

Development of the Western Australia Cancer Nurse Coordination Service

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Abstract

The cancer care coordinator role is a rapidly emerging one, whose mandate is to achieve some potentially far-reaching reforms to systems of care. To ensure these developments realise their potential, it is timely to consider the most effective ways to design and implement models of care coordination that achieve the improvements being sought for the Australian cancer care system¹. The *National service improvement framework for cancer* delivered 19 critical intervention points, one of which addressed coordination of care. This recommended that people with cancer have a designated coordinator of care who knows about all aspects of their disease, treatment and support. The care coordinator will help people with cancer move between treatment components, and ensure that they have access to appropriate information and support and that the treatment team is fully aware of a person's preferences and situation². This paper provides an insight into the development of the West Australian Cancer Nurse Coordination Service and a variety of the factors that have been considered and addressed in striving towards improving care coordination. Information about the West Australian health context and components of the role development to date will inform the reader of the complexity associated with this system reform.

Introduction

Australia has a very complex health system – people with cancer often move between the public and private sectors and care must also be provided to people in regional, rural and remote parts of the country³. Therefore, the coordination of cancer care has been high on the strategic health agenda across Australia in recent years.

In 2003, leading Australian cancer organisations concluded that there are many places for the person with cancer to get lost in the system, causing unnecessary morbidity and undue distress; this lack of an integrated care system was identified as a major failing of today's health system³. In response, many States in Australia implemented care coordination services. Yates provided an overview of the planned developments for Queensland, New South Wales and Victoria¹ and, since this time, coordination services have developed in the remaining States.

This paper will outline the development and context that underpins the Western Australian Cancer Nurse Coordination Service.

The Western Australian health system

Western Australia has a rapidly expanding population of 2.1 million and a land mass of 2.55 million km², with a combined regional population of 454,000 people (almost a third of the State's population), including 44,900 Aboriginal people (around 10% of the State's total population). Currently the distribution of cancer services are largely focused in the Perth metropolitan area, although health reforms are driving the development of coordinated health services outside of these central locations. In 2006 there were 9692 new cases of cancer recorded in Western Australia and 3570 deaths due to cancer. The most common cancers were prostate (1635), breast (1244), colorectal (1080), melanoma (1052) and lung (875). The rural cancer incidence was 1966 new cases⁴.

The Western Australian health system comprises four area health services (Figure 1):

- North Metropolitan Health Services.
- South Metropolitan Health Services.
- Women's and Children's Health Services.
- WA Country Health Services, the single biggest area health

service in Western Australia, and the largest country health system in Australia.

WA Health has been undergoing an active period of reform in recent years. The reforms are led by health networks which bring together interested people and organisations, including health professionals, consumers, carers, policy makers and others, to discuss, debate, plan and develop health policy and services across WA. The major functions of health networks are:

- Planning of services based upon community needs.
- Developing innovative healthcare policy.
- Setting meaningful targets and monitoring patient outcomes.
- Promoting efficiency, effectiveness and safety.
- Providing opportunities to develop skills and knowledge, and fostering leadership.
- Helping to set priorities across WA Health⁵.

There are 18 health networks in Western Australia; the Cancer Nurse Coordination Service is based within the WA cancer and palliative care network.

Cancer Nurse Coordination Service: Tumour collaborative groups

Early in its inception, the WA cancer and palliative care network called for interested health professionals from all disciplines working with patients with the main tumour types to form tumour collaborative groups. In the early stages of developing the collaboratives, an orientation service mapping was undertaken by cancer nurse coordinators (CNCs). The findings of these mapping exercises contributed to informing the collaborative groups of priority areas for improvement of services with each patient group.

These groups bring together expert health professionals in a

voluntary capacity, whose collective task is to inform and advise the Network about priorities for clinical reform and service development. The ultimate aim is to improve outcomes and the patient experience for people with those tumours in order to achieve the following goals:

- Defining standards of care and developing evidence-based treatment guidelines.
- Improving survival and other defined outcomes for the specified tumours or population groups.
- Providing a resource for appropriate management of specific tumours⁶.

Each of the 15 collaboratives that have been developed comprise a lead medical clinician with expertise in the specific tumour group, the relevant tumour-specific CNC, a tumour collaborative officer (TCO) providing administrative and organisational support, and representatives from various specialist and allied health disciplines, across sectors and area health services. Many of the collaborative groups have also integrated consumer participation within these groups.

Whilst the composition, function and priorities of each of the collaborative groups differs, the role of the CNC within each group is to provide a holistic and patient focus to the clinical aspects of the group's priorities and to inform the collaborative members of the issues and priorities from the patient's perspective. Within many of the collaborative groups, the CNC plays a key role in achieving some of the identified goals and is a key participant in determining reform priorities.

Cancer Nurse Coordination Service: The CNC teams

The CNC teams working within these collaboratives form a central part of the WA cancer and palliative care network. The Director of Nursing of WA cancer and palliative care network provides leadership for these teams.

The CNC roles were developed to complement existing health services. The comprehensive orientation mapping undertaken in the early phases was used to reduce boundary issues and enable communication and negotiation to resolve such issues. To assist with this, during the early stages of service development, the team was supported by a staff development nurse and mentoring programme.

This team comprises 18 CNCs who are considered to be the clinical nurse leaders of cancer care for the State (Table 1). Of these, 11 are situated in the metropolitan area and have tumour-specific roles, with the exception of the paediatric and adolescent CNC whose brief is age-specific, and the rural CNC whose role is to coordinate care for patients visiting from rural areas who have complex coordination needs exacerbated by staying in hostel accommodation whilst undergoing treatment. The remaining seven CNCs have generic cancer nursing roles and are allocated to each of the seven health regions. The

Figure 1. Health divisions of Western Australia.



rural CNC team are the point of contact for all rural cancer patients and health professionals within their region. In the Kimberley and Pilbara regions, the CNCs are the only health professionals within the discipline of cancer based in their respective regions.

The CNC role incorporates clinical expertise, strategic capability, research, resourcing and education. The overall aim of the CNC role is to provide a seamless patient journey for each individual with cancer within the WA public health system. This autonomous and innovative model of nursing was designed to ensure CNCs would not be encumbered with the usual barriers and boundaries of health services and departments often experienced within the State health system. The model was endorsed by the Chief Executive Officers, Executive Directors of Nursing and the Director General of the WA Health Department.

Components of the CNC role

Clinical expert

Highly qualified, experienced and dynamic senior nurses were selected for the CNC roles in order to be able to achieve the necessary outcomes required. Educationally, all have a strong background clinically and academically within oncology nursing, many having previously working in roles as nurse consultants. The nurses have to have up-to-date clinical knowledge within their field of practice across all treatment modalities, and an indepth understanding of treatment options, plans and outcomes. This facilitates continuity of care by ensuring high quality communication with all other members of the healthcare team⁷.

The role requires that patients referred with complex needs are case managed. Case management is a collaborative process

of assessment, planning facilitation and advocacy for options and services. The aim is to meet an individual's health needs through communication and available resources, while at the same time promoting quality, cost-effective outcomes⁸.

The CNC is required to provide expert clinical and psychosocial needs assessment and then facilitate the ongoing management of these individuals by maintaining an overarching view of the patient's journey. The CNC provides the patients with a central point of contact, which in turn enables the CNC to inform and direct patients to services, where appropriate, and also ensure necessary referrals to other service providers⁹.

The CNCs have a primary role as a mentor and an educator. They act as a resource for other health professionals, and enable them to give the detailed explanations of treatment options to patients and relatives to assist the patient to make informed decisions. The CNCs also participate in and lead clinical audit and research. This promotes the integration of evidence into practice by dissemination of specialist knowledge.

A strong leadership component is required of the CNCs in order to facilitate strategic development¹⁰. The CNCs contribute to the development of policy by promoting evidence-based practice relating to the tumour group or area served and the nursing profession as a whole. The CNCs are required to be both innovative and motivated, with an integral part of the role being the ability to problem solve both as individuals and as part of the tumour collaborative team. The CNCs are required to identify issues pertinent to their tumour group or patient caseload and ensure that concerns are addressed and evaluated.

Psychosocial support, intervention and communication

The provision of information and psychosocial support for cancer patients throughout diagnosis, treatment and post-treatment is a fundamental component of the WA CNC role. This component of the role promotes a 'whole of health' approach to cancer care, assessing each patient for their individual needs and providing care coordination that comprises empowerment, effective communication, information and education, timely referrals and access to resources.

An integral aspect of the CNC role is the empowerment of the individual. Cancer treatments are challenging, with patients often being offered a combination of treatments that can be given over extended periods of time. A patient's ability to cope with a diagnosis of cancer and manage the gruelling schedule of treatments and appointments often leads to confusion and anxiety which can have a devastating effect on their quality of life. The lasting effects of these treatments influences the lives of cancer patients and their families, even after treatments are completed and disease is no longer evident, and affecting their ongoing health and normal daily activities.

Effective communication helps to ensure patients receive and understand information about their disease and treatments.

Table 1. The WA CNC team.

Metropolitan CNC roles	Regional CNC roles
Tumour-specific	Generic
Colorectal	Goldfields
Gynae-oncology	Great Southern
Haematology	Kimberley
Head and neck	Mid West
Melanoma	Pilbara
Neuro-oncology	South West
Thoracic	Wheatbelt
Upper GI	
Urology	
Other	
Paediatric and adolescent	
Rural (central coordinator)	

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The CNC provides information at diagnosis that gives them the opportunity to ask questions, allowing them to make informed decisions about their care and helping them to shape the care they will receive. Promoting the individual as a member of the healthcare team reinforces their place in the decision making process and empowers the patient to become actively involved in their own care plan. Having expert knowledge of the many facets of a cancer patient's journey and understanding the impact that poor psychosocial support has on a patient's health means the CNC can provide appropriate and necessary information at the time of diagnosis and throughout their treatment and follow up. Providing patients with information on, and access to, support services, prevents the patient from missing out on services and provides them with a point of contact for information and support. This process aims to limit the patient's experience of any gaps that exist in service provision.

For example, the psychosocial assessment of cancer patients ensures referrals to other allied health services are timely and that patients' support needs are met at appropriate intervals in their treatment schedule. This includes effective communication with primary healthcare teams such as GPs and the rural CNCs, as well as local support services who may have limited access to information or knowledge of the patient's treatment and care.

The psychosocial care of cancer patients also involves a significant educational component, including the promotion of positive health attitudes and lifestyle changes for those patients in at risk groups, as well as the provision of cancer-specific information to patients, their families and the healthcare teams that are involved in their care so that individuals are informed and benefit from knowledgeable healthcare teams in their local areas.

Coordination of care demands an overarching view of the patient's care pathway and its success is dependant on appropriate psychosocial assessment, effective communication and the utilisation of and access to support services.

Linking metropolitan and rural CNCs

In addition to the introduction of a CNC for each of the seven regions within the WA country health service, a CNC (the metropolitan rural CNC) has also been appointed in the WA country health service area office. This role has both clinical and strategic intent and provides a formal link between the WA regions and the tumour collaboratives. The link also provides a resource with regard to the development of appropriate regional cancer service delivery, as well as advocating for regional, rural and remote cancer patients within the metropolitan health services. The role is continuously being refined in response to both community and service providers.

The clinical component of the role involves patient advocacy, complex discharge planning and shared coordination with other CNCs, with a particular focus upon vulnerable groups such as Indigenous patients, the elderly and frail, and those patients socially isolated. These patient groups have increased support needs to navigate the healthcare system and the metropolitan

environment, both of which are alien to them and experienced at a time when they are physically distant from their usual support networks.

Strategically, a key initiative highlighting the potential scope of the metropolitan rural CNC role is the development and implementation of 'virtual family visiting' as a pilot project in collaboration with WA country health service and two tertiary hospital sites. The broad objective of the project is to provide a mechanism whereby regional cancer patients are able to have contact with family members or significant others using videoconference technology during their stay within the metropolitan area for treatment. Following favourable evaluation of this pilot, the scope of the project could be widened to include more hospital sites and has the potential to promote the use of telehealth technology within the clinical setting.

Role implementation

The initial brief for all CNCs upon appointment was to undertake a mapping task to comprehensively scope and review all metropolitan public health services currently providing care for cancer patients within his/her tumour group or region. The primary rationale behind this exercise was to orientate the CNC to their individual services and environments.

Mapping cancer services in WA

Metropolitan cancer services are predominantly delivered in Perth's tertiary hospitals – Sir Charles Gairdner Hospital, Fremantle Hospital, Royal Perth Hospital, King Edward Memorial Hospital for Women and Princess Margaret Hospital for Children. The aim of the mapping exercise was to follow the patient's cancer journey from point of referral onwards to identify the extent of service provision, including good practice as well as gaps in service. The goal was to identify issues that influence the health services' ability to deliver a comprehensive and complete range of care to cancer patients throughout the cancer trajectory.

The mapping process used included the following steps:

- Face to face and telephone interviews with health, allied professions and services involved in the diagnosis, treatment and support of cancer patients.
- Anecdotal comments from patients in various clinical settings.
- Observational data collected in the clinical settings visited.
- A review of supportive care services for specific tumour groups both within and external to the hospital, for example, cancer support groups, screening services.
- A review of professional and educational resources available for nurses working within the designated cancer specialty.

The findings were structured to provide an outline of services provided at each centre or region, as well as a description of the specific roles of health professionals involved in the delivery of care and any specific service delivery gaps.

The mapping process resulted in a number of benefits:

- The identification of specific needs of each group of patients and the challenges they encounter in obtaining appropriate care.
- The provision of a useful forum for the introduction for the role of the CNC and assistance in establishing networks with colleagues.
- The provision of clarity to the role of the CNC.
- The significance of clinical practice was highlighted. It was identified that CNCs would be required to devote a minimum of 0.5FTE to clinical practice, with the remaining time allocated to strategic activity, education and professional development.

Mentoring project

During the initial planning of this service it was recognised that there would be a variety of skill sets both available and required across the CNC team. A successful Commonwealth funding application has provided the resources required to implement a training and development mentoring programme based on the individual needs of each nurse as well as the teams' needs, for example systematic change management strategies.

The programme funds the education and travel between rural and metropolitan locations to raise awareness of specific cancer care delivery issues and to build the network of relationships required to coordinate patient care. A key component of this project is the attention paid to raising awareness of the Aboriginal and Torres Strait Islanders in relation to cancer service provision. This is particularly important as many of the team previously had a very limited knowledge or experience related to this population of patients.

Clinical supervision

Clinical supervision was identified as a key strategy required for support within the nursing team. To date, this has been delivered on an individual monthly basis. Group supervision has been considered but has not been supported by the team at present, although peer support and discussion is essential and ongoing. Financial support for this aspect of the service was factored in at the service foundations. This has proved a valuable support structure for each of the CNCs, enabling confidential debriefing and the development of intervention strategies to improve the coordination experience for all.

Teamwork

Multidisciplinary care (MDC) has been the focus of increasing attention in recent years, with efforts to promote its broad implementation increasing as evidence of its benefits become apparent. MDC relates to a team of various healthcare professionals who use a team approach to agree on a diagnosis and stage of a patient's disease and then decide on the best treatment options and follow up care required for that patient. Various studies support the integrated approach to healthcare and there is evidence to suggest that MDC in cancer reduces mortality and improves quality of life¹¹. MDC that consists of

teams of individuals with specialist skills, who have access to a wide variety of facilities, can significantly improve patient care by not only providing effective, efficient and comprehensive services but by allowing patients to make informed choices¹².

The primary aim of the MDC team meetings is to review diagnostic investigations and pathology, and use a team approach to determining the best management options for individual patients¹³. Within WA, CNCs are becoming integral members of these teams and have been instrumental in the support and development of primary care communication following team meetings and rural meetings via video conferencing.

Conclusion

This paper provides a snapshot of the key developments and domains of the Cancer Nurse Coordination Service in WA. It has been a rewarding and exhausting 18 months integrating a new model of nursing care delivery into the State. The progress to date has been achieved with dedication and professionalism that has maintained the focus of coordinating care of cancer patients.

The next cycle of this service development is to comprehensively evaluate the domains of coordination that these roles are providing within the context of an ever changing health system. Alongside this evaluation, support for CNCs in high volume tumour groups remains a challenge. This issue will be explored as part of a pilot project of cancer coordinator support nursing roles. Networking with cancer coordinators from other Australian States is also of paramount importance to the WA CNC team who are hosting an inaugural Cancer Coordination Conference in Perth in October 2008.

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