6(16.2)
During a course of radiotherapy	0(0.0)	0(0.0)	0(0.0)
During a course of chemotherapy	5 (16.7)	0(0.0)	5(13.5)
When had surgery	1(3.3)	1(14.3)	2(5.4)
When phoned at home	2(6.6)	0(0.0)	2(5.4)
When I phoned them	1(3.3)	0(0.0)	1(2.7)
When sent information	0(0.0)	1(14.3)	1(2.7)
When coming to Perth for treatment	1(3.3)	2(28.6)	3(8.1)
Stage at which contact occurred (n=40)			
At diagnosis	8(27.6)	6(54.5)	14(35.0)
Before first treatment	10(34.5)	2(18.2)	12(30.0)
After first treatment	6(20.7)	1(9.1)	7(17.5)
At a crisis	1(3.4)	2(18.2)	3(7.5)
When cancer returned	4(13.8)	0(0.0)	4(10.0)
Contact wanted earlier in cancer journey (n=37)			
Yes	14(53.8)	4(36.4)	18(48.6)
No	12(46.2)	7(63.6)	19(51.4)
Frequency of contact with CNC (n=36)			
Several times a week	3(12.5)	0(2.9)	3(8.3)
Weekly	3(12.5)	1(8.3)	4(11.1)
Fortnightly	1(4.2)	3(25.0)	4(11.1)
Monthly	4(16.7)	1(8.3)	5(13.9)
Less than monthly	2(8.3)	1(8.3)	3(8.3)
A few times overall	11(45.8)	6(50.0)	17(47.2)
Once only	0(0.0)	0(0.0)	0(0.0)
Type of contact with CNC (n=40)			
Person	28(100.0)	11(91.7)	39(97.5)
Telephone	23(82.1)	10(83.3)	33(82.5)
Email	6(21.4)	0(0.0)	6(15.0)
Other	1(3.6)	0(0.0)	1(2.5)
Contact preference (n=40)			
No preference	8(28.6)	2(16.7)	10(25.0)
Telephone	1(3.6)	2(16.7)	3(7.5)
Email	0(0.0)	0(0.0)	0(0.0)

In person	5(17.9)	5(41.7)	10(25.0)
Combination of telephone, email, in person	16(57.1)	5(41.7)	21(52.5)
Other	0(0.0)	0(0.0)	0(0.0)

* Multiple responses allowed



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