Clinical Oncology Society of Australia

Cancer Care Coordinator

Position statement

November 2015

ABOUT COSA

The Clinical Oncology Society of Australia (COSA) is the peak national body representing multidisciplinary health professionals whose work encompasses cancer control and care. COSA members are doctors, nurses, scientists and allied health professionals involved in the clinical care of cancer patients. COSA is affiliated with and provides medical and scientific advice to Cancer Council Australia.

COSA is the only organisation that provides a perspective on cancer control activity in Australia from those who deliver treatment and care services across all disciplines. The benefits of membership include discounted registration to COSA's Annual Scientific Meeting, access to a range of education programs and workshops, Cancer in the News daily email and subscriptions to Cancer Forum and the Asia Pacific Journal of Clinical Oncology. Please visit our website at www.cosa.org.au for more information.

The COSA Cancer Care Coordination Group aims to provide a national approach to planning, implementation and evaluation of Cancer Care Coordinator and cancer care coordination positions and activities in Australia.

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INTRODUCTION

The growing demand for cancer care, increasing complexity of cancer and its treatments, a shrinking workforce, and rising costs, present major challenges to the delivery of cancer care[1]. In this context, effective coordination of care across different clinicians, teams and health services is essential to high-quality cancer care[2]. Consumers consistently identify coordination of care to be a priority issue and an important influence on their cancer experience.[3] Coordination of care has also been identified as a critical element of person-centred care[1] and is an important element of national safety and quality standards for health care services.[4]

Coordination of care is a complex task that requires action at a number of levels and engagement of a wide range of health professionals. The purpose of this document is to outline the position of the Clinical Oncology Society of Australia (COSA) regarding the role of dedicated care coordinator positions, one key strategy that has been implemented in many health services to achieve improved care coordination. Specifically, this paper seeks to provide an overview of the role of cancer care coordinators and to provide guidance for consumers, health professionals, health service managers and funders on the effective integration of these roles into cancer care delivery. For the purposes of this document, we focus on the role of professional care coordinators who perform clinical or health service functions associated with coordination of a person's care. Issues associated with implementation of coordinator roles that involve primarily an administrative function are not addressed in this paper.

IT IS COSA'S POSITION THAT:

- All people affected by cancer require effective care coordination.
- Effective care coordination is an essential element of person-centred care and critical to ensuring optimal cancer outcomes and delivery of high quality and efficient cancer services.
- Effective care coordination involves interventions at many levels, including the health system, health care provider, and individual consumer level.
- Designated care coordinator positions should be implemented within the context of a comprehensive approach to care coordination that includes health system, health care provider and consumer level interventions.
- Care coordinator roles should be implemented following a comprehensive assessment of existing care pathways and service capabilities to inform the way in which the roles will be operationalised. This assessment should be undertaken on a regular basis to ensure care coordinator roles are responsive to new developments in cancer treatments and supportive care, and changing service needs.
- When implementing care coordinator positions, careful consideration should be given to distinguishing between roles that require coordination of a person's clinical care from roles which serve primarily an administrative function.
- Consistent with CNSA's position on the role of cancer care coordinators[5], key elements of the care coordinator role that involves coordination of a person's clinical care and health services include:
    - Assessment and screening for clinical and supportive care needs and people at risk for adverse clinical and psychosocial outcomes

  - Facilitating delivery of cancer care consistent with established evidence based guidelines
  - Ensuring timely and appropriate referral to specialist, allied health and support services
  - Facilitating continuity of care between health professionals and across settings for care delivery
  - Providing timely and consistent education and information to patients and their families
  - Participating in service improvement activities that aim to improve coordination of care and optimise outcomes for individuals and services.
- While no studies are available to confirm the qualifications and experience required for cancer care coordinator roles, the complexity of cancer care coordinator functions requires that cancer care coordinators have sufficient experience, qualifications and capabilities that enable them to perform a broad range of clinical, supportive care and strategic roles in the cancer context.
- A shared understanding of the roles and functions of the care coordinator is required by all involved in the cancer care team, including consumers.
- Referral pathways for access to a care coordinator service should be clearly defined and based on policies and criteria that support the holistic assessment of an individual's needs.
- The effectiveness of care coordinator services should evaluated using indicators that are relevant and sensitive to the specific nature of this care coordination strategy.
- Care coordinators require a supportive professional practice environment and adequate professional development opportunities to enable them to function optimally.
- Ongoing efforts are required to ensure care coordinator roles evolve in response to changing service needs.

COSA CALLS FOR:

- Appropriate resourcing of interventions to improve the coordination of cancer care at all levels, including resourcing for dedicated cancer care coordinator positions and administrative support to enable coordinators to achieve optimal outcomes.
- The development of a national framework for cancer care coordinator positions, which provides guidance for workforce planning in relation to these roles and which describes the experience, qualifications, capabilities, principles, role responsibilities, expected outcomes and key performance indicators for these positions. This framework should be flexible to accommodate local circumstances and clearly define minimum standards associated with implementation of the roles to minimise unacceptable variation.
- Application of the Oncology Nursing Society Nurse Navigator Core Competencies[6] and/or the Canadian practice framework for Nurse Navigators[7] to inform the design, implementation and evaluation of care coordinator roles (in the absence of an Australian Framework).

- Ongoing efforts to ensure care coordination is a major priority for health services and embedded as part of standard practice.
- The development of a systematic process where indicators of effective care coordination are routinely incorporated into cancer data systems and used to drive service improvements.

BACKGROUND

Locating care coordinator interventions in the context of a multilevel approach to care coordination
A range of interventions at the system, service, team and individual patient level are important to improve coordination of care[8] (see Table 1). There is widespread agreement that coordination of care is not the responsibility of an individual health professional, but rather requires action at a number of levels and is a responsibility of all health professionals.

Table 1: Levels of care coordination interventions and associated outcomes (Adapted from the COSA Cancer Care Coordination Workshop 2008[8]).

Level	Potential outcomes	Example Cancer Care Coordination Interventions
Patient level	Every patient aware of their pathway of care Time from diagnosis to treatment is appropriate The patient experience is positive	Patient involvement/needs accounted for within individualised care planning Referral pathways utilised
Health services/teams/ networks level	A clear pathway is defined for each patient, information moves with patient through system Effective multidisciplinary team relevant to each cancer Transfer points are well managed across networks and sectors	Documented care pathways including providing team member education on same Multidisciplinary teamwork including meetings and case conferences
Funder/system level	More patients cared for by an effective multidisciplinary team Patients receive appropriate treatment Knowledge of/access to primary care and other services is improved Variation and duplication of service provision is reduced	Treatments received in an efficient manner through coordination of appointments Multidisciplinary teams and information and knowledge-sharing reduce duplication of service

While a range of interventions involving several members of the multidisciplinary team exist to improve coordination of care, dedicated nurse navigator, case manager, cancer nurse coordinator or cancer care coordinator positions have been implemented in many countries as one strategy to improve coordination of care. The literature also distinguishes between professional and lay navigators in cancer care.[6,9] In the Australian context, the term cancer care coordinator is the most commonly used term for professionals involved in dedicated care coordination roles. The use of lay navigators has not received significant attention in Australia to date. It is also important to distinguish care coordinator roles that involve coordination of a person's clinical care and service delivery from other coordinator roles which serve primarily an administrative function. For the purposes of this

document, we therefore focus on the role of professional care coordinators only who perform clinical or health service functions associated with coordination of a person's care. While the role is predominantly filled by nurses in the Australian context, we use the term cancer care coordinator to refer to health professionals appointed to a role specifically focused on improving coordination of a person's clinical care and service delivery.

DEFINING CARE COORDINATOR ROLES AND FUNCTIONS

Issues associated with defining coordinator roles

There is notable variation between and within countries with regard to the scope and function of the cancer care coordinator role. Moreover, the literature highlights that while care coordinator functions have a strong focus on coordination activities, other functions of the care coordinator are shared by a number of other health professionals (e.g. needs assessment, communication, information and education). The shared responsibilities of various health professionals in the cancer care team in relation to coordination confirm that there are generic coordination capabilities that apply to all health professionals. Dedicated care coordinators distinguish themselves from other members of the cancer care team, as the primary focus of their role is as a facilitator responsible for implementation of care coordination interventions in the context of multidisciplinary team efforts to achieve care coordination.

In developing their competency standards for Oncology Nurse Navigators in the US, the Oncology Nursing Society[6] highlighted a number of additional challenges associated with defining roles and functions that are similar to those faced in Australia, including that:

- nurses enter the role with diverse clinical experiences and educational preparations, leading to variability in the skills and knowledge brought into the role
- oncology nurse navigators operate differently across geographic and institutional settings, i.e. some specialise in one type of malignancy, whereas others function in more of an oncology generalist role
- those who practice in larger centres with access to significant resources (e.g. a wider range of health care providers, community and institutional support programs) function quite differently to those in smaller rural settings
- orientation and development of oncology nurse navigators is not standardised and in many cases, the oncology nurse navigator must learn on the job and can have difficulty locating resources to meet their learning needs.

Care coordinator roles are also likely to evolve over time in response to changes in the health care system and technological advances.

The Australian Experience

In Australia, the Cancer Nurses Society of Australia developed a Position Statement[5] which identified functions of the care coordinator as including:

- Assessment and screening for clinical and supportive care needs and patients at risk for adverse clinical and psychosocial outcomes
- Facilitating delivery of cancer care consistent with established evidence based guidelines

- Ensuring prompt referral to specialist, allied health and support services
- Facilitating continuity of care between health professionals and across settings for care delivery
- Providing timely and consistent education and information to patients and their families.

There are three major reports describing the role of cancer care coordinators in Australia[10-12]. These reports identified that cancer care coordinators performed a diverse range of functions at patient, team and clinical, and system level. While the reports demonstrate significant variation in the extent to which care coordinators perform these various functions, some activities were more commonly reported. At the patient level of influence, common cancer care coordinator activities included undertaking comprehensive assessment and screening of cancer patients for clinical, psychosocial and supportive care needs, facilitating delivery of cancer care consistent with evidence based guidelines and ensuring prompt referral to specialist, allied health and supportive care services. Within the context of a multidisciplinary team, common cancer care coordinator activities included actively facilitating multidisciplinary care to maximise patient outcomes and acting as a liaison between people affected by cancer and members of the health care team, facilitating continuity of care across different settings by establishing clear referral pathways, and timely communication.

Many care coordinators also described functions including clinical leadership, mentoring, practice development and standard setting. At the system level, common cancer care coordinator activities included implementing quality improvement initiatives that drive patient focused care across whole systems. Some coordinators also described facilitating access to clinical trials. Importantly, the implementation of the role varies considerably, depending on a range of factors including case loads, service profile, and service capacity. For example, Australian care coordinators can have a case load that is tumour specific, or they can have a case load comprising individuals with various cancer types. Differing levels of supportive care within hospitals currently exist. The role can also be shared by a number of health care providers who perform different care coordinator functions.

The US Experience

In the US, the Oncology Nursing Society[6] defines an oncology nurse navigator as being a professional registered nurse with oncology-specific clinical knowledge who offers individualised assistance to patients, families, and caregivers to help overcome healthcare system barriers. The ONS definition specifies:

> *Utilizing the nursing process, an oncology nurse navigator provides education and resources to facilitate informed decision making and timely access to quality health and psychosocial care throughout all phases of the cancer continuum. The oncology nurse navigator demonstrates critical thinking and uses the nursing process to assess and meet the needs of patients by providing care coordination throughout the cancer continuum. He or she works between the domains of the patient and family unit and the healthcare delivery system to improve health, treatment, or end-of-life outcomes.*

The ONS project team identified four categories of knowledge base and function that underpinned oncology nurse navigator work, including:

1. Professional role: demonstrates professionalism within both the workplace and community through respectful interactions and effective teamwork. He or she works to promote and advance the role of the oncology nurse navigator and takes responsibility to pursue personal professional growth and development.
2. Education: facilitates the appropriate and efficient delivery of healthcare services, both within and across systems, to promote optimal outcomes while delivering patient-centred care.
3. Coordination of care: provides appropriate and timely education to patients, families, and caregivers to facilitate understanding and support informed decision making.
4. Communication: demonstrates interpersonal communication skills that enable exchange of ideas and information effectively with patients, families, and colleagues at all levels. This includes writing, speaking, and listening skills.

Within each of these categories, the ONS team developed detailed competency statements to assist with describing a standard of practice that could be expected of those performing these roles. For example, in the coordination of care category, some examples of competencies included:

- Assesses patient needs upon initial encounter and periodically throughout navigation, matching unmet needs with appropriate services and referrals and support services, such as dietitians, [other service] providers, social work, and financial services
- Identifies potential and realized barriers to care (e.g. transportation, child care, elder care, housing, language, culture, literacy, role disparity, psychosocial, employment, financial, insurance) and facilitates referrals as appropriate to mitigate barriers
- Facilitates timely scheduling of appointments, diagnostic testing, and procedures to expedite the plan of care and to promote continuity of care
- Participates in coordination of the plan of care with the multidisciplinary team, promoting timely follow-up on treatment and supportive care recommendations
- Supports a smooth transition of patients from active treatment into survivorship or end-of-life care.

The Canadian Experience

In Canada, a Professional Navigation Framework[13] has been developed. This bi-dimensional framework consists of two dimensions and six concepts. These include:

1. continuity of care, incorporating information, management, and relational continuity and a set of organizational functions
2. patient empowerment, incorporating active coping, cancer self management, and social support.

In this framework, informational continuity involves facilitating a collaborative approach by helping the patient/family and the health professionals to work as a team. Management continuity involves facilitating a coordinated approach by using assessment skills to identify and address changing health and supportive care needs throughout the cancer continuum.

A collaborative group subsequently identified specific areas of competency that mapped against these dimensions of practice.[7] These competencies included:

- Providing information and education
- Providing emotional and supportive care
- Facilitating coordination of services and continuity of care within the context of an interdisciplinary team approach.

EVIDENCE RELATING TO CARE COORDINATOR INTERVENTIONS

A recent systematic review of 76 articles (reporting on 60 studies) examined the impact of care coordinator interventions on ten patient-reported outcomes, two family-reported outcomes, two clinician, coordinator or other staff-reported outcomes, and nine health service outcomes.[14] The review concluded that there was some evidence that coordinator interventions had an effect on three patient-reported outcomes: psychological morbidity (specifically uncertainty; no effect was shown on depression, anxiety or mood); satisfaction with care; and satisfaction with the coordinator. The majority of health professionals in each study perceived coordinator interventions to be beneficial. The impacts of the coordinator intervention were most evident with regard to health service outcomes. There is some evidence that coordinator intervention patients have a reduced likelihood of hospital admissions (and possibly fewer admissions, if admitted); reduced likelihood of emergency department visits; reduced delays in periods prior to the start of treatment, and during treatment; and that they are more adherent to follow-up after an abnormal screening finding. Some studies indicate that services also experience improved patient volume or retention after implementation of a coordinator intervention, although data for this outcome were of poor quality.

There are, however, a number of limitations in research in this field. The majority of studies used non-randomised designs, which means it is difficult to attribute any results to the care coordinator intervention. A number of studies provided inadequate details to allow assessment of the risk of bias of the studies. There was also a lack of detailed information regarding the elements of the interventions used within a number of studies. For some studies, basic information such as the characteristics of the person(s) providing the coordinator intervention (for example, a nurse, other health professional or a lay person), the activities conducted to coordinate care (i.e. what the coordinator actually did), and the period of the care coordinator intervention was not provided. Moreover, differences in quality of life in cancer patients, at least over the short time frame of most studies, may be evident later in the course of a person's disease. With two thirds of the evidence presented in this review being Level III-3 or IV, and a further 16% Level III-2, there is a need for further higher-level explorations into this area. The large variation that was evident across all aspects of the included studies (populations, settings, interventionists, and intervention components) led to difficulties in discerning the essential elements and implications of the cancer care coordinator role to provide conclusions regarding the effectiveness of care coordinator interventions. In particular, the review was not able to determine if the care coordinator's professional background or the setting of the intervention influences effectiveness, or to identify the elements most essential to improving patient outcomes.

ENABLERS AND BARRIERS TO IMPLEMENTATION OF CARE COORDINATOR INTERVENTIONS

In the Victorian Cancer Council systematic review described above[14], eleven studies were identified that examined the factors enabling or inhibiting integration of the cancer care coordinator role within standard care. Three main barriers to the implementation of the care coordinator role were identified: poor communication about the care coordinator role, and the resultant lack of understanding and/or trust in the care coordinator; role confusion and clarity issues; and limitations on the availability of a variety of resources considered necessary for the programs. The identified enablers to the integration of the care coordinator role were categorised as: support/recognition for the coordinator by clinicians and other staff; prior affiliation of the care coordinator within the organisation/service; interpersonal skills and personal characteristics of the care coordinator; and organisational support in terms of administration and IT support. The demands made of care coordinators can be significant. The effectiveness of the coordinator role and is therefore influenced by the individual coordinator's professional competence and resilience.

INDICATORS OF EFFECTIVENESS OF CANCER CARE COORDINATOR INTERVENTIONS

The Agency for Health Care Research and Quality in the US has developed an atlas to help evaluators identify appropriate measures for assessing care coordination interventions, particularly those measures focusing on care coordination in ambulatory care[15]. Consistent with the view that care coordination involves interventions at multiple levels, the report notes that obtaining a comprehensive understanding of care coordination requires measurement including patient/family, health care professional, and system representative perspectives. The Atlas report recommends that identification of relevant measures first requires that the specific mechanisms or strategy that is being used to achieve care coordination is specified. As the care coordinator role is just one of many strategies that should be used in a health care service to achieve care coordination, selection of an appropriate measure of effectiveness requires careful consideration.

In 2010, the COSA Cancer Care Coordination Interest group hosted a workshop led by Professor Kathy Eagar from University of Wollongong to identify principles which could underpin a system for measuring outcomes from care coordinator interventions in practice and research contexts.[16] The key conclusions from this workshop were that outcomes from Cancer Care Coordinator interventions can occur at various levels, e.g. patient, provider system and for short intermediate and long term (see Table 1, page 3). It was agreed that since the Cancer Care Coordinator role focuses to a great extent on improving continuity and coordination, in particular at transition points for people affected by cancer, patient and service level outcomes should be amenable to this intervention. In particular, measures which are sensitive to the person's experience of the coordination of their care and to efficiencies in terms of health service usage will be critical. However, the complexity of health service delivery means that it is difficult to clearly attribute the contribution of Cancer Care Coordinators as they are part of a multilevel strategy comprising a range of inter-related interventions to improve outcomes. In this context, the Cancer Care Coordinator's impact is influenced by many system and organisational factors. For example, the cancer care team will have a major influence on the extent to which care coordination is achieved. The selection of measures to assess the impact of an individual cancer care coordinator service therefore needs careful consideration, and outcomes data should not be considered out of context of the system within which the coordinator operates.

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ENDORSING ORGANISATION

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