

Mapping Cancer Care Coordinators in Victoria

Background

Following a systematic review of cancer care coordinator (CCC) models and the impact of the role on the delivery of cancer care (Langbecker, Hunt & Yates 2013), Cancer Council Victoria established a steering committee to progress activities to improve patient access to care coordinators. The first activity was a mapping project to ascertain the current landscape of CCCs across Victoria, including identification of their geographical locations and scope of practice. A research team from Deakin University was commissioned to undertake this project, which aimed to:

1. Identify geographical locations where CCCs were located
2. Identify tumour streams where CCCs were most utilised
3. Identify patient groups that gained most from having access to a CCC
4. Determine current roles and functions of CCCs within the Victorian care coordination framework
5. Identify current patient pathways into and discharge from cancer care coordinator programs
6. Identify enablers and barriers to accessing CCCs
7. Understand sustainability of the role across Victorian cancer services.

Methods

The project comprised two main components:

1. A survey of health professionals whose role included some aspect of cancer care coordination. The survey was distributed widely amongst peak organisations for health professionals working with cancer patients. It asked for information about the CCC's role, working environment, tasks undertaken and suggestions for improvements. Responses were analysed from 91 individuals.
2. Consultation with managers of CCC positions. Seven managers (primarily Directors of Nursing and Directors of Oncology/Cancer Services) from two rural and four metropolitan health services were interviewed (two were from the same health service). The purpose of the interviews was to determine how CCC roles were funded and structured, the sustainability of the funding and the perceived impact of the CCC role on patients and staff.

Results

Nature of the role

A total of 67% of respondents held positions that were specifically funded to coordinate the care of cancer patients. Seventeen per cent were funded to coordinate cancer care as part of their role and 14% had been employed to do other things but it had become part of their role.

Only 26% of respondents had 'Cancer Care Coordinator' as their job title and 31% devoted all their time to cancer care coordination tasks.

Most respondents had nursing backgrounds (91%) and worked in public health services (80%). The two main funding sources for CCCs were public health services (60%) and philanthropy (21%).

Results of the survey indicate that during consultations with patients the majority of CCCs always:

- Assessed the patient's clinical and supportive care needs
- Provided them with information and education about their cancer
- Planned and coordinated their clinical care, and
- Referred them to other services.

Most of the CCCs surveyed reported that they monitored their patients' progress both during and after cessation of treatment.

As well as consulting with individual patients, the majority of CCCs frequently attended meetings with other health professionals in relation to patient care, undertook administrative tasks, and assessed and responded to the needs of carers.

Service improvement tasks were part of the role for 60% of CCCs. This work included implementing strategies to streamline care, developing new services, reviewing existing services, improving data collection systems and providing education to other staff.

The qualifications, skills and experience required of CCCs

Post graduate qualifications in oncology or a related field were seen as important for CCCs, as was previous experience working in oncology. Nursing skills were important for some aspects of the role but other professionals, such as social workers, could also undertake cancer care coordination. A team approach was suggested, and this cancer care coordination team could comprise an oncology nurse, allied health professional and an administration assistant.

Communication was identified as a key skill for those undertaking care coordination, particularly in relation to communicating with patients and their families, and also for working effectively with other health professionals. Organisational skills, particularly time management, were required, as were clinical skills such as knowledge of cancer treatments and patient assessment. An understanding of the health system, especially services that cancer patients could be referred to, was also important.

Location of CCCs

Overall, 37% of CCCs responding to this survey worked in rural Victoria. This figure was slightly higher than the proportion of cancer cases in rural Victoria (31%). However there may be a greater need for CCCs in rural Victoria as rural cancer patients have worse survival rates than their metropolitan counterparts (Victorian Cancer Registry 2015).

The roles of rural and metropolitan CCCs appeared to differ. Rural CCCs were more likely to work with patients in the community, than hospital inpatients or outpatients. They were also more likely to work part-time and be funded by philanthropy.

Coordination of the Victorian CCC workforce

The funding for CCC positions in Victoria is derived from multiple sources which may make planning and coordination of the service more challenging. The funding source can determine patient eligibility and may result in inequities in care for cancer patients. This study found that CCCs funded by philanthropy were more likely to see patients with particular types of cancer, or patients residing in rural areas. Only 12% of CCCs were located in private health services, suggesting reduced access for private patients.

Enablers and barriers

More than half the respondents to the survey believed that patients experienced barriers to accessing care coordination. Constraints on the CCC role including restricted time, staffing or funding were seen by many as barriers to patients accessing the service. Furthermore, 68% of respondents believed the demand for the service was greater than its capacity.

Limited patient awareness of the service was another barrier and may be related to limited staff awareness and knowledge of the CCC role. Patients receiving a referral to the service from a clinician was a key factor in improving access to care coordination. Therefore good communication and collaboration between the CCC and other clinicians was essential.

Management support for the CCC role was important, as was administrative support to carry out coordination tasks. Clearly defined position descriptions, and clear and appropriate referral pathways also facilitated the work of the CCC.

Integrated IT systems that could promote communication between health professionals, both within organisations and between them, was another key enabler of the CCC role.

Multidisciplinary teams

All of the metropolitan CCCs and 85% of rural CCCs participated in a multidisciplinary team (MDT). Of those, 67% felt their role was perceived as very important within the team.

Impact of cancer care coordination on patients

Survey respondents believed that the main impacts of care coordination were improved patient satisfaction with care, improved treatment compliance and increased uptake of support services.

All of the managers who were interviewed were very positive about the impact of the CCC role on patients, which they believed included the following:

- Assistance with navigation of the health system and streamlining care
- Clinical management of symptoms
- Help with understanding medical information
- Advocacy
- Remaining a constant across disciplines
- Availability to provide advice, reassurance and emotional support
- Provision of person centred care.

Impact of cancer care coordination on staff

All of the managers interviewed commented that the CCCs were highly valued and respected members of the team. The impact of CCCs on other staff was considered to be:

- Provision of expert advice and assistance with complex patients
- Contribution to MDT meetings
- Improving workflow by providing assistance to patients
- Reducing medical staff workload by taking up components of their work
- Providing a link for patients moving across institutions.

Measuring outcomes

Patient satisfaction surveys and monitoring the number of patients who accessed care coordination were used by some organisations to demonstrate the impact of the CCC role. Data on the impact of care coordination on treatment outcomes was limited.

Patient eligibility

Patients did not have to meet any specific eligibility criteria to receive care coordination in 48% of cases. For 37%, patients were required to have a particular type of cancer, often breast or prostate cancer, to be eligible.

While the majority of survey respondents believed that all patients could benefit from care coordination, with limited resources it may be necessary to prioritise patients. Specific groups identified in this study as more likely to benefit from care coordination included those living in rural areas, or those with poor social support or health literacy.

Sustainability of the role

Most of the managers interviewed stated they would like greater numbers of CCCs to be employed in the future. With the ageing population there is a projected increase in cancer incidence in Victoria (Thursfield & Farrugia 2015) and the demand for cancer care coordination is likely to increase over time. Health budgets may not be adequate to ensure all cancer patients have access to a CCC. It may be necessary to consider systematic approaches to improving coordination between health services to enable the majority of cancer patients to navigate the system with minimal assistance, while ensuring that those who require support, due to issues such as limited health literacy or advanced age, have ready access to a CCC or a cancer care coordination team.

References

Langbecker, D, Hunt, K & Yates, P 2013, *Systematic review of cancer care coordinator interventions, prepared for Cancer Council Victoria's Clinical Network*. Institute of Health and Biomedical Innovation.

Thursfield, V & Farrugia, H 2015, *Cancer in Victoria: Statistics & Trends 2014*, Cancer Council Victoria,, Melbourne.

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